EORTC Quality of Life Group newsletter 2022

The EORTC QLG – A Creative Force for Change

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Dear readers,
It is a pleasure to introduce this special issue of the EORTC Quality of Life Group's newsletter on the occasion of its 40th anniversary, which will be celebrated in September 2022 in Amsterdam under the auspices of our wonderful colleagues at NKI.

This issue of our newsletter is themed 'Creative Force for Change' – and it is change indeed that we hope it can inspire, by finally helping us to turn the page on the COVID-19 pandemic!

In this issue, you will be taken back in time by visions from past Chairs and other long-standing members of the Group, and be reminded of the relevance, importance, rigour and timeliness of the various activities undertaken by QLG members over the decades.

This issue also provides the opportunity to tell the story of the birth of the EORTC QLQ-C30, to describe the Group in its infancy, to highlight the Group's accomplishments, and to look ahead to the Group's future – from methodological endeavours to the development and provision of rigorous tools and approaches to research, and the clinical applications of these.

The EORTC QLG has, over the last forty years, succeeded in bringing together, developing and maintaining a rich and enthusiastic network of health professionals from a variety of backgrounds in the field of healthcare, be they clinicians or methodologists or both, and more recently – and even more enrichingly – has included among its research collaborators the partnership of people affected by cancer.

Among its main accomplishments, the EORTC QLG has enabled a subjective, global and multidimensional view of the quality of life of the person affected with cancer, broadening the observer's perspective that would otherwise be limited merely to the functional aspects of the patient. It is also unique in its approach, having been able to take into account the subjective views of individuals from different cultural and linguistic backgrounds. Members of the EORTC QLG can thus learn from one another and benefit from collaboration that encourages acceptance and understanding of others.

This newsletter, prepared with the very efficient assistance of Cheryl Whittaker, is an opportunity to retrace the path that has led to the realisation of innovative and cutting-edge research projects with important clinical relevance, and to look further up the path to see what lies ahead. Thanks are also owed to Anne Lanceley, who began this issue with her ideas for submissions and articles when she was editor all the way back in 2019.

We wish you an exciting read – and an exciting celebration!

Anne Brédart

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Quality of Life Group Executive Committee

Don't let it slip!

Jaap C. Reijneveld
VU University Medical Center and Academic Medical Center, Amsterdam, The Netherlands

It's fair to say that the Quality of Life Group is in good shape on its 40th (and a bit) anniversary! This March, we were reviewed by the Scientific Audit Committee (SAC) as instituted by the Board of the EORTC, and the overall judgement was extremely positive: we are a very active group, that continuously improves its procedures and transparency, constantly updates its tools, runs an amazing number of projects, and really puts effort into collaborating with the disease-oriented groups (DOGs). I fully realise that we are standing on the shoulders of giants – all those members before us who have worked so hard to put the concept of quality of life on the cancer research map, and to make a success of this Group during the past 40 (and a bit) years. Therefore, during our Amsterdam Autumn 2022 Meeting, we will celebrate our 40th (and a bit) birthday and honour many past members. So actually, it might look relatively easy to chair a group with such a solid foundation. And yes, in many ways it is. During our Cyprus Spring 2022 Meeting it was fantastic to see how happy everybody was to catch up again, and I felt my main task was simply facilitating everyone to keep up the spirit!

There are some challenges for our Group, though. First of all, being a successful group comes with the risk of losing momentum and the willingness to further improve. So we have to constantly sharpen the saw, and create and take opportunities at the right time. Secondly, being a successful group comes with obligations on a different level. For example, in the light of current societal discussions, are we as inclusive as we think we are? Does everybody in our Group feel safe and free to speak, no matter what age, gender, sexual preference, disability, nationality, or skin colour? Shouldn't we share our wealth of knowledge with other groups or organisations, and society in general? And does it make sense to organise meetings across Europe twice a year, forcing many members to travel long distances, in this time of increased awareness of sustainability? Several of these issues have passed through the agenda of our Executive Committee (EC) since I started my term, and it might be wise to handle such issues in a more structural way. I would like to ask QLG members who are interested in sharing their thoughts to get in touch with me or other EC members.

But for now, thanks to everyone for contributing to such a fantastic group! Keep up the spirit, and… don't let it slip!

"... we are a very active group, that continuously improves its procedures and transparency, constantly updates its tools, runs an amazing number of projects, and really puts effort into collaborating with the disease-oriented groups."

Secretary's Report

Karin Kuljanic, EORTC QLG Secretary and Gracia Dekanic Arbanas,
EORTC QLG Assistant Secretary, Clinical Hospital Center Rijeka, Croatia

Dear Members,

The current status of EORTC's Quality of Life Group membership is looking very good. Membership has significantly grown, despite us holding only virtual Group Meetings in 2020 and 2021, and we are happy to announce that in the spring of 2022 we had a total of 457 members. Of those, 193 are active members and 265 are currently corresponding members. We are fortunate to have members from all over the world – and therefore can safely say that our impact on PROs is truly global! That our vibrant community is drawn from so many nationalities, languages and disciplines remains one of our core and distinctive strengths.

Attendance at the first face-to-face meeting since the pandemic went far better than we expected, especially given that Cyprus is not easy to reach for everybody. Unfortunately, as we were quite far away from the Northern countries of the EU, we missed our Scandinavian members. But even without them, we had 122 members attending the spring meeting: 81 active members and 4 corresponding members, as well as 37 other registrants who are not (yet!) members of the QLG.

Thank you as always for your support. I promise to do my best to share the core values of the QLG and to serve you, our Group members, in my second term as Group Secretary.

Karin and Gracia

HOW CAN I BECOME A FULL ACTIVE MEMBER ?

If you are a clinician or an academic researcher with interest in PRO measures, this is the group for you. To become a full active member of the EORTC Quality of Life Group, first you have to become a member of EORTC by sending an email of interest to membership@eortc.org. After receiving your confirmation from the EORTC Membership Office, you should forward your expressed interest in the QLG to Karin at kuljanickarin@gmail.com and we will send you a link to complete your specific interest in the Group's projects.

After completing your registration with EORTC and QLG you become a corresponding member of the QLG. Attending two QLG meetings up front (within 2 years) and being actively involved in EORTC Quality of Life Group research qualify you for an active membership. On your third meeting you will become an active member.

MAINTAINING YOUR QLG MEMBERSHIP

To maintain active QLG membership you have to continue with active research activities and attend a minimum of 2 QLG meetings every 2 years.

Our Group has a long-standing custom of sending apologies, so if you are unable to attend our Group meetings just email Karin at kuljanickarin@gmail.com. If you are unable to attend meetings regularly, your membership status will revert to corresponding member. We actively check the emails of our members in order to keep our membership database up to date. If you change job and email, or project or working status, please let us know.

If you wish to discontinue your membership please notify Karin at kuljanickarin@gmail.com.

Those working in the commercial sector are not allowed to participate in QLG meetings and projects due to EORTC policies.

For more information on membership please visit our website: https://qol.eortc.org/how-to-become-a-qlg-member/

"Attendance at the first face-to-face meeting since the pandemic went far better than we expected, especially given that Cyprus is not easy to reach for everybody."

In Memory of Jeff Sloan

Andrew Bottomley, Head of the Quality of Life Department, EORTC HQ, Brussels, Belgium

5th May 2022

This last week I lost a friend, and we all lost a star in the quality of life field.

It was over 22 years ago when I first encountered this tall, looming figure walking past me at ASCO in Chicago. I remember thinking, 'That's Jeff Sloan!' We had just recently jousted by letter over an article and its interpretation. We debated that issue in a nice way despite never having met before, like academics do. We did not have email back then so you can imagine how that went! But at the time, I thought surely I was right – and that must be Jeff Sloan!

It was not until a couple of years later when we met again at the international quality of life research conference. There, we both forgot about our letters and debates and we simply started chatting. Jeff said 'Congratulations, Dr Bottomley, on your Lancet Oncology paper! I am Jeff Sloan,' and from that day on we got on like a house on fire. Jeff was a statistician, and I am always one to joke and say, 'Those statisticians are so brilliant and gifted with numbers that they may be challenged by talking to mere mortals like me.' But Jeff was different. He never took himself seriously and was always joking and making light of things. He was a brilliant orator. His relaxed way always put mere mortals like me at ease, allowing people to learn about quality of life in a relaxed manner.

Over the years, I always took joy from inviting Jeff to come and present at the EORTC QoL and Clinical Trials Conferences. He was a regular feature, and he was always certain to win everyone over, and would even sometimes put on a show.

One day before one of our conferences, during the faculty dinner at a posh restaurant, he arrived dressed in a shabby shiny track suit. I teased him and said, 'Jeff, you don't dress like this for a faculty dinner in a fancy restaurant! You look like a rapper!' He explained that although the story was that the airport had lost his luggage, actually he was comfortable in his track suit. 'You cannot feel comfortable like that!' I joked, 'And if you do, I dare you to present tomorrow to the 400 people at our conference dressed like a rapper in your shiny track suit'. His response was that he never refused a bet. The next morning, he turned up in a formal suit and said that his luggage had arrived. I felt the matter had ended, but I was mistaken. As the audience took their seats, I, as conference chair, made a grand introduction of Professor Jeff Sloan, and he stood up and came to the podium. He then told the audience about our bet, and right in front of 400 people, he took off his suit to reveal underneath not a naked Jeff, but a Jeff in a horrible shiny track suit! The audience and faculty were laughing so hard, many of them were in tears! He then, of course, presented a brilliant talk. That was Jeff – a real star.

I have so many funny and interesting stories to share to keep me happy in the dark hours. Jeff and I were always in touch. I called him one day, before he started his cancer therapy, and he said, 'Call me whenever you can, it always brings a smile to my face to see it's a Belgium number and it's always great to talk.' While Jeff was undergoing his cancer treatment, we talked a few times over the following months. We had big plans. We planned to write a book on his cancer experience. With Jeff being a cancer survivor, a QoL expert and a world-leading statistician, it would be a total winner for a future book prize – at least that's what I thought. But unfortunately, things didn't go according to plan. Jeff's passing is a big loss to so many. He touched the hearts of so many in the cancer field, and led so many PRO efforts. Jeff was lucky to have a wonderful family, and was a true family man. I wish his wife Vesna and his children all the best in these difficult times. Our thoughts are with you all, and we will all miss Jeff for a long time to come.

An Unofficial Personal History of the QLG

Neil Aaronson, QLG Member

It's often said that success is, at least in part, a question of dumb luck; of being in the right place at the right time. That was certainly the case for me with the EORTC Quality of Life Group. When I arrived in Europe in January 1984 as an EORTC postdoc fellow funded by the Dutch Cancer Society, the QLG (then called a 'study group' to distinguish it from a fully fledged EORTC cooperative group) had been up and running for about 4 years. I had recently received my PhD from the School of Public Health at UCLA in Los Angeles, California. My background was heavy in research methodology, questionnaire development, and psychometrics, and thus I was eager to sink my teeth into the development of a questionnaire to assess the HRQoL of patients with cancer, which was the focus of my fellowship. By the time I arrived on the scene, significant progress had already been made in developing the framework for such assessments. Key players in the early days of the group, including Frits van Dam, Hanneke de Haes, and Jan Bernheim, had already generated preliminary versions of such a questionnaire. Anita Stewart, who was my predecessor at the EORTC, played a particularly important role in proposing the use of an HRQoL measurement model that she and John Ware had developed for the SF-36 that included three key components of health: patients' physical, emotional and social functioning and well-being.

