



The EORTC QLQ: resetting after COVID



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Dear readers,

One of the biggest non-COVID issues to arise during the pandemic has been the way in which it has affected cancer patients. Many of us have been on the frontline as treatments were paused, procedures delayed and even halted while others of us sought new ways to deliver quality of life studies amid the pandemic. Across the board the pandemic has underlined the extent to which digital interaction is no substitute for the real thing.

This issue of our newsletter is themed '*The EORTC QLQ: resetting after COVID*'. There is much high-level thinking and newspaper coverage about

life after COVID and the great 'reset'. In this issue we begin to unpack this idea and what it might mean for our Group. What have we learnt from the pandemic? What needs to change? How can we recover and what are our priorities going forward? The issue highlights individual group members' takes on 'reset'; how to realise its evolutionary potential and avoid a return to 'set' ways of doing things. It also includes an important update on the development of the OSLO COVID-19 QLQ-PW71 Quality of Life Questionnaire and a commissioned piece on psychological aspects of the pandemic. There are also tributes to our revered members Hanneke de Haes, David Osoba and Frits Van Dam, who died recently.

My editorial role has become a dream job since Cheryl Whittaker took up the reins of assistant editor. Thank you, Cheryl, for keeping everything on course to successful publication.

Uncertainty persists as we each in our separate countries emerge from the various restrictions imposed by the pandemic. A return to life as usual will not cover up the emotional toll COVID has had on so many of us. Even more reason to celebrate our Group and our resolve to shape our future. I hope you agree that this edition of the Newsletter does just that.

Anne Lanceley

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Message from the Chair

Anne-Sophie Darlington,
School of Health Sciences, University of Southampton, UK



It has been an immense privilege to be the Group's Chair for the last three years. We have been able to achieve such a lot in this time, mainly because of the continued dedication of all of you, our group members, to produce the best science – especially during such challenging times.

In the last few years, we have aimed to be more ambitious, staying at the forefront of the science. We've proactively initiated major projects focused on, for example, developing guidelines for effective use of our Item Library, or assessment of quality of life for patients with progressive disease. We are also committed to further funding clinical trial work, carried out in conjunction with the disease-oriented groups. We have also renewed our strategy, to develop a clear vision for our Group, and to have coherent plans for the next five years. As ever we keep growing as a group and we continue to work hard to become quicker and more efficient in everything we do. Increased enthusiasm of researchers to join our Group has also meant that we are able to work on more projects and increase the work. This can only be good.

We have also aimed to be more inclusive and to listen – to patients, to clinicians and to our early career researchers; to continue work to include patients at every stage of our research; to understand the needs of clinicians so that QoL measurement is meaningfully included in clinical practice and trials and incorporated in decision-making; and to think about the needs of those at the start of their career and how we can promote the next generation of research leaders.

The last eighteen months have been dominated by COVID-19 and its consequences. As Chair, I have only led two meetings face to face: one EGAM meeting in Brussels and our Group meeting in Naples. They seem so long ago. But what became acutely apparent to all of us in the Group was that relationships matter. Relationships are everything. We were reminded how well connected we are as a group, which enables us to respond to and overcome challenges within our projects. A strong foundation – which needs to be fuelled by our face-to-face interaction. Hopefully, soon we will be able to connect again and be inspired to do our best work!

“We are ... committed to further funding clinical trial work, carried out in conjunction with the disease-oriented groups. We have also renewed our strategy, to develop a clear vision for our Group, and to have coherent plans for the next five years.”

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Reset means new opportunities

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

Dear fellow QLG members, The theme of this year's newsletter is 'reset', and, without the upfront intention, I'm probably part of it as the new Chair of the Group as of autumn 2021.

The 'reset' in this respect is probably not too big a change for most of you, as I have been a member of the EORTC QLG since 2010, when I was appointed QoL liaison for the EORTC Brain Tumour Group. It was 'love at first sight' for me at the QLG's 2010 Rome meeting, and I've been an active member ever since. In 2012, I became a member of the Executive Committee, and was responsible for this very newsletter myself for the next six years! And from 2015, together with a dedicated team of members of the QLG and the Quality of Life Department (QLD) at EORTC HQ, I contributed to remodelling the Module Development Committee (MDC) into the Project and Module Development Committee (PMDC). You might wonder what's in a name, but the underlying goal was to widen the scope from developing new, and updating existing, QoL questionnaires to also improving analytical methods and involving the disease-orientated EORTC groups (DOGs) in collaborative research projects. In other words, 'not only building planes, but also teaching people how to fly them!'

Throughout my QLG membership, I've always tried to add the clinical perspective to discussions in the Group. I've been involved in many research projects on QoL, cognition and epilepsy in (neuro)oncological patients, some of them funded by the QLG and many of them

“... I will continue along the lines of all the good work already done by Anne-Sophie and her team.”

supported by the QLD. I also served as Secretary of the EORTC Brain Tumour Group from 2015 to 2021, where in return I constantly tried to add the QoL perspective. Currently, I'm combining a research appointment at the Amsterdam University Medical Center in the Netherlands with clinical work at a tertiary referral centre for epilepsy patients, called SEIN. And, good to know, I am also father to three adopted kids of 6, 11 and 13 years of age now, which is quite a job in itself, but extremely good for my quality of life!

The 'reset' in terms of strategy of the QLG won't be too shocking either, as I will continue along the lines of all the good work already done by Anne-Sophie and her team. I am deeply convinced that QoL assessment is crucial in cancer treatment evaluation. Adequate ways of assessing and analysing QoL are pivotal for that purpose, and the QLG is probably the largest group of experts in this field in the world. In order to keep that position we need to consolidate our portfolio of tools, through constantly asking if our questionnaires are up to date. We should also, however, explore new avenues by creating and testing new measurement applications and assessment methods. Our Group should be leading the way in setting standards for study design, data collection and analysis

of QoL data. We have a tremendous amount of expertise, but we should not ignore the outside world in this respect. And by outside world, I mean both the EORTC DOGs and our clinical partners, but also pharma and other health companies and regulatory bodies.

