



EORTC QLQ Meeting, Naples, September 2019

## Perspectives on the COVID-19 pandemic

Anne Lanceley, Newsletter Editor  
Department of Women's Cancer,  
EGA Institute for Women's Health, Faculty of Population Sciences  
University College London, UK



Dear readers,

Internationally work practices and our daily lives have been turned upside down in a grief-laden pandemic. None of us was prepared to face a pandemic and what quality of life means is a question on most people's minds. Researchers have been quick to capture the most immediate changes during the pandemic and their impact on quality of life with the aim of helping to shape the response to the crisis. The eye of our Group has remained firmly on patients as we witnessed too many of them missing out on the treatment and care they need and a backlog building up. As we seek to 'return to normal' difficult decisions over treatments will continue and decisions about the extent and nature of ongoing measures to limit the spread of COVID-19 will be more difficult. The

choices require careful balancing and in our field that means the likely direct effects on mortality from COVID-19 against the likely indirect impacts on mortality from cancer, due to inadequate access to necessary services and reluctance of the public to attend clinics and hospital.

This issue of our Newsletter highlights the Group's innovative response to the pandemic. Our theme '*Perspectives on the COVID-19 Pandemic*' includes reports of COVID-19 studies, and accounts and personal experiences of the pandemic. Brief reports also reflect how members have been going the extra mile for patients and a new EORTC HQ QLD member reflects on her very first pre-pandemic face-to-face Quality of Life Group meeting.

I thank my wonderful assistant editor Cheryl Whittaker who has been instrumental in achieving a fast-turnaround, topical newsletter. She has also patiently borne my last-minute working habits to get this newsletter in shape.

These are tough times and our strong international collaborations and leadership in quality of life are key to providing patients with the best possible care and quality of life outcomes. Our Group is made up of dedicated people who are used to doing their best in very difficult situations. That I believe is reflected in this newsletter and that will be what gets us through.

Anne Lanceley



**Contacts**

For more information on the Quality of Life Group and its activities:

<https://qol.eortc.org/>

**Address:**

Avenue E. Mounier, 83  
1200 Brussels, Belgium  
Tel. +32 (0)2 774 16 11  
E-mail: eortc@eortc.org

**Editorial committee:**

Editor: Anne Lanceley  
Assistant Editor: Cheryl Whittaker  
Member: Andrew Bottomley

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## Message from the Chair

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

These are unprecedented times. Therefore, I hope this newsletter finds you well.

As we were moving towards spring this year, our lives changed rapidly and radically because of the COVID-19 outbreak.

The extraordinary and challenging past few months have shown that quality of life, and our understanding of it, are as important as ever.

The pandemic has had a significant effect on the Quality of Life Group and many of our ambitious plans for 2020 have obviously had to change considerably. We were due to come together for our eagerly anticipated Group meeting in Cyprus in the spring, and in September to celebrate our landmark 40th Anniversary in Amsterdam. Preparations were well underway to come together to celebrate the past, our journey to date as a group, and our bright future.

Instead, unfortunately we were forced to cancel our spring meeting, which was due to take place during the peak of the virus outbreak for many countries. Our autumn Group meeting will now take place virtually. This has demonstrated several things for us: we are able to conduct some of our business successfully online (such as the great pitch session, which was well attended and had great engagement); we are able to continue our international collaborative work as we always do;

we find ways to stay connected. On the other hand it has also shown that we very much need sustained connection to allow us to exchange ideas – which most often happens during the coffee breaks and over dinner ('water cooler conversations'); and most of all, we really enjoy our twice-yearly meetings because we want to see our friends – again enforcing the strength of our QLG community! I am sure the changes over the last months will lead to a renewed assessment of how we do our work best, while aligning with our aims to be sustainable and environmentally friendly.

Developments over the past year have included our continuous effort to pursue a bold and ambitious strategy. We are commissioning more projects and have seen some very exciting projects being proposed, which always solidify our reputation for strong methodological and clinically relevant work. Finally, with our gaze firmly on the future we have initiated an Early Career Researchers group. We are fortunate to have many very talented early career researchers in our group, who will come together to define what they need, what we can do to support them, and how we as a group can learn from them – and strengthen their research trajectory.

