

# The Translation and Cultural Adaptation of Patient-reported Outcome Measures for a Clinical Study Involving Traditional Health Providers and Bio-medically Trained Practitioners

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## Abstract

This study reports on the cultural and language translation of measures for use with Zulu speakers in South Africa. The translation process was purposefully used to integrate our diverse 14 person study team by employing Community Based Participatory Research (CBPR) strategies.

Measures included: the Medical Outcomes Study HIV Health Survey (MOS-HIV), Center for Epidemiologic Studies Depression Scale (CES-D), and Perceived Stress Scale (PSS).

The translation was made complex by the variation in Zulu dialects

across regions and even between two cities only forty-five minutes apart.

Carefully conceived translations can simultaneously produce good translations and deepen team members' understanding of each-other .

**Keywords:** Translation, outcome measures, CBPR

## **Introduction**

An estimated 5.4 million South Africans are infected with the human immunodeficiency virus (HIV) (Dorrington *et al.* 2006). Rates of HIV infection are highest in the province of KwaZulu-Natal where the prevalence is estimated to be between 16.5% and 40% (Dorrington *et al.* 2004; Dorrington *et al.* 2006). Measurement of patient-reported outcomes of HIV disease, such as increased depression and anxiety are important as they have been shown to adversely affect the course of the disease (Leserman 2003; Kopnisky *et al.* 2004). However, there is a shortage of appropriate culturally-adapted and language-translated measures for use with the Zulu speaking residents of KwaZulu-Natal. The lack of properly translated measures is important as it threatens the validity of data, interferes with comprehensive evaluations of interventions, and prohibits the safe aggregation of global data sets (Wild *et al.* 2005). The primary aim of this study is to report on the process of cultural adaptation and language translation of patient-reported outcome measures for use with Zulu speakers.

Conducting a sound cultural adaptation and language translation process can be quite challenging as it is complicated by contextual factors. For example, this challenging task is more difficult when one seeks to translate a health measure from one language to another (e.g. English to Zulu) as compared to producing a same language version (e.g. American English adapted for use with English speaking South Africans). The process becomes further complicated when the measures being translated are based on psychological constructs, such as quality of life, which are heavily culturally laden. For example, translating a measure of nutritional intake would require one to establish an understanding of the types of locally available foods and measurement system (e.g. metric vs. inch-pound system), but would not require the researcher to establish whether individuals in the target group ingests food to survive. In contrast, more culturally laden

constructs like quality of life may not have relevance for all and it should not be assumed that a western understanding of this construct is relevant in other cultures (e.g. anorexia nervosa is not observed in numerous cultures throughout the world). For this reason, conducting sound cultural adaptation and language translations of measures for use with a new population requires attention to the relevance of the underlying constructs of the target measures.

While the overall aim of any translation measure is to produce a new language version which is both conceptually equivalent to the original and relevant in the new target culture, the actual methods employed to produce a quality product vary greatly depending on each context. Guidance on the proper approach for translating such measures for use in new contexts has been available for some time (Monika *et al.* 1998; Koller & West 2005). However, in 1999 the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) created the Task Force for Translation and Cultural Adaptation in order to create a consensus statement on best practices. Drawing heavily on earlier guidelines (Monika *et al.* 1998; Koller & West 2005), the Task Force published the 'Principles of Good Practice' for the translation and cultural adaptation of patient-reported outcome measures in 2005 (Wild *et al.* 2005). This paper reports on our experience of applying these guidelines for the translation and cultural adaptation of three patient-reported outcome measures for use in a randomized clinical trial set in KwaZulu-Natal, South Africa.

With the HIV/AIDS epidemic placing enormous pressure on an already strained public health care system (Barnett 2006), many South Africans do not have access to adequate health care (Magasela 2006). Currently THPs provide important health care for many who do not have access to (Barnett 2006) or wish to use allopathic health care (Puckree *et al.* 2002). While the exact percentages are unknown, it is estimated that  $\geq 70\%$  of rural South Africans regularly visit THPs and that the majority of all South Africans will seek the services of THPs at some point in their lives (Puckree *et al.* 2002; Babb *et al.* 2007; Aceme 2007). Despite a long history of marginalization, many in South Africa including the government have begun to recognize THPs as a valuable health resource (Devenish 2005). However, their inclusion in the mainstream public health care system is only just beginning. Given the long standing distrust between THPs and allopathic health care providers (Devenish 2005) and the need to have these health care providers

work together to administer the clinical trial and, more importantly, to address the HIV/AIDS epidemic in South Africa (Morris 2001; Aceme 2007), our second goal for this paper is to report on how we deliberately used the translation process to build bridges between these two worlds by employing Community Based Participatory Research (CBPR) strategies. We report on our successes, struggles and lessons learned in this paper.

