Lost in translation: using standardised self-report measures in cross-cultural research

Why *Know our story*?

Welcome to the *Know our story* initiative.

Our ambition is to inspire, encourage and support clinical and population health researchers to work towards greater social inclusion and equity in research practices. *Know our story* is about working in partnership with communities of refugee and migrant backgrounds. It is also about consultation, collaboration and co-design of research; the sharing of knowledge; and different ways of working that promote social equity and inclusion.

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We acknowledge the traditional owners and custodians of the lands on which we live and work. We pay our deepest respects and express our gratitude to their Elders past, present and emerging. We recognise and value the resilience and diversity of Aboriginal and Torres Strait Islander people and their spiritual connections to land, community and culture.

Purpose

The goal of this resource is to provide guidance regarding the use of standardised self-report measures in research involving people of refugee and migrant backgrounds.

There are many standardised and validated self-report measures and screening tools in common use in population health and clinical research. These tools include validated measures of common mental disorders, such as depression, anxiety, post-traumatic stress disorder and complex trauma. For children and adolescents, validated measures include: the Strengths and Difficulties Questionnaire (SDQ), the Child Behaviour Checklist (CBCL) and the Children and Young People Resilience Measure (CYRM). Adult measures include: the Edinburgh Postnatal Depression Scale (EPDS), the Center for Epidemiological Studies – Depression Scale (CES-D), the Patient Health Questionnaire (PHQ-9) and the Harvard Trauma Questionnaire (HTQ).

Most of these measures were initially developed and validated in Anglo-Celtic populations in English-speaking countries. Despite the cultural diversity of countries such as Australia, Canada and the UK, there are relatively few studies assessing the cultural validity and acceptability of either the English language or translated versions of these study measures for use with refugee and migrant populations in high-income countries.[1-5]

The lack of translated and culturally adapted study measures often leads to the systematic exclusion of refugee and migrant populations from research studies. Even in studies that facilitate participation of migrant populations, for example, by translating study instruments and/or using interpreters, there is significant potential for bias when using outcome measures that have not been assessed for linguistic or cultural equivalence.

This resource provides

- an overview and examples of **common challenges** researchers may encounter when using standardised self-report measures and screening tools with people of refugee and migrant backgrounds
- a summary of **steps that researchers can take to address these challenges.**

Ten common challenges using self-report measures in cross-cultural research

Challenge #1
Lack of cultural equivalence

Self-report measures and screening tools developed for Anglo-Celtic English-speaking populations in high-income countries may result in under ascertainment of symptoms when applied to refugee and migrant populations. For example, in adults and children, cultural differences in somatisation of symptoms, and ways of expressing emotional distress have been identified as potential sources of misclassification in measures of depression.[5-8]

Challenge #2
Lack of semantic equivalence

There may be semantic differences in the way words are understood and translated that result in subtle or overt changes in meaning.[9] In some languages, particularly those with strong oral traditions, there is no direct translation for the concept of 'depression'. For example, the commonly used S'gaw Karen (an ethnic dialect from Burma and Western Thailand) word to describe depression can be translated as 'poor heart'. Without additional framing to provide context, the intended meaning may be lost.[10]

Challenge #3
Use of Likert-style responses

The language used and format for self-report measures may be difficult to translate in ways that work for some populations, particularly those with strong oral traditions or low literacy. The use of Likert-style response options, which are common in standardised measures, can be problematic. For example, a study with Burmese and Karen-speaking people found it was necessary to provide lengthy explanations for distinctions between 'a little bit', 'moderately' and 'quite a bit'.[11] Other studies have also documented difficulties using Likert-style response options in populations with low literacy[12] and/or where English is not a first language.[1]

Challenge #4
Use of colloquialisms specific to cultural context

Colloquialisms or idioms are specific to cultural context and can be difficult to translate. For example, the Edinburgh Postnatal Depression Scale (EPDS) item referring to 'things getting on top of me' is challenging to translate in some languages and cultures, where this metaphor for human experience is unfamiliar.[13]

Challenge #5
Indirect ways of asking questions

Indirect ways of asking questions can also be problematic. Small and colleagues found that the last item on the EPDS which asks about 'the thought of harming myself' (referring indirectly to thoughts of suicide) was challenging to translate into Vietnamese, Turkish and Tagalog. Even with careful attention paid to this in iterative stages of translation, back-translation, and consultation with community advisors, they found that the question was sometimes misunderstood as referring to the possibility of something bad happening to the woman herself or a family member, rather than to thoughts of suicide as intended.[13]