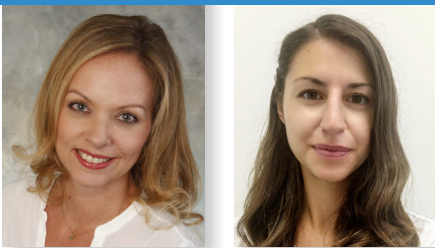
Last but not least, the COVID-19 pandemic 'reset' has had a negative impact on all of us, but might also provide new opportunities. Everyone misses the joy of getting together in person. However, many of you are much more used to digital highways now, which makes connecting a lot easier. Moreover, I remember that shortly before the pandemic several QLG members had already noted that we should rethink our annual meeting agenda, as travelling has such a large environmental footprint. The challenge for our Group in this respect is to find the optimal hybrid between the 'physical' and the 'digital' for our group meetings and all spin-off get-togethers.

Well, it's going to be challenging, but I hope that by serving as Chair, I will have the opportunity to contribute to the success of our Group!



EORTC Quality of Life Group membership facts & figures

Karin Kuljanic & Gracia Dekanic Clinical Hospital Center Rijeka, Croatia



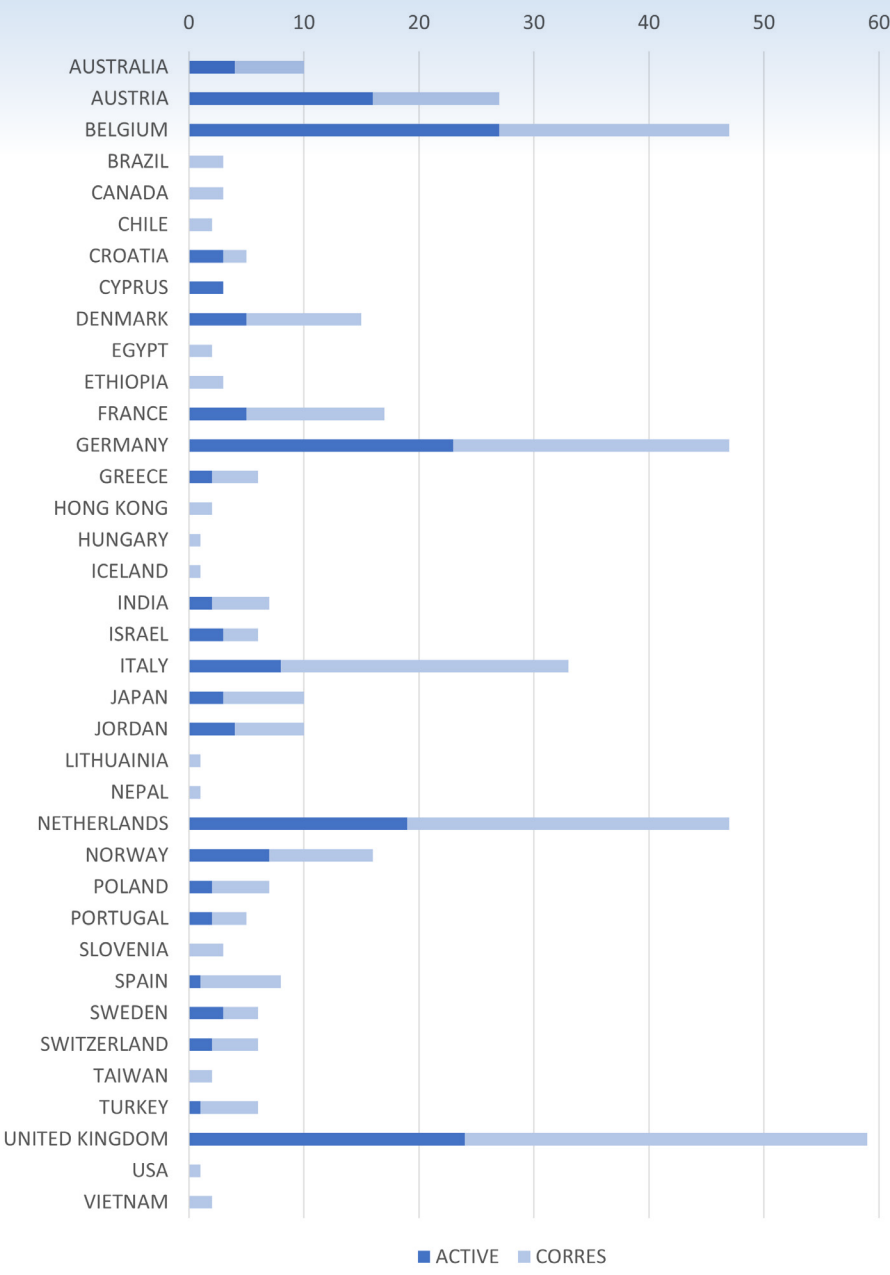
We are pleased to share that our membership list has grown significantly. Several new members from various countries and professional backgrounds have been enthusiastically joining the Quality of Life Group. This puts the QLG on the visible scope of the international arena: as the number of our projects has been substantially increased, our scientific contribution is also rising.

At the moment we have a total of 448 members, of which 165 are active members and 283 are corresponding members. Our work is spreading across the continents and countries as you can see from the graph on the right.

Looking at the quickly rising numbers of members and non-members registering for our meetings, as well as the growing number of new members joining our Group, it is clear that we are widening our network of international collaboration to strengthen both the Group and the work we do. Since the last face-to-face Autumn Meeting in Naples in 2019 we have had 36 new members.

A total of 408 attendees participated in the Autumn Virtual Meeting 2020, and at our Spring Virtual Meeting 2021 there were 446 participants. Although the COVID-19 situation has made it impossible for us to see each other in person, it seems that since we moved our meetings online, more participants have been able to join the QLG meetings. This is helping our science community grow faster and allowing more ideas to be shared. We are grateful to the local organisers of our Amsterdam meeting, who have waited a whole year to host the next Group meeting, which we hope will be a hybrid meeting, in September 2021.

But hybrid or not, we are looking forward to seeing you all, any way you can attend!



QLG membership information

There have been some changes to the way our membership works, so we are providing the details below.

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 the QLG you become a corresponding member of the QLG. Attending two QLG meetings within 2 year 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: <http://groups.eortc.be/qol/>

SAVE THE DATES!

