The Australian Centre for Behavioural Research in Diabetes

Important User Information for the Type 1 and Type 2 Diabetes Stigma Assessment Scales (DSAS-1 and DSAS-2)

Introduction

The Type 1 Diabetes Stigma Assessment Scale (DSAS-1) and the Type 2 Diabetes Stigma Assessment Scale (DSAS-2) have been designed as self-report measures of perceived and experienced diabetes stigma, for completion by adults with type 1 diabetes and type 2 diabetes respectively. The Australian Centre for Behavioural Research in Diabetes (ACBRD) holds the copyright for the original scales and any subsequent modified or translated versions.

Protecting the integrity of the scales

The integrity of the DSAS-1 and DSAS-2 is important, which is why we require you register your use of the scale(s) or, in the case of commercially funded projects, complete a user agreement. The purpose of this process is to ensure:

- you access the latest and most appropriate (in terms of language, culture) versions of the scales and scoring guidelines;
- we are able to track all the various uses of the scales and their translations, to protect the integrity of the measures, and guide development of new languages, user tools and information guidelines;
- there is no unauthorised use, alteration or translation of the questionnaire, and no breach of copyright.

It is important that any copies of the scales made for completion by study respondents are of good quality. This means:

- ensuring the font size and formatting aid ease of reading (in print and online); users are advised to keep the formatting as similar as possible to the original provided
- no alteration of instructions, item wording, response format or response options, except with the express written permission of the ACBRD.

Permission to use the DSAS-1 or DSAS-2 name will not be granted for any unauthorised modification or translation. Any analyses or publications of unauthorised versions may not use the DSAS-1 or DSAS-2 names and may be considered a violation of copyright protection.

Conditions of use in non-commercially funded projects or clinical practice

The DSAS-1 and DSAS-2 are made available free of charge to students, clinicians and academic researchers for use in non-commercially funded projects or routine clinical practice. Non-commercially funded projects include those that are unfunded (e.g. student projects), or funded by charities / foundations (e.g. Diabetes Australia Research Program, Diabetes UK), or by public funds (e.g. NHMRC, ARC, NIHR, MRC, NIH).

If you are planning to use an existing, validated version of the scale(s) in a non-commercially funded project, then we require you to simply sign a declaration to that effect and send it to us to register your study (**Appendix 1**). NB. Scoring guidance will provided upon receipt of a signed declaration.

If you wish to translate the questionnaire, please see the relevant section below and complete the relevant form in **Appendix 2**.

If you are at all unsure, please review the conditions for use in commercially funded projects below and/or contact the ACBRD (e: info@acbrd.org.au).

Conditions of use in commercially funded projects

The DSAS-1 and DSAS-2 are made available to researchers for use in commercially funded projects by formal arrangement with the ACBRD. Commercially funded projects include those commissioned or sponsored by industry (e.g. pharmaceutical or medical device company). In this situation, a fee is applicable for each language version of the DSAS-1 and DSAS-2.

If you are planning to use the questionnaire in a commercially funded project, then you will need a copy of the Commercial User Agreement Information to enable an agreement to be drawn up. Please request a copy from the ACBRD (e: info@acbrd.org.au).

Translation to other languages and cultures

The DSAS-1 and DSAS-2 are currently available in the following languages:

- English (Australian), validated in an Australian non-clinical sample.

Use of the DSAS-1 or DSAS-2 in other cultural or linguistic groups would require appropriate adaptation.

Internationally accepted translation methodology involves forward-backward translation and reconciliation, to ensure the cultural and linguistic validity of the translation. It is a rigorous process, which may take 12-16 weeks. This can be undertaken by a reputable agency. Alternatively, academics may conduct their own cultural adaptation and linguistic validation without employing an agency, but assurances will need to be provided to the ACBRD that appropriate methodologies are being used (e.g. a protocol will need to be reviewed by ACBRD in advance, provision of a report upon completion).

In theory, if the translation process has created a questionnaire that is equivalent to the English version in meaning, and culturally appropriate for the target population, then the psychometric properties of the original questionnaire can be expected to also apply to the translation (though this would need to be confirmed through statistical analyses). All new translations:

- need to be authorised (i.e. agreed in advance) by the ACBRD;
- need to be overseen by the ACBRD, to ensure the integrity and appropriateness of the new translation;
- will remain the copyright of the ACBRD.