## Method

A large team of individuals with a range of degrees, life experience, and expertise was created to address the specific goals of this project. This team included a USA-trained clinical health psychologist who had experience with the target measures, the translation process, and team building; one USA-trained medical doctor with extensive knowledge of the translation process; two South African trained medical doctors who are Zulu; a South African trained nurse who is Zulu and has an intimate understanding of THP's practices; eight well known and respected Zulu THPs, and one Xhosa biochemist who is fluent in Zulu and works closely with the THPs.

This project was carried out to support a National Center for Complementary and Alternative Medicine funded study in order to conduct a randomized clinical trial to test the safety of a particular herb used by THPs (i.e. *Sutherlandia* or unwele) in a sample of HIV+ adults with  $\geq 350$  CD4 cells (who are not on antiretroviral therapy [ART]). To our knowledge, this is the first clinical trial of *Sutherlandia* (unwele) in HIV+ individuals and the first trial to utilize a fully integrated team of allopathic and traditionally-trained health care providers. The setting for this study is the Umgungundlovu Hospital Complex in KwaZulu-Natal, South Africa. Approximately 10%-15% of the 1 million adults who seek services at the Complex are believed to be HIV+ and currently there are over 6000 patients registered with the HIV Clinic. The Complex also has a network of well-integrated Communicable Diseases Clinics that provide opportunistic infection prophylaxis for HIV+ adults and, more recently, ART as part of the South African Government's rollout programme. The main site of the study is Edendale Hospital which is the largest hospital in the Complex and serves a predominantly peri-urban and rural population.

For the purpose of the larger clinical trial, we selected the following well-validated measures that have all been successfully translated into other languages. For example, the Medical Outcomes Study HIV Health Survey (MOS-HIV) has been translated into 14 European and North/South American languages. However, as we note below, the only known African language translation is Lugandan for use in Uganda. To our knowledge, the Center for Epidemiologic Studies Depression Scale (CES-D) and the Perceived Stress Scale (PSS) have been translated into European and North/South American languages only.

### *Quality of Life*

The MOS-HIV is a brief (35-items, 5 minute administration) but comprehensive health status measure that has been used extensively in studies of HIV+ individuals (Wu *et al.* 1997). The MOS-HIV covers ten dimensions including: 1) general health perceptions, 2) pain, 3) physical function, 4) role function, 5) social function 6) cognitive function, 7) mental health, 8) energy/fatigue, 9) health distress and 10) quality of life. Each sub-dimension is scored such that higher scores indicate better health and overall physical and mental health summary scores can be generated (Revicki *et al.* 1998). The MOS-HIV has been shown to be internally consistent and validity has been established by numerous studies demonstrating its: 1) consistent association with concurrent measures of health, 2) ability to discriminate between distinct groups, 3) ability to predict future outcomes, and 4) responsiveness to changes over time. It is available in at least twenty languages; however the only available African language translation is for Lugandan-speaking individuals in Uganda. Sample items include: 1) ‘Does your health keep you from working at a job, doing work around the house or going to school?’; and 2) ‘How has the quality of your life been during the past four weeks? That is, how have things been going for you?’

### *Depressive Symptoms*

We used the 15-item short form of the Center for Epidemiologic Studies Depression Scale (CES-D) in this study (Radloff 1977). This scale has

established reliability and validity (e.g. correlations with other self-report measures, clinical ratings of depression, and other variables which support its construct validity) through use in a wide variety of patient populations. A sample item is: ‘How often (in the past week) did you feel that your life had been a failure?’

### *Perceived Stress*

The Perceived Stress Scale (PSS) (Sheldon Cohen 1997) is a 10-item self-report scale designed to assess how unpredictable, uncontrollable, and overloaded respondents find their lives. The PSS has good reliability, and validity has been established via correlations with physical symptoms, depressive symptoms, and life events. Typical questions include: ‘In the past month, how often have you felt that you were unable to control the important things in your life?’, or ‘How often have you felt that things were going your way?’

