

Linguistic translation and cultural validation of the COST-FACIT-V2 questionnaire in Odia to measure financial toxicity in India

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Abstract

Background

Cancer treatment can be associated with numerous direct and indirect financial burdens. These burdens, described as financial toxicity, can often affect care-based decision making of cancer patients. Breast cancer is the leading cause of cancer death of women in India, who often face the detrimental effects of financial toxicity. Measuring financial toxicity can be assessed through the COST-FACIT-V2 questionnaire, yet it is only available in limited languages. This study aimed to translate the widely used COST-FACIT-V2 tool used for assessing financial toxicity in Odia, one of India's most commonly spoken regional languages.

Methods

We followed the prescribed linguistic translation guidelines for the 12-item COST-FACIT-V2 developed by the tool developers. This entailed a forward translation and back translation, facilitated by artificial intelligence (AI), confirmed by human validation, and pilot testing with 10 native Odia speakers at a comprehensive cancer center in Odisha, India.

Results

The AI forward and back translations demonstrated accuracy with human validation. Minor changes were needed to enhance contextual accuracy and consistency with previous FACITtrans key phrases such as "paid work at home", which were not well understood by the pilot sample group, leading to culturally adapted modifications in the final translated version.

Discussion

The findings of this paper support the linguistic validity and cultural appropriateness of the Odia COST-FACIT-V2 and highlight the importance of rigorous translation methods to enable equitable measurement of financial toxicity and inform financial protection efforts in diverse cancer care settings. The use of AI represents an important innovation to support translation of standardized tools used in health systems research.

BACKGROUND

Cancer treatment can be associated with significant financial burdens stemming from direct treatment costs, medications, travel expenses, caregiving expenses, and variable employment income.^{1,2} These burdens, often described as financial toxicity in the literature³, can create barriers to cancer treatment

access and completion, forcing patients and their families to make critical decisions surrounding their care.^{2,4-6} In India, where breast cancer is the leading cause of cancer death in women,⁷ there are significant inequities regarding breast cancer treatment plans and access to care.^{4,8} This is created by inequitable publicly financed healthcare insurance plans where many patients are required to cover their treatment partially or entirely out-of-pocket.^{4,8-10} These out-of-pocket costs have caused one-third of households impacted by a cancer diagnosis to spend more than half of their per-capita annual household expenditure solely on hospitalizations.¹¹ Coupling these costs with the risk of discontinuing cancer treatment, there is reason to hypothesize that such critical decisions are directly impacting specific health outcomes.^{12,13}

The COmprehensive Score for financial Toxicity – Functional Assessment of Chronic Illness Therapy Version 2 (COST-FACIT-V2) is a validated and reliable instrument for measuring financial toxicity in cancer populations.¹⁴ Its psychometric properties have been established across multiple English-speaking populations, including in studies conducted in India.¹⁵⁻¹⁷ Validated translations are currently available in Hindi and Marathi¹⁷⁻¹⁹, languages spoken by a significant majority of the population. However, India has 22 officially recognized languages, and more than 130 active languages²⁰, underscoring the risk of limited linguistic coverage systematically excluding large populations from clinical and health-systems research. Language barriers are a well-documented source of inequitable participation and under-representation in clinical research.²⁰⁻²² Odia is one of India's 22 official languages, and the primary language spoken in Odisha, however it is not an available language of the COST-FACIT-V2 questionnaire.¹⁹

To address this gap, we conducted a translation and validation study of the COST-FACIT-V2 in Odia. Odisha, an eastern Indian state with a population exceeding 40 million, has a predominantly Odia-speaking population and a high reliance on out-of-pocket spending for cancer care, particularly among rural and socioeconomically disadvantaged groups^{23,24}, making accurate measurement of financial toxicity essential for informing financial protection strategies.