16-17 September 2021: Amsterdam

The QLG autumn meeting this year is planned to be a hybrid virtual and in-person event. The hosting city, if the pandemic allows, will be Amsterdam, The Netherlands. We will continue to keep members updated as the situation develops.

26-29 April 2022: Limassol

Something to pack your suitcase for: we'll be returning to Limassol, Cyprus in 2022, where the excellent hosts led by Vassilios Vassiliou will facilitate a long-awaited reunion for QLG members.

22-23 September 2022: Innsbruck

Next autumn, the wonderful team in Innsbruck, Austria will once again play host to the QLG meeting. We hope by then to have fully 'reset'!

Remembering Hanneke de Haes

Mirjam Sprangers, Academic Medical Center, University of Amsterdam, The Netherlands



Hanneke de Haes, professor emeritus at Amsterdam University Medical Centers (UMC), unexpectedly passed away on 21 November 2020.

Hanneke participated in the EORTC Quality of Life Group from 1984 to 2000. By being an early member, she had a profound impact on the Group's mission and direction and can be considered one of the founding mothers. She was a pioneer and visionary: she united people towards a vision of what the field could become. Not surprisingly, she was also the co-founder of other networks, including the European Society for Psycho-social Oncology, the Dutch Society for Psychosocial Oncology, and the European Association for Communication in Healthcare.

Hanneke joined the Department of Medical Psychology of the Academic Medical Center in Amsterdam, the Netherlands – now Amsterdam UMC – in 1990. In 1995, she became Professor of Medical Psychology, and, immediately after, Department Chair. She kept both roles until her retirement in 2014. I joined her department in 1995. At that time, she handed over her research line on quality of life to me and started a new research line on medical communication from scratch. It was a daring endeavour, but it turned out to be highly successful. As Deputy Chair and colleague, I collaborated closely with Hanneke and witnessed her in many roles.

Throughout her career, Hanneke's mission was to enhance patients' quality of life and to improve the communication between physicians and patients. She laid the groundwork for the fields of quality of life, psycho-oncology,



medical decision-making, and communication in healthcare. Hanneke has supervised, mentored and inspired numerous PhD students and researchers both nationally and internationally. For her efforts, she was awarded many prestigious prizes and given a knighthood in the order of the Dutch Lion. In recent years, after her retirement, she stimulated and safeguarded the principles of scientific integrity as Ombudsman for Scientific Integrity at Amsterdam UMC and Confidential Adviser for Scientific Integrity for the entire University of Amsterdam.

I experienced Hanneke as a 'mensch' in the Yiddish sense of the word. A mensch is not just a human being, but a noble, humane person with a high level of integrity. She created a safe environment for all of my colleagues by listening to them and accepting and respecting them. At the same time, she did not avoid confrontation; she did not spare anyone. She was capable of providing incisive – but always constructive – feedback, thereby helping her target to grow as a professional and as a person. Thanks to this combination of characteristics, she is for me and many others a role model: as an excellent scientist, an outstanding board member and a respectful and reliable head of department. She was also gifted with a warm personality. She was wise, caring and kind. And she was critical, not in the least toward herself. In short, she was a person to love.

I feel immense gratitude to have been able to learn so much from her in her role as superior, colleague and friend. I will remember Hanneke for the person she was: inquisitive in seeking answers to scientific and clinically relevant questions, critically reflecting on the scientific process, and personally involved with her many colleagues and friends.

Tribute to David Osoba

Neil Aaronson, Netherlands Cancer Institute, The Netherlands

Dr David Osoba, a key player internationally in incorporating health-related quality of life considerations into clinical research and clinical practice in oncology, passed away on 13 December 2020 from complications of Parkinson's disease. Born and raised in Alberta, Canada, David first had a very successful clinical and research career as an immunologist. After a sabbatical year in Kenya and Tanzania, he returned to Canada to pursue a full-time career in clinical oncology, first in Toronto and later in Vancouver, British Columbia, where he was Professor of Medicine at the University of British Columbia and Head of the Communities Oncology programme at the British Columbia Cancer Agency.

David was an active member of the National Cancer Institute of Canada's Clinical Trials Group where, in the late 1980s, he served as the inaugural chair of its Quality of Life Committee. At

that time, the science of health-related quality of life (HRQoL) research within oncology was in its infancy. David, as a respected clinician and clinical researcher, was passionate about the role of the patient's voice in clinical research and care.

It was also in the late 1980s that David joined the EORTC Quality of Life Group, serving as a liaison with the NCIC. Perhaps his greatest contribution around that time was demonstrating, together with his Canadian clinical trials colleagues, that HRQoL measures could be successfully integrated into phase III clinical trials and that they had clear added value in evaluating emerging cancer treatments. Another key contribution was his seminal paper, published in the Journal of Clinical Oncology in 1998, which has been cited more than 2,500 times in the journal literature, that provided guidelines for defining and interpreting clinically relevant change scores for the QLQ-C30. David was the author of more than 150 publications in the scientific journal literature, edited one of the first books on quality of life in cancer, was a long-standing associate editor of the journal Quality of Life Research, and was a frequent invited speaker at professional meetings and conferences.

David also served on the board of directors of the International Society for Quality of Life Research (ISOQOL) from 1995 to 2003, and was its President in 2001-02. He brought a critical eye, a clinician's perspective, and a sense of mission to the deliberations within the board and to discussions at the annual scientific meetings. In 2006, David received ISOQOL's prestigious 'President's Award' in recognition of his outstanding contributions to the Society and to the field.

