



Executive Committee 2013 Canterbury

Editorial

Jaap C. Reijneveld – Newsletter Editor

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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!

RIGHT Mogens Groenvold



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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 last two meetings have been extremely well attended. (see p.24 & 26)
- The increasing numbers of subgroups needing to meet at each semiannual meeting has made the scheduling of parallel sessions ever more difficult for the secretary and has necessitated that the number of sessions – each with five parallel subgroup meetings – had to be increased to five, thus allowing up to 25 subgroups to meet to discuss their work at each meeting.
- The treasurer is currently administering 30 grants allocated to group projects, again illustrating the multi-faceted activity – and the increasing workload for the treasurer.
- The number of modules is increasing (19 completed phase 4, 14 completed phase 3, 10 in earlier stages).
- Increasing numbers of publications using the QLQ-C30: the number of hits for 'qlq-c30' in PubMed is 1,871 by 24 October 2013 – with 166 from 2011, 214 from 2012, and 241 from 2013.
- Ever increasing numbers of translation of the QLQ-C30 (currently 89, including various country-specific versions) and the modules – some of the latest translations are into such languages as: Albanian, Bengali, Nepalese, Persian and Tagalog. This illustrates that the QLG instruments are being used globally.
- The number of signed User's Agreements for the EORTC QLQ-C30 per year is now about 5,000.
- The CAT project is nearing completion and more than 250 items have been developed. A field study in ten countries is now being initiated (see also p.12)

A facility for electronic data collection using the EORTC.CHES was recently placed at the web site, and this provides a good example in the transition from paper and pencil questionnaires to electronic versions on various platforms.

Besides the developments internally in the QLG, the 'mother' organization, the EORTC, is in the process of changing its research strategy. The new initiatives that are of most interest to the QLG are an increased focus 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 growth in activity and the changing environment have led the QLG to launch a number of new strategic initiatives:

- The existing portfolio of modules will be reviewed with the aim of identifying possible gaps and needs of updates.
- Whereas modules are usually proposed by individual QLG members the Executive Committee has decided to fund the development of a survivorship module/questionnaire, and has invited its members to create a subgroup with this aim. A research proposal will be prepared, and the project will start early in 2014 (see also p.5).
- The QLG collaborates with the EORTC about the preparation of the 1st EORTC Survivorship Summit in Brussels, 30-31 January 2014.
- The anticipated completion of the EORTC CAT (see also p.12) makes it relevant to develop plans for further validation, the future relationships between the new CAT measure and the existing QLQ-C30, the administration of the CAT on various platforms, the use of short-forms based on the new CAT item banks, etc. An Advisory Committee

developing a plan for this has been appointed. The EORTC measures are being used more and more globally, and the QLG Translation Committee will carry out a review of the need for translations of the QLG's many instruments.

- The QLG has not previously been working with preference-based measures leading to utility weights, whereas other groups have been engaged in this, sometimes using the QLQ-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.

Finally, based on grant proposals submitted by QLG members the Executive Committee has recently decided to fund three projects (a major revision of a fourth is pending):

- Cross-cultural adaptation of the EORTC cancer in-patient satisfaction with care module (EORTC IN-PATSAT32) for ambulatory settings (PI: Anne Brédart)
- Phase 4 - 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: Zoë 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 Poll-Franse (NL) as chair-elect the QLG will be in good hands when Lonneke takes over at the autumn meeting, 2014.

RIGHT Irma Verdonck de Leeuw

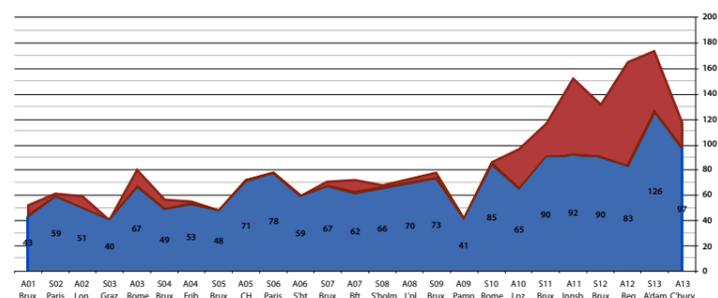
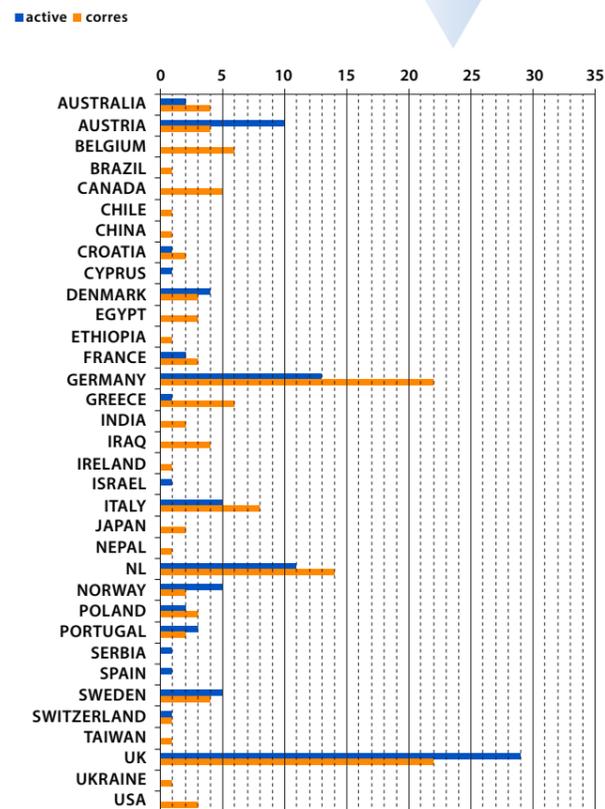


EORTC Quality of Life Group Facts & Figures

Irma Verdonck de Leeuw, VUMC Amsterdam

98 members of the EORTC QLQ were present at the Autumn meeting in Canterbury, UK. At this moment we have 245 members (134 corresponding, 98 active and 12 EORTC QOL Department) from all over the world, as you can see below.

The number of active members (red) and the number of participants (blue) of the meetings has steadily increased over the years with a record attendance at the Amsterdam 2013 meeting, as you can see below.



TO BECOME A FULL ACTIVE MEMBER OF THE EORTC QUALITY OF LIFE GROUP, you must attend two meetings within two years, and be actively involved in research in the group.

On the third meeting you will then become an active member. To maintain active membership you have to continue with research activities and attend a minimum of two meetings within every two years.

When you are unable to attend meetings regularly, it is possible to become a corresponding member.



RIGHT Jaap C. Reijneveld



Survivorship

What are the challenges for the Quality of Life Group?

