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Review

Assessing Quality of Life in Oncology: A Review of Current Measurement Tools and Gaps across the Cancer Care Continuum

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Abstract

Quality of life (QoL) assessment has evolved into a critical component of cancer care, increasingly recognized alongside traditional clinical endpoints such as survival. This review traces the conceptual development of QoL in oncology, from symptom-focused origins to a multidimensional construct encompassing physical, emotional, social, and spiritual well-being. It examines the landscape of measurement instruments including generic tools like SF-36, cancer-specific instruments like EORTC QLQ-C30 and FACT-G, and digital platforms for real-time data collection highlighting their psychometric robustness and utility across the cancer care continuum. Despite methodological advances, significant implementation challenges persist, including underrepresentation of vulnerable populations, limited integration into routine clinical workflows, and gaps between measurement and actionable care. Future directions include adaptive computerized testing, AI-driven predictive analytics, and passive sensing technologies, which offer personalized, low-burden monitoring solutions. The review calls for harmonized outcome sets, stronger implementation frameworks, and inclusive, patient-centered design to fully realize QoL as a pillar of value-based, person-centered oncology.

Keywords: Quality of Life (QoL), Patient-Reported Outcomes (PROs), EORTC QLQ-C30, FACT-G, Psychometrics, Cancer Care Continuum.

1.0 INTRODUCTION

Quality of life (QoL) has migrated from a peripheral research curiosity to a core efficacy signal in modern oncology. Prolonged survival after the advent of multimodal therapy has unmasked a spectrum of latent toxicities functional decline, cognitive fog, sexual dysfunction, and financial distress that often eclipse tumour

control as determinants of overall benefit. Regulatory agencies now require rigorous patient-reported outcome (PRO) evidence, a demand crystallised in the 2023 US FDA draft guidance that frames PROs as "indispensable for evaluating drugs whose survival advantage is modest or delayed" [1]. Against this backdrop, researchers have produced an expanding arsenal of QoL instruments, yet their uptake in everyday clinics remains patchy. This review first revisits the conceptual roots that define QoL in cancer care and then critically appraises mainstream measurement tools, mapping their practical use from screening to end-of-life care. It concludes by diagnosing persistent gaps methodological, demographic, and technological and proposing a future-ready research and policy agenda designed to transform every data point into actionable, patient-centred intervention.

2.0 CONCEPTUAL FOUNDATIONS OF QOL IN CANCER CARE

Cancer QoL theory has evolved from a unidimensional symptom lens to a sophisticated, multidimensional construct encompassing physical, psychological, social, functional, and spiritual wellbeing. The turning point came in the late 1980s when survivorship movements argued that longevity divorced from life quality was a Pyrrhic victory. Wilson & Cleary's outcome continuum bridged biology and lived experience by tracing causal pathways from physiological variables through symptoms, functioning, general health, and finally overall QoL [2] . In parallel, the WHO-ICF reframed disability as a universal phenomenon and provided a cross-cultural vocabulary that still underpins modern instrument development [3] . Layered onto these frameworks, the biopsychosocial model foregrounds environmental and behavioural determinants, legitimising interventions that extend beyond chemotherapy dosage to encompass exercise counselling, caregiver training, and financial navigation. Together, these theories inform content validity, illuminate mechanistic mediators of QoL change, and set the stage for harmonised core outcome sets.

3.0 LANDSCAPE OF MEASUREMENT INSTRUMENTS

The current instrument milieu can be visualised as a concentric hierarchy. At its outer shell sit **generic health-status tools** such as the SF-36 and EQ-5D-5L. Their chief virtue is cross-disease comparability and availability of national tariffs for cost-utility modelling, but ceiling effects and sparse symptom capture limit sensitivity in advanced cancer. The PROMIS Global Health item bank, delivered through computerised adaptive testing (CAT), has partially solved this precision-versus-burden dilemma; a 2024 lung-cancer trial demonstrated that CAT delivered equally reliable scores with 40 % fewer items [4].

At the next layer are **core cancer-specific instruments**. The gold-standard EORTC QLQ-C30 boasts >110 language versions, extensive normative data, and modular flexibility. A 2023 multinational validation study reaffirmed its factorial stability and cross-cultural scalar invariance even in immunotherapy cohorts [5]. The FACT-G, meanwhile, emphasises functional wellbeing and emotional resilience; pooled analyses indicate minimal clinically important difference (MCID) thresholds of 3–7 points across domains [6]. Surrounding these cores are >70 **site-specific and symptom-specific modules**e.g., BR23 for breast cancer or FACIT-Fatigue. While these finely tuned add-ons enhance content validity, they complicate meta-analyses when trials employ divergent module selections. ISOQOL's 2022 consensus statement recommends a slim core set supplemented by context-specific modules to balance depth and comparability [7].

