

# Giving a voice to patients





# About the Quality Of Life Group (QLG)

Created in 1980, the QLG strives to improve health-related quality of life (HRQoL) of cancer patients, through dedicated research and the use of HRQoL measures within cancer clinical trials and clinical practice, including questionnaires and customised item lists. HRQoL constitutes an important aspect of cancer research and care: it gives a voice to patients, putting their experience at the forefront.

# » Who are we?

The QLG comprises a broad range of professionals, including psychologists, psychiatrists, neurologists, medical and radiation oncologists, oncologic surgeons, palliative care specialists, social workers and importantly research methodologists. This cultural mix, defined as much in terms of professional background as language and geography, has proven invaluable in shaping the QLG's approach to Quality of Life (QoL) assessment.

The QLG is part of the European Organisation for Research and Treatment of Cancer (EORTC).

## KEY HIGHLIGHTS

32

VALIDATED QUESTIONNAIRES

31

QUESTIONNAIRES IN DEVELOPMENT

28

ONGOING OTHER PROJECTS (METHODOLOGICAL, META-ANALYSES, LONG-TERM FOLLOW-UP STUDIES...)

1000+

ITEMS (QUESTIONS) IN THE EORTC ITEM LIBRARY

10

PUBLISHED MANUALS

120+

LANGUAGE VERSIONS OF THE EORTC QLQ-C30 CORE QUESTIONNAIRE

37

COUNTRIES REPRESENTED WITHIN THE QLG

# About the QLG questionnaires

A questionnaire is an instrument designed to assess (some of) the different aspects that define the QoL of (a specific group of) cancer patients.

## Core questionnaire:

The EORTC QLQ-C30 is a questionnaire developed to **assess the QoL of cancer patients**. It has been translated into over 120 languages and used in more than 3,000 studies worldwide. The most recent version is QLQ-C30 Version 3.0 and this version should be used for all new studies.

## Disease-specific questionnaires or 'modules':

While the EORTC QLQ-C30 is an important tool for assessing the generic aspects of QoL, it has limitations for disease-specific treatment measurements. An essen-



tial aspect of QoL assessment adopted by the EORTC QLG is the development of **modules specific to tumour site, population, treatment modality**, or a QoL dimension, to be administered together with the core questionnaire (EORTC QLQ-C30). The modules, similar to the core questionnaire, are designed for use in cancer clinical trials.

## Stand-alone questionnaires:

Stand-alone questionnaires are questionnaires designed

to **assess the different aspects that define the QoL** (or a specific aspect of the QoL) **of cancer patients** (or of a specific group of cancer patients). Stand-alone questionnaires can be used independently: they do not need to be used in conjunction with the QLQ-C30.

Access our  
Questionnaires



## QLU-C10D:

The **QLU-C10D is a cancer-specific multi-attribute utility instrument** which can be used for health economic evaluations in cost-utility analyses. Other utility instruments tend to be generic and not cancer-specific, while the QLU-C10D is based on the QLQ-C30 and includes 10 of its 15 domains.

Therefore, it captures symptoms and aspects of functioning specific to cancer patients, making it more applicable to this patient group. An ongoing study aims at assessing the relative validity of the QLU-C10D in cancer patients compared to other widely used generic utility instruments, such as the EQ-5D and the SF-6D. Furthermore, a manual for the use of the QLU-C10D is under development.

