

Measuring the Social Impact of Burn Injuries in Australia: An Adaptation of the Life Impact Burn Recovery Evaluation—The Aus-LIBRE Profile

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Burn survivors can experience social participation challenges throughout their recovery. The aim of this study was to develop a novel Australian English translation of the Life Impact Burn Recovery Evaluation (LIBRE) Profile, the Aus-LIBRE Profile. This study consisted of 3 stages: (1) translation of the LIBRE Profile from American to Australian English by Australian researchers/burns clinicians, (2) piloting and cognitive evaluation of the Aus-LIBRE Profile with burn survivors to assess the clarity and consistency of the interpretation of each individual item, and (3) review of the Aus-LIBRE Profile by colleagues who identify as Aboriginal Australians for cross-cultural validation. In stage 2, investigators administered the translated questionnaire to 20 Australian patients with burn injuries in the outpatient clinic (10 patients from Victoria and 10 patients from Western Australia). Face validity of the Aus-LIBRE Profile was tested in 20 burns survivors (11 females) ranging from 21 to 74 years (median age 43 years). The total body surface area burned ranged from 1% to 50% (median 10%). Twelve language changes were made based on the feedback from the burn clinicians/researchers, study participants, and colleagues who identify as Aboriginal Australians. Using a formal translation process, the Aus-LIBRE Profile was adapted for use in the Australian burn population. The Aus-LIBRE Profile will require psychometric validation and testing in the Australian patient with burns population before broader application of the scale.

Key words: burns; burns recovery; social participation; outcome measure.

INTRODUCTION

Burn injuries are a global health concern. The World Health Organization estimates 11 million burn injuries occur annually worldwide, with a greater than 98% survival rate.¹ Over

the years, there has been a steady increase in survival rates following a burn injury. With improvements in survival rates after a burn injury, there is a need for patient-reported outcome measures (PROMs) to capture the impacts of burn injury and recovery patterns.

Following a burn injury, patients can experience physical as well as psychosocial symptoms. Research has found that

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approximately 30% of burns survivors experience moderate to severe difficulties in social participation.² Many burn survivors report difficulties with maintaining personal relationships and participating in activities that are important to them.³ Existing burn-specific PROMs focus on physical measures rather than social outcomes.³ PROMs are used in both clinical and research settings to determine the patient's needs and to guide therapeutic treatment. A systematic review found most PROMs used in current research with adult patients with burns were not validated.⁴

The Life Impact Burn Recovery Evaluation (LIBRE) Profile was developed to measure the psychosocial and social participation ramifications of burn injury.⁵ The conceptual grounding for the LIBRE Profile is based on the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) model.⁶ The LIBRE Profile measures six areas of social participation including relationships with family and friends, social interactions, social activities, work and employment, romantic relationships, and sexual activity.

While the LIBRE Profile provides information that can potentially inform treatment plans to address social participation following severe burn injury, this profile was developed in the United States and has not been tested or validated in the Australian setting. Significant cultural and language differences exist between the two countries. Successful adaptation of a PROM into a different language or for use with a different cultural group can only be achieved if the content of the PROM reflects experiences that are common across the source and target cultures.⁷

Prior to implementation in an Australian context, the Aus-LIBRE Profile requires testing for appropriateness in an Australian population, including both Indigenous and non-Indigenous Australians. Therefore, the aim of this study was to adapt American LIBRE Profile items and test if the translated version met Australian cultural and language preferences.

METHODS

This study comprised: (1) Translation of the LIBRE Profile from American to Australian English, (2) piloting and cognitive evaluation of the Aus-LIBRE with burn survivors to assess the clarity and the consistency of the interpretation of each individual item, and (3) cross-cultural validation review by colleagues who identify as Aboriginal Australians (Figure 1).

Ethics approval

The project was approved by the SMHS (RGS3920/HREA 2657) and Alfred Health (623/22) HRECs.

Translation of the LIBRE profile

The translation of the LIBRE Profile entailed a forward and backward translation based on the standard methodology of translation and adaptation following PROM guidelines.⁷ The forward translation from source language (American English) to target language (Australian English) was performed independently by 2 Australian English-speaking researchers/burns clinicians (E.C. and T.R.) before being reconciled by 2 Australian English-speaking researchers/burns clinicians (H.S. and D.E.). Minor differences in language were reviewed and

reconciled independently by an Australian English-speaking researcher (Y.S.). After consensus was reached, the process was repeated as a backward translation, from Australian English back into US English to check for consistency by four American English-speaking burn researchers (L.K., C.R., H.B., and A.V.). Refer to Figure 1 for a flow chart of the translation process.