Challenge #6
Lack of cultural equivalence in expectations of children

Behaviours in children that potentially signify emotional difficulties in Anglo-Celtic populations in high-income countries, may not be good indicators of emotional difficulties in other cultural contexts. In a study examining the cultural validity of the CBCL and the SDQ, Dang and colleagues found that the SDQ item 'gets along better with adults than children' was not discriminatory in identifying Vietnamese children with emotional difficulties. They conjectured that this was because many children in Vietnam are expected to participate in family-based agricultural labour, and thus children who relate well to adults are viewed favourably.[14]

Challenge #7
Lack of experiential equivalence

Items that seek to capture the experience of daily life that work well in one country and cultural context, may not work well in another cultural context. For example, the CBCL asks about a range of sports and activities (e.g. baseball) that children may be engaged in. Some of these may not be familiar to children who have grown up outside of the US.[14]

Challenge #8
Lack of conceptual equivalence

Words may hold different conceptual meanings in different cultures and cultural contexts. For example, questions about connectedness to 'family' may be interpreted as referring to immediate (or nuclear) family or extended family depending on culture and context. For a child (or an adult) in a family that has been forced to leave their homeland,

the term 'family' may signify extended family members who remain in their homeland (country of origin) from whom they may feel disconnected, while still having close connections with immediate family members, such as their parents and siblings.[15]

Challenge #9
Translation and back-translation is not enough

Use of translation and back-translation to develop community language versions of standardised measures and screening tools is generally viewed as best practice. However, even when measures are subject to careful translation and back-translation, this does not guarantee that measures will work well in practice.[9,13] Careful translation and back-translation, and repeated checking with community researchers and community advisors are essential to the quality of translated study measures and improve the cultural acceptability and validity of study measures. These steps are important to reduce the potential for ascertainment bias.[15,16]

Challenge #10
The way that standardised tools are introduced matters

Finally, the way that questions and standardised tools are introduced to research participants also matters. Adding a preamble to explain what is coming next can make a big difference to how people respond to standardised measures. Offering to pause for a moment or skip a set of questions if the research participant appears reluctant to answer questions on a particular topic ensures that research participants know that they have a choice not to answer any questions should this be their preference. People who have experienced totalitarian regimes or been subject to lengthy detention and migration processes, may feel anxious when asked to fill in forms or answer direct questions from researchers. This anxiety may affect their willingness to participate in research and their readiness to disclose personal information.[17] It is also important for researchers to think carefully and seek advice about processes for offering culturally appropriate support and referral pathways to research participants as an integral part of study protocols.

In summary, there are many challenges for researchers seeking to use standardised measures and screening tools with people of refugee and migrant backgrounds. The translation and back-translation of study measures alone may not be sufficient to bridge these cultural differences and ensure the acceptability and validity of screening tools across diverse cultural and linguistic contexts. Researchers need to pay particular attention to the semantic, experiential and conceptual equivalence of study measures and ensure that research methods and approaches are culturally appropriate to the populations they seek to engage in research.

CASE STUDY

Pre-testing the Edinburgh Postnatal Depression Scale

The Edinburgh Postnatal Depression Scale (EPDS) is a 10-item self-report scale which asks women to rate how they have felt in the previous week. In 2017, we undertook a study to assess the cultural acceptability and validity of the EPDS for use with four refugee background populations: Assyrian Chaldean women from Syria, Afghan women, Karen women from Burma, and Vietnamese women.

