By means of this issue of the Newsletter we hope to provide a view on the spectrum of activities of the EORTC Quality of Life Group.

Mogens Groenvold, chair of the group, will kick off with a description of the current activities of the group and his view on the strategy for the coming years. Subsequently, Irma Verdonck-de Leeuw, who joined the Executive Committee last year as the secretary of the group, will illustrate the vitality of our group through ever increasing numbers of members and meeting participants. The Executive Committee underscores the vital importance of defining priorities of the group, and some of the strategic activities of the group, e.g. the development of modules, the computer-assisted testing (CAT) project and the development of web-based technology, will also be highlighted in this issue.

We've had two very successful group meetings in 2013, the Spring meeting in Amsterdam and the Autumn meeting in Canterbury. These meetings imply a lot of work and long hours for many group members, but also offer a very much appreciated cultural and social program. Last year, Quality of Life Group members enjoyed a 4-course dinner while floating through the Amsterdam canals and attended the more than 600-year-old tradition of 'Evensong' at Canterbury Cathedral. Reports on both meetings, including a visual impression, can also be found in this Newsletter. As mentioned before, the Quality of Life Group has the moral obligation to keep at least her own quality of life at a high standard, and this is not too difficult with such inspiring group members.

We will try to meet with this challenge during the upcoming meetings as well, and the prospects regarding our Spring 2014 meeting in Cyprus are favourable, as the local organiser will tell us in his contribution.

A special focus in this issue, and also the reason for accelerating the publication of this Newsletter, is the EORTC Survivorship Initiative. The necessity to focus on survivorship nicely illustrates the success of the EORTC, amongst others, in fighting cancer. The organisation recently celebrated its 50th anniversary, and wouldn't it be wonderful if the EORTC would make itself completely redundant in the next 50 years? But for now, a lot of work still needs to be done and we think that the QLG should play an important, even crucial role within this initiative.

Many of the specific problems in long-term cancer survivors relate to (diminished) quality of life and many group members have a lot of expertise in this field. After a successful Survivorship Workshop during our 2013 Autumn meeting, we therefore decided to move on as quickly as possible with the development of a Survivorship Questionnaire, and our plans will be presented during the first EORTC Cancer Survivorship Summit in January 2014.

I hope you will enjoy reading this Newsletter. I would especially like to thank Sheila Sanderson for her assistance in editing this Newsletter issue. Please contact me if you wish to contribute to the next issue!
Increasing Activity & New Strategic Initiatives

Mogens Groenvold, Chairman of the EORTC QLG

Despite financial crises and other global concerns, there does not seem to be any crisis in quality of life research. The EORTC QLG continues its high level of activity with substantial growth in several areas:

- The number of modules is increasing (19 completed phase 4, 14 completed phase 3, 10 in earlier stages).
- The CAT project is nearing completion and more than 250 items have been administered. A field study in ten countries has recently concluded (see p.24 & 26).
- New developments include in-patient satisfaction with care module (PI: Anne Brédart) and additional modules focused on survivorship and long-term follow up of patients in EORTC trials as well as plans to carry out more comprehensive evaluation of new treatments including health technology assessment.
- The EORTC QLG has recently decided to fund three projects (a major revision of a fourth is pending): A facility for electronic data collection using the EORTC QLG system, the ‘mother’ organization, the EORTC, is in the process of changing its research strategy. The QLG, the ‘mother’ organization, the EORTC, is in the process of changing its research strategy. The QLG measures are being used more widely, whereas other groups have been engaged in this, sometimes using the QLG-C30. A new sub-group has been created with the intent to go further into this area via collaboration with international researchers already doing such developmental work.
- An investigation into the use of the EORTC measures in patient satisfaction with care module (EORTC IN-PATSAT32) for ambulatory settings (PI: Anne-Sophie Darlington).
- An international field study of the Reliability and Validity of an EORTC breast reconstruction questionnaire to assess quality of life in all types of breast reconstruction (PI: Zoi Winters).
- An investigation into the use of the EORTC Core instrument and the possible need of a module for the assessment of Health Related Quality of Life in Adolescents and Young Adults (AYA) with cancer (PI: Anne-Sophie Darlington).

It is really highly rewarding to see so much excellent activity take place in the QLG. Finally, I am happy to know that with the recent election of Professor Lonneke van der Pol-France (NL) as chair-elect the QLG will be in good hands when Lonneke takes over at the autumn meeting, 2014.
Improving Cancer Survivorship: A Global Perspective

Irma Verdonck de Leeuw, VUMC Amsterdam

The number of active members (red) and the number of participants (blue) of the meetings has steadily increased over the last years, as you can see below.

Over the past decades, survival rates of many cancer types have increased due to the introduction of multi-modality treatments. The EORTC has been a pioneer in modern cancer care, Europe-wide collaboration and modern cancer treatment protocols. The efforts of the EORTC and many others have resulted in a large and rapidly increasing number of people who are long-term survivors of cancer. Unfortunately, it has become clear that the quality of life of long-term survivors might be complicated by the occurrence of a whole spectrum of late adverse effects of disease and treatment.

Both radiotherapy and some types of chemotherapy increase the risk of, amongst others, new (second) primary malignancies, cognitive deterioration, and cardiovascular disease in the long run. Apart from these more or less ‘medical’ and sometimes disease-specific issues, many cancer patients encounter difficulties in adjustment after the shock of diagnosis and the consequences of treatment, and are exposed to societal discrimination. Employers do not accept a slower performance, chronic fatigue or partial inability due to disease and adverse treatment effects. Furthermore, many patients report problems in dealing with insurances and financial issues, which is also my own experience at the neuro-oncology outpatient clinic in Amsterdam; not infrequently long-term surviving brain tumour patients are forced to give up their job, have difficulties in obtaining a mortgage, and are not allowed to adopt children. So new challenges arise for cancer specialists, psychologists, social workers, but also general practitioners, policy makers and health insurers in accompanying and supporting former, or chronic, cancer patients.

Oncologists and patients at follow-up are always asking what to expect when they receive the diagnosis of cancer. It is therefore important to have a shared understanding of the principles of treatment effects. Furthermore, many patients are not aware of the existence of late adverse effects, which may be caused by chemotherapy, radiotherapy, or surgery. The efforts of the European Organisation for Research and Treatment of Cancer (EORTC) have been recognized by the quality of life (QoL) Working Group, which has developed the EORTC QLQ-C30, a QoL instrument to be used across studies.