Consumer cognitive debriefing: Assessment of face validity and expression

Previous authors have highlighted the need for the final translation to be tested by means of one-to-one interviews with several (typically 15-20) relevant representatives of the target population.⁸ This is done to ensure linguistic, face and content validity.⁸ The investigators administered the translated questionnaire to 20 patients (10 patients from Victoria and 10 patients from Western Australia) with burn injuries recruited from the Victorian Adult Burns Service and South Metro Health Service outpatient clinics. Screening and recruitment were completed by research co-investigators. Researchers deferred recruitment to another coinvestigator if they were the treating clinician of the patient to ensure participants did not feel obliged to participate. Patients were invited to participate if they were ≥ 18 years, had sustained a burn injury, spoke Australian English as their first language, and had no cognitive deficits recorded in their medical history. Eligible patients were provided with a verbal explanation of the study with the Patient Information and Consent Form and given the opportunity to discuss the study. If the patient indicated their interest in the study, informed consent was obtained.

The cognitive debriefing and evaluation of the Aus-LIBRE Profile was completed by questioning participant's perceptions of the clarity and the consistent interpretation of each item.⁹ For the cognitive evaluation interviews, participants were asked if the intent and language of the questions and responses scales were clear (interview questions available in the supplementary file). Feedback was requested if the patient felt the language could be improved for any item and/or response scales. After the cognitive interview process was completed, the research group examined the feedback and revised items as required.

Cross-cultural validation

A PROM produced in one language (eg, US English), for use with one cultural group within a national population, reflects the values, experiences, and preoccupations of that societal group.⁷ The final step before psychometric testing of the Aus-LIBRE Profile was review by colleagues in Western Australia who identified as Aboriginal Australians. The aim was to ensure that the validation phase version of the Aus-LIBRE Profile was not offensive or culturally inappropriate to Aboriginal and Torres Strait Islander peoples. The reviewers provided feedback on the appropriateness of language, expression, and cultural sensitivities that may hinder engagement of Aboriginal patients with burns during the next phases of Aus-LIBRE Profile development.

RESULTS

The original LIBRE Profile items and their refinement to the Aus-LIBRE Profile based on clinician, academics, and patient