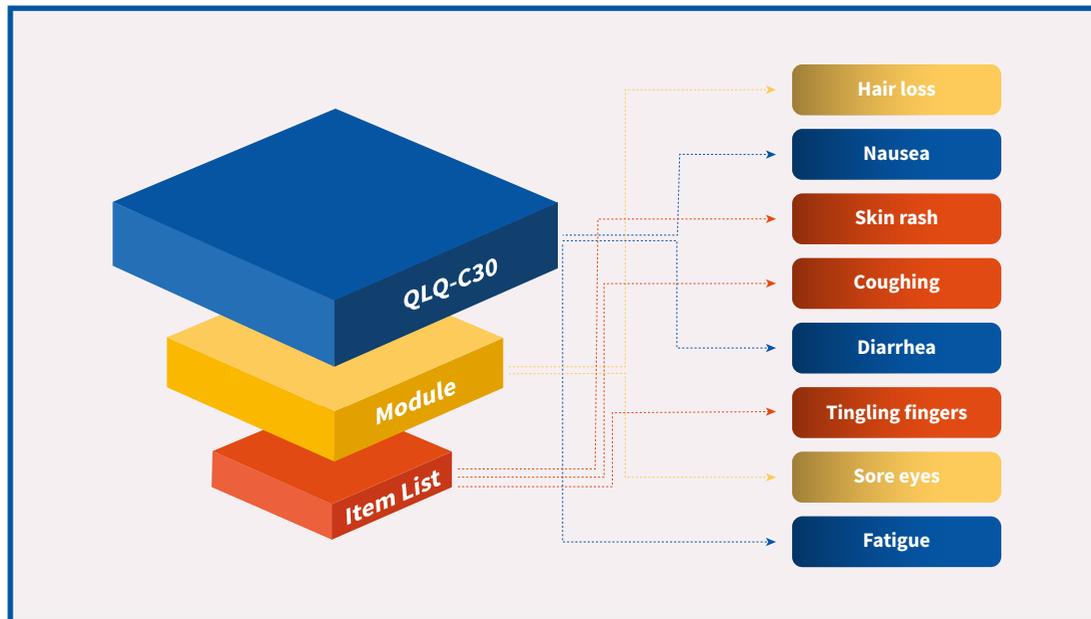
## About the EORTC Computer Adaptive Testing (CAT) Core

The QLQ-C30 is a static questionnaire. It presents the same set of items in the same order to all respondents to ensure that scores are comparable across patients. In contrast, **computerised adaptive tests (CATs) tailor the questionnaire to the individual without compromising comparability across patients.** CATs are dynamically administered, computer-based questionnaires.

**Based on responses to prior items, CATs select and present the most informative item to the individual respondent.**

This approach results in CAT measures being more precise and efficient (i.e., fewer questions needed to reach the same measurement precision) than static questionnaires.

The EORTC QLQ has developed CATs for the 14 functional and symptom domains of the EORTC QLQ-C30: the EORTC



CAT Core, a fully validated tool. Its development has been thoroughly detailed through more than 20 publications (e.g., for an overview, see Petersen et al., 2018\*) and its use will be further facilitated by upcoming publications providing guidance for users (e.g., standard EORTC CAT Core settings, EORTC standard short forms). The software underlying the functioning of the EORTC CAT Core, which is located on secured EORTC

servers, can be linked to any ePRO system allowing for the full adaptability of this tool to any study IT requirements.

*\*Petersen, M. A., Aaronson, N. K., Arraras, J. I., Chie, W. C., Conroy, T., Costantini, A., ... & EORTC QLQ (2018). The EORTC CAT Core—The computer adaptive version of the EORTC QLQ-C30 questionnaire. European Journal of Cancer, 100, 8-16.*

### About the EORTC Item Library

Development and validation of a QoL measure takes a long time and requires various resources. Also, a given

well as to **complement the existing questionnaires with any missing symptoms or problems by adding them as an item list (set of questions)** created with the Item Library. This approach offers users much more flexibility by facilitating assessment of a wider range of symptoms and events, which in turn makes it easier for patients to describe their experiences more fully.



### About CTCAE mapping

In its current form, the Item Library is an online platform comprising more than 1,000 individual items from over 50 EORTC questionnaires and their translations. Detailed information about items and instruments (including phase, translations, scales, publications, etc.) is provided to help users during different stages of their research.

