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Chapter

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Translating patient-reported outcome measures (PROMs) for cross-cultural studies

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Introduction

An increasing number of multi-national studies are conducted within the field of health care. Because most instruments are originally developed in English (either U.K. or U.S.), an increasing number of instruments are translated to allow for cross-cultural comparisons. One example in neurodegenerative conditions is the PDQ-39 for Parkinson's disease, which was originally developed in U.K. English (1) and has been translated into more than 50 different languages. Patient-reported outcome measures (PROMs) are used in different countries to allow cross-national and cross-cultural comparisons of health outcomes. The importance of rigorous, high-quality translations is increasingly recognized, and a systematic review on translation methods has found that a rigorous and multi-step approach leads to a better translation (2). Internationally recognized translation guidelines were outlined by Guillemin and colleagues (3) more than 15 years ago. More recently, task forces such as the ISPOR (International Society for Pharmacoeconomics and Outcomes Research) Translation and Cultural Adaptation group have outlined principles of good practice for translations and adaptations of PROMs (4).

To ensure that true cross-cultural comparisons are achieved, the process of translating needs to be rigorous and needs to include assessments of the

quality of the translation. Thus, it is important to follow international guidelines to ensure the quality of the translation, to standardize the translation process within different countries, and to evaluate the validity of translated questionnaires. In some instances, specific guidelines, for example, SF-36 (5) or the EQ-5D (6), are related to the translation of a named PROM, and these must be adhered to if the translated instrument is to be recognized as an official version. Therefore, when translating an instrument, it is essential to first contact the original developers of the instrument to get their permission and to establish if any guidelines are available for translation of the instrument. Furthermore, it is important to meticulously describe the translation process in publications to allow readers to assess the rigor and quality of the translation process. This chapter focuses on the translation of existing instruments and outlines the different types of translations and current guidelines for the translation of instruments.

Translation

Many PROMs are initially developed for one study but are later translated to other languages, cultures, or both. Translating an existing instrument means a shorter developmental period and lower costs than required for developing a new

instrument cross-culturally (7), but this does not mean that no financial and time investment is necessary. Translations do cost money and require an investment of time, especially if they are carried out to a high standard. If the translation process is not successfully implemented, the validity of the research can be brought into question (8). The intent when translating a questionnaire is to develop another version of the instrument with equivalence to the original one (9).

For a limited number of PROMs, the initial process of development included concurrently developing multiple language versions (10, 11), which helped ensure that the instrument contains only items that are valid in a variety of cross-cultural settings. The concurrent development of several language versions is costly and highly time-consuming. Furthermore, even when several language versions are developed initially, there will be a limitation as to how many language versions are produced, and hence later translations of the instrument may still occur. The concurrent development of several language versions applies methods of translation similar to those used when an instrument is translated at a later stage.

In the literature, the terms “translation” and “adaptation” are used, and frequently these terms are used interchangeably. The Medical Outcomes Trust states that language adaptation might be differentiated from translation (12). If indeed translation and adaptation are different, translation of an instrument may be defined as the instrument’s being translated from one language into another (e.g., English to French). Adaptation, on the other hand, may be defined as adapting questionnaires to country- or region-specific dialects (12) and to cultural context and lifestyle (3). According to that definition, an example of adaptation would be the development of a U.S. version of the PDQ-39 for Parkinson’s from the original U.K. version (13) even though the authors refer to it as “translation” of the U.K. PDQ-39 to a U.S. PDQ-39. Adaptation can go as far as involving complete transformation of some items to capture the same concepts cross-culturally (14).

A more recent method that avoids having to adapt a PROM is to produce a “universal translation,” meaning the development of a single translation that will be appropriate for use in different regions or countries where the same language is spoken (15, 16). The article by Wild et al. (16) gives useful and practical information on when and how to carry out a universal translation, as, for example, that translators should come from different countries. Universal translations still rely on traditional translation methods; the difference lies in the production of a single translated instrument that can be used in different regions or countries where the same language is spoken.