Jaap C. Reijneveld, Neurologist, member of the EC Department of Neurology, VU University Medical Center, Amsterdam, The Netherlands

Over the past decades, survival rates of many cancer types have impressively 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 compromised 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 on problems in dealing with insurances and financial issues, which is also my own experience at the neuro-oncology outpatients' 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.

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 economics 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.

Early 2013, the Executive Committee concluded that the Quality of Life Group should play an important role in this initiative, as cancer survivorship has everything to do with quality of life, and as many of our members have vast experience in cancer survivorship research. We therefore stimulated the participation of members of the Quality of Life Group in the EORTC Survivorship Platform and we decided to organise a Survivorship Workshop during the Canterbury meeting. This workshop was chaired by Dr Lotte Moser, coordinator of the EORTC Survivorship Platform, and myself, as appointed delegate from the Executive Committee. During the workshop several experts highlighted different aspects of cancer survivorship and cancer survivorship care, setting the stage for a fruitful discussion on the research questions to be answered and the role of our group in this. At the end of the day, the approximately 50 participants of the workshop agreed upon developing a new generic survivorship module/

questionnaire that can be used along with the QLQ-C30 +/- modules. In order to guarantee that the initiative should keep up with the speed of the EORTC Survivorship Platform, a tight time schedule for founding and funding this Survivorship Module Group was set, aiming at presentation of plans during the summit in January 2014.

It was also decided that a Survivorship Working Group should be installed. This group should coordinate the input of the Quality of Life Group into other survivorship activities which are initiated by the EORTC, the EORTC Survivorship Platform, cooperative EORTC groups, and various individual members. We think that there may be benefits from increased communication between QLQ members involved in all these activities. Ideally, a common QLQ methodological and practical approach that could be used across studies could be outlined, and would be efficient (to avoid re-inventing the wheel in each study) and would facilitate cross-study analyses. Similarly, experiences could probably be exchanged, again to the benefit of all, and as a means of developing a clear 'EORTC Survivorship approach', which will accelerate research and increase the QLQ profile in this area.

All together, the challenges for the Quality of Life Group will be twofold. First of all we will have to develop a high-quality Survivorship Module that will become the standard for HRQOL research in cancer survivors. Apart from that, the group needs to develop and implement a clear strategy, in concordance with the EORTC Survivorship Platform, on the priorities for further research into cancer survivorship in the near future.

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. As part of this project we will also work on a manual covering issues relevant to the use of the EORTC measures in daily clinical practice.

In its current version CHES.EORTC is fully web-based (relying on the programming language HTML5). So after obtaining a user account for the website it can be run in the web-browser without any local installation of 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 QLQ-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 beneficial in particular with regard to multi-centre studies.

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 QLQ-TC26 testicular cancer module.

LEFT TO RIGHT Johannes M. Giesinger, Bernhard Holzner



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

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 QLQ-BRR26 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 Grønvold 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 on stepped psycho-oncological care (PI: Susanne Singer), and a study investigating patient-reported symptom burden during the period after administration of chemotherapy when patients are at home (PI: August Zabenigg).

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 OncoT.Net, 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 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.