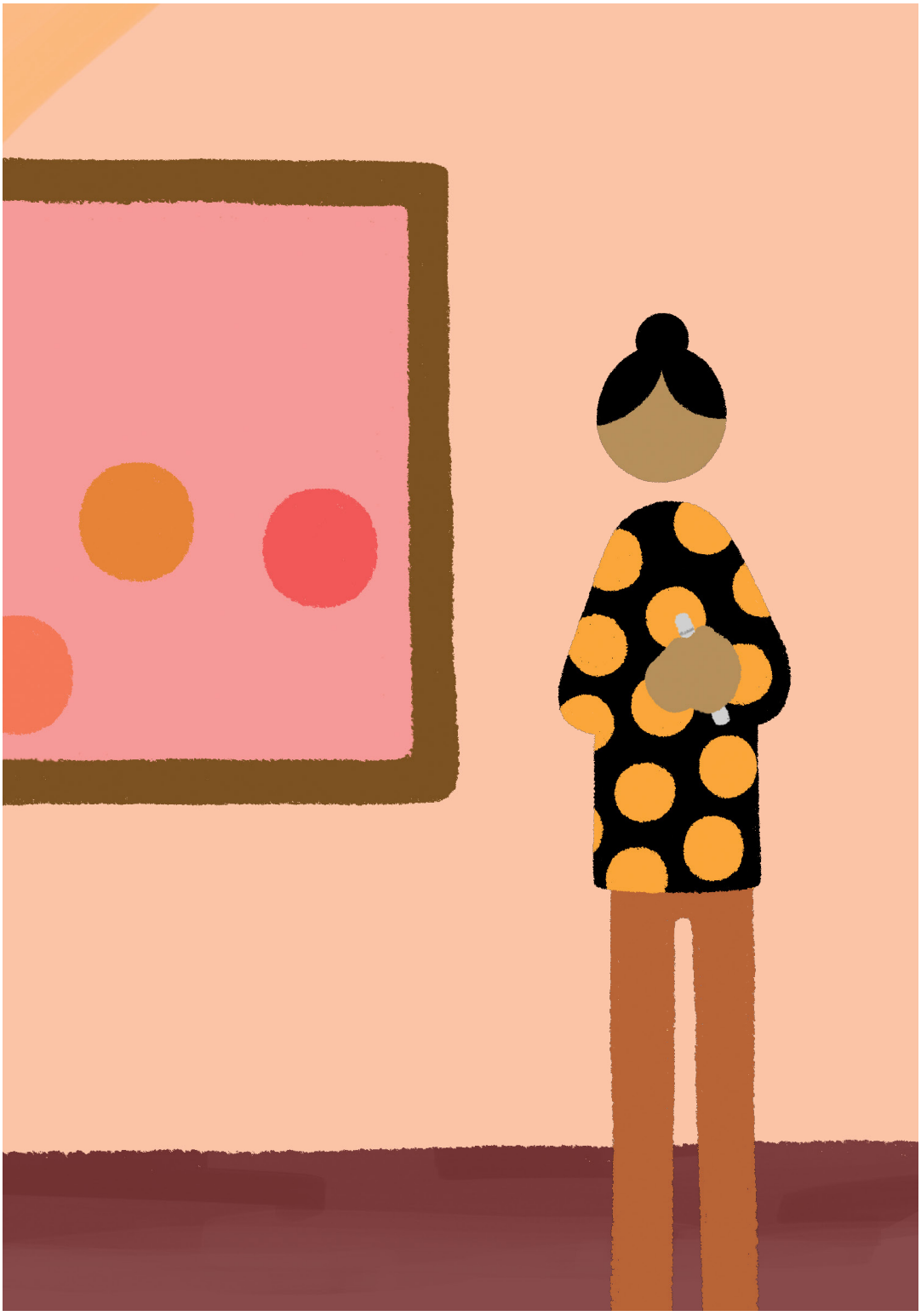
Study procedures involved:

- translation of the EPDS by a qualified NAATI (National Accredited Authority for Translators and Interpreters) accredited translator and back-translation by community researchers in our team
- careful checking of translated versions of the EPDS with community advisors for each community
- further checking of translated versions of the EPDS with community discussion groups
- pre-testing with pregnant women in each community in women's preferred language.

Key findings:

- Arabic-speaking women from the Assyrian Chaldean community were able to understand the language and concepts in each question of the EPDS and were comfortable with this measure.
- Karen women had difficulty understanding the formal written Karen language used by the NAATI accredited translator. Women participating in discussion groups and interviews were more comfortable and familiar with conversational Karen language, requiring a second round of translation into conversational Karen and further testing.
- Some words and colloquial phrases, such as 'things were getting on top of me' and 'seeing the funny side of things' were difficult to translate into Karen and Dari. For example, in Dari, the word 'funny' was translated as 'crazy'.
- Karen women had difficulty with the format of questions and responses, especially the questions that required looking back in time and comparing this time with the past 7 days. For example, the item 'I have looked forward with enjoyment to things' requires participants to compare their feelings in the past 7 days with their feelings looking back in time. In practice, the community researchers found they needed to break this item down into a series of questions to make it easier for women to understand and respond.
- The community discussion groups also identified the reluctance of some women to disclose mental health issues due to a sense of shame and stigma.

As a result of this feedback, we decided **not** to proceed with use of the EPDS as a measure of depressive symptoms in these communities.



What can researchers do to improve cultural acceptability and equivalence of standardised self-report measures?

