



National Quality Registry for Neurological Care (NEUROreg)

NEUROreg is represented in all counties and all hospitals, covering 8 diagnosis:

- multiple sclerosis,
- Parkinson's disease,
- myasthenia gravis ,
- narcolepsy,
- epilepsy,
- motor neuron disease,
- inflammatory polyneuropathy
- severe neurovascular headache.

Key metrics:

- Demographic data and medical history (e.g. age of onset, initial symptoms and disease course type).
- Outcome of diagnostic investigation with MRI and cerebrospinal fluid exam.
- Measurement of disease activity.
- **Rating scales of disability, quality of life, fatigue and cognition. (PROM)**
- Disease-modifying therapy.



HealthMeasures consists of four precise, flexible, and comprehensive measurement systems that assess physical, mental, and social health, symptoms, well-being and life satisfaction; along with sensory, motor, and cognitive function.



PROMIS®

Self-reported and parent-reported measures of global, physical, mental, and social health for adults and children in the general population and those living with a chronic condition



Neuro-QoL

Self-reported and proxy-reported measures of physical, mental, and social health for adults and children living with a neurological condition



Adult Sickle Cell Quality of Life Measurement Information System

ASCQ-MeSM

Self-reported measures of physical, mental, and social health for adults living with sickle cell disease



NIH Toolbox®

Performance tests of cognitive, motor, and sensory function and self-reported measures of emotional function for adults and children in the general population and those living with a chronic condition



Standardized Scoring—

All scores are based on the same metric to enable cross-measure comparison



Neuro-QoL (Quality of Life in Neurological Disorders) is a measurement system that evaluates and monitors the physical, mental, and social effects experienced by adults and children living with neurological conditions.

**INTRO TO
NEURO-QOL**

**OBTAIN &
ADMINISTER
MEASURES**

**MEASURE
DEVELOPMENT &
RESEARCH**

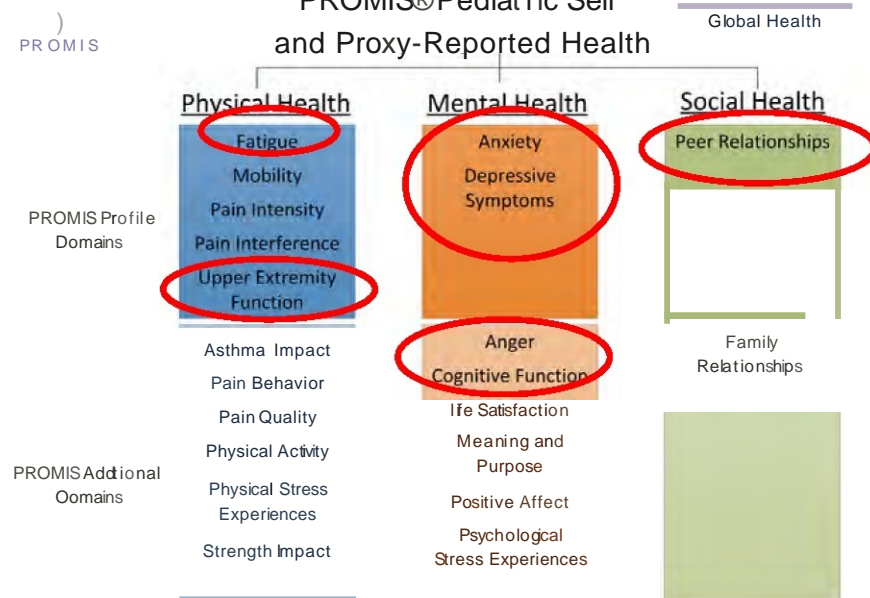
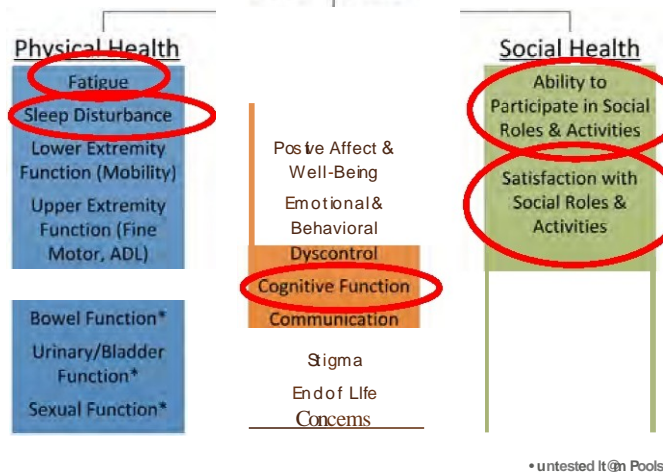
Why Use Neuro-QoL?