Types of translation

Two types of translation are used: symmetrical and asymmetrical. In symmetrical translation, the original and translated instruments need to be equally familiar and have loyalty of meaning and colloquialness (9) or, in other words, must be culturally relevant in the target population, have conceptual equivalence to the original, and employ language expressions that are commonly used in the target population. In asymmetrical translation, also called literal translation, emphasis is put on loyalty to one language, usually the original language (9). This means that items translated into another language maintain a one-to-one correspondence between words. Asymmetrical translation is therefore often unnatural in the translated version, and concerns arise for “functional equivalence” of words and concepts between the two languages; hence, international guidelines favor conceptual translation (3).

Translation methods

Three types of translation methods are used: 1) one-way translation, 2) the committee approach, and 3) forward and back translation. One-way translation is the fastest (and cheapest) method to translate a PROM; however, concerns arise about the

quality of the translation, and it is generally not recommended. Views on whether forward and back translation or the committee approach is the preferred method of translation vary, but generally forward and back translation is recommended more frequently.

Forward and back translation is the most frequently recommended or used approach within translation guidelines (3, 4, 5, 9, 17). Forward and back translation requires at least two translators, who work independently. The first translator produces a translated version in the target language, and the second translator translates the translated version back to the original version (9). However, it is generally recommended that two translators produce a forward translation, and the two translated versions need to be reconciled before being back translated (2, 3, 4). Three methods of reconciliation have been described: 1) a translation panel with the key in-country person, all forward translators, and the project manager; 2) an independent native speaker of the target language who did not do the forward translation; or 3) an appointed in-country investigator, who may have prepared one of the forward translations and who will also conduct pilot testing and cognitive debriefing (4).

According to Wild et al. (4), guidelines vary as to how back translations should be carried out. Some guidelines recommend more than one back translation, whereas others recommend a back translation panel or a single back translation. Whichever option is chosen, once a PROM has been back translated, it will need to be reviewed (4). When discrepancies occur between the original and the back translated versions, researchers need to assess the significance of these discrepancies, and if necessary, modify the translated version to produce a more appropriate and adequate translation.

Another method of translation is panel translation (i.e., the committee approach); some authors believe this to be the best method to ensure high-quality translations (18). This approach involves two panels with five to seven members on each: one panel for the forward translation, and a second panel, including lay people who speak the tar-

get language only to assess the translation. A third panel, to include a backward translation, could also be involved. Thus, the panel approach may also involve forward and back translations, but the difference between the panel approach and forward and back translations lies in the fact that, in the panel approach, multiple translators translate the instrument simultaneously, whereas forward and back translation is carried out by one translator, or several translators who work independently.

Different translation techniques can be combined within one project and have been reported in the literature, such as forward and back translation, pilot-test techniques, and the committee approach (3), or back translation in combination with the committee approach (19). Ideally, a panel of bilingual experts compares the equivalence between forward and backward translation (19). Favorable results have been reported from using a combination of techniques; therefore, it is desirable to use multiple methods whenever possible (19).

After completion of the translation process, an instrument needs to be tested in its translated version and within the new target population. This should include pilot testing and cognitive debriefing (4). It is beyond the scope of this chapter to describe psychometric testing, but it is important to note that any translated instrument needs to be subjected to testing. Validating and testing a new language version of a PROM is important to verify the validity and reliability of the translated version. Equivalence will be supported further if the psychometric properties of the original and translated versions are found to be similar.

Quality of the translation

The quality of the translation is an important factor in producing an instrument that corresponds to the original. Quality of the translation is assessed by different types of equivalence between the original and target versions of the questionnaire. The more rigorous the translation process, the more likely the translation supports equivalence (9).

In back translation, when the original and the back translated version show no substantial differences, it suggests that the target version (from the middle of the process) is equivalent to the source language version (19). However, good back translation can *seemingly* create equivalence; therefore, researchers need to be careful. Problems may occur because translators may have a shared set of rules for translating certain nonequivalent words, and also, some back translators may be able to make sense out of a poorly written target language version (19). The bilingual translation from the source to the target may retain many of the grammatical forms of the source. This version would be easy to back translate but worthless for the purpose of asking questions of target-language monolinguals because its grammar is that of the source, not that of the target (19).