### *Translation Process*

The ISPOR ‘Principles of Good Practice’ detail 10 steps that include: Preparation, Forward Translation, Reconciliation, Back Translation, Back Translation Review, Harmonization, Cognitive Debriefing, Review of Cognitive Debriefing Results and Finalization, Proofreading, and Final Report. Below, we describe the critical components of each step, as well as how we addressed each step.

*Step 1. Preparation:* The critical components of this step are: a) to obtain permission to use the instrument(s), b) invite the instrument developer to be involved, c) develop an explanation of concepts in the instrument, and d) recruit key in-country persons to participate in the project.

In order to address these critical components, we selected measures that were in the public domain (a), we invited one of the developers of the main outcome measure (MOS-HIV) to consult on this project (b), and with the help of our Zulu colleagues at the study site in South Africa (d),

we developed what we hoped would be understandable explanations of the concepts in the instruments selected for translation (c).

*Step 2. Forward Translation:* There are two critical components in this step: a) at least two independent forward translations and b) provision of explanation of concepts in the instrument to the key in-country persons and forward translators.

We addressed this step by having two of our Zulu-speaking research team members complete independent translations of the measures (a). We had numerous e-mail and telephone conversations prior to the translations being conducted in which we discussed the concepts in the instruments and both were familiar with the content of questionnaires (b).

*Step 3. Reconciliation:* This step requires the two independent translations to be reconciled. We had our two independent translators meet to review each questionnaire item by item and to resolve any discrepancies between their two versions.

Because we wanted to ensure that our adaptation of these measures of psychological constructs were appropriate for use with Zulu speakers and to more fully develop our working relationships with our THP colleagues, we conducted additional forward translation/reconciliation efforts. First, knowing that our THP colleagues were experts in Zulu culture and language, we established several meetings that focused on the reconciled translations of the measures described above. We developed detailed focus group guides and conducted two meetings with our THP colleagues at Edendale Hospital. In the first five-hour meeting, we focused on each construct in turn (first depression, then perceived stress, then quality of life), to ensure that they made sense and were recognized by the expert THPs. The second four-hour meeting focused on instructions and response categories for the measures. Next, we conducted a meeting with our THP colleagues in Durban where we reviewed all measures with particular attention paid to issues that had been contentious in our earlier efforts or that were still unresolved.

*Step 4. Back Translation:* This step involves back-translating the reconciled translation into the source language. This was accomplished by having another independent Zulu speaker review the reconciled translation. The back translator read every instruction, question and response category out loud. A word-for-word record of the English translation was recorded by a native English speaker.

*Step 5. Back Translation Review:* This step mandates a review of the back translation against the source language. We accomplished this step by comparing the word-for-word back translation to the original English version to ensure that concepts had not been lost.

*Step 6. Harmonization:* The goal of this step is to ensure conceptual equivalence between the source and target language versions and between all translations. It is an additional quality control step that helps to ensure that data from global trials can be safely aggregated. We accomplished this task by bringing members of the project team together to examine the back translation review.

*Step 7. Cognitive Debriefing:* This step assesses the level of comprehensibility and cognitive equivalence of the new translation, usually among individuals from the target population. During this process, any translation alternatives that have not been resolved by the steps above should be discussed. Because this step is done with members of the target population, it is also likely to highlight anything that may be confusing or inappropriate. We accomplished this task by asking three Zulu-speaking first year nursing students to review the questionnaires. Nursing students were selected because they were easily accessible at the study site, and representative of the ultimate target population of sexually active Zulu-speakers.

*Step 8. Review of Cognitive Debriefing Results and Finalization:* This step is a purposeful review of the results of the Cognitive Debriefing process to produce a final translation. We accomplished this step by having members of the project team meet with each of the nursing students to



get their feedback on the measures. We sought feedback on the readability, complexity and appropriateness of the translated versions.

*Step 9. Proofreading:* This often omitted step requires one last review of the finalized translation to ensure that no minor or typographical errors remain. A member of our project team who is fluent in Zulu and English finalized the translations. We also sought two independent professional forward translations conducted by paid consultants and compared those to our finalized versions.

*Step 10. Final Report:* This last step involves the documentation of how each of the steps was addressed and how all translation/wording choices were made. This important step is key to ensuring that future translations of the same measure can be harmonized with previously developed versions. Working together, our project team created this report to address this final step.

