Ensuring health equality amid the great diabetes epidemic: Translating the Leicester Self-Assessment Risk Score

Andrew Willis, Laura Gray, Kamlesh Khunti

Andrew Willis is Research Associate; Laura Gray is Associate Professor of Population and Public Health Sciences; Kamlesh Khunti is Professor of Primary Care Diabetes and Vascular Medicine, all at University of Leicester

There has been a rise in popularity of self-assessment risk scores for chronic conditions such as type 2 diabetes, which allow individuals to self-assess their own risk of developing a condition and take steps to reduce this risk if necessary. One such tool is the Leicester Self-Assessment Risk Score (Gray et al, 2010), which has been developed to predict the risk of type 2 diabetes in multi-ethnic populations. The success of this measure as a tool for prevention relies on the participant having a conceptual understanding of being at "high risk", including the steps that can be taken to reduce this risk. Comparatively, little emphasis has been placed on conceptual understanding of the results when translating such documents (Weidmer, 1994). This is of particular importance in the calculation of disease risk, as subsequent behaviour change could be undermined if participants do not fully understand the concept of being at high risk.

There is a wealth of literature describing the translation of a variety of health scales (Brislin, 1970; Beaton et al, 2000). For the most part, translators have focussed on maintaining content validity and reliability between languages. Presumably, this is because these tools are most commonly used within a clinical or research setting to assess treatment effects, or to screen individuals prior to intervention. The ability of the person completing the score to interpret and understand the results is of lesser importance when used in this context.

Translating the Leicester Risk Score

Recently, Patel et al (2016) have developed and utilised a translation model to translate the Leicester tool from English into Gujarati, in order to meet the needs of communities from a multi-ethnic population in the East Midlands. The eight-stage model consisted of revision and refinement of the original version to make the language conducive to translation; development of a conceptual guidance document for translators to use; forward translation (English to Gujarati); backwards translation (Gujarati to English); reconciliation and agreement of translations; clinician review; pilot testing; and final revision and checks.

The study highlights that a focus on linguistic equivalence in the translation may be counterproductive, as words which have a similar definition in different languages can be conceptualised very differently. From the experience of translating the Leicester score, for example, the direct Gujarati translation of the word "risk" – "*jokhem*" – was interpreted as meaning "danger" by focus group participants. To overcome this, the authors followed an approach using a phonetic spelling of the Gujarati word, adding a detailed explanation of the meaning of the word "risk" to describe the context in which it was being used. This resulted in good understanding of the information contained in the diabetes risk score, and it allowed the majority of focus group participants to fill out the score unaided and to interpret the results.

The authors acknowledge that some people still have difficulties in completing the risk score, and there are still issues with communicating the concept of being at "high risk". Fatalistic beliefs, low levels of health literacy and misunderstanding of risk factors for type 2 diabetes are common amongst members of the South Asian community in particular (Carr-Hill et al, 1996; Lucas et al, 2013). Low levels of literacy limit individuals' ability to self-calculate BMI using their body weight and height, and to understand its significance in contributing to diabetes risk. Alternative strategies, including the promotion of web-based versions that can automatically calculate BMI and support from family members/healthcare professionals, may need to be considered to meet the needs of some communities.

Overall, the methods developed by Patel and colleagues promoted conceptual understanding

of the risk score, and the translational model is of relevance to the development of existing self-assessed measures of disease risk. It is of vital importance to continue working on adapting methods to engage non-English-literate populations, who are often at high risk of type 2 diabetes, in screening and prevention. In not doing so, there is the potential to promote health inequality, as these tools are being widely implemented amongst the English-speaking population (NICE, 2012), thus improving rates of early detection and preventing complications in one group while failing to do so in others. ∎

The study by Patel and colleagues can be read in full at: http://dx.doi.org/10.1155/2016/8107108

Beaton DE, Bombardier C, Guillemin F, Ferraz MB (2000) Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila Pa 1976)* **25**: 3186–91

Brislin RW (1970) Back-translation for cross-cultural research. *J Cross Cult Psychol* **1**: 185–216

Carr-Hill R, Passingham S, Wolf A, Kent N (1996) *Lost opportunities: the language skills of linguistic minorities in England and Wales*. Basic Skills Agency, London. Available at: http://bit.ly/2e26jTI (accessed 02.11.16)

Gray LJ, Taub NA, Khunti K et al (2010) The Leicester Risk Assessment score for detecting undiagnosed type 2 diabetes and impaired glucose regulation for use in a multiethnic UK setting. *Diabet Med* **27**: 887–95

Lucas A, Murray E, Kinra S (2013) Health beliefs of UK South Asians related to lifestyle diseases: a review of qualitative literature. *J Obes* **2013**: 827674

NICE (2012) *Type 2 diabetes: prevention in people at high risk* (PH38). NICE, London. Available at: www.nice.org.uk/guidance/ph38 (accessed 02.11.16)

Patel N, Willis A, Stone M et al (2016) Developing a conceptually equivalent type 2 diabetes risk score for Indian Gujaratis in the UK. *J Diabetes Res* **2016**: 8107108

Weidmer B (1994) Issues and guidelines for translation in cross-cultural research. *Proceedings of the Survey Research Methods Section*. American Statistical Association, Alexandria, VA, USA: 1226–31

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Further information

The **Leicester Diabetes Risk Score** is recommended by NICE and used by Diabetes UK for the identification of people at risk of diabetes. The score identifies people who may be at high risk of diabetes or currently have undiagnosed type 2 diabetes using data on age, sex, BMI, ethnicity, family history of diabetes and antihypertensive use.

The **Self-Assessment Risk Score** has been developed by the University of Leicester and Diabetes UK to allow people to self-calculate their risk of having undiagnosed diabetes now, or developing it in the future.

The self-assessment score is currently available in English, Gujarati and Bengali. Punjabi and Urdu versions are due to be published soon.

Interested parties can request print versions of the translated versions free of charge by filling in the form at: **http://leicesterdiabetescentre.org.uk/testing**