

Patient involvement in the development of obesity and weight loss-specific patient reported outcome measures



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Summary

- + Most obesity-specific quality of life measurement tools were developed with minimal patient input - over half had no patient involvement at all, and none had more than basic consultation with patients.
- + Current quality of life instruments may not capture the full range of patient experiences, especially in the era of GLP-1 medications that significantly transform how people experience obesity and weight loss.
- + Even instruments that are technically sound and reliable may miss what matters most to patients today, requiring continuous updates through meaningful patient involvement to ensure they remain relevant and valid.

Background

- Obesity significantly impairs quality of life (QoL)¹, and **numerous instruments have been developed to quantify obesity-specific QoL**.
- However, the development processes for these patient-reported outcome measures (PROMs) have historically involved patients to varying degrees, raising **concerns about content validity and the applicability of these measures to challenges associated with obesity and weight loss treatments**.
- This is particularly relevant in the age of glucagon-like peptide-1 (GLP-1) receptor agonists, which produce substantial weight loss benefits and transform the lived experience of obesity.²

Methods

In this study, we systematically evaluated the extent of patient involvement in the development of thirteen obesity-specific QoL instruments, adapting a four-stage framework (**concept identification, item generation, item reduction, psychometric validation**) previously applied by Frew et al. (2013)³. For each of the stages, two independent reviewers gave each instrument a score ranging between 0 and 3 (see Table 1).

Table 1. Patient involvement evaluation framework.

Score	Interpretation
0	No patient involvement
1	Patient consultation: Patients are consulted for their views (eg, via survey, focus group, or other methodology), but these views may not necessarily be adopted.
2	Collaboration with patients: This involves active, ongoing partnership between researchers and patients in the development of the PROM.
3	Collaboration with patients: This involves active, ongoing partnership between researchers and patients in the development of the PROM.

Table 2: Evaluation of patient involvement across existing obesity-specific QoL measures.

Instrument	Concept and domain identification	Item wording and selection	Item reduction	Psychometric evaluation	Total Score
Impact of Weight on Quality of Life (IWQOL)	1	1	0	0	2
Impact of Weight on Quality of Life (IWQOL-Lite)	0	0	0	0	0
Impact of Weight on Quality of Life (IWQOL-Lite) Clinical Trials Version	1	1	0	0	2
Moorehead-Ardelt Quality of Life Questionnaire II (MA-QoLQII)	0	0	0	0	0
Obesity and Weight-Loss Quality of Life (OWLQOL)	1	1	1	0	3
Obesity-Related Well-Being questionnaire (ORWELL-97)	1	1	0	0	2
Sizing Me Up (child self-report)	0	0	0	0	0
Sizing Them Up (parent-proxy)	0	0	0	0	0
Youth Quality of Life Instrument – Weight Module (YQOL-W)	1	0	0	0	1
Quality of Life for Obesity Surgery (QOLOS)	1	1	0	0	2
Bariatric Quality of Life Index	1	0	0	0	1
Treatment-Related Impact Measure (TRIM) - Weight	1	2	0	0	3
Obesity-Related Problems Scale	0	0	0	0	0

Results

We found that most instruments had minimal patient input during development: over half had no documented involvement at any stage, and none exceeded a consultative role (Level 1 involvement) at any given stage of the development process. Even instruments with strong reliability and validity often lacked patient involvement (see Table 2).

Conclusions

Here, we argue that current QoL instruments, many of which were developed before the GLP-1 era, risk becoming outdated in content—and, indeed, may already be limited in the extent to which they capture the full breadth of patient experiences. We argue that even psychometrically sound instruments may fail to reflect what matters most to patients today unless they are continuously updated through patient-centred design. Patient involvement in PROM development is needed to ensure content validity in the context of modern obesity treatments.

References:
1. Kolotkin et al. 2008. Quality of life and obesity; Obesity Reviews; 2(4); <https://doi.org/10.1046/j1467-789X.2001.00040.x>
2. Michos et al. 2023. Role of GLP-1 RAs in achieving weight loss and improving cardiovascular outcomes in people with overweight and obesity. JAHA; 12(11); <https://doi.org/10.1161/JAHA.122.029282>
3. Frew et al. 2013. Patient involvement in the development of asthma-specific patient-reported outcome measures: a systematic review; J Allergy Clin Immunol; 132 (6); 1434-6; doi: 10.1016/j.jaci.2013.05.047