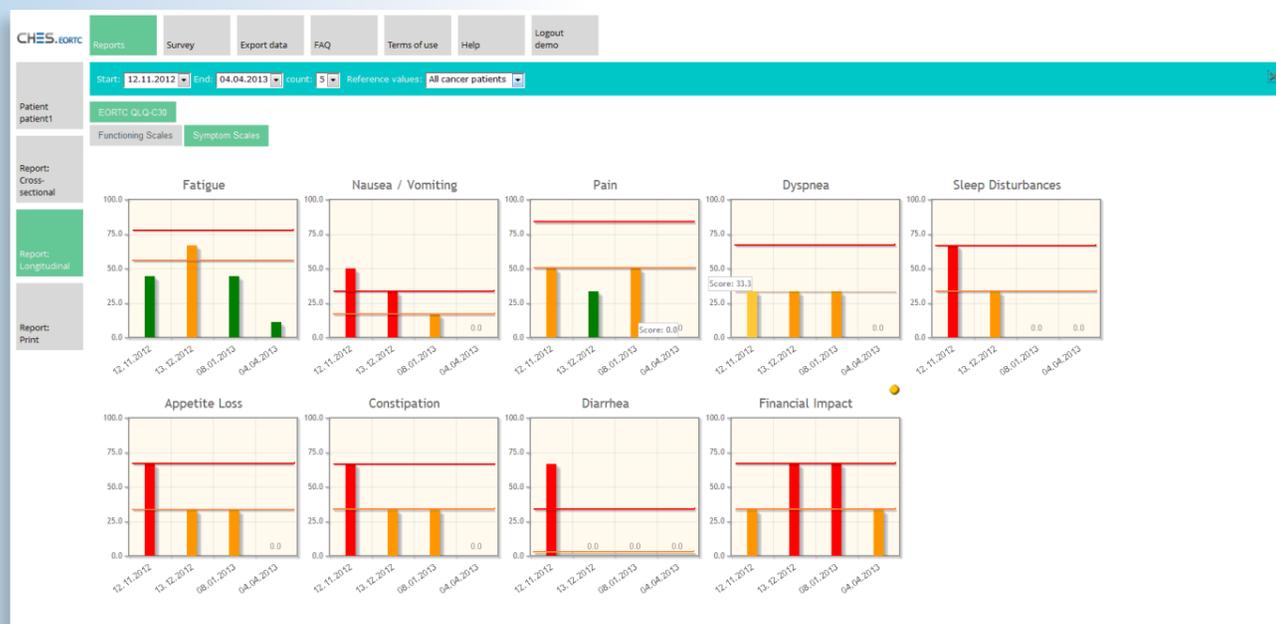


Figure 1: Screenshot of EORTC QLQ-C30 scores in CHES

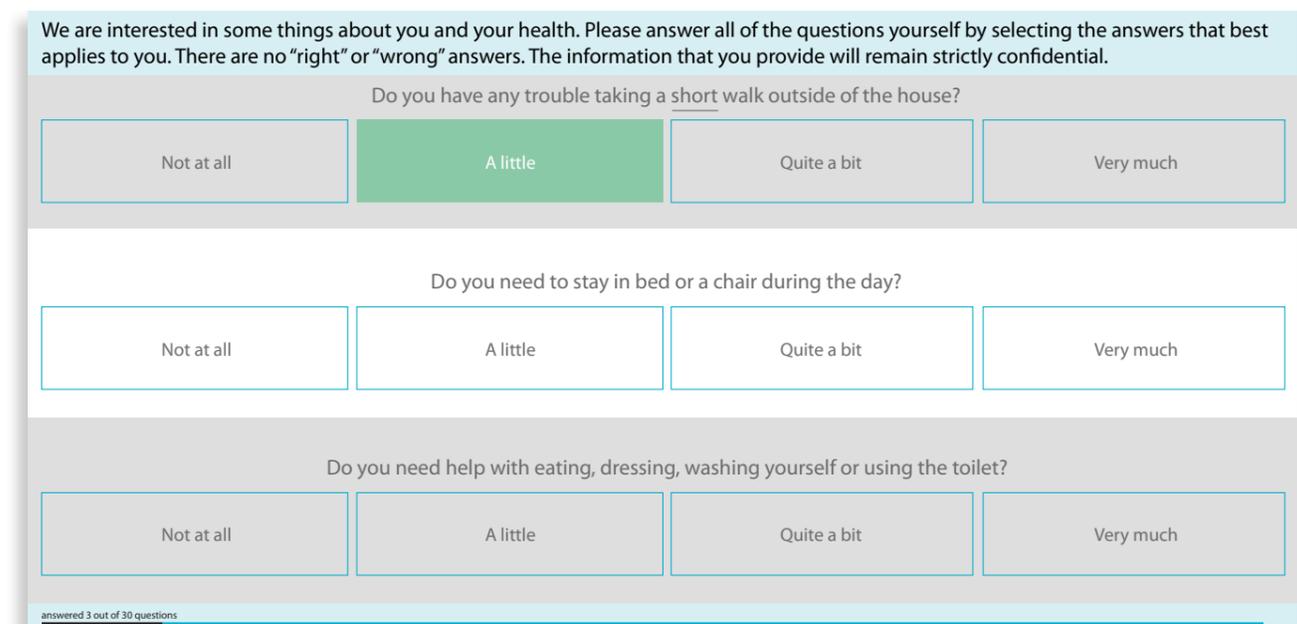


Figure 2: Screenshot of EORTC QLQ-C30 items in CHES

Development of the EORTC Sexual Health Questionnaire for Cancer Patients

RIGHT Eva Greimel



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

Several 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 consensus 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

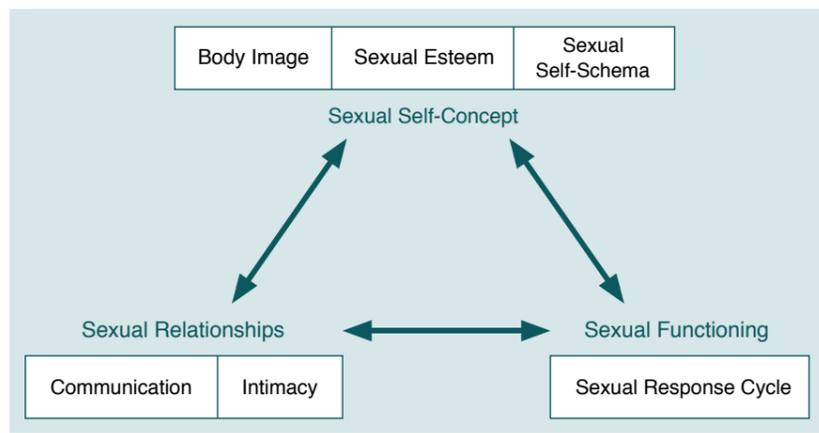


Figure 1. Neotheoretical Framework of Sexuality
 Note. Based on information from Andersen & Cyranowski, 1994; Hughes, 2000; Kaplan, 1979; Price, 1990; Snell & Papini, 1989; Tierney, 2008; Woods, 1987.

Figure: Cleary et al. (2011)

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. 2011). 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 HCPs 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.

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EORTC Quality of Life Group, sexual health group.

News

Eva Greimel, a member of the Executive Committee of the EORTC Quality of Life Group has been appointed Professor of Medical Psychology and Psychotherapy at the Medical University Graz, Austria. She holds a position at the Department of Obstetrics and Gynecology where she started her professional career 25 years ago.

Trained as a clinical psychologist she began counseling women with gynecological cancer during their treatment trajectory. Through her clinical work with female cancer patients she became interested in quality of life research. She has been an active member of the EORTC QLG for more than 15 years. Within this cross-cultural setting she has coordinated the development of several quality of life modules for gynaecologic cancer patients including the QLQ-OV28, QLQ-CX24, and QLQ-EN24.

Currently she is chairing the sexual health working group which is developing a comprehensive sexual health instrument applicable for patients with various cancers. She continues to contribute her expertise to various cancer trial groups where she assists

with the clinical application and implementation of patient reported outcome measures in gynaecologic cancer trials. A very rewarding result of research to include QOL in a German Ovarian Cancer Trial was that in the AGO OVAR 3 trial it led to a change in the standard treatment of ovarian cancer based on the QOL results.

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 Graz. Within that role she coordinates psychology 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.

TOP Sally Wheelwright
BELOW Colin Johnson



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 response 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.

However, special interest organisations, including the EORTC Cancer in the Elderly Task Force, are now actively promoting research in elderly patients with cancer so the validation of a module to supplement the QLQ-C30 in this patient group is timely.

Work on the module began in 2006 and followed the standard Phase I-III module development, as described in the guidelines, leading to a provisional module, the QLQ-ELD151. The aim of the recently published Phase IV study², was to test the psychometric properties of the QLQ-ELD15 in conjunction with the EORTC QLQ-C30 in cancer patients aged 70 years or above. A total of 518 elderly patients, across ten countries and with eight languages took part in this phase. The study was open to new patients from September 2010 to December 2011. A sub-sample of patients, n=82, who were predicted to be clinically stable completed a second questionnaire a week after the first for the test-retest analysis. A different sub-sample of patients, n=107, completed a second questionnaire three months after the first. This second group were predicted to change clinically and so could be included in the responsiveness to change analysis.

At baseline, along with the QLQ-C30 and QLQ-ELD15, participants completed a debriefing questionnaire which recorded time for completion, whether any help was needed and whether any of the items were upsetting, confusing or difficult to answer. Sociodemographic and clinical data were recorded at each completion of the questionnaires, along with a geriatric screening tool and measures of performance status, comorbidity, toxicity and self-care activities.

Information from the debriefing interview, factor analyses and item response theory analyses 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-items 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.