- Developed and validated for common neurological conditions with state-of-the-science methods to be psychometrically sound
- Designed to be completed in approximately one minute
- Created with flexible administration—pen & paper, web-based, or interviewer
- Translations available in Spanish and other languages
- Available without license, fee, or royalty

HealthMeasures is the official information and distribution center for PROMIS, Neuro-QoL, NIH Toolbox, and ASCQ-Me, which were developed and evaluated with National Institutes of Health (NIH) funding.

Neuro-QOL: Special Features

- Target neurological conditions
- Adult and pediatric disorders
- Inclusion of ethnic minorities
- Assessment of acceptability to neurology research and clinical community
- IRT-based approach/CAT
- Available in the public domain





Pilot stage

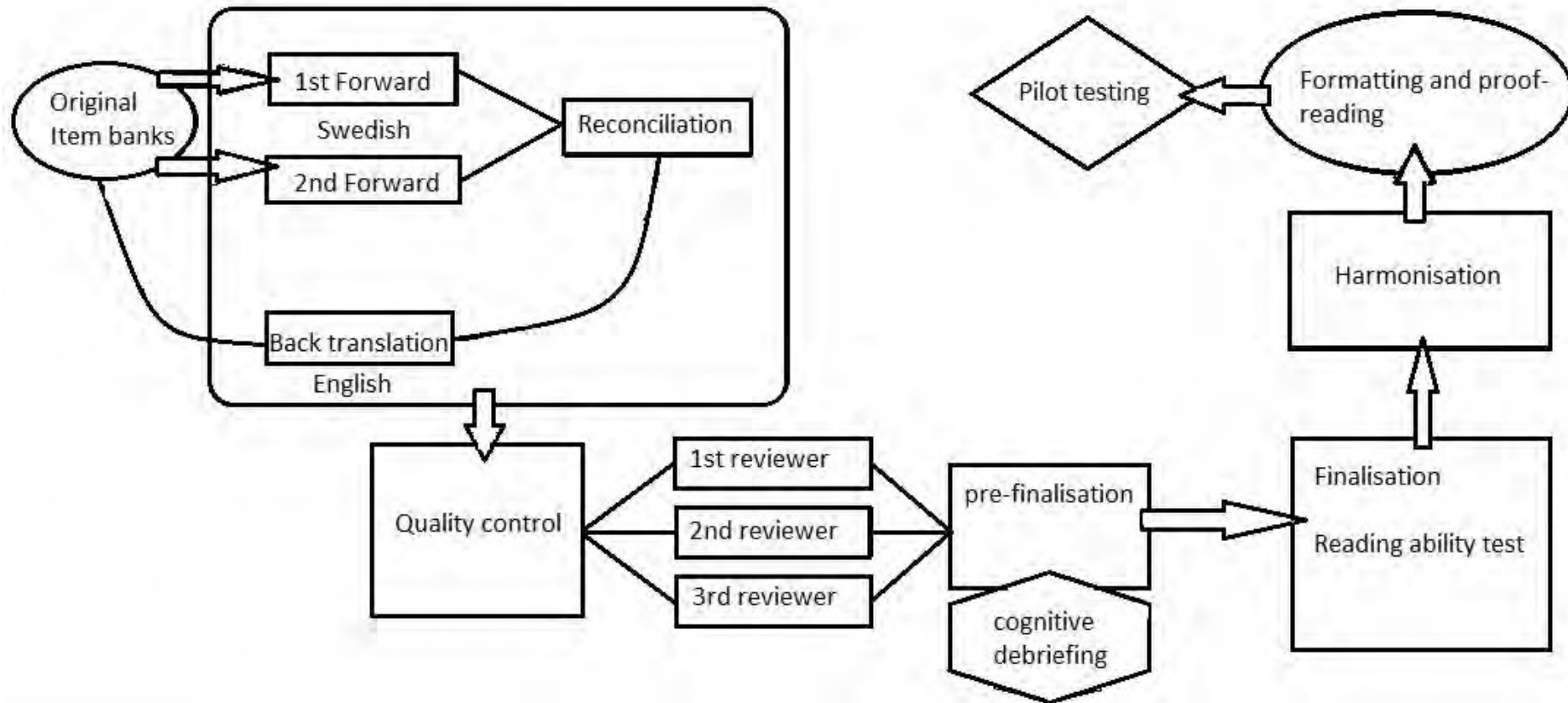
- Establish a multidisciplinary team including patient representation.
- Select item banks reflecting common registry needs.
- Agree a protocol for the translation.
- Identify where different clinics can participate.
- Create a demo CAT using the translated item banks.