All of my other colleagues in the EORTC QLG at that time had full-time day jobs that placed significant demands on their time. I had the luxury of being able to work unimpeded on the emerging science of HRQoL assessment within the larger EORTC clinical trials research programme. Being the 'new kid on the block', I was confronted with a steep learning curve in the field of oncology. Fortunately, clinical colleagues both within the EORTC and at my home base, the Netherlands Cancer Institute, were generous with their time, knowledge and expertise.

For those relatively new to the field, it may be difficult to imagine the degree of resistance that we then faced in trying to introduce HRQoL assessment into the clinical trials programme at the EORTC. That resistance ranged from benign disinterest to unbridled hostility. I and other behavioural scientists in the Group could talk until we were blue in the face and still not convince the clinical trialists of the potential value of assessing HRQoL in their research. It was the clinicians within the QLG who played a crucial role in legitimising HRQoL assessment in clinical trials, and in ensuring that the questions that we posed in our questionnaires were clinically relevant. While it's always risky to start naming names for fear of forgetting some, I feel compelled to mention at least some of the clinical colleagues who were so critically important to the early success of our HRQoL assessment programme: Sam Ahmedzai, Bengt Bergman, Kristin Bjordal, Henning Flechtner, Stein Kaasa, Mogens Grønvold, David Osoba, Darius Razavi, Simon Schraub and Robert Zittoun. The Group has continued to recognise the importance of having clinicians centrally involved in the Group, often in key leadership positions. At the same

"(...) the seminal 1993 paper in which we reported the psychometrics of the QLQ-C30 when used internationally has been cited more than 9,000 times in the journal literature, according to Web of Science. In fact, it is the most frequently cited paper ever published in the Journal of the National Cancer Institute. This is something we can all be very proud of."

time, the rich mix of professional backgrounds represented in the Group ensures the depth of vision and methodological sophistication so important to keeping the Group on the cutting edge of its field.

The first, formal version of the EORTC quality of life questionnaire, the QLQ-C36, was published in 1991 [1], followed soon thereafter by the QLQ-C30, version 1 [2] and version 2 [3]. Although quantitative metrics represent only one way of assessing the success and the impact of a research programme, it is striking that the seminal 1993 paper in which we reported the psychometrics of the QLQ-C30 when used internationally has been cited more than 9,000 times in the journal literature, according to Web of Science. In fact, it is the most frequently cited paper ever published in the Journal of the National Cancer Institute. This is something we can all be very proud of.

Equally important as the core questionnaire was the more general approach that we adopted to assessing the HRQoL of cancer patients. Early on, we recognised the importance of supplementing the QLQ-C30 with condition-specific or treatment-specific questionnaires. In those early days, many of us had young children, and our homes were littered with Lego blocks. Thus emerged the phrase 'modular' to characterise our approach to HRQoL assessment [4-6]. There are many colleagues who have contributed over the years to the extensive library of questionnaire modules that the EORTC now has, but a number of individuals deserve special recognition for their early and, in many cases, sustained efforts in developing and advancing our approach to module development. They include Sam Ahmedzai, Kirsten Bjordal, Jane Blazeby, Monika Bullinger, Ann Cull (Smyth), Mogens Grønvold and Mirjam Sprangers.

I look back at my 38 years of involvement in the EORTC QLG with enormous pride and pleasure. With each new generation of members, the Group continues to grow, to mature and to revitalise itself. While a good deal of the work of the Group is protocol driven (i.e., module development), innovative projects have kept the Group at the forefront of the HRQoL field (e.g., the CAT project of Mogens Grønvold and Morten Petersen; digital platforms for administering EORTC questionnaires developed by Bernard Holzner and colleagues; efforts to define minimally important differences and clinically relevant thresholds for questionnaire scores by Johannes Giesinger et al.; integrating HRQoL assessments in daily clinical practice by Galina Velikova and others, some of whom have written an article in this issue (pp.15-17); and more).

In the early days, Lego inspired the QLG's approach to HRQoL Assessment

Above all, the Group is an extended family of colleagues and friends who share a common interest and goal of improving the lives of those affected by cancer. I feel privileged to have been able to contribute over a period of decades to its mission, and thankful for all of the friendships and memories and fun times that that involvement has brought with it. While this may read like a swan song, don't yet count me out. I hope to continue my involvement in a number of the Group's activities for some time to come.

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The First Ten Years of the QLG

Henning Flechtner, Director of the Clinic for Child and Adolescent Psychiatry (KKJP), Medical School University Hospital Magdeburg, Germany

After a meeting in Brussels in 1979 and another in Marseille in 1980, and the subsequent foundation of the Group as the EORTC Quality of Life Study Group, the first official EORTC Quality of Life workshop was held on 22 May 1981 in Amsterdam under the title 'QUALITY OF LIFE: Methods of Measurement and Related Areas'. A few years earlier Manfred Heim from our Oncology Department at the University of Heidelberg (Mannheim Oncology Center) had started to attend the first meetings of a small group of Europeans who had founded the Quality of Life Study Group within the EORTC around 1980. After Amsterdam in 1981 regular meetings of the Group followed in Copenhagen, Paris, Birmingham and Milan. From Zürich in October 1984 onwards meetings were held yearly. The Regensburg meeting in October 1985 was the seventh workshop of the Group, and the first meeting I attended. It was organised by Friedrich von Bültzingslöwen, a lung physician with great interest in the quality of life of his oncology patients. The Group meetings were 2½ days long and included subgroup and plenary sessions.

The subgroups at that time were:

1. Conceptual views on quality of life (chair: Jorn Bergmann)
2. Assessment of quality of life (chair: Frits von Dam)
3. Quality of life in paediatric oncology (chair: E. Pichler)
4. Psychotherapeutic and psychosocial intervention (chair: Gerjanne Bos)
5. The terminally ill patient (chair: Barry Lunt)

The subgroup meetings lasted for the full first meeting day and the results were reported in plenary on the first evening before dinner. The Group had participants from a variety of professions including oncology doctors, surgeons, psychologists, nurses, palliative care physicians, medical sociologists, etc. That also meant a wide variety of interests in quality of life ranging from the oncology study context to more philosophical topics like the conceptualisation issues around quality of life.

Chairman of the Group at that time and one of the most influential founding members was Robert Zittoun, an internationally well-renowned haematologist from Hotel Dieu in Paris, and Jorn Beckmann, a charismatic psychologist from Odense in Denmark, served as Secretary. Together with Frits van Dam, these two represented the most important topics within quality of life and within the subgroup Methods of Assessment and concepts of Quality of Life. From 1987 until 1993 additional interim meetings were held in spring in Paris at Hotel Dieu, hosted by Robert Zittoun. From 1994 onwards Group meetings turned into spring meetings in April and autumn meetings in September at various locations throughout Europe.

The medical doctors in the Group shared a main interest: to know more about the quality of life of their patients. They wanted to use quality of life aspects to better determine if a treatment was really helpful for the patient. In the 1970s a lot of chemotherapy regimens were used causing massive side effects while having only moderate or minor effects on the tumour disease itself, so dealing with the quality of life of the patient was something like giving the patient a clear voice about their own quality of life under treatment. The main focus was, however, not the single patient but subgroups of patients treated in large Phase-III studies with the aim of establishing quality of life endpoints as clinical decision criteria besides survival and response rates. Therefore in the following years the assessment subgroup gained enormous influence within the Group as they developed a self-rating instrument in the form of a questionnaire to assess the different aspects of quality of life for use in clinical trials. During this process, in September 1986, EORTC study protocol 15861 was approved by the Protocol Review Committee: 'Development of a core quality of life questionnaire for use in cancer clinical trials'. Since many people had been waiting for an internationally validated instrument in various languages, the EORTC QLQ-C36, which was tested in this study, very quickly became extremely successful and the consolidated version, the EORTC QLQ-C30, published in 1993, is today one of the most-used quality of life instruments in the world.

EORTC Quality of Life Study Group Meeting History **1979 – 1991** ➔

Evolution and Collaboration: Gynaecological Quality of Life

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

1979

1st Meeting, **1979**, Brussels – pre-QLG

2nd Meeting, **1980**, Marseille – pre-QLG

Foundation of the Group as EORTC Quality of Life Study Group (Jan Bernheim/Frits van Dam)

1st Annual Meeting, 22 May **1981**, Amsterdam

Interim Workshop, 13-14 November **1981**, Copenhagen

2nd Annual Meeting, **1982**, Paris

3rd Annual Meeting, **1983**, Birmingham

Interim Workshop, **1983/84**, Milan

4th Annual Meeting, October **1984**, Zürich

5th Annual Meeting, 10-12 October **1985**, Regensburg

6th Annual Meeting, 9-11 October **1986**, Gothenberg

7th Annual Meeting, 10-13 September **1987**, Seamill, Ayrshire

8th Annual Meeting, 20-21 October **1988**, Leiden

9th Annual Meeting, 2-4 November **1989**, Munich

Interim Meeting, 26-27 April **1990**, Paris

10th Annual Meeting, 16-17 November **1990**, Paris

Interim Meeting, 26-27 April **1991**, Paris

11th Annual Meeting, 22-23 November **1991**, Leicester

1991

"With patient-reported outcome measures designed for female cancer patients, we have given these women a voice."

In 1996, I attended my first Quality of Life Group meeting in Pamplona, hosted by Dr Juan I. Arraras. Before the meeting I contacted a highly respected female scientist, Dr Ann Cull (Smyth), a Consultant Clinical Psychologist and at that time Head of the ICRF Edinburgh Psychology Group. I had the honour of joining a small but very effective working group under her leadership, when we started developing the first module for ovarian cancer – the EORTC QLQ-OV28 – and she encouraged me to take the lead of this group when she became the first female chair of the EORTC QLG in 1997. I was delighted to be working with her. We continued to develop modules for various gynaecological cancer sites as our working group expanded from one meeting to the next.

With patient-reported outcome measures designed for female cancer patients, we have given these women a voice. But things have not always been this way. As a clinical psychologist I have been counselling female cancer patients in the Department of Gynaecology at the Medical University Graz for more than 30 years. I have noticed the changing culture from a patriarchal model of care to patient empowerment and shared clinical decision-making. Today many clinical trial groups and major stakeholders in the healthcare system recommend the input of the patient perspective. The modules developed by the QLG in collaboration with the EORTC GCG (Gynecological Cancer Group) are tailored to female patients with cancers in different gynaecological sites such as ovarian, cervical, endometrial, and vulval (QLQs OV28, CX24, EN24, and VU34). Our modules have become essential tools, used worldwide as patient-reported outcome measures. Our latest research focused on the development of a sexual health measure (QLQ-SHQ22) to assess sexual health in male and female cancer patients and cancer survivors. This is a subject often neglected in oncology and the questionnaire may help patients to present their sexual health concerns and to stimulate the discussion about these sensitive issues with health professionals.

