



EORTC QoL Group Meeting, Kiel, September 2017

Fasten your seatbelts!

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Dear readers,

These are turbulent times as everyone well knows. Reading the news has become a health hazard and this can push some people to want to retreat. However, the opposite is happening within the EORTC Quality of Life Group! We previously highlighted how it was time for us to wake up as a group, to engage with external stakeholders more actively and to showcase our work more effectively.

These recommendations have been clearly taken on board and as you can see from the content in this Newsletter, as much of our work is focused on rising to the challenges the field of Quality of Life faces. We are actively making sure that Quality of Life as a concept to measure is at the forefront of assessment for patients, as highlighted by our chair.

Indeed we are actively recognising that the needs of clinicians and official bodies are shifting and that we

are responding to this, as highlighted by the phenomenal work carried out around the Item Library. Equally, we are mindful that our core activities are extraordinarily valuable and therefore we continue our work on module development, and even more important module updates, following the rigorous methods, which put the patient voice front and centre. In relation to this, we are also actively engaging with patients, and their representative organisations. We are incorporating their views, and actively seeking their input, as illustrated by our close relationship with the European Cancer Patient Coalition.

We also realise that the Quality of Life Group is becoming a grant-issuing body more and more, necessitating transparent procedures during the process from the first pitching of an idea at one of our meetings to the actual funding of a project. In

this issue, you will learn more on how to apply for funding in the most effective way, as well as get some information on the most recently awarded grants.

As ever, the Quality of Life Group has the moral obligation to live according to its own principle, which is maintaining Quality of Life as optimally as feasible. So, you will also find reports, including loads of pictures, on our 2017 meetings in Brussels and Kiel, as well as invitations to join us during our upcoming meetings in Paris and Opatija.

Last but not least, we would like to thank Christopher Courtois for his excellent support in editing this Newsletter. We hope that you will enjoy reading!

Best,

Anne-Sophie Darlington
Jaap Reijneveld

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A few words from the Chair

Fabio Efficace, Chair of the EORTC Quality of Life Group, Head of Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

“Over the last decade, major steps have been made to ensure the highest possible quality of PRO assessments (...)”

I have been involved in the EORTC Quality of Life Group since 2001 and have had the privilege to see our research activities greatly expanding in several directions over the years. Our research portfolio now ranges from purely methodological work, aimed at further refining our patient-reported outcome (PRO) measurement system, to more clinically oriented projects. Indeed, several collaborations are ongoing with a number of EORTC Disease Oriented Groups trying to answer important clinical research questions.

Over the last decade, major steps have been made to ensure the highest possible quality of PRO assessment and to make the patient’s voice more loudly heard in the medical establishment. For example, we have seen the publications of key guidelines, such as the CONSORT PRO criteria, and prominent recommendations by regulatory stakeholders. For example, the recent ones issued in 2016 by the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA): “The use of patient-reported outcome (PRO) measures in oncology studies” (EMA/CHMP/292464/2014). In parallel, however, we have also seen the development and validation of a number of other PRO tools (such as the PRO-CTCAE and the PROMIS measures) and have appreciated the dramatic

changes occurring in cancer therapies. For example, the rapid development of new drugs and the development of new classes of targeted therapies (including small molecule inhibitors and monoclonal antibodies), for many cancer populations. Overall, these examples illustrate the extent to which the landscape has changed and is actually still changing.

Indeed, while some twenty years ago the competition in the science of PRO measurement was relatively low, we now have moved into a very competitive arena and we are also pressured by the medical community to more robustly prove PRO data can really make a difference in the real world-setting.

Therefore, the key question for us is: should we respond to all these changes and if yes, how? I guess we need to respond and eagerly embrace all the challenges we see around us and, most importantly, consider these challenges as opportunities to keep growing. If I had to summarize in one word how to best face this evolving scenario, I would definitely say: “flexibility”. Actually we are already adapting and responding to all these “new” instances from the outside world, and I have to say we are not alone in this effort as the EORTC Headquarters is greatly supporting us by sharing our plans and

views. Just to mention one of the most relevant initiatives where we invested lots of resources, I note the recent release of the EORTC Item Library. This Library adds ample flexibility to our measurement portfolio and it is an example on how we are adapting to some of the challenges we have ahead of us. Also, the US Food and Drug Administration (FDA) now includes PRO as one of the four types of Clinical Outcome Assessment (COA) and notes that COAs can be used to determine whether or not a drug has been demonstrated to provide treatment benefit. Within this framework, the FDA has now in place a COA qualification program (which entails also PRO tools) and myself and the QLQ leadership feel it is of strategic importance to make sure the EORTC QLQ-C30 (or one of its domains) eventually successfully pass through this qualification process. This is far from easy and will require major efforts, but this is now on our agenda.

To conclude, the keeping of our amazing visibility in the international arena requires continuous efforts, not only for me as chair of this group or the QLQ leadership, but also for all of you. Your outstanding dedication to our mission and goals and your enthusiastic active participation have been, are, and will be even more essential in the future for the flourish of novel and cutting edge research initiatives.

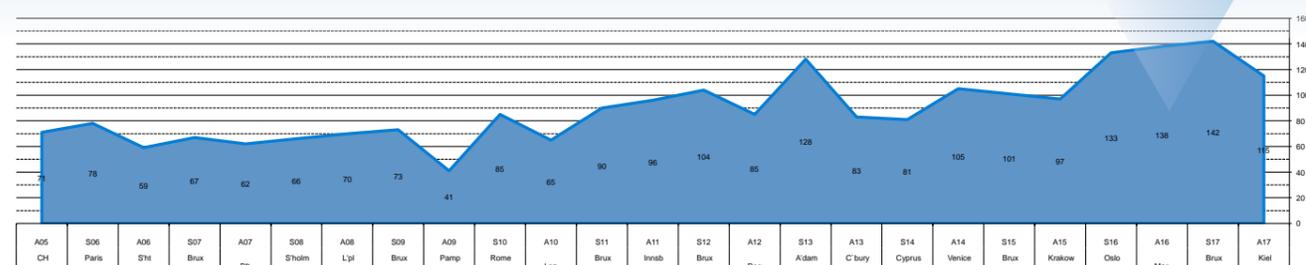
“We are pressured by the medical community to more robustly prove PRO data can really make a difference in the real world-setting.”



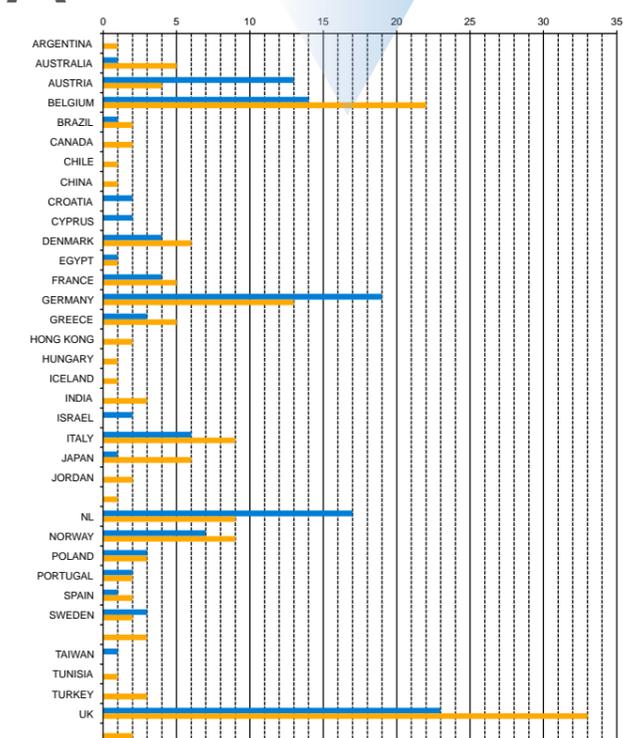
EORTC Quality of Life Group – facts & figures

Krzysztof Tomaszewski, Jagiellonian University Medical College, Poland

A total of 142 members of the EORTC QLG were present at the 2017 spring meeting in Brussels (Belgium), and 115 at the autumn meeting in Kiel (Germany). The graph below shows the quickly increasing number of people registering for the EORTC Quality of Life Group meetings. For our 2018 spring meeting in Paris we project an even higher number of registered participants!



Almost two years after our membership update in 2016 we currently have 292 members (162 corresponding, 130 active) from all over the world, as you can see below (Figure 1). This shows that about 50 new members joined our Group since spring 2016!



HOW CAN I BECOME A FULL ACTIVE MEMBER ?

To become a full active member of the EORTC Quality of Life Group, you have to first contact our Secretary in order to register as an EORTC QLG corresponding member (information that you need to send in are your name, surname, affiliation, e-mail address, and your EORTC QLG-related scientific interests). Next, you must attend two meetings (within two years) and be actively involved in research in the Group. On the third meeting you become an active member. To maintain active membership you have to continue with research activities and attend two meetings every two years.

