Adaptation and Preliminary Testing of Six Neuro-QoL Item banks for use in the Swedish Neuro-registries/ Multiple Sclerosis registry (NEUROreg/MSreg)

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TAKE-HOME MESSAGE

NEURO-QOL WILL INCREASE MEASUREMENT ACCURACY OF PATIENT REPORTED OUTCOMES AND LOWER PATIENT BURDEN

Background

Neuro-QoL provides a clinically relevant and psychometrically robust tool for assessment of quality of life (QoL) in both adults and children with common neurological disorders. We report here the protocol for the translation and cultural adaption of a subset of Neuro-QoL item banks into Swedish and the integration strategy for the Swedish Neuro-registries/Multiple Sclerosis registry (NEUROreg/MSreg).

Method

A multidisciplinary team including patient representation was established. Six Neuro-QoL item banks were selected, representing the needs for patient-reported data collection in MS. These included two full item banks # applied cognition and # fatigue; and four short-form item banks # lower extremity function (mobility), # positive affect and well-being, # satisfaction with social roles and activities, and # ability to participate in social roles and activities (Fig 1). A protocol for the translation and cultural adaptation of the item banks was agreed (Fig 2).
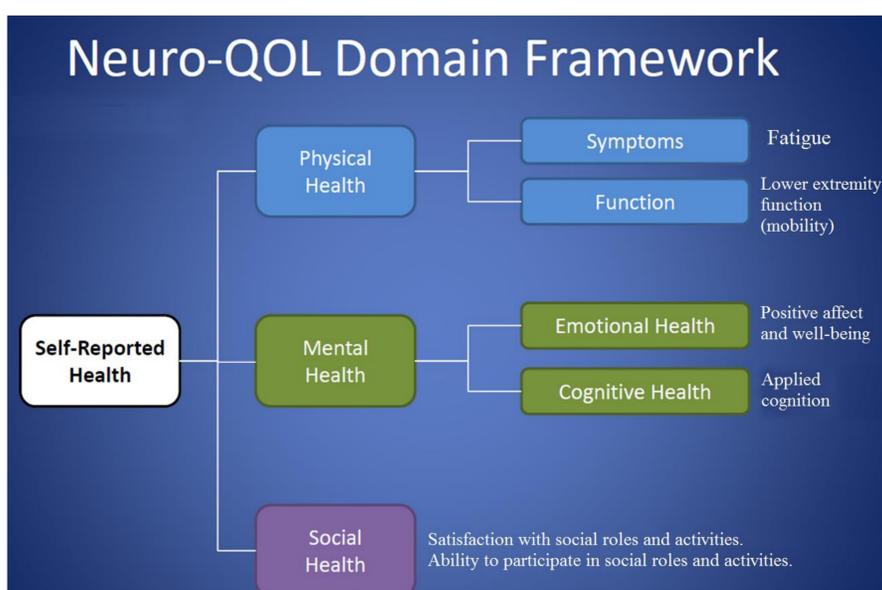
Results

Initial analysis indicates a close agreement with the original items; however, some cultural adaption, clarification and updating is required. Terms which might be clear in the English context may not be in the Swedish context, for example, "*work at home*" might mean distance work or housework. Questions using topical terms or referring to technology e.g. "*touch-tone keypad*" need to be updated regularly or avoided. More fundamental cultural issues also arose, such as the extent to which someone would use absolute terminology e.g. "*my life had purpose*" as opposed to "*my life felt like it had purpose*".

Advantages of Neuro-QoL

❖ **Improves the psychometric quality of the data.**

❖ **New subtests and tests, with predictable characteristics, can be developed easily, thus saving time and resources.**

❖ **Increases the possibilities of web-based assessment.**

❖ **Establishes a common language for discussing health goals and patients' health objectives.**

❖ **Facilitates long-term follow-up, national and international comparisons.**

Conclusions

Rigorous review and extensive cognitive debriefing is required in order to identify appropriate language equivalents. Item banking will contribute to the integration of the patient's perspective into the quality data registry and lead to a better understanding of quality of life in MS. In the future, comparisons of PRO registry data will be possible both nationally and internationally.
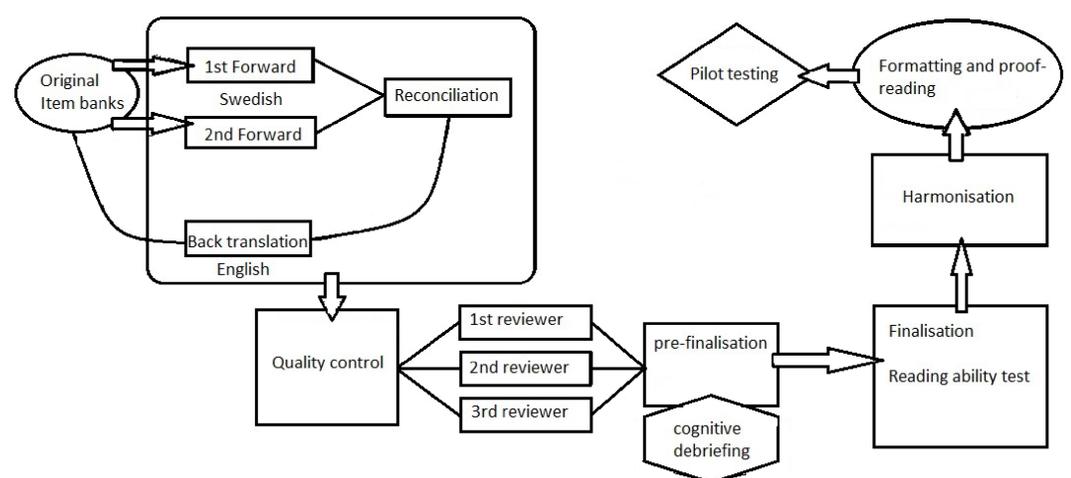

Fig.1 The Neuro-QoL domain framework and the item banks and short forms translated for testing in the MS Registry.

Fig.2 The standard process of translation and verification used in adapting PROMIS for Swedish use: Each item is translated independently by two native Swedish speakers into Swedish and reconciled. This is then back-translated into English and reviewed by three independent reviewers prior to cognitive testing with the target population. Finally, readability is evaluated and the translation harmonized with other translations. Pilot testing is undertaken on the standardized, formatted questionnaire.

Session Title: Poster Session 1
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Presenting Time: 15:45-17:00 hr.

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