The EORTC QLQ-C30 has been developed to measure the QoL of cancer patients with a spectrum of cancer types. It has been used in clinical trials and in routine practice to assess the effects of treatment and to monitor patients’ well-being. The QLQ-C30 is a modular instrument that has been developed in collaboration between EORTC and CAPSURE researchers, and is widely used in clinical trials and routine practice to assess the effects of treatment and to monitor patients’ well-being. The QLQ-C30 is a modular instrument that has been developed in collaboration between EORTC and CAPSURE researchers, and is widely used in clinical trials and routine practice to assess the effects of treatment and to monitor patients’ well-being.

The QLQ-C30 comprises 36 items, divided into nine scales: five functional scales (physical, role, emotional, cognitive, social), three symptom scales (fatigue, nausea/vomiting, pain), and one global QoL scale. The QLQ-C30 is a modular instrument that has been developed in collaboration between EORTC and CAPSURE researchers, and is widely used in clinical trials and routine practice to assess the effects of treatment and to monitor patients’ well-being. The QLQ-C30 comprises 36 items, divided into nine scales: five functional scales (physical, role, emotional, cognitive, social), three symptom scales (fatigue, nausea/vomiting, pain), and one global QoL scale.

On January 30th and 31st 2014, the first EORTC Cancer Survivorship Summit (see http://www.eortc.org/survivorship2014/) will be organised, bringing together cancer specialists, psychologists, social workers, as well as patients and patient advocacy groups, and representatives of the health care industry, insurance companies, governmental agencies, health economists and politicians to specifically discuss the needs of cancer survivors. The Summit, which will be organised in Brussels by the EORTC Survivorship Platform, will not only facilitate the discussion on priorities for future research and guideline development, but also stimulate international networking for better data collection, analysis, education and guidance of cancer survivors and their caregivers.

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CHES. EORTC
New developments

Bernhard Holzner, University of Innsbruck, Austria
Johannes M. Giesinger, NCI Amsterdam, The Netherlands

Development of a CHES.EORTC version started in 2010 and was fuelled by a 2.5 year grant from the EORTC Quality of Life Group. This grant allowed developing and refining various software features and making CHES.EORTC freely available to members of the group for academic studies. In a follow-up project focusing on the graphical presentation of QOL results we are currently evaluating different presentation styles for longitudinal and cross-sectional QOL data which will then be integrated into the software. Developing CHES.EORTC into a web application not only avoids implementation barriers but also allows using it on various devices and for all common operating systems. Making CHES.EORTC available for tablet PCs includes full usability on touch-screens. The current version includes the EORTC QLC-C30 in several languages, and further languages and EORTC modules can be added upon request. Further details on using CHES.EORTC in your own study and a link to software are given on the EORTC Quality of Life Group website: http://groups.eortc.be/qol/electronic-version.

We would like to emphasize that web-based data capture allowing completion of questionnaires and CRFs via the web-browser is often necessary for data collection at six hospitals across Europe for the phase IV field study on the validation of the EORTC QLQ-TC26 testicular cancer module.

For about two years we have used CHES.EORTC for data collection at six hospitals across Europe for the phase IV field study on the validation of the EORTC QLC-C30 in several languages, and further languages and EORTC modules can be added upon request. Further details on using CHES.EORTC in your own study and a link to software are given on the EORTC Quality of Life Group website: http://groups.eortc.be/qol/electronic-version.

Participating researchers receive a user account allowing administration of questionnaires and completing CRFs, and also creation of user accounts for patients.

The availability of such patient accounts facilitates follow-up assessments as patients can log on to the website at home and complete the required questionnaires. In a similar manner CHES.EORTC will also be used for cross-cultural validation of the EORTC QLC-C30 breast reconstruction module which is about to start. A further application of CHES.EORTC will involve the validation study for the EORTC CAT measures. Linking the software to the CAT engine developed by the team coordinated by Morten Petersen and Mogens Grambol allows presentation of EORTC CAT measures in a patient-friendly way. In addition to the standard CHES.EORTC version we have developed customised CHES versions to meet the requirements of specific studies, e.g. a trial on the efficacy of stepped psycho-oncological care (PI: Suzanne Singer), and a study investigating patient-reported symptom burden during the period after administration of chemotherapy when patients are at home (PI: August Zabernigg).

The future development of CHES.EORTC will focus on the further enhancement of the graphical presentation of QOL results to patients and clinicians. In addition, we continue to work on linking CHES to the oncological expert system SARATIBA (formerly known as Onco2Net, developed by World Direct and Oncotyrol) which is currently being tested in several hospitals in Austria. The availability of sophisticated software packages allowing on the one hand efficient administration of questionnaires and CRFs in a busy hospital setting and on the other easy access to their results will substantially contribute to an increased use of EORTC measures, not only in clinical trials, but also for quality assurance and symptom monitoring.

“Patient accounts to facilitate the follow-up assessments...”

We are interested in some things about you and your health. Please answer all of the questions yourself by selecting the answers that best apply to you. There are no “right” or “wrong” answers. The information that you provide will remain strictly confidential.

Do you have any trouble taking a short walk outside of the house?

- Not at all
- A little
- Quite a bit
- Very much

Do you need to stay in bed or a chair during the day?

- Not at all
- A little
- Quite a bit
- Very much

Do you need help with eating, dressing, washing yourself or using the toilet?

- Not at all
- A little
- Quite a bit
- Very much

Figure 1: Screenshot of EORTC QLC-C30 scores in CHES

Figure 2: Screenshot of EORTC QLC-C30 items in CHES
Development of the EORTC Sexual Health Questionnaire for Cancer Patients

Eva Nagele, Eva Greimel
Medical University Graz, Department of Obstetrics and Gynecology

Sev eral EORTC Quality of Life Group (QLG) modules developed for specific cancer sites include a limited number of sexual functioning items. However, these modules do not cover the whole range of sexual health, where many different aspects of the sexual response cycle are involved. The need for developing a broader Sexual Health Questionnaire for cancer patients has been discussed in the QLG and the quality of life gynaecological cancer working group has moved this initiative forward.