METHODS

Study Design and Setting

This cross-sectional linguistic translation and cultural adaption of the COST-FACIT-V2 questionnaire was undertaken at the Department of Oncology in KIMS Cancer Centre (KCC). KCC is a comprehensive cancer care centre located in Bhubaneswar, Odisha, India, operating within a mixed public–private health system. The centre provides diagnostic, surgical, medical, and radiation oncology services for a broad range of adult cancers and receives referrals from public sector facilities, private providers, and self-referrals across Odisha and neighbouring states. KCC serves approximately 2,000 cancer patients annually, many of whom rely on out-of-pocket payments and/or state and national insurance schemes,

underscoring the importance of measuring financial toxicity to inform financial protection strategies for cancer care in this setting. The study was conducted between September 2024 and March 2025.

Instrument

The COST-FACIT-V2 is a 12-item patient outcome self-report tool that measures financial distress and financial toxicity among adult cancer patients (Fig. 1). Responses are rated on a 5-point Likert scale, ranging from 0 (not at all) to 4 (very much), with total scores ranging from 0 to 44. All items are based on a 7-day recall period.

Translation Process

The FACITtrans Team, the translation team for the FACIT Group, provided the guidelines for the translation process (Fig. 2) with two approved modifications: the use of AI to support the forward and back translations with manual validation by a human, and the inclusion of both patients and healthcare providers in the pilot testing of conceptual understanding. A revision history was completed to examine and categorize the types of revisions needed during each stage of the translation process. The challenges and solutions encountered during the translation of questionnaire items and pilot testing were documented and presented.

Step 1: Forward translation

The English version of the COST-FACIT-V2 was first translated into Odia using two different generative AI platforms, ChatGPT-4 and Microsoft Copilot. Each item on the English source was entered individually into the AI engines, which were prompted to “translate from English to Odia” by a research team member.

Step 2: Reconciliation

Three native Odia speaking authors (DN, SP and SM) made up the linguistic team who reviewed forward translations and reconciled discrepancies.

Step 3: Back translation

ChatGPT-4 was used to back-translate the reconciled Odia translation into English and reviewed by the same linguistic team.

Step 4: FACITtrans analysis

The FACITtrans translation manager reviewed all forward-back translations for quality and consistency with terms and phrases used in their existing validated translations, which is referred to as the translation memory bank. Issues identified by the FACITtrans translation manager were resolved by the Odia translators. The FACITtrans translation manager approved the final Odia version of the tool for pilot testing.

Step 5: Interview for conceptual understanding

The Odia questionnaire was administered to 10 participants recruited from KCC. Both patients and hospital staff were included for participation if they self-identified as fluent Odia speakers. A cognitive interview was conducted to assess participants' understanding of questionnaire items and terminology, ensuring they accurately understood the intended meaning.

Step 6: Review and licensing

The FACITtrans team provided final proofing of the translated tool and generated a license for use in research.

RESULTS

Forward-back translation results

The linguistic team reviewed two independent AI-generated forward translations and identified several minor discrepancies requiring revision during reconciliation (Table 1). In most instances, the forward translations captured the intended meaning of the English source; however, when neither version fully reflected the semantic or contextual intent of a given term or phrase, the linguistic team selected the most appropriate alternative to ensure conceptual equivalence with the original instrument. Subsequent back translations of the reconciled Odia version demonstrated strong alignment with the English source text, with no substantive discrepancies identified. The FACITtrans analyst and linguistic team jointly reviewed all back translations and confirmed that the reconciled Odia items preserved the original intent, tone, and measurement concepts of the COST-FACIT-V2.

Throughout the reconciliation process, the linguistic team worked closely with the FACITtrans analyst to maintain consistency with the FACITtrans translation memory bank. For a limited number of terms ($n = 5$) the team intentionally deviated from the translation memory bank to improve contextual accuracy or grammatical completeness, especially where direct equivalence risked obscuring meaning for local respondents. To enhance readability and consistency with Odia writing conventions, the team removed all full stops from the translated items.

Several recurrent linguistic issues emerged across multiple items ($n = 4$), most notably, the spelling of the term to denote expenses or costs. The team selected “କଟାକ୍ଷେପ” over “ଖର୍ଚ୍ଚ” to better reflect standard

usage pronunciation and clarity of meaning in Odia. Another challenge was the translation of culturally bounded phrases or expressions without direct Odia equivalents. For example, the phrase “out-of-pocket” medical expenses does not have a literal translation in Odia. Rather than adopting a word-for-word translation, we revised the phrasing to convey the underlying concept of *personally bearing medical costs* or paying with *personal funds*.