The Scientific Committee of the Medical Outcomes Trust described review criteria for the assessment of health status and quality of life instruments, including criteria for cultural and language adaptations and translations. Developers are recommended to describe the methods to achieve linguistic and conceptual equivalence, to identify and explain any significant differences between the original and translated versions, and to explain how inconsistencies were reconciled (12). When addressing equivalence, it is important to note the difference between semantic and conceptual equivalence, because items that are equivalent in meaning may not be equivalent conceptually (7). None of the translations of the Nottingham Health Profile (NHP) exactly mirrored the English version. Literal translations were limited to a few items, whereas other items were translated semantically or conceptually. For example, in Swedish, the use of the pronoun “I” posed problems because the preferred mode of expression is to distance the self from some experiences. Hence, the phrase “I am in pain when I walk” would translate more naturally as “it hurts when I walk” (7).

Other types of equivalence have been proposed to assess the quality of the translation. Examples of differences in the types and definitions of equivalence

are shown in Table 11.1. The problem with the many different types of equivalence is that the definitions of the different types of equivalence are not always clear. A review focusing on “equivalence” (20) found 19 different types of equivalence. For some types of equivalence (e.g., semantic and operational equivalence), there is almost universal agreement on the definition, but for other types of equivalence (e.g., conceptual and functional equivalence), the study showed that consensus was notably lacking (20). In particular, a substantial amount of variation in the definition of conceptual equivalence was found.

Achieving equivalence between different language versions of a PROM can be challenging because not all concepts are equally applicable to different cultures. Herdman and colleagues (21) suggest that rather than using an “absolutist” approach to achieving equivalence, a “universalist” approach should be used. An “absolutist” approach assumes that there will be little or no change in the concept and organizations of a PROM across cultures, whereas a “universalist” approach does not make the assumption that constructs are the same across cultures. Six types of equivalence need to be taken into account when the universalist approach is used: 1) conceptual equivalence, 2) item equivalence, 3) semantic equivalence, 4) operational equivalence, 5) measurement equivalence, and 6) functional equivalence (21). Although the terminology used by Herdman and colleagues is the same or similar to other authors’ terminology about equivalence, the definitions can differ (as shown in Table 11.1). The universalist approach is specific and may mean that some instruments will not be considered as suitable for translation because the different types of equivalence cannot be achieved between cultures.

Translators

Number of translators

Hilton and Skrutkowski (9) recommend at least two translators, one of whom will translate the

Table 11.1 Types of equivalence and definitions

Authors (year)	Type of equivalence	Definition
Guillemin et al. (1993) (3)	Semantic	Equivalence in the meaning of words. Achieving it may present problems with vocabulary and grammar.
	Idiomatic	Equivalent expressions have to be found for idioms and colloquialisms that are not translatable. This is more important for emotional and social dimensions.
	Experiential	Situations evoked or depicted in the original version should fit the target cultural context.
	Conceptual	Validity of the concept explored and the events experienced by people in the target culture.
Herdman et al. (1998) (21)	Conceptual	Questionnaire has the same relationship to the underlying concept in different cultures, primarily in terms of the domains included and the emphasis placed on domains.
	Item	Validity of items is the same in different cultures.
	Semantic	There is transfer of meaning across languages.
	Operational	Using a similar questionnaire format, instructions, mode of administration, and measurement methods.
	Measurement	Different language versions achieve acceptable levels in terms of psychometric properties (such as reliability, validity, responsiveness).
Hilton and Skrutkowski (2002) (9)	Functional	The extent to which a measure does what it is supposed to do equally well in two or more cultures.
	Content	Each item's content is relevant in each culture (some constructs cannot be insinuated into instruments for other cultures).
	Semantic	Similarity of meaning of each item in each culture after translation.
	Technical	Data collection method is comparable.
	Conceptual	Instrument measures the same theoretical construct in each culture.
Meadows (2003) (22)	Criterion	Interpretation remains the same when compared with the norm for each culture.
	Item or content	Each item describes a phenomenon for both cultures, or the situation described or experiences evoked in the original version are applicable to the target population.
	Semantic	The meaning of each item, word, or expression is retained after translation into the language of the target culture.
	Operational	The way in which data collection is carried out (self-completed versus structured interviews) may have differential effects on data collection.
	Conceptual	Existence and relevance of the concepts (ideas and experiences, etc.) in both cultures.
	Functional	The degree to which equivalence in the preceding stages has been achieved.

original version to the target language, and one of whom will back translate the translated version to the original language. Guillemin et al. (3) recommended producing several forward translations, with at least two independent translators and preferably a team of translators rather than individual translators. For panel translations, a trans-

lator panel of five to seven translators (18) is recommended.