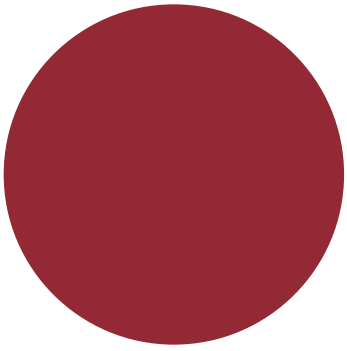
There is no simple way to improve the cultural acceptability and equivalence of standardised self-report measures for use with populations of refugee and migrant backgrounds. Best practice involves:

- translation and cultural adaptation of study measures
- working with community researchers and community advisors
- pre-testing to identify how well culturally adapted study measures work in practice, and
- concerted efforts to incorporate iterative cycles of feedback and optimise data integrity.

The steps needed to improve the validity of study measures will vary according to the type of study, the population/s involved, and the extent of prior work assessing the cultural acceptability and content validity of translated and English language versions of study measures.

For studies to include people with limited English language fluency, it will be essential that study measures are available in community languages. However, it is important to note that considerations of cultural acceptability and content validity of study measures do not only apply to translated versions of study instruments. Many of the same issues need to be considered when using English language versions of study measures with people of refugee and migrant backgrounds who are fluent in English.

Considerations for improving cultural acceptability and equivalence of self-report measures



Consideration #1
Lessons from the field

Where possible, when conducting research with people of refugee and/or migrant backgrounds, it is best to select study measures that have been assessed for their cultural acceptability and validity with similar populations. In rare cases, a culturally adapted and validated measure may be available for a specific population.[3] More often, there may be evidence from prior work identifying potential sources of cultural bias. For example, Fellmeth and colleagues found that the *Refugee Health Screener-15* – even though designed specifically for refugee populations – performed poorly as a method for identifying mental health disorder compared to diagnostic interview, when used with people living on the Thai-Myanmar border.[11] In part, this was due to the lack of semantic and experiential equivalence in the translated version of this scale. The more open ended nature of diagnostic interviews provided an opportunity for people to describe states of health in their own words, leading to the identification of a much higher burden of mental health disorder. Evidence of this kind can be very helpful background information to inform selection, cultural adaptation and pre-testing of study measures for use with refugee and migrant populations living in Australia.

Consideration #2
Best practice approaches

There are now several international guidelines outlining best practice approaches to cross-cultural adaptation of self-report measures that can be used to maximise the attainment of semantic, idiomatic, experiential, and conceptual equivalence between source questionnaires and culturally adapted questionnaires.[9,15,18]

The first of these was produced by Beaton and colleagues, who outlined the 5-step process shown in Figure 1. Beaton's 5-step process involves: forward translation by two translators; synthesis and resolution of discrepancies between the two translations; back-translation by two English language speakers; expert committee reviews; and pre-testing the complete questionnaire with 30-40 research participants, with probing to understand item response.[9]

Beaton's 5-step process has been affirmed in two recent reports on good practice for the translation and cultural adaptation of patient-reported outcome measures. These reports were produced by a working group of the Quality of Life Sub-group of the International Society of Patient-Reported Outcome Research and the International Society for Quality of Life Research Translation and Cultural Adaptation Special Interest Group.[18]

Figure 1. Beaton's 5-step process for cross-cultural adaptation of self-report measures.[9]