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

Table 1: The EORTC QLQ-ELD14

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

RIGHT Morten Aa. Petersen



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 using the responses to the previously asked items to select from an item bank the most informative next item. We develop such an item bank for each of the QLQ-C30 dimensions (except overall health/quality of life). This 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 analyses

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

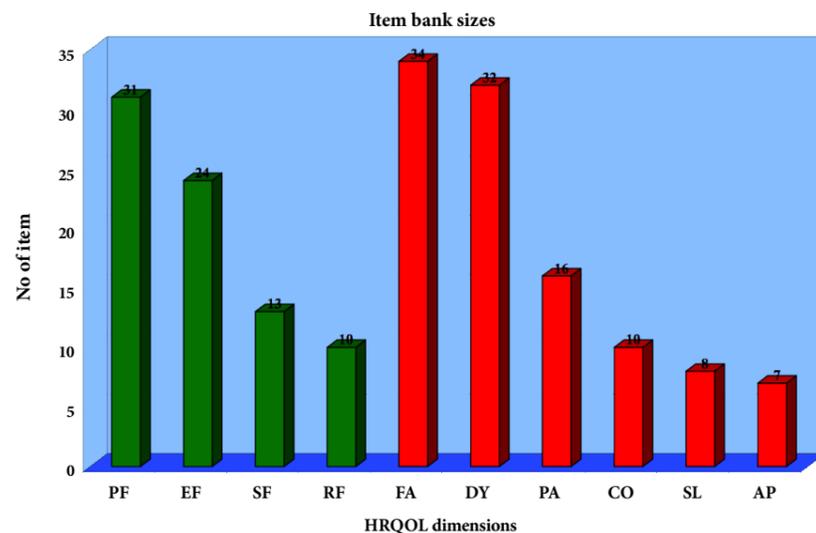


Fig. 1. Number of items in each of the 10 completed item banks.

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 measures has been 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 measurement 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 officially released. Until then, preliminary versions (both CAT and short forms) based on the currently completed items banks are available for experimental use.

It is well-known that validation is an ongoing 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/>

News

Chair of the Module Development Committee

I am a Reader in Applied Health Research and Dean of Postgraduate Research at Swansea University. Swansea is a small city of approximately 240,000 inhabitants nestled between the Gower Peninsula and South-West Wales Valleys. I work closely with the multi-disciplinary cancer teams across South Wales (particularly breast and gastro-intestinal groups) and work with the National Coordinating Centre for Cancer which is responsible for developing NICE guidelines for the NHS in England and Wales on treating and caring for people with cancer.

With a background in cancer nursing, my research career has a long association with the Quality of Life Group (QLG). Like many of us who join the QLG, my role began with module development; co-ordinating the development of the pancreatic cancer module between 1995 and 1999 which was led by Colin Johnson.

After a break from the QLG due to career and family, I became an active member of the group again a few years ago with my involvement in the development of the QLQ-ELD14 and more recently the cachexia and symptom based module developments. In Swansea, I am part of a health economics and outcomes research group, leading the patient reported outcome and health economic evaluation of a number of cancer trials and studies.

I have thoroughly enjoyed my role of Chair of the Module Development Committee since being elected in April 2012. The chance to contribute to important decisions which shape the direction of the QLG and in particular, module development is an exciting and challenging one. I look forward to working with everyone in the QLG and QL department over the next few years.

- Deborah Fitzsimmons

Patient Reported Outcome Measurements Over Time In ONcology (PROMOTION) Project

Fabio Efficace, PhD

RIGHT Fabio Efficace



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 (HRQL) 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 patients' 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 HRQL-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 HRQL 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 criterion 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).

PRINCIPAL INVESTIGATOR

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Health Outcomes Research
Italian Group for Adult Hematologic Diseases
(GIMEMA) Data Center.
Rome, Italy.

ADVISORY BOARD TEAM

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Peter Fayers, PhD
Institute of Applied Health Sciences, University
of Aberdeen.
Aberdeen, UK

PROJECT MANAGER:

Alessandro Perreca, MSc
GIMEMA, Health Outcomes Research Unit
E-mail: promotion@gimema.it

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 analyze data and provide tables to support the drafting of manuscripts. If you are interested

in knowing 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.

Efficace F, Feuerstein M, Pusic A, Cafaro V, Fayers P, Blazeby J. (October, 2013). Patient-Reported Outcomes In Randomized Controlled Trials of Genitourinary Cancers. Methodological Quality and Impact on Clinical-Decision-Making. 20th Annual Conference of the International Society for Quality of Life Research, Miami (FL), USA. Quality of Life Research, 22(1):13 (abs.103.1), 2013

2. Rees J, Blazeby J, Pusic A, Feuerstein M, Whale K, Jacobs M, Kieffer J, Cemal Y, Fish D, Yanagawa J, Fayers P, Efficace F. (October, 2013). Concordance of patient

reported (PROs) and clinical outcomes in randomized controlled trials (RCTs) of cancer treatment. Evidence from 192 RCTs of patients with solid tumors. 20th Annual Conference of the International Society for Quality of Life Research, Miami (FL), USA. Quality of Life Research, 22(1):13 (abs.103.2), 2013.

Full-length manuscript

1. Efficace F, Feuerstein M, Fayers P, Cafaro V, Eastham J, Pusic A, Blazeby J. EORTC Quality of Life Group (Patient Reported Outcome Measurements Over Time In ONcology-PROMOTION Project). Patient-Reported Outcomes In Randomized Controlled Trials of Prostate Cancer: Methodological Quality and Impact on Clinical-Decision-Making. European Urology, 2013 Oct 30. doi:pii: S0302-2838(13)01090-7.

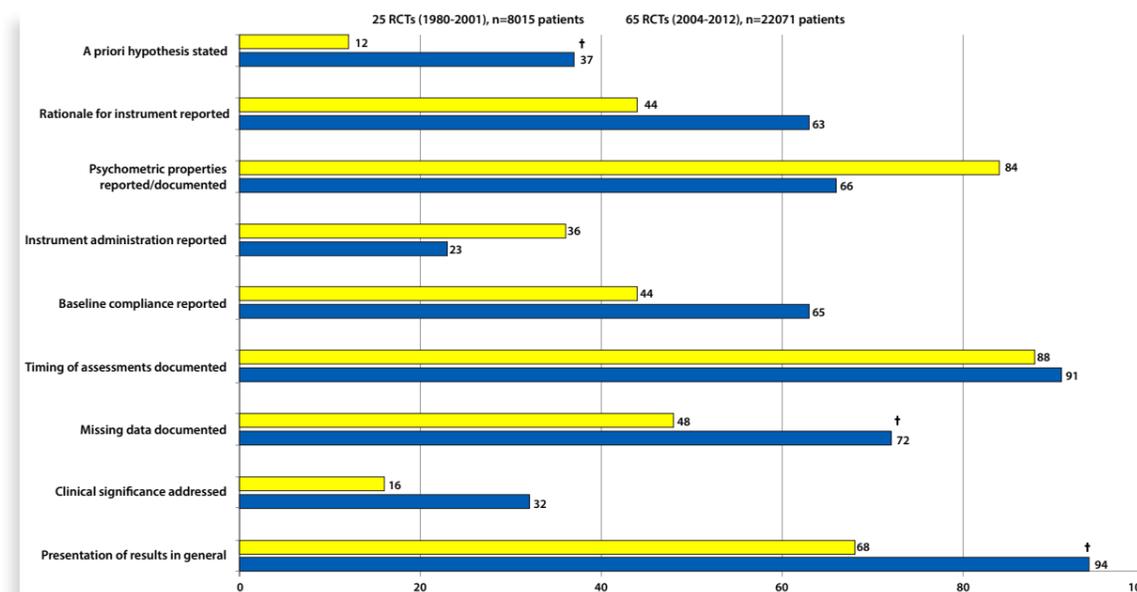


Figure 1.