When multiple alternatives were proposed for a given term, the team selected the final wording based on alignment with FACITtrans conventions, as described in the FACITtrans translation memory, or the extent to which the terms accurately conveyed the contextual factors of the English source. For instance, in FT4, the English concept of “choice” refers to the perceived restriction due to the cost of care. To better reflect this meaning, the Odia translation used a term equivalent to “options,” explicitly linked to financial expenditure, preserving the intended measurement construct.

Conceptual Understanding

Four patients and six healthcare workers participated in the pilot study and cognitive interviews with a mean age of 42.2 [35–56]. The linguistically translated COST-FACIT-V2 was well understood by the majority of the pilot sample. All participants self-reported that they had no difficulty understanding the items. None of the participants reported feeling that any of the translated items were unnatural, irrelevant or offensive.

No participants self-reported that they found any of the items difficult to understand. Primary concerns included minor discrepancies in how key terms were translated across items. For example, there was a discrepancy in how the term “money” was translated between items FT1 and FT4, specifically between “ଫିନାନ୍ସ” and “ମନି”. ଫିନାନ୍ସ was chosen as it is the most used and understood by the public in Odisha. “Financial situation” is another term that was translated differently across multiple items [FT6, 10, 11]. The translation for FT6 was revised to ensure consistency without compromising contextual relevance.

The concept of “paid work from home”, although translated accurately, was not understood by nearly any of the participants, denoting a possible cultural misunderstanding of the concept and a potential lack of relevance for this population. The term remains in the translated version as it is an established item in the validated English source.

DISCUSSION

This study demonstrates that the Odia translation of the COST-FACIT-V2 achieved strong linguistic and conceptual equivalence with the English source instrument. The forward-back translation and reconciliation process required only minor revisions, primarily to optimize semantic clarity, ensure consistency across items, and adapt culturally specific expressions, such as “out-of-pocket” medical expenses, without altering the underlying measurement constructs. Cognitive interviews with patients and healthcare workers confirmed that the translated items were generally well understood and acceptable, with no reported difficulties in comprehension. These findings support the linguistic validity

and cultural appropriateness of the Odia COST-FACIT-V2 and highlight the importance of rigorous translation methods to enable equitable measurement of financial toxicity and inform financial protection efforts in diverse cancer care settings.

The use of AI to support study material translation has been an emerging research topic since the development of large language models such as ChatGPT.²⁵ While the forward and back translations themselves were completed rapidly, the entire process was not significantly accelerated as the AI translations were still embedded on a human-led process that strictly adhered to the COST-FACIT-V2 developer guidelines. Future researchers using AI for similar translation, may not encounter the same time barriers. One limitation with the AI translations was the inconsistent uses of words to translate terms such as “illness” or “money”. Additionally, AI software was unable to recognize cultural differences in semantics such as idioms or concepts such as “paid work from home”. This further emphasises the importance of human pilot testing for effective cultural adaption.

This paper is a part of a series of translations working to support a study understanding inequities in breast cancer treatment and care. While the translation process is rigorous and thorough, certain limitations present themselves. During the pilot testing process, only 10 participants were included, and the robustness may have been improved with a larger sample size. Additionally, four of these participants were men which is not reflective of the larger study population, however the COST-FACIT-V2 is neither gender specific, nor specific to breast cancer, thus maintaining validity for general use. However, considering the self-reported nature of the pilot testing, certain biases, including social desirability and recall biases, may have been present.

CONCLUSION

The Odia translation of the COST-FACIT-V2 has been incorporated into the FACITtrans portfolio of officially validated languages available for future research use. This translation expands the capacity to measure financial toxicity in India and among an Odia-speaking population. While the use of AI in this study accelerated the initial forward and back translation stages, the iterative review and approval process underscored the continued importance of expert linguistic oversight and participant input to ensure conceptual and cultural validity. Cognitive interviewing proved essential in refining the key terms to reflect locally meaningful understanding of money, financial strain and work, concepts that are core to the examining financial toxicity, strengthening the tool’s ability to capture patient-reported financial hardship. By enabling linguistically inclusive measurement, the Odia COST-FACIT-V2 supports more equitable financial protection research and contributes to a broader evidence base that reflects the lived economic experiences of diverse cancer populations.