A study which mapped 950 EORTC items onto the Common Terminology Criteria for Adverse Events (CTCAE) showed that 625 items could be linked to 208 different side effects, or 'adverse events' (AEs). This **highlights the range of coverage provided by the Item Library** as well as its utility for measuring patient-reported AEs.

Access our  
Item Library



Read our  
Press Release





### Quality of Life Projects



QLG-FUNDED



OTHER

## QLG projects

Members of the QLG are also engaged in numerous clinical and methodological projects, all aiming, in one way or another, to provide the means to ensure that patients' voice is heard loud and clear in clinical trials and practice. Please find hereafter information about some of these projects.

### Development of an interpretation guideline for the EORTC PRO measures

Robust conclusions based on EORTC patient-reported outcome (PRO) data affecting clinical care and research require correct interpretation. The inherent meaning of scores is unclear, and interpreting PRO data merely via statistical significance is misleading. There is an ongoing debate about how to interpret PRO results but actual reporting reflects uncertainty in doing so: only 39% of routine PRO assessment implementations in oncology include guidance on this, and only 38% of trials with EORTC PRO measures address clinical significance.

The QLG aims to address this gap by developing the EORTC QLG **guidance on how to evaluate the clinical relevance of scores**

**derived from the EORTC PRO measures** at group or individual patient levels. The guideline will include best practice recommendations on interpreting EORTC PRO/ QoL data for scientific and clinical use. This guideline will be based on available evidence on minimal important differences, thresholds for clinical relevance and reference values, as well as consensus among QLG experts and information needs of the users of our measures.

### Update of the EORTC QLG Reference Value manual

Reference values (RV) for specific patient subgroups or the general population provide the much-needed context to interpret PRO scores.

The aim of this project is to **update the EORTC QoL RV manual and to develop a**

### corresponding, dynamic IT infrastructure for managing EORTC RV data.

This will include a database available via a web-based interactive software interface and user guideline including recommendations on the use of EORTC QoL RV. The infrastructure should enable continuous updates and data expansion within the established framework.



## Setting International Standards of Patient-Reported Outcomes and Quality of Life Endpoints in Cancer Clinical Trials (SISAQOL-IMI)

SISAQOL-IMI is an international multidisciplinary consortium, co-led by the EORTC and Boehringer Ingelheim. The consortium has been convened with **the aim to develop recommendations for standardising the use, analysis, and interpretation of PRO and QoL data in cancer clinical trials.** It comprises leading HRQoL researchers and statisticians, key individuals from various international oncologic and medical societies, advisory and regulatory bodies such as the Food and Drug Administration (FDA) and European Medicines Agency (EMA), academic societies, pharmaceutical industry representatives, cancer institutes and crucially patient advocacy organisations, so that standards can be set that are technically correct, comprehensive, and balanced.

### About SISAQOL-IMI



## Early Career Investigators (ECIs)

The QLG Early Career Investigators (ECIs) Group was formed to connect new researchers in the QLG with each other and the group. This network comprises over 50 researchers establishing their career in QoL research in one way or another. The group provides the opportunity to get to know each other, to learn from each other and to be a voice for early researchers in the QLG. This initiative drives academic, mentorship, and funding opportunities to support ECIs and inspire a new generation of QoL researchers.



### About QLG ECIs



## QoL in Cancer Clinical Trials Conference

This two-day conference, organised by the QLG every two years, provides the opportunity to discuss the latest topics and developments in QoL and PRO research. This conference aims to bring together some of the world's most influential QoL thought leaders.

### Stay informed about QLG Events



## Interested in joining the EORTC QLG?

To become a full active member, you have to:

- Attend **2 meetings** within **2 years**
- Be actively involved in EORTC QLG research

On the **third meeting** you will become an active member.

To remain a member, you have to continue to participate in research activities and attend a minimum of 2 meetings every 2 years.

Until you are a full member, you will be registered as an EORTC QLG corresponding member, and you will be included in the EORTC QLG mailing list.

If you wish to be a member, **please contact us.**





# EORTC

Quality of Life Group