(from Efficace et al, Eur Urol, 2013 Oct 30. doi:pii: S0302-2838(13)01090-7)

Descriptive comparison of level of reporting on selected key PRO issues in RCTs of prostate cancer by year of publication.

EORTC QLG Website for your eyes only!

Mélodie Cherton, Executive Assistant - Quality of Life Department EORTC Headquarters
 Anne-Sophie Darlington, Executive Committee Web Representative, University of Southampton UK

As many of you will know by now the QLG website was renewed last year with an updated design.

Members were asked for input on the website and at the 2012 Autumn QLG 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.

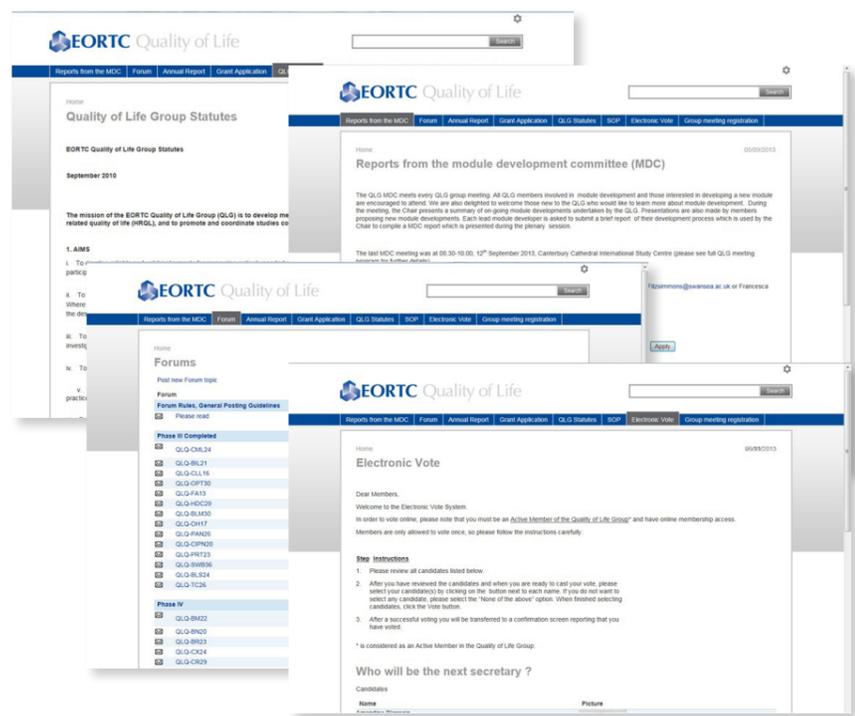
Currently, Melodie is responsible for the maintenance of the website and the development of the restricted membership area, in close collaboration with the Web Developer, the EORTC IT Department and the EC Web Representative. Once the membership area is 'live' every active member will be given a unique login/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 include several categories of information such as: Reports from the Module Development Committee, Forum, Grant Applications, Group Meetings, Standard Operating Procedures, Annual Reports, QLG Statutes, and Electronic Voting etc. The majority of these pages will include text, pictures and downloadable documents. It will also be possible to update and upload files. In addition to important information, only accessible to members, the site will also offer the opportunity to register for QLG meetings online. The form will be emailed to a

nominated email address (Group Secretary) and confirmation that your request is being dealt with will be sent.

An important feature will be the Forum. The group has frequently indicated that a means of reaching the entire group, for instance for requests for help, would be useful. The intention is for the Forum to provide that opportunity. When posting a message, the member's name (first name - last name - assuming this information is available to be stored in the member's database) will accompany any posting. The EC Web Representative will be in charge of moderation of activity on the Forum.

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.



NEWLY AWARDED GRANTS

EORTC – Breast Reconstruction

Phase IV validation with options for electronic self-reporting using CHES

Zoe Ellen Winters PhD FRCS FCS MBBCh*

RIGHT Zoe Ellen Winters



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 clinical outcomes, and the patients' self-report of their symptoms and functional status known as Health-Related Quality of Life (HRQOL). Breast reconstruction (BRR) 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 BRR-specific 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 BRR procedures, underlining their importance alongside newly-validated BRR PROMs. In 2009, the BREAST-Q was validated in BRR patients using Rasch methodology to predict individual item responses and evaluate changes in an individual's HRQOL.

The EORTC BRR 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 BRRs. Phases I-II identified all potential 'issues' relevant to PROs 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-BRR31 following publication of its' 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 BRR 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 selected non-conditional (applicable to all patients) items in relation to the EORTC QLQ-C30 and QLQ-BR23.

The QLQ-BRR26 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-BRR26, 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 BRRs, in the context of adjuvant treatments. It may be used to evaluate HRQOL effects between types of BRRs and assessment in individual patients. This PROM will enable the collection of reliable, valid and clinically important information on HRQOL outcomes in BRR 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=260) undergoing two administrations of the QLQ-BRR26 at baseline and 8 months after BRR. Two main types of BRR 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 BRR 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 QLQ-BRR26 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 QLG. The author would like to thank all collaborators and patients helping us to develop this module.

* = Director of the Breast Cancer Patient Reported and Clinical Outcomes Research Group, School of Clinical Sciences, level 2 Learning and Research, University of Bristol and Bristol Breast Care Centre, Southmead Hospital, BS10 5NB, UK.

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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

RIGHT Anne Brédart



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 settings. The purpose of this proposal is twofold: 1) to adapt the EORTC cancer in-patient satisfaction with care module (EORTC IN-PATSAT32) 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 QLQ, a 32-item cancer in-patient satisfaction with care questionnaire was developed, the EORTC IN-PATSAT32, 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.¹ This questionnaire has been further validated for the South-Asian setting 2, 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 health service (closeness 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, while 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-PATSAT32) 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-PATSAT32 into a core satisfaction with cancer care module. Items of the EORTC IN-PATSAT32 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 care module composed of items only appropriate to the cancer care out-patient hospital setting. This will follow the EORTC Quality of Life Group guidelines for updating existing modules¹², including an updated literature review, interviews with patients and health care professionals for the selection and prioritizing of issues (Phase 1) and for psychometric pilot-testing (Phase 3).