If you are not able to attend meetings regularly, you can maintain your corresponding member status.

For more information on how to become a member of the EORTC Quality of Life Group please visit: <http://groups.eortc.be/qol/membership>

Even in times of uncertainty the EORTC QLG membership course is an unwavering ones

Krzysztof Tomaszewski, EORTC Quality of Life Group Secretary, Jagiellonian University Medical College, Poland

“It looks like, in the long-run, the review will lead to an ever greater increase of our Membership and our Group’s activity.”

It has been 1.5 year since I was elected Secretary of our Group – for which, yet again, I would like to wholeheartedly thank you – the Members of the EORTC QLG!

of registered participants well exceeding the expected number. A big “thank you!” to the Organizers as the feedback after the meetings was extremely positive!

growing amount of registrations for our meetings, the increasing diversity of our Group in terms of members from new countries and from new specialist areas, we are becoming stronger than ever – ready to face any challenges that may lie ahead of our Group.

Looking back it has been a very good time – challenging, very busy in terms of the Executive Committee’s work but fruitful and fully to the benefit of our Group. We are currently one of the largest EORTC Groups with a total of almost 300 members and about 30–40 new members joining us on an annual basis. Our 2016 membership review led, in the short-term, to a temporary decrease of corresponding members but also to a major increase in the number of active members! It looks like, in the long-run, the review will lead to an ever greater increase of our Membership and our Group’s activity.

Due to the ever growing number of scientific projects led within our Group, each QLG meeting saw a greater number of parallel sessions. This demonstrates excellently the “scientific power” within our Group but also demands new ways in which to organize our future meetings. What has been already implemented by several PIs is to present a number of projects within one parallel session. Other solutions for the future may involve adding a further time slot for parallel sessions (with possibly shortening some parallel sessions to one hour) or adding a parallel session on Friday morning (please bear in mind that the EC does not want to scare anyone with this “early morning” idea).

Finishing with a personal note, I just wanted to say that I cannot help but to smile looking on this extremely positive overview of our Group – it simply makes me proud to be a member of this community. We are a Group that the EORTC can be proud of!

Our recent meetings took us again to new places across Europe – such as Manchester in the UK (meeting hosted by dr Kim Cocks and her Team) and Kiel in Germany (meeting hosted by dr Claudia Schmalz and her Team). These were overwhelmingly popular, with the amount

Even though a lot of challenges lie ahead of our Group and many uncertainties loom before us, our membership follows a steady course. With the number of QLG members rising rapidly, the

“Even though a lot of challenges lie ahead of our Group and many uncertainties loom before us, our membership follows a steady course.”



Money, money, money

Susanne Singer, Kathy Taylor, Mainz, Germany

When it comes to money, it comes to numbers. You need to be a bit obsessive-compulsive to take on the job of EORTC QLG treasurer. Luckily, we probably are, “we” being the new treasurer, Susanne Singer, and the new treasurer assistant, Kathy Taylor. Both of us are epidemiologists, so we already had a love for numbers.

Before the official take-over at the Kiel meeting, we both went to Innsbruck to visit Bernhard Holzner and Monika Sztankay for an intensive training on treasurer tasks. We headed home with a lot of information, awe for what the two of them have done in the previous years (seriously, hats off to those two and all the previous treasurers), and a creeping feeling that there would be a huge amount of work for us in the future. But at least we were still smiling (see picture)!

After the Kiel meeting, it really kicked off. We documented the time we needed for all the various tasks – because we love numbers – and we found that we were spending about 20 hours per week on treasury tasks at the beginning. Now, in December 2017, we spend about 5 hours per week, so there is obviously a steep learning curve. However, these 5 hours sometimes balloon to 10 and unfortunately do not come in one block; the tasks come email by email, and they fragment our days pretty harshly.

For those who do not know what the treasurer has to do, here it is in a nutshell:

- Set up contracts between the EORTC and principal investigators and between principal investigators and their collaborators.
 - This involves drafting the initial contract, then managing the

review of contracts between the EORTC and study sites and eventually coordinating signatures. - Keeping track of the status of all the open contracts is a challenge.

- Check invoices sent to us, approve them, and forward them to the EORTC
- Correctly allocate and track expenses for each project as the invoices arrive.
- Communicate with headquarters and the QLG members if payments are delayed.
- Reconcile the monthly bank statements and code each transaction.
- And of course all the usual executive committee tasks (teleconferences, reviewing papers and reports, etc.)

So, there is a lot to be done. Fortunately, Monika and Bernhard were (and are) very generous in sharing their expertise and helping us. Moreover, the people from the Accounting, Finance and Contract Departments at the EORTC Headquarters, Pablo Reja (Contract Officer) and Christian Brunet (Chief Financial Officer), are also very nice to work with – always extremely quick, well informed, knowledgeable, and very kind.

You can make the life of the treasurer and her assistant easier (and keep us smiling) if you prepare your emails, documents, and requests in a certain way. Hence, here comes our ultimate wish-list:

Wish-list:

- All principal investigators (PIs): please ensure we have a **table** showing the patient enrolment at all collaborating sites plus **the total amount of Euros per collaborator**.
- Please put the **QLG reference number** of your project (= the grant number) in the email subject line because it makes it easier to manage all the emails. An example for such a number is “004-2010”. You should find this number in the footnote of the contract. Each PI should inform his or her collaborators about this number. If you aren’t sure, just ask us!
- Please keep **single emails** specific to a project or invoice. For example, please don’t ask about 2 collaborator contracts in 1 email. It makes it much easier to track email conversations.
- We are now **separating the signature pages** on all new contracts so that all parties can simultaneously sign and then send their pages to HQ. The institutions just need to let us know how many signed hard copies they need for their site if they require more than one.
- It would be great if people could give Kathy a **short message when they receive and/or send hard copies of contracts and signature pages**. We have had a few examples now where we thought the contract was at a site for signing, but in fact the site never received it. This has led to unnecessary waiting time.

Despite the work load, we are happy to be in these positions. Kathy was brand new to the EORTC, and she has really enjoyed the email contact with various members. We thank all

the members for their patience while we got up to speed and continue to learn and are looking forward to working with you all over the next years. We don’t bite; if you have a

question about a contract, invoice, or your project’s finances, please just ask!



LEFT TO RIGHT: Kathy Taylor and Susanne Singer on treasurer training tour in Innsbruck, Austria. © picture taken by Eva Gamper

News from the EORTC Quality of Life Department

Andrew Bottomley, Assistant Director, EORTC, and Head of Quality of Life Department, Brussels, Belgium



It has been **another hectic year for the EORTC Quality of Life Department**. We have experienced major staff changes and started many new large scale and challenging projects. You can read about many of these projects in more detail in other parts of the newsletter. For now, what we can definitely say is that we are constantly adapting to the changing external environment, as well as to the needs of the ever-evolving EORTC Headquarters (HQ) with its new internal structure and configurations, which were announced and introduced last summer. We hope that the changes will bring an even better integration of the QLD and improve the processes between the QLG and the HQ.

One of the major projects has been, of course, **the Item Library**, officially launched in October and enjoying considerable interest from users. You can read more about it on p.13.

We have also worked hard on **adapting the QLG grant process**, to ensure it fits well within the existing EORTC internal procedures. This harmonization project has taken a lot of effort from long standing QLG member and Chair of the Grant Review Committee, Prof. Michael Koller, along with Dr. Madeline Pe and Francesca Martinelli. We hope that grants will soon start to be issued more quickly, but with the same high quality of peer review.

Additionally, there was also a drive from within the QLG Executive Committee to have **better quality assurance procedures for all on-going QLG-funded projects**. This is critical, when we have over 50 ongoing funded research projects, and many that are being run from dozens of centers across the EU and beyond. Madeline Pe, Francesca Martinelli and

Melanie Beauvois have been working on aligning the existing QLG QA procedures to fit the needs of both the QLG (through the Project and Module Development Committee) and the EORTC HQ. This has meant tightening up our procedures and developing new ways of working which has, of course, placed a greater demand on the investigators. However, with this extra effort, we expect to see the best of projects delivering high quality results, which we hope will lead to improvements in patient care.

Our **Translation Team** was exceptionally busy in 2017. Over 80 new translations were finished with 40 out of these for pharmaceutical companies. This brought in a fourfold increase in the fees charged for translations in comparison to 2016. With so many ongoing grants, new translations are always needed and keep the team busy. It was also an important year for methodology research with the newest version of the Translation Manual completed, a poster presented at ISOQOL, three oral presentations at various conferences and a paper on the back translation review that was published in December.

