The Neuro-QoL® Utility (NQU) Scoring System

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Key research personnel

- Louis Matza (PI, Evidera)
- Katie Stewart
- Dennis Revicki
- Janel Hanmer
- David Cella
- David Feeny
- Deborah Miller
- Glenn Phillips
Health-related quality of life (HRQL)

- HRQL is multidimensional: physical functioning, cognitive functioning, depression, fatigue, dexterity...
  - Condition-specific
  - Generic

Figure: Wilson & Cleary (1995).
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Utility-based HRQL

We will be focusing on utility-based HRQL measures.

- Utility captures preferences for health (usually the public’s preferences).
- Summarizes the value of a state of health by a single number, allowing the comparison of all states of health.
- Useful for many applications
  - Economic analyses (e.g., QALYs, cost-effectiveness analysis)
  - Population health
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Summary of a utility-based HRQL measure

- "Rarely get enough sleep"
- "Never in distressing pain"

Sleep poorly 0 Sleep well

Worst pain 0 No pain

-1.0 1.2
Summary of a utility-based HRQL measure

- "Rarely get enough sleep"
  - Sleep poorly: 0
  - Sleep well: 1.0
  - (-1.0, 1.2, cognition, physical functioning, ...)

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  - Worst pain: 0
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Summary of a utility-based HRQL measure

Neuro-QoL Utility Score

Background
Overview
Domain selection
Survey and sample
Scoring function
Validation

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Worst utility
Best utility (i.e., the value of full health)

(-1.0_{sleep}, 1.2_{pain}, cognition, physical functioning, ...)

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... cognition, physical functioning, ...
Summary of a utility-based HRQL measure

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<tr>
<th>Domain</th>
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**Neuro-QoL Utility Score**

**Barry Dewitt**

**Background**

**Overview**

**Domain selection**

**Survey and sample**

**Scoring function**

**Validation**

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**“Rarely get enough sleep”**

- Sleep poorly: 0
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**“Never in distressing pain”**

- Worst pain: 0
- No pain: 1.2

...(cognition, physical functioning, ...)

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- **“Never in distressing pain”**
  - Worst pain
  - No pain
  - Scoring function: $1.2$

Worst utility: $-1.0$

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The **Neuro-QoL® Utility (NQU) Scoring System** is a utility-based HRQL measure that uses the Neuro-QoL to describe states of health.

It allows studies to collect patient-reported outcomes data through the Neuro-QoL and automatically have the capability to perform preference-based analyses without extra data collection.

Developed with a particular focus on multiple sclerosis.
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Most utility-based HRQL measures describe health using classical test theory-based instruments. The NQU benefits from the psychometric advances of the Neuro-QoL.

The PROMIS®-Preference (PROPr) project produced a generic utility score for health states described by PROMIS domains.

The NQU project follows a similar methodology to PROPr.
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NQU development: A bird’s-eye view

- Neuro-QoL domain selection
- Survey development, sample recruitment, and data collection
- Calculation of the scoring function
- Validation
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Six Neuro-QoL domains were selected:

- depression (*mood*)
- fatigue
- ability to participate in social roles and activities (*social roles*)
- cognitive function (*thinking*)
- upper extremity function (*upper limbs*)
- lower extremity function (*lower limbs*)
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Survey development: Preference elicitation

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Sample recruitment and data collection

- In-person administration in the UK.
- Two groups: general population ($n = 203$) and MS patients ($n = 62$)
- Survey included:
  - Preference elicitation
  - Neuro-QoL
  - Legacy measures (EQ-5D, HUI)
  - PDDS (for MS group)
  - Clinical characteristics
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Health status: Describe health states as

\[ \Theta = (\theta_{\text{mood}}, \theta_{\text{fatigue}}, \theta_{\text{social}}, \theta_{\text{thinking}}, \theta_{\text{upperlimb}}, \theta_{\text{lowerlimb}}), \]

where \( \theta_{\text{domain}} \) is a score on one of the chosen Neuro-QoL domains.

⇒ Attach a utility value \( u(\Theta) \) to \( \Theta \), for every possible \( \Theta \).
Utility-based HRQL in practice

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Neuro-QoL Utility Score

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\[ \Rightarrow \] Attach a utility value \( u(\Theta) \) to \( \Theta \), for every possible \( \Theta \).
Single-attribute utility functions
The NQU scoring function is defined via a multiplicative model:

\[
NQU(\Theta) = 1 - \frac{C}{C} \left[ \prod_{d \in \text{domains}} (1 + C \cdot c_d (1 - u_d (\theta_d))) - 1 \right],
\]

where

\[
\Theta = (\theta_{\text{mood}}, \theta_{\text{fatigue}}, \theta_{\text{social}}, \theta_{\text{thinking}}, \theta_{\text{upperlimb}}, \theta_{\text{lowerlimb}})
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is a health state formed from Neuro-QoL measurements, and \(c, C, c_d\) are constants.
Some highlights of the validation analyses

- Mean NQU score of the general population sample is 0.94 (on a 0-1 scale). Mean NQU score of the MS sample is 0.82. Variation is small enough that the difference is significant ($p < 0.01$).
- Positively correlated ($\approx 0.6$) with generic legacy measures (EQ-5D and HUI) in the MS sample.
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  - NQU provides different information than generic measures.
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- Lower PDDS scores $\Rightarrow$ higher NQU scores
A summary score for 6 domains of the Neuro-QoL will soon be available, allowing anyone collecting Neuro-QoL data to undertake preference-based analyses, such as comparative effectiveness analyses.

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Carnegie Mellon University
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Preference elicitation: What’s your utility for a given health state?

The Standard Gamble (SG)

**Choice A**

- **Worst Health**
  - Chance 60%
- **Best Health**
  - Chance 40%

**Choice B**

- **Middle Health**
  - Guaranteed
### Example health states

#### Perfect Health

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<td><strong>Upper Limbs</strong></td>
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### Example Corner State (Fatigue)

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### Example Marker State (Moderate)

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<td>I am sometimes able to participate in leisure activities.</td>
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<td><strong>Thinking</strong></td>
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