Feeding and Nutrition Screening Tool for Children with Cerebral Palsy: Cross-Cultural Adaptation Guidelines

Introduction

Purpose: This document was developed to guide the linguistic and/ or cultural adaptation of the 'Feeding and Nutrition Screening Tool for Children with Cerebral Palsy (herein described as 'FNST' for use in non-English speaking countries/ regions.

The development of the Red Flags Screening Tool has undergone a series of processes internationally, since its conception in 2013 to final validation in 2018 (**Figure 1**). The final validation of the English tool was conducted on n=89 children with cerebral palsy (mean age=6;11 years, Gross Motor Function Classification System levels I-V) in Queensland, Australia¹ This resulted in four items with a maximum score of 4 (with scores ≥3 indicating referral for comprehensive assessment). The psychometric properties of the tool are therefore based on a predominately urban Australian English-speaking sample. As such, a formalised process is necessary to translate the tool for different populations, including adaptation of the concepts to ensure item equivalence of translations.

Figure 1: Progress to Date from the Red Flags to the Feeding and Nutrition Screening Tool¹⁻³

Original Red Flags Feeding Screening Tool proposed

- Prof Joan Arvedson (United States)
- 4 key areas (feeding duration, mealtime stress, weight gain, respiratory status)

Nutricia Expert Advisory Panels

- Representatives from France, Hungary, Turkey, Sweden, Czech Republic, Germany, Netherlands, United Kingdom, Spain, Slovenia
- 18 questions from 5 key areas (feeding duration, mealtime stress, weight gain, respiratory status, gastrointestinal)
- November 2015, May 2016

Preliminary analysis of Red Flags Questions and other screening items

- Statewide Australian preschool sample
- 61 questions from 6 key areas (feeding duration, mealtime stress, weight gain, respiratory status, gastrointestinal, other feeding related indicators)

Final validation of the screening questions

- Urban Australian sample
- 33 questions from 6 key areas (feeding duration, mealtime stress, weight gain, respiratory status, gastrointestinal, other feeding related indicators): resulted in 4 items

It is well-established in the literature that in order to use self-administered questionnaires in new countries/ cultures/ languages, it is critical to engage in a rigorous process of cross-cultural adaptation, rather than simply translation⁴. In addition to an accurately translated tool, the cross-cultural adaptation process aims to develop a conceptually and statistically equivalent tool for a different cultural/ linguistic context. It may involve a qualitative phase, with or without a final quantitative process. The qualitative phase consists of the adaptation of the tool through linguistic/cultural validation, which is the focus of this guideline, and considered the minimum requirement for use of the Feeding and Nutrition Screening Tool. The quantitative phase involves the evaluation of one or more psychometric properties (including validity, reliability, diagnostic accuracy).

The guidelines in this document are based on other internationally recognised cross-cultural adaptation guidelines including a review by Koller et al 2014 (in which 16 guidelines of 'major players' were reviewed) and an additional eight guidelines. The majority of translation procedures utilise a variation of forward-backward methodology, with reconciliation by expert panels and pretesting (Koller 2014). This process should be conducted by a team of professionals (n=3-8), both content and non-content experts who have bilingual cultural and linguistic skills, ideally in collaboration with the original tool developers. The specific process selected for the adaptation of the Feeding and Nutrition Screening Tool is described in detail in the following sections. For further information please refer to the PowerPoint presentation "Cross-Cultural Adaptation Guidelines for the Feeding and Nutrition Screening Tool" Dr Katherine Benfer presented during the Nutricia Expert Advisory Panel on 18th of February 2019 in Barcelona.

Phase 1: Planning the adaptation

Before beginning the translation, read this document carefully and register your intention to undertake an adaptation with Nutricia (email: zoe.vanzyl@nutricia.com). This ensures there is no duplication of the translation, and that there can be representation of the original developers in the adaptation process. This translation request should identify the names, qualifications/profession and role of each member of the project team, projected timing of the adaptation milestones, minor modifications to these standard guidelines, and any additional support required.