We had a great many users contacting the department to use **EORTC QOL tools**. Over the last year, more than 5000 academic users from over 100 countries contacted us. Furthermore, there was an increase in industry users, with more than 220 agreements signed with industry partners, a record number since we began over three decades ago. More than a hundred of these partners used one module or more, with the lung cancer (QLQ-LC13) and multiple myeloma (QLQ-MY20) modules being the most used. Industry-sponsored trials are often using our tools in Phase III studies with

an average of 950 patients. However, more than 50% use our tools in smaller phase studies or even exploratory studies. Finally, we are seeing an increased diversification in the locations of the sponsors, with now more than 15% of the pharma partner-based studies launched from Asia-Pacific, 40% from the US and 30% from the EU. Hence, perhaps showing a reflection of the growing global diversification and interest in measuring QOL with EORTC tools.

In Spring 2017 our **4th QOL and Clinical Trials Conference** was a great success, with nearly 400 attendees from over 40 countries attending the 2-day event. This was such a success that 90% of respondents rated the meeting as "excellent" in a post conference evaluation. Given this and interest expressed for a future conference, we are undertaking another 5th QOL and Clinical Trials Conference on the 11 and 12 of April 2019. We invite you all to attend, and send us your letter of interest if you wish to apply for several travel awards. Attendance will be free for academics thanks to a grant from the QLG and support from the HQ. To those readers from industry who wish to support our initiative, additional funding opportunities still exist, and past conferences have provided a great online training for QOL and PRO researchers (see <http://events.eortc.org/qol-conference/final-program/>).

The **QOL website** has been undergoing a total overhaul. Prof. Anne-Sophie Darlington and Melodie Cherton have been working extremely hard over the last year with an external company. We will have a brand-new web site that better suits the needs of the users (see p.11).

Given all these activities, one can easily forget that the department is involved in **scientific**

activities too. For example, our staff have had an impressive scientific output, co-authoring over 15 peer-reviewed papers in journals like JCO or The Lancet Oncology, often co-authored with QLG members, and frequently in collaboration with EORTC Disease Orientated Groups (DOG) such as the Breast, Brain or Melanoma Group. For example, Corneel Coens was the lead author on a Lancet Oncology publication of QOL results from our phase III trials in melanoma with patients taking adjuvant ipilimumab versus placebo. Dagmara Kuliś was the first author of a conceptual paper examining the back translation review process, which was published in a specialized PRO journal. Many of the staff have been invited to speak at prestigious international conferences and meetings, to share their knowledge and experience with the US FDA, EMA, and other academic societies (e.g. the International Society for Quality of Life Research or European Cancer Patients Coalition).

One of the key roles of the QOL Department is to act as a centralized resource to help ensure the **smooth integration of QOL endpoints in EORTC clinical trials**. We have been actively working with many DOG and QLG members to ensure that protocols are developed quickly, consistently and robustly. In 2017 alone, of the 21 projects/trials under protocol development, 17 (80%) will have QOL as an endpoint, almost exclusively a secondary endpoint in our clinical



trials. In addition, QOL is an active endpoint in 29 actively recruiting studies, and 15 RCTs in long-term follow-up studies. Some 18 EORTC studies closed to patient entry, for which QOL analyses are expected. This brings the number of studies the HQ and Department is currently busy with to 79 (with different levels of activity). In 2017 QOL staff have helped develop the new "Guidelines for Inclusion of Patient-Reported Outcomes in Clinical Trial Protocols: the SPIRIT-PRO Extension", recently published in JAMA Oncology. These guidelines aim to standardize QOL writing in clinical trial protocols. We will be recommending integrating these where possible into future EORTC protocols with QOL.

Two key inter-departmental QOL projects (SISAQOL and MID) are now beginning to deliver new knowledge, with new results starting to come out (see see p.14 and p.15). In addition, 2017 saw the start of three new large QLG studies to be conducted via the EORTC HQ,

which will be reported on in more details in future newsletters:

- Follow-up study of gynecological cancer patients (Principle Investigators (PIs): Eva Greimel and Antonio Casado)
- Follow-up in Early and Locally Advanced Breast Cancer Patients (PIs: Vesna Bjelic-Radicic & Fatima Cardoso)
- Assessment of the Quality of Life of childhood acute lymphoblastic leukemia patients enrolled in EORTC Children Leukemia Group trials between 1971 and 1998 (PIs: Anne-Sophie Darlington & Caroline Piette).

In summary, the QOL Department is adapting well to the ongoing challenges, and have an ever growing portfolio of activities in support of the EORTC QLG and DOGs. We hope to continue to adapt, and offer more support and solutions to address cancer patients' needs in the future.



LEFT TO RIGHT: Claire Piccinin, Francesca Martinelli, Jammbe Musoro, Melodie Cherton, Dagmara Kuliś, Andrew Bottomley, Christopher Courtois, Alena Niculae, Irina Ghislain, Melanie Beauvois, Front Lien Dorme, Mekdes Taye, Justyna Mierzynska

Where are we now? Looking back and moving forward with the Project and Module Development Committee (PMDC)



Deborah Fitzsimmons, PhD, Co-Chair - Jaap C. Reijneveld, MD, Co-Chair - Andrew Bottomley, PhD
Eva Greimel, PhD - Hans-Henning Flechtner, MD - Francesca Martinelli, MSc - Madeline Pe, PhD

The PMDC was launched under the current name in the spring 2017 QLG meeting, with the aim of overseeing all aspects of EORTC QLG funded projects, both modules and non-modules.

This means that the PMDC monitors QLG projects from conception to completion, ensuring among other things that they fall within the QLG strategy and portfolio and that of the broader EORTC strategy (e.g. collaboration with the EORTC Disease-Oriented Groups [DOGs]) and that they meet international standards of quality.

The PMDC staff at the EORTC QLD (Mélodie Beauvois, Francesca Martinelli and Madeline Pe, joint email address pmdc@eortc.be) supports investigators through the whole route from research idea to completed project.

The PMDC works with the Executive Committee (EC) and has delegated responsibility to:

- receive and collate new research ideas; organize the open parallel sessions where these ideas are presented (during QLG meetings); advice and collate feedback from the attendees and report to the EC, who then makes the endorsement (or not endorsement) decision as part of the new grant application process;
- oversee the progresses of endorsed proposals on the path to full grant application;
- support and facilitate collaboration with the DOGs;
- monitor funded projects to ensure good quality assurance;

- ensure that the intellectual property of all QLG funded projects remains with the EORTC QLG.

We have been continuously learning and hence reviewing our processes along the way, with always an eye on clarity, transparency, efficiency and better quality assurance procedures.

To this end, the following changes in processes have been adopted in 2017.

New research ideas to be endorsed

- All new research ideas need to be endorsed by the QLG EC before investigators can apply for grant funding.
- In order to achieve this, all investigators who have a research idea need to send an email to pmdc@eortc.be and ask for the two-page outline form. This form needs to be filled in and sent back to the same email address at least three weeks before the QLG meeting.
- In every QLG meeting, the PMDC has two parallel sessions (instead of one as in the past) where investigators can present their ideas. The second session is a repeat session. The idea is to maximize the attendance of QLG members who are welcome to give their comments.
- During the plenary session the PMDC chairs present a summary of the new research ideas that have been presented and the comments received.
- The PMDC gives recommendations to the QLG EC on whether to endorse a research idea (or not), based on their expertise and on the comments received during the parallel sessions.

- The EC then makes the endorsement (or not endorsement) decision. After the investigators have been informed by the EC chair of the EC's decision, the PMDC circulates the minutes of the PMDC sessions (with the final EC decision) to all the attendees of the PMDC parallel sessions.

Monitoring of QLG funded projects

EORTC QLG funded projects are done on behalf of the EORTC QLG, which gives EORTC accountability for these projects. For good governance and better quality assurance procedures certain documents need to be filed at the EORTC HQ. These documents are listed below and can be provided through the already mentioned email address pmdc@eortc.be.

- During set-up (or before data collection starts for projects with data collection): copies of ethic approvals and blank informed consent forms in local languages; copy of the final protocol; and list of collaborators and sites – these documents will be requested by the PMDC staff.
- Twice per year (before QLG meetings) while the project is on-going: duly filled in follow-up forms, with updates on publications and information for the QLG website – these documents are circulated (empty) and collected (full) by the PMDC staff.

The follow-up forms are very important and should be filled in with care. They are used to update the website and consequently inform researchers on the status of ongoing projects; and they are also used to monitor progresses, which helps ensure QLG resources are used

optimally and assess the current risks of a project.

The updates collected twice per year through these follow-up forms are presented to the QLG by the PMDC chairs in plenary.