Our working group has grown over the years, and has developed a fascinating spirit, dedication, and friendship. I am honoured to have had the opportunity to chair this outstanding working group for more than a quarter of a century: it has been a very rewarding experience in this evolution in patient-reported outcome research.

Improving the content validity of PROMs in clinical trials across the decades

Mogens Grønvold, Department of Public Health, University of Copenhagen, Denmark

One of the key contributions from the EORTC QLG to the evolution of QoL research globally is the Core + Module Strategy, including the Module Development Guidelines. This strategy has had major implications for content validity, i.e., ensuring that the content of questionnaires matches the research questions.

While content validity is a simple concept, it is still a major practical and scientific challenge, so I will focus on how the QLG has contributed to the improvement of content validity in clinical trials over the years.

The Core Questionnaire

The first element in the Core + Module Strategy was obviously the Core questionnaire. It ensured that ALL patients were asked about important aspects of functioning in addition to their symptoms, using a multidimensional QoL model with 15 dimensions. This comprehensive model has proven sustainable, and has ensured that cancer trials measure not only the specific consequences of cancer and treatment but also the broader impact on daily life. Furthermore, having a common instrument for the many different groups of cancer patients made it possible to investigate and compare outcomes across sub-populations.

Disease-Specific Modules

Supplementing the Core questionnaire with disease-specific modules added another layer of content validity by ensuring assessment of the patient-perceived consequences of the specific cancer and its common treatments.

The importance of the Core + Module Strategy cannot be over-estimated, as it secured a broad range of questionnaires built in accordance with a common model using a common methodology.

However, there is always a risk when you take responsibility and deliver easy off-the-shelf solutions: many investigators chose to rely on the simple and sensible model, and simply picked the core questionnaire plus the disease-specific module. Paradoxically, this may be problematic: even though the content of the Core + Module is usually relevant, it may not be sufficient to provide a comprehensive and balanced evaluation of the treatments studied in clinical trials, thus leading to suboptimal content validity, which may compromise the validity of trial results.

Item Library

About 25 years later, the New QLG Strategy was launched, in 2016. The 'Core/CAT Core + Module + Item Library Strategy' introduced the Item Library as the main tool to address gaps in content validity. The strategy thus reminds the investigator(s) that the responsibility of securing content validity lies with them.

In my view, the extensive use of the EORTC Item Library (as well as its elegant development into a user-friendly tool) is a very significant success, which has increased the content validity of many studies and has also been valuable from a didactic point of view ('content validity is the investigator's responsibility'). However, we are only at the beginning of this change in research practice, and it is my impression that not all item lists constructed from the Item Library have been sufficiently carefully prepared in order to actually improve content validity.

CAT Core

The final element of content validity to be emphasised is the range of measurement. It is not enough that the right QoL issues or domains (e.g., physical function) are assessed; we also need

to ensure that the right levels of these domains are addressed. For example, adequate measurement requires that we study a higher level of physical function in relatively healthy cancer survivors than in patients with severely advanced disease. This is difficult to achieve with traditional measures but easy to do with computer-adaptive testing (CAT), where the items are selected from an item bank based on the person's previous responses (or via a 'short-form' designed to measure a specific level). The increased content validity within domains is just one of the many advantages of CAT-based measurement. One of the latest developments in EORTC CAT is sub-domains, e.g., the option of extracting separate scores for anxiety and depression from the assessment of Emotional Function, which can be seen as yet another way of contributing to the improvement of content validity.

Despite these major achievements, we should remember that theory is one thing, but practice is another. It is my impression that many clinical trials still do not report a systematic and exhaustive process documenting the content validity of the selected instruments, and that inspection of the questionnaires in such trials often reveal likely deficiencies in terms of content validity.

Systematic evaluations of whether clinical trials of specific treatments measure the same QoL domains are scarce.

The next major challenge will be to achieve a higher level of transparency in relation to the content validity in clinical trials, particularly in trials of new drugs. Obviously, a correct and unbiased result can only be achieved if the impact of both (all) treatment regimens in the trial are assessed in an adequate and balanced (unbiased) way.

Ideally, this should be an incremental process where important, patient-perceived adverse events demonstrated in early studies are continuously added to the QoL instruments used in subsequent trials. We do not yet have sufficiently easy access to repositories of questionnaires from ongoing and previous studies, continuously updated systematic reviews ('core outcome sets') or other infrastructure that can make the task of securing high content validity simple and transparent.

Taken together, the four pillars of the new EORTC QLG Strategy (QLQ-C30, CAT Core, Modules and Item Library) are in place after four decades of hard work – but there is still lots of work to do!

We should be proud of these four great boxes of LEGO bricks, and we should continuously improve, refine and build new bricks. However, it remains a very difficult challenge to guide the players around the world towards building the right things with the bricks, i.e., important and well-designed clinical trials using QoL instruments that have adequate content validity. It is therefore important that the QLG continues its multifaceted efforts to support colleagues around the world in composing questionnaires with high content validity – and maybe even invent new approaches.

The Changing Landscape of Clinical Trials

Andrew Bottomley, Irina Ghislain, Corneel Coens, Jammbe Musoro, Madeline Pe, Ahu Alanya, Hugo Vachon, Abigirl Machingura,
Quality of Life Department, EORTC HQ, Brussels, Belgium

Evaluating quality of life in cancer clinical trials has come a long way over the past 40 years. Even in the 1990s, few trials at the EORTC assessed QoL. But then, in 1993, the EORTC QLQ-C30 Core questionnaire was developed by our early QLG researchers. This paved the way for consistently using quality of life assessment in our clinical trials.

The EORTC quickly came to recognise the immense value of adding QoL endpoints in their trials, done mainly in Phase III studies. Interest has steadily grown, with the percentage of EORTC studies assessing quality of life rising from 20% in the early 2000s to around 40% ten years later. Today, well over 60% of EORTC studies include QoL assessments.

The design of new trials within the EORTC also requires experts in the disease site and with knowledge of QoL. Expert members of the QLG play a key role in advising on relevant QoL objectives and practical implementation issues. However, as methods and practices evolve, we need to evolve as well. The EORTC is contributing to new standards and applying these to new trials (e.g. SISAQOL, SPIRIT-PRO and CONSORT-PRO). These guidelines should ensure a greater level of harmonisation, and greater confidence in the results of these trials, and thus they have a greater chance of altering clinical practice.

The EORTC has made some recent advances in the way QoL is measured in its trials. For example, we are moving to a more flexible system of assessment, whereby on top of the standard approach of using the core tools, we also use the Item Library. This is a database of over 3,000 validated questions that can be added to a trial to better understand the treatment on a specific treatment study. Investigators are able to create their own checklist of items, to thus try to understand the impact of newer agents in their patients' QoL that could not be evaluated with the existing tools. Following this idea of providing flexible solutions for QoL assessment, the software supporting the use of the EORTC Computerised Adaptive Testing (EORTC CAT Core) is now in the process of being fully validated for future implementation in clinical trials.

Given that the number of trials and their complexity has grown in recent years, the EORTC has had to adapt its support infrastructure. We now have a dedicated QoL support (QLS) committee based within the Quality of Life Department (QLD) at HQ to coordinate the design and oversee all aspects of these trials. This means close collaboration with the 14 EORTC disease-oriented groups (DOGs), the QLG liaisons and the HQ team. In 2022, based on a new grant from the EORTC QLG, we will be looking to develop this more, and explore how to provide better training and education for those taking up the role of liaison, as well as how to ensure the systematic use of new guidelines across all trials. Indeed, the EORTC QLG are creating new interpretation guidelines that will help us better understand the data collected from our trials. The QLG are also moving into helping funding research where QoL is a primary endpoint (e.g. the TOLERANCE Trial). Therefore, it's very clear that the field of QoL in the EORTC continues to evolve at a rapid pace.

"Expert members of the QLG play a key role in advising on relevant QoL objectives and practical implementation issues. However, as methods and practices evolve, we need to evolve as well."

The Evolution of EORTC QLG Tools and their Contribution to Industry

Kim Cocks, Senior Director and Principal Statistician, Patient-Centred Outcomes, Adelphi Values, UK

1980 was a cool year for the EORTC QLG to be born. It was the year the Rubik's cube and the Pac-Man video game made their debuts and the year that 83 million people watched Dallas to find out who shot JR. (I don't remember who did it; do you?) We also celebrate our anniversary alongside the pharmaceutical company Amgen, who are one of the many industry users of our QLG tools in oncology. But what contribution has our Group made to the pharmaceutical industry over the last 40 years?

Now, I'm a little young to remember our conception (it's true!) but I started my career when the EORTC instruments were still a novelty for industry. I joined a biotech company in 1996 and remember the Clinical Director proudly telling me I would be working on their first trial to include a questionnaire for the patients, the QLQ-C30. They were genuinely excited, but had no idea what the emerging scores meant. So that is where my passion for QoL research began, and I joined the QLG four years later.

Fast-forward to today, and I can't remember the last time I saw an oncology trial which didn't have patient-reported outcomes. A review in 2019 [1] highlighted that 70% of oncology trials for regulatory submission included PROs, with EORTC instruments cited as frequently used in those submissions. This is due to the work of the QLG over the years in developing a whole suite of tools for specific cancer sites and making them available in many languages. We have also seen the QLQ-C30 endpoints move up in the endpoint hierarchy, from an initial tentative exploratory endpoint – last on the analysis list and rarely appearing in the trial publication – to key secondary and even primary endpoints for some cancers. The tailoring of the QLG tools to specific populations has been key in the patient voice contributing more to the decision-making from clinical trials.

Importantly, the QLG has not solely focused on development of tools. Additional research, such as publication of reference values and estimates of meaningful change, has increased the potential impact of PRO data. Reference values can be invaluable for earlier-phase studies, single-arm and registry studies, and the estimates of minimally important differences give credibility to differences between treatment groups.

Thankfully the technology for delivering the questionnaires has moved on, too. It wasn't that long ago that we used to post paper questionnaires to patients. They would be returned with pages missing, two responses per question or no responses ticked, coffee stains on so that the scanner couldn't read the data, or maybe just not returned at all. I was even once involved in a randomised substudy to test whether sending pens out with questionnaires improved compliance (it did, for those who are wondering!). We now have computers or tablets for clinic visits, or patients can receive text reminders and fill in questionnaires on their own devices at home. We have a CAT version for greater efficiency and precision. These have contributed to more sensitive, robust and complete data which in turn increases the credibility of the endpoints measured using the QLQ-C30. It is no surprise that the demand for commercial licenses increases year on year. To date the EORTC has granted over 4,000 commercial licenses for use in countries across the globe. On average 1.5 new contracts are signed per day between industry and the EORTC for use of the QLQ tools, with clients ranging from small biotech to the largest pharmaceutical companies. Our overall impact on industry, and therefore drug development and ultimately patients, is clear to see from those numbers alone. These developments are a credit to every member of the QLG, past and present, and industry eagerly awaits the current and future developments too!