I look forward to seeing everyone online in September, and 'live' again very soon.

## Quality of Life Group Executive Committee

**Chair**

Anne-Sophie Darlington,  
University of Southampton, UK  
e-mail: a.darlington@soton.ac.uk

**Past Chair**

Fabio Efficace, Italian Group  
for Adult Hematologic Diseases (GIMEMA),  
Rome, Italy  
e-mail: f.efficace@gimema.it

**Secretary**

Karin Kuljanic,  
University Hospital Center, Rijeka, Croatia  
e-mail: karin.kuljanic@ri.t-com.hr

**Treasurer**

Susanne Singer,  
University Medical Centre, Mainz, Germany  
e-mail: singers@uni-mainz.de

**Project and Module Development Committee  
Co-Chair (Modules)**

Sally Wheelwright,  
University of Southampton, UK  
e-mail: S.J.Wheelwright@soton.ac.uk

**Project and Module Development Committee  
Co-Chair (Projects/Non-Modules)**

Kristin Bjordal,  
Oslo University Hospital, Norway  
e-mail: KBJ@ous-hf.no

**Chair of Grant Review Committee**

Martin Taphoorn,  
Leiden University Medical Center, Netherlands  
e-mail: m.taphoorn@mchaaglanden.nl

**EORTC QoL Department Representative**

Andrew Bottomley,  
EORTC HQ, Brussels, Belgium  
e-mail: andrew.bottomley@eortc.org

**Publications & Newsletter Editor**

Anne Lanceley,  
University College London, UK  
e-mail: a.lanceley@ucl.ac.uk

**New Development Officer**

Olga Husson,  
Netherlands Cancer Institute, Amsterdam, Netherlands  
and RMH/ICR, London, UK  
e-mail: Olga.Husson@icr.ac.uk

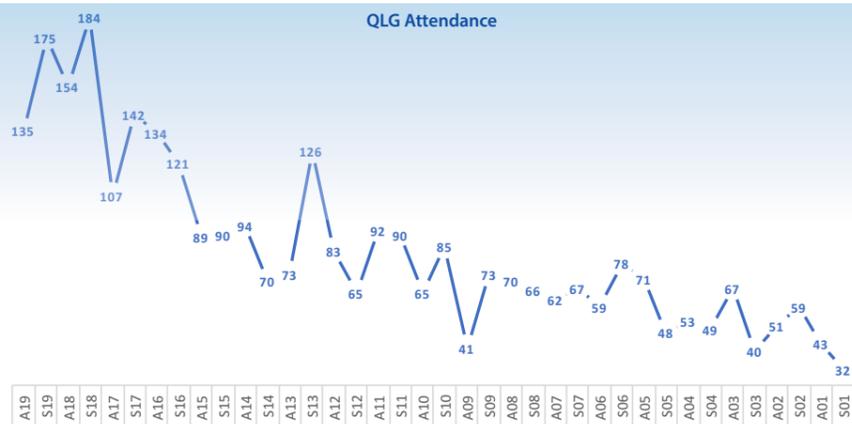
**SAVE THE DATE!**  
17 & 18 September 2020  
**EORTC Quality of Life Group Autumn Meeting 2020**  
is going to be a Virtual Event taking place fully online.  
QLG Members will be informed very soon about how to register.  
We look forward to 'meeting' you again!



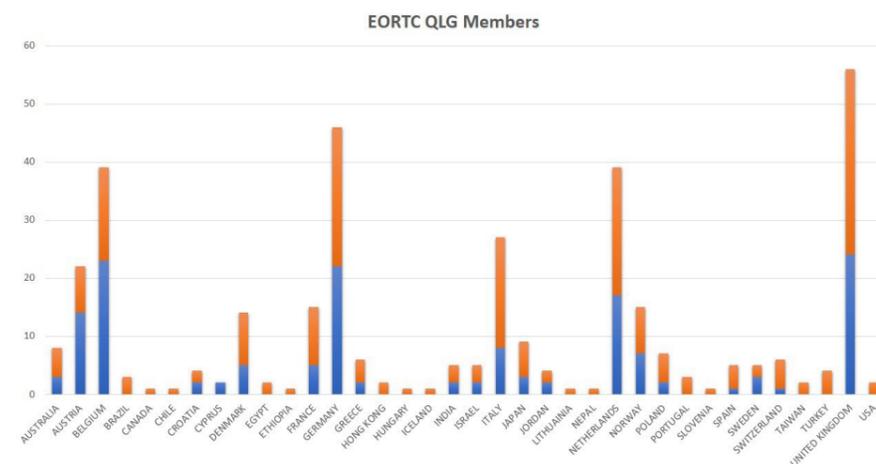
# EORTC Quality of Life Group – facts & figures