Once a QLG funded project is completed

Once a project is completed the PMDC staff will contact the PI(s) to ask for a copy of the final locked database, protocol and relevant forms. This is already being done for modules and it applies also to non-modules; in a nutshell, to everything that is QLG funded. It is important that the QLG has a copy of these documents for quality assurance, possible future audits and data requests.

Deborah and Jaap's term as PMDC chairs has come to an end. It is their hope that the processes they have set-up with the rest of the PMDC (Hans-Henning Flechtner, Eva Greimel, Andrew Bottomley, Madeline Pe and Francesca Martinelli) have brought the QLG one step closer to improved clarity, transparency, efficiency, quality assurance and, last but not least, good collaboration.

KEEP CALM AND KEEP RESEARCHING!

The renewal of the EORTC main website



Anne-Sophie Darlington, Web Representative
Melodie Cherton, Web Administrator

It was time for us to update and improve our communication and information strategy as a group, and therefore we decided to renew our website. This work has coincided with the renewal of the main EORTC website, and we were able to ensure that many of the features of the two new websites are similar, which will reinforce our strong liaison within the EORTC..

The current QLG website is well visited and is the main interface between our Group and academic/commercial users. However with the changing landscape we are noticing that 1) the number of visits to our website is increasing each year, 2) our group is constantly growing and welcoming new members from all over the world 3) our last Quality of Life conference was a huge success, 4) our meetings are very well attended and 5) there are rapid technological changes. This has led us to review our communications approach and actioned us to seriously redesign our QLG website.

Having been responsible this last 5 years for the maintenance of the QLG website and its development, we (Mélodie Cherton, QLD executive assistant and web administrator & Anne-Sophie Darlington, EC Web Representative) in a joint effort with Frédéric Rince, EORTC's webmaster, the IT Department, and the website development external company, we have engaged in a re-think of the website's functionality, to optimize the user's visit.

In order to align with the EORTC main website, while keeping our identity both in terms of the visual aspects and content, we have revamped our QLG website, giving more prominence to Questionnaires, the Item Library and Events which are now on top of the homepage and

creating an "in the spotlight" box to be able to promote some of our most exciting work on the webpage. This box can display different information depending on our needs.

The new QLG website will have a new design but most importantly will be more user-friendly, more intuitive and will give a better user experience, as all audiences (academics, commercial and patients) will be able to quickly identify the information they are looking for.

The website will be launched at our Spring meeting in Paris (2018) giving QLG members the opportunity to provide feedback.

Once the QLG website is live please do not hesitate to contact us to give feedback or suggestions or with any news which you would like to see posted on the site.



The CHES Platform – Update: Grant Report and Patient Portal

An Electronic Data Collection Infrastructure for EORTC Quality of Life Group (QLG) Projects: <https://ches.eortc.be/>

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Lisa M. Wintner, MSc, Department of Psychiatry, Psychotherapy and Psychosomatics Medical University of Innsbruck

For several years now, the CHES software accompanies the QLG and next to Austrian public funding, it has also received financial support from the QLG. In December 2017, a final grant report was submitted to the EC, illustrating that the two aims of the IT infrastructure grant (March 2015 – March 2018, i.p. providing and maintaining a versatile electronic data collection tool for QLG phase III and IV studies and a demo tool for EORTC CAT measures facilitating their dissemination) have been completely fulfilled.

Since autumn 2016, a master agreement signed by the EORTC HQ and the company ESD ensures the free and unrestricted use of the software for QLG members within QLG-funded studies for the duration of the grant period. Along with that, all data previously collected with CHES has been transferred to the EORTC servers until July 2017, where all data collected with CHES in EORTC QLG studies is securely stored since then. Maintenance services are split between IT personnel from the EORTC Headquarters (servers) and IT specialists of the CHES team (active CHES instances).

Currently, the CHES platform services 12 ongoing projects (7 with ongoing data collection and 5 being presently set up, see Table 1), including international collaborations with more than 40 centres in 19 countries, providing 20 available EORTC questionnaires in more than 15 languages. So far, CHES is mentioned in two publications of QLG phase IV studies, which used CHES for data collection

(breast reconstruction[1] and testicular cancer [submitted]).

Table 1 EORTC QLG studies using the CHES platform (ongoing and being set up)

DATA COLLECTION WITH THE CHES PLATFORM	
ONGOING	SET UP
QLQ-HL27	QLQ-ANL27
QLQ-NHL-HG29	QLQ-BR23 (ePRO only, no sCRFs)
QLQ-NHL-LG20	
QLQ-CLL17	QLQ-VU34
QLQ-CML24	EORTC CAT measures and comparator PRO measures
QLQ-COMU26	
QLQ-C30, QLQ-CAT (thresholds clinical relevance)	QLU-C10D
QLQ-CAT	
QLQ-C30 response scale	
QLQ-CAX24	

Device independence of the CHES platform – full compatibility with mobile devices

The CHES platform can be used with any given internet-ready device, as the screen size is automatically identified and the appropriate design presented. This feature is useful for both scientific/professional users and patients: irrespective of the given device, the CHES platform can be accessed to manage data, prepare assessments or complete questionnaires (see Figure 1).

In this way, resources can be preserved, as at clinical settings already available devices can be used or (especially out-) patients can be encouraged to complete EORTC measures

at their own devices for home monitoring or assessments at clinical sites (corresponding to the Bring-your-own-device concept).

Potentials of a patient portal

Including a versatile patient portal, the CHES platform offers a range of possibilities and potential areas of use. A new study highlights that lymphoma patients are interested to see their own QOL results (as reported assessed with the QLQ-C30) and that they are keen to having access to reference values. The study provided such of other patients of the same diagnosis group and the general population, age- and sex-matched respectively [2]. The CHES platform provides such information to patients via the patient portal as well. Using newly established thresholds for clinical relevance [3] and traffic lights colouring, the QLQ-C30 scores are presented as bar charts, indicating if they are below, tending to exceed or exceeding the cut-offs (see Figure 2). As many patients seek advice and want to know what they can do, the system also provides the possibility to link patients' scores to self-help advice. It is even possible to distinguish between advice for scores tending to exceed and those actually exceeding cut-offs. Next to the benefit of enabling patient-centred and individualized care, one might



Figure 1 Full compatibility with mobile devices



Figure 2 Display of patients' results (left) and self-help advice according to QLQ-C30 scales (right)

assume that patients are more motivated to take part in follow-up assessments, if they receive information interesting for and relevant to them. Educational and self-help content can act as an incentive to keep patients completing assessments and by doing so improving long-term participation rates.

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The Item Library Sets Sails

Dagmara Kuliš, Translation Team Leader, Quality of Life Department, EORTC, Brussels, Belgium

Claire Piccinin, Researcher, Quality of Life Department, EORTC, Brussels, Belgium

2017 was a busy and important year for the EORTC Item Library and our group's new strategy. The first half of the year was spent on the technical development and thorough testing of the Item Library's new features, while the second half focused on its launch and utilization, and the early stages of methodological research.

The first phase of official launch came in September with the Kiel Group Meeting. The Item Library was presented in the program every single day – from the very well attended Wednesday workshop (thank you for very active participation!), through the Thursday parallel session and the Friday plenary update and discussion. The active participation in the discussions showed how important the new strategy and the Item Library are to the members of our Group. Importantly, we also introduced our new Item Library researcher, Claire Piccinin, who has joined the Quality of Life Department for a 4-year research position.

The big official launch of the Item Library took place on the 25th of October 2017. It was accompanied by a press release on the EORTC.org website, which was also circulated on social media. As a result, in the first few weeks after the launch we experienced considerable interest from new users, both academic and commercial.

In November, we presented the new strategy as a poster at the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Europe meeting in Glasgow, UK. In the Autumn, we were also working on other publications, such as manuals for use of the Item Library and a paper on the new strategy. The first manual – on the technical aspects of the Item Library – has recently been published online and is available on the QLG's website. The second manual, which focuses more on scientific and methodological guidelines, is currently in the works and will be updated regularly, as research on the Item Library evolves.

In 2018, we will be focusing on furthering research and publications. So far, the main areas have been content analysis and cross-mapping of the Item Library items with the PRO CTC-AE and CTC-AE systems. The primary focus now is to publish the new strategy paper in order to demonstrate how the Item Library fits into the scope of the broader strategy and how it can be used to supplement existing EORTC questionnaires. Content analysis and cross-mapping will then allow us to have a better picture of what the Item Library has to offer as well as any possible gaps that may need addressing.

Each user and each new item list bring with them new questions that must be addressed, which is why we have been recording all of these issues as a list of research topics and possible improvements to the Item Library. These questions and issues are then incorporated into our technical and content guidelines, and – in the future – the next phases of online platform development. As item lists are implemented in clinical trials, we will continue to follow-up with users so that we can see how they are being used, from the early phases of study design through to implementation and analysis. Hopefully, these efforts will enable us to keep the Item Library a modern, dynamic, and user-friendly tool that corresponds to the needs of our users.



Setting International Standards in the Analyzing Patient-Reported Outcomes and Quality of Life data

Lien Dorme¹, Madeline Pe², Corneel Coens³ and Andrew Bottomley⁴

- 1 Fellow
- 2 Specialist in Quality of Life
- 3 Statistician
- 4 Head of the QLD



Health-related quality of life (HRQOL) and other patient-reported outcomes (PROs) have become important endpoints in cancer research. However, the lack of consensus on how to analyze HRQOL/PRO data in cancer clinical trials make it difficult to compare results across trials. The Setting International Standards in the Analyzing Patient-Reported Outcomes and Quality of Life data (SISAQOL) Consortium was set up to standardize the analysis HRQOL/PRO data in cancer randomized trials.

In 2016, a kick-off meeting at the EORTC headquarters marked the beginning of SISAQOL. In 2017, a second consensus meeting in Amsterdam was set-up to discuss concrete strategies for addressing the lack of standards for analyzing HRQOL and other PRO data. A key focus of this meeting was to set the priorities and actions for the year to

ensure that SISAQOL could achieve its future objectives of producing internationally recognized guidelines. Three multidisciplinary working groups were set-up: the research objectives working group, statistical methods working group and the missing data working group. These three working groups will join forces to work on three SISAQOL priorities: (1) generating a taxonomy of research objectives; (2) matching research objectives with appropriate statistical methods; and (3) developing recommendations for the appropriate handling of missing data.

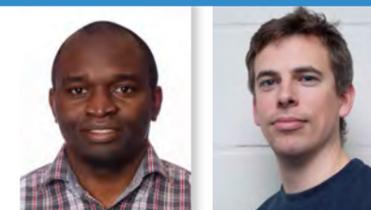
Because of the growing amount of work and interest in SISAQOL, a new fellow, Lien Dorme, has joined the team to assist Andrew Bottomley, Corneel Coens and Madeline Pe in leading the SISAQOL consortium.

The consortium is currently working on an initial draft of the taxonomy of research

objectives, and standardizing definitions of common research objectives. Furthermore, the consortium identified crucial statistical terms where no consensus definitions are available; work towards standardizing these terms is on-going.

It is clear from the discussions that there is a strong commitment from the consortium to tackle the current problems in analyzing HRQOL/PRO data in cancer clinical trials. Members of the SISAQOL consortium have a shared interest in working together to develop a set of standards, best practices, and tools for the analysis and interpretation of HRQOL and other patient-reported outcome endpoints in cancer clinical trials.

For more information about SISAQOL, please visit www.eortc.org/sisaqol



MID Project

Led by Jammbe Musoro and Corneel Coens, This is an international collaborative project with a methodological and a clinical advisory board.

As patient assessment of health-related quality of life (HRQOL) in cancer clinical trials has increased over the years, so has the need to attach meaningful interpretations to aggregated HRQOL scores, and investigate whether differences in HRQOL scores between groups or within-patient changes in HRQOL over time. Determining what represents a minimally important difference (MID) in HRQOL scores is useful to clinicians, patients and researchers, and can be used as a benchmark for assessing the success of a healthcare intervention (e.g., a new treatment) or the design of future clinical trials (e.g., determining sample sizes).

The aim of this project is to establish MIDs for all QLQ-C30 scales according to cancer sites, using individual patient data from archived EORTC trials. The project focuses on the anchor-based approach and relies on constructing clinical anchors using available clinical variables. A disease-oriented and methodological panel provide independent guidance on anchor selection. The project will also examine how the estimated MIDs compare with previously published guidelines, hence further contributing to robust MID guidelines for the EORTC QLQ-C30. The project is funded by an unrestricted academic grant from the EORTC Quality of Life Group.

The first findings from the MID project were presented at the ISOQOL 23rd Annual Conference in Copenhagen, Denmark (October 2016). Recently, we gave two presentations at ISOQOL 24th Annual Conference in Philadelphia, USA (October 2017) where more findings on constructing clinical anchors as well as the results from melanoma studies were presented. We have also just published a paper that gives an overview of the general goals of the project and highlights the various methodological considerations for the MID project. For more information please visit: <http://bmjopen.bmj.com/cgi/content/full/bmjopen-2017-019117?ijkey=2Ba3lUuizgZ0OmN&keytype=ref>

The project is in its final phase which entails mainly performing final analysis and drafting manuscripts for publications. A manuscript on MIDs for adjuvant melanoma is in preparation. This will be followed by the publication of other disease specific MIDs e.g., head and neck, breast and prostate cancer.



Survivorship

Marieke van Leeuwen, Netherlands Cancer Institute, Amsterdam, The Netherlands

The number of cancer survivors is growing steadily and increasingly, clinical trials are being designed to include long-term follow-up to assess not only survival, but also late effects and health related quality of life (HRQOL). The primary objective of this project is to incorporate survivorship into the EORTC QLG strategy to accommodate the increased research interest in the HRQOL of cancer survivors.

In phase I of this project we reviewed 134 publications on cancer survivorship and interviewed 117 disease-free cancer survivors with 11 different types of cancer across 14 countries in Europe to generate an exhaustive, provisional list of HRQOL issues relevant to cancer survivors. The resulting issue list, the EORTC core questionnaire (QLQ-C30), and site-specific questionnaire modules were reviewed by a second group of 458 survivors.

Based on the responses of the survivors in Phase II we developed a provisional survivorship core questionnaire, the QLQ-SURV111, and three site-specific survivorship modules, the BR-SURV31, the CR-SURV34, and the PR-SURV30, for respectively breast, colorectal and prostate cancer survivors. The QLQ-SURV111 includes the items and scales of the QLQ-C30 to ensure continuity in the evaluation of different scales over time (from the moment of diagnosis using the QLQ-C30 until long-term survivorship). Exceptions are the following scales: Nausea/vomiting, appetite loss, constipation, and diarrhea, that are included in the C30 but are not included in the QLQ-SURV111. The items assessing gastrointestinal symptoms (constipation and diarrhea) will be included in the relevant cancer-site specific survivorship modules, like the CR-SURV34 and PR-SURV30. Further, additional items are included in the physical functioning, sleep problem, fatigue, cognitive functioning, and role limitations scales to improve measurement precision. Specific scales and items are added addressing survivorship issues, including fear of recurrence, health awareness, posttraumatic growth, and physical complaints related to chronic side effects of cancer treatment (e.g. Raynaud symptoms).

The site-specific survivorship modules consist of the items of the site-specific modules supplemented with the site-specific survivorship items. We are now in the middle of phase III, the pretesting of the questionnaires. In this phase, the final selection of items will take place. We aim to develop a core questionnaire of 50 items maximum. The core questionnaire will be administered to 400 survivors, and each of the site-specific survivorship modules to 80 survivors, stratified by time since completion of treatment (between 1 and 10 years earlier). Currently, collaborators from 21 countries are participating in our project. We expect to complete phase III in the summer of 2019.

Development of a module to supplement the EORTC Core instrument for the assessment of Health Related Quality of Life in Adolescents and Young Adults



Led by Associate Professor Anne Sophie Darlington¹
and Coordinated by Dr Samantha Sodergren²

^{1,2}; Faculty of Health Sciences, University of Southampton, UK

Health related quality of life (HRQoL) assessment of adolescents and young adults (AYAs) with cancer is especially relevant as, compared with children and older adults, this group is regarded as particularly vulnerable. The epidemiology of cancer in this group differs from other age groups. While cancer in AYAs is relatively rare, its incidence is increasing and is higher than that in children¹. Cancer types in this age group are less prevalent in other age groups and there is evidence to suggest that survival outcomes for some cancers in this group have not improved in line with figures achieved for paediatric or older adult groups². In addition, irrespective of a cancer diagnosis, AYAs find themselves having to negotiate complex developmental challenges.³

Working within the framework of EORTC QLQ module development guidelines, the AYA study looks at the optimal way of measuring HRQoL in a younger population with cancer. The initial study was designed to capture HRQoL issues of AYAs undergoing treatment and receiving palliative care for cancer and identify whether the EORTC QLQ-C30 or other existing measures capture these issues or whether an AYA-specific module is required. In Phase 1, AYAs were defined as aged between 14-25 years which, at the time, was in line with UK AYA service provision.

As with other module development work, we started by generating relevant HRQoL issues from systematically reviewing the literature⁴ and conducting semi-structured interviews

with 45 AYAs from 7 research centres covering France, Israel, Norway, Poland, the Netherlands and UK. Activity limitations such as interrupted education, inability to work and participation in hobbies and leisure time activities were particularly prevalent (87% of those interviewed), in addition 91% talked about the social impact in terms of isolation from peers and difficulties with intimate relationships. A separate group of 33 AYAs and 8 Health Care Professionals involved in the care of AYAs were then asked to review the relevance and importance of the list of 77 issues covering the following themes: Symptoms, Activity limitations, Disrupted life plans, Social, Emotional, Body image, Self-appraisals, Outlook on life, Lifestyle, Treatment-related, Fertility, and Financial. Inspired by the development of the Elderly module⁵, we also carried out age comparisons by inviting 25 patients from two older adult cancer cohorts (26-50 years and 51-60 years) to review the list.

A number of issues were rated as more important to AYAs, including loss of friends, interrupted education, greater motivation to achieve academic and personal goals, boredom and lack of age appropriate education. In addition, some issues were specific only to the "older" AYAs (19-25 year olds) and included change in living situation (i.e., having to move back home with parents).

We also invited leading International experts in AYA oncology to provide feedback on our research which then shaped the following

recommendations to the EORTC QLQ: (1) The EORTC QLQ-C30 is acceptable for use with AYAs; (2) There is a rationale for developing an AYA-specific HRQoL questionnaire. We envisage that there will be a core AYA measure with separate age-specific questions; and (3) there is merit in extending the age range of AYAs to include patients up to 39 years which will align our work more closely with International AYA oncology work and this will require additional qualitative work (Phase 1a interviews) to identify the specific issues for 26-39 year olds.

The Phase 1 module report has been approved by the EORTC QLQ and the recommendations from this work were formally presented at the Autumn EORTC QLQ meeting in Kiel. Our Phase 2 and 3 work will be carried out with AYAs aged 14-39 years and will involve generating AYA-specific HRQoL questions. We will continue to work closely with the EORTC QLQ survivorship research team. In addition, we have been liaising with the EORTC Children's Leukemia Group as well as the UK National Cancer Research Institute Teenage and Young Adult Health Services Research Group and the European Research and Innovation Network for Teenage and Young Adult Cancer.

We are delighted that new research centres from Australia, Denmark and Germany have expressed an interest in collaborating with us on the next phase of work and we welcome any additional collaborators who wish to join us.

If you would like more information about the AYA module development work or if you are interested in becoming a collaborator, please contact either Anne Sophie Darlington (A.Darlington@soton.ac.uk) or Samantha Sodergren (S.C.Sodergren@soton.ac.uk).

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Clinical validation of the EORTC CAT – an update

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The EORTC Quality of Life Group has developed a CAT (computerized adaptive testing) version of the core questionnaire, the EORTC QLQ-C30. The EORTC CAT includes item banks for the 14 QLQ-C30 symptom and functional domains. The banks comprise between 7 and 34 items each and a total of 260 items.

CAT measurement adapts the questionnaire to the individual patient by using the responses to the previously asked items to select the most informative next item, and has increased measurement precision compared to standard, static questionnaires. This means studies using CAT may include fewer patients without losing power.

This significant theoretical advantage of CAT is currently being tested in a large, clinical validation study comparing the EORTC CAT and the QLQ-C30 in independent data. Study participants are assessed twice, before and after chemotherapy / radiotherapy. The study design allows for assessing the ability to detect both expected group differences (sensitivity) and changes over time (responsiveness).

The validation includes a mixed sample of cancer patients coming from eight European countries. Currently (December 2017), about 650 patients have been included. The plan is to close the data collection in the beginning of 2018. When the analyses have been completed, the EORTC CAT will be released as a validated EORTC instrument. The current version is available for use with the understanding that the validation may result in minor refinements of the instrument (for further details see <http://groups.eortc.be/qol/eortc-cat>). The item banks may also be used to construct customised static questionnaires, so called short forms. Short forms for physical and role function have already been made. Please contact the authors if you are considering using a customised short-form (morten.aagaard.petersen@regionh.dk).

The EORTC QLQ has developed software for conducting online CAT assessment and for selecting items for short forms. A significant update of this software has just been initiated and is expected to be fully developed by the end of 2018.



Patients are Experts

Susanne Singer, Mainz, Germany

Patients are experts. They are experts for their disease and for the treatment they have received. They are experts because they have experienced all this. For this reason, the EORTC QLG involves patients in all phases of the module developments on a regular basis. However, until now, their role was mainly to tell us what quality of life issues are important to them and how frequently and with what intensity they experienced a certain problem.

Can we go beyond that? Yes, we can. We can involve patients more closely in two main areas of research: 1) in study planning and 2) in interpreting its results. Patients can help to define a research question that is relevant to their needs and they can comment on the study design.

During the development of the Thyroid Cancer Module, we had good experiences with both.

First of all, the impulse to start this module came from a patient: It was at a nuclear medicine conference in Leipzig, Germany. I had been asked to give a talk on quality of life and psychosocial issues of thyroid cancer patients. At first, I was reluctant because I had little clinical experience with thyroid cancer patients, but eventually I agreed to share my sparse knowledge. During the discussion, a patient raised her arm. She said it was so frustrating that everybody thought thyroid cancer was the „easy cancer“ and that nobody seemed to care about their anxieties and needs. In that moment, I decided something should be changed, and I started working on the thyroid cancer module. Secondly, we presented the results of the phase I study at a national patient conference in Germany and the attendants discussed the findings intensively. Subsequently, the director of the German Association of Thyroid Cancer

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Quality-of-life Priorities in Patients with Thyroid Cancer: A Multinational European Organisation for Research and Treatment of Cancer Phase I Study

Susanne Singer,¹ Olga Husson,² Iwona M. Tomaszewska,³ Laura D. Locati,⁴ Naomi Kiyota,⁵ Ulrike Scheidemann-Wesp,¹ Dirk Ofmeister,⁶ Melanie Winterbotham,⁷ Christine Brannan,⁷ Cláudia Araújo,⁸ Eva M. Gamper,⁹ Dagmara Kulis,¹⁰ Harald Rimmele,¹¹ Guy Andry,¹² and Lisa Licitra⁴
on behalf of the EORTC Quality of Life Group, the EORTC Head and Neck Cancer Group, and the EORTC Endocrine Task Force

Patients (Bundesverband Schilddrüsenkrebs, Ohne Schilddrüse leben e.V.), Harald Rimmele, was a co-author of the phase I paper. Now, at the start of phase IV, he reviewed our study protocol and gave very helpful feedback. Just as an example: The standard patient consent form for phase IV studies includes - according to our EORTC template - the statement "The EORTC Quality of Life Group can use my data (without my name, address or other information that could identify me) for secondary purposes and other studies and store them in their data repository." He suggested to separate this from the rest of the agreement so that patients can agree to participate in the study without agreeing to use their data for undefined further studies. We think this is indeed a good point and it could be applied to other phase IV studies as well. He also pointed our interest towards some HRQOL problems of patients with medullary thyroid cancer. In summary, we found it very helpful to have a patient representative involved on a more "advanced" level of study planning and interpretation of results.

Some of the prerequisites for such a procedure are in my view:

- The patient representative has the time and motivation to be involved.
- The patient representative speaks English well enough.

- The patient representative is at least a bit experienced with research so that he or she can understand our documents (study protocol, papers, etc.) and comment on them.
- It should not be a one-way procedure. The principal investigators must be willing to attend patient conferences and share research ideas and results with them.

Finally, are patients interested in such things? What are their needs and wishes towards us? Let's hear what they say:

Commentary of Harald Rimmele:

I would like to be involved as early as possible. And, personally, I would like to have more time (work overload), also to be able to discuss some of the research questions within our Association.

I was happy to help, but the comment that you mentioned in this text as an example could have been provided by a data protection officer as well.

I participated because "patients can help to define a research question that is relevant to their needs and they can comment on the study design." I feel that my contribution here was only minor.



EGAM: a bridge between the different EORTC groups?

Linda Dirven, PhD, (1) Leiden University Medical Center in Leiden and (2) Haaglanden Medical Center in The Hague.

The EORTC Groups Annual Meeting (EGAM) provides members of the different EORTC groups the opportunity to contribute to the joint scientific activities of the EORTC, e.g. setting the research agenda. For the 2017 EGAM meeting, a new format was introduced. Next to the traditional group meetings, several transversal sessions were organised with the objective to develop projects which build on the EORTC assets, and to bring multidisciplinary expertise together through collaborations across EORTC groups. I attended 'Session 3: Bridging clinical research to real-life and outcome research'. The focus of this session was on the infrastructure of the EORTC, which supports cross-tumour research on outcome, real-life effectiveness and survivorship of cancer patients. I enjoyed the discussions during this session, combining information on the value and practicability of the EORTC infrastructure with ideas about important outcomes research in cancer patients.