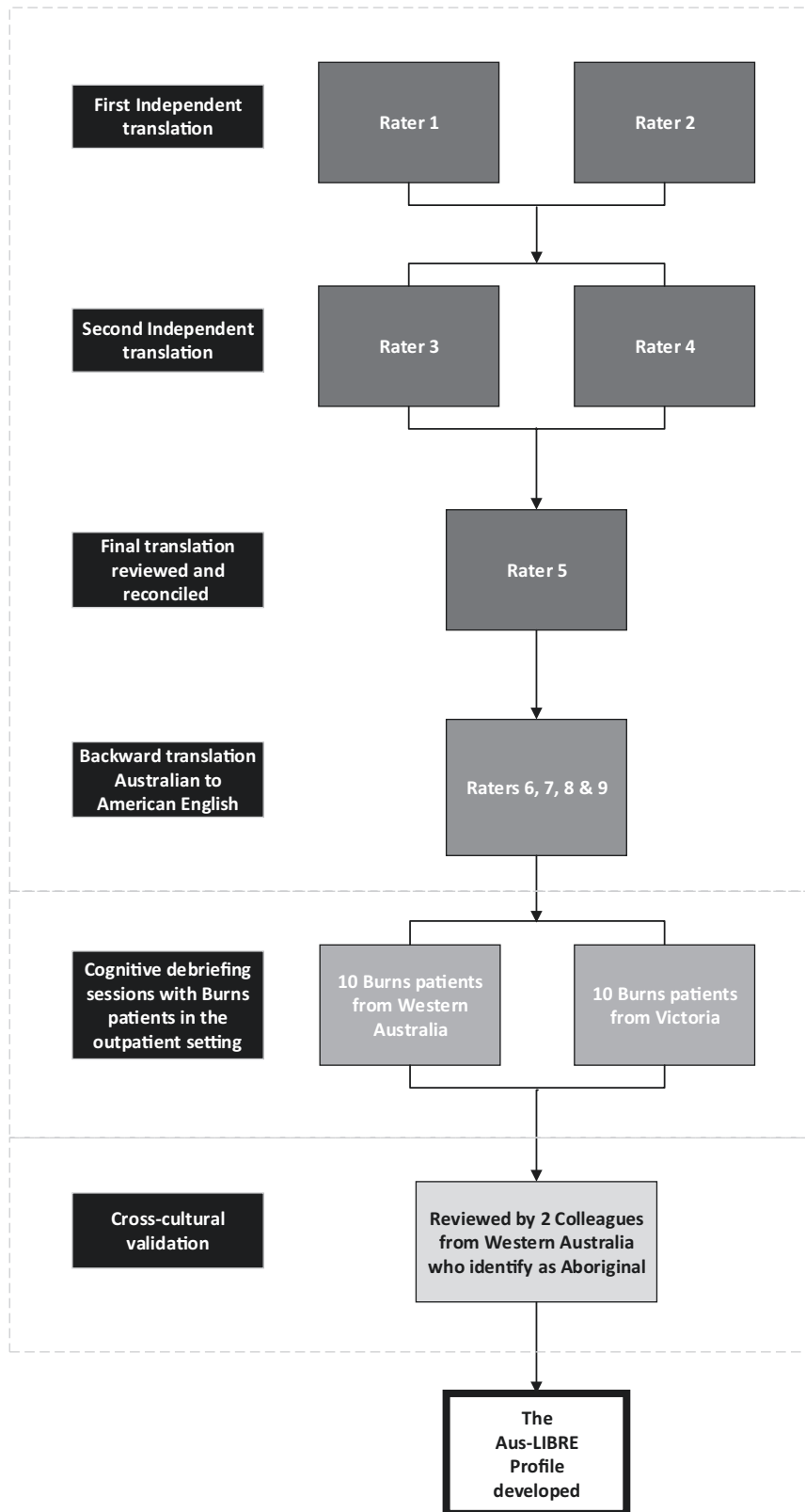


Figure 1. LIBRE Translation Process From American to Australian English

Table 1. Language and Expression Changes Post Initial Translation (Clinician and Reverse Translation)

US original LIBRE short form			AUS-LIBRE profile
Domains	Question number	Questions	Translations
<i>Relationship with friends and family</i>	Q7	I have many friends in the city where I live.	I have many friends in the place where I live.
<i>Social interactions</i>	Q3	I can help strangers feel comfortable around me.	I am able to help strangers feel comfortable around me.
<i>Social activities</i>	Q4	I am able to socialize with my friends.	I am able to socialize with my friends.
	Q6	I am disappointed in my ability to do leisure activities.	I am disappointed in my ability to take part in leisure activities.
<i>Work and employment</i>	Q7	My burns limit me being active.	My burns limit me from being active.
	Q7	At my job, I can do everything for work that I want to do.	At my job, I can complete all the tasks that I want to do.
<i>Romantic relationships</i>	Q2	My partner is very loving to me.	My partner is very loving toward me.

Table 2. Cognitive Interview Participants: Demographics

	Victoria	Western Australia
N	10	10
Gender		
Female <i>n</i> (%)	5 (50%)	6 (60%)
Male <i>n</i> (%)	5 (50%)	4 (40%)
Age (yr)	22-74	21-58
TBSA range (Median)	1%-50% (9%)	1%-51% (10%)
Surgical procedure <i>n</i> (%)	7 (70%)	7 (70%)

feedback are demonstrated in Tables 1, 3, and 4. The bold text indicates the language changes made to specific items in the Aus-LIBRE Profile.

The first version of the Aus-LIBRE Profile was developed following the initial clinician and researcher forward and backward translation. This version involved 7 language changes, including common spelling variations between the 2 languages including “socialize” (American English) and “socialise” (Australian English). There were multiple language variations between US English and Australian English, these are shown in Table 1.

Face validity was tested in 20 burns survivors; median age 43 years, 55% female, a median %Total body surface area of 10 (Table 2).

The second version of the Aus-LIBRE Profile was developed following cognitive debriefing interviews with 20 patients following burn injuries and included 4 language changes after this process was completed (Table 3). There were suggestions from the cognitive debriefing interviews to include additional items including “Does your burns limit you going on dates?” and “I am nervous seeing people I know who aren’t aware of my burns.” There was also a suggestion that “it would be good to have a question around whether quality of life is improving post-incident.” The purpose of the cognitive debriefing interviews was to review the language of the Aus-LIBRE Profile rather than changing the meaning or the addition of new items to the PROM. From a language perspective, a participant stated a preference for questions to read “Do you” or “Are you” instead of “I” or “I am.” They didn’t feel they related well to statements instead of questions. This change was not implemented due to

the nature of the response scales and how the item answers were analyzed in domains.