Karin Kuljanic, Clinical Hospital Centre Rijeka, Croatia

A total of 135 members of the EORTC QLQ were present at the autumn meeting in Naples (Italy). Unfortunately due to the COVID-19 situation we had to cancel the spring meeting in Limassol (Cyprus) which we were all really looking forward to. The graph below shows the upward trajectory of new membership, although we have some decline from spring to autumn 2019.



At the moment we have 383 members of the Quality of Life Group, of which 150 are active members and 233 corresponding members. Our work is spreading throughout many countries as you can see from the graph.



## HOW CAN I BECOME A FULL ACTIVE MEMBER ?

To become a full active member of the EORTC Quality of Life Group, you have to first attend 2 meetings within 2 years and be actively involved in EORTC QLQ research. At the third meeting you will become an active member.

To maintain membership you have to continue with research activities and attend a minimum of 2 meetings every 2 years. If you are not able to attend meetings regularly, you can become a corresponding member.

For more information on membership please visit our website: <http://groups.eortc.be/qol>

# COVID-19 QLQ-## : An exciting and fun cross-over project

Kristin Bjordal, University Hospital Oslo, Norway

On 15 April, Cecilie Amdal and I had a request for advice on PROs to be included in the Norwegian part of the WHO Solidarity Trial – an international randomised COVID-19 intervention trial. Naturally, no questionnaire was validated for such a patient group. The suggested surrogates did not seem to cover the important issues described in recent publications and in the press. Why not develop a COVID-specific health-related quality of life questionnaire based on the EORTC module development guidelines?

This is how the project started, and two and a half months later, we had already achieved a lot!

When approached, many of our EORTC friends joined in with their enthusiasm, experience and much-needed knowledge. From the EORTC QLQ: Andrew Bottomley, Dagmara Kuliš, Claire Piccinin, Madeline Pe. Members of the QLQ: Bernhard Holzner, Anne-Sophie Darlington, Sally Wheelwright, Alexandra Gilbert, Susanne Singer, Kathy Taylor, Juan Ignacio Arraras, Gracia Dekanić. From Norway, we have some crucial partners, all of them involved in local HRQoL work: Nina M Jørgensen, our medical librarian; Ragnhild Sørum Falk, statistician; Kristin Hofso, clinical researcher; and Stein Arne Rimehaug, a colleague who was an expert in the review app we needed. In addition, a friend of Madeline's from the Philippines, Melissa Mariano, is involved.

A Phase I-II protocol was written in two weeks with valuable input from the study group members. Nina performed extensive literature searches, and all titles and abstracts were

“This has been a fantastic experience, with everyone on board doing this on a voluntary basis. No funding has been provided.”

reviewed in no time using a fascinating app provided by Stein Arne. The relevant publications have been reviewed, issues retrieved and a list has been prepared for the Phase I interviews. Over the last few weeks prior to writing this, we have interviewed six health care professionals from seven countries, and in July, we will have interviewed eight patients from each of the same seven countries. The EORTC Item Library will be used for creating the item list for Phase IIIA, and an exciting moment will be when we see how many new items we have to construct. We believe that most issues are already represented in the Item Library.

WOW!

This has been a fantastic experience, with everyone on board doing this on a voluntary basis. No funding has been provided. Cecilie and I have been working day and night, but everyone else has also devoted much more time and energy than we ever could have expected. A real encouragement is that the FDA is very supportive, and they are waiting for the test version of the questionnaire to be included in pharma trials that are being planned. The WHO is also supportive and interested in using this instrument for a COVID-19 clinical trial platform.