Previous research on sexual functioning has focused on women with breast or gynaecologic cancer and men with prostate cancer. Less is known about how other types of cancers affect sexuality. An individual’s sexual response can be affected in a number of ways which involves the physical, psychological, interpersonal, and behavioural aspects of a person. Several aspects of the sexual response cycle should be considered to describe sexual functioning, e.g. sexual desire or sexual arousal. The assessment of sexual health in clinical settings may help physicians and patients to make better informed treatment choices. However, there is a lack of consistent regarding valid outcome measures for assessing sexual functioning in cancer patients (Burnett et al. 2007). There is no single self-report measure that can be recommended for cancer clinical trials (Cull et al. 1992; Jeffrey et al. 2009).

Initially the idea was to collaborate with the Patient Reported Outcomes Measurement Information System® (PROMIS®) sexual function committee and share experiences with US researchers. However, the research approaches are different between the European and the US research groups. The main difference is that within the EORTC QLG questionnaire development requires a multi-disciplinary and multi-cultural involvement of researchers within a multi-national working group (Johnson et al. 2013). The EORTC QLG provides an ideal cross cultural setting and supported the development of the Sexual Health Questionnaire with a grant for phases 1-3. Eva Greimel is the principal investigator (PI) of this study and with her research assistant Eva Nagele the project started in January 2012. There has been great interest from collaborators to take part in this project from the beginning and the working group continues to grow.

The development of the Sexual Health Questionnaire follows the EORTC QLG guidelines to ensure a high quality standard questionnaire. Primarily a literature search was performed on sexual health in cancer patients by Brenda den Oudsten from the Netherlands. The majority of research articles focus on sexual functioning. About 40 different measures related to sexuality were reviewed. However, the existing instruments mainly cover the sexual response cycle whereas the psychological and social aspects are often missing. Therefore the decision was made to adapt the model of Cleary et al. (2011) who proposed a comprehensive theoretical framework of sexuality (see Figure).

Sexuality related issues retrieved from the literature were clustered and eight themes identified (e.g. intimacy, sexual satisfaction, distress, communication/relationship issues). Based on the literature review a provisional list of issues was established and reviewed. The final list including 54 issues was rated by health care professionals (HCP) and patients concerning the appropriateness of the content and breadth of coverage. A total of 84 HCPs representing different disciplines (clinicians, psychologists, nurses, etc.) were interviewed. The HCP’s experience ranged from 10 to 20 years and gender was equally distributed. For the patient interviews the issue list was translated into several languages. Up to October 2013 66 male and female patients with various cancer sites from six countries have been included. In some countries it was difficult to get approval by the local ethical review boards due to the sensitivity of the topic. Patient interviews are still on going in order to reach a good cross-cultural balance.

In January 2014 a meeting will be held in Brussels to discuss the conceptualization of the questionnaire. A clear conceptual frame work will help to select issues related to sexuality which are most important to all cancer patients. The Sexual Health Questionnaire is expected to be ready for pilot-testing after the spring meeting in Cyprus. The instrument will then be psychometrically tested in a large cross-cultural validation study. The PI will apply for a phase 4 grant and hopes to get further funding.

References


Eva Greimel has broad international experience including a research fellowship at UCLA and visiting professorship at the University of Hiroshima where she investigated cross-cultural indicators for health, well-being and quality of life in two very diverse cultures.

Since last year she has led the clinical psychology group at the Medical University of Graz. Within that role she coordinates psychological services in all medical departments and disciplines. With the experience gained in these different environments she has a commitment to the implementation of the psychological services offered not only to cancer patients but also to patients with different psychological needs in various health care settings.

Figure: Cleary et al. (2011)
EORTC QLQ-ELD14 Module for Quality of Life Assessment in Elderly Patients

Sally Wainwright, Colin Johnson - University of Southampton, UK

Older people represent the majority of cancer patients but their specific needs have usually been ignored in the development of health related quality of life (HRQOL) instruments and, until now, there has not been an HRQOL instrument for older people with cancer. Such a questionnaire is required because older patients have a different HRQOL profile. There are substantial age-related differences in responses on the QLQ-C30, the EORTC QOL group core questionnaire, and the QLQ-C30 does not adequately cover the psychosocial issues which are particularly important to older patients.

HRQOL assessment is especially important in routine clinical practice for elderly cancer patients because they are more often treated with a non-curative approach and may be vulnerable to treatment toxicities: measurement of HRQOL can help the clinician to decide whether the benefits of treatment outweigh the associated side effects. Older patients have usually been under-represented in clinical trials and this may partly explain the lack of a HRQOL instrument specifically designed for this group.

Table 1: The EORTC QLQ-ELD14

<table>
<thead>
<tr>
<th>SCALE</th>
<th>ITEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>31. Have you had difficulty with steps or stairs?</td>
</tr>
<tr>
<td>Single item: Joint stiffness</td>
<td>32. Have you had trouble with your joints (e.g. stiffness, pain)?</td>
</tr>
<tr>
<td>Mobility</td>
<td>33. Did you feel unstable on your feet?</td>
</tr>
<tr>
<td>Mobility</td>
<td>34. Did you need help with household chores such as cleaning or shopping?</td>
</tr>
<tr>
<td>Single item: Family support</td>
<td>35. Have you felt able to talk to your family about your illness?</td>
</tr>
<tr>
<td>Worrying about others</td>
<td>36. Have you worried about your family coping with your illness and treatment?</td>
</tr>
<tr>
<td>Single item: Worrying about others</td>
<td>37. Have you worried about your family coping with your illness and treatment?</td>
</tr>
<tr>
<td>Future worries</td>
<td>38. Were you worried about your future health?</td>
</tr>
<tr>
<td>Future worries</td>
<td>39. Did you feel uncertain about the future?</td>
</tr>
<tr>
<td>Future worries</td>
<td>40. Have you worried about what might happen towards the end of your life?</td>
</tr>
<tr>
<td>Maintaining purpose</td>
<td>41. Have you had a positive outlook on life in the last week?</td>
</tr>
<tr>
<td>Maintaining purpose</td>
<td>42. Have you felt motivated to continue with your normal hobbies and activities?</td>
</tr>
<tr>
<td>Burden of Illness</td>
<td>43. How much has your illness been a burden to you?</td>
</tr>
<tr>
<td>Burden of Illness</td>
<td>44. How much has your treatment been a burden to you?</td>
</tr>
</tbody>
</table>

Information from the debriefing interview, factor analyses and item response theory analysis resulted in the removal of one item from the QLQ-ELD15 and revision of the proposed scale structure. The final version of the questionnaire, the QLQ-ELD14 (Table 1), has 14 items, comprising five scales (mobility, worries about others, future worries, maintaining purpose and burden of illness) and two single items (joint stiffness and family support). The questionnaire was found to be acceptable, quick and easy to complete, with good content and convergent validity and is appropriate for patients with all types of malignancy. It is able to discriminate between groups of patients defined by disease stage, number of comorbidities, treatment intention, performance status and normal or abnormal score on a geriatric screening tool. Although the internal reliability analysis, which examines the homogeneity of the multi-item scales, indicated that the maintaining purpose scale fell just short of the threshold, this scale has good face validity and was retained in its original form.

