

Generic outcomes measurement: a systematic review of domains and patient-reported instruments

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Objective

Patient-reported outcomes (PROs) are an essential part of health outcome measurement and vital to patient-centred and value-based care. PROs are measured using patient-reported outcome measures (PROMs). Several international consortia, including ICHOM, have developed core outcome sets and many of them include PROs. PROs and PROMs can be generic or specific to certain diseases or conditions. While the characteristics of generic PROs and PROMs are well recognised, a comprehensive overview is missing. The objective of this study was to identify the most commonly measured generic domains across different chronic diseases, the instruments used to measure these generic domains, and the medical/health areas in which these generic domains and instruments have been applied to date.

Methods

We conducted a review of systematic reviews in compliance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) 2020 Statement. Four databases were used: Medline[PubMed], CINHAL[Ebsco], Cochrane[Cochrane library], and PsycINFO[Ovid]. Systematic review articles reporting on PROMs applied in different disease areas in adult populations were included. We extracted generic PROs/domains and PROMs/instruments and calculated frequencies of the disease areas in which they were applied. We compared our findings to the ICHOM core outcome sets published by January 2021.

Generic PROMs facilitate outcome comparison across different diseases and could reduce the burden for patients, especially in multi-morbidity.

The generic PROMs with the widest domain coverage and disease usage are the

- Short Form Health Surveys (e.g. SF-36),
- European Quality of Life Questionnaire,
- PROMIS Global and
- WHO Quality of Life Questionnaire.

These PROMS are also included in existing standards (e.g. the ICHOM sets).

Results

2,357 articles were identified of which 286 were duplicates. Our analysis showed that more than 200 PROMs can be considered generic and were administered in all disease areas listed in the International Classification of Diseases, Tenth Revision (ICD-10). Cancer is one of the major diseases in which generic PROMs were applied. We grouped the identified PROs into 11 key concepts: mental, physical, social, and overall well-being, quality of life, pain, sleep, energy/vitality, fatigue, cognition and self-efficacy. Some PROs, such as cognition and self-efficacy, are not or rarely covered by generic PROMs.

Conclusion

PROMs with comprehensive domain coverage are scarce despite being recommended in different ICHOM sets. With the availability of larger data sets and the focus on interoperability, the values of generic PROs and PROMs as health outcome measurements are likely to increase in the future. Generic PROMs enable the comparisons between diseases with less items needed to be answered by patients. Thus such generic focus could reduce burden, especially for patients with multi-morbidity.

