

HRQoL assessment in Routine Clinical Practice

Key points to consider for the use of QoL measures in Routine Clinical Practice

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Review

The use of EORTC measures in daily clinical practice— A synopsis of a newly developed manual



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Outline

- ↓ Selection of QoL measures
- ↓ Assessment time points
- ↓ Scoring of QoL measures
- ↓ Presentation of the results
- ↓ Integrating QoL assessment into the clinical workflow and treatment
- ↓ Data collection infrastructure
- ↓ Other aspects
- ↓ Conclusion

Selection of QoL measures

- ↓ Choice of the QoL questionnaires depending on aim of the measure and cancer localization
 - ↓ QLQ-C30
 - ↓ specific modules
 - ↓ Items from EORTC item library > increased specificity
- ↓ Need Psychometric properties to be validated
- ↓ Computive adaptive testing: patient-tailored instrument
 - ↓ ↘ patient burden
 - ↓ focus on questions relevant for patients
 - ↓ ↗ measurement precision
- ↓ Electronic vs paper-pencil?

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SPECIAL SECTION: PROS IN NON-STANDARD SETTINGS (BY INVITATION ONLY)

Mode of administration does not cause bias in patient-reported outcome results: a meta-analysis

Claudia Rutherford¹ · Daniel Costa¹ · Rebecca Mercieca-Bebber^{1,2} ·
Holly Rice³ · Liam Gabb⁴ · Madeleine King^{1,2}

Assessment time points

- ↓ Timing of assessments need comprehensive knowledge of the considered disease (clinical change). Guidelines are needed.
- ↓ Frequency of assessments
 - ↓ At each visit
 - ↓ Whenever the patient needs it
 - ↓ Need to consider the time frame assessed by questionnaires (EORTC measures usually the week before)
- ↓ Balance between scientific goals and workload for health care personnel, patient burden, disease stage and treatments

Scoring of QoL measures

- ↓ Scoring should be done according to standard procedures
- ↓ Interpretation of the score depending on functioning or symptomatic scales
 - ↓ High score in functioning scale = better
 - ↓ High score in symptoms = worst
- ↓ Scores in reference populations are available > comparison
 - ↓ Depends on the context (advanced/disease free survivor)
- ↓ Score interpretation
 - ↓ Not comparable between them
 - ↓ Comparison to reference values depends on symptoms
- ↓ Thresholds for clinical importance (more to come with Johannes talk)

Presentation of the results

- ↓ Depends on the purpose
 - ↓ group-level data for therapeutic choice
 - ↓ Data from a patient in routine care
- ↓ Graphical presentation
 - ↓ Maybe different depending on who see the results (doctors/patients)
 - ↓ Need training
- ↓ Research on the best way to present QoL results are on-going

What Do These Scores Mean? Presenting Patient-Reported Outcomes Data to Patients and Clinicians to Improve Interpretability

Claire F. Snyder, PhD^{1,2,3}; Katherine C. Smith, PhD^{2,3}; Elissa T. Bantug, MHS³; Elliott E. Tolbert, PhD^{1,2}; Amanda L. Blackford, ScM³; and Michael D. Brundage, MD, MSc⁴; and the PRO Data Presentation Stakeholder Advisory Board

Integrating QoL assessment into the clinical workflow and treatment

- ↓ Numerous people involved, with different behaviours, and you want to make them change their practice >Complex intervention
- ↓ Technical and psychometric issues but also innovation process and organizational changes
- ↓ Need to find « leaders » that will help to change the practice
- ↓ Define goals and expectations
- ↓ Make data actionable, clinical practices guidelines are needed
- ↓ Provide training, coaching and support for professionals and patients
- ↓ Need evaluation and regular reviews
- ↓ Consider organizational context
- ↓ Long-term evaluation of effective integration

Data collection infrastructure

- ↓ Electronic assessment requires technical and educational infrastructure
- ↓ Electronic assessment prevents a burden compared to paper-pencil and results are comparable
- ↓ Several softwares with several features exist, depends on what are your goals
- ↓ Technical considerations (compatibility, interoperability)
- ↓ Choice of assessment devices (laptop, tablets, self-service kiosk)

Others aspects

- ↓ PRO assessment can be used to monitor PRO between hospital visits and patients portals can be developed
- ↓ QoL and EORTC measures can be used for quality assurance and health economics
- ↓ Ethical aspects should be considered
 - ↓ Patients burden
 - ↓ Computerized adaptive testing can be used
 - ↓ Privacy, confidentiality and disclosure are major issues
 - ↓ As many patients as possible has to be included (underprivileged persons)

Conclusion

- ↓ Numerous aspects have to be considered
- ↓ Involving a lot of actors
- ↓ Beyond the scope of clinical trials
- ↓ Innovation process