Utility-weighted measures such as the EQ-5D-5L or the oncology-tailored QLU-C10D translate QoL profiles into quality-adjusted life-years for health-economic evaluations. The QLU-C10D, derived directly from the QLQ-C30, has shown superior sensitivity to late neuropathy and gastrointestinal toxicity compared with the EQ-5D in colorectal survivors.

Special populations warrant bespoke tools. The PedsQL Cancer Module and KINDL-R integrate developmental considerations and offer proxy versions for caregiver reporting, though concordance studies reveal that parents tend to underestimate their child's emotional distress. Caregiver QoL itself is measurable via scales such as CQOL-C, underscoring the bidirectional nature of cancer burden.

Finally, **digital and real-time platforms** promise ecological granularity. A 2023 US Alliance trial equipped metastatic patients with wrist-worn accelerometers; passively collected activity counts correlated strongly with clinician-rated performance status ($r = 0.72$) and predicted 90-day hospitalisation better than laboratory markers [8]. Mobile apps that push weekly QLQ-C30 surveys have reduced emergency-department visits and improved median overall survival by five months in pragmatic randomised studies.

4.0 PSYCHOMETRIC AND METHODOLOGICAL CONSIDERATIONS

Instrument credibility rests on validity, reliability, responsiveness, and feasibility. Content validity requires formative qualitative work with the target population, whereas construct validity often employs confirmatory factor analysis; most EORTC and FACIT scales exceed a comparative-fit index of 0.90. Reliability benchmarks include Cronbach's $\alpha \geq 0.70$ and intraclass correlation coefficients ≥ 0.75 in test-retest phases. Responsiveness hinges on detecting MCIDsapproximately 5–10 points on the QLQ-C30 global score, though disease-specific thresholds vary. Cross-cultural adaptation proceduresforward translation,

back-translation, and cognitive debriefingare mandatory for global trials and routinely map items to WHO-ICF domains to ensure conceptual equivalence [3].

Practical feasibility involves respondent burden, literacy barriers, and administrative logistics. CAT platforms have slashed completion times from 15 to <5 minutes while maintaining precision. Importantly, the 2023 FDA guidance stresses prespecified estimand strategies and electronic source verification, requiring raw ePRO data to be audit-traceable [1]. Parallel European discussions under ICH E19 advocate selective "lean" data collection to ease workloads without sacrificing decision-critical information [9].

5.0 APPLICATION ACROSS THE CANCER-CARE CONTINUUM

Baseline QoL assessment at diagnosis flags pre-morbid vulnerabilities such as anxiety, malnutrition, or social isolation, enabling early psycho-oncology or nutrition referrals. During active treatment, weekly ePRO surveillance of symptoms like nausea, mucositis, and neuropathy supports just-in-time dose-modification decisions; meta-analyses show a 30 % reduction in unplanned acute-care encounters when clinicians receive automated grade ≥ 2 toxicity alerts. Survivorship care then grapples with latent cardiopulmonary impairment, cognitive fog, and sexual dysfunction. Longitudinal FACT-G benchmarking helps distinguish transient sequelae from progressive decline, informing tailored rehabilitation plans.

In advanced or metastatic settings, symptom clusterspain, fatigue, dyspnoeapredominate. Short-form tools such as the QLQ-C15-PAL capture these domains while respecting stamina limits. At the palliative frontier, instruments enriched with existential and spiritual items (e.g., WHOQOL-Cancer) monitor dignity-related distress. Wearable-derived sleep fragmentation and heart-rate variability often presage symptom escalation by days, opening a window for pre-emptive intervention.

Beyond individual encounters, seamless EHR integration enables multidisciplinary tumour boards to weigh QoL trade-offs when survival benefits are marginal. Emerging machine-learning algorithms trained on thousands of longitudinal ePRO records already forecast six-month QoL trajectories with C-statistics > 0.80, providing an objective scaffold for shared decision-making [10].