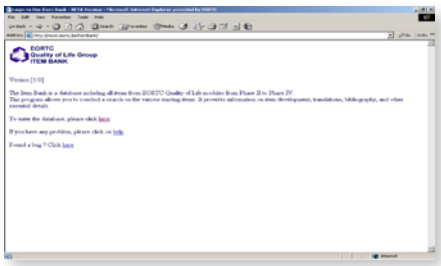
[1] Gnanasakthy, A., Barrett, A., Evans, E., D'Alessio, D., & Romano (de Muro), C., 'Health Policy Analysis: A Review of Patient-Reported Outcomes Labeling for Oncology Drugs Approved by the FDA and the EMA (2012-2016)', *Value in Health*, 2019: 22 (2), pp.203-209.

"...I can't remember the last time I saw an oncology trial which didn't have patient-reported outcomes... The tailoring of the QLG tools to specific populations has been key in the patient voice contributing more to the decision-making from clinical trials."

The Evolution of the Item Library

Dagmara Kuliś and Claire Piccinin, Quality of Life Department, EORTC HQ, Brussels, Belgium

In the past, there was a bank



How the Item Bank looked, a long time ago

What we now know as the Item Library began as a totally different type of institution – a bank. After a decade of developing questionnaires, some QLG members suggested that the growing pool of questionnaires and items could be of use when developing new measures. And so, the Item Bank was born – an online repository of already developed and tested items from the EORTC measures, easily searchable and available to QLG members.

The Item Bank allowed users to browse through existing items after identifying relevant issues in the questionnaire development stage. This tool helped foster collaboration, minimise unnecessary additional work, and ensure consistency and a high quality of work. Later on, the addition of translations to the database made it easier to re-use existing wording, which helped to streamline the linguistic development and validation process, and in turn, gave rise to a more consistent, efficient and harmonised approach across all our measures.

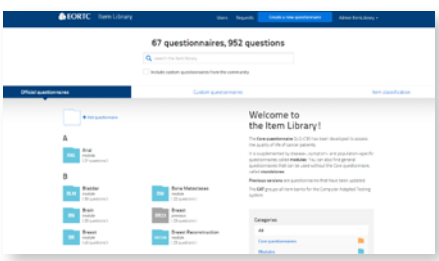
2009 saw the release of the first revamped version of the Item Bank. With all functionalities retained, this version offered a more modern, clean and user-friendly layout, making it easier for developers to browse through the portfolio of items and their available translations.

The Item Bank, revamped

Then the bank changed into a library

In late 2017, development of the long-awaited new platform was complete. After almost a year of hard work on IT development and populating the new database with all the items, the Item Bank officially metamorphosed into the Item Library, as it is known today. The change in name happened for two reasons: one, to differentiate the tool from CAT item banks; and two, to mark the birth of a new tool rather than simply an updated version.

The transformation of the Item Bank was brought about by a novel idea to allow users to make their own item lists from the existing validated items from our measures. This was made possible by a major update to the QLG Assessment Strategy, enabling the creation of customised ad hoc item lists to complement static questionnaires.



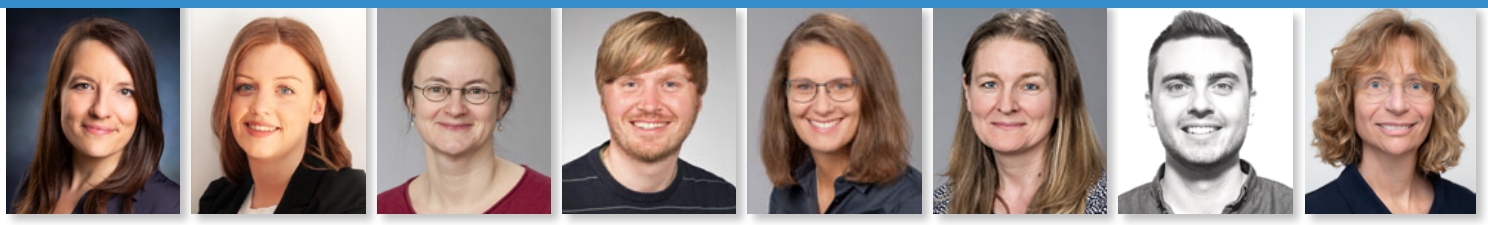
The Item Library: new look, new feel, new purpose

The library is the future

What does the future hold for the Item Library? The possibilities of what can still be achieved are limitless. As the library of customised item lists grows, we will continue to track usage, which may highlight new areas for questionnaire and item development. There is also the potential to systematically validate frequently used item lists, creating a more sophisticated online organisation in which they are classified by treatment and disease type. Building this repository of user-created item lists fits perfectly within the scope of open science ideas, demonstrating that once again, the QLG is at the forefront of the PRO field.

In addition to the current classification by symptom/issue type, as the methodological research continues to progress, we will implement different classification systems, starting with the CTCAE and the WHO's International Classification of Functioning, Disability and Health. These alternative systems will provide another means of searching for items, and make it easier for users wishing to select items based on specific issues or types of functioning. Use of these universal classification systems will also help to ensure that our measures can be compared to others, through use of a common framework.

Equipped with an annual budget from the QLG EC, the Item Library will keep on evolving to meet the needs of patients, researchers, and clinicians alike. No idea is too far-fetched, so please contact us with any functionalities you would like to see implemented!



Reaching the Users of the EORTC Quality of Life Measures: Implementation in Clinical Practice

Monika Sztankay[1], Daniela Krepper[1], Susanne Singer[2], Matthias Büttner[2], Melanie Schranz[2], Andrea Csipak[2], Niclas Hubel[1], Heike Schmidt[3]

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We probably all agree that overcoming obstacles to implementing the EORTC PRO in clinical practice and maintaining its use in clinical research is a challenge that requires commitment, persistence, persuasion, and, above all, teamwork. Therefore, we have joined forces across three QLG projects currently advocating the use of EORTC QoL measures by dedicating research efforts to the clinical use of EORTC QoL instruments in several ways: interpretation of EORTC PRO measures, updating and modernising the reference values for EORTC PRO measures, and developing an e-learning course on EORTC PRO measures in clinical practice. All these projects feed into the EORTC QLG's vision of communicating the value of the Group's measures to various users by building relevant educational materials for researchers, the public and patients to explain and advocate for QoL assessment and its application in both clinical research and routine practice.

Figure 1. Extended portfolio of EORTC QLG guidance documents

DEVELOPMENT OF AN INTERPRETATION GUIDELINE FOR THE EORTC PRO MEASURES

"With this project, we will add to the comprehensive portfolio of QLG guidance documents by developing the EORTC QLG guidance on how to evaluate clinical relevance of the scores derived from the EORTC PRO measures at group or individual patient level."

(PI: Monika Sztankay, Team: Daniela Krepper, Caroline Martini; supported by an international Advisory Board)

For conclusions based on EORTC PRO data to be reliable, robust and clinically meaningful for patient care and outcomes, the correct interpretation of these data needs to be ensured. Scores are abstract; the inherent meaning of PRO scores is not clear, and interpreting PRO data merely via statistical significance is misleading. There is an ongoing debate about how to interpret PRO results, with recent initiatives providing recommendations on PRO data interpretation [1, 2]. Uncertainty in doing so is mirrored in reporting: only 39% of oncology implementations include guidance on this [3], and only 38% of trials with EORTC PRO measures address clinical significance [4].

The QLG aims to bridge this gap. With this project, we will add to the comprehensive portfolio of QLG guidance documents (see Figure 1) by developing the EORTC QLG guidance on how to evaluate clinical relevance of the scores derived from the EORTC PRO measures at group or individual patient level. The guideline will include best practice recommendations on interpreting EORTC PRO / QoL data for scientific and clinical use, based on the available evidence (scale content, minimal important differences, thresholds for clinical relevance and reference values), consensus in the Quality of Life Group based on QLG expertise (among others, from J. Musoro, C. Coens, and J. Giesinger) and the information needs of the users of our measures.

Checking the status quo of the interpretation of QoL as a co-primary/secondary endpoint in trials in major cancer entities using EORTC measures and reaching out to the EORTC disease-oriented groups (DOGs) and stakeholders to assess their perspective on the interpretation of EORTC PRO data are only two of many ongoing tasks in the process of developing the EORTC PRO Interpretation Guidelines.

Figure 2. Aims of the QLQ RV Database Project

We would like to thank everyone who has already shared their knowledge and views with us by participating in our online survey!

UPDATE OF THE EORTC QLQ REFERENCE VALUES MANUAL

"The update will be based on existing evidence from the literature, consensus among experts in the field (from the QLG and beyond), and buy-in from relevant stakeholders."

(PIs: Monika Sztankay & Susanne Singer; Team: Matthias Büttner, Melanie Schranz, Andrea Csipak, Daniela Krepper, Niclas Hubel)

Reference values (RV) for specific patient subgroups or the general population provide the much-needed context to facilitate the interpretation of PRO scores discussed above.

The main goals of this project are:

1. Updating and expanding the pool of RV data sets.
2. Developing a new dynamic IT infrastructure for EORTC RV data management, calculation and presentation (a database, a web-based interactive software interface, and user guidelines including recommendations on the use of EORTC RV and on the handling of the online interface).
3. Standardising the procedures for collecting and updating RV data sets – the infrastructure should enable subsequent continuous updates and data expansion within the established framework.

The update will be based on existing evidence from the literature, consensus among experts in the field (from the QLG and beyond), and

buy-in from relevant stakeholders. The latter will be engaged to assess their needs concerning availability and presentation of EORTC RV data and the type of data required, and to explore the desirable features of a user interface. To enable higher degrees of stratification when using the RV, we plan to enrich the database from different sources. First contact with pharma providers has been established – and we are excited to dig deeper into this!

DEVELOPMENT AND EVALUATION OF AN E-LEARNING COURSE ON EORTC QOL MEASURES IN CLINICAL PRACTICE

"Healthcare professionals (HCPs) are more likely to engage in PRO data collection and use if they have received interactive training addressing their needs ... this project aims to develop the content for an e-learning course for HCPs on the utilisation of EORTC QoL measures, to facilitate the implementation of EORTC QoL measures in clinical practice."

(PI: Heike Schmidt and co-PI for Phase II: Monika Sztankay)

Successful implementation of PROs in clinical practice requires targeted and needs-based training of users. Healthcare professionals (HCPs) are more likely to engage in PRO data collection and use if they have received interactive training addressing their needs [5]. Though recommended for successful integration of PROs into clinical practice, there are no such validated training concepts available for EORTC QoL measures. Interactive and easily accessible e-learning resources for EORTC QoL measures are needed to increase their dissemination and uptake in clinical practice. This project aims to develop the content for an e-learning course for HCPs on the utilisation of EORTC QoL measures, to facilitate the implementation of EORTC QoL measures in clinical practice.

The e-learning course is being developed following a stepwise participatory design approach in cooperation with experts and stakeholders, especially HCPs. Phase I included three individual sources of information for content development (1. Scoping review of relevant literature; 2. Qualitative interviews with HCPs; and 3. An international online survey) and was successfully completed. We invite you to have a look at the first paper on this project reporting on HCPs' preferences for learning content and methods [6].