What's next?

A Phase IIIA/B protocol has been written. We need to recruit collaborators from countries outside Europe. The ethical reviews take time, but hopefully we are able to start in some countries in early autumn. Funding? Yes, we have to look for that. I will try to approach some rich people in Norway...

All in all, much work, great fun, and nice to see that all our work within the EORTC QLQ is also useful for other DOGs (Disease-Oriented Groups). I don't think that any other Groups could have mobilised such a high-quality team in so little time!



# The importance and use of the EORTC measures in daily oncology practice

Monika Sztankay & Lisa Wintner, Medical University Innsbruck, Austria

At the time of writing and publishing, a public health emergency, the COVID-19 pandemic, is still unfolding, presenting patients and health care professionals as well as the general public with new challenges. This is truer for the vulnerable group of oncological patients who need to reconsider their ways of communicating with health care providers due to the new contact restrictions while still dealing with symptoms related to their disease and its treatment. In this challenging time, the European Society for Medical Oncology (ESMO) is advising health care professionals to utilise web-mediated consulting to support patients remotely and meet their needs [1]. In this context, web-based patient-reported outcome (PRO) assessment could be an essential supplement helping to support patients and keeping track of their functioning and symptoms remotely, even when they cannot or should not attend their clinical appointments.

Routine PRO assessment should, however, not only be considered as an exceptional measure but preferably as an integral part of standard care. It has already proven beneficial in different settings for sustainable symptom screening and monitoring [2] linked with medical information and tailored self-management advice to support patient activation [3], enhancing continuity of care [4] as well as patient-provider communication [5, 6], enabling better symptom control [7] with benefits for survival [8] and healthcare utilisation [9]. As far as EORTC measures are concerned, a recent review exploring the implementation

of PROs in routine care [10] states that they are often used in intervention studies, but only rarely in published routine implementations. The available literature usually reports on studies investigating the use of PROs in daily clinical practice, but not on actual routine implementations and the real-world data collected in this context.

Everyone engaged in the business of getting PRO assessment into clinical practice will agree that there are unmet challenges in routine implementation. Changing clinical routine is complex, with multiple interacting components on different levels of the clinical system, all of which are sensitive to multiple

**“...we propose a standardised and structured procedure...to advance the integration of PROs into clinical routine.”**

influences and barriers [11]. Although the body of guidance on how to integrate PRO into clinical practice is growing, health care systems lack roadmaps for how to change multiple system levels and infrastructures to integrate PRO measures into clinical workflow [12]. Literature investigating relevant aspects for successful PRO implementation has identified a number of particularly important elements for successful implementation including: top-down initiation, early stakeholder engagement,

user training tailored to their respective needs and clear guidance on symptom management [2, 13].

The QLG already engages in the development of EORTC guidance [14] and educational materials for health care professionals targeting routine PRO assessment (001-2019: the development of an e-learning program, PI: Heike Schmidt) thus contributing to the implementation and use of EORTC PRO measures in clinical practice. Similar to other areas of PRO research, for which there are comprehensive efforts to develop a standardised procedure (e.g. SISAQOL [15]), we propose a standardised and structured procedure in accordance with the methodo-

logical framework of implementation research to advance the integration of PROs into clinical routine. Making PROs a part of routine clinical practice is not only about implementing an (electronic) measure. It is about changing work flow patterns and ensuring that PROs are blended with the usual techniques and procedures that health care professionals rely on to inform their decisions, while enabling timely patient reflection on (self-)care. Of course, with the pandemic's disruption of the 'routine'