The test-retest reliability of the instrument was generally good but there was an unexpected significant improvement in the family support item and a significant reduction in illness burden. There were also some unexpected changes on the QLQ-C30 between the two time points, with physical, role and social functioning all getting significantly worse. Responsiveness to change was difficult to assess because many patients selected for this analysis did not show a change in their clinical status.

However, we found that patients with a lower performance status scored worse on the mobility scale on the second administration but patients with improved performance status did not have a corresponding improvement on the mobility scale. Although the responsiveness to change analysis was equivocal, we feel that this relative weakness is outweighed by the strengths of the QLQ-ELD14.

In conclusion, the EORTC QLQ-ELD14 is the first validated HRQOL questionnaire for cancer patients aged 70 years and over. The equivocal results from the test-retest and responsiveness to change analyses suggest that changes in elderly patients' self-reported HRQOL may be related to both cancer evolution and non-clinical events.

Factors other than clinical status may affect elderly patients more than younger patients and future studies should explore this hypothesis.

“An unexpected significant improvement in the family support item and a significant reduction in illness burden”
EORTC CAT Project

Moving from development to clinical validation.
Morten Aa. Petersen and Mogens Groenvold

The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark

The EORTC Quality of Life Group (QLG) is developing a computerized adaptive testing (CAT) version of the EORTC QLQ-C30. The work is coordinated by Mogens Groenvold and Morten Aa. Petersen and involves several QLG members. The development is in the final stages and a clinical validation study has just been initiated. The following summarizes the current status of the development and the validation study.

DEVELOPMENT

The basic idea of CAT is to adapt the questionnaire to the individual patient. This is done by selecting the items to be administered. The EORTC CAT development consists of four phases (similar to QLG module development):

- Phase I: Literature search
- Phase II: Formulation of new items and expert evaluations
- Phase III: Pre-testing (patient interviews)
- Phase IV: Field-testing and psychometric analysis

These four phases have been completed for 10 of the 14 QLQ-C30 dimensions. The number of items in the resulting item banks are shown in Fig. 1. As shown in the figure the number of items per dimension has been increased quite significantly, with the largest increases for fatigue and dyspnoea.

The four dimensions still under development (cognitive functioning, financial difficulty, diarrhea, and nausea/vomiting) are in phases II or III. They are expected to be completed by fall 2014. Preliminary validation of the CAT measurement is being conducted based on data used for the item bank development. The results have been promising, e.g. indicating potential savings in sample size requirements of 15-50% compared to using the QLQ-C30. However, validation of the “real-life” performance of the CAT instrument in new, independent data, i.e. where patients are actually administered the CAT, has not been performed. Such validation is essential before releasing the CAT instrument for general use.

CLINICAL VALIDATION

As a result, the QLG has funded a clinical validation study. This study will consist of two parts: a feasibility study investigating the acceptability, optimal design and logistics of web-based administration of the CAT and a field study testing the validity and measurement precision of the EORTC CAT. This validation is planned as a 3-year study.

The primary aim is to evaluate the measurement precision of the EORTC CAT compared to the QLQ-C30 scales by investigating known groups validity (sensitivity) and the ability to detect changes over time (responsiveness). This will be done in a mixed, international sample of cancer patients (N=1,000). Currently, there are participating centres from 10 countries. The basic design of the study is to assess patients before and after chemotherapy using both CAT and QLQ-C30. Based on these assessments, the relative validity to detect expected differences and changes is estimated.

‘EXPERIMENTAL’ USE OF EORTC CAT OR CAT-BASED SHORT-FORMS

Although the EORTC CAT will not be released as a validated EORTC instrument until the validation study has been completed, the current version of the EORTC CAT may be used for ‘experimental’ purposes. By ‘experimental’ it is meant that until the validation study is completed, the EORTC CAT should be used in parallel with the EORTC QLQ-C30. Thus, if you include one or more CATs in a study you should still expect to use the QLQ-C30 as the primary outcome in the study. For more information on this preliminary use of the EORTC CAT please visit http://groups.eortc.be/qol/experimental-eortc-cat.

Besides using the EORTC CAT electronically, the item banks may also be used to construct so-called (paper) short forms. For example, if a trial is comparing a new analgesic to the standard treatment, then to increase the study power (without increasing sample size) it may be advantageous to supplement the QLQ-C30 with a pain short form of e.g. five additional pain items, targeted to the study population of focus. As short forms are based on the same item banks as the CAT, scores based on short forms are on the same metric, and hence, directly comparable with scores based on the EORTC CAT. Such “experimental” short forms may now also be used.

SUMMARY

In summary, item banks for CAT measure- ment are available for 10 of the dimensions in the QLQ-C30. An international validation study of the EORTC CAT has been initiated when this has been completed the EORTC CAT will be offi- cially released. Until then, preliminary versions (both CAT and short forms) based on the currently completed item banks are available for experimental use.

It is well-known that validation is an on- going process – a single study is not enough. Therefore, in order to extend the validation of the CAT in as many languages, settings, and populations as possible we highly encourage users of the QLQ-C30 to supplement the core questionnaire with CAT or short forms. In addition to the contribution to additional validation studies such projects may benefit directly from the likely increase in measurement precision.

Updated information on the EORTC CAT project and its publications can be found on: http://groups.eortc.be/qol.