The third version of the Aus-LIBRE Profile was reviewed by the Aboriginal Australian colleagues in Western Australia. This final check prior to the validation phase resulted in one language change (Table 4) regarding the instructions page with the addition of a choice to answer questions only if you feel comfortable to do so. In the “Relationships with family & friends” domain, there were lengthy discussions regarding “I have many friends in the place where I live.” The initial clinicians who reviewed the Aus-LIBRE Profile, thought “city” should replace “place” however following the cross-cultural validation review, “place” was found more culturally appropriate for the Australian and Indigenous population.

Another variation between languages included “Members of my family” (US English) and “My family” (Australian English). One of the colleagues who identify as Australian Aboriginal reviewed the Aus-LIBRE Profile and acknowledged the definition of family was quite different for Aboriginal people compared to non-Indigenous Australians are likely to view or interpret their family. The reason for not changing the wording from “My family” allows for broader interpretation of the phrase.

DISCUSSION

The Aus-LIBRE Profile had several item level language changes based on the feedback from the burn clinicians/researchers, study participants, and Aboriginal Australian

Table 3. Language and Expression Changes Post Cognitive Debriefing Interviews With Burns Patients

US original LIBRE short form		AUS-LIBRE profile	
Domains	Question number	Questions	Translations
<i>Relationship with family and friends section</i>	Q1	Members of my family give me the support that I need.	My family give me the support that I need.
	Q4	Members of my family enjoy meeting my friends.	My family enjoy meeting my friends.
<i>Social interactions</i>	Q7	I avoid doing things that might call attention to my burns.	I avoid doing things that might bring attention to my burns.
<i>Work and employment</i>	Q6	I get tired too quickly at my job.	I get tired very quickly at my job.

Table 4. Language and Expression Changes Post Cross-Cultural Validation

US original LIBRE short form		AUS-LIBRE profile	
Domains	Question number	Questions	Translations
<i>Instructions</i>	N/A	Some questions are very similar and are meant to be that way. Please answer all questions.	Some questions are very similar and are meant to be that way. Please answer all questions if you feel comfortable to do so. If you do not feel comfortable answering any of the survey questions, please leave blank and move onto the next item.

colleagues. The process and outcomes from the development of the Aus-LIBRE Profile are described. The documentation of the development of the Aus-LIBRE Profile may assist clinicians worldwide in future translation of the LIBRE Profile into different languages. The development of the Aus-LIBRE Profile aims to provide a PROM which can be used by burn survivors and clinicians to monitor return to community based social participation and social functioning.

As recommended, this study used a formal adaptation process^{7,10} to ensure high-quality translations and that the original intention of items were not lost during the adaptation process. It is insufficient to produce a new language version of a PROM by simple literal translation, as cultural factors are often fundamental to the spoken language.⁷ There are also nuances specific to a language that are not always clear to non-native speakers.¹¹ Overall, a literal translation may produce an item that appears identical to the original, however it may have missed the actual meaning of the item. This could lead to variations in the understanding of the original and translated items. Future iterations of the LIBRE Profile into various languages should undergo a formal adaptation process to ensure that cultural sensitivity is maintained.

There are strengths and limitations to the approach and findings in this study. A strength of the study was the inclusion of two varied population samples within Australia, from Victoria and Western Australia. This introduced greater diversity into the interpretations and perceptions of relevance of the items in burn survivors from different Australian geographic contexts and social backgrounds. While colleagues who identify as Aboriginal participated in reviewing the Aus-LIBRE Profile for cross-cultural validation, no Aboriginal or Torres Strait Islander patients were able to be recruited in the timeframe allocated to completion of the cognitive debriefing interviews. Also, the Torres Strait Islander population specifically was not represented in this phase of the study. For future iterations of the Aus-LIBRE

Profile, the authors would prefer to co-design a specialized version with Aboriginal and Torres Strait Islander peoples. Lastly, the planned number of participants recruited for this phase of the Aus-LIBRE Profile development was consistent with other PROM adaptation processes^{7,8} and thus, a sample size calculation for this study was considered unnecessary. Future validation studies should consider the level of education as this was not collected and therefore we were unable to ascertain the level of education required to complete the Aus-LIBRE Profile.

In addition, future work in a much larger study will also involve the authors in a review of the translations of the entire original LIBRE Profile item bank, which is now available in an Item Response Therapy based Computerized Adaptive Testing model of the LIBRE profile.

This study has reported on the process of translation and development of the Aus-LIBRE Profile, a self-reported outcome measure for social participation of burn survivors. The next step toward clinical use of the Aus-LIBRE Profile is psychometric validation and testing in the Australian patient with burn population before broader application of the scale so that analytic bridges can be built for future cross-country comparisons.

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