Resources

The resources required to complete the adaptation need to be arranged by the organisation completing the adaptation process. Nutricia is able to provide technical guidance/ support. Assistance for funding should be discussed on a case by case basis. The resources required are predominately human (technical), as well as a small sample of parents of children with CP for testing of the translated tool.

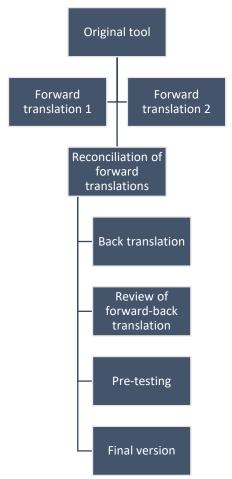
Specifically, the five members of the project team should include:

- <u>Cultural Adaptation Coordinator</u>: to oversee the process and ensure documentation. This
 Coordinator is ideally a bilingual health professional with knowledge of tool development.
- <u>Three translators</u> who also act as expert panel members.
- Representative from the original tool development team (Nutricia or University of Queensland): may be directly involved or externally consulted through the process.

10-15 parents/caregivers of children with cerebral palsy are required to test the adapted tool and undergo a brief interview as part of the pre-testing phase (see Figure 2). Allow adequate time and resources to obtain the required ethical reviews for the project. In order for final results to be publishable, ethical review of the project will be required for all participating teams. **Process & Milestones**

The Feeding and Nutrition Screening Tool consists of four concise questions. Figure 2 shows an overview of the cross-cultural adaptation process from the original tool to the adapted version.

Figure 2: Overview of the Cross-Cultural Adaptation Process from the Original Tool to the Adapted Version



Copyright,

Any adapted versions of the Feeding and Nutrition Screening Tool must (1) acknowledge the original publication and (2) not be for commercial purposes. By participating in the process outlined in this document you are agreeing to the translated versions being available for download free of cost on the Nutricia website or another website nominated by the developers and Nutricia. The organisation responsible for conducting the adaptation may also provide a copy of the adapted tool on their website with appropriate acknowledgements.

Phase 1 Checklist:

- ☐ Establish your project team including one coordinator and three translators.
- ☐ Register your intention to complete the adaptation with Nutricia (email to: zoe.vanzyl@nutricia.com)
- ☐ Establish a process to include 10 15 families in the pre-testing phase
- ☐ Obtain required ethical approvals

Phase 2: Forward translation (appendices 1 & 2)

Goal

To develop two independent forward translation documents from the source version of the tool (original).

Documentation of phase 2 should be completed in the table included in Appendix 1 and 2.

Note: A cultural adaptation would often begin with a process to determine whether all concepts in the tool items exist and are interpreted similarly in the target language/ culture. As the Feeding and Nutrition Screening Tool consists of only four descriptive items assessing symptoms, with dichotomous (yes/ no) or numeric (1-10 rating) response scales, the developers felt this process did not warrant a separate detailed step. However, if your project team feels that any overarching concepts/ items do not exist or will not be interpreted similarly in your culture (i.e. there is a need for addition or omission of items, or significant changes to the item or response scale), this should be discussed with the developer team prior to the forward translation. You may choose to begin the adaptation process with a team review of the source tool to ensure all items are relevant and acceptable in your culture.

Selection of translators

- Two forward translators should be selected from your project team.
- Both should have the target language as their native tongue and be proficient in English.
- One should be knowledgeable about feeding and/or nutrition; the other should not have content specific knowledge.
- Two independent teams can be used, (i.e. one team with content knowledge, the other with non-content knowledge. If this composition is difficult, the 'content' team should have at least one content expert).