Based on 73 interviews with HCPs conducted in 9 countries, eight topic areas emerged as essential for inclusion:

1. Basic information on PROs in clinical routine;
2. Benefits of PRO assessments in clinical practice;
3. Implementation of PRO assessments in clinical routine;
4. Setup of PRO assessments for clinical application;
5. Interpretation of PRO data;
6. Integration of PROs into the communication with patients;
7. Use of PROs in clinical practice; and
8. Self-management recommendations for patients based on PROs.

The online survey included a further 233 HCPs from 33 countries who indicated the highest preference for content on: interpretation of PRO data (97%), the description of clinical benefits of assessing PRO data (95.3%), and implementation of routine PRO data assessment (94.8%). Regarding learning methods, participants indicated a high preference for practical examples that use a mixed approach of presentation formats (written, audio, video and interactive).

The grant proposal for the second phase of the project (the actual creation of content and structural development of the e-learning course) was recently submitted. We look forward to further progressing with this project and a big thank you is given to our QLG collaborators for their excellent work!

CONCLUSION

The three ongoing projects described above are building solid resources for the use of EORTC PRO measurements and EORTC PRO data in research and clinical practice. Appropriate, straightforward guidance will encourage transparent and understandable decisions based on EORTC PRO data, being consistent across stakeholder groups and individual decision settings. These joint efforts strengthen the standing of the EORTC QLG as a serious force in medical research and routine clinical practice. Thank you to all our collaborators, our fellow QLG members and the QLD for their valuable work and contributions!

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Changing the Regulatory Focus of PROs

Daniel O'Connor, Medicines and Healthcare products Regulatory Agency (MHRA), UK

'The importance of the patient's point of view on their health status is fully acknowledged and such information may be used in drawing regulatory conclusions regarding treatment effects, in the benefit/risk balance assessment or as specific therapeutic claims.'

This is the opening statement of the European Medicines Agency's guideline on the use of patient-reported outcome (PRO) measures in oncology studies. I was privileged to lead on this guideline over a period of 4 years of development, and it was a significant moment to see it reach publication following dedicated workshops, a written public consultation and input from many different experts, both within the regulatory framework and externally (including patient groups and the EORTC).

The publication of the PRO appendix was an important regulatory milestone, promoting more patient-centric drug development and regulatory decision-making. However, there are a number of other notable initiatives of international importance which are driving up the use of PRO measures, including quality of life tools. These initiatives have recognised the need for multi-stakeholder engagement and as a regulator I have contributed and am contributing to the SPIRIT-PRO Extension (provides consensus-based guidance on PRO-specific information that should be included in clinical trial protocols), the PROTEUS Consortium (promotes the application of the methodologic tools developed to optimise the assessment and reporting of PROs in clinical trials) and the EORTC's IMI SISAQOL project, enthusiastically and expertly led by Andrew Bottomley. The ongoing IMI SISAQOL project has already achieved an impressive body of work, with the much-needed objective of creating standards for the analysis of health-related quality of life and other PRO data in cancer RCTs.

"An outcome of a more patient-centric approach to drug development will be more PRO measures being included in clinical study designs."

In parallel to the development of these standards, IMI PARADIGM's mission is to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement. This is important as patients should be consulted regarding what is important to measure and what they want from their medicines. In the UK in 2019, the Medicines and Healthcare products Regulatory Agency (UK) held a public consultation on patient and public engagement, as the agency wants to adopt a more systematic approach to listening to and involving patients. More recently in 2021, this was built on to develop the Patient Involvement Strategy. An outcome of a more patient-centric approach to drug development will be more PRO measures being included in clinical study designs. This is reflected in the UK Innovative Licensing and Access Pathway (ILAP), where patient engagement and involvement and PRO are topics for discussion in the Target Development Profile (TDP) roadmap.

Outside of clinical trials there is lots of interest in using real-world data to support regulatory decision-making. However, information about how a patient feels and functions, as captured directly from patients themselves, is often missing, and PRO collection has been limited. With colleagues from Birmingham University (Prof. Mel Calvert, UK) and UNC School of Medicine (Prof. Ethan Basch, USA), we published a paper to highlight that without PRO data, real-world evidence will not actually reflect how real patients experience real therapies in the real world, and there is a need for international collaboration to develop the required toolkit to consistently collect PRO in this setting.

Importantly, PROs are also now being applied in many different areas, including in broadening the definition of tolerability (collaborative work with Friends of Cancer Research and others) where the current definition lacks focus on how adverse events can be best evaluated from the patient's perspective) and a Lancet Haematology Commission identifying important areas for improvements of safety reporting in haematological malignancies.

At 40 years old, the QLG has had many successes, and in particular the IMI SISAQOL initiative is bearing fruit of international importance. With improved methodology and practice, and increasing patient engagement, high-quality and clinically meaningful generation of PRO data becomes the norm, and the importance of PROs becomes much less debatable.

Ours to Reason Why: The Importance of Patient-Centred Research

Roger Wilson, CBE

Why are you doing a research study? The answer, of course, is that you are doing it to improve patient care, to deliver benefit to patients. The inference is that your research is patient-centred. Really? After nearly 20 years as a patient involved with research I have recently begun to understand how the patient can be secondary in actual research practice, whatever is claimed otherwise.

All research has an opportunity context: right moment and right place are important; so too are the right people. There are also imperatives which come with the funding. To be fair, direct patient benefit is not necessarily an issue for some studies because other important things are learned. As an example, I am involved currently with a project using technology to gather HRQoL data. The challenges are about managing data, sharing it and understanding how patients and their doctors respond to this opportunity. This is technology-centred research necessarily framed as a patient study. The patient is important and the QoL data will be valuable but a main focus of the study is the technology.

So what do I see looking back on my experience? There is technology-centred research, as in my example. Here what patients do and how they respond are as important as the health-related data they give. The driver is the opportunity to change practice. I have also seen technique-centred research, where similar issues apply. Then there is methodology-based research, which gets trickier. Where one theoretical method (my way of doing it) is tested against another (your way of doing it) the issue of ethics begins to raise its head. People get precious about their ideas, and patient benefit may lie further down the road.

> "I believe that research into Quality of Life, in the widest sense, is important for the future of medical research. The only way of measuring patient benefit reliably is by patients doing it themselves."

Centre-centred research is similar (our way versus their way of doing it) and interestingly cost-centred research can be closely related. As cost underlies so much decision-making in healthcare these days, cost-centred studies can have an immediate impact on patient care, although benefit to the individual patients who participate may be harder to identify.

There are two more approaches where my concerns are raised highest. There is researcher-centred research, driven by the need for publication, citations and so-called 'impact'. Browsing the literature, we can identify studies answering really interesting questions but which deliver no value to patient care. Were they undertaken to further a career, or to score points in an academic review, personal or institutional? Scientific publishers and (some) peer reviewers are complicit in this. I suspect such studies are lazy choices, because if a study is interesting there is a reason for that and it is likely that a different question or approach could potentially have delivered benefit.

Last of all is drug-centred research. This has a commercial driver. The drive for precision medicines in cancer means there is rather a lot of this at the moment. The indicators are surrogate endpoints, small numbers of patients accrued, and accelerated regulatory decisions. None of these lead to significant overall patient benefit, although some individual benefit may be an outcome. Regulatory decisions based on weak data create risks which are then carried by patients, not by regulators.

I am sure you see where I am heading. I believe that research into Quality of Life, in the widest sense, is important for the future of medical research. The only way of measuring patient benefit reliably is by patients doing it themselves. Put a PRO approach into the models I have described and we might 'change the game': research would become patient-centred, and the question of why you are doing it goes away.

Meaning of Quality of Life to Patients: An Ordinary Cancer

Martin Kirby, cancer survivor and patient advocate

I read once that cancer, like the devil, has many names. I know now that it also has its own language, and in that language I am ypT3 N1b M1a. Both name and language are potentially deadly, being as corrosive and destructive as each other, opening a thinly veiled doorway to what is for many a medical and emotional hell. I decided early on, whether by conscious choice or inclination, that I would not enter that first circle of hell. I took no one with me to clinics, and asked few questions; it would simply be another experience. No one wants to hear they have cancer whatever it's called, but tears, rage or regret for my sudden change of status seemed pointless.

Mine was a bloody inconvenient diagnosis (and yes, I too have yet to meet someone who says that their cancer was perfectly timed), as it forced me away from the hot North African sun and fulfilling employment, and back to referendum rage and the prospect of learning the name, type and extent of my cancer; something ubiquitous or slightly fashionable and easy to explain, or something exotic, rare and unpronounceable for which there may be many questions but few reassuring answers. Thinking to spare my family and friends (and probably myself) any social discomfort I had intended not to mention the 'colorectal' tag of my cancer; but this small omission died during the first telling: the time I told myself about the cancer. With that boil lanced and deciding that I was not going to notice the 'Where? Oh there!' look, I told anyone who asked just about everything. I believe that it's called 'oversharing', but I found it enormously cathartic. It allowed me not to worry, in fact almost not to think about the ramifications at all, as I had my CNS, friends and family who did all of the heavy lifting, which allowed me to get on with life while I could.

As things turned out it wasn't quite that simple: there were choices to be made. The cancer had also spread to my liver, and I was asked to participate in a trial. Its outcome, the cheerful and efficient doctor explained, would have no bearing on my medical outcome, but it would shape the clinical choices of those who would follow. Of course I said yes; I was patient 004. By mid-December 2018 I had had two major operations to remove the disease, and was recuperating at home. Six months of chemotherapy started in February 2019, and entailed weekly visits to the wonderful Macmillan Centre in Huntley Street, London.

A year later, and again lying in a hospital bed recovering from another operation, the cold January rain splattering against the ninth-floor windows of the tall, sleek white UCLH building on Euston Road, I considered my situation. So far I had been very fortunate. I liked white wine (in fact insert most alcoholic beverages here), I had liked cigarettes, and I had regularly flown in and out of a war zone for two years teaching in Libya. It could have been far worse, and indeed my chances of survival were slim. However, inexplicably, it had been this work that probably saved my life, landing me, as it did, dazed and confused (I thought I had an amoeba), in one of the best hospitals in the world with a diagnosis far earlier than I would otherwise have had.