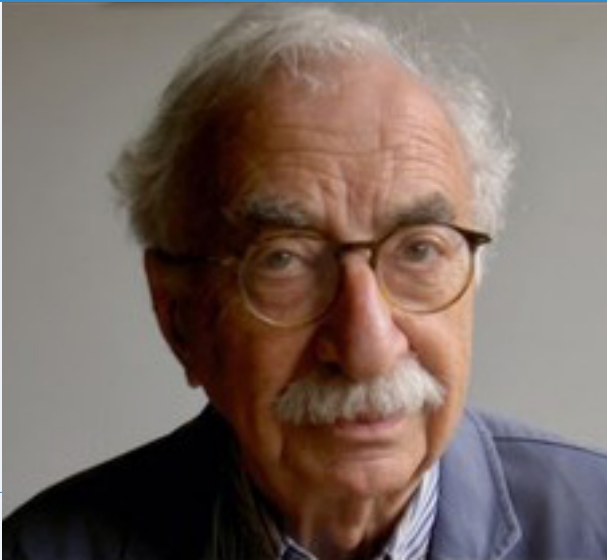


Those of us who were lucky enough to know David beyond his professional role were rewarded with loyalty and friendship. He had an active, if somewhat corny, sense of humour, and he loved nothing more than to trade jokes during meals and over a glass of wine, with a twinkle in his eye. He was a long-term practitioner of meditation, a fervent birder, an avid baseball fan, a choir singer, a sailor, a golfer, and he even pursued line dancing for a time.

David's legacy is his body of work, his vision of a more comprehensive approach to clinical research and practice that encompasses the whole person, and his sense of commitment to colleagues, family and friends. Our thoughts and best wishes go out to Leslie, his loving and lovely wife, his children and his extended family and circle of friends.

Frits van Dam : Goodbye to a founding father

Neil Aaronson and Sanne Schagen, Netherlands Cancer Institute, The Netherlands



Professor Frits van Dam, a pioneer in the field of psychosocial oncology and one of the initiators and founding members of the EORTC Quality of Life Group, passed away on 26 July 2021 at the age of 81. Born and raised in Amsterdam, Frits began his professional career in the Department of Clinical Psychology at the University of Amsterdam, where he became part-time professor, with a chair in Quality of Life in Chronic Illness. Early in his career, he joined the staff of the Netherlands Cancer Institute/Antoni van Leeuwenhoek Hospital, a specialised research institute and cancer treatment centre in Amsterdam, as its first clinical psychologist.

Frits' first major research line focused on the study of quality of life and symptom burden experienced by people with cancer. In 1980, together with other colleagues, including Hanneke de Haes and Jan Bernheim, Frits initiated the EORTC Quality of Life Group, with the then quite novel goal of integrating the assessment of patients' quality of life as an integral part of clinical trials in oncology. Frits successfully secured a major grant from the Dutch Cancer Society for a full-time postdoc position within the EORTC to kick-start the development, psychometric testing and implementation of QoL measures in EORTC clinical trials. The rest, as they say, is history.

Frits was also one of the founders of the European Psychosocial Oncology Society (ESPO), which eventually merged with its American counterpart to form the International Psycho-oncology Society (IPOS). And he was successful in obtaining a designation from the

World Health Organization as the Amsterdam Collaborating Center for Research and Training in Methods of Assessment of Quality of Life in Relation to Health Care.

In his work at the NKI-AVL, Frits developed other research lines to investigate and ultimately improve cancer pain management, speech and sense of smell following laryngectomy, and the neurocognitive functioning of cancer patients. He also had a long-standing interest in cancer patients' use of alternative medicine. He was an active and long-standing member of the Dutch Association Against Medical Quackery, serving as its secretary for 20 years.

Frits was an exceptional supervisor, direct and critical, patient and supportive, intense and driven. He brought out the best in people, and taught young researchers the importance of dialogue – with fellow researchers, with health-care providers, and with patients. His research ideas emerged from the clinic, and he always emphasised to his students the importance of implementing the results of their research in daily clinical practice. In 2006, Frits received the prestigious Muntendam Prize of the Dutch Cancer Society for his efforts to 'build a bridge between doctors, psychologists and nurses'.

Years after his formal retirement from the NKI-AVL, Frits joined forces with several prominent lung physicians to fight the tobacco lobby in the Netherlands in an effort to dramatically reduce the incidence of smoking among young people. He was secretary of the Smoking Prevention Youth Foundation and editor-in-chief of the website TabakNee.

Frits was a smart, tenacious, humorous, caring, generous and involved colleague, teacher and friend. His passion for his work bore fruit in the knowledge it generated, and in the improvements in clinical care that it facilitated.

Our thoughts and best wishes go out to Mies, his wife, to his family and to his many friends and close colleagues.

QLG Heroes

What ‘reset’ means to our QLG members

‘Deeply wishing that having to talk to your dad in the Nursing Home from behind a glass window will be over before it is too late.’

Dr Serdar Turhal

‘The first sunny spring days helped to overcome the COVID winter and I’ll be very happy to see everybody soon.’

Andreas Boehm

‘Although I’ve witnessed the difficulties, concerns, and anxieties related to the successive waves of the COVID pandemic, in patients and the youth especially, my life as a psycho-oncologist, researcher and clinician has been quite stable and productive. I have been able to maintain a rhythm between my clinical work at the hospital and face-to-face relationships, and teleworking for research at home, interacting through Visio conferences and so having the pleasure of interacting with colleagues not only through email but also visually.

To be able to still attend the EORTC QLG meetings, which were carried out smoothly in spite of the limited technical conditions, was a real support. It is always moving and very pleasant to see each other again, even if it’s at the obligatory distance.’

Anne Bredart

‘The COVID-19 pandemic has caused a public health crisis the world has never experienced before. It has had a major effect on our lives with many facing very stressful and overwhelming challenges.

Despite these challenges, our Radiation Oncology team at the Jules Bordet oncology centre in Belgium showed great strength during the crisis and adapted strategies to ensure the continued delivery of high-quality treatments to all our patients.

We are very proud to say that our academic activity has also continued throughout the pandemic. Besides 11 ongoing PhDs and participation in a lot of studies, we managed to actively participate in the QLG study led by Susanne Singer and Kathy Taylor on late side effects in Head and Neck Survivorship.’