Declarations

ETHICAL AND FUNDING DECLARATIONS

Human Ethics and Consent to Participate

Ethics approval was secured from the Kalinga Institute of Medical Sciences Institutional Ethics Committee [1844/2024], and University of Toronto Research Ethics Board [44562]. Verbal consent was obtained for all participants prior to pilot testing.

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Author Contribution

DN: Data Collection, Data Analysis and Interpretation, Visualization, Writing – Original Draft, Writing – Review & Editing
IAC: Visualization, Writing – Original Draft, Writing – Review & Editing
LCB: Visualization, Writing – Original Draft, Writing – Review & Editing
SP: Data Collection, Data Analysis and Interpretation, Visualization, Writing – Review & Editing
DR: Conceptualization, Methodology, Writing – Review & Editing
SM: Data Collection, Data Analysis and Interpretation
BE: Conceptualization, Methodology, Supervision, Data Analysis and Interpretation, Visualization, Writing – Review & Editing
All authors read and approved the final manuscript.

References

1. Donkor A, Atuwu-Ampoh VD, Yakanu F et al (2022) Financial toxicity of cancer care in low- and middle-income countries: a systematic review and meta-analysis. *Support Care Cancer* 30(9):7159–7190. 10.1007/s00520-022-07044-z
2. Abrams HR, Durbin S, Huang CX et al (2021) Financial toxicity in cancer care: origins, impact, and solutions. *Translational Behav Med* 11(11):2043–2054. 10.1093/tbm/ibab091
3. Salek M, Silverstein A, Tilly A et al (2023) Factors influencing treatment decision-making for cancer patients in low- and middle-income countries: A scoping review. *Cancer Med* 12(17):18133–18152. 10.1002/cam4.6375
4. ACTION Study Group, Jan S, Kimman M, Peters SAE, Woodward M (2015) Financial catastrophe, treatment discontinuation and death associated with surgically operable cancer in South-East Asia: Results from the ACTION Study. *Surgery* 157(6):971–982. 10.1016/j.surg.2015.02.012
5. The ACTION Study Group (2015) Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. *BMC Med* 13(1):190. 10.1186/s12916-015-0433-1
6. Vijaykumar DK, Arun S, Abraham AG, Hopman W, Robinson AG, Booth CM (2019) Breast Cancer Care in South India: Is Practice Concordant With National Guidelines? *J Glob Oncol* 5. JGO.19.00052