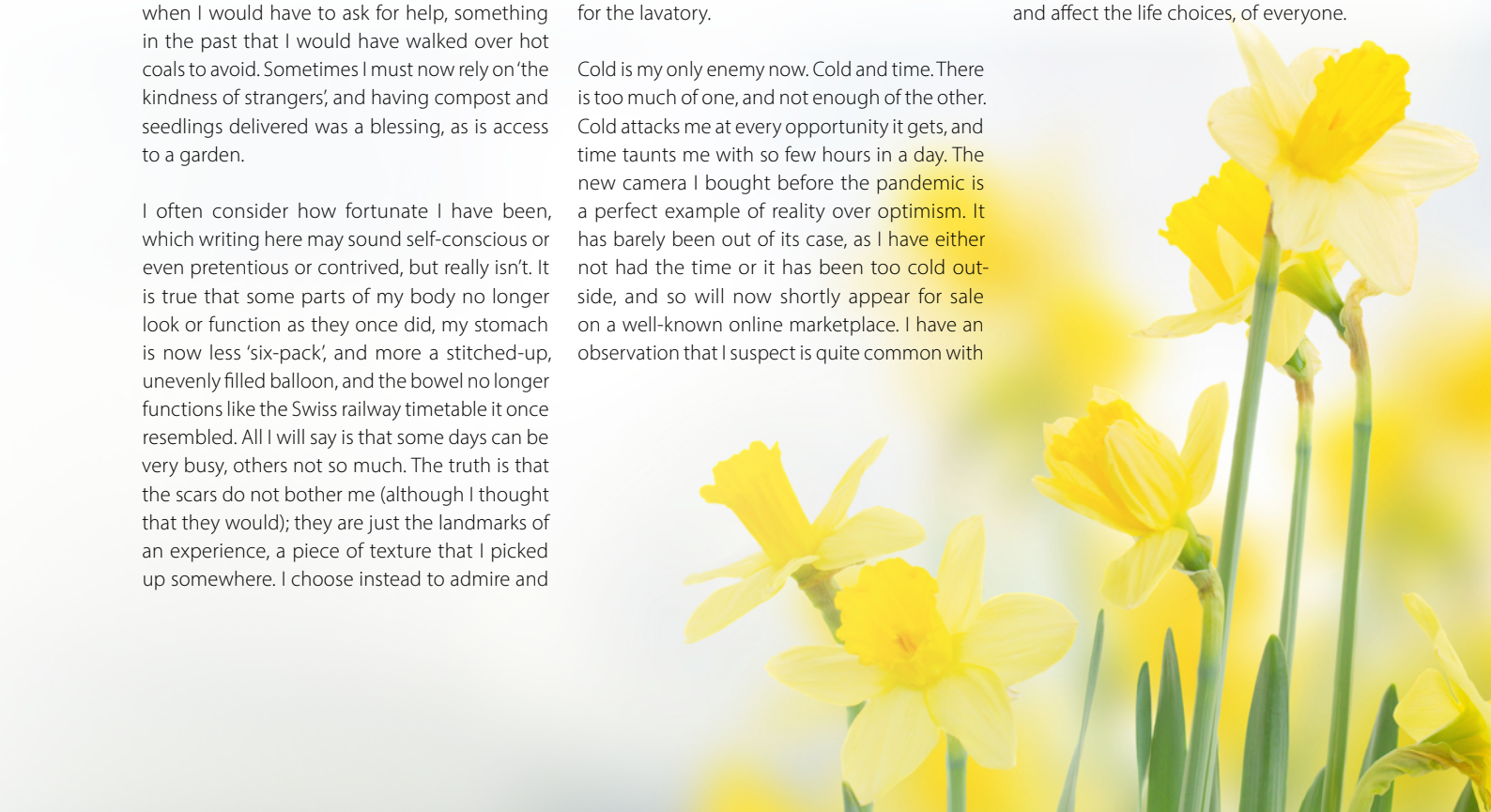
Throughout the treatment process the questions that only really concerned me focused on quality of life. While the medical teams were 'aiming for a complete cure', I concentrated on what that meant in practice. I wanted to be able to walk (I had needed a stick during the chemotherapy), plant seeds, pot-on and plant out, to develop a renewed interest in photography, to write, paint and frame pictures; to basically carry on living as best I could. Should I survive long term, then other horizons may reopen; being able to swim at a quiet Greek island beach, to work in the garden all day, or to be more creative, and to travel more, much more. This last choice in the treatment process, and the one that left me again on that ninth-floor ward, was for a stoma reversal, and while the plumbing is now working, it is far from a normal service. I have been assured that the body will remember and functions will return to normal, but there are no guarantees. Frankly the tumours were less trouble and I have found this hiatus more debilitating than chemotherapy, for which at least there had been a predictable routine. A friend thoughtfully wrote in a card that 2020 would be 'your year', and as Mack (the dog) and I watch storm Ciara rage around us from the warm security of the garden room, I realize that I have been sitting without pain or discomfort for a couple of hours now. I heard someone say once that 'this is probably not the end, but maybe the end of the beginning', and if so, the seeds and pots will be out tomorrow.

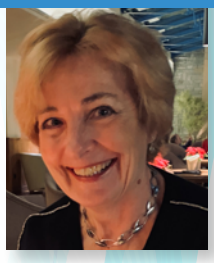
A short update

Two years later and Mack and I are again in the garden room, looking through the three large glass doors, assessing the horticultural prospects for the coming year. Gazing out at the drab drizzly day past cheerful groups of early Narcissus I can confirm that I have spent a lot of time in the garden, and that it has never looked so good. As fate would have it, I was unintentionally prepared for the first lockdown, having bought many of the materials I would come to need when I started to grow plants from seed while having chemotherapy the previous year, and yet more after the stoma reversal. I learnt also that my new reality was that there would be times when I would have to ask for help, something in the past that I would have walked over hot coals to avoid. Sometimes I must now rely on 'the kindness of strangers', and having compost and seedlings delivered was a blessing, as is access to a garden.

I often consider how fortunate I have been, which writing here may sound self-conscious or even pretentious or contrived, but really isn't. It is true that some parts of my body no longer look or function as they once did, my stomach is now less 'six-pack', and more a stitched-up, unevenly filled balloon, and the bowel no longer functions like the Swiss railway timetable it once resembled. All I will say is that some days can be very busy, others not so much. The truth is that the scars do not bother me (although I thought that they would); they are just the landmarks of an experience, a piece of texture that I picked up somewhere. I choose instead to admire and enjoy the 'Tete a Tete' that brighten my day, waving brightly just inches away in the garden. Or indeed to plan the plants and vegetable varieties I would like to introduce this year, and puzzle at how I am going to squeeze them in. Time has gifted me another bonus, as there is far less discomfort than there was two years ago, and I have come to realise that it was not until I really started to feel better and more myself that I could comprehend just how frail and unwell I had been. That, coupled with the well-received, and hopefully honestly delivered 'you look so well' from friends and neighbours, which is obviously pleasing to hear, but is also a compensation for the times I have had to repeatedly abandon guests for the lavatory.

Cold is my only enemy now. Cold and time. There is too much of one, and not enough of the other. Cold attacks me at every opportunity it gets, and time taunts me with so few hours in a day. The new camera I bought before the pandemic is a perfect example of reality over optimism. It has barely been out of its case, as I have either not had the time or it has been too cold outside, and so will now shortly appear for sale on a well-known online marketplace. I have an observation that I suspect is quite common with cancer patients, which is of having experienced intense concerted medical attention. During diagnostics, diagnosis and treatment, I found myself at the centre of a process that focused on me and only me, and on those other me's around me. That family of patients that did not look like me but were in fact just like me. It is a bit disconcerting when that focus recedes ever faster, and the strings of support are slowly cut. The point I think I want to make is that I eventually concluded that I am almost ordinary again, not the same ordinary mentally or physically, but I am generally able to get on with the kind of life I wish to live; and most of the restraints that hold me back in 2022 seem to have invaded the lives, and affect the life choices, of everyone.





Reflections from a Past Chair: Ann Smyth

Professor Ann Smyth, QLG Chair 1997-2000

"I look back with great affection on my experience of working with this international, multidisciplinary group of highly talented and hard-working individuals."

By the 1990s interest in QoL was increasing and more of us were involved in educating, encouraging and supporting others in the appropriate use of QoL assessment, whether in the EORTC cooperative groups, in the pharmaceutical industry or in our local clinical settings. We were very concerned to ensure consistent high quality in work undertaken using our name and the Group became an important reference group for setting and maintaining quality standards. We published rigorous methodological guidelines for the development of modular additions to the QLQ-C30 and for translation of questionnaires. Our statisticians helped us with the analysis of data missing for understandable clinical reasons while we worked hard to identify and overcome the systemic obstacles to effective data collection.

It became clear our modest grant from the EORTC was not sufficient to sustain this increasing volume of activity. In spite of our initial high-minded principles that scientific knowledge should be disseminated freely, we began charging industry for the use of the tools which we had developed, giving us more resource to support the accelerating workload.

As the EORTC appreciated the increasing importance of QoL assessment we were able to establish the QoL Unit as a permanent professional presence in the Data Centre. The status of the Group was enhanced in 1997 when its Chair was invited to serve on the EORTC Board. The EORTC embarked on a major strategic review and organisational reform, following which QoL issues were given greater prominence.

Our members continued to address important fundamental questions, e.g. differential item functioning, or response shift in repeated assessments.

I look back with great affection on my experience of working with this international, multidisciplinary group of highly talented and hard-working individuals. We learned a lot from each other and had a lot of fun doing so. It gives me great pleasure to see how the Group has flourished since then and I wish everyone well in continuing to attend to patients' experiences of cancer and its treatment.

Professor Ann Smyth
EORTC QLG Member 1987-2000;
Secretary 1991-93; Treasurer 1993-96;
Chair 1997-2000

Reflections from a Past Chair: Jane Blazeby

Professor Jane Blazeby, QLG Chair 2003-2005

"The EORTC QLG is a fantastic group with a great vision, and it was an honour to become Chair."

Chairing the Quality of Life Group (QLG) between 2003 and 2005 was an enjoyable and educational experience. Looking back, it felt like the experience of designing and conducting a clinical trial: there are celebrations when the trial wins grant funding, then reality sets in and a sustained major effort is required to optimise trial delivery which critically depends on successful teamwork. The EORTC QLG is a fantastic group with a great vision, and it was an honour to become Chair: major attention to group conduct was needed to keep everyone on board and maintain research outputs. It's nearly 20 years since I led the Group (I had previously chaired the module development committee); but in the last two decades I have often put the skills I learnt during that time into practice. One of my favourite ones I call 'clinical-methodological translation'.

A key feature of the QLG is its multidisciplinarity. Nurses, dieticians, statisticians, methodologists, administrators, social scientists, oncologists, palliative care physicians, and surgeons are among its members. It is multi-cultural and international. Membership ranges from PhD students to senior professors. Some members are 'long in the tooth', while others attend only one meeting. At the time I was Chair I was a practising cancer surgeon with a specialist interest in oesophageal and gastric surgery. I had led the development of a portfolio of EORTC modules for upper gastrointestinal cancers and contributed to many others. As a female surgeon I was trained in making decisions and implementing them sometimes swiftly to save lives, but I needed to take a different approach with the EORTC QLG. I needed to be able to understand psychometrics, practical issues of using patient-reported outcome measures, and to listen well so I could understand how things worked differently in different hospitals and clinical areas. I often found myself 'translating' clinical terms into patient language for questionnaire development. I translated methodological phrases into clinical speak to explain many things (e.g., why we needed to test questionnaires so extensively before they could be used) and I translated clinical language into methodological terminology. At the interface between the disciplines, once we understood each other, it felt as if we made progress.

Following my term as Chair of the QLG I was extensively involved in clinical trials. I led a trials methodology research group for a decade, designed and led several surgical trials, and have worked closely with professional organisations in the UK to develop a new generation of surgeons that understands trials and can design and deliver them. We are aiming for evidence-based surgical oncology practice. Working with the QLG was an important stepping stone on that journey for which I am grateful.