Where new translations are to be commissioned and funded by a commercial organisation, the per language fee is waived but consultancy services from the ACBRD will be required.

NB. If you are planning to translate the questionnaire before use in a study or clinical practice, then you will need to complete **Appendix 2**.

Publications

Browne JL, Ventura AD, Mosely K, Speight J. Measuring the stigma surrounding type 2 diabetes: development and validation of the Type 2 Diabetes Stigma Assessment Scale (DSAS-2). *Diabetes Care*, in press.

Browne JL, Ventura AD, Mosely K, Speight J. Development and validation of the Type 1 and Type 2 Diabetes Stigma Assessment Scales. Poster presented at the 76th American Diabetes Association Scientific Sessions, 10-14 June 2016, New Orleans, USA.

Appendix 1: Declaration for Non-Commercial Use of Questionnaire

Name: Position:

Organisation:

Address:

Email: Telephone:

Name (and language version) of questionnaire(s) requested:

Language(s) in which questionnaire(s) to be used:

Title of study / project in which questionnaire is to be used:

Study start and end date:

Study population (e.g. type of diabetes, age group):

Study sample size (expected):

How will the questionnaire(s) be administered (paper / online)?

How many times will each respondent complete the questionnaire?

Declaration:

- ☐ I declare that I wish to use the above questionnaire(s) in a non-commercial study / research project, or for routine clinical practice.
- ☐ I confirm that I have received no monetary contribution from a commercial organisation (e.g. pharmaceutical or medical device company), that my project has no sponsor OR that it has received only charity or public funding.
- ☐ I acknowledge that this declaration will authorise me to use the questionnaire(s) named above for the limited purpose described above.
- ☐ I acknowledge that I am not permitted to:
  - use the questionnaire(s) in any project other than that named above
  - copy, sell or sublicense use of the questionnaire to any third party
  - modify, translate, copy or otherwise duplicate the questionnaire(s), except with express permission of the Licensor (ACBRD)

Signature: _____ Date:

Name:

Your privacy matters. This information is intended for ACBRD use only and will be treated in confidence. You have the right to access, modify, rectify and delete any data that concern you. To exercise that right, please contact the ACBRD (e: info@acbrd.org.au).

Appendix 2: Declaration for Non-Commercial Translation of Questionnaire

Name: Position:

Organisation:

Address:

Email: Telephone:

Name of questionnaire(s) requested:

Language(s) in which questionnaire(s) will be translated / culturally adapted:

Title of study / project in which questionnaire is to be used:

Start and end date:

Cognitive debriefing population (e.g. type of diabetes, age group):

Declaration:

- ☐ I declare that I wish to translate or adapt the above questionnaire(s) in a non-commercial study / research project, or for routine clinical practice.
- ☐ I confirm that I have received no monetary contribution from a commercial organisation (e.g. pharmaceutical or medical device company), that my project has no sponsor OR that it has received only charity or public funding.
- ☐ I acknowledge that this declaration will authorise me to culturally adapt and linguistically validate the questionnaire(s) named above for the limited purpose described above.
- ☐ I acknowledge that I am not permitted to:
  - use the questionnaire(s) in any project other than that named above
  - copy, sell or sublicense use of the questionnaire to any third party
  - modify, translate, copy or otherwise duplicate the questionnaire(s), except with express permission of the ACBRD
- ☐ I confirm that I will use industry-standard methods to develop a quality translation / cultural adaptation of the questionnaire, and that I will provide evidence of the process to ACBRD upon request.
- ☐ I confirm that I will liaise with ACBRD at key points, to enable the translation / cultural adaptation process to be overseen by ACBRD, thereby ensuring the integrity and appropriateness of the new translation.
- ☐ I acknowledge that the translation of the questionnaire remains the copyright of ACBRD.

Signature: _____ Date:

Name:

Your privacy matters. This information is intended for ACBRD use only and will be treated in confidence. You have the right to access, modify, rectify and delete any data that concern you. To exercise that right, please contact the ACBRD (e: info@acbrd.org.au).