

# NFTI-QOL

The NFTI-QOL is a robustly constructed disease-specific [QOL questionnaire](#) for [neurofibromatosis type 2](#). It correlates strongly and significantly with [EuroQOL](#) and all [SF-36](#) domains ( $p < 0.01$ ). It is straightforward and quick ( $\leq 3$  minutes) for patients to complete and easy to score. It is suitable as a quantitative method of assessing QOL in NF2 both in a clinical setting and as an outcome measure for treatment. The NFTI-QOL has been validated for adults ( $>16$  years) in the [United Kingdom](#), and could be adapted for use in other countries <sup>1)</sup>.

**Appendix 1: NFTI-QOL****Neurofibromatosis 2 Impact on QOL (English Version for the UK)****INSTRUCTIONS FOR COMPLETING THE NFTI-QOL****Please complete the following information:**

Age: \_\_\_\_\_ years

Gender: Male ☐ 1    Female ☐ 2    (please tick)**For each of the questions on the next page, please tick the one box that describes how you feel today****Usual activities include: work; housework; study; sport; social; family or leisure activities**

Patient ID/Label:

Q1. Do balance or dizziness problems stop you performing your usual activities?

- No balance problems or dizziness ☐ 0
- Balance or dizziness problems but no difficulties ☐ 1
- Balance or dizziness problems cause me some difficulties ☐ 2
- Balance or dizziness problems stop my usual activities ☐ 3

Q2. Do hearing problems stop you performing your usual activities?

- No hearing problems ☐ 0
- Hearing problems but no difficulty ☐ 1
- Hearing problems cause me some difficulty ☐ 2
- Hearing problems stop my usual activities ☐ 3

Q3. Does facial weakness stop you performing your usual activities?

- No facial weakness ☐ 0
- Facial weakness, but no difficulty ☐ 1
- Facial weakness causes some difficulty ☐ 2
- Facial weakness stops my usual activities ☐ 3

Q4. Do problems with your sight stop you performing your usual activities?

- No problems with sight ☐ 0
- Sight problems, but no difficulty ☐ 1
- Sight problems cause me some difficulty ☐ 2
- Sight problems stop my usual activities ☐ 3

Q5. Do you have any problems in mobility and walking?

- No problems in mobility and walking ☐ 0
- Some difficulty but can manage on my own ☐ 1
- Unable to walk around without some help ☐ 2
- Unable to walk at all ☐ 3

Q6. Has your medical condition affected your role and outlook on life? (e.g., confidence, vulnerability, relationships, caring for family, career, having children)

- No effect or positive effect ☐ 0
- Small negative effect ☐ 1
- Moderately negative effect ☐ 2
- Large negative effect ☐ 3

Q7. Pain; throughout our lives, most of us have had pain from time to time such as mild headaches, sprains and toothaches. Have you had pain *other than this* in the last week?

- None ☐ 0
- Mild pain ☐ 1
- Moderate pain ☐ 2
- Severe pain ☐ 3

Q8. Do you currently suffer from anxiety or depression?

- No ☐ 0
- Mild anxiety or depression ☐ 1
- Moderate anxiety or depression ☐ 2
- Extreme anxiety or depression ☐ 3

**If you have any further comments regarding the impact of NF2 on your QOL, please write them here:****You have now completed the NFTI-QOL. Thank you for your input.**

The aim of the study of Lawson McLean et al was to produce and validate a German version of the NFTI-QOL (NFTI-QOL-D) and to correlate **QOL scores** with a **depression** score (**PHQ-9**) and clinical **disease** severity.

The original English-language NFTI-QOL was translated into German and then back-translated in order to preserve the questionnaire's original concepts and intentions. A link to an **online survey** encompassing the NFTI-QOL-D and the PHQ-9 depression questionnaire was then sent to 97 patients with NF2 by **email**. The respondents' scores were compared to clinician-reported disease severity scores.

77 patients completed the online survey in full. **Internal consistency** among NFTI-QOL-D responses was strong (**Cronbach's alpha**: 0.74). Both PHQ-9 and clinician disease severity scores correlated with NFTI-QOL-D scores (**Pearson correlation coefficient** rho 0.63 and 0.62, respectively).

The NFTI-QOL-D is a reliable and useful **tool** to assess patient-reported QOL in German-speaking patients with **neurofibromatosis type 2**. The correlation of **QOL** with both psychological and physical disease parameters underlines the importance of individualized interdisciplinary patient **care** for NF2 **patients**, with attention paid to mental well-being as well as to somatic disease **manifestations** <sup>2)</sup>.

## Case series

Data were evaluated for 288 NF2 patients (n = 464 visits) attending the English national NF2 clinics from 2010 to 2012. The male-to-female ratio was equal and the mean age was 42.2 (SD 17.8) years. The analysis included NFTI-QOL eight-item score, ClinSev graded as mild, moderate, or severe, and GenSev as a rank order of the number of NF2 mutations (graded as mild, moderate, severe). The mean (SD) 8.7 (5.4) score for NFTI-QOL for either a first visit or all visits 9.2 (5.4) was similar to the published norm of 9.4 (5.5), with no significant relationships with age or gender. NFTI-QOL internal reliability was good, with a Cronbach's alpha score of 0.85 and test re-test reliability r = 0.84. NFTI related to ClinSev (r = 0.41, p < 0.001; r = 0.46 for all visits), but weakly to GenSev (r = 0.16, p < 0.05; r = 0.15 for all visits). ClinSev related to GenSev (r = 0.41, p < 0.001; r = 0.42 for all visits). NFTI-QOL showed good reliability and ability to detect significant longitudinal changes in the QOL of individuals. The moderate relationships of NFTI-QOL with a clinician- and genetic-rated severity suggest that NFTI-QOL taps into NF2 patient experiences that are not encompassed by ClinSev rating or genotype <sup>3)</sup>

<sup>1)</sup>

Hornigold, R. E., Golding, J. F., Leschziner, G., Obholzer, R., Gleeson, M. J., Thomas, N., Walsh, D., Saeed, S., & Ferner, R. E. (2012). The NFTI-QOL: A Disease-Specific Quality of Life Questionnaire for Neurofibromatosis 2. *Journal of Neurological Surgery. Part B, Skull Base*, 73(2), 104-111.  
<https://doi.org/10.1055/s-0032-1301396>

<sup>2)</sup>

Lawson McLean AC, Freier A, Lawson McLean A, Kruse J, Rosahl S. The German version of the neurofibromatosis 2 impacts on quality of life questionnaire correlates with severity of depression and physician-reported disease severity. *Orphanet J Rare Dis*. 2023 Jan 6;18(1):3. doi: 10.1186/s13023-022-02607-z. PMID: 36604703.

<sup>3)</sup>

Ferner RE, Shaw A, Evans DG, McAleer D, Halliday D, Parry A, Raymond FL, Durie-Gair J, Hanemann CO, Hornigold R, Axon P, Golding JF. Longitudinal evaluation of quality of life in 288 patients with

neurofibromatosis 2. J Neurol. 2014 May;261(5):963-9. doi: 10.1007/s00415-014-7303-1. Epub 2014 Mar 12. PMID: 24619350; PMCID: PMC4008785.

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