Dr Tatiana Dragan



The Radiation Oncology team at the Jules Bordet Institute

QLG Heroes

‘Reset’ for the TOUR teams

Mieke Van Hemelrijck, School of Cancer and Pharmaceutical Studies, King's College London, UK

Resetting

Whilst several of our trials and studies have been blocked due to delayed R&D and ethics approval, we have found a way to continue patient-centred research. We have developed an entirely new workstream focused on COVID and cancer, which has focused on treatment outcomes, risk factors, and the patient experience. We have published >10 papers and presented >15 abstracts at cancer conferences. It has also provided an opportunity for our academic team to work more closely with the clinical teams, and this has now led to a wider strategy to develop our Real World Evidence Programme – which also incorporates a specific focus on the implementation of PROMs collection in our Cancer Centre. However, reset also means that we have to continue finding ways to re-start our trials and studies, a challenge that is proving difficult on a daily basis.

Adapting

We have been working from home since 13 March 2020, but many of us have been coming in since last summer for a few days a month to ensure our clinical studies can continue. Microsoft Teams is our daily way of communicating and we were all looking forward to our TOUR garden party in June 2021. A positive outcome of COVID is that our travel budget has not limited our attendance at the QLG meeting. All our team members interested in QoL research were able to attend and as a result have engaged in a variety of projects.

Lessons learned

While COVID-19 has been a challenge for all of us on a work and a personal level, working in a supportive team where patient care is at the heart of the research strategy has made it possible for all of us to get through. Social interaction is important and even though online quizzes are fun, we cannot wait to hang out again in person and share our stories and experiences – whether that is work related or not. Quality of life is important, not only from a research point of view.



Translational Oncology and Urology Research (TOUR) team: a multidisciplinary team of epidemiologists, data scientists, qualitative researchers, trial coordinators, and a patient and public involvement coordinator.

HEAR FROM SOME OF THE TEAM...



Louis Fox, Research Associate

‘Having passed my PhD during lockdown, I am looking forward to resetting by being able to return physically to work and embrace the team dynamic that you only get from working together in person. The pandemic has taught me a lot about myself and my ambitions in life. I think that the health sciences community has learnt a lot about itself too, and I hope that these lessons are taken and used for evolution, rather than reset.’



Elke Rammant, Research Fellow

‘I’m “resetting” from the COVID pandemic in a new country and a new research team. In March 2021 I moved from Belgium to London. After I moved country everything started to re-open again in London so I chose the right time! I’m still working from home but I have a great roomie (Katharina Beyer), who is also from the TOUR team, and we have created a cosy and sporty home office. So, no place better to reset from the pandemic!’



Charlotte Moss, Database and Project Manager

‘Despite the struggles and difficulties of living and working during the pandemic, there have also been some silver linings which I will take forward in my working life. I started my PhD last April and am optimistic that the move towards telemedicine will assist with the successful implementation of routine PROM collection in our Cancer Centre, the primary aim of my thesis. In addition, COVID has provided me with the opportunity to work collaboratively with many healthcare professionals and research staff who I may never have crossed paths with before the pandemic, and I am looking forward to continuing these projects long after the reset.’

Updates and lessons learned from the COVID-QLQ project

Kristin Bjordal and Cecilie Amdal, University Hospital Oslo, Norway

In the EORTC newsletter of September 2020, we explained our development of an international COVID-19-specific health-related quality of life questionnaire (QLQ) together with colleagues from the EORTC Quality of Life Department, the Quality of Life Group and other partners.

This exciting and educational process started in April 2020, a few weeks after the pandemic came to Europe. Based upon the module development guidelines, Phase I, Phase II, and Phase IIIA with pretesting of the preliminary version in 49 patients from ten countries followed by item reduction, the OSLO COVID-19 QLQ-PW71 has now been finalised. The name of the questionnaire follows the usual format of the EORTC questionnaire titles, with QLQ- and the number of items. The 'PW' stands for 'provisional, weekly version'. Upon request from the FDA, we also have a daily version, the OSLO COVID-19 QLQ-PD71 (where 'D' stands for 'daily'). The 'P' will be removed from both titles once Phase III is completed.

The QLQ's methodological framework is very useful in such a crossover project from cancer to other diseases. The available resources, established infrastructure and international network made it possible to initiate and perform this work in an ultra-efficient manner. Suitable items were identified in the EORTC Item Library for the majority of issues identified in Phase I. Dagmara Kuliś played a key role in this work. Previously established relationships and collaboration with partners and friends in the QLQ have been essential for our success so far.

The project benefited from the initial fast-track systems established for COVID-19 research in

“This is an example of what we can accomplish when we roll up our sleeves and stand together.”

the first weeks of the pandemic. Enthusiasm in the research community arising from the sense of importance and urgency was essential. We all felt there was a clear need for a COVID-19-specific QLQ, due to the major impact on patients' quality of life at diagnosis and during the active disease stage. Over the past year, it has become evident that patients also face long-term health-related consequences. The FDA and WHO were involved from the start. They provided valuable input and facilitated contact with collaborators outside Europe.

Although the process has been completed quickly compared to the normal timelines for questionnaire development, in the end some things took more time than first expected. Obtaining ethical approvals was increasingly challenging in some countries. In Norway, the ethical approval for Phases I and II took only two weeks thanks to a fast-track system available during the spring of 2020. But then the approval of Phase III took three months. In other countries, Phase III was delayed by up to five months (UK) due to the ethical approval process.

As COVID-19 was a new disease, the peer-review process of published papers was less strict than usual. A huge amount of literature of variable quality was constantly being published, and the systematic literature search was updated twice. Long COVID issues were not applicable

from the start and different measures had to be implemented to pick up new issues along the way. Naturally, this was a problem for our reviewers in Quality of Life research, but now, the literature review has finally been published! (doi:<https://doi.org/10.1007/S11136-021-02908-Z>)

Another challenge was periods with low prevalence of COVID-19 in collaborating countries leading to low patient recruitment. This highlighted the need to expand the collaboration to more countries. We also had to rethink how to recruit and interview patients that were really sick, hospitalised or in isolation at home. New ways of obtaining informed consent were needed and consent by email or SMS was approved. As face-to-face interviews required personal protective equipment, interviews performed by video or telephone were allowed.

This is an example of what we can accomplish when we roll up our sleeves and stand together. We hope that experiences from this project will inspire other members of the Group to undertake new crossover projects using the available resources, established infrastructure and international network provided by the EORTC QLQ.