To assess patients before and after chemotherapy using both CAT and QLQ-C30.”
Patient Reported Outcome Measurements Over Time In ONcology (PROMOTION) Project

Fabio Efficace, PhD

Project History and Update in Brief
The project started in April 2012 with a research grant from the “EORTC Quality of Life Group” and is also co-financed by GIMEMA. This is a large international initiative involving several key experts in Patient-Reported Outcomes research from various countries.

Randomized controlled trials (RCTs) play a key role in cancer research as they provide the scientific evidence needed to adopt the best treatment for all cancer patients.

The provision of quality care depends on the ability to make choices from robust scientific data. Health-related Quality of Life (HRQoL) and other types of Patient-Reported Outcomes (PROs) are now often included as an endpoint in a RCT setting and could potentially provide invaluable information related to functional ability as well as treatment side effects from the patient’s perspective.

What is this PROMOTION Project about?
The broad scope of the EORTC QLG PROMOTION Project is to investigate whether there has been a learning curve in terms of the quality of HRQoL-PRO assessment in RCT reports.

Such an evaluation is being performed separately for each cancer disease site. Cancer patients require information not only related to survival estimates, but also regarding HRQoL issues. Therefore, providing patients and the scientific community in general, with high quality data in this area is of paramount importance.

Updates on this project can be followed at the study website: http://promotionproject.gimema.it

The ultimate goal is to develop a large (and up to date) online accessible database (DB) with all cancer RCTs having included a PRO component using a uniform evaluation criteria across all studies.

This will allow making a number of analyses by crossing and extracting information to answer specific research questions.

To ensure the highest possible quality data extraction procedure, a double blind data entry system (by two independent Investigators) has been implemented.

Several members of the EORTC Quality of Life Group are involved, at different levels, and we have very much appreciated the enthusiastic participation of our colleagues and friends. We are in debt with all co-investigators involved that are helping us in this effort to eventually build a large online accessible DB.

Where are we with the development of PROMOTION online DB?
As of November 2013, more than 500 Cancer RCTs have been identified and included in the DB, which now contains more than 30,000 variables.

These include aspects on the methodology for assessing PROs in RCTs (based on the recently published ISOQOL and CONSORT PRO recommendations) or other clinical information regarding the study (e.g., differences in survival outcomes or other trial demographics).

Current achievements
As of November 2013, three publications have been made: two abstracts and 1 full length manuscript in a leading peer-review high impact factor Journal (European Urology). One of the key findings of this paper was that of highlighting important improvements over time in the quality of PRO reporting in prostate cancer RCTs (see Figure 1). If this is true in other cancer disease sites it will be the topic for future papers stemming from the PROMOTION Project. Actually, much more is expected in the coming weeks and months from this Project in terms of publications. Several Co-Investigators are leading specific papers as the PROMOTION Project management team can easily analyse data and provide tables to support the drafting of manuscripts. If you are interested in keeping more, please do not hesitate to ask us for more information and procedures: promotion@gimema.it

Publications
1. Two Oral presentations at the 20th Annual Conference of the International Society for Quality of Life Research, Miami (FL), USA.

Full-length manuscript

![Figure 1.](image-url)


Descriptive comparison of level of reporting on selected key PRO issues in RCTs of prostate cancer by year of publication.
As many of you will know by now the OLG website was renewed last year with an updated design.

Members were asked for input on the website and at the 2012 Autumn OLG meeting. The decision was made to go ahead with Phase II of the website development; the development of a restricted area for active members only. This development of a restricted membership area started in January 2013. The aim of this new development is to facilitate communication within the group of active members and sharing of information in a secure format.

Currently, Mélodie is responsible for the maintenance of the website and the development of the restricted membership area. In close collaboration with the Web Developer, the EORTC IT Department and the EC Web Representative. Once the membership area is set up, every member will be given a username and password, in order to register. Members will all have the same level of access rights. Once logged in, via the ‘member’s area’ button, the main navigation will change to active member’s content only.

The Membership Restricted Area will be available to members only and will include several categories of information such as: Reports from the Module Development Committee, Forum, Grant Applications, Group Meetings, Standard Operating Procedures, Annual Reports, OLG Statutes, and Electronic Voting etc.

Once the restricted area is live please do not hesitate to contact us to give feedback or suggestions on ways to improve its functionality. Indeed please contact us with any feedback on the website or with any news which you would like to see posted on the site. In the meantime please look out for news from us about the launch of the restricted membership area.

Mastectomy is recommended in 30-40% of 44,000 women diagnosed annually with breast cancer in the United Kingdom (UK) with increases in 10-year survival endorsing survivorship programs. National Health Service commissioners have ratified the inclusion of standardised reporting of outcomes, and the patient’s self-report of their symptoms and functional status known as Health-Related Quality of Life (HRQOL). Breast reconstruction (BR) is recommended by the National Institute of Health and Care Excellence as a patient choice for all eligible mastectomy patients, with the annual incidence increasing to 21% of 17,000 women.

Two systematic reviews show the absence of a validated BREAST-Q, patient-reported outcome measure (PROM), which has prompted the use of other generic, disease-specific and symptom-specific PROMs. Phase II surgical studies have demonstrated the significant effects on such PROMs following BR procedures, underlining their importance alongside newly-validated BREAST-Q. In 2009, the BREAST-Q was validated in BR patients using Rasch methodology to predict individual item responses and evaluate changes in an individual’s HRQOL.

The EORTC BREAST-Q PROM is intended for use alongside EORTC QLQ-C30 and QLQ-Br23 in women diagnosed and treated for breast cancer before and after mastectomy and undergoing all types of BRs. Phases I-II identified all potential ‘issues’ relevant to PROM through a systematic literature review and semi-structured interviews with health care professionals and patients. Phase III pre-testing of the provisional 31 item EORTC QLQ-BR23 following publication of the BREAST-Q early development aimed to assess all aspects of questionnaire administration (patient-reported difficulties, comprehensibility and comprehensiveness) and the decisions made regarding item retention or deletion. This involved assessing the content, acceptability and relevance of the provisional item list in a large representative group of BR patients across different countries and languages. Although, psychometric testing is not a primary aim of Phase III, provisional multi-trait scaling analyses were included on the seven non-conditional (applicable to all patients) items in relation to the EORTC QLQ-C30 and QLQ Br23.

