

2022 ANNUAL REPORT

SIG/Committee Name: Translation & Cultural Adaptation SIG

Date: April 1, 2022

Co-Chairs: Dagmara Kuliś, Emily Parks-Vernizzi and Dana Weiss (secretary)

Board Liaison: Richard Skolasky

Mission: The overall objectives of the TCA-SIG are to identify and advance research into practices and outcomes of translation and cultural adaptation of patient-reported outcome instruments; and to promote visibility of cross-cultural issues in development and use of COAs in ISOQOL.

Number of SIG Members: 126

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
 Working group: Best practice guideline for global UX/UI practices of COAs destined for electronic based studies 	Aim of this working group is to create a guideline of best practices for visual aspects of UI/UX for the instrument developers within digital based studies, for use in initial measure development and with an emphasis on the visual and functional capabilities. - Literature reviews of existing guidelines/ practice (ongoing now) - Survey on relevant areas following lit reviews (TBD) - Evaluation of results - Identification specific aspects for guideline Submission as manuscript to JPRO [deliverable]	Application	Anna Richards	Megan Turner, David Churchman, Justin Raymer, Jeanne Landgraf, Vladimir Zah, Marlene Knupfer, John Chaplin, Yoshimi Suzukamo, Ay-Woan Pan	Under progress but estimated: Literature review complete by April Surveys held in May-June Evaluation in July/Aug Identifying – Sept Write-up and reviews – Oct to Feb Submission: March 2023
2. Working group: Concept Definition Standards	The objective of this working group is to prepare a good practices document for the development of concept definitions as part of the translation and cultural adaptation of COAs. As of March 2022, survey analysis is being concluded with manuscript authoring to follow.	Methods	Dana Weiss	Dana Weiss, Ben Arnold, Ana Popielnicki, Barbara Brandt, Sonya Eremenco, Emily Parks-Vernizzi, Jussi Repo, Jie You, John Chaplin, Alexandra Crane, Elizabeth Yohe Moore, Mark Wade, Carter Cassedy, Teresa Williams,	Draft manuscript completion expected by December 31, 2022.



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					Miguel Ruiz, Holger Muhlan-Rehmer, Clayton Hamilton, Adelina Lear, Zheng- kun Hou	
3.	Identify and advance research into cognitive debriefing (CD) methods in pediatric and adolescent populations during translation and adaptation processes	Discussion with the leaders of the working group on the next steps, a proposal to be submitted for the Board's review	Methods/ Application	Monika Vance, Jeanne Landgraf	John Chaplin, Holger Muehlan-Rehmer, Sonya Eremenco, Jeanne Landgraf, Monika Vance, Ligia Chavez, Ana Popielnicki, Beatrice Tedeschi, Rita A., Ahmed Osman	On-going through 2023.
4.	Working group: Principles of Good Practice for Translation of Electronic Clinical Outcome Assessment (eCOA) Measures	This work proposal was accepted in the summer of 2018 after the working group team submitted a proposal. This working group aims to create and outline a step-by-step descriptive approach of the methods to be used to translate non-instrument text needed for eCOA implementation; this need currently is not yet met in the field. In order to prepare a manuscript, the team did a literature review and conducted a survey for eCOA and translation providers to be able to collect data. A second survey with copyright holders/developers was conducted autumn 2021. Currently, the group is working on analysing the results of the 2 nd survey and writing the discussion section of the manuscript.	Methods/ Application	Huda Shalhoub, Megan Turner	Anita Smarandache, Ben Arnold, Caroline Anfray, Dagmara Kuliś, Emily Parks-Vernizzi, Holger Muehlan- Rehmer, Jason Bredle, John Chaplin, Mark Wade, Sonya Eremenco, Jussi Repo	Draft manuscript completion expected by December 2022.
5.	Webinar: Good Practices for the Translation, Cultural Adaptation and Linguistic Validation of Clinician- Reported Outcome, Observer- Reported Outcome, and Performance Outcome Measures – February 16, 2022	Live presentation of research carried out by TCA-SIG members and led by Shawn McKown, which was published in JPRO in 2021.			Shawn McKown, Ben Arnold, Dana Weiss, Caroline Anfray	Completed February 16, 2022.

Issues Requiring Board Attention: