Dear readers,

The aim of our annual Newsletter is to provide an overview of the activities of the Quality of Life Group of the EORTC, and to function as a “who’s-who” for the Group members, members of other EORTC groups and taskforces, and for the outside world. For that reason, we are happy that we are able to launch this issue right before the 2017 EGAM meeting!

I think this Newsletter demonstrates that the Quality of Life Group (QLG) still is one of the leading groups in quality of life (QoL) research in cancer patients, but also that nothing in life comes for granted. In 2014 the review by the Scientific Advisory Committee (SAC) served as a wake-up call that the group had to further define its position towards the rest of the EORTC. Nobody (at least, not normal people), likes wake-up calls very much but they are necessary every now and then, and the Group took up the challenge through stimulating collaboration with the EORTC disease-oriented groups (DOGs) and platforms, resulting in a considerable number of QLG-funded collaborative projects and strengthened transversal bonds since then.

Late in 2015 another wake-up call emerged as a discussion in several journals and meetings made the QLG (again) realize that this leading position in research into health-related quality of life and other patient-reported outcomes requires continuous maintenance. The outside world is increasingly competitive and we need to continuously adapt our strategy to keep up with it. As dynamic a Group as we are, we again took up the challenge and during that process realized our strengths and particularly that we should show them (I am trying to avoid the rather worn-out term of “unique selling points” here...). This has, for instance, resulted in the Item Library, demonstrating our added value in tailor-made QoL monitoring.

So, never a dull moment in our Group, and you can read about all this in the next 28 pages. I think that this is also the right place to thank our Chair for the past three years, Lonneke van de Poll-Franse, and to welcome our Chair Elect, Fabio Efficace. Lonneke has done an incredible job guiding our group through rough seas, including the wake-up calls mentioned above, and at the same time keeping up the spirit within our Executive Committee and within the Group as a whole. I think many people do not realize that being Chair of this Group is only a little less than a full-time job (and she already has one of those), which is really different from, let’s say, 15 years ago. I know Fabio is fully aware of that, and I wish him all the best!

For now, I want to thank Cheryl Whittaker for her excellent support in editing this Newsletter, which I hope you’ll enjoy reading.

Best,
Jaap Reijneveld
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NEWS

A new term, a new Chair

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

“It will be my honour and a privilege to serve as Chair of such an outstanding research group for the coming years”

I would first like to thank our members for electing me as the next Chair of the EORTC Quality of Life Group. We are a leading research group worldwide that has made remarkable contributions to raise the patient voice in cancer clinical research, and we should be proud of all the achievements we have accomplished over the years of dedicated work. Therefore, it will be my honour and a privilege to serve as Chair of such an outstanding research group for the coming years.

I also would like to thank the current Chair, Lonneke van de Poll-Franse, for the hard work done during the previous years. I am grateful for such a solid foundation to build on and I am happy to continue to rely on her service and support within our Executive Committee.

Our visibility has grown in the international arena and the number of projects we have been leading has substantially increased of late. In parallel, our membership list has also grown significantly, with several new members from various countries and professional backgrounds enthusiastically joining our Group. We are now performing cutting-edge research studies across many different cancer areas, ranging from purely methodological studies to clinically focused projects.

It is my intention, in close collaboration with my excellent colleagues within the Executive Committee, to continue to build closer cooperation with the EORTC disease-oriented groups (DOGs). I am confident this will enhance our portfolio of clinical studies, which will eventually better inform clinical decision-making and make an impact on real-world practice. Going forward, we will make efforts to reach out to other cancer organizations to enrich our activities and to invest in educational initiatives that can continue to attract and educate young scientists.

We will also continue to set aside a reasonable budget to sustain high-quality research studies, through a competitive and fully transparent grant review system. In doing so, we will of course consider the overall strategic objectives of the EORTC Headquarters, work closely with their teams, and adapt our procedures accordingly if needed.

We do have several challenges ahead of us, as the whole arena of patient-reported outcomes measurement in oncology and their application in clinical practice and clinical trials is rapidly changing. Therefore, we must be able to adapt to these changes and successfully adopt strategies that will keep our visibility high in the international arena.

“I firmly believe there is only one way we can achieve these lofty goals, and that is by working together in a positive manner completely focused on doing what is best for our Group as a whole. We all have different areas of interest and expertise, with a remarkable diversity of viewpoints, skills and abilities. I see this as an incredible strength for our Group and I have no doubt at all that we will succeed in facing all the challenges ahead of us by collaborating closely.

I am looking forward to working with all of you over the coming years!”

“We must be able to adapt to these changes and successfully adopt strategies that will keep our visibility high in the international arena”
EORTC Quality of Life Group – facts & figures

Krzysztof Tomaszewski, Jagiellonian University Medical College, Poland

After our 2016 membership update we have 251 members (131 corresponding, 120 active) from all over the world, as you can see below.

A total of 133 members of the EORTC QLG were present at the spring meeting in Oslo (Norway) and 138 at the autumn meeting in Manchester (UK). The graph below shows the quickly increasing number of people registering for the EORTC Quality of Life Group meetings.

HOW CAN I BECOME A FULL ACTIVE MEMBER?

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 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 become a corresponding member.

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

“A new Secretary – opportunities and challenges”

Krzysztof Tomaszewski, Jagiellonian University Medical College, Poland

“This is a great privilege but also a huge challenge – one I will gladly accept”

First of all I would like to once again thank you very much for putting your trust in me and electing me for the position of Quality of Life Group Secretary. Personally, this is a great privilege but also a huge challenge – one I will gladly accept! Looking at the quickly rising numbers of members and non-members registering for our meetings, as well as the growing number of new members joining our Group, I see both opportunities and challenges: opportunities to further widen our network of international collaboration to strengthen both the Group and the work we do, and challenges, as fostering collaboration within such a large group always presents difficulties; however, none that cannot be overcome with good organization.

I want to do as much as possible to serve and support the QLG and its members. I plan to be a proactive Secretary and a good supporter of the members – to help represent your position to the QLG executive and to the EORTC. I promise to devote my time and energy to serve you to the best of my abilities. I am also heavily dedicated to promoting, in Poland, the concept of health-related quality of life and I would like to foster cooperation between our Group and centres in Poland and beyond, such as countries like Lithuania and Ukraine.

I was born and bred in Krakow, Poland. I trained in musculoskeletal tumours and skeletal metastasis, as well as the elderly. I have undertaken several fellowships, at the University of San Diego (USA), the University of Dublin Trinity College (Ireland) and the University of Cambridge/University of Oxford (UK). I am interested in quality of life from both a methodological and clinical perspective.

Finally, for those of you who have not had enough time to speak to me in person, let me say, I am happily married to Iwona, also a QLG member, and a big fan of dogs, yacht sailing, and trekking. We had our first baby, a girl called Zuzia, in January 2016, and Zuzia tells me she may also be a future QLG member!
News from the EORTC Quality of Life Department

Andrew Bottomley, Assistant Director, EORTC, and Head of Quality of Life Department, Brussels, Belgium on behalf of the QLD

Some things are (temporarily) changing

In 2017 a lot of changes are occurring as new temporary staff join the QLD.

Francesca Martinelli, QoL specialist, will be temporarily replaced (for 6 months) by Carmen Peuters. Carmen has a master’s degree in Clinical Psychology and Health Sciences and she will be working closely with Madeline Pe. Mélodie Cherton, Executive Assistant & QoL Web Administrator, will also be out for 6 months for her maternity leave. She is being replaced for those 6 months by Cristina Pilato.

As Mélodie’s temporary replacement, Cristina will take over the maintenance of the website and will be working in close collaboration with the web developer, the EORTC IT Department and the QLD’s Web Representative, Anne-Sophie Darlington. In addition, close liaison with the Secretary of the QLD will be necessary for the online registration for Group meetings. Moreover, Mélodie has trained Cristina to correspond with large academic institutions, for example hospitals and clinics, as well as academic individuals studying throughout the world, for the provision of the QLQ-C30 questionnaire and modules for their academic studies. She will manage all academic download requests – for which, in 2016, there were over 4,300 agreements signed.

Mélodie was already preparing and coordinating the various meetings and conferences of 2017, in liaison with the rest of the Quality of Life Department but also with the Communications and Events office at EORTC HQ. So Cristina will have her work cut out for her... but, as I always say, never come to the QLD expecting a quiet time!

As I predicted in my newsletter article last year, things are indeed getting busier – and there is no sign yet of any change in that respect! But all of the QLD remain at your disposal for any help you might need so do feel free to reach out to us.

2017 QoL Cancer Conference

We have been preparing the ground for the 2017 Quality of Life and Cancer Clinical Trials Conference, 20–21 April 2017 in the Crowne Plaza Brussels – Le Palace. Chaired by myself and Manja Matias (Member of the European Parliament), this conference is free for all attendees and is kindly sponsored by the EORTC, QLD and the EORTC-HQ and other industry partners.

This two-day conference covers a broad range of topics in HRQoL, PROs, Symptom Research and Cancer Clinical Trials and policies. Bringing together 30 senior international PRO leaders, it addresses recent developments of tools as well as other systems for use in clinical trials and provides a platform for discussing international development and research guidelines. The meeting presents an opportunity to meet the developers of EORTC tools as well as EU MEPs, policy-makers and researchers.

The new grant review process

Madeline Pe and Francesca Martinelli/Carmen Peuters are now supporting the QLD to help harmonize the quality assurance policy with that of the EORTC. Additionally they are supporting the needs of the PMDC (Project and Module Development Committee – see p 119) and the GRC (Grant Review Committee). To ensure a smoother and faster process for the QLD grants, they will keep track of the grants as they enter the HQ process, making sure that they go to the right people in a timely manner. The EORTC HQ has also assigned Melanie Boavuso to be the QLD Project Manager and she will help on all HQ-based projects to help ease the workload.

On the commercial side “Business is booming” wouldn’t be an understatement: in 2016 we saw yet another increase on the previous year’s numbers, now reaching a total of 175 agreements signed. Cheryl Whittaker has been doing a great job of co-ordinating the commercial agreements, liaising with the EORTC HQ’s Contracts and Accounting Departments, advising and assisting pharmaceutical companies in obtaining and employing our questionnaires, managing the signature of contracts for trials, as well as for new translation projects, and also doing the dirty work like chasing unpaid invoices. But it’s all to good effect: 2016 was our record year in terms of income since charging for our tools, and the increased revenue from questionnaire licenses means more grant money, and more opportunity for further growth of the QLD.

From the translation team leader

It was another busy year for translations and other translation-related projects. In 2016, we finalized over 70 new language versions of validated questionnaires and prepared over 50 translations needed for Phase III studies. A lot of these projects were quite challenging from both the linguistic and logistical points of view, and the linguistic difficulties of one of them were presented as a poster at the ISOQOL Annual Meeting 2016. With a few interesting ongoing projects, we have now reached a total of 108 different language versions of our core questionnaire, expanding our linguistic coverage even further.

We are also still busy with the Item Library (previously Item Bank – see p 119) Dagmara Kulis presented the current version and the plans for further developments at ISOQOL 2016 and received very good feedback. The Item Library is fully usable as a reference tool for developing new questionnaires, since it includes all the English items developed by the QLD as well as their translations. In order to get access, visit the website: www.eortc/itemlibrary or contact Dagmara Kulis.

Other projects: CODAGLIO

In September, the CODAGLIO (Combining Clinical Trials Datasets in Gliona Patients) project started. This project aims to combine clinical and HRQoL data of all available RCTs in glioma patients. The project is a true collaboration between the members of the QLD, the QLG and the Brain Tumor Group. We currently have access to the data of more than 3,000 patients, and the number is growing. Marjolein Cooman, visiting PhD student from Leiden University Medical Center and VU University Medical Center in Amsterdam, is currently working in the QLD to build the database, learn about the trials and gain experience. She is doing a great job, and the project is going well thanks to the support of the other QLD members who are actively helping on the project.

MID

The QLD is also working with the QLG on other research projects, and in December 2015 started a three-year project on Minimal Important Differences (MID) to look at the clinical significance of QoL tools. The first findings from the MID project were also presented at the 2016 ISOQOL Conference in Copenhagen.

Data Repository

The Data Repository Project is still ongoing and it is an important part of the QA procedure, as requested by the Scientific Audit Committee (SAC). Please don’t hesitate to contact Francesca/Carmen to obtain the standard Protocol Template and CRF for your Phase IV studies, and please don’t be shy in providing a copy of the protocol and of the final dataset once the study has been published.

In Brief:

In October 2016, Dagmara Kulis accepted a position of secretary of the ISOQOL Special Interest Group on Translation. She will serve for two years.

In June 2016, Madeline Pe was awarded an ISOQOL New Investigator/Student Scholarship.

At ISOQOL in October 2016, the EORTC and QLD presented a record 16 abstracts (eight oral, eight poster).

If you have any news to share, we want to hear from you! Please send an email to Cheryl Whittaker.
The Consortium had its first kick-off meeting in The Hilton in Amsterdam in January 2017, which was well attended by members of the Consortium. EORTC Evidence from various systematic reviews on the current state of the analysis of HRQoL and PRO data in cancer clinical trials was presented by Jean-François Hamel. These reviews also paved the way for identifying the statistical issues that need to be standardized. Although many issues need to be urgently addressed, it was agreed that the priority this year would be to broadly match research objectives with statistical methods within the area of cancer randomized controlled trials (lead: EORTC), and to develop recommendations for the appropriate handling of missing data (lead: Mayo Clinic). Moreover, a key discussion point was to broaden the scope of SISAQOL and apply for longer-term funding to further support its work.

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

Expanding the EORTC Quality of Life measurement strategy

Mogens Grønvold, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, and Department of Public Health, University of Copenhagen, Denmark

The same point was recently made by the US Food and Drug Administration (FDA), which pointed out that “static questionnaires” may miss important adverse events, while “item libraries” such as PRO-CTCAE offer more flexibility.

Should we now give up the static questionnaires and go back to the situation where each researcher creates a trial-specific item list?

This was discussed in the plenary session at the Group meeting in OslO in April 2016. The conclusion was that we should certainly NOT give up the successful Core + Module Strategy, BUT that we should start using our Item Library much more actively as a supplement.

A few days after the Oslo meeting I was able to present the first outline of this new strategy at the 7th Annual Patient-Reported Outcomes Workshop of the Patient-Reported Outcome (PRO) Consortium, a partnership established by the Critical Path Institute (C-Path) in cooperation with the FDA, in Washington, DC.

The EORTC Item Library is the new database of all PRO and other PRO data (see the article in the Lancet Oncology: https://www.ncbi.nlm.nih.gov/pubmed/27949796) and presented their work at the 2016 EOCQL Conference in Copenhagen, and the 2017 EOCQL Conference in Amsterdam.

The EORTC Item Library is the new database of all PRO and other PRO data (see the article in the Lancet Oncology: https://www.ncbi.nlm.nih.gov/pubmed/27949796) and presented their work at the 2016 EOCQL Conference in Copenhagen, and the 2017 EOCQL Conference in Amsterdam.

The EORTC Item Library is a huge success with more than 50 modules currently in various stages of development.

In terms of content validity, the Core + Module strategy was a major step forward because the common and frequent symptoms and functional problems (physical and psychosocial), were covered by the QLQ-C30, while the disease-specific module covered the frequent symptoms and functional problems related to the diagnosis and its treatment.

At the same time, it is important to note that the combination of the QLQ-C30 and a disease-specific module does not automatically secure content validity. A new trial may be comparing new treatments having side effects that are not addressed in the QLQ-C30 or the module. This was confirmed in the Symptom-Based Questionnaires Project where systematic reviews of symptoms of targeted therapies were carried out. As the number of new drugs being tested in oncology is rapidly increasing, it will never be possible to keep all modules fully updated.
Moving forward: Procedures for proposing new modules and projects, and establishing the Project and Module Development Committee (PMDC)

Deborah Fitzsimmons1, QLG Module Projects Coordinator, Co-Chair, PMDC
Jaap Reijnjeld2, QLG Non-Module Projects Coordinator, Co-Chair, PMDC

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1 Centre for Health Economics, Swansea University, Swansea, UK
2 Neurologist, Departments of Neurology, VU University Medical Center and Academic Medical Center, Amsterdam, The Netherlands

One of the most widely known areas of work for the Quality of Life Group (QLG) has been in the area of developing questionnaire modules to assess health-related quality of life (QoL) for use in clinical trials and studies. Currently, the QLG has a portfolio of 59 modules, 21 of which have completed the full validation process (Pia et al., see p.37). With the need to reflect changes in the treatment landscape and other innovations, a number of modules (such as lung, breast, and head and neck) are currently being updated. Other developments such as the symptom-based and the QoL module portfolio are being reviewed and will be replaced as priorities emerge in line with the QLG strategy and portfolio as well. The health outcomes research unit which now comprises a young and enthusiastic team of five psychometricians and public health researchers, is being strengthened and the PMDC will play a key role in this process.

A fundamental driver for change is how we make decisions about which projects to invest in. As a Group has been the strategic move by the QLG to fund clinical, methodological and QoL module development projects. This work has culminated in the Executive Committee (EC), including a common set of procedures in managing their respective project portfolios.

This work has culminated in the Executive Committee (EC) approving the establishment of a merged committee – the Projects and Modules Development Committee (PMDC) – formally launched during the spring 2017 QLG meeting. The PMDC will oversee all aspects of new projects undertaken on behalf of the EORTC QLG. A considerable activity for the EC in recent months has been the alignment of our procedures in order to ensure that this fits in with the changing grant review processes. A key requirement is that all projects must have a statement of support from the EC before being submitted as an application for the QLG grant. The projects which are reviewed by the EC have a further immediate effect, anyone with an idea or proposal for developing a project which requests endorsement and/or funding from the QLG will need to adhere to the following procedures.

At the earliest opportunity, the Principal Investigator (PI) for a new project is encouraged to contact the PMDC via the dedicated email (pmdc@eortc.be) to discuss their ideas. This is managed by the Quality of Life Department (QLD) team (Madeline, Carmen and Francesca) who will respond quickly and ensure that the PI is put in contact with the relevant co-chair of the PMDC depending on whether it is a proposal for a module or a non-module project. On receipt of the idea, the proposer will be invited to give a 5–10 minute presentation of their proposal at the PMDC parallel session during the next bi-annual QLG meeting. In addition, the proposer will be asked to complete a short ‘New Project Proposal Form’ and send it to the PMDC. The PMDC parallel sessions are open to all QLG members to attend and the basic idea is that sharing the proposal within the QLG will facilitate the recruitment of collaborators and further improve the quality of the proposal. Discussion will be encouraged and the PMDC will highlight any notes of the wider views expressed. A summary of all new proposals will then be presented by the PMDC chairs at the PMDC meeting during the Friday plenary session. The PMDC will make an initial recommendation to the EC on whether the project should be endorsed or not, and thus be eligible for grant application or not. The PMDC will, in making its recommendation, check: (1) whether the PI is an active member of the QLG; (2) whether the project fits within the QLG portfolio; and (3) whether the project is broadly within budget limits (e.g. within budget available for Phase I–II module development projects). The intention is that the PMDC will make these recommendations on the day with the EC making the final decision within a few weeks following review of the PMDC recommendation. For projects that are thus ‘endorsed’, the PMDC will notify the Chair of the QLG Grant Review Committee (ORC) with a copy of any comments made. The project will then go forward (should a grant application be made) as ‘endorsed’ by the QLG. Where projects are not endorsed, clear reasons will be given. The PI will be able to resubmit their project in the future but this will be treated as a new submission. We expect to notify PI’s of decisions by email within two working weeks of the QLG meeting.

We recognise that this is a new way of working for the QLG. We already know from our piloting of the process that lessons will be learnt along the way and refinement will undoubtedly be required. We are not encouraged through any challenges to ensure it works for all. Of fundamental importance is that this process enables the creation of globally leading research through strong international collaboration within the field of cancer PROs, on behalf of the QLG. We look forward to the work ahead in order the next 12 months!

From bank to library: the EORTC QLG item library

Dagmara Kuliś, Quality of Life Department, EORTC, Brussels, Belgium

H aving developed a revamped and considerably improved database of all items and their translations developed by the Quality of Life Group (QLG) over the years, after the Oslo meeting in April 2016 we focused on turning the current Item Bank into a modern tool that would allow users to customize their questionnaires to better fit the needs of their research. Initially, the Item Bank was merely a reference tool useful to search for existing items covering certain issues, the Item Library adds a whole new layer of user interaction with the items and questionnaires. Depending on their needs, the user can remove items or add new ones from other modules. This way they can create, for example, a symptom checklist that will accompany the official questionnaire and cover side effects of a new drug that is being tested.

Following the launch of the new Item Bank, we saw a great deal of interest in its use, as well as challenges to ensure gaining access flowing in almost daily. It proves that there is a great need for such a database, especially from academic researchers. However, in order to accommodate the needs of our commercial users and the changing regulatory perspective on the use of PRO measures in clinical trials, we had to rethink the functionalities offered by the Item Bank. This is how the Item Library was born.

While the Item Bank was merely a reference tool, in the new Item Library our item database is being used as a platform for searching through language availability of items. We have also added all the CAT item banks, together with the validated translations. When new translations are finalized, they are also added to the Item Library, ensuring the pool of available language versions of PROs on behalf of the QLG. We look forward to the challenges of supporting the EORTC QLG’s present and future translation efforts of the many current and new HRQoL questionnaires.

New Translations Representative of the EORTC QLG Executive Committee

Sandra Nolte, Charité – Universitätsmedizin Berlin, Berlin, Germany

I t is both a pleasure and an honour to introduce myself to you as the new Translations Representative of the EORTC QLG. Thanks to all of you who trusted me with your votes in last year’s election.

By way of brief introduction, I am based in Berlin, Germany where I lead a research group at the Department of Psychosomatic Medicine, Charité – Universitätsmedizin Berlin. Charité is one of Europe’s largest teaching hospitals with over 3,000 beds and 13,200 employees.

I have been working at Charité since mid-2012 when I first established, and then expanded, the Health Outcomes Research Unit which now comprises a young and enthusiastic team of five psychometricians and public health researchers, and an additional group of clinicians who regularly join our weekly departmental meetings to exchange ideas about current and future research projects. The Unit’s focus is the development and validation of health-related quality of life (HRQoL) instruments, using both classical and modern test theory methods, with a special emphasis on computerized adaptive testing.

Our current research projects span instrument development (for example, development and validation of a computer-adaptive test for children, the Kids-CAT), numerous translation projects of HRQoL instruments, interventional studies (for example the EVIDENT trial, a large-scale RCT on the effectiveness of internet-based cognitive behavioural interventions for depressive symptoms), to global health projects such as the Global Burden of Disease Study.

One of the current projects is the CAT project (see p.29) where our unit not only supports the validation study but also heads the European norm data study. At the centre of this exciting project, which takes place in collaboration with a group of co-investigators from Austria, Denmark, Italy, the Netherlands, Poland, and the UK, is the collection of norm data from 15,000 people from the general population, including 13 European countries as well as the USA and Canada.

This project, as well as experience from many past projects on translations for the EORTC and other groups, has already given me a good taste of the many challenges involved in the translation and cultural adaptation of HRQoL instruments. However, knowing that I will get to work with a fantastic team, in particular Dagmara Kuliś from the EORTC Quality of Life Department in Brussels, I very much look forward to taking on the challenge of supporting the EORTC QLG’s present and future translation efforts of the many current and new HRQoL questionnaires.

Naturally, the basic and most important aspect of all new proposals will be to ensure that the item database is kept up to date. The QLG and EORTC Executive Committee (EC) will oversee all aspects of the Item Library and see how it can help you.

From bank to library: the EORTC QLG item library

1 Project refers to any module development, methodological and clinical project that is supported by the EORTC QLG.
The Quality of Life Group (QLG) has a long-standing tradition of engaging with patients to understand the issues that influence their quality of life (QoL) and to make sure that the quality of life instruments we develop are user-friendly and cover the issues that are important to them. Patients are involved in several stages during the questionnaire development process, from finding out how cancer and its treatment impacts on QoL, to assessing which issues are most important and relevant to a given patient group.

It is time for the QLG to engage with patients at more than just the level of input on questionnaire content and format. It is important to emphasize that this should constitute meaningful engagement across the patient voice. Continuous engagement with patient representatives will be able to assist us in shaping strategy, study design and execution, as well as with dissemination and buy-in on a wider level. In addition, patient engagement could be sought around governance. As we are engaging in more studies with the EORTC, clinical groups this input will be even more pertinent. The most important aspect is to embrace the real values of collaboration while at the same time producing relevant outcomes for patients.

In order to start this process we invited a patient representative, Barbara Woroncow, to our Group meeting in Manchester, UK, in September 2016. Barbara participated in interactive sessions and general meetings, and experienced the gathering on many levels, so she was able to feed back some valuable points for the Group to consider.

The need for patients to have some prior knowledge of the activities of the Group and an understanding of the steps in questionnaire development and validation

The need for a clear explanation of terminology throughout the meeting, in lay language, as well as an explanation of acronyms

The need for a clear explanation of the structure of the EORTC, how it is funded, and how it is related to other groups within the organization and more widely

Contributions from patients can be made on several levels: discussions on generic issues, such as structure and socio-economic factors, commenting on documentation, and contributing to general discussions in order to have a patient perspective

The need to feature some relevant experience from a patient representative at local level who has, if possible, some presentation skills.

Most importantly it needs to be clear what the parameters are around their contribution. Making sure that the Group as well as patient representatives understand what is expected, and what status and value these contributions have, will serve everyone best. Finally, Barbara confirmed that she was made to feel welcome, and that she enjoyed the experience and found out the scope of the work that is carried out by the Group.

As a Group we are continuing to build on this work and are actively engaging with the European Cancer Patient Coalition, which has a history of working with the EORTC, and other organizations such as SOPHE, the European Society for Paediatric Oncology, EUROCARE (Rare Diseases Europe), the European Patient’s Forum, PatientView, and EuropaDoma, to explore how we might be able to work together in the future. To be continued!

### Background

The original EORTC QLQ-C30 (now the QLQ-C30) was published in 1988. The conceptual framework was developed by oncologists and researchers according to guidance at that time and was informed by literature, epidemiological studies and clinical experience.

Since its development, the treatment landscape has transformed and toxicity profiles for newer agents may be different to the side effects experienced when the QLQ-C30 was developed. The standards for development of patient-reported outcomes have also changed, with more emphasis now on patient input to support content validity. The US Food and Drug Administration (FDA) defines content validity as evidence from qualitative research demonstrating that the instrument measures the concept of interest including evidence that the items and domains of an instrument are appropriate and comprehensive relative to its intended measurement concept, population, and use.

### Aims

The EORTC QLC-Q30 has been widely used and development of more recent disease-specific modules has included patient input. However, there is little in the literature to support the concept validity of the EORTC QLC-Q30. The aim of this two-year study is to fill this evidence gap. The study is being conducted in two phases: Phase 1 to collate the existing evidence from the development of disease-specific modules, and Phase 2 to conduct patient interviews to confirm whether the existing conceptual framework is still appropriate and comprehensive and the items are relevant and important to patients.

### Phase 1 Results

The Phase 1 results were presented at ISOQOL 2016. Thirty-four module development reports were reviewed. The majority had patient involvement; however, as the QLQ-C30 was not the focus of these studies, there was minimal information in the reports relating to arising concepts already covered in the QLQ-C30. Using the new EORTC Item Library, items from each module were mapped against concepts. The rationale was that concepts common across cancer types could warrant inclusion in the QLQ-C30. Furthermore, if a concept is broadly covered by the QLQ-C30 and assessed more specifically in multiple modules, this supports the existing concept in the QLQ-C30.

The 539 items were grouped into 417 concepts. Nine of these concepts found across ten or more of the disease-specific modules (Figure 1).

The concepts were further grouped into domains, starting with the 15 domains of the core questionnaire and adding new domains as required. Thirteen new domains, i.e. not currently in the QLQ-C30, were defined: general symptoms, sexual function, body image, eating and drinking, side effects, vision, bladder, bowel, dermatological, vaginal, GI, oral health and respiratory.

In summary from Phase 1, we found many of the disease-specific modules cover the same domains as the QLQ-C30 but in more detail or are specific to that disease. Common domains that aren’t currently covered by the QLQ-C30 include sexual function, body image and side effects.

### Next steps

In Phase 2 we will be conducting open-ended interviews with patients in the UK, Poland, Denmark, The Netherlands and Spain. This will generate evidence to support the relevance and understanding of existing items and identify relevant items that are missing from the QLQ-C30. Results from both phases will be discussed with the EORTC Quality of Life Group to consider the evidence for the existing core questionnaire and, given the move towards a more flexible measurement system, any recommendations for additional domains.

### References

Follow-up in gynecological cancer survivors: A collaboration between the EORTC Quality of Life Group (QLG) and the Gynecologic Cancer Group (GCG)

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Gynaecological cancer survivors experience significant levels of distress, often persisting years after completion of treatment. Patients’ main concern is recurrence, especially during the first two to three years after treatment, and they consider regular follow-up visits, and expertise from specialists, to be reassuring. Periodic follow-up aims to: 1) provide psychosocial support, 2) diagnose and treat possible complications following primary treatment, and 3) diagnose recurrent disease early if at least two routine follow-up visits are carried out. These aims have been widely accepted, the value and appropriateness of routine scheduled follow-up visits have been questioned. Additionally there is disagreement as to whether patients with early-stage disease should be followed more or less frequently compared to patients with a major risk of recurrence. There is limited evidence to know whether intensive follow-up schedules with multiple routine diagnostic interventions result in any survival benefit compared to non-intensive follow-up schedules. Several reviews on the value of routine follow-up procedures reached the conclusion that follow-up programmes do not improve survival. Thus, the effectiveness of routine follow-up procedures in terms of survival and quality of life (QoL) need to be redefined.

While survival and detection of early (local) recurrences still remain important for several gynaecological cancers, such as endometrial and cervical cancers, it is insufficient to evaluate the quality of follow-up care based on objective outcomes only. Gynaecological cancer patients are diagnosed in different disease stages and the adverse effects of treatment are different as well. Therefore survivors may not have the same problems and needs regarding follow-up.

Bosely et al1 reported that more than 40% of gynaecological cancer patients had psychosocial needs, including sexual health care needs, that are not adequately addressed during follow-up by their health care professionals.

The integration of the psychosocial domain into the primary care setting is critical for allowing measurement of this aspect of quality of life in chronic myeloid leukemia patients: the QoL-CML24. Indeed, the life expectancy of patients with chronic myeloid leukemia (CML) is five TKIs overall that can be used as second or greater lines of therapy, thus making treatment decision-making more difficult. In addition, we are also happy with the involvement of the CML Advocates Network, the largest CML Patient Association, and we are confident their participation will enrich our work.

Four groups of 324 patients overall will be enrolled patients in first-line therapy with imatinib patients in first-line therapy with any TKI other than imatinib, patients in second or higher line of therapy being resistant or intolerant to first-line therapy, and patients in treatment for at least three years and at least in complete cytogenetic response. Two assessments will be performed in order to evaluate the scale structure of the QoL-CML24, the test-retest reliability and internal consistency, and the analysis of the responsiveness to change.

We are now eager to conclude accrual soon and present data at major international conferences. Also, we expect our results will significantly contribute to improving healthcare delivery in CML and will facilitate the decision-making process.

References
Major advances have been made in the treatment of cancer, with a remarkable number of new drugs approved between 2012 and 2013 by the US Food and Drug Administration (FDA).

Many of these clinical achievements stem from randomized controlled trials (RCTs) that are the gold standard with which health care professionals and policy-makers make decisions regarding treatment effectiveness. Over the last 20 years, the number of trials that assess patient-reported outcomes (PROs) has increased substantially. In 2009, the FDA issued the first draft Guidance for Industry on Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. This FDA publication has led to widespread discussion about domains of PROs that should be considered as endpoints in RCTs. Indeed, PROs include a wide spectrum of measures, ranging from single-item instruments assessing a specific health domain (e.g., pain or fatigue) to broader multidimensional constructs such as quality of life (QoL). For example, it has been suggested that inclusion of symptom reports only, in RCT settings, “may provide data sufficient to make decisions about the value of a therapy or to allow judgment about the relative value of one therapy compared with another.”

Our IORTQ Quality of Life Group (QoL) has already greatly contributed to a better understanding of the methodological barriers to using PRO endpoints effectively in RCTs, and has provided guidance on QoL design in study protocols. With the DIRECTORY project, we aim to go beyond inspection of methodological issues of QoL implementation in RCTs, broadening our focus to include the identification of challenges related to interpretation of PRO data from RCTs, and the investigation of how authors “translate” (combined) clinical and PRO results into overall treatment recommendations. For this purpose, we are thus creating a large Data Repository of “traditional” clinical outcomes (e.g. overall survival, progression-free survival or clinical response) and PRO results across all cancer RCTs. We are also collecting data on the magnitude of these outcomes as well as other information on trial characteristics.

For example, a challenge deserving consideration when interpreting results from RCTs with a PRO endpoint is the possibility that findings based on traditional clinical endpoints can be discordant with PRO results (i.e. not favouring the same treatment arm). Assessment of clinical outcomes and PROs is necessary to fully understand the impact of therapy. Some interventions may have beneficial effects on both clinical outcomes and PROs; others may have discordant effects. Understanding the interplay between clinical and PRO outcomes is critical to informing shared decision-making. Information should be provided to allow patients to “trade off” potential gains and losses and make an informed treatment decision.

Finally, we have to say this is a great team effort and we are happy and proud to rely on the close collaboration of eminent experts in this area, including: Jane Blazebty, Peter Fayers, Marcia Sprangers and Neil Aaronson, plus an extensive research network of collaborators from European and US Universities. We are eager to present all of you further progress of this project during our Group meetings, as well as draft manuscripts soon.

References
The EORTC questionnaire for individuals at risk for Hereditary Cancer Predisposition Syndrome: an update

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The quality of life (QoL) of individuals at risk for Hereditary Cancer Predisposition Syndrome (HCPS) has become an increasingly important scientific topic in cancer research. This reflects the increased inclusion of genetic counselling and testing in routine clinical practice. Cancer worry, comorbidities, EORTC questionnaire for decisional conflicts are only some examples of HCPS-related QoL impairments. So-called high-risk families include not only cancer patients but also their healthy relatives confronted with risk for HCPS. With the development of an EORTC QoL questionnaire for HCPS, we aim at closing the methodological gap of lacking QoL outcomes for this target population. The questionnaire is planned to cover the QoL demands of families living with HCPS, including both cancer patients and their healthy relatives confronted with a higher risk of developing cancer.

The project is currently in the first phase of the questionnaire development process. We have been busy working on the literature review in order to achieve first results for two major project milestones: (1) the identification of issues relevant to the target groups, and (2) the exploration of the question of whether a single-generic EORTC questionnaire is sufficient to comprehensively cover the full range of QoL issues relevant to all HCPS, or whether there is a need for supplementary modules for specific conditions (e.g. familial adenomatous polyposis patients).

Sally Wheelwright did a great job on the literature search, extracting a total of almost 6,000 references which were evaluated by two independent reviewers for eligibility. Out of a final set of 326 full papers, 693 HCPS-related issues were extracted. In order to work on a strategy for issue reduction towards an issue list applicable for patient and healthcare provider evaluation, an expert panel of five QLG members experienced in HCPS was formed. In December 2016, Innsbruck hosted a productive QLG HCPS Consensus Meeting allowing the expert panel to elaborate on this strategy and find an expert consensus on the issues finally included for further evaluation by patients and health care providers. This issue list was close to finalization in December 2016.

From January 2017, the final issue has been undergoing a comprehensive evaluation by families living with HCPS, and health care providers. We would like to thank all collaborators for their great participation and support for the project.
The CHES platform: An electronic data collection infrastructure for EORTC Quality of Life projects

Clinical validation of the EORTC CAT – results of feasibility study and initiation of field study

In recent years, the CHES platform has become a reliable and versatile online tool supporting the methodological and scientific work of the EORTC Quality of Life Group (QLG) by assisting several Phase IV studies, the EORTC CAT project and routine collection and processing of PRO data.

To utilize the advantages of such modern measurement methods the EORTC Quality of Life Group (QLG) has developed a CAT version of the EORTC QLQ-C30. The EORTC CAT includes item banks for each of the fourteen QLQ-C30 symptom and functional domains comprising a total 260 items. A clinical validation project has been initiated with the primary aim to compare the measurement precision of the EORTC CAT with the standard QLQ-C30 questionnaire in independent data. The validation consists of two parts: a smaller feasibility study investigating the acceptability, optimal design and logistics of web-based administration of the CAT and a field study, the main validation, evaluating the measurement precision of the EORTC CAT compared to the QLQ-C30 in a large international sample of cancer patients.

The feasibility study has been completed. In all, 93 patients from 8 countries completed the web-based CAT software and were subsequently interviewed about the experience. The majority of the patients liked the electronic questionnaire (about 90% preferred the electronic questionnaire or were indifferent when compared to a paper questionnaire) and found the number of items acceptable. Only a few minor adjustments to the software were needed before launching the field study. The field study will include 1,000 patients, who are assessed before and after chemotherapy/radiotherapy. By early December 2016 about 150 patients were already included. Following the expected completion of the field study in 2017, the EORTC CAT will be released as a validated instrument for general use. Until then, the EORTC CAT and short-forms for e.g. physical or role function are available for experimental use.

For more information on the EORTC CAT please visit:
http://groups.eortc.be/qol/eortc-cat

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

<table>
<thead>
<tr>
<th>Study Overview feature</th>
<th>Quality of Life Group (QLG)</th>
<th>Cut-off scores for clinical relevance</th>
<th>Colour chart flag</th>
<th>Cuts-off scores for clinical relevance</th>
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| New features for improved study monitoring | Bernhard Holzner1, Lisa M. Wintner1, Gerhard Rumpold2 | Coloured pie chart flags | (http://groups.eortc.be/qol/eortc-cat) or https://eortc.ches.pro/ | For more information on the EORTC CAT please visit: http://groups.eortc.be/qol/eortc-cat

1 University of Innsbruck, Innsbruck, Austria
2 Evaluation Software Development, Rum, Austria

To access the more comprehensive cross-sectional or longitudinal reports, please visit the EORTC QLG group website (http://groups.eortc.be/qol/eortc-cat) or https://eortc.ches.pro/ to access the CHES platform and to try our newly developed features. Feel free to provide any suggestions or comments to the developers (bernhard.holzner@eortc.org).
Improving standards of patient-reported outcome measurement for patients with lymphoma and chronic lymphocytic leukaemia

Lonneke van de Poll-Franse1,2, Fabio Efficace3, Simone Oerlemans4

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On behalf of the co-investigators

We are currently developing four EORTC questionnaires to assess quality of life (QoL) in patients with Hodgkin lymphoma (HL), high-grade (HG: aggressive) and low-grade (LG: indolent) non-Hodgkin lymphoma (NHL) and chronic lymphocytic leukaemia (CLL). Treatment of these patients has witnessed dramatic changes in the last three decades, leading to more prognosis; intensified treatment with improved survival rates and/or remission duration.1,2 Despite the changing landscape of treatment of lymphoproliferative disorders and in contrast to the large number of QoL studies in patients with solid tumours, relatively few studies have reported QoL in patients with hematological malignancies.3 Also, the American Society of Hematology (ASH) has voiced concern about the lack of data in this area, advocating urgent efforts to raise the standards of QoL research.4

Unfortunately, questionnaires to assess QoL in patients with different phases of disease and systematic literature searches.1,2 In Phase I, 75 QoL issues were identified through focus groups and systematic literature searches.1,2

What has been done so far?

Phase I has been completed. In Phase I, QoL issues were identified through focus groups and systematic literature searches.1,2

In Phase II, 245 patients (75 HL, 66 HG-NHL, 66 LG-NHL and 86 CLL) were interviewed. In none of the four tumour groups, 3 in none of the groups, 3 in none of the groups, 1 in one group, 1 in one group and 1 in one group.

The reference list includes:

7. van de Poll-Franse, L.C., et al., Quality of life: the ‘feel’ of the Baltic is tangible all around you. In Kiel, we find a beautiful restaurant and meeting hall.

References

One doesn’t have a direct view of the coastline from anywhere in Kiel; however, the smell of the “feel” of the Baltic is tangible all around you. Even though I was newly arrived, I could tell that the water was fresh and salty. Probably because of the ever-present western wind or the seagulls’ calls, or maybe because of the sounds from the harbor: ferries, cruise ships and cargo ships entering and leaving the Kiel Canal.

Before Kiel started to grow at the beginning of the 20th century, it had been a cozy settlement on the Baltic Fjord for centuries. Due to the

Russian ambitions to become a colonial power, Kiel’s naval port and large shipbuilding centers made the city prosper immensely. As a consequence of being one of the major construction sites for submarines and the German “Reichsmutter”, Kiel was heavily bombed during World War II and the vast majority of it lay in ruins. But the Baltic Sea remained.

The large university with its many students had a remarkable impact on the new image of the emerging city. Additionally it was the Baltic on our way, we will have the exciting experience of being locked on our way through the Kiel Canal while dancing the night away on a historic steamboat.

On Friday afternoon the scientific meeting breaks. On Thursday evening, we will go on a boat trip, where we will have the exciting experience of being locked on our way through the Kiel Canal while dancing the night away on a historic steamboat.

On Friday afternoon the scientific meeting will end with some drinks at the rooftop bar of our conference hotel. Afterwards, we have arranged a guided tour around the Geomar research facility. For decades, this building was used as a public bathing house during the early 20th century, when regular citizens didn’t have a bathtub in their own homes. Recently the building was restructured – and today we find a beautiful restaurant and meeting hall there.

I look forward to welcoming you all to this historic city!

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Manchester reminded me of my own home town, Newcastle-upon-Tyne, with its plethora of elegant buildings, proof of the history of wealth and culture upon which it is built. Nevertheless, I was blown away by the iconic Town Hall where our Quality of Life Group (QLG) meeting was held. Manchester Town Hall, neo-gothic in style, is one of the most important Grade 1 listed buildings in England and it was sometimes difficult to concentrate on the sessions with so much beauty all around. Even so, we did manage to get through an impressive amount of work on the Thursday. I am always impressed by the enthusiasm of the Group, the proof of which can be seen in the ever-growing list of questionnaires and modules being developed. Age, gender and nationality are unimportant; what matters is a passion for quality of life in cancer care which bonds all our Group members together.

It is often said that if you want something done, then ask a busy person. This can be seen in the QLG, who are all essentially volunteers holding down important jobs and often managing a family as well, yet who still devote a lot of time to the Group. This devotion is much appreciated by the Executive Committee who themselves have worked hard to become Committee members.

It is delightful to see the camaraderie that exists between the newest (sometimes timid) members and the older (in experience) members who are only too willing to pass on their expertise. And each Group meeting would not be a success without the hard work of the local organizing committee. Manchester was hosted by Kim Cocks of Adelphi and several of her colleagues who did a wonderful job. All the arrangements were perfect. As our group gets bigger, more and more break-out rooms are needed and it isn’t easy to find a venue that can accommodate us. It’s also a problem finding restaurant venues which can cater for us.

No problem in Manchester, though, as the Town Hall provided a variety of grand ceremonial rooms, and much to the delight of many husbands, partners and sons the Thursday night dinner was at Old Trafford stadium, the famous home of Manchester United Football Club. Even I, a dedicated rugby fan, was impressed with the panoramic view of the pitch. The food was also excellent. Thank you, Kim – a brilliant choice.

Friday mornings are traditionally business-oriented, and it was good to hear that the Group’s finances continue to grow, thanks to the popularity of the QLQ-C30 and all our modules, as well as our many translations. More money in means more money available for funding new projects and modules so perhaps the next year will produce some exciting new projects. The Module Development Committee (MDC) and the Clinical Development Committee (CDC) session brought us up to date on the status of the modules and some new projects that were suggested by members.

The dinner on the Friday evening was a much more formal affair, at the Albert Square Chop House in the Memorial Hall. The food was traditionally British with a modern twist, served in an elegant cream and gold setting.

Personally I am always sad when our meeting is over, as it is lovely meeting old friends and making new ones. “See you next time” is always genuine. Thank you once again to Kim and her colleagues for a job well done and thank you Manchester for providing such a wonderful backdrop for our meeting.
Viking Law § 1: Be Brave and Aggressive
Amid a number of outstanding aspects, one thing truly stood out at the QLG’s Oslo Group meeting in April 2016: if Viking Law § 1 is to be brave and aggressive, the QLG arrived in Norway in a suitable frame of mind. In the wake of growing competition emerging from the US, we all came together to back our own quality of life measures and to express our support for the development of new ways of using them, as presented to us by Mogens Grønvold via Skype (see p.9). A stronger sense of alliance and community would be hard to achieve.

Viking Law § 2: Be Prepared
The evening entertainment was a perfect mix of culture and socialising – clearly our hosts knew their fellow QLG members well, and sold Oslo to us using some of its most impressive features. On the Thursday evening they took us to the Oslo Opera House, an incredibly modern building remarkable not least for its being completed in 2007 ahead of schedule and under budget. A tour of the building gave us a view of its breathtaking architecture, while dinner next to 15-metre-high windows gave us views over the water to “She Lies”, a glass-and-steel iceberg sculpture by Monica Bonvicini.

Viking Law § 3: Be a Good Merchant
Friday’s treat was a fascinating and humbling guided tour of the Nobel Peace Center. After a busy two days in full meeting mode, this was an opportunity to step out of the QLG bubble again. Warm and cosy, the restaurant’s opulence was in striking contrast to the hard, clean lines of the Opera House the night before.

Viking Law § 4: Keep the Camp in Order
At this Oslo meeting we broke the attendance record, numbering 133 attendees. The introductory session was kicked off by Andrew Botsmeley (EORTC HQ) and then QLG Chair Lonneke van de Poll-Franse – and then, as always, it was over to the members to stand up and introduce themselves. With 133 people it took a bit of time to make it around the room... but we made it!
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