Ready for use?

Translation & cultural adaption of the Carer Support Needs Assessment Tool (CSNAT) for German-speaking countries



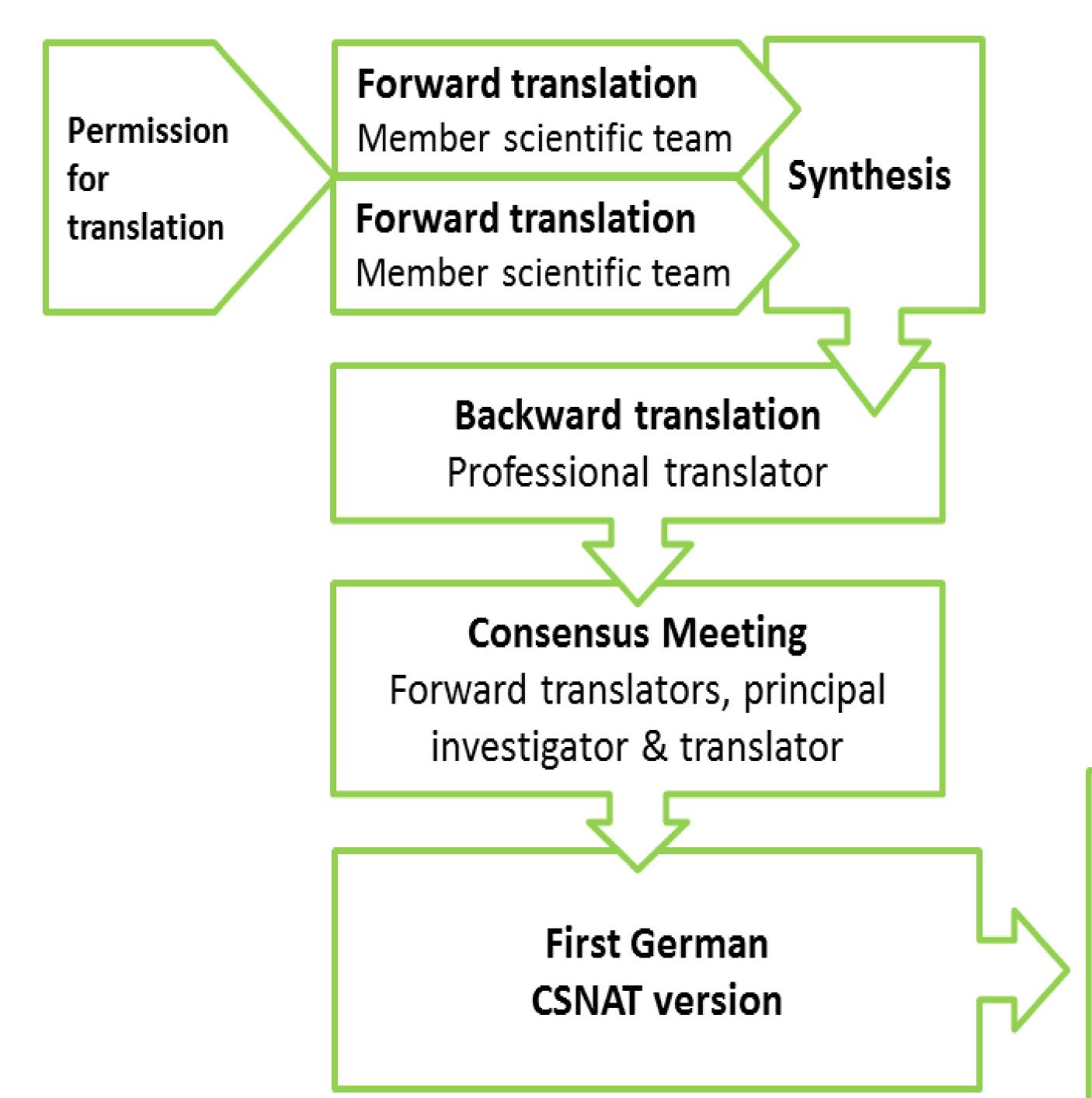
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Background & Aim

Support for informal carers is of increased interest on the political agenda as well as in palliative care research. However, a systematic assessment of informal carers' needs usually is not part of delivering palliative home care, especially in the German speaking countries, where a suitable tool has not been available.

The Carer Support Needs Assessment Tool (CSNAT) has been shown to be valid and effective in several studies.^{1,2} It is structured around 14 broad support domains and represents a novel, carer-led approach to empower family carers to express and prioritise their support needs.³

The aim was to translate and culturally adapt the CSNAT for a German-speaking context and to assess comprehensibility and acceptability as part of a larger project on developing carer support within palliative home care.