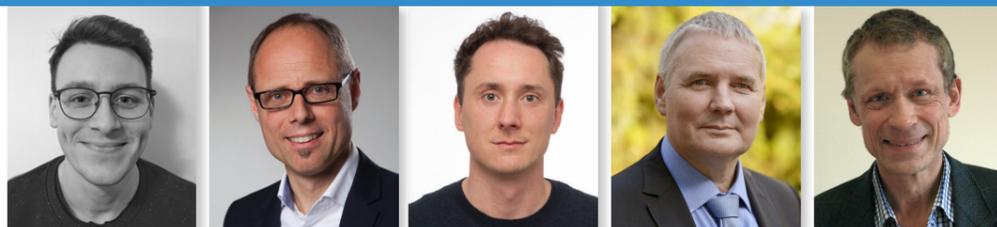
part of clinical practice at the moment, this will be an even greater challenge – not only to attempt to include PRO usage in whatever current practices are being recommended and used, but also to not allow PRO usage to fall

by the wayside if and when we do eventually return to a 'normal' routine. The EORTC QLG should consider extending their aims by providing their expertise and guidance to support patients, health care professionals and health

care systems in order to fully realise the potential of routine PRO assessments using EORTC PRO measures.

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# Estimating the impact of COVID-19 on functional health, symptoms and quality of life in the Spanish general population

Jens Lehmann<sup>1</sup>, Bernhard Holzner<sup>1</sup>, Johannes M. Giesinger<sup>1</sup>, Andrew Bottomley<sup>2</sup>, Georg Kemmler<sup>1</sup>

<sup>1</sup> Medical University Innsbruck, Austria  
<sup>2</sup> Quality of Life Department, EORTC HQ, Brussels, Belgium

In 2019, general population data were collected in several European countries as part of the EORTC Quality of Life Group's QLU-C10D utility project (PI: Georg Kemmler). These data contained, among other things, the EORTC QLQ-C30 as an indicator of functional health symptoms and global quality of life. We decided to use one of these datasets (N=1.010 participants from Spain) and to compare it to new data assessed during the pandemic. The second assessment (N=504), which used the same methodology as the first one, was realised pro bono with the help of a survey company (SurveyEngine). The equal sampling and methodology allowed us to compare

functional health, symptoms and quality of life as measured using the QLQ-C30 between two representative samples of the Spanish population. The assessment during the pandemic took place in April 2020, shortly after the peak of new infections and deaths per day had been reached (see Figure 1).

A first look at our results (unpublished, pending submission) may indicate that the sample recruited during the pandemic showed lower emotional functioning, lower role functioning, but also less fatigue, pain, dyspnea, and appetite loss compared to the sample recruited in 2019. Effect sizes, however, were relatively small (Cohen's d < 0.25).

We also found the degree of self-reported social distancing to be associated with lower functional health and higher symptom burden.

Our findings may suggest an impact of the COVID-19 pandemic on functional health and symptom burden in the general population. The comparison of the assessments before and during the pandemic can be used to benchmark cross-sectional results raised only during the pandemic, which have been published prolifically but suffer from a lack of comparability with the time before the pandemic. We are currently in the process of publishing our findings.