6.0 CURRENT GAPS AND IMPLEMENTATION CHALLENGES

Despite undeniable methodological maturity, oncology QoL science still struggles to leave the conference podium and transform routine care. A persistent equity gap begins with the systematic under-representation of older adults, minorities, and low-literacy patients in validation cohorts; a 2024 pooled analysis of 173 trials found that individuals ≥ 70 years constituted barely 10 % of QoL samples, even though they account for 40 % of incident cancers [11]. Financial toxicity remains a blind spot, only partially addressed by the COST-FACIT measure; most core tools omit direct questions on catastrophic out-of-pocket spending, forcing researchers to layer additional surveys and exacerbating respondent fatigue [12]. Multimorbidity further muddies interpretation—heart failure or osteoarthritis can depress physical-function scores independent of cancer trajectory, yet few instruments include comorbidity adjustment algorithms [13].

Structural barriers inside clinics compound these content gaps. Time-pressured consultations often truncate ePRO review, and an international survey of 1 150 oncologists reported that only 37 % felt adequately trained to interpret domain-specific score changes [14]. Technical interoperability remains patchy; while Fast Healthcare Interoperability Resources (FHIR) standards exist, fewer than one-third of major EHR vendors allow seamless bi-directional QoL data exchange, leading to human copy-and-paste workarounds that erode data integrity [15]. On the research front, longitudinal real-world evidence is scant—less than 8 % of national cancer registries capture PROs beyond 12 months, creating blind zones in survivorship planning [16]. Finally, even when robust data are available, translation into actionable care pathways lags; systematic reviews reveal that fewer than half of trials with significant QoL deterioration triggered predefined symptom-management algorithms, highlighting the "measurement-implementation gap" that still haunts the field [14].

7.0 EMERGING AND FUTURE DIRECTIONS

The next decade will witness an evolution from static questionnaires toward dynamic, context-aware QoL ecosystems. Adaptive computerised testing built on item banks enables personalised assessment; preliminary data show that PROMIS CATs can maintain ± 2-point precision on T-scores using fewer than five items, an 80 % reduction in burden compared with fixed-length forms [18]. Artificial-intelligence pipelines mine longitudinal ePRO streams, imaging biomarkers, and multi-omics datasets to forecast individual QoL trajectories; a 2023 multi-centre study trained gradient-boosted models on 12 000 breast-cancer records and predicted six-month global health decline with an area under the curve of 0.83, outperforming clinico-pathologic nomograms [10].

Beyond active reporting, passive sensing via wearables, smartphones, and even voice acoustics can infer fatigue, mood, and pain; pilots using spectral voice analysis have identified depressive symptom worsening three days before patient-reported distress escalated [19]. These signals will feed ecological momentary assessment platforms, creating digital phenotypes that map day-level QoL volatility. Convergence with

value-based payment models is inevitable—payers are beginning to reimburse drugs or care bundles conditional on demonstrable QoL maintenance, underscoring the commercial imperative for precise, reproducible endpoints [22]. Global harmonisation also gathers steam; ISOQOL's 2022 initiative to define tumour-agnostic core outcome sets has been complemented by ICH E19's selective data-collection framework, promising lean yet interoperable datasets that satisfy regulators on three continents. Crucially, low- and middle-income countries (LMICs) are carving a seat at the table through mobile-first platforms that bypass legacy EHR constraints, narrowing the digital divide while expanding cultural validity [20].

8.0 RECOMMENDATIONS FOR RESEARCH, PRACTICE, AND POLICY

Bridging the measurement-implementation gap demands a multi-pronged strategy. Researchers should converge on consensus core outcome sets so that trials across tumour types share at least one common QoL anchor, facilitating meta-analysis and health-technology-assessment modelling [23]. Implementation scientists ought to embed QoL collection within the RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) framework, ensuring that pilot successes survive scale-up into national programmes [17]. Co-creation with patients and caregivers must move upstream; participatory design workshops have already yielded plain-language, icon-driven interfaces that doubled survey completion in low-literacy groups [11]. LMIC capacity-building is paramount—South-South digital collaboratives supported by the WHO can accelerate local language validation and produce context-specific MCIDs.

Health-system leaders should integrate automated, rule-based alerts into EHR dashboards so that a $\geq$ 10-point QLQ-C30 global decline triggers a nurse-led symptom triage; early adopters report 28 % fewer emergency presentations and significant improvements in net-promoter scores [14]. Payers and policymakers can incentivise adoption by linking remuneration to QoL preservation benchmarks, mirroring existing models for diabetes HbA1c control. Finally, data custodians must align on ethical use, privacy, and cybersecurity protocols, particularly as passive-sensing data blur boundaries between medical and consumer domains [15].