Professor Jane Blazeby
QLG Chair 2003-2005

International Perspective: Australia

Madeleine King, Professor Emeritus, University of Sydney, Australia

"My connection with the QLG began in 1991 when my boss... asked me to find an HRQoL questionnaire for a cancer grant application... Little did I know then that my path would later criss-cross over decades with Neil [Aaronson]'s and those of other early QLG members who became legends in our field, including David Osoba, Peter Fayers, Galina Velikova and Mogens Grønvold..."

Let me begin by congratulating the EORTC Quality of Life Group (QLG) on a magnificent first 40 years, and wishing you well for the next 40! You will surely, as a vibrant research community of clinicians, statisticians, psychometricians and other disciplines, continue setting international best-practice standards in health-related quality of life (HRQoL) questionnaire development, translation, analysis and interpretation as well as championing the value of HRQoL endpoints in cancer clinical trials. It has been a privilege to collaborate with you. Now recently retired, I happily reflect on my experiences as a corresponding member contributing from far-away Australia.

My connection with the QLG began in 1991 when my boss, a professor of health economics at the University of Sydney, asked me to find an HRQoL questionnaire for a cancer grant application. I sent an enquiry to Neil Aaronson via an exciting new communication technology – email! Neil snail-mailed back a pre-publication hard copy of the now legendary 1993 JCNI paper that introduced the QLQ-C30 to the cancer research world, with a hand-written note wishing me well with my research. Little did I know then that my path would later criss-cross over decades with Neil's and those of other early QLG members who became legends in our field including David Osoba, Peter Fayers, Galina Velikova and Mogens Grønvold – all such clever, caring people.

I would have loved to attend two QLG meetings each year, getting to know Europe city by city. But alas, for an Australian, the financial and time cost of the required regular attendance at meetings (at least two QLG meetings over two years) was too great. Hence my long-standing status as a corresponding member. Although this meant I was not able to lead EORTC QLG grants, I contributed to quite a few over the years, some of which I now reflect on.

My EORTC-related work began with my early work on interpretation guidelines for the QLQ-C30, influenced by John Ware's approach with the SF-36. When presenting my findings at ISOQOL's 1995 conference in Montreal, I recall sharing my frustration that the paper had been bench-rejected by various journals – they just didn't get it! I was gratified by the audience's interest, and elated when John handed me a note of encouragement! Thankfully, the paper was published in 1996 in the new journal, *Quality of Life Research*, and became widely cited. These early guidelines have been greatly improved since. One project arose from a presentation I gave at the 2003 Rome QLG meeting. Kim Cocks responded to my call for a collaborator, and then did a superb job during her PhD (co-supervised by Fayers, Velikova and Julia Brown), yielding two papers on evidence-based interpretation guidelines for the QLQ-C30 (2011-2012), now both highly cited. Then there is the notable series of minimally important difference (MID) projects that began as part of the QLG's PROBE Project (Patient Reported Outcomes and Behavioural Evidence) led by Andrew Bottomley (with two MID papers led by John Maringwa, published 2011), and continued in a QLG-funded project led by Corneel Coens, with numerous papers led by Jammbe Musoro from 2018 to 2021, plus an overview paper in preparation. I have enjoyed contributing to all these, and am delighted to see the work continues with a new QLG-funded project, Development of an Interpretation Guideline For the EORTC PRO Measures, led by Monika Sztankay, and that I continue to contribute as a member of the Expert Panel.

The EORTC QLG-led SISAQOL Consortium (Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data), led by Andrew Bottomley, has likewise done such important work! I have been privileged to contribute, also, to the development of two QLQ modules (melanoma and breast reconstruction, led by Julie Winstanley and Zoe Winters, respectively), and some of the QLG's computer adaptive testing (CAT) projects/papers led by Mogens Grønvold and Morten Petersen.

In the past decade I have worked closely with the EORTC QLG Health Technology Working Group, led by Georg Kemmler, with the goal of facilitating the inclusion of HRQoL information from the QLQ-C30 into health policy decisions about funding new treatments for cancer. In 2010, I convened the Multi-Attribute Utility in Cancer (MAUCa) Consortium, including founding members Aaronson, Fayers and Velikova. I was lucky enough to win an Australian grant to develop the preference-based EORTC QLU-C10D plus valuation methodology, then Georg Kemmler and Eva Gamper won several QLG grants to expand the work. This productive collaboration has attracted considerable interest from health economists internationally. The QLU-C10D is now the EORTC's official preference-based measure, with value sets available for Australia, Austria, Canada, France, Germany, Italy, Netherlands, Poland, Singapore, Spain, UK and USA, and further valuation studies underway in China, Denmark and Japan. Despite being retired, I am committed to completing these projects as Professor Emeritus at the University of Sydney. It is a rewarding end to a long career in HRQoL research in which the EORTC QLG has played a key role.

International Perspective: Canada

David Osoba*, Joe Pater, Andrea Bezjak, Jolie Ringash and Michael Brundage, on behalf of the Canadian Cancer Trials Group (CCTG) Quality of Life Committee

Forty is an age with gravitas, one that makes you think about where you've been and where you are going in life. It is a time for late-night, soul-searching (occasionally wine-flavoured) conversations with your best buddies. EORTC QLG: the CCTG Quality of Life Committee is here for you on this big birthday.

After all, weren't we 'young blades'[1] together, back in our salad days[2] (1986….)? Bravely wading out into this new field of 'Quality of Life Research' – David Osoba[3] proposing and Joe Pater[4] accepting that every Canadian cancer trial should have a QoL outcome! Remember the tough old dogs in our profession, criticising us for promoting 'soft science'? If only those Luddites[5] were around now, to see the funding agencies insisting on seeing PROs in our protocols. Anna Sadura et al convinced them by describing 90% compliance in the JNCI paper (even though the reviewers thought perhaps Canadians were 'naturally compliant').

Recall the back and forth between our haunts as we validated the early versions of the QLQ-C30… and learned a lot about patients, QoL and our different cultures in the process… Frits van Dam and Neil Aaronson encountering the 'stubby'[6] Canadian beer bottle, while David was introduced to fine European wines… 'Herman'[7] cartoons on 35mm slides… and the glamorous days of the 90s, Andrea Bezjak[8] and Andrew Bottomley elegant at conferences from Vienna to Vancouver, demonstrating the impact of QoL data in our trials.

Oh, we've been there for you, QLG – through the great PROBE experiment in pooled data (our Canadian patients joining your larger number of European ones), through international guidance initiatives (CONSORT-PRO, SPIRIT-PRO, SISAQOL); through thick and thin, ISOQOL and FDA, from classical testing to item-response theory. Now, we are entering a new era, with PROs and patient-centred care at the core of both clinical trials and clinical practice.

May our long friendship survive today's challenges and continue for another splendid 40 years. Congratulations, old friend – you don't look a day over 35 ☺

*David Osoba sadly passed away on 13 December 2020, but participated enthusiastically in drafting this message to the EORTC QLG in March of 2020.

[1] Dashing young men (authors' note: and women!)
[2] A period of youthful inexperience
[3] Founding Chair of the National Cancer Institute of Canada's Clinical Trials Group QoL Committee
[4] Founding Chair of the National Cancer Institute of Canada's Clinical Trials Group
[5] Someone who is opposed to new technologies or technological change
[6] A short-neck beer bottle; all Canadian beer bottles used to be this way
[7] A comic strip written and drawn by the late Jim Unger, in newspapers from 1975-1992
[8] Former Chair of the CCTG QoL Committee

"We are entering a new era, with PROs and patient-centred care at the core of both clinical trials and clinical practice."



SISAQOL: Setting International Standards in Analysing Patient-Reported Outcomes and Quality Of Life Endpoints Data

Madeline Pe, Corneel Coens and Andrew Bottomley on behalf of the SISAQOL Consortium; Quality of Life Department, EORTC HQ, Brussels, Belgium

Patient-reported outcome (PRO) measures allow the evaluation of benefit/risk assessment of cancer treatments based on a patient's functioning, symptoms and general quality of life. These measures are often rigorously developed and tested with an agreed set of standards to ensure that they are reliable and valid for their context of use. However, the problem comes when these measures are used in clinical trials, where there is a lack of standards related to the analysis and interpretation of PRO data, which can call into question the robustness and reliability of PRO findings.

EORTC launched the Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data (SISAQOL) project in 2016, with the aim of creating international standards for the analysis and interpretation of PRO data in cancer clinical trials. A critical part of SISAQOL was to establish an international and multidisciplinary partnership, consisting of quality of life researchers, statisticians, regulators, HTA representatives, clinicians, and patient organisations. This Consortium was then able to review the best available evidence, and based on consensus, to make recommendations taking into account the different needs and requirements of the various stakeholders.

The first set of SISAQOL consensus recommendations for randomised controlled trials was published in The Lancet Oncology (2020). Additionally, a complementary easy-to-use web tool was developed to aid various stakeholders in formulating relevant PRO research objectives that can be aligned with appropriate SISAQOL-recommended statistical methods to be used for cancer clinical trials. This web tool can be accessed through the SISAQOL website. In the meantime, the initiative has expanded into a public-private collaborative research project under the Innovative Medicines Initiative (IMI) bringing together 41 stakeholder groups.

To improve how PROs are implemented in cancer clinical trials, good methodology should be complemented with good reporting standards. Through the PROTEUS Consortium, SISAQOL is collaborating with SPIRIT-PRO and CONSORT-PRO to ensure that the recommendations are harmonised across these various initiatives and promote the optimal design and reporting of clinical trials. More information on these initiatives can be found below.

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Threshold Scores: Facilitating interpretation of the EORTC patient-reported outcome measures

Johannes M. Giesinger, Medical University of Innsbruck, Austria

Patient-reported outcome (PRO) measures, such as the EORTC questionnaires, have frequently been considered challenging to interpret because of their rather abstract scoring methods. To guide interpretation of scores from these questionnaires, previous studies have provided normative data and defined minimal important differences between groups or between time points. More recently, thresholds allowing the identification of clinically important symptoms and problems have been gaining interest. Such thresholds for clinical importance (TCIs) support the use of PRO measures for screening in daily clinical practice, and allow the conversion of continuous scores into prevalence rates.

In a mixed methods study including 150 cancer patients and health professionals (e.g., oncologists, nurses, psycho-oncologists) in six European countries (Giesinger et al. 2018), followed by a consensus process within the EORTC Quality of Life Group, we have developed criteria for establishing TCIs that reflect the limitations of daily life, the need for help or treatment, or worries by the patient (or his/her family or partner). Relying on these criteria we have developed TCIs for the widely used EORTC QLQ-C30 (Giesinger et al. 2020a) and the EORTC CAT Core (Giesinger et al. 2020b). While the EORTC QLQ-C30 and the EORTC CAT Core, with their coverage of key cancer symptoms and functional health domains relevant across cancer patient groups, may be particularly useful in daily practice, the EORTC measurement system also offers numerous questionnaire modules for the assessment of symptoms and health issues relevant to specific patient groups.