Adult Banks and Scales

NeuroQoL item banks
prioritized by NEUROreg

Domain	Format	# Items	# Items in Short Form
Anxiety	Bank	21	8
Depression	Bank	24	8
Fatigue	Bank	19	8
Upper Extremity Function - Fine Motor, ADL	Bank	20	8
Lower Extremity Function – Mobility	Bank	19	8
Cognitive Function	Bank	28	8
Emotional and Behavioral Dyscontrol	Bank	18	8
Positive Affect and Well-Being	Bank	23	9
Sleep Disturbance	Bank	8	NA
Ability to Participate in Social Roles and Activities	Bank	45	8
Satisfaction with Social Roles and Activities	Bank	45	8
Stigma	Bank	24	8
Communication	Scale	5	NA

Translation process

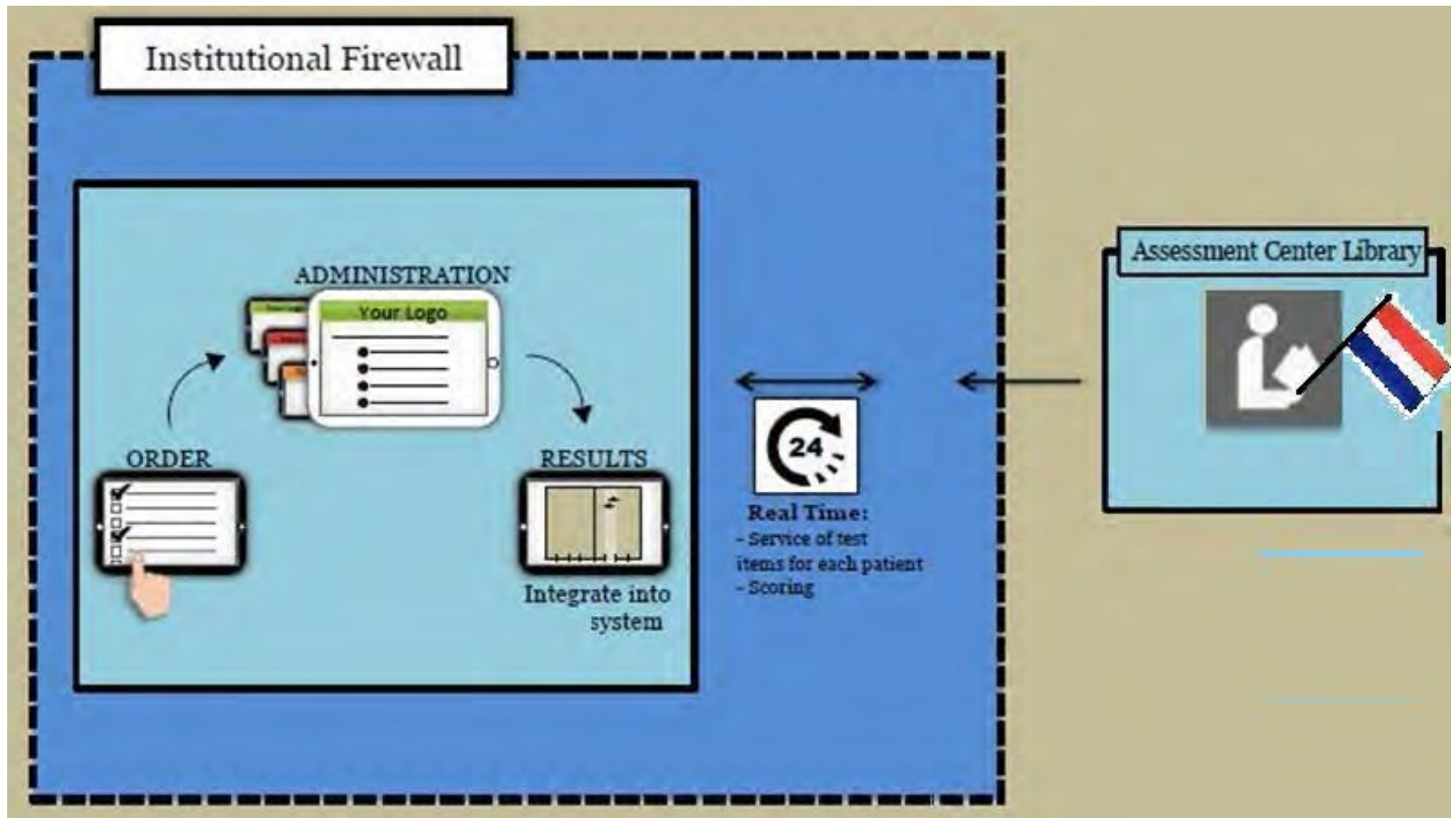


The standard process of translation and verification used in adapting PROMIS for Swedish use:

Each item is translated independently by two native Swedish speakers into Swedish and reconciled. Back-translated into English and reviewed by three independent reviewers prior to cognitive testing with the target population; readability is evaluated and harmonized with other translations.

CAT system

The system allows the utilization of available CATs in different languages.



A Dutch solution