Skills and background

Generally, there is consensus that the qualifications and skills of translators are important, and

that competent translators should be used. However, the definition of a competent translator varies between authors. Competence may refer to the linguistic skills of the translator, and the use of linguistically competent translators who are conversant in the target language is recommended (22). Competence can also refer to the translator's area of expertise, and it is recommended that translators who are familiar with the content (i.e., subject area) involved in the source material be used (19). Brislin (19) showed that translators' familiarity with English contributed to translation quality and that translation quality was better for concepts with which the translators had greater familiarity. A systematic review of translations of quality of life instruments concluded that the people involved in translations are critical in determining a questionnaire's performance in a new country or culture (2).

For forward and back translations, it is always best to use translators who translate into their mother language (3, 4). Hilton and Srutkowski (9) believe that translators should include professional interpreters, lay people who are monolingual and representatives of the populations under study, people who are bilingual with the source language as their first language, and people who are bilingual with the target language as their first language. Furthermore, Wild et al. specify that translators should have prior experience in translating PROMs (4). However, it seems impossible to achieve this diversity, particularly when only two translators (one forward and one back) are involved in the research. Swaine-Verdier et al. (18), who are in favor of panel translations, recommend that translators should be as "ordinary" as possible (because the questionnaire is completed by "ordinary" people).

Instructions to translators

To ensure that translators use the same approach to their translations, they should be given instructions on how to proceed. Translators should be fully aware of their role and should ideally have prior experience in translations (22). Translators should be instructed to translate conceptually, rather than

literally (5), and to refrain from using technical and difficult language (indication of reading age may be useful). Forward translators, but preferably not back translators, should be aware of the intent and concepts underlying the material (3). The use of dictionaries is not recommended because this might entice the translator to a literal, word-by-word translation rather than the conceptual translation of a whole sentence.

Assessors

Assessors, also called raters, are recommended as part of the translation process (3, 19, 22). Assessors are bilinguals who are concerned with assessing the quality and the equivalence between the original and the translated version. Ideally several assessors should examine the original and translated versions for errors (19), and a committee of assessors can be used to fulfill this role (3). Sperber (8) suggests that, prior to psychometric testing, a comparability and interpretability test should be carried out by at least 30 raters who rank the translated and back translated version in terms of comparability of language and similarity of interpretability. This gives the opportunity to revise items that score poorly or that are not thought to be equivalent to the original by the assessors, thus further increasing the likelihood of equivalence.

Reports about the translation process

It is important to carefully document the translation process, including consideration of format, administration, and translator selection; translation issues raised; and decisions made during the validation process (9, 23). Information on the translation procedure helps to assess the quality of the process and may give an indication of the quality of the translation, thus, increasing the credibility of the translation (2). A high-quality translation process is not a guarantee of a good translation, but a rigorous and inclusive translation process can increase the likelihood that the original and translated versions will be equivalent (9).

Conclusion

When translations are performed, it is important to use rigorous and well-documented methods. Forward and back translation is the preferred method, but it may be less important whether the translations (forward and back) are performed by individual and independent translators or a panel of translators. Because there is no scientific evidence on whether individual translations or panel translations produce higher-quality instruments, the decision of using individual translators or a panel may have to be based on the researchers' preference and practical issues such as the availability of suitable translators or other resources such as time and finances. A systematic review found no evidence in favor of one specific method of translation, but the authors concluded that a rigorous multi-step approach leads to better-quality translations and should therefore be used as a guarantee of quality (2). Furthermore, having standardized guidelines for translations can improve the quality of translations.