Therefore, in a follow-up project, funded by the EORTC Quality of Life Group, we are currently developing TCIs for seven disease-specific modules (QLQ-LC29 (lung), QLQ-PR25 (prostate), QLQ-BR45 (breast), QLQ-CR29 (colorectal), QLQ-EN24 (endometrium), QLQ-H&N43 (head and neck), and QLQ-OV28 (ovarian cancer)) and the module for elderly cancer patients (QLQ-ELD14). Relying on the same methodological approach as for the development for the QLQ-C30 and the EORTC CAT Core, this additional work will facilitate interpretation of scores from these modules in a consistent manner and foster their use in daily clinical practice.

The success of these projects is only possible thanks to the much-appreciated contribution of both the patients and clinicians, as well as the commitment of the project collaborators*.

* Sincere thanks to the collaborators Neil Aaronson, Juan Arraras, Andrew Bottomley, Giovanni Caocci, Anna Costantini, Fabio Efficace, Mogens Grønvold, Bernhard Holzner, Jacobien Kieffer, Marieke van Leeuwen, Fanny Loth, Morten Petersen, Katarzyna Pogoda, John Ramage, Heike Schmidt, Krzysztof Tomaszewski, and Teresa Young.

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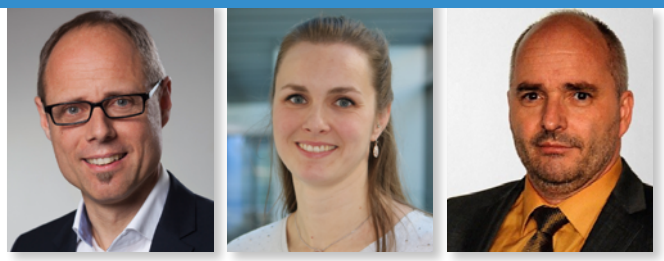

CHES and its Emerging Uses: Promoting the patient's voice in the era of digital health

Bernhard Holzner[1], Lisa M. Wintner[1], Gerhard Rumpold[2, 3],
[1]University Hospital of Psychiatry II, Medical University of Innsbruck, Austria
[2]University Hospital of Medical Psychology, Medical University of Innsbruck, Austria
[3]Evaluation Software Development GmbH, Innsbruck, Austria

It was back in 2011 that the first article about electronic patient-reported outcome (ePRO) assessments with CHES appeared in a QLG newsletter – and since then it has faithfully accompanied the Group's activities, enriched its work and grown with it. At present, CHES services 15 QLG module development and research studies (4 of them in the process of being set up, and 8 having been successfully completed). The international collaborations encompass numerous centres across Europe and Asia, using a broad variety of EORTC questionnaires in a myriad of languages (including those posing special challenges like Arabic or Japanese). Access to the Computerised Adaptive Testing (CAT) engine also enables ePRO assessments to use CAT and all data collected with CHES is securely stored on EORTC servers. The Erasmus Medical Center in Rotterdam is among the first centres with an implementation project assessing the QLQ-C30 for routine screening with the EORTC CAT engine, which it has been doing since October 2021, integrating the results into the patient record. Within the EORTC-1617-QLG-BCG-ROG trial, an interface to VISTA Remote Data Capture, the online capture system for Case Report Forms used by the EORTC, is being developed. This represents a major step forward to facilitate the assessment and integration of ePRO data into EORTC clinical trials.

All these developments show that the collection of ePRO is a growing field which, by far, has not yet exhausted its potential. It can add to clinical trials, health economics and reimbursement decisions, as well as to direct patient care by linking scores with clinical action – for both medical staff and patients themselves. The implementation of ePRO in clinical studies and daily clinical routine generates tremendous amounts of data, which represent a rich source of information and await investigation with artificial intelligence (AI) methods and to bring new and previously unknown insights to light. Hence, ePRO can be seen as a vehicle providing versatile contribution to high-quality healthcare by being a driving force in the transformation of a patriarchal care structure towards a participatory, shared decision-making approach leveraging the patient's voice. https://eortc.ches.pro

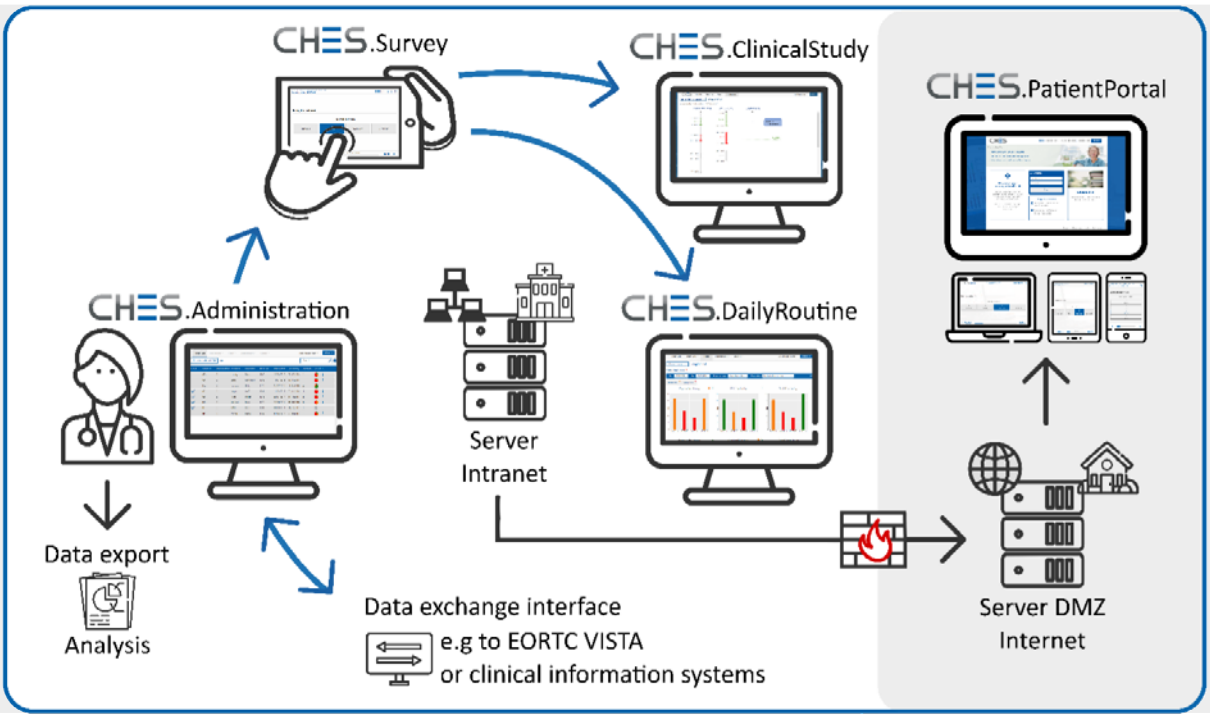

Figure 1. Schematic diagram illustrating the link between ePRO and the VISTA Remote Data Capture System.

Back Together Again: Cyprus Spring 2022 Meeting

Karin Kuljanic, EORTC QLG Secretary and Gracia Dekanic Arbanas, EORTC QLG Assistant Secretary, Clinical Hospital Center Rijeka, Croatia

The EORTC QLG Spring Meeting was held in Cyprus from 26-29 April 2022.

We waited for two years to come to Cyprus, ever since the COVID-19 pandemic forced us to move our meetings online. Our Group was formed over four decades ago, and this was the longest time that we had gone without our face-to-face meetings. Therefore, it was a meeting that many of the members didn't want to miss, while for some of them this was the first time back on a plane after the pandemic.

I was not there at the Cyprus meeting in 2014, but I remember how afterwards the members talked about it with a sparkle in their eye. They would share photos and memories of exploring the island and praise the warm hospitality. Then as now, the host and local organiser was Dr Vasilis Vasiliou, who joined our Group in 2013. His Greek hospitality quickly became known, and in 2014 he set a high bar, which he surpassed himself this spring.

The venue could have not been better selected, and it was a perfect choice after having two years of pandemic fear and months spent in lockdown. The Four Seasons Hotel was very tasteful and beautiful – perfect for recovery after a long and stressful period. A gem of a hotel on the seashore of this wonderful Mediterranean island, with highly professional, kind, and helpful hotel employees, was exactly what we all needed.

The meeting started with a feeling that we might be dreaming: is this really happening?! As the Chair of the Group, Jaap Reijneveld, opened the meeting and welcomed members, I could feel the excitement of the attendees in the plenary room. I don't know if was it just me, but I felt like I had a film running in parallel in my head recollecting past meetings' opening speeches,

remembering past Chairs' greetings… I pinched my left arm and looked around to see if it was all real, and I saw that I was sitting in a room with over 120 other participants listening to Andrew Bottomley, Head of the Quality of Life Department, Vasilis Vasiliou, and Dr Anastasia Constantinidou, the Vice President of the Cyprus Oncology Society, all welcoming the Group and most definitely sharing the same here and now, time and space, together.

As always, the first day was dedicated to the parallel sessions. I would say that our Group has fantastically smart and hardworking members, and accordingly we had a very intense workshop schedule from early in the morning till late in the afternoon, and the timetable was full of interesting new research proposals in the Clinical Trials slot and PMDC sessions. The ideas were sharp, discussion was constructive, and it felt productive thanks to the motivated members whose comments were spontaneous and fast. And something that would never have needed to be mentioned previously: there were no screens in between us. We were side by side with our colleagues and we were able to laugh and share in the same moments: research ideas, discussions, brainstorming, and joking about things old and new.

During the second afternoon's plenary session, we got to hear Kim Cocks's presentation on important scientific work on Qualitative Evidence of Content Validity for the QLQ-C30; Claire Piccinin's linking of the EORTC Item Library to the Common Terminology Criteria for Adverse Events; Madeline Pe talking animatedly on SISAQOL-IMI: First Reflection; and Vasilis Vasiliou sharing experiences of working on the EORTC QLG Anal Cancer Questionnaire.

Thanks to the local expertise and natural hospitality of the host, the social programme was great. We set off strolling along the marina in Limassol, where we had a Group photo taken. Then followed a delicious dinner at the Epsilon restaurant. The dinner on Thursday took us to heaven as it was accompanied by a professional violinist dressed as an angel with feather wings, who played various hits for a couple of hours. We enjoyed traditional dishes and a variety of other flavours, but we also had the opportunity to share and maintain eye contact with others sitting at the table exchanging stories. There was a lot to catch up on! And even after heaven, Friday's dinner at Carob Mill took everyone to the next level: as well as the delicious food, the entertainment was exceptional! A traditional Cypriot dancing show was followed by everyone joining in and dancing the night away. The social events were a fantastic opportunity to network again, as well as gain new collaborators and insight into possible future steps to ensure high-quality research.

Everyone got to take something home as a souvenir from the beautiful meeting in Cyprus. Most of us got sunburn and a sweet rahat lokum in an Afrodite's box. But certainly everyone took with them some new stories to be told back home, ranging from travel adventures to new scientific ideas. Thank you, Vasilis, for your dedication in hosting us all on your beautiful island!

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