Guidelines for translators

- 1. Translators should work independently from one another.
- 2. Translators should read through the entire tool before beginning and discuss any concepts or expressions that are unclear with the original tool developers.
- 3. Translate the instructions and scoring guidelines, as well as the screening items and response categories.
- 4. Translations should use natural and acceptable common language for the broadest audience.
- 5. Emphasis should be placed on translation of the intent of the item (conceptual equivalence), rather than a literal word-or-word translation. The framework based on Guilleman⁵should be used to guide this:
 - a. Ensure the meanings of words and grammar are the same between translations.
 - b. Ensure any expressions or sayings should be carefully considered, to ensure the meaning rather than individual words are conveyed (e.g. 'feeling down').
 - c. Consider substituting an equivalent activity or experience that may be more relevant in certain cultural contexts (e.g. in some countries use of private vehicles is uncommon, so this may be substituted with use of public transport, if the purpose of the item is about ability to move between locations).
 - d. Consider the concept and ensure this reflected in the choice of words, rather than a direct translation. For example, in some country's cousins are like brothers, living in the same home and having a strong relational bond. In this case, 'cousin' may be translated.
- 6. Guidance on language use⁶:

- a. Use short and simple sentences;
- b. Use active rather than the passive voice;
- c. Repeat nouns rather than using pronouns;
- d. Use specific rather than general terms, while avoiding jargon and technical terms;
- e. Avoid using metaphors and colloquialisms;
- f. Avoid using the subjective mode such as verb forms with could or would;
- g. Avoid words indicating vagueness such as "probably";
- h. Avoid double negatives;
- i. Avoid having two different verbs in one sentence if the verbs suggest different actions.
- j. The level of comprehension should be at the reading level of children aged 10-12 years.
- 7. It may be useful to temporarily make one question into two alternate translations of the question and select the best question during pre-testing phase⁷.
- 8. If the translators feel any items should be added or removed to ensure cultural appropriateness or conceptual equivalence, this should be discussed with the authors prior to proceeding.
- 9. Comments or queries during the translation process should be documented to assist in the reconciliation and final review process.
- 10. Submit to Cultural Adaptation Coordinator.
- 11. Document early learnings in forum.

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Briefly review the tool to ensure that all items are relevant and acceptable in the target	
culture	
One content expert (or a team led by the content expert) independently translates the tool	l
from English into the target language.	
One non-content expert (or a team of non-content experts) independently translates the	
tool from English into the target language.	
Document this phase in appendices 1 and 2.	

Phase 3: Reconciliation (appendix 3)

Goal

To merge the two forward translations into a single translation, through identification and resolution of major and minor inconsistencies in the dual forward translation, with reference to the original English version.

Documentation of phase 3 should be completed in the table included in Appendix 3.

Composition of the reconciliation panel

- Cultural Adaptation Coordinator
- Two forward translators (or 2 translation teams) from Phase 2
- External support (e.g. an additional panel member and/ or member of the original tool development team) can be sought if needed

Guidelines for reconciliation (Koller 2014)

- 1. Panel members are provided with both forward translations and the original English version of the tool.
- 2. A single forward translation should be reconciled, using the decision-making process based on Koller et al's criteria, to ensure a transparent process. For each item, this may involve preferring either forward translation 1 or 2 in its entirety, merging the 2 forward translations, or creating a new translation.

Decision criteria for choosing any of the above options

1. Source and comprehensibility

- 1.1 Best reflects the conceptual definitions and meaning of the source text
- 1.2 Best reflects the stress of the source text (i.e., what the main point of the source text is)
- 1.3 Is understandable for a lay person without medical knowledge
- 1.4 Is understandable to a population of varied education levels
- 1.5 Is as close as possible to the source text
- 1.6 Reads more naturally in the target language

2. Cultural

- 2.1 Is culturally appropriate in the scope of sensitive topics
- 2.2 Is culturally appropriate in the scope of cultural differences of life

3. Grammatical

- 3.1 The syntax is correct
- 3.2 The verbal forms and tenses are correct
- 3.3 Gender and number are adapted and correct
- 3.4 Other elements are correct (especially articles and prepositions)

4. Terminology

- 4.1 Includes all the keywords
- 4.2 Is semantically precise
- 4.3 Vocabulary/terminology is consistent throughout the translation

Koller 2014

3. Document early learnings in the discussion forum (appendix 7).

Phase 3 Checklist				
	Both forward translators and the coordinator review all translated versions and the original English version.			
	Reconcile the translated versions into one single version, this may involve choosing one of the forward translations in its entirety, or merging the 2 forward translations, or creating a new translation.			
	Document the process in appendix 3			
	Document early learnings in forum (appendix 7)			

Phase 4: Blinded Back Translation (appendix 4)

Goal

To translate the reconciled forward translation version back into English.