The QLQ-BR26 having completed Phase III development is now available for psychometric validation in a large international sample. The Phase IV study will use traditional psychometrics and Rasch analysis to refine item selection within scales, and may potentially change following Phase IV psychometric testing. The use of the EORTC QLQ-BR26, alongside the QLQ-C30 and QLQ-Br23 modules constitutes an assessment system developed from patient-reported data for the measurement of HRQOL and satisfaction in breast cancer patients recommended for mastectomy comprising either immediate or delayed types of BRs, in the context of adjuvant treatments. It may be used to evaluate HRQOL effects between types of BRs and assessment of individual patients. This PROM will enable the collection of reliable, valid and clinically important information on HRQOL outcomes in BR patients in the context of breast cancer treatments in clinical trials, cohort and registry studies.

The phase IV validation will comprise a prospective patient cohort (n=200) undergoing two administrations of the OLG BREAST-Q at baseline and 8 months after BR. Two main types of BR will be evaluated: 1) implant only, and 2) tissue dissection of a donor site (back, abdomen, buttock or thigh). The cross-sectional cohort (n=100) will relate to women undergoing BR in the last 12-36 months, with the cross-sectional administration of PROMs at any time point. All patients will be given the choice of whether to complete the OLG-BR26 using EORTC CHES across 17 centres, including centres in Australia and Brazil and will occur over 26 months starting in Spring 2014.

Acknowledgements: This project was supported by a grant from the EORTC OLG. The author would like to thank all collaborators and patients helping us to develop this module.
NEWLY AWARDED GRANTS

EORTC Quality of Life cancer patient satisfaction core questionnaire & supplementary cancer outpatient satisfaction module: phase I study

Anne Brédart, Institut Curie, Psycho-Oncology Unit, Paris, France

Cancer care is increasingly provided in out-patient settings for treatment follow-up or cancer survivors’ surveillance. Patient satisfaction is now recognized as an important indicator of care quality, related to adherence and health outcomes. Whilst surveys addressing cancer patients’ care experience are available, these questionnaires have not been simultaneously developed and validated across linguistic and cultural contexts for the specific out-patient setting. The purpose of this proposal is twofold: 1) to adapt the EORTC cancer in-patient satisfaction with care module (EORTC IN-PATSAT) into a core questionnaire and 2) to develop a complementary satisfaction with care module composed of items specifically addressing care within the ambulatory hospital settings (chemotherapy, surgery, radiotherapy, targeted biological therapy surveillance).

Within the EORTC QLG, a 52-item cancer in-patient satisfaction with care questionnaire was developed, the EORTC IN-PATSAT2, which measures cancer patients’ perception of the quality of care provided by hospital doctors and nurses, in addition to aspects of care organisation and services. Cross-cultural psychometric testing of this questionnaire over oncology settings from Northern and Southern Europe, and Taiwan, supported its acceptability, internal consistency, convergent validity, reliability, and discriminant validity. This questionnaire has been further validated for the South-Asian setting in Spain 3 and in Iceland 4 and has been used in different studies 5-7.

Cancer out-patients are generally confronted with frequent travelling between home and hospital, waiting time in the out-patient waiting room before a medical consultation or before a treatment or medical intervention, and uncoordinated contacts with health care professionals. Ease of access to the service (closer to home), ease of transport (parking), availability of health professionals (ease to join the service by phone), to obtain a medical appointment), coordination and continuity of care (information on treatment and care at home, interaction between hospital and extra-mural health care professional) may carry an increased importance relative to the in-patient setting 8-11.

While common aspects of care (e.g. technical, interpersonal issues) may be relevant across cancer care contexts, whether or not they vary in location, personnel, type of treatment, other care aspects may be specific depending on the care setting. Such care aspects could be waiting time before chemotherapy administration, information provided on hospital discharge etc. Common issues should be included in a core ‘satisfaction with care’ module to allow for the comparability of results, whilst specific issues should be included to permit adequate assessment of the specific relevant issues relating to the concerned context of care.

The main objectives of this proposal are 1) to adapt the EORTC cancer in-patient satisfaction with care module (EORTC IN-PATSAT) into a core questionnaire and 2) to develop a complementary satisfaction with care module composed of items specifically addressing care within the hospital ambulatory settings (chemotherapy, surgery, radiotherapy, targeted biological therapy, surveillance). We aim to adapt the existing EORTC IN-PATSAT into a core satisfaction with cancer care module. Items of the EORTC IN-PATSAT2, appraised by experts and patients as not appropriate for assessing cancer patient satisfaction with the care provided in any hospital setting will be deleted. In addition, we will develop a complementary specific satisfaction with cancer care module composed of items only appropriate to the cancer care outpatient hospital setting. This will follow the EORTC Quality of Life Group guidelines for updating existing module12, including an updated literature review, interviews with patients and health care professionals for the selection and prioritizing of issues (Phase 1) and for psychometric piloting (Phase 2).
The Module Development Committee: Future Directions?

Deborah Fitzsimmons, Chair, Module Development Committee - Swansea University, Swansea, UK

The development of modules specific to tumour site, treatment modality or a quality of life (QL) dimension has been an essential part of the ‘modular’ approach to QL assessment adopted by the QLG. On behalf of the Executive Committee (EC) the Module Development Committee (MDC) is responsible for coordinating module development that come under the umbrella of EORTC ‘QL’ modules.

The MDC meeting takes place at the bi-annual QLG meeting. Open to all QLG members involved in module development, an overview of module development is presented, new ideas proposed and collegiate debates on ‘all things module development’ occur. Much of the MDC’s work is behind the scenes, coordinating the monitoring, peer-review and quality assurance activities of module development. The central reference point is the Guideline for Developing Questionnaire modules (updated in April 2011 by Colin Johnson and others) aimed at assisting module developers to standarise module development process in order to ensure uniformity high scientific quality across the modules. As part of supporting the work of module development teams, the MDC has a vital role in communicating and collaborating across other areas of QLG activities such as the translations committee. The MDC works closely with the EORTC QLG department, Francesca Marchetti and Sheila Sanderson being much valued colleagues in helping me to coordinate MDC activities!

Building on the MDC’s rich history, this is a timely opportunity to ensure the MDC looks forward to ensuring the module development activities contribute to the QLG’s strategic aims. To support this, a consultation exercise was launched at the recent MDC meeting in Canterbury (September 2013). The aim of this exercise is to review the work of the MDC and provide recommendation to the EC in order to guide the future direction of module development activities. Two key questions underpin this exercise: 1) How can the MDC continue to develop and enhance its role in quality assurance module development activities? and, 2) How should the MDC facilitate future strategic priorities for module development?