Daily electronic symptom monitoring in paediatric oncology: showcasing the value of eHealth solutions during the pandemic

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Towards the end of 2019, we implemented electronic in- and outpatient symptom monitoring at the Medical University of Innsbruck for paediatric patients with newly diagnosed cancer. Little did we know that it was perfect timing to set up an eHealth solution that incorporates remote monitoring. In fact, the ePROtect platform (running on CHES; see Figure 1) not only hit a sweet spot in terms of enriching the inpatient care of our young patients, it also enabled the healthcare team to interact with patients and parents during the COVID-19 lockdowns. In a way, the pandemic turned out to be a powerful driver of eHealth solutions – a notion that was shared all around the globe.

Using ePROtect, patients can complete short item lists of cancer-relevant symptoms and a more extensive questionnaire at longer intervals. For younger children (<5 years), parents complete proxy reports as well as reporting their own quality of life. The item lists were constructed and adapted for different age groups (2-4 years, 5-7 years, >8 years) and assess relevant symptoms such as pain, sleep impairments, or nausea. The reported symptoms are screened daily and if a high symptom burden is reported, the treating physician contacts the family to enquire about the symptom and discuss further action. This kind of continued communication with the treatment team, especially after a patient has been discharged, has resonated with both patients and parents. We are delighted to announce that a first case report of the use of ePROtect is now in press (Meryk et al.: 'Bridging the gap in outpatient care: Can a daily patient-reported outcome measure (PROM) help?'). In the case report, we describe the therapeutic benefit of rapid symptom detection and early admission of a case of severe mucositis after chemotherapy (see Figure 2).

In Figure 2 (A), a child's self-report of symptoms reaches threshold for sleep impairments (day 0 on x-axis). The parents were contacted via telephone and the child was admitted to the hospital the same day (inpatient stay marked in red). Figure 2 (B) shows that the CRP value reached its peak 6 days after the symptom report that led to the admission. And in Figure 2 (C), the WHO mucositis grading reached its peak two days after the admission. Admission without the symptom report would likely have been delayed by 2-3 days and in turn would have delayed the subsequent treatment.

Despite these positives, we also realised that all current instruments for assessing health-related quality of life in children with cancer have some problems regarding questionnaire development (e.g., they were developed a long time ago with different standards), content validity, or psychometrics. Moreover, they are often complex in their application (e.g., too long, or with ambiguous wording) and not sufficiently validated. The development of an EORTC paediatric quality of life questionnaire (PIs: David Riedl & Samantha Sodergren) is therefore greatly anticipated, not only for use in clinical trials but also for clinical practice.

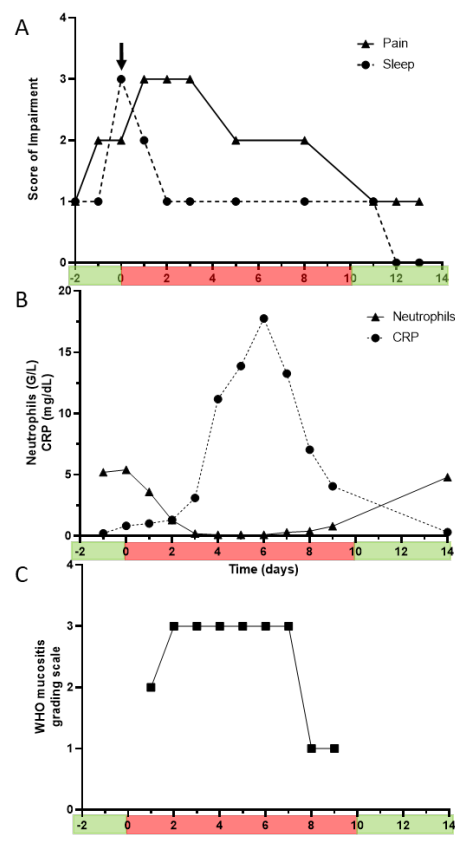


Figure 2 Early identification of mucositis via symptom self-reporting.

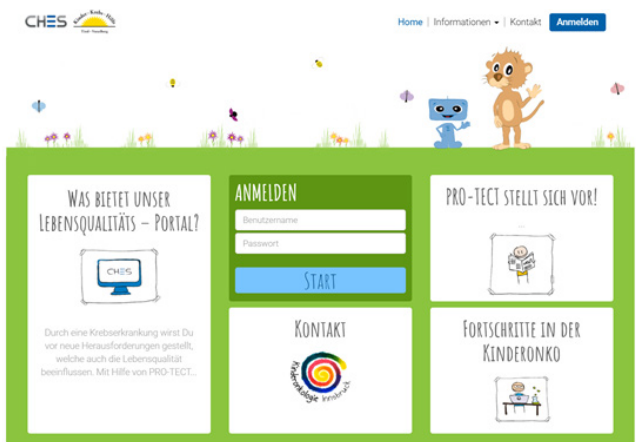


Figure 1 Screenshot of the entry page of the ePROtect patient portal (<https://ches.tirol-kliniken.at/protect-portal>).



Between suffering and defence: the psychological effects of COVID-19

Susanne Singer, University Medical Centre Mainz, Germany

‘They all came in briefly, did what was necessary, and were out again in a flash.’

These are the words of Mrs Smith,¹ a COVID-19 survivor. She is a physician in her sixties. When the pandemic started, she was asked to help in a local test centre, at a time when the role of aerosols was unclear and no protective measures were taken, which is why she became infected relatively quickly. Her symptoms worsened rapidly and so she went to the hospital for a check – the test results were negative, but she was kept there for infusions. A subsequent CT scan then showed severe lung problems. She was informed that she had to receive general anaesthesia within the next 10 minutes. She was only just able to inform her relatives and then she was ‘away’, as she puts it, for two weeks.

After waking up, she suffered from a symptomatic transitory psychotic syndrome with hallucinations. She missed conversations with the doctors and nurses about her situation and her future. Nobody stayed in the room, and she felt left alone with all her questions and anxieties. She says:

‘The reason... I wanted to be discharged from the hospital and go home as soon as possible was that the [doctor] came into the room in the morning for the ward round, in his protective gear, and he said, literally: “How are you? Well, I see you are fine; then I will be back tomorrow,” and left the room. And I felt there was nobody who talked to me, you know, what happens now, how long will I be here... And that was difficult, to communicate with anybody in the hospital. They all came in briefly, did what was necessary, and were out again in a flash... That was horrible. [...] One would have liked to have a perspective, what are the next steps, the procedures, how long do I have to stay here, how will my health develop?’

