

This is a **Sample** version of the

# Graves' Ophthalmopathy Quality of Life Questionnaire (GO-QOL)

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- GO-QOL Scoring/ Administration instructions
- GO-QOL Complete questionnaire/ Assessment (15 sets of question criteria)
- GO-QOL Clinical Validity

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# Development of a disease specific quality of life questionnaire for patients with Graves' ophthalmopathy: the GO-QOL

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## Abstract

**Aim**—To develop a reliable and valid disease specific quality of life questionnaire (the GO-QOL) for patients with Graves' ophthalmopathy (GO), that can be used to describe the health related quality of life and changes in health related quality of life over time as a consequence of disease and treatment.

**Methods**—70 consecutive GO patients (age >18 years) who were referred for the first time to the combined outpatient clinic of the orbital centre and the department of endocrinology completed the 16 questions of the GO-QOL. Additional information on general quality of life and disease characteristics was obtained. Construct validity and internal consistency of the disease specific questionnaire was determined, based on principal component analysis, Cronbach alphas and correlations with MOS-24, three subscales of the SIP, demographic, and clinical measures.

**Results**—The a priori expected subdivision of the questionnaire in two subscales, one measuring the consequences of double vision and decreased visual acuity on visual functioning, and one measuring the psychosocial consequences of a changed appearance, was confirmed in the principal component analysis. Both scales had a good reliability and high face validity. Correlations with other measures supported construct validity. Mean scores (range 0–100) were 54.7 (SD 22.8) for visual functioning and 60.1 (24.8) for appearance (higher score = better health).  
**Conclusion**—The GO-QOL is a promising tool to measure disease specific aspects of quality of life in patients with GO and provides additional information to traditional physiological or biological measures of health status.

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Graves' ophthalmopathy (GO), associated with Graves' thyroid disease (GTD), is an incapacitating eye disease, causing disfiguring proptosis, pain, redness, and swelling of the eyelids, grittiness of the eyes, diplopia, and sometimes even blindness.<sup>1,2</sup> Several studies have shown that visual problems in general can have a major impact on daily functioning and wellbeing.<sup>3–6</sup> Furthermore, the psychological burden of the progressive disfigurement result-

ing from GO is well recognised.<sup>7,8</sup> Bartley *et al*<sup>9</sup> report that after treatment 61% of the patients believed that the appearance of their eyes had not returned to baseline status, 51% thought their eyes continued to be abnormal in appearance, and 37% were dissatisfied with the appearance of their eyes. Overall, the effects of GO on physical and psychological functioning have a significant impact on a patient's health related quality of life.<sup>10</sup>

The outcomes of GO disease and treatment are mostly assessed with biological and physiological measures—for example, combined in the NO SPECS classification.<sup>11</sup> While these measures provide important information to clinicians, they often correlate poorly with functional capacity and perceived health as experienced by the patient.<sup>12,13</sup> For example, Prummel *et al*<sup>14</sup> found a response rate of 50% and 46% respectively to prednisone and radiotherapy measured by the NO SPECS classification, but the benefit of both treatments on the subjective judgment of the eye condition by the patient (expressed in the subjective eye score<sup>15</sup>) was only modest. In a recent study we found low correlations between scores on a general health related quality of life questionnaire and measures of severity and activity of disease.<sup>10</sup>

These different outcomes can be regarded as different concepts on a causal pathway from biological and physiological measures to perceived symptoms, then to the functional consequences of these symptoms, and finally to more complex elements such as general health perceptions and overall quality of life.<sup>12</sup> Following on the WHO definition of health, health related quality of life (HRQL) can be defined as the physical, psychological, and social domains of health, as perceived by the patient, which are influenced by a patient's experiences, beliefs, and expectations of their disease and treatment.<sup>16,17</sup>

In general, HRQL measures are among the best predictors of the use of general medical and mental health services as well as strong predictors of mortality.<sup>12</sup> Although implicitly (health related) quality of life always has been an important goal in medicine, it is only quite recently that it became explicitly an outcome measure in medical studies. In 1992, a joint committee of thyroid associations recommended that self assessment of the eye condition by the patient should be included in evaluations of treatments for patients with GO.<sup>18</sup> While a number of studies have assessed

**This is the end of the SAMPLE GO-QOL clinical validity.  
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## Instructions for users of the GO-QOL

### *About the GO-QOL*

- The GO-QOL is a disease-specific quality of life questionnaire, especially designed to measure health-related quality of life (HRQL) of patients with Graves' ophthalmopathy (GO).
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### *Use of the GO-QOL*

- The GO-QOL is a self-administered questionnaire that patients should complete by themselves.
- If the GO-QOL is administered in an interview session or if patients need help from others, questions and answering options should be read to them in a neutral way to ensure that the answers reflect the patient's opinion.

### *Use of the GO-QOL in different languages*

- The GO-QOL is available in a Dutch and (UK) English version.
- Users of the GO-QOL are advised to use the GO-QOL in its present form and layout. Please do not change the sequence of the questions and keep the questions together on the same pages as they are, because changes in the layout or sequence of the questions may affect the validity and reliability of the questionnaire.
- When using the English version of the GO-QOL, the only thing that users may want to adjust is the name of the disease: In general, the name "thyroid eye disease" is used in the UK, while "Graves eye disease" is common in the US. Local circumstances may be different and users of the GO-QOL are advised to check this and adjust the questionnaire on this point if necessary.

### *Scoring of the GO-QOL*

- The 15 questions can be summarized into two subscales, called "visual functioning" and "appearance" as described above. Answers should be scored 1 to 3 points

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## GO-QOL English version

The following 15 questions deal specifically with your thyroid eye disease. Please focus on the past week while answering these questions.

The boxes correspond with the answers above them. Tick the box that matches your answer. Please tick only one box for each question.

**Q 1-7 During the past week, to what extent were you limited in carrying out the following activities because of your thyroid eye disease?**

	<b>Yes, seriously limited</b>	<b>Yes, a little limited</b>	<b>No, not at all limited</b>
1. Driving [no drivers' licence <input type="checkbox"/> ]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Moving around in the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Walking outdoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Hobby or pastime ie.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<b>Yes, severely hindered</b>	<b>Yes, a little hindered</b>	<b>No, not at all hindered</b>
7. During the past week, did you feel hindered from something that you wanted to do because of your thyroid eye disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q 8-15 The following questions deal with your thyroid eye disease in general**

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