### *Strategies Employed for Team Development and Diffusion of Expertise*

Working from a CBPR perspective, we deliberately used the translation process to build trust and collaboration among group members and to diffuse the expertise of all members to the larger group. CBPR is a collaborative approach to conducting research by which community members affected by the problem fully participate in the process of developing research questions, data collection, intervention implementation, and analysis, interpretation, and dissemination of results (Isreal *et al.* 2005). Use of CBPR methods have been found to assist in the development of socially-validated research methods, for building greater trust and respect between researchers and communities, and for increasing sustainability of intervention methods. In Table 1, we outline the nine guiding principles of CBPR (Isreal *et al.* 2005) and how we addressed each in this process. Using principles of CBPR was especially important as this project involves health professionals from worlds that have experienced historically poor integration and suffered from a great deal of mistrust (i.e. traditional and western medicine). We carefully selected our team members to include individuals who were recognized leaders and who

had an interest in making a connection with other recognized leaders from other health care traditions. Recognizing the historical discrimination that THPs have experienced, we deliberately assigned tasks to the South African trained staff that required them to depend on the THPs in order to successfully accomplish their assignment. For example, we asked our South African trained Zulu nurse and one of our South African trained Zulu medical doctors to perform the initial forward translation and then to lead the translation focus groups with THPs.

## **Results**

### *Translation and Cultural Adaptation*

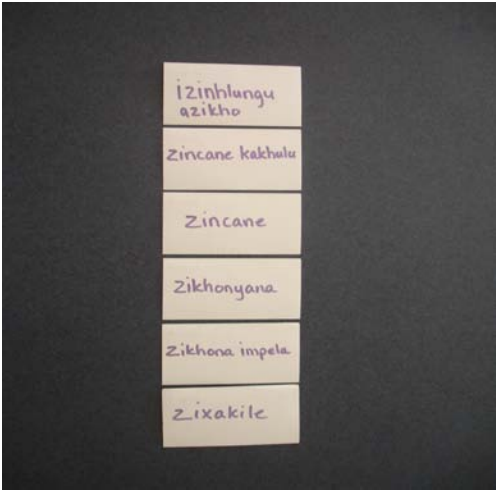
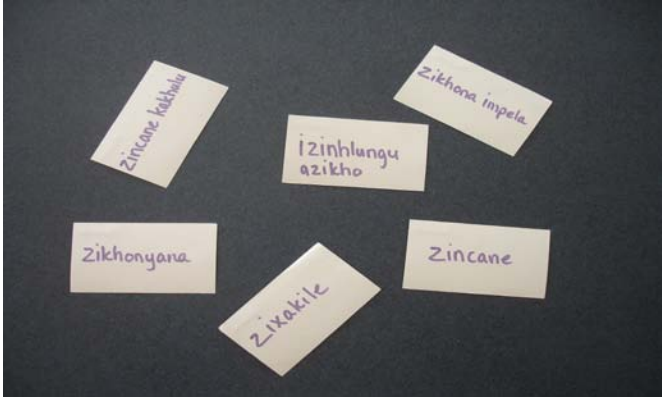
We successfully completed each of the ten steps described in the Method. Selection of the measures, description of the concepts covered and recruitment of in-country team members was easily accomplished as we had established our team early in the process to prepare our grant proposal. Similarly, the first two forward translations and reconciliation were straight forward and quick. However, our meetings with the THPs proved to be more challenging and informative than we could have anticipated.

Following the guidance of our expert consultant, we had developed detailed focus group guides. These guides started by thanking THPs for their willingness to teach us; stressed that they were the experts, and that we needed to hear their thoughts even if they were different to what others were expressing. We asked questions that focused on: 1) establishing the validity of each underlying construct for Zulu speakers (e.g. ‘Can the English word *depression* be translated into Zulu?, If so, what meaning does it have?’), 2) establishing what symptoms are associated with each construct (e.g. ‘If the phrase quality of life means something, what would you expect someone with good quality of life to look like?’), and 3) establishing that the anchors in the response categories made sense. Focus group guides ended with questions focused on ensuring that we had not missed anything important and understanding THPs’ experience of the process. There were two purposes to these guides: 1) to ensure that we created an environment where the THPs’ expertise could emerge and 2) to provide, if necessary, sufficient explanations of the concepts in the patient outcome measures to make our

discussions of appropriate translations meaningful. We will discuss results related to the first goal in more detail below. In terms of the second goal, our guides were extremely helpful in keeping the group on task and ensuring that clarifications were available if necessary. In addition to the guides, we used a variety of visual aids (e.g. dry-erase boards) and group activities (e.g. sorting of response categories) to encourage participation and to keep individuals focused over the course of two very long sessions. Pre-printed index cards were especially useful in allowing the group to work together to clarify their understanding of symptoms of syndromes and response categories (see Figure 1).