REFERENCES

- Jenkinson C, Fitzpatrick R, Peto V, Greenhall R, Hyman N. The Parkinson's Disease Questionnaire (PDQ-39): development and validation of a Parkinson's disease summary index score. *Age Ageing* 1997 Sep; **26**(5): 353–357.
- Acquadro C, Conway K, Hareendran A, Aaronson N. Literature review of methods to translate health-related quality of life questionnaires for use in multinational clinical trials. *Value Health* 2008 May; **11**(3): 509–521.
- Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 1993 Dec; **46**(12): 1417–1432.
- Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value Health* 2005 Mar; **8**(2): 94–104.
- Bullinger M, Alonso J, Apolone G, Leplege A, Sullivan M, Wood-Dauphinee S, et al. Translating health status questionnaires and evaluating their quality: the IQOLA project approach. International Quality of Life Assessment. *J Clin Epidemiol* 1998 Nov; **51**(11): 913–923.
- Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. *Ann Med* 2001 Jul; **33**(5): 337–343.
- Hunt SM, Alonso J, Bucquet D, Niero M, Wiklund I, McKenna S. Cross-cultural adaptation of health measures. European Group for Health Management and Quality of Life Assessment. *Health Policy* 1991 Sep; **19**(1): 33–44.
- Sperber AD. Translation and validation of study instruments for cross-cultural research. *Gastroenterology* 2004 Jan; **126**(1 suppl 1): S124–S128.
- Hilton A, Skrutkowski M. Translating instruments into other languages: development and testing processes. *Cancer Nurs* 2002 Feb; **25**(1): 1–7.
- WHOQOL group. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med* 1998 Jun; **46**(12): 1569–1585.
- Niero M, Martin M, Finger T, Lucas R, Mear I, Wild D, et al. A new approach to multicultural item generation in the development of two obesity-specific measures: the Obesity and Weight Loss Quality of Life (OWLQOL) questionnaire and the Weight-Related Symptom Measure (WRSM). *Clin Ther* 2002 Apr; **24**(4): 690–700.
- Scientific Advisory Committee of the Medical Outcomes Trust. Assessing health status and quality-of-life instruments: attributes and review criteria. *Qual Life Res* 2002 May; **11**(3): 193–205.
- Bushnell DM, Martin ML. Quality of life and Parkinson's disease: translation and validation of the US Parkinson's Disease Questionnaire (PDQ-39). *Qual Life Res* 1999 Jun; **8**(4): 345–350.
- Guillemin F. Cross-cultural adaptation and validation of health status measures. *Scand J Rheumatol* 1995; **24**(2): 61–63.
- Eremenco SL, Cella D, Arnold BJ. A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Eval Health Prof* 2005 Jun; **28**(2): 212–232.
- Wild D, Eremenco S, Mear I, Martin M, Houchin C, Gawlicki M, et al. Multinational trials: Recommendations on the translations required, approaches to using the same language in different countries, and

- the approaches to support pooling the data: the ISPOR patient-reported outcomes translation and linguistic validation Good Research Practices Task Force report. *Value Health* 2008 Nov 12(4): 430–440.
17. Skevington SM, Sartorius N, Amir M. Developing methods for assessing quality of life in different cultural settings: the history of the WHOQOL instruments. *Soc Psychiatry Psychiatr Epidemiol* 2004 Jan; 39(1): 1–8.
 18. Swaine-Verdier A, Doward LC, Hagell P, Thorsen H, McKenna SP. Adapting quality of life instruments. *Value Health* 2004 Sep; 7(suppl 1):S27–S30.
 19. Brislin RW. Back-translation for cross-cultural research. *J Cross-Cultural Psychol* 1970; 1(3): 185–216.
 20. Herdman M, Fox-Rushby J, Badia X. 'Equivalence' and the translation and adaptation of health-related quality of life questionnaires. *Qual Life Res* 1997 Apr; 6(3): 237–247.
 21. Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach. *Qual Life Res* 1998 May; 7(4): 323–335.
 22. Meadows KA. So you want to do research? 5: Questionnaire design. *Br J Community Nurs* 2003 Dec; 8(12): 562–570.
 23. MAPI Institute. Linguistic Validation. Methodology. May 11, 2009. Available at: <http://www.mapi-institute.com/linguistic-validation/methodology>