As a member of both the Quality of Life and Brain Tumour Group, EGAM was for me the perfect opportunity to meet with other researchers from the Brain Tumour Group, particularly those of the Brain Tumour Group Quality of Life Committee, to discuss currently ongoing and new projects including health-related quality of life (HRQOL) measurements. As an example, a question from a radiotherapist to look at

the association between radiation volume and HRQOL in low-grade glioma patients, as measured with the EORTC QLQ-C30 and brain tumour module (QLQ-BN20) in a closed EORTC trial, is currently being carried out. Since this Committee is relatively new, I expect that more projects focusing on HRQOL in patients with brain tumours will be initiated.

Although EGAM acts as a bridge for the Quality of Life Group with the Brain Tumour Group, as well as many other EORTC Disease-Oriented Groups (DOG), it is unclear to me if it enhances the collaboration between different DOGs. In my opinion, the collaboration between various DOGs should be strengthened and facilitated to enhance the quality of research. This became clear to me during discussions in the first session of the EORTC Early Career Investigator (ECI) Leadership programme, for which I was selected on behalf of the Quality of Life Group. In this programme, two early career investigators of each DOG were selected to be trained as the EORTC leaders of tomorrow. During a two-year period, participants will attend five in-person sessions that are focused on EORTC-specific themes, such as the EORTC and the industry or EORTC and European policies, as well as on specific leadership attributes. These leadership attributes, such as leading self and others, problem solving and effective communication are taught by

McKinsey & Company. In addition, we will contribute to a range of practical activities, such as observing the EORTC peer review committees or joining conferences. Lastly, we will develop in small teams our view on an important topic for the future of the EORTC, in my case on the EORTC and the pharmaceutical industry, and report this vision to the EORTC Board in 2019. The group discussions on the EORTC as an organisation and participation in the leadership skills sessions, in my opinion, are perfect examples of building a bridge between members of the different DOGs, and are therefore promising for a more cohesive EORTC. I am looking forward to the next sessions of this ECI programme!



Travel Grant awardee My Experience with the EORTC conference

Dr Aanchal Satija, Research Scholar, Department of Onco-anaesthesia and Palliative Medicine, Dr B.R.A, Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi, India

I am a research scholar in the department of Onco-anaesthesia and Palliative Medicine, at All India Institute of Medical Sciences, New Delhi, India.

I have been working on research aspects of issues like spiritual distress, total pain, social concerns and quality of life (QOL) issues for cancer patients. I would like to take this opportunity to express gratitude to the EORTC for awarding me travel grant to attend the 4th International Quality of Life Conference on Symptom Research and Patient Reported Outcomes in Cancer Clinical Trials, held in April 2017 in Brussels, Belgium. This award enabled me to understand the QOL aspects in more depth and with precision. It cultivated skills by virtue of which I could improve patients' overall QOL and improve care delivered to them. Talks by visionary leaders enabled me to obtain educational competency by understanding the fundamentals of QOL, develop both personal and professional qualities, skills and attributes required for the effective practice, training on QOL methodology and patient reported outcomes, obtain guidance for interpreting and reporting QOL, learn ways to measure and improve patients' QOL in difficult situations, discover advancements in the field of QOL and patient reported outcomes, learn the knowledge, attitudes and skills required to foster timely and efficient communication with patients, learn to develop and promote clinical and educational programs and, learn and manage challenges in cancer-related education and research. I realized the need and scope of expansion of QOL concerns in the field of

palliative care which can be actively taken up by young people like me. I was informed about the support and opportunities provided by the EORTC group like education tools, journals, grants etc. It was an overall wonderful learning experience whereby I could get direct guidance from experts in the field of QOL. It inspired

me to work more meticulously and spread the knowledge gained amongst peers. I express my heartfelt gratitude to the organisation for sharing the valuable knowledge and enhancing my skills which could not have been possible without the generous travel grant.



EORTC QLG Meeting Autumn 2017 in Kiel

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What better place to set sail and face the unknown than one of the biggest harbours in Germany?

As four newcomers to the group and the department, some of us arrived a few months earlier and others as recently as a few days, we brought with us very different backgrounds and expectations. Arriving late on a rainy night, we found precisely what we had pictured for a seaside town in northern Germany: cruise ships, containers, docks, and a maritime climate. What surprised us though was another side of Kiel we had not expected, having never before visited the city: a rich history, warm inhabitants, picturesque alleyways, parks, cafés, and a lovely seafront, all within walking distance of our hotel and meeting point! Some of us decided to enjoy our free time before the meeting started by exploring Kiel and we were not disappointed by what we saw!

Kicking off the meeting with workshops created a smaller platform in which to interact with members and to start to learn more about the people that make the Quality of Life Group what it is. From the very beginning of these workshops, we were greeted with warm smiles in an enthusiastic and welcoming environment. We were able to dig deeper into certain projects and initiatives (like the Item Library and Item Response Theory), participating in hands-on activities under the guidance of our fellow group members. Being able to work closely with others in a smaller setting proved to be an excellent icebreaker and we quickly became comfortable interacting with the others as we learned more about the group's projects and goals.

The Quality of Life Department and the EC work very closely together, so it was a real treat to meet many members face-to-face



for the first time over a lovely shared meal during our evening at "Kieler Kaufman". As time passed, we got to know more group members even better during the many incredible social events that were planned. Sailing down the famous Kiel Canal on the steamboat "Frey" and witnessing the amazing volume of maritime traffic was a huge highlight, as was the moment when we literally saw our buffet dinner rise up from beneath us! The guided museum tours offered us the chance to learn more about Kiel's marine research, as well as its pharmacy/medical history, which was particularly interesting for those of us with a liking for the slightly gruesome!

In addition to the lively and stimulating discussions we participated in during parallel and plenary sessions, we also enjoyed exchanging ideas for projects and long-term group ambitions whenever we had the chance, which was sometimes late at night or on the rooftop bar! And the more we talked with people, the more passion and resolve we discovered. When you take the time to talk and learn more about the people behind the

scenes, you really start to realize how much time, work and effort is put into these projects. This was also very true for the whole Kiel team lead by Claudia Schmalz that made sure everything ran smoothly! The organization was truly amazing and we were thrilled to get our dose of "Vitamin Sea"!

In difficult times and occasionally rough seas, during which doubt arises, we are reminded of our common goals, shared agendas, and unity as a group. In addition to our training and planning, we also took the time to remember members and friends who had left us too soon, and whose memories will continue to inspire our work. It was a great experience to be with so many people with shared goals, who are prepared to face challenges not as individuals but as a group. Kiel is a prime example and metaphor for the Quality of Life group as it has faced storms and unfriendly seas but this has never stopped its ships from setting sail. We are so happy to be part of the crew and we look forward to moving ahead and seeing you all again in Paris!

EORTC QLQ Meeting Autumn 2017 in Kiel



Welcome to EORTC QLG Autumn meeting in Opatija, Croatia



Karin Kuljanic, Department of Psychology and Department of Gynecology and Obstetrics, University Hospital Center Rijeka, University of Rijeka, Croatia

Duska Petranovic, Department of Hematology, University Hospital Center Rijeka, Medical Faculty University of Rijeka, Croatia

If 150 years ago, you were a doctor somewhere in Europe, you would probably prescribe a trip to Opatija to your patients as a cure for a variety of illnesses.

pinias, rosemary, tamaris, laureus and camellias. The last one is a symbol of Opatija, and you can see one of the rarest Camellias among more than 150 plants from all over the world in the beautiful horticultural monument of Angiolina Park, the central Opatija's park with the oldest building in Opatija, the Church of St. Jakov, famous Villa Angiolina and Music Pavillion (picture 2).

wine and music. We are partly depending on the weather, but we do hope that you will enjoy a warm Mediterranean night under open skies, looking at the stars and listening to the waves, during your gala dinner in the Hotel Royal next to the Congress Center.

Following this spirit, on behalf of the EORTC QoL group you are cordially invited to spend a few working and pleasant days in the Kvarner region of Croatia, along the shores of the Adriatic coast, getting away from all the stress and the strains of modern day life.



Picture 1. Lungo mare

Opatija has been known as the world-class wellness centre for centuries, and many famous people have declared themselves as friends of Opatija. We hope that during your stay you will become one of them. As you will walk through the same parks and swim in the same sea as Emperor Franz Joseph, dr Theodor Billoth, dr Rudolf Virchow, Isadora Duncan and many others did, hopefully you will manage to embrace the joys of past, present and future pleasures. At every step, you will find tracks of outstanding contributors in the field of science, culture, art and sports. On the coastal promenade in Slatina you will see Opatija's Walk of Fame: the 32 stars of famous Croatian people whose achievements have helped spread the word about Croatia throughout the world.