Consideration #3
Involving community researchers and community advisors

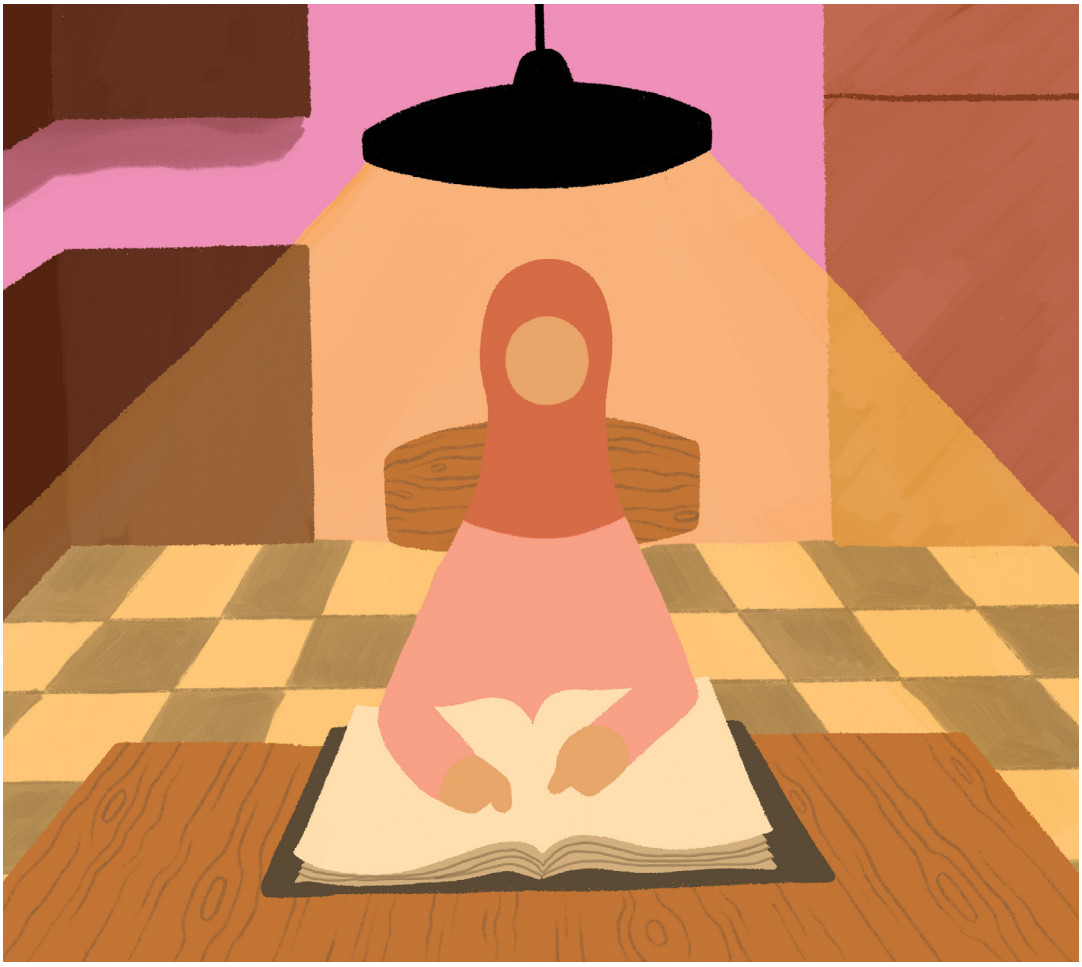
Thoughtful consideration of study procedures – for example ways of obtaining consent, ways of introducing questions, and the sequence in which questions are asked – is also an important element of protocol development in studies involving people of migrant or refugee backgrounds. Pre-testing study procedures with a pilot group can be helpful to identify any cultural or language issues that may need to be considered with respect to study procedures as well as the wording of study measures.

In our work, we also involve community advisors (specific to the populations we are working with) in the review and pre-testing of study measures.[17,19] We ask them to provide advice and support us to interpret feedback and responses from community participants taking part in pre-testing of study measures and procedures. This assists us to:

- gauge the way in which all parts of a questionnaire or interview schedule, including the preambles to each section, individual questions, and response options for each question or item are understood by research participants
- establish that no questions are likely to cause distress to research participants or our community researchers.

We also routinely offer research participants the opportunity to complete study measures in their preferred language in an interview facilitated by community researchers. Participants are encouraged to ask questions to clarify anything that is unclear or confusing to them. This is particularly important for communities that have strong oral traditions and less familiarity with both written language and the structure of standardised questionnaires. Other strategies that our team have used include the use of pictorial prompts to anchor a Likert-style set of responses, and pre-prepared prompts providing a consistent way to explain what particular questions are asking of participants.

It is important to keep in mind that what works with one community may not work with another. It is vital that study procedures and study measures are pre-tested with *every* community that a research study intends to engage.



Consideration #4
Resource implications and timelines

Each of these steps take time and resources. It is important for researchers to build into their timelines and research budgets sufficient time and resources to implement high quality processes for assessing and improving the cultural validity of self-report measures to be used with specific populations of refugee and migrant backgrounds.

As noted in other resources in this series, working with community researchers (culturally and linguistically matched to communities that researchers are intending to engage) and seeking the advice of community advisors are critical to facilitate community engagement and support careful pre-testing of study measures and procedures with individual communities.[1,20]

There are costs and other resource implications associated with each of these processes, including the need to employ and train community researchers, and provide mentoring and support to establish relationships with specific communities. These resource implications are akin to some of the costs involved in developing culturally appropriate and culturally safe processes for working with Aboriginal and Torres Strait Islander communities.

In summary

There are a number of steps that researchers can take to improve cultural acceptability and validity of self-report measures for use with refugee and migrant background communities. Building in time for careful pre-testing of study measures and procedures, whether used in translation or in English, is one of the most important ways in which the cultural acceptability and equivalence of study measures can be gauged. The involvement of community researchers and community advisors (specific to the communities that researchers are seeking to engage in research) is critical to optimise data integrity.

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