The first two THP groups revealed that there are few direct translations of the words *depression*, *stress* and *quality of life*. Taking each construct in turn, the THPs clarified that these constructs exist and that it is something that they regularly see and treat in patients. However, because their belief system of disease etiology is divergent from the western allopathic model, they do not necessarily recognize depression as a syndrome made up of specific symptoms. With that said, they were also clear that when they see patients who are experiencing a low mood, they often see other accompanying symptoms like loss of appetite, disturbed sleep, suicidal ideation, hopelessness, apathy, and sexual dysfunction (which we had not presented for discussion as it does not appear on the CES-D). Similar discussions regarding stress and quality of life emerged. Despite the lack of standardized diagnostic criteria, appropriate translations for depression (*umoya ophansi*—‘low spirit’), stress (*ingcindezi*—‘pressure or oppression’), and quality of life (*izinga/iqophelo lempilo*—‘quality of health’) and all associated symptoms were identified. The most striking and difficult part of these meetings involved producing meaningful translations of the Likert-type response categories for the questionnaires. We presented index cards with each response option printed in Zulu (Figure 1). We then asked the THPs to put the response options in order from most to least of each response option (e.g. ‘strongly agree’ to ‘strongly disagree’). Difficulty arose as some comparisons of concepts (like small increments of time) are ambiguous in any language, but especially difficult to do without context. For example, communicating that a symptom occurs ‘some or a little of the time’ vs. ‘occasionally or a moderate amount of time’ was particularly difficult until the corresponding question was presented. After considerable conversation,

consensus was reached, with the greatest number of changes from the initial reconciled forward translation associated with the response categories and quality of life measure.



**Figure 1<sup>1</sup>: Index cards in isiZulu**

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<sup>1</sup> Index cards in isiZulu used to establish the translation for the response category of ‘None of the time’, ‘A little of the time’, ‘Some of the time’, ‘A good bit of the time’, ‘Most of the time’, and ‘All of the time’.

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After making all of the agreed upon changes, we presented the new reconciled translations to another independent group of THPs and another colleague fluent in Zulu in Durban. This meeting produced additional changes in the wording of scale instructions, questions and response categories. Consistent with the prior focus group meetings, most of the discussion focused on the response categories. We edited the translations consistent with the feedback obtained in this focus group with our Durban colleagues and preceded to the back translation stage.

The back translation process quickly revealed that the suggested changes obtained from our colleagues in the Durban focus group had altered the meaning of items and relied on more formal and/or local Zulu than the version from our first two focus groups that were held with THPs who worked and resided in the area around the trial site. Because our goal was to produce translations that would be readily accessible to participants drawn from the area surrounding the trial site, we decided to go back to the prior version that was produced in the meetings with the THPs and completed the back translation process. This proved to be a good decision and the back translation and review process was completed with only a few minor issues to be resolved (e.g. tense of a few words, unnecessary density in one set of instructions). These issues were easily resolved in the harmonization meetings. The back translation process revealed that a word-for-word translation was possible, but difficult as sentence structure is quite different in Zulu as opposed to English. Further, translating the tense of words is quite difficult without context. Therefore the back translator tended to read the entire sentence, consider its meaning, and then provided a word-for-word translation of the material.

Participants in the cognitive debriefing process (nursing students) were interviewed individually. Feedback on appropriateness, understandability and content was uniformly positive with some minor suggestions for simplifying one set of scale instructions. Team members asked each of the participants to read aloud several items that had been the most contentious in earlier discussion (i.e. specific items and the response categories). The team considered the suggestion to simplify one of the scale's instructions, but no changes were ultimately made as they required a significant deviation from the original English version and were not seen as improving the translation in a meaningful way. Results of this process reassured us that the final Zulu

versions were accurate reflections of the English versions.

Proofreading was accomplished by project team members and allowed for the opportunity to ensure that all earlier drafts were properly labeled and retained, and that the final versions were error-free. As an additional check, we had additional forward translations completed by two independent professional certified translators. We compared these independent translations to our versions which revealed some minor recommended changes. After discussion with the certified translators about the process we had used to ensure the appropriateness of our translations, it was agreed that the majority of the suggested changes would not improve the translations. Then, after another round of proofreading, the final report was completed by the project team which resulted in a final version of the patient-outcome measures.