- The patient receives a personal invitation to complete the test. When the test is complete a report containing the interpreted results is available within the register.



1 Wat vindt u, over het algemeen genomen, van uw gezondheid?

☐ Uitstekend
☐ Zeer goed
☐ Goed
☐ Matig
☐ Slecht

2 In vergelijking met een jaar geleden, hoe zou u nu uw gezondheid in het algemeen beoordelen?

☐ Veel beter dan een jaar geleden
☐ Iets beter dan een jaar geleden
☐ Ongeveer hetzelfde als een jaar geleden
☐ Iets slechter dan een jaar geleden
☐ Veel slechter dan een jaar geleden

... op dit moment beperkt bij deze bezigheden? Zo ja, ...
... enstig beperkt



Under de senaste 7 dagarna

Jag kände mig uttröttad.

Aldrig

Sällan

Ibland

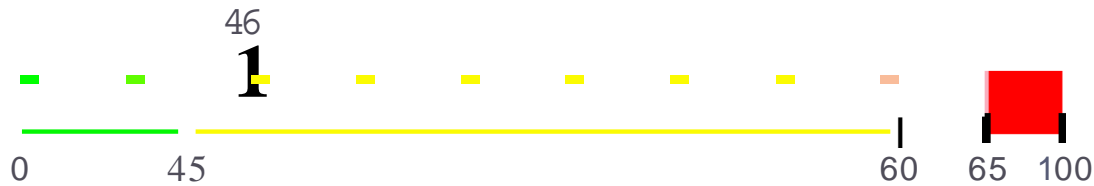
Ofta

Alltid

Ditt trötthet poäng är : 46 (Medelvärde för befolkning är 50)

Antal besvarade frågor : 2

Tidl : 00:00:13



Inga problem

Milda problem

Måttliga problem

Svåra problem



Future activities

- ❖ Validate the item banks in national clinical populations.
- ❖ Evaluate patient's needs for and satisfaction with feedback.
- ❖ Demonstrate the psychometric quality of the data.