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Cancer Sciences, University of Southampton, Southampton, UK

RIGHT Irma Verdonck de Leeuw



QLG Executive Committee Secretary Introduction

Irma Verdonck de Leeuw, VUMC Amsterdam

At the Spring Meeting this year, I joined the Executive Committee of the Quality of Life Group (QLG). I was elected as Secretary by the QLG members and took over this position from Susan Singer and Fabio Efficace who have done a wonderful job over the last few years. I would like to thank both of them, as well as the members of the EORTC Quality of Life Department, for their help: it took me only a few months to get settled.

Fortunately, I also have invaluable help from Sandra Biemans, who assists me in getting things done. An overview of the current situation regarding QLG membership can be found elsewhere in this Newsletter. To contact the QLG secretary, we have established a new email address: eortc.qol@vumc.nl.

I graduated as a psychologist, speech pathologist, and linguist. I am professor at the Department of Otolaryngology – Head & Neck Surgery of VU University Medical Center (VUMc) and the Department of Clinical Psychology of VU University in Amsterdam, the Netherlands. I hold the chair "Living with Cancer: innovative care programs and e-health" established by the Dutch Cancer Society (KWF) / Alpe d'HuZes Foundation. I am chair of the research program "Quality of life in Cancer and Immunology" of the two largest Research Institutes of VUMc and VU University (Cancer Center Amsterdam (CCA) and EMGO).

Furthermore, I am chair of the MASCC Study Group on Cancer Survivorship, Rehabilitation, and Quality of Life. Within the EORTC QLQ, I actively participate in four groups (head and neck cancer, oral health, computerized adaptive testing, and the CHES.EORTC web-platform). The main aim of my research is to generate

knowledge on quality of life issues and psychosocial care in cancer patients and their relatives and to assess cost-efficacy of supportive cancer care. Cohort studies focus on the impact of cancer on the course of quality of life in relation to a broad perspective of possible moderators and mediators such as sociodemography, comorbidity, coping style, lifestyle, and tumour and treatment related aspects.

Several randomised controlled trials are ongoing on cost-effectiveness of psychosocial care, allied health services, and (stepped) care programs.

A special focus is on patient empowerment and information technology to improve the efficiency of supportive care targeting advanced cancer patients and cancer survivors.

RIGHT Deborah Fitzsimmons



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 'QLQ' modules.

Developing Questionnaire modules (updated in April 2011 by Colin Johnson and others); aimed at assisting module developers and to standardise module development process in order to ensure uniformly 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 QOL department; Francesca Martinelli 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 core role in quality assuring 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 'pooled' 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.

	Number
Validated (completed phase 4)	19
- In phase 4	15
- In active phase 4 study	6
- Analysis outside EORTC QL study	2
- Phase 4 study pending	2
- Phase 4 study not planned	3
In phase 3	7
- In active phase 3 development	4
- Report submitted on phase 1 & 2	3
In phase 1/2	11
- In active phase 1/2 development	6
- 1 'on-hold'	1
- Analysis outside EORTC QL study	1
- Phase 1 pending	4
TOTAL OF MODULES IN DEVELOPMENT	33
GRAND TOTAL	52

RIGHT Anne-Sophie Darlington



QLG Executive Committee

Web Representative Introduction

Anne-Sophie Darlington,
Senior Research Fellow University of Southampton UK

Before the summer I was elected to join the Executive Committee as the Web Representative. I would like to take this opportunity to introduce myself.

I am a research Psychologist by background and work in the Faculty of Health Sciences at the University of Southampton (UK). I am interested, as all of you are, in research into quality of life, with a particular focus on the influence of coping strategies which patients use.

I first joined the group in 2010, when I worked in Southampton on the Elderly Module. I have since been involved in the development of the Symptom Based Questionnaires and the Cachexia Module. The latest project I will be working on is around quality of life issues of adolescents and young adults (AYA) with cancer.

I am very pleased to have been elected to join the EC as Web Representative and have been trying to become familiar with what is expected of this role. On the whole, this is a new position which coincides with developments of the website. The aim of the updated website is to have a strong image and present the increasing output of high quality work which the group produces. In addition, since the group is growing in terms of membership, it seems natural to create a place to communicate and share more effectively.

Therefore the group decided to invest in the development of a restricted area on the website, for active members only, where information can be shared and members can communicate with each other. In the future I will try and focus, together

with Melodie Cherton (Executive Assistant - Quality of Life Department), on additional profiling of the group's activities and outputs, in essence showing off the work that the group is undertaking. We will look into increased monitoring of social networking, which might also engage younger investigators.

Finally, we will respond to suggestions and queries in order to continue to improve the website, so please get in touch.

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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 consideration 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.

Diolch yn 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 now the Quality of Life Department this year completes 20 years of successful coordination and advancement of HRQOL 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 with a symposium looming or a research grant deadline to meet it is sometimes all hands to the pump.

The day to day running of the department is supervised by Dr. Andrew Bottomley who joined the EORTC in 1998. He is responsible for liaison with HQ and other EORTC groups and the integration of our work into the workplace through courses seminars etc.

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 re-vamped 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.

QLG 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 Quality of Life group. The Department provides administrative aid in the organisation of the bi-annual group meetings.

In the last few years the Dept. has organised three very successful symposiums on QOL research, these involve a considerable amount of work over several months including funding finding Faculty members organising venues etc.

The present newsletter is our 14th, under the watchful eye of the Newsletter Editor it is produced here in the Department.

Abstracts posters presentations and publications are an important showcase for our work we take pride in making them as effective as possible.

Translation of questionnaires plays an important role in the PRO field, allowing researchers to collate data from different countries. At the moment there are more than 700 translations of the various EORTC modules, with more than 80 different languages available for use. The Translation Unit comprises three people, who take care of the coordination of projects, support in the process of developing new modules and management of computer tools, quality assessment, and methodological research. In the beginning, in the Department there was one person who would, amongst other tasks, collect translated questionnaires and their documentation. Now with two and a half full-time positions, we coordinate more than 100 projects at any given moment, including the administration and coordination of commercial projects from beginning till end – a new mode of work introduced in 2012, which allows more control over the development of new language versions of questionnaires for commercial users.

All translations are developed in accordance with the EORTC Translation Procedure, a strict process that involves various steps (forward and backward translations, reconciliation, pilot-testing) and requires input from many people. The procedure we follow conforms to all the gold standards in the PRO translations field and allows us to control and ensure the quality of our translations.