### *Team Development and Diffusion of Expertise*

As detailed in Table 1, we strategically employed CBPR methods which encouraged team members to work with and learn from each other. For example, asking our South African trained Zulu health care providers to perform the initial translation and then lead the THPs' focus groups was intended to create a situation where the expertise of the THPs was needed in order to successfully complete their task. What these biomedically-trained team members learned was that despite being Zulu and fluent in Zulu, their biomedical training and day-to-day work primarily in English made them less than ideal translators. In contrast, the THPs conduct the majority of their work in Zulu which allowed them to correct the biomedically-trained staff's translations and offer a richer understanding of the underlying psychosocial concepts represented in the measures. This open exchange of ideas allowed the THPs to see that the biomedically-trained staff could learn, and more importantly acknowledge learning, from their expertise.

A secondary goal of this purposeful use of the translation process was to make this new, richer understanding and respect among members diffuse to the larger community from which each came. This was accomplished by carefully selecting individuals who are influential in their own worlds and consistent with a diffusion of innovations approach (Rogers 1995), constructing an experience in which all members could learn from

each other and take their new understanding of the others back to their respective worlds. Feedback from the individuals involved with this portion of the translation process was strongly positive and indicated that we were successful in accomplishing this goal. For example, all members reported having a better understanding of what it takes to produce cultural and language translations of questionnaires for use in research studies. Our biomedically-trained team members reported that they had developed new skills in conducting focus groups and translation processes that they would use in future studies. Most important, all reported a deeper understanding of the procedures and practices of health care providers from traditions divergent from their own and a commitment to share these observations with others.

## **Discussion and Conclusion**

Despite being laborious, the approach to translation and cultural adaptation of patient-reported outcome measures described here proved to be very successful in allowing us to simultaneously accomplish both of our goals. We were struck by several things that emerged in our work: firstly, that we continued to have new insights at each step of the translation process; secondly, that the translation of response categories would be so difficult, which has, however, been observed in other studies (Ware 1995); thirdly, that despite speaking Zulu daily with their families and some patients, our biomedically-trained Zulu health care professionals' translations were not as accurate as those provided by the THPs. Lastly, and most striking, was the fact that the Zulu spoken in two cities forty-five minutes apart was very different. This should not be surprising as language is constantly evolving and this is especially true in an urban environment like Durban where there are numerous competing languages that influence each other. In the end, it is important to note that the very best translation for any project comes from careful work with members of the target population or as close a surrogate as possible.

Replicability of the ten-step translation and cultural adaptation process employed here is likely to present potentially insurmountable challenges in situations with limited resources. However, careful planning can allow for the consolidation of steps that will maintain the integrity of the

process while making it feasible. For example, several of us have used a more streamlined approach to conduct a cultural and language translation of the same measures into another South African language, Xhosa. Specifically, we consolidated the ten-step process into three stages. In the first stage, we consolidated steps 1-3 by drawing on our experience with these measures and identifying two Xhosa-speaking individuals to conduct the initial translation. Consistent with the process described above, these individuals produced independent translations and then met to reach consensus on a final translation. Unresolved issues were few and just like our experience translating into Zulu, mostly involved the response categories. The second stage addressed steps 4-7 and included conducting the Back Translation which was completed by the project director who is fluent in Xhosa and English and facilitation of a meeting with the original translators and two community health care workers who have vast experience with the target population to ensure the appropriateness of the translated versions and to resolve any remaining issues. The final stage addressed steps 8-10 and included administering the newly-translated versions of the measures to Xhosa-speakers from the target population and obtaining their feedback and editing the final version accordingly. This three stage consolidated process produced a well received Xhosa version of the measures and was conducted on a minimal budget in a short period of time. Future efforts that employ similar approaches are necessary to ensure that these techniques can be replicated in other resource-poor environments.

More research on the reliability, validity, and usefulness of these translated and culturally-adapted instruments with members of the specific target population are necessary. However, large scale validity studies may not always be practical in resource-limited settings. Other strategies to improve the integrity of data from translated measures include carefully selecting measures that allow for convergent, divergent, concurrent, and predictive validity analyses within studies; employing community advisory boards that review and provide feedback on measures, and seeking feedback from participants throughout the study. As Aceme (2007) and Mills (2005) have noted, given the dearth of properly translated patient-reported outcome measures for use with Zulu speakers and the need for well-designed studies that address these important outcomes in the midst of the HIV/AIDS epidemic in South Africa, reports like this one are greatly needed.