Documentation of phase 4 should be completed in the table included in Appendix 4.

Selection of the Back Translator

- The back translator should be a native English speaker, who is proficient in the target language (if a native English speaker is not available, at a minimum they should have a strong command of English).
- No content knowledge (of feeding/ nutrition) is preferred.
- No prior involvement in the tool development or adaptation (blind to the tool).

Guidelines for back translation

- 1. No prior knowledge of the source tool should be given. The back translator only receives the reconciled forward translation (from phase 3).
- 2. While the aim is still conceptual equivalence for the back-translation (translation of the intent of the item), a more literal translation may make it easier to compare the adapted tool the original tool.
- 3. Comments or queries during the translation process should be documented to assist in the final review process.
- 4. Document early learnings in forum (appendix 7).

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It is essential that the blinded back translator has no previous knowledge of the screening tool. It is also preferred that the back translator has no content knowledge of feeding or nutrition (if possible).	
The back translator translates the screening tool from the target language, back into English	١.
The back translator documents any queries or comments regarding the translation	
Document phase 4 in appendix 4.	
Document early learnings in forum (appendix 7)	

Phase 5: Review cross-cultural equivalence of source and final versions (appendix 5)

Goal

The final step before pre-testing the tool is to verify the equivalence of the source and back-translated versions and resolve any discrepancies.

Documentation of phase 5 should be completed in the table included in Appendix 5.

Selection of Review Panel

Cultural Adaptation Coordinator

- Two forward translators from Phase 2
- Back translator from Phase 4
- Member of the original tool development team (if this is not possible, they should review the documents which result from this phase and provide additional feedback).

Guidelines for Review

- 1. All documents should be provided, including both forward translations, the reconciled forward translation, back translation and source tool.
- 2. A framework based on Guillemin⁵ proposes the following to guide this review:
 - a. Ensure the meanings of words and grammar are the same between translations.
 - b. Ensure any expressions or sayings should be carefully considered, to ensure the meaning rather than individual words are conveyed (e.g. 'feeling down').
 - c. Consider substituting an equivalent activity or experience that may be more relevant in certain cultural contexts (e.g. in some countries use of private vehicles is uncommon, so this may be substituted with use of public transport, if the purpose of the item is about ability to move between locations).
 - d. Consider the concept and ensure this reflected in the choice of words, rather than a direct translation. For example, in some country's cousins are like brothers, living in the same home and having a strong relational bond. In this case, 'cousin' may be translated.
- 3. A summary report should be prepared describing decision-making and how any discrepancies were resolved.
- 4. If items from the back-translated version are inadequate or cannot be resolved, it may be necessary to repeat steps from the forward translation (phase 2-5) for these items only.
- 5. Document early learnings in forum (appendix 7).

Phase 5 Checklist				
	All team members review the final translated document and the original screening tool.			
	Resolve any discrepancies in the documents			
	Document this in appendix 5 and the early learnings forum.			
	Document early learnings in forum (appendix 7)			

Phase 6: Pre-Testing (appendix 6)

Goal

To test the adapted tool on a representative group of caregivers of a child with CP, to determine comprehension, interpretation and appropriateness of items.

Documentation of phase 6 should be completed in the table included in Appendix 6.

Selection of Pre-Testing Sample

10-15 caregivers of children with CP aged 2-18 years, without feeding tubes (2-3 per Gross Motor Function Classification System (GMFCS) level
 https://www.canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf. Translations of the GMFCS can also be accessed freely from this site.

- Native speakers of target language.
- Representative of the target population regarding gender, age, education. Consider the feasibility of gaining representation of the regional variability in the country.