Over time, we have moved from translations being faxed, sent by mail or on floppy discs to e-mail correspondence, electronic archiving and computer tools which enable us to speed up the process without a loss of quality. Thanks to the translation memory and the Item Bank, identical and similar items from different modules can be reused – saving time and resources, and making the questionnaires more consistent.

With the EORTC Translation Manual and many other publications, the Translation Unit together with the members of the Translation Committee of the Quality of Life Group have contributed vastly to the methodological discussions in the field, making the EORTC a well-known brand for experts in translation of questionnaires.

The Contracts Unit of the QLD plays an important role in the provision of the QLQ-C30 and its modules to the commercial sector for use in clinical trials worldwide. The Contracts Unit is administered by Julie Walker whose customer care is a priority and to whom the prompt and accurate provision of the questionnaires is of great importance. Close liaison with the Translation Dept. is a vital part of the process. The Contracts Unit is also in close collaboration with the QLG and the EORTC Finance Dept. for legal and financial issues.

RIGHT QOL Department Staff



The commercial sector agreements consist of the top 15 pharmaceutical companies as well as more than 60 other pharma companies. The QLQ-C30 questionnaire and its modules are and continue to be the most sought after measures of Quality of Life in clinical trials around the world. The popularity of this measure in the commercial market is reflected by the keen interest taken year on year, an increase of over 20% 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- team, established in 2009, undertakes detailed analysis of clinical trial data, from closed and fully published EORTC clinical trials. One of the major challenges is to pool data and test meaningful HRQOL hypotheses of psychosocial and HRQOL functioning to improve cancer care and treatment delivery. The PROBE database has over 22000 patient data, coming from 58 closed clinical trials, it is a point of HRQOL research reference in the field, for more efficient data use and improvement in understanding the impact of treatment and disease in patients' lives. Another important assignment for the PROBE team is to expand the database by including commercial clinical trials and biomarker data for the better information of the cancer patient on the impact of cancer on patient's lives. The PROBE team has established an interactional consortium of advisors, global thinkers and established professionals from the fields of psychology, biostatistics, psychometrics, medicine, ethics, oncology, radiotherapy, psychiatry and neurology from nine different countries. Prognostic indicators of survival and meaningful interpretation of change of HRQOL scores are only some of the research topics for PROBE as we move towards a more accurate mapping of symptoms and functioning related to each cancer

The QOL Department reviews the added value of HRQOL data for all new study proposals which come through the EORTC Headquarters. Where quality of life is included as an endpoint, the department will participate in the protocol development in collaboration with the study team and the study coordinator. This exposes the department to many different facets of cancer clinical 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 allowed is often subject to overall trial constraints. Analyzing QOL data can be complicated for several reasons e.g. repeated measures are obtained, data may be collected on ordered categorical response scales, the instrument 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 analysis methodology that allows enough flexibility. Both longitudinal modeling 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 QOL data and systematic reviews. In addition, investigation into time windows around QOL assessments, minimal important differences, joint modeling, sample size, patient-proxy agreement in QOL data and sources of missing data are ongoing research areas.

The QLD closely collaborates with the QLG. One of the aims of the QLG is to develop reliable instruments to measure HRQOL in cancer patients participating in clinical trials. In order to measure such a subjective matter valid and reliable instruments are needed. The QLQ-C30 was created in 1993 and is used for generic cancer patients. During the following years

disease-specific modules have been developed, together with treatment-specific or population-specific instruments.

The module development procedure follows four phases. In phase 1 relevant HRQOL issues are generated. In phase 2 the selected issues are converted into a set of items. In phase 3 the provisional list of items is pre-tested. Phase 4 is the large-scale test or field study. The Data Repository project aims to create a standard protocol template in order to harmonize the way field studies are conducted and the way data for field studies are collected and to create a central dataset for storage of all field study data.

This is important for several reasons. The standard protocol template ensures harmonized and high quality data, which is an asset in terms of quality control. The maintenance of the dataset prevents data loss. The long-term value of data is enhanced by giving new researchers the opportunity to conduct new research on existing data, according to established rules.

Under the EORTC umbrella and its continuous support for HRQOL research, the QLD team will expand further, as more research fields become important in the changing landscape of trials, and technological advances in cancer care require more innovative methods of HRQOL assessment. Due to this, EORTC undertakes the challenge to provide all EORTC HRQOL tools electronically, which will result in multiple benefits both for patients, and for researchers conducting research and collecting data, and also help to remove some barriers in completing HRQOL questionnaires. The e-PRO development will help EORTC to successfully complete the long-term follow-up of cancer survivors...

HAPPY BIRTHDAY QOL DEPARTMENT LONG MAY YOU CONTINUE.

Canterbury Meeting Fall 2013

RIGHT Karen Kuljanic



Karen Kuljanic,
University Hospital Center
Rijeka Croatia



Quality of Life Group Meeting Canterbury 2013

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 impressive Cathedral, as we were told, the greatest Cathedral of the Anglican Church. As I was closing my umbrella on a Thursday morning greeting colleagues and friends, Sheila 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 underway after a brief introduction by the Chair Mogens, the Head of the HQ QOL Department Andrew and a warm welcome from Andy Nordin. Although we worked hard in selected parallel sessions most group members shared the same experience, working in a clinical and interest groups was productive, problem sharing/solving and goal oriented.

The special atmosphere was "colored" with the beautiful music of the cathedral bells which could be heard during the sessions marking full hours. Friday morning was reserved for the Module Developers Meeting, the Business meeting attended by active members of the

group and followed by plenary sessions in the afternoon. The survival initiative went beyond concept and made its way to form a survivorship module development group within QOL and branches that are going to reach and grow towards EORTC clinical and special interest groups.

The cultural and more spiritual hour was a Thursday Evensong choral service where Tom, Andy's youngest son had his first solo performance as a Chorister of the Cathedral's Choir. We were touched by his beautiful voice which was pure, round and warm, his tunes were in tempo and the lyrics were clear and easy to understand. I hope that Tom will continue his young singing career and enjoy it as much as we enjoyed his performance.

The social evening started with cocktails and group pictures (thank you Dirk, the official group photographer!) on the terrace overlooking the Cathedral. During dinner musical entertainment continued with The Ex Choristers performing a cappella from medieval music to contemporary classics adding some new arrangements to popular songs of Sting, Adele and Seal... True to a group tradition, the evening continued after dinner as our host kindly encouraged us to join him and experience the Canterbury night

life in local pubs along St. George Street and adjacent narrow streets.

On Friday evening Andy took us to the Goods Shed Restaurant (situated in the West Train Station) in the brilliant farmers market for a six course dinner. The restaurant was awarded the Trip Advisors' Certificate of Excellence in 2013. We appreciated the food which was fresh and 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 marking 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 (dear 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!