From all accounts, we were successful in meeting our second goal to use the translation process to fully develop our team and allow for members' expertise to diffuse to the larger group of individuals who will ultimately participate in and be impacted by our work. All team members were clearly committed to the process as they dedicated significant time and effort to it. Members also clearly took pride in what had been accomplished and were eager to continue working together. Most importantly, as a result of participating, team members reported that they had acquired a better understanding of each other, new skills that will be useful in future collaborations, and an eagerness to share their experiences with others in their communities. Clearly, a very respectful and meaningful exchange had occurred.

Employing this type of careful planning is important if we are to capitalize on the full impact that the research process can have on a community. More importantly, thoughtful approaches like the one described here can do much to encourage previously marginalized communities to address and initiate solutions for important public health problems.

### **Acknowledgements**

We would like to thank Matanja Coetzee, Zanele Mgcaba, Deborah Hayes, and Jack Killen for their assistance with this project and feedback on an earlier version of this manuscript. We also wish to acknowledge the leadership of C.J. Khondo for facilitating this important exchange and thank Harold Torrence for his expert consultation regarding some of the linguistic aspects of this work. This work was supported by the National Center for Complementary and Alternative Medicine grant U19 AT003264.

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Table 1. Community-Based Participatory Group Development and Expertise Diffusion

<b>Guiding Principles of Community Based Participatory Research</b>	<b>How we addressed</b>
1) Acknowledging community as a unit of identity	<ul style="list-style-type: none"> <li>● Selected leaders from both the THP and allopathic health care provider communities who are all part of the larger community of care providers for those who are HIV+ and at-risk for HIV infection.</li> </ul>
2) Building on strengths and resources within the community	<ul style="list-style-type: none"> <li>● Recruited members of both communities that have an expressed interest in building bridges between the THPs and allopathic health care worlds.</li> <li>● Created opportunities for members of both communities to share their expertise with the group.</li> </ul>
3) Facilitating a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities	<ul style="list-style-type: none"> <li>● Met with leaders from both communities early in the process.</li> <li>● Asked leaders to define the problems to be addressed and solicited their help in addressing them together.</li> </ul>
4) Fostering co-learning and capacity building among all partners	<ul style="list-style-type: none"> <li>● Created a group task (translation of measures) that highlighted the expertise of members from both communities.</li> <li>● Made visits to THPs offices to learn more about how they practice.</li> </ul>
5) Integrating and achieving a balance between knowledge generation and intervention for the mutual benefit of all partners	<ul style="list-style-type: none"> <li>● Dedicated time to the tasks at hand as well as the exploration of group members' dreams and goals for this and future collaborations.</li> </ul>

<p>6) Focusing on the local relevance of public health problems and on ecological perspectives that attend to the multiple determinants of health</p>	<ul style="list-style-type: none"> <li>• Spent time exploring how our collaboration interfaces with the provision of HIV/AIDS and general health care in the community.</li> <li>• Talked about what footprint we would and would not like to leave as a result of our collaboration.</li> </ul>
<p>7) Involving systems development using a cyclical and iterative process</p>	<ul style="list-style-type: none"> <li>• Continue to include all members in all levels of the research process.</li> <li>• Continually requested feedback from all members to ensure that our materials, procedures and public statements are an accurate reflection of what we have done and make adjustments as appropriate.</li> </ul>
<p>8) Disseminating results to all partners and involving them in a the wider dissemination of results</p>	<ul style="list-style-type: none"> <li>• As decided on by the group, we take pictures at each working session and provide copies to all members.</li> <li>• Produce written minutes of all formal meetings and provide copies to all members.</li> <li>• Conduct regular meetings with all members.</li> <li>• Acknowledge the contributions of all members who engaged in the writing process on publications.</li> </ul>
<p>9) Involving a long-term process and commitment to sustainability</p>	<ul style="list-style-type: none"> <li>• Dedicated time to discussing how our efforts together can lead to stronger relationships between THP and allopathic health care providers.</li> <li>• Continue to write grants and develop strategic partnership to meet these goals.</li> </ul>

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