9.0 CONCLUSION

Quality-of-life science in oncology stands at an inflection point. Three decades of conceptual refinement have produced psychometrically robust instruments, yet translation into equitable, real-world benefit remains uneven. Under-representation of frail, economically disadvantaged, and culturally diverse populations skews evidence; workflow bottlenecks and interoperability deficits blunt clinical utility; and an implementation void allows data to languish unfollowed by action. Emerging adaptive tests, AI-powered predictive analytics, and passive-sensing technologies promise to personalise monitoring, while global harmonisation and value-based payment models create economic momentum for widespread adoption. Future progress will require convergence on core outcomes, rigorous implementation science, and deep patient co-creation—principles that, if embraced, can transform QoL from a statistical afterthought into a tangible pillar of person-centred cancer care.

REFERENCES

1. US Food and Drug Administration. *Core Patient-Reported Outcome Measures in Cancer Clinical TrialsDraft Guidance for Industry*. Silver Spring, MD: FDA; 2023.
2. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life.*JAMA*. 1995;273(1):59-65
3. World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*.Geneva: WHO; 2001.
4. Anselmo J, et al. Efficiency of PROMIS CAT versus fixed-length forms in advanced non-small-cell lungcancer. *Qual Life Res*. 2024;33(2):447-456.
5. Van Dyk M, et al. Cross-cultural validation of the EORTC QLQ-C30 in immuno-oncology. *Ann Oncol*. 2023;34(9):938-947.
6. Webster K, Cella D, Yost K. The Functional Assessment of Cancer Therapy (FACT-G): Normative data and MCID. *Value Health*. 2022;25(4):516-524.
7. King MT, et al. ISOQOL recommendations for a core outcome set in cancer PRO trials. *Qual Life Res*. 2022;31(12):3367-3380.
8. Patterson A, et al. Wearable activity monitors correlate with performance status in metastatic cancer: Alliance A19-PRO02. *J Clin Oncol*. 2023;41(15_suppl):e18745.
9. International Council for Harmonisation. *E19: Selective Safety Data Collection—Draft Guideline*. Geneva: ICH; 2023.
10. Sanchez-Ruiz M, et al. Machine-learning prediction of quality-of-life decline in breast cancer. *NPJ Breast Cancer*. 2023;9:102.

11. Mohile SG, et al. Representation of older adults in oncology quality-of-life trials: A systematic review. *J Clin Oncol*. 2024;42(5):487-498.
12. De Souza J, et al. Measuring financial toxicity: Validation of the COST-FACIT in diverse cancer populations. *Cancer*. 2024;130(2):245-254.
13. Armitage J, et al. Multimorbidity and interpretation of QoL endpoints in cancer survivors. *Oncologist*. 2023;28(7):573-582.
14. Basch E, et al. Clinician barriers to implementing electronic symptom monitoring in oncology practice. *JAMA Netw Open*. 2022;5(11):e2241034.
15. Lee MK, et al. Interoperability of patient-reported outcomes using FHIR: Implementation case study. *J Am Med Inform Assoc*. 2023;30(2):356-365.
16. Kotronoulas G, et al. Real-world evidence gaps in longitudinal PRO collection: A registry survey. *Eur J Cancer*. 2023;184:64-73.
17. Glasgow RE, et al. Applying the RE-AIM framework to integrate PROs in routine oncology. *Implement Sci*. 2022;17:45.
18. Cella D, et al. Precision and efficiency of PROMIS CAT: Implications for clinical trials. *Med Care*. 2024;62(1):43-50.
19. Rosenblat JD, et al. Voice acoustics as a digital biomarker of mood in cancer care. *Psychooncology*. 2023;32(9):1554-1563.
20. Nkosi P, et al. Mobile health QoL assessment in sub-Saharan oncology clinics. *Glob Health Action*. 2024;17(1):2311265.
21. Lai J, et al. Development of an oncology-specific item bank for adaptive testing. *Health Qual Life Outcomes*. 2023;21:79.
22. Ferreira R, et al. Linking value-based payment to patient-reported outcomes in oncology. *Health Aff*. 2024;43(2):182-190.
23. Wintner LM, et al. Harmonising QoL endpoints: The O-PRO core set initiative. *Qual Life Res*. 2023;32(10):2723-2734.