7. Singh K, Grover A, Dhanasekaran K (2025) Unveiling the cancer epidemic in India: a glimpse into GLOBOCAN 2022 and past patterns. *Lancet Reg Health - Southeast Asia* 34. 10.1016/j.lansea.2025.100546
8. Horton S, Rodriguez RC, Anderson BO et al (2020) Health System Strengthening: Integration of Breast Cancer Care for Improved Outcomes. *Cancer* 126(Suppl 10):2353–2364. 10.1002/cncr.32871
9. Essue BM, Laba TL, Knaul F et al (2017) Economic Burden of Chronic Ill Health and Injuries for Households in Low- and Middle-Income Countries. In: Jamison DT, Gelband H, Horton S, eds. *Disease Control Priorities: Improving Health and Reducing Poverty*. 3rd ed. The International Bank for Reconstruction and Development / The World Bank; Accessed June 29, 2025. <http://www.ncbi.nlm.nih.gov/books/NBK525297/>
10. Prinja S, Dixit J, Gupta N et al (2023) Financial toxicity of cancer treatment in India: towards closing the cancer care gap. *Front Public Health* 11. 10.3389/fpubh.2023.1065737
11. Rajpal S, Kumar A, Joe W (2018) Economic burden of cancer in India: Evidence from cross-sectional nationally representative household survey, 2014. *PLoS ONE* 13(2):e0193320. 10.1371/journal.pone.0193320
12. Alexander A, Kaluve R, Prabhu JS et al (2019) The Impact of Breast Cancer on the Patient and the Family in Indian Perspective. *Indian J Palliat Care* 25(1):66–72. 10.4103/IJPC.IJPC_158_18
13. Boby JM, Rajappa S, Mathew A (2021) Financial toxicity in cancer care in India: a systematic review. *Lancet Oncol* 22(12):e541–e549. 10.1016/S1470-2045(21)00468-X
14. de Souza JA, Yap BJ, Hlubocky FJ et al (2014) The development of a financial toxicity patient-reported outcome in cancer: The COST measure. *Cancer* 120(20):3245–3253. 10.1002/cncr.28814
15. de Souza JA, Yap BJ, Wroblewski K et al (2017) Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). *Cancer* 123(3):476–484. 10.1002/cncr.30369
16. Kim B, Rutherford C, Lehane L et al (2025) Cross-Cultural Validation of the COmprehensive Score for Financial Toxicity (COST) Measure in an Australian Sample. *Cancer Med* 14(6):e70779. 10.1002/cam4.70779
17. Dar MA, Chauhan R, Sharma KK, Trivedi V, Dhingra S, Murti K (2021) Assessing the reliability and validity of comprehensive score for financial toxicity (COST) among radiation oncology patients in India: a cross-sectional pilot study. *Ecancermedicalscience* 15:1219. 10.3332/ecancer.2021.1219
18. Joshi A, Kalra D, Menon N et al (2022) Translation and Validation of COST - FACIT (Version 2) Questionnaire into Hindi and Marathi to Assess Financial Toxicity in Indian Cancer Patients. *South Asian J Cancer* 11(2):97–104. 10.1055/s-0041-1741074
19. Palai L, Odia, Identity (2021) Language and Regionalism: A Historical Perspective. *IAR Journal of Humanities and Social Science*. ;2:N/A-N/A
20. Narayan L (2013) Addressing language barriers to healthcare in India. *Natl Med J India* 26(4):236–238

21. Shah JY, Phadtare A, Rajgor D et al (2010) What Leads Indians to Participate in Clinical Trials? A Meta-Analysis of Qualitative Studies. PLoS ONE 5(5):e10730. 10.1371/journal.pone.0010730
22. Hussain-Gambles M, Atkin K, Leese B (2006) South Asian participation in clinical trials: The views of lay people and health professionals. Health Policy 77(2):149–165. 10.1016/j.healthpol.2005.07.022
23. Singh J, Paul K, Pradhan J (2022) Hospitalization & health expenditure in Odisha: Evidence from National Sample Survey (1995–2014). Indian J Med Res 156(1):130–138. 10.4103/ijmr.IJMR_412_19
24. Meher M, Majhi M (2025) Out-of-pocket Health Care Expenditure and Impoverishment Effect: A Comparative Study of Rural–Urban Health Care in Odisha. J Health Manage 27(3):469–477. 10.1177/09720634251340133
25. Lu SC, Xu C, Kaur M, Edelen MO, Pusic A, Gibbons C (2025) Can machine translation match human expertise? Quantifying the performance of large language models in the translation of patient-reported outcome measures (PROMs). J Patient Rep Outcomes 9:94. 10.1186/s41687-025-00926-w

Tables

Table 1 is available in the Supplementary Files section.

Figures

COST – FACIT (Version 2)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
FT1	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.....	0	1	2	3	4
FT2	My out-of-pocket medical expenses are more than I thought they would be	0	1	2	3	4
FT3	I worry about the financial problems I will have in the future as a result of my illness or treatment	0	1	2	3	4
FT4	I feel I have no choice about the amount of money I spend on care.....	0	1	2	3	4
FT5	I am frustrated that I cannot work or contribute as much as I usually do.....	0	1	2	3	4
FT6	I am satisfied with my current financial situation	0	1	2	3	4
FT7	I am able to meet my monthly expenses	0	1	2	3	4
FT8	I feel financially stressed.....	0	1	2	3	4
FT9	I am concerned about keeping my job and income, including paid work at home.....	0	1	2	3	4
FT10	My cancer or treatment has reduced my satisfaction with my present financial situation	0	1	2	3	4
FT11	I feel in control of my financial situation.....	0	1	2	3	4
FT12	My illness has been a financial hardship to my family and me	0	1	2	3	4