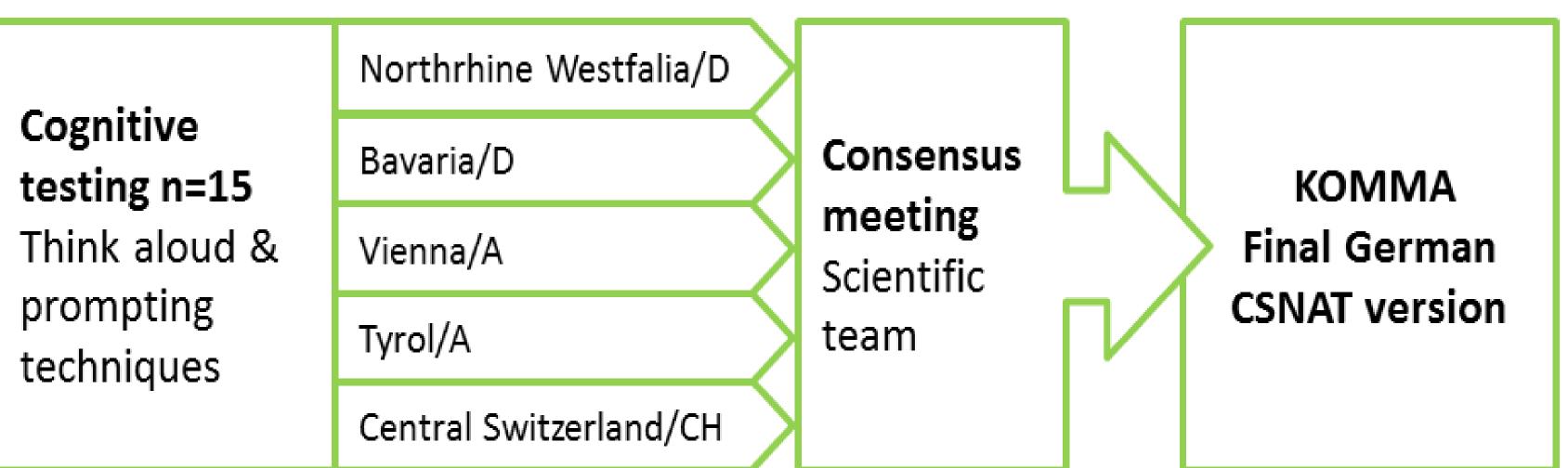


Method & procedure

Following ISPOR guidelines⁴ and with support of professional translators, forward and backward translations were performed and discussed in a consensus meeting of the scientific team.

A specific feature of the German language its wide regional variation. To achieve comprehensibility of the CSNAT further steps included cognitive interviews (n=15) with informal carers in five geographically distinct regions in Germany, Austria, and Switzerland. In the interviews we applied "think aloud" and prompting techniques.

A second consensus meeting was held to agree on a first German version. Additional input was obtained from the CSNAT developers in the UK repeatedly throughout this process.



Results

12 of the 14 CSNAT questions as well as the introduction and final text had to be discussed and carefully adapted after testing alternatives for some phrases. Semantic, conceptual and idiomatic issues occurred. Two terms raised questions especially in the Swiss context, and were adapted. Finally, a comprehensible German title for the tool was requested by carers and professionals. Suggestions were checked with users, and KOMMA, an acronym for "Kommunikation mit Angehörigen" ("communication with carers") turned out to work best.

Semantic:

There is no equivalent for the term "practitioner" in the German language. We discussed several alternatives, like "professional", "qualified person" or "doctor or nurse", but all these seemed to be too narrow. We decided to use the wording "our staff member" instead.

Conceptual: The translation of the statement "Do you need more support with getting a break from caring overnight?" was identified by the thinking aloud technique as misinterpreted. Participants understood different things, eg. receiving day-care or taking a short-break. After consultation of the CSNAT's authors to clarify the original meaning we reformulated the phrase.

Idiomatic:

The term "need" is difficult to translate into German, because it carries more than one meaning. The term "benötigen" for "you need", a phrase which is used in the introduction and final text of the CSNAT, was identified as not common in Switzerland, furthermore seen as snobbish. It was replaced by the term "brauchen", which is common in all areas.



Wir würden gerne wissen, was Ihnen bei der Betreuung Ihrer/Ihres Angehörigen helfen könnte, und welche Unterstützung Sie für sich selbst brauchen. Bitte kreuzen Sie bei jeder Aussage das Kästchen an, das Ihre aktuellen Bedürfnisse am besten wiedergibt.

Brauchen Sie mehr Unterstützung	nein	etwas mehr	deutlich mehr	sehr viel mehr
um über die Erkrankung Ihrer/Ihres Angehörigen Bescheid zu wissen?				
um auch Zeit für sich selbst zu haben?				
um auf die Symptome Ihrer/Ihres Angehörigen angemessen zu reagieren (einschließlich Gabe von Medikamenten)?				

Conclusion

KOMMA, the German version of the CSNAT, was validated linguistically and culturally and is now ready for use to assess content validity and feasibility. For translations into other languages a team approach, including professional translators, is recommended, in close cooperation with the CSNAT's developers to make sure that what is being translated is an accurate reflection of the original intention. Additionally, testing regional differences might be required in several languages especially because the tool is carer-led.

¹ Grande, G. E. et al. (2015). Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. BMJ supportive & palliative care.

² Aoun, S. M. et al. (2015). The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. PloS one, 10(4)

³ Ewing, G. et al. (2013). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. Journal of pain and symptom management, 46(3), 395–405.

⁴ Wild, D. et al. (2005). Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. Value in health: the journal of the International Society for Pharmacoeconomics and Outcomes Research, 8(2), 94–104