But it is not only that she missed information. There was also a threat to her autonomy and dignity because her ability to move around was drastically reduced:

‘I... was not allowed to get up. There were bed-rails; they were up for one week in this room. And in that week... this led to a loss of muscles of course. So, I could not get up to use the lavatory. When I told the nurses “I would like to use

the lavatory,” they replied: “You have a diaper, go and have a shit in that.” And that is, well, not what you’d expect as a patient.’

We have conducted interviews with other COVID-19 survivors, and the same theme came up in every conversation: being left alone or feeling that they were alone at a time of considerable existential fear. Another theme frequently mentioned was problems due to the collapse of the assistance systems – doctors themselves became infected or had to go into quarantine and were thus no longer available as helpers; health insurance companies declined to pay for the hospital stay because COVID-19 was not yet in their catalogue of diseases; etc. Of course, there were also economic worries, including those that arose due to long-term effects of the disease.

Why am I telling this story? Because it shows several layers of the psychological aspects of this pandemic. First, there is this enormous fear. It is fuelled by knowing that there is a potentially deadly threat and by not knowing what to do to protect oneself against it. This alone is a recipe for nightmares. In such a situation, talking to other people and sharing one’s emotions with others usually helps. However, these very interactions have been

prohibited because of the infectious nature of the coronavirus! We have had to keep a distance while we need proximity. Consequently, the usual psychological adaption processes are hindered.

Another layer in this vignette is how people deal with their anxieties when the usual adaption process is not possible – they turn to other defence mechanisms. Understandably perhaps given the depth of the anxiety, they use, for example, flight (the doctor leaves the room as quickly as possible) or displacement (the nurse turns aggressively against the patient instead of the against virus that frightens her). Another defence we often observed is denial – people claiming that the virus does not exist or that it is nothing more than a common cold. A contrary behaviour we can often see in health authorities or in other people in positions of responsibility is the wish to control the pandemic (and probably also to control their own anxieties) by prohibiting everything – every single contact, every single move. Better safe than sorry. This has in some part led to delayed treatment for patients with cancer and other chronic diseases.

We all have our own ways of dealing with this anxiety, we have our own style of defence, and there is no right or wrong. It is important to acknowledge that we do (or don’t do) many things exactly

because of that – because of our anxieties, and not (only) because of ‘facts’.

So, what can we do to support COVID-19 patients, their relatives, and their healthcare providers? None of us are out of the reach of COVID-19: we are all susceptible to becoming sick, we are all unfamiliar with it and none of us know enough about it. Therefore, providing a lot of information is not something we can offer. However, we can still be supportive. How?

We found in our interviews that the patients were able to deal with their emotions best when they experienced interest and attention from family members, friends, employers, colleagues, employees of the health authorities, and medical personnel. Interest and attention – this is what is needed, not necessarily information. Patients know that we cannot provide a lot of information, and that we do not know what will happen to them. But they acknowledge our efforts to understand the disease and their personal situation. We can simply address the difficulties they (and we) are going through. We can show respect. We can express our attention and care. By doing so, we can stay close to them despite physical distancing and therefore support them in coping with the disease.

¹ Name changed due to data protection



Creating a new vision for the Quality of Life Group

Roger Wilson, Keena McKillen, Johnnie Moore

Keena and Johnnie were the outside facilitators of the vision process and Roger is a cancer patient who has worked with EORTC and the QLG for over 10 years.

One of the consequences of the pandemic was the postponement of a strategy meeting planned for early 2020 in London. The aim was for the EORTC Quality of Life Group to rethink its strategic vision. A two-day face-to-face in London was thought to be the best way to work on this together, assembling practitioners, researchers and patient representatives to review the past few years and shape plans for the future.

However, postponement brought on the realisation that we'd have to try to do this online instead. Expectations were not high: many of us were pretty 'Zoomed-out' by the end of 2020. And could we really create online the exchange of ideas that a live event would have provided?

Nonetheless, we scheduled a series of five one-hour sessions over Zoom, hoping for the best but being careful not to expect too much.

We were pleasantly surprised at how things worked out. By breaking the meeting into bite-sized chunks, we spread the workload and built in lots of time to reflect on what we were achieving. Moving online made it more inclusive: it was much easier for participants to join for an hour rather than commit to the stress and time of flying all the way to a remote city. We used a simple participatory process. There was no PowerPoint. Instead, we framed simple questions for each session and created lots of small, more intimate breakout groups which encouraged involvement and allowed creative conversations to emerge.

At the first meeting participants were asked to explore what they wanted to achieve in the strategy process and to share their hopes and fears as well as their aspirations for the final output. The second meeting dived into more detailed consideration of the value and mission of the EORTC QLG, with the small groups challenged to not only think of ideas but also consider the practical issues which might result.

The third session used the Open Space technique to allow participants to set the agenda

by convening a breakout group on whatever most interested, concerned or excited them. From this emerged some key ideas. The first was about building a patient involvement group in the QLG. Next were ways of simplifying and speeding up the grant awarding process. Then there was the proposal for appointing a dedicated communication expert to advocate for the QLG across all public and scientific forums. There were other ideas too.

We were so satisfied with the results of these three sessions that we decided we only needed one more!

The final session explored the big questions relevant to the QLG and how to prioritise them to ensure the Group stays ahead of the field. A series of specific ideas were forthcoming which reiterated the value brought by patients to help ensure that what is developed is applicable internationally. The key ambitions were about integrating QoL assessment with other PROs and exploring their use in long-term toxicity assessment; utilising technology for data capture and AI/machine learning to support

analytics; and ensuring the understanding and implementation of QoL measures and outputs into policy making, regulatory decisions and everyday clinical practice.