Figure 1

English Version of the COST-FACIT-V2

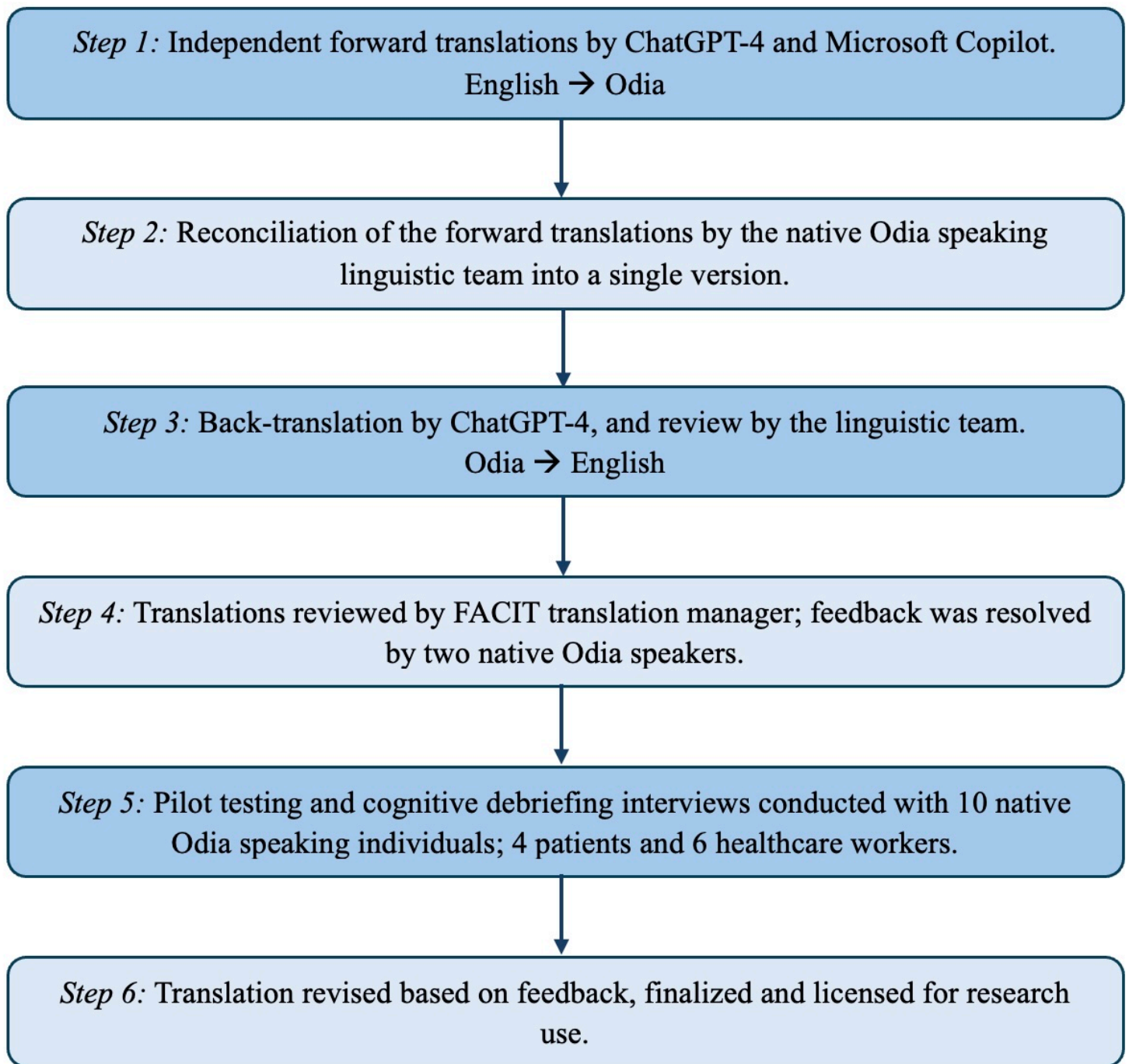


Figure 2

Translation process of the COST-FACIT-V2 Questionnaire from English to Odia.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [COSTODIATABLE1.docx](#)