With respect to question 1, a considerable amount of work has been done in delivering the aims of the data repository project which Francesca has been working on, led by Colin Johnson and Galina Velikova and which I was invited to join in Spring 2013. Francesca presented an update on the excellent progress being made in Canterbury including the work to produce a ‘posiled’ dataset of phase 4 studies together, with a minimum dataset for clinical socio-demographic and QLQ-C30 values for phase 4 studies and a protocol template (now available for QLG members).

The EC and MDC have streamlined procedures and time taken for the consideration of new modules, to ensure new modules contribute to the strategic aims of the QLG and fit with the QLG’s approach to QL assessment. For proposals given a decision to move forwards as a module development, and where eligible, an application can be made at the next QLG grants round and the proposal presented at the next MDC meeting. A new form has been piloted in September 2013 to support the monitoring of module developments and standard operating procedures are being produced to underpin the MDC’s administrative tasks.

The second question has already raised important points at the Canterbury meeting. Key issues already discussed include the need for a clear strategy in place for ensuring modules remain fit for purpose in the rapidly changing landscape of cancer treatments and care. Whilst very early module developments were initiated from a ‘more top-down’ approach by the QLG, the traditional approach in recent times has been a more organic approach to module development, based on the expertise and common interests of individuals and teams. Key questions need to be asked on whether there are gaps in the current module portfolio and if so how best to facilitate development, particularly in harder to reach groups or where there is limited specialist interests or access to patients within the QLG. The globalisation of module development brings with it, alongside the opportunities for cross-cultural collaboration, challenges in the co-ordination and management of multi-centre and multi-linguistic projects. Ensuring our guidelines for module development keep ahead of methodological development and ensure continuation of the highest scientific standards will also raise important considerations on topics such as RASCH analysis.

The plan is to ask QLG members to respond to this consultation exercise through a short questionnaire that will be sent out in late 2013. In parallel, a paper-based review of MDC activities is in progress. The formation of an MDC advisory panel is being discussed with the EC to help guide future MDC activities. Progress will be reported in the Spring 2014 meeting. It will be a busy few months ahead and I thank everyone in advance for their support in helping to inform the future direction for the MDC.

Dioch ym fawr (Thank you)
EORTC QOL Department

20 YEARS
in Support of Patient Reported Outcomes Research

Quality of Life Department Staff

Established in 1993, to provide scientific and administrative support to co-operative groups conducting randomised clinical trials the EORTC Quality of Life Unit (QOL Department) this year completes 20 years of successful coordination and advancement of HROQL research globally, providing tangible results for the benefit and improvement of cancer patients' care.

From its humble beginnings twenty years ago the Department has seen many changes. It now has a dedicated team of 12 staff members who each have a definite role to play although working of the office considerably. Gone are the days of mailing dozens of manuals and questionnaires. Thanks to the recently revamped website, with a few clicks interested researchers can be aware of the latest developments in QOL research and also download our Manuals and the QLQ C30 and modules. The questionnaires are available free of charge to Academia.

The electronic era has changed the day to day working of the office considerably. Gone are the days of mailing dozens of manuals and questionnaires. Thanks to the recently revamped website, with a few clicks interested researchers can be aware of the latest developments in QOL research and also download our Manuals and the QLQ C30 and modules. The questionnaires are available free of charge to Academia.

EOLG members can also access the Item Bank which was conceived and developed a few years ago in the department. The overwhelming interest now being shown in QOL research has resulted in more and more people joining the EOLG. The Department has a well-known and respected reputation for its contributions to the field of QOL research. The QLQ C30 and modules are an important part of the QOL Department's work and continue to be the most sought after measures of Quality of Life in clinical trials around the world. The population of the measure in the commercial market is reflected by the keen interest taken year on year; an increase of over 30% per annum. In the past decade, over 700 commercial contracts have been provided to the pharmaceutical industry. The most requested modules to accompany the QLQ C30 are the QLQ BR23 (Breast) and the QLQ LC13 (Lung) followed by the QLQ OV28 (Ovarian). Other modules are constantly being developed and once validated are available for use with an EORTC User Agreement.

The PROBE - Patient Reported Outcomes and Behavioural Evidence (PROBE) team has established an interactional consortium of advisors, global thinkers and established professionals from the fields of psychology, biostatistics, medicine, oncology, radiotherapy, psychiatry and neurology from different countries. PROBE is an indirect measure of QOL and its use with an EORTC User Agreement.

The PROBE Patient Reported Outcomes and Behavioural Evidence (PROBE) team has an ongoing interest in all of these areas to establish a standard approach for QOL research methodology that allows reproducibility. Other longitudinal and summary measures are evaluated for their properties, relevance and sensitivity to missing data.

Projects of the QOL Department have included assessing the intercollinearity problem of the various QOL scales. The prognostic value of baseline and change from baseline are ongoing research areas.

The QOL Department reviews the added value of HROQL trials for new study proposals, which come through the EORTC Headquarters. Where quality of life is included as an endpoint, the department participates in the protocol development in collaboration with the study team and the study coordinator. This exposes the department to many different facets of cancer trials from early to late trials, across various diseases and covering many therapeutic interventions.

Statistical research activities at the QOL Department focus on evaluating and implementing various methods of collecting, analyzing, interpreting and reporting QOL data in cancer clinical trials. Optimal design and analysis will often require a balance between broad generalizable concepts and study-specific requirements. Moreover as QOL is often a secondary endpoint, the design space is often subject to overall trial constraints. Analysing QOL data can be complicated for several reasons. e.g. repeated measures are obtained, data may be collected on ordered categorical response scales, the item may have multi-dimensional scales and complete data may not be available for all patients in addition, it could be necessary to integrate QOL with clinical outcomes. The QOL Department has an ongoing interest in all of these areas to establish a standard approach for QOL research methodology that allows reproducibility.

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Projects of the QOL Department have included assessing the intercollinearity problem of the various QOL scales. The prognostic value of baseline and change from baseline are ongoing research areas.
The 2013 Autumn meeting of the EORTC Quality of Life Group meeting was hosted by Andy Nordin and his team in the heart of Kent in Canterbury.