RIGHT Johannes M. Giesinger



Hello Amsterdam

Johannes M. Giesinger, NCI Amsterdam

In March 2013 I started my two-year Erwin Schrödinger-Fellowship (named after the Nobel Prize winning Austrian quantum physicist and funded by the Austrian Science Fund) at the Division of Psychosocial Research and Epidemiology (PSOE) at the Netherlands Cancer Institute (NKI) in Amsterdam. This allows me to further develop my expertise in patient-reported outcome (PRO) research under the supervision of Neil Aaronson. Being part of his research team has been one of my plans for some time. In fact it took me about 18 months to get my application approved and I regard myself as being very lucky in receiving this prestigious grant. The research division in which I am now working is rather large, employing about 60 researchers and support personnel at all stages of their career and with different professional backgrounds (e.g. psychologists, social scientists, epidemiologists, sports scientists). This diversity makes the NKI a stimulating and productive working environment.

Aside from the job, I've had to deal with the somewhat tricky housing situation in Amsterdam. After much hunting, I finally got lucky with a nice apartment on the banks of the harbour, separating the city of Amsterdam from the Amsterdam North. This requires me to take a ferry to go to work, which even after some months still feels a bit special for someone coming from the Alps.

And then of course, the bicycle culture is impressive and probably also good for my health. Although I soon had to learn that one should not become too attached to his bike, as the chance of it getting stolen is pretty high. Even two massive locks were not enough to protect my first bike from being stolen. To lower the risk of theft, my second bike is the ugliest one that I could find which still functions adequately, if not properly.

As part of my fellowship I will conduct a project on the development of cut-off scores for the EORTC QLQ-C30 to make it useable for screening for physical and psychosocial symptom burden in daily clinical practice. Despite the QLQ-C30 being one of the most widely used questionnaires for quality of life assessment in cancer patients, to date only very few studies have dealt with the issue of cut-off scores for this questionnaire. My project starts with evaluating an anchor-based approach for the scales physical functioning, emotional functioning, pain and fatigue scales. The scores from these scales are analysed with regard to patient reports on perceived burden, limitations in everyday life and need for help. In this project we are making use of the recently developed EORTC CAT item banks. This extension of the QLQ-C30 scales with larger item banks increases measurement precision and also allows us to relate the anchor-based cut-off scores to the EORTC CAT measures. Morten Petersen kindly helped me with the extension of the QLQ-C30.

Conducting the project in collaboration with Neil Aaronson and Wilma Kuijpers (Amsterdam), Bernhard Holzner (Innsbruck) and Teresa Young (London) allows to also shed some light on possible cross-cultural differences in cut-off scores. We will recruit a total of 700 patients receiving chemotherapy from the participating institutions for the study (start of data collection in October 2013). If the anchor-based approach proves to be methodologically sound the next step will be to apply it to the other scales of the QLQ-C30 (each extended with items from the EORTC CAT item bank) and conduct a multi-centre study to further examine cross-cultural issues. The availability of cut-off scores for screening purposes will hopefully further promote the integration of the QLQ-C30 into routine QOL monitoring as an integral part patient care and management.

LEFT TO RIGHT Eva Nagele, Marieke van Leeuwen



Amsterdam Meeting Spring 2013

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

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 Verdonck-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 “Red Hat” (Rode Hoed), 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. - Melanoma, - Thyroid, - Vulva, - Lymphoma/CLL) including the two update sessions (Head and Neck, Lung) the development of our modules had progressed. In the interdisciplinary sessions

and sessions with a mainly methodological orientation the discussion was also very active (e.g. Symptom Based Questionnaires, Communication, Sexual Health and Spiritual Well-being Questionnaire). The Sexual Health session was really well-attended, we would say even a bit overcrowded, but the session facilitated a lively debate, enabling us to get ready for patient interviews in phase 1.

During the plenary session after the chairman’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 Verdonck-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 multi-cultural involvement in interdisciplinary and multi-national research groups. This time

also many young researchers participated and there was the highest attendance of QLG members ever. Besides the working sessions we consumed plenty of snacks and sweets and one of our colleagues told us (whose name we don’t want to reveal) that there was even beer for free at the meeting venue.

Before and after work we had the chance to experience Amsterdam. Sometimes we just watched the fast cyclists or walked around buying tulips or crossing a few of the 1200 (!) bridges. Thursday night we enjoyed dinner on board of two glass topped canal boats (one “vegetarian boat” and one “meat boat”) to get spectacular views from the water. While admiring the opulent houses of the Keizers- and the Prinsengracht, the tour guide on the “meat boat” told funny facts about Amsterdam and the many house boats. Did you for instance know that Amsterdam has the highest percentage of female singles in the Netherlands? On Friday we had dinner in an Italian restaurant named “Pasta e Basta” with hosts who also were professional singers. We enjoyed a fresh and healthy cuisine and the pleasant atmosphere with some collaborators even dancing. One of our Italian members confessed that he had never had such good Italian food outside Italy! As the Queen of the Netherlands was opening the completely renovated Rijksmuseum that particular Saturday, we unfortunately could not visit this beautiful museum which includes many Rembrandt and Vermeer paintings as originally planned. This is another reason to come back once more.

We really want to thank you Irma, Neil and Jaap for your excellent organisation including the evening program and for all the impressive moments in Amsterdam, which we will never forget!



RIGHT Vassiliou Vassilios



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 and 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, Mycenaean’s, Phoenicians, Persians and Romans have all used the island for either political or economical 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 in the city of 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 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 archaeological 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 mosaic floors and an early Christian Basilica among other treasures. Petra tou Romiou (Rock of the Greek), also known as Aphrodite’s Rock, is a sea stack in Pafos, Cyprus. The combination of the beauty of the area and its status in mythology as the birthplace of Aphrodite makes it a popular tourist location. A welcome cocktail at the sunset bar and a dinner with traditional Cypriot dance and music will follow at the resort of Intercontinental Aphrodite Hills Resort (www.intercontinental.com/aphrodite).

Group members and attendants will be sent information through email on how they can book their hotel rooms. Apart from the venue hotel there are excellent nearby 4 and 3 star hotels that can be used. Reservation forms and other information will be sent to all members for all hotels in due time. The districts of Famagusta and Kyrenia and part of Nicosia are nowadays under Turkish occupation since the Turkish invasion in 1974. Travellers arriving in the Republic of Cyprus may enter the Republic only through the legal ports of entry: Larnaca and Pafos International Airports, or the ports of Larnaca, Limassol and Pafos. To reach Limassol from the 2 international airports it takes about 50 minutes car drive. From the airport one could hire a taxi (costs about 55 euro per ride - 4-seated) or the minibus service.



The ancient theatre of Kourion



Aphrodite’s Venous Rock



The ‘Four Seasons’ Hotel

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