We think there are two conclusions which can be drawn from this experience. First is that a virtual event must be thoughtfully designed to be effective. Our doubts were unjustified: the distributed conversational approach certainly encouraged creative ideas. Second is that the QLG members brought a huge range of experiences and ambitions, but there was a focused energy and clarity of collective purpose which many multinational collaborations would envy.

The Group is moving forward into the post-COVID world in sure hands.

Vision

We will make your quality of life count, more and more, throughout cancer care.

And we will never stop seeking ways to improve it, in ways measurable and unmeasurable.

Mission

The EORTC QLG actively involves patients, clinicians and researchers from diverse disciplines to drive excellence and innovation in quality of life research and education.

We advocate for quality of life assessment as a critical component of the cancer care pathway.

We work to make sustainable improvements to the quality of life of people with cancer internationally.

The Quality of Life Group's first virtual meeting: September 2020

Monika Turek, Quality of Life Department, EORTC HQ, Belgium

With the COVID-19 pandemic our lives have moved to a virtual world. Usually, EORTC organises a face-to-face meeting twice a year in different places throughout Europe, but in September 2020 we organised our first virtual QLG meeting.

One of the most important success factors for our first virtual meeting was the availability of the right technological infrastructure. None of us had ever organised this kind of event so we didn't know what attendees might or might not like. The platform had to have an easy-to-use interface for both speakers and participants. And because the pre-pandemic opinion was that remote meetings do not deliver the same sort of exposure and networking value that face-to-face events can give, the main point of concern was the absence of opportunities for live engagement. Our meetings are not only made up of speeches and presentations, but also thought exchange – and that is why we had to find an answer to the question of how to provide our speakers and participants with interaction opportunities that would allow them to brainstorm. We used the built-in live chat feature and short breakout sessions where attendees could have conversations as well as interact during presentations.

Not everyone is likely to be equally technologically experienced, so the entire process had to be made as simple as possible. Some people would be using mobile devices to join the virtual meeting, while others might prefer to join from their web browsers on their PC. Organisations' firewalls, problems with internet connection, technical equipment... we had to be prepared for all possible issues that we, and the meeting participants, might encounter. When you do something for the first time, it is not so obvious what can go wrong. We needed to set up some house rules, so that people knew



what to do. There are no physical check-ins or guidance available in a virtual world. If people come up against difficulties, it can make them unhappy. Therefore, we had to have different scenarios prepared.

After this first virtual meeting we asked participants for their comments. We learned that while they were happy to join the event, they were looking forward to a face-to-face meeting. But something that made us think seriously about carrying on with the virtual side, in the form of a hybrid meeting in the future, was praise from people who wouldn't usually have been able to join our events physically because of a lack of funds or their being too far away to travel.

The next QLG meeting, on 16 & 17 September, is planned as a hybrid event. If the in-person part goes ahead it will be held in Amsterdam, and the virtual part means that if someone is too busy, has family issues, a fear of flying or some other reason for not being able to attend Amsterdam in person, they will still have the chance to

participate. We will continue with the hybrid model, and will always be happy to receive any comments and feedback on how to improve our meetings going forward, both virtual and physical. The COVID-19 pandemic forced us to move to a different platform, but in future we hope to give participants a choice.



Cyprus: The Crossroads of Europe, Africa and Asia

Vassilios Vassiliou, Bank of Cyprus Oncology Centre, Nicosia, Cyprus

Dear Quality of Life Group members and friends, I am delighted to invite you to Cyprus for the next spring meeting that will be held on 28 & 29 April 2022.

Cyprus is a beautiful island located in the Eastern Mediterranean sea; a crossroads between Europe, Africa and Asia. It is a famous tourist destination characterised by its hospitality, ancient historical monuments that date back to 5800 BC, beautiful beaches, and warm weather. It is blessed with natural beauty that ranges from golden beaches and rugged coastlines to rolling hills and forest-clad mountains dotted with picturesque villages. Autumn and spring are very short seasons, but still warm enough for sunbathing and swimming, making it the ideal time to visit the island and avoid the peak season crowds.

Taking into account the difficulties that we had with the COVID-19 pandemic and the fact that the situation seems to be improving, I think that this meeting will be an excellent opportunity to meet again as a group in person, something that we have all missed! Most of the longer-standing members who attended the QLG meeting in Cyprus in 2014 still miss the productive and exciting time that we had! The information below will convince you to pack your suitcase for Cyprus once again!

Venue and information on the social programme

Our meeting is to be held in the city of Limassol at the Four Seasons Hotel, an outstanding 5-star hotel. For more information please visit <http://www.fourseasons.com.cy>. Limassol is a beautiful town with 15 kilometres of coastline lined with hotels, interspersed with eucalyptus groves and linked by a promenade popular with walkers and joggers.

The first social dinner will be held on 28 April at Epsilon restaurant (Tasteful Miracles, Epsilon

Resto Bar, PNS Restaurants) which is located at the new Limassol marina, just next to the sea. Before enjoying the excellent food and a famous violin player, we will walk along the Limassol promenade and through the marina (Promenade (Molos) Limassol (cyprusalive.com)), and take a group photo at Molos. The Limassol promenade is considered to be one of the most beautiful parks in the Mediterranean!

On 29 April we will have the chance to visit the old town at the heart of the city, with its narrow streets radiating out from the old fishing harbour. We will have dinner at the Carob Mill restaurant which is located next to the mediaeval castle (www.carobmill-restaurants.com). Entertainment from a Cypriot folkloric dance show will follow! The castle was the site of a royal wedding in the Middle Ages between Richard the Lionheart, King of England, and Berengaria of Navarre.

Group members and attendees will be sent information by email on how they can book their hotel rooms. In addition to the venue hotel, there also are excellent 4- and 3-star hotels nearby. Reservation forms and other information will be sent to all members for all hotels in due time.

Travelling to Cyprus and Limassol

Travellers arriving in the Republic of Cyprus may enter the country only through the legal ports of entry: Larnaca and Paphos International Airports, or the ports of Larnaca, Limassol and Paphos.

To reach Limassol from either of the two international airports it takes about 50 minutes by car. From the airport one can hire a taxi (at the cost of about €55 per ride for a 4-seater) or use the minibus service.



The 'Four Seasons' Hotel



Limassol promenade



Limassol Marina and coastline



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