The meeting venue was perfectly chosen since the International Conference Center is placed in a city center within the Cathedral Precincts overlooking the imposing Cathedral, as we were told, the greatest Cathedral of the Anglican Church. As I was closing my umbrella on a Thursday morning going to colleagues and friends, the taxi driver quietly whispered that “survivorship is the big issue of this meeting.” And she was right, as always.

The Survivorship Workshop was organized to support the initiative from EORTC Headquarters and it turned out to be of huge interest to the Canterbury meeting. Many group members participated—an aspiring project.

The parallel sessions were traditionally held on the first day of the meeting and got under way after a brief introduction by the Chair Morgan, the Head of the HQ-OQL Department Andrew and a warm welcome from Andy Nordin. Although we worked hard in selected parallel sessions most group members shared the same experiences working in a clinical and interest groups was productive, problem sharing/solving and goal oriented.

The special atmosphere was “coocked” with the beautiful music of the cathedral bells which could be heard during the sessions marking full hours. Friday morning was reserved for the local and it proved to be a perfect choice combining traditional English and Mediterranean cuisine. Instead of watching the chef as he cooked we enjoyed great wine, fine food, group member’s conversations and laughter making our memories for future meetings.

I would like to take the opportunity and in the name of members of the QOL Group to thank our host Andy Nordin and his team for the wonderful meeting we had in Canterbury!

Also, many thanks to secretaries the organizing committee the Brussels QOL Department (Helen Sheila, Andrew and all the musketeers) as well as to everybody who came to Canterbury and with their presence and open minded active discussion made it special!
An EORTC QLG spring meeting with lively discussion and a great number of young researchers

Eva Nagele, PhD MA, Department of Obstetrics and Gynecology, Medical University of Graz

Marieke van Leeuwen, NCI Amsterdam

Amsterdam Meeting

Spring 2013

The 2013 Spring meeting of the EORTC Quality of Life Group was hosted from the 11th to 13th of April in Amsterdam, The Netherlands by Irma Verdöck-de Leeuw, Neil Aaronson, and Jaap Reijneveld. Amsterdam – one of the most attractive destinations to go to! Yes, definitely. As a moving cosmopolitan city, also called the “Venice of the North”, with numerous canals and many beautiful historic buildings, Amsterdam was present with a lively city centre full of adventures. The meeting was held in the “Four Seasons” Hotel which is the largest and oldest remaining hidden church in the Netherlands. In fact, we were proud that the QLG meeting took place in such an impressive area, in the middle of the canal district in the very heart of Amsterdam, we are sure that most of the participants found this setting very suitable for their lectures and workshops.

The 21 parallel sessions were held in tiny old chambers reached by climbing scary old stairs. In many cancer specific sessions (e.g. - Neck, Lung) the development of our modules was also presented and the data repository was updated. The two EORTC QLG Secretaries Susanne Singer and Fabio Efficace facilitated a lively debate, enabling us to get ready for patient interviews in phase 1.

During the plenary session after the chairmen’s welcome and introduction, we got to know about the use of the QLQ-C30 in Health Economics, about both the PROMOTION and the CAT projects, and about the value of proxy assessments of QoL and methodological aspects of assessment of HRQOL. In long-term surviving cancer patients (Testicular and Prostate cancer). The EORTC survivorship initiative was also presented and the data repository project was updated. The two EORTC QLG Secretaries Susanne Singer and Fabio Efficace passed their work over to Irma Verdöck-de Leeuw, and Susanne gave a nice farewell speech. There was a unanimous vote to organise the next spring meeting in Cyprus. We wondered whether this had anything to do with the fact that it rained cats and dogs throughout the meeting in Amsterdam. With the next voting regarding the application process for future proposals the atmosphere in the Red Hat became however tense. The final outcome offered us a good subject for further debate until late in the evening. All in all, there was a respectful academic discussion with professionals of several disciplines independent of age and experience. What we as collaborators all have in common, is the strong will to encourage HRQOL research with professionals of several disciplines.

The ‘Four Seasons’ Hotel

EORTC Quality of Life Group

Spring 2014 Meeting in Cyprus

Dr. Vassiliou Vassilios, MD, PhD, Bank of Cyprus Oncology Centre

Nicosia, Cyprus.

I am delighted to invite you to Cyprus for the next spring meeting on the 24-25th of April 2014.

Cyprus is a beautiful island located in the Eastern Mediterranean sea. It is famous for its tourist attractions and is characterised by its hospitality and warm weather. There is sunshine year-round, long summers with little rain and mild winters. Autumn and spring are very short seasons, but still warm enough for sunbathing, swimming, making it the ideal time to visit if you want to avoid the main peak season crowds. The island has been a settlement since 5800 BC. Egyptians, Mycennaeans, Phoenicians, Persians and Romans have all used the island for either political or economic reasons, but the influence from the Greeks has been the most lasting. The island is blessed with beauty, natural beauty that ranges from golden beaches and rugged coastlines to rolling hills and forest clad mountains, dotted with picturesque villages.

Our meeting is to be held at the Limassol at the ‘Four Seasons’ hotel which is an outstanding 5 star hotel. For more information please visit: http://www.fourseasons.com.cy.

Limassol is a beautiful town with 15 kilometres of coastline lined with hotels, interspersed with eucalyptus groves and linked by a promenade popular with walkers or joggers.

On the 24th of April we will have the chance to visit the old town which is the heart of the city with its narrow streets radiating out from the old fishing harbour. We will have dinner at the “Carob Mill” restaurant which is located next to the medieval castle (www.carobmill-restaurants.com). The castle was the site of a royal wedding in the Middle Ages between Richard the Lionheart, King of England, and Berengaria of Navarre. On the afternoon of the 25th right after the meeting program, we are planning to visit the archaeological site of Kourion and/or the site of Aphrodite’s venous rock (depending on the afternoon meeting schedule). Kourion is one of the most spectacular archaeologically rich sites on the island. It was an important city kingdom where excavations continue to reveal impressive new treasures. Noted particularly for its magnificent Greco- Roman Theatre, Kourion is also proud home to stately villas with exquisite mosaics, and the old town which is the heart of the island.

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The ‘Four Seasons’ Hotel

Aphrodite’s Venous Rock
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For more information on the Quality of Life Group and its activities, please visit our website: http://groups.eortc.be/qol