Guidelines for pre-testing

- 1. Cognitive interviews should be ideally conducted by an experienced interviewer (this may be a member/s from the preceding phases of adaptation or an additional team member).
- 2. Record basic characteristics of the caregiver and child: gender (caregiver and child), age (child), GMFCS level (child), highest education level (caregiver), referring service, urban/regional/rural.
- 3. Provide the screening tool to the participant to complete independently, providing help as needed. If alternative versions of an item were generated during the forward translation phase, both should be administered, and feedback received.
- 4. After the caregiver has completed the tool, for each item, conduct the cognitive interviewing process (see Collins 2003 for further detail):
 - a. Determine appropriateness of the item: was this item (i) difficult to answer; (ii) confusing; (iii) difficult to understand; (iv) upsetting/ offensive.
 - b. Comprehensibility of the item (check understanding of specific items/ phrases):
 - i. "What do you mean when you gave [response]?"
 - ii. "Can you repeat the question in your own words?"
 - c. Comprehensibility of the response scales, and how the caregiver drew on their observations and experiences to generate the answer they gave:
 - i. "How did you decide on your answer?"
 - ii. "Were the response options adequate to answer properly? How would you have answered if you could use your own words?"
 - d. Comprehensibility of the instructions
- 5. The cognitive interviewing process should ideally be done iteratively, with the project team making amendments to the tool as problems are identified (unacceptability/ difficulty to understand). [Alternatively, items/ terms not understood by 80% of those interviewed may be revised.]
- 6. Comments or queries during the cognitive interviewing process should be documented to assist in the final review process.
- 7. Document early learnings in forum (appendix 7).

Phase 6 Checklist:				
	Ensure ethical approvals have been obtained			
	Recruit 10 – 15 families of children with CP to participate. Children should be oral feeders			
	and from all GMFCS levels.			
	Complete cognitive interviews with each primary caregiver to determine (step 4 above)			
	Complete any changes to the tool as they are required			
	Document all findings and changes in the forum and appendix 6.			
	Document early learnings in forum (appendix 7)			

Phase 7: Final Review and Documentation

All cultural adaptation processes outlined in this document should be traceable through the relevant documents, provided to Nutricia. Prior to finalisation of the adapted version, a member of the original tool development team will review all documents. These include:

- 2x forward translations;
- Reconciled forward translation, including summary of forward translation reconciliation process, decision codes and how discrepancies were resolved;
- Back-translation;
- Summary of back translation expert panel, including how discrepancies were resolved and/ or need for subsequent iterations;
- Summary of pre-testing of the tool:
 - Sample characteristics gender (caregiver and child), age (child), GMFCS level (child), highest education level (caregiver), referring service, urban/regional/ rural.
 - Responses to cognitive interviews
 - Modifications proposed
- Final adapted version, including information about the organisation/ authors involved in the translation (including a corresponding author) and any acknowledgements you would like to make.

Part of the final review may include a harmonisation process (by the developer team), to ensure the various translations remain consistent with one another.

The final approved version will be returned to the project team for proof reading, prior to the tool being made publically available with reference to the original validation paper¹

Document early learnings in the forum (appendix 7).

Phase 7 Checklist

Send all completed documents to Nutricia for review by Nutricia and the original developers.
Following review by Nutricia and the original developers, the final version will be returned to
the project team.

Use of the Feeding and Nutrition Screening Tool in English Speaking Countries

A review of the tool should be completed prior to implementation in non-Australian English contexts to ensure appropriate terminology in the new context.

A single reviewer should be selected, who is a native English speaker from the target country. The review process should include:

- 1. Consideration of whether all concepts and terminology are adequately reflected for the new
- 2. Discussion with a representative from the original tool development team to consider needed modifications. Should modifications be considered significant, a pre-test phase should be completed.

3.	Documentation of this process, including the local reviewer's name and qualifications, should be retained for future comparisons and tool use.

References:

- Bell K, Benfer K, Ware R, et al. Development and Validation of a Screening Tool for Feeding/Swallowing Difficulties and Undernutrition in Children with Cerebral Palsy *Dev Med Child Neurol*. accepted for publication on 1 Feb 2019;In Press.
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