"Camellia" is also the name of the restaurant and the lobby at our EORTC QLG meeting venue in Grand Hotel 4 Opatijska cvijeta (meaning four flowers of Opatija) where you will taste Croatian traditional autochthone cuisine. Our working sections will be held under the same roof, within the "Tamaris" Congress Center.

On Friday, we will take a guided tour by bus from Opatija to Rijeka, Croatia's third largest city and main Croatian seaport, a town of interesting history, culture, science and sports. Rijeka has been awarded the prestigious title of the European Capital of Culture 2020 for its program "The Port of Diversity", which promotes the European cultural diversity. During the sightseeing, you will hear some interesting facts like: who invented the necktie, where is the birthplace of the torpedo, how the names of two Croatians appeared on the map of the Moon, why you should wear Morcic jewelry, how many Croatian territories have been declared nature

On Thursday evening, we are planning to stay in Opatija (pictures 3 and 4) and take a glimpse of Opatija during the Habsburg's Monarchy. We will relax together near the sea with good food,

parks, and where the ship Carpathia was going after saving Titanic's survivors? We will end our sightseeing at the Tavern Tarsa known as the "oasis of gastronomic traditions" in the warm atmosphere of our grandmothers' kitchens and accessories that were used a long time ago.

On Saturday morning - for those who plan to stay for one more day - we suggest to join us for a trip around the Istrian peninsula. Istria has been called for a reason "Istra Terra Magica" (Magic land of Istria). You will hear, feel and



Picture 2: Park and Villa Angiolina

taste some of the Istrian specialties (like world famous truffles, teran, prosciutto) and see some special places like the smallest town in the world named Hum (with 30 inhabitants). We will take you to the wine and food roads and you will see some of the famous wine cellars and olive-groves. If you want to escape from everyday work and fill your batteries swimming, taking bike tours, diving, paragliding or just lying under the olive tree listening to the monotonous sound of crickets - you are more than welcome. We are certain that you will enjoy the day.

Opatija is very easy to reach; this Mediterranean oasis is now closer to Central Europe than ever before thanks to its network of new roads. You can, of course, choose other means of transport - a train station, airports and harbors are easily accessible within a 40 kilometers radius. The shuttles provided by local transportation services can be booked in advance. Further information will follow the spring meeting.

We look forward to welcoming you all at the EORTC QLG autumn meeting from 12th to 15th September in Opatija, Croatia.



Picture 3: The symbol of Opatija - Woman with a seagull



Picture 4: Opatija's main sea stroll called Slatina

Next QLG meeting in Paris in Spring 2018



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

Welcome to Paris for the EORTC QLG Spring meeting 2018!

This year, the EORTC QLG is back to its old habits: the organization of one of its meetings in Paris. Indeed, when the group was created in the 1980s and was composed of only about twenty people, this meeting was held each year in the library of the Hôtel Dieu de Paris. The atmosphere of this location transcended a long history of discovery in medicine and care for the ill person. It gave an inspired seriousness to the reflections and discussions on the concept of quality of life and its measurement. (PPT Picture 1 and 2)

The city of Paris has a long medical history, its Faculty of Medicine appointed its first dean in 1267. However, Paris is also the capital of arts and celebrated monuments which recount the history of a 2,000-year-old capital. Moreover, every evening, a special kind of magic takes hold of the city when these majestic architectural sites are illuminated. All this will offer pleasant moments of relaxation aside from the meeting. (other pictures)

This EORTC QLG 2018 Spring meeting is organized by Institut Curie and the French National Platform Quality of Life and Cancer. It will take place at FIAP Jean Monnet (30 rue Cabanis, 75014 Paris; accessed by Glacière Metro, RER B Denfert-Rochereau). After a guided bus sightseeing, a gala dinner is organized on Thursday at the "Brasserie Mollard" (115 rue Saint-Lazare, 75008 Paris).

Institut Curie, founded in 1909 by Marie Curie, comprises three sites (Paris, Saint-Cloud and Orsay), and is a leading player in the fight against cancer, bringing together an internationally-renowned Research Centre and an advanced Hospital Group that provides

care for all types of cancer – including the rarest forms. (PPT Picture 3 and 4)

Created in 2009, the French National Platform Quality of Life and Cancer is composed of a network of 25 research teams, and is certified by the Ligue Nationale Contre le Cancer and supported by the French National Cancer Institut (INCa). It has established links with the EORTC QLG through long-standing satisfaction with care (Anne Brédart) and more recent Q-RECIST (Amélie Anota) research projects.

Looking forward to meeting you in Paris next Spring!

This Spring 2018 EORTC Quality of Life Group meeting is supported by the French National Platform Quality of Life and Cancer, the French National Cancer Institute (INCa), the ARC foundation for Cancer Research and AstraZeneca.



Module overview

As the module developers progress with their projects, this list will change, so please check our webpage for the latest updates: <http://groups.eortc.be/qol/why-do-we-need-modules>

Validated Modules

BONE METASTASES	QLQ-BM22
GASTRIC	QLQ-STO22
BRAIN	QLQ-BN20
NEUROENDOCRINE CARCINOID	QLQ-GINET21
BREAST	QLQ-BR23
HEPATOCELLULAR CARCINOMA	QLQ-HCC18
COLORECTAL	QLQ-CR29
INFORMATION	QLQ-INFO25
CERVICAL	QLQ-CX24
LUNG	QLQ-LC13
ELDERLY CANCER PATIENTS	QLQ-ELD14
MULTIPLE MYELOMA	QLQ-MY20
ENDOMETRIAL	QLQ-EN24
OESOPHAGEAL	QLQ-OES18
CANCER RELATED FATIGUE	QLQ-FA12
OESOPHAGO-GASTRIC	QLQ-OG25
HEAD & NECK	QLQ-H&N35
OVARIAN	QLQ-OV28
COLORECTAL LIVER METASTASES	QLQ-LMC21
PROSTATE	QLQ-PR25
ORAL HEALTH	QLQ-OH15
CHOLANGIOCARCINOMA AND GALLBLADDER CANCER	QLQ-BIL21
BREAST RECONSTRUCTION	QLQ-BRECON23

Modules in Phase IV

CANCER CACHEXIA	QLQ-CAX24
CHRONIC LYMPHOCYTIC LEUKAEMIA	QLQ-CLL17
CHRONIC MYELOID LEUKAEMIA	QLQ-CML24
COMMUNICATION	QLQ-COMU26
HEAD & NECK CANCER	QLQ-H&N43
LUNG CANCER	QLQ-LC29
HIGH GRADE NON-HODGKIN'S LYMPHOMA	QLQ-NHL-HG29
LOW GRADE NON-HODGKIN'S LYMPHOMA	QLQ-NHL-LG20
SEXUAL HEALTH	QLQ-SHQ22
HODGKIN'S LYMPHOMA	QLQ-HL27
ANAL CANCER	QLQ-ANL27
RADIATION PROCTITIS	QLQ-PRT23
SPIRITUAL WELLBEING	QLQ-SWB32
TESTICULAR CANCER	QLQ-TC26

UPDATE OF QLQ-H&N43

UPDATE OF QLQ-LC13

Modules in Phase III

SYMPTOM-BASED QUESTIONNAIRE	
BREAST CANCER	UPDATE OF QLQ-BR23
IADL IN BRAIN TUMOR PATIENTS	
NASOPHARYNGEAL CARCINOMA	QLQ-NPC42

Modules Phase III Completed

CHEMOTHERAPY-INDUCED PERIPHERAL NEUROPATHY	QLQ-CIPN20
MUSCLE INVASIVE BLADDER CANCER	QLQ-BLM30
HIGH-DOSE CHEMOTHERAPY	QLQ-HDC29
MELANOMA	QLQ-MEL38
NON-MUSCLE-INVASIVE BLADDER CANCER	QLQ-NMIBC24
OPHTHALMIC CANCER	QLQ-OPT30
PANCREATIC CANCER	QLQ-PAN26
SATISFACTION WITH CANCER CARE - CORE QUESTIONNAIRE	PATSAT-C33
SATISFACTION WITH OUTPATIENT CANCER CARE	OUT-PATSAT7
THYROID CANCER	QLQ-THY34
VULVA CANCER	QLQ-VU34

Modules in Phase I-II

Adolescents and Young Adults
Hereditary Cancer Predisposition Syndrome
Pancreatic Neuroendocrine Tumor
Spinal Cord Compression
Survivorship

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As part of the EORTC Fellowship Program, we are currently recruiting two QOL research fellows

Learn about patient-reported outcomes and quality of life in cancer clinical studies
by participating in the activities of the Quality of Life department
and being immersed in the activities of an international academic research organization.

More information at: <http://www.eortc.org/education-training/fellowship/>