Figure 1. Timeline of COVID-19 outbreak and assessment period

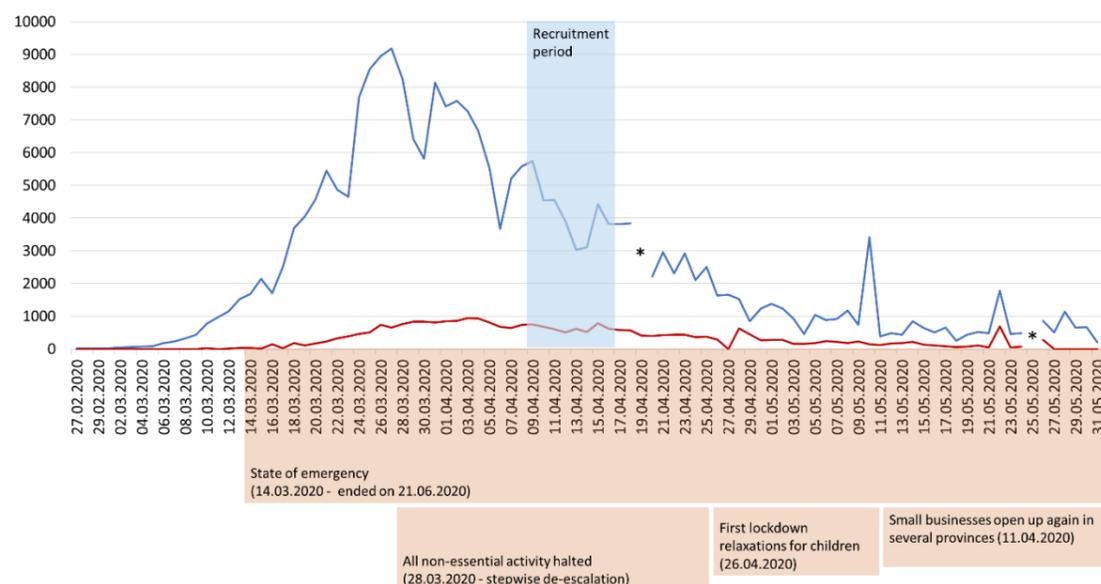


Figure 1 shows the number of new reported infections in blue and the number of new reported deaths in red; the recruitment period is shaded in blue. Data from the European Centre for Disease Prevention and Control (ECDC). \* negative values are not shown.



# Using ePROs to stay in touch with patients

Jens Lehmann, Bernhard Holzner & Gerhard Rumpold  
 Medical University Innsbruck, Austria and Evaluation Software Development (CHES)

Usually in March, discussions start about the upcoming EORTC spring meeting. But this year, many things were different and March brought an unexpected and drastic turn in clinical and scientific routine. In order to limit the harmful effects of the COVID-19 pandemic, a lockdown was imposed which affected all areas of life. All non-essential work at the Tyrol clinics in Innsbruck was paused and our efforts to recruit patients for EORTC-QLG studies stopped. Fortunately, the scientific work did not come to a complete standstill and could be handled from remote offices at home. By the end of June, most of us had returned to the office and now we are slowly transitioning back to a normal work routine and enjoying (appropriately socially distanced) coffee breaks together.

During the lockdown, our patients experienced the same fate as we did. Fortunately, the routine ePRO monitoring with CHES at the local haematology ward enabled us to maintain contact with these patients, although many appointments were postponed or even cancelled. The contents of the patient portal were quickly adapted to the current situation and COVID-19-specific information was added. We made an effort to call and motivate patients to stay in touch with the hospital and communicate their subjective health

status via the portal using the EORTC questionnaires. Even though this cannot replace a doctor's appointment, it provides some information on a patient's state of health during the pandemic. Subsequently, we will have less of a blind spot in the trajectory of a patient's quality of life once they re-visit the hospital. From March to June 2020, almost 100 ePRO assessments were completed remotely by patients using the CHES patient portal. Many of them expressed their gratitude to be able to stay in touch in this way and provided encouraging feedback.

Furthermore, we devised a short ad-hoc questionnaire on patients' experiences of the pandemic and their own health, which we ran in addition to our normal EORTC questionnaire battery. Those questions were answered by all patients who completed their ePRO assessments remotely and by a few patients inside the hospital. Drawing from those questions, we hope to get a clearer picture of how our patients perceived the pandemic and what their worries and concerns were during this time.

On the IT development side of CHES, special emphasis was placed on finding ways to best mitigate the physical gap between healthcare practitioners and patients. A video conferencing tool was designed that can be used for secure digital doctors' appointments. In this way, CHES

not only enables the collection and display of data, but also supports virtual contact between doctor and patient. The first tests and applications of the tool will be implemented before the end of 2020 and we look forward to bringing patients and medical professionals closer together.

**“From March to June 2020, almost 100 ePRO assessments were completed remotely by patients using the CHES patient portal.”**



# QLG heroes

Cheryl Whittaker, Assistant Editor, Lancaster, UK

The Quality of Life Group is proud to say that its members come from all over the world – it’s a great asset that leads to brilliant collaboration, and always makes for excellent Group meetings. But the distance is keenly felt when we can’t all come together for one of those spring or autumn meetings, as has happened this year. Instead of coming together, QLG members have been working heroically in their own domains head-on against the COVID-19 pandemic. Here’s what some of them have been doing these past few months:

### Nazim Serdar Turhal, Turkey

“My duties continued more or less the same during the pandemic, but the number of patients decreased as we recommended that they stay away for routine follow-ups, etc.

Although I volunteered, I was not allowed to do COVID-19 triage work because of the risk of carrying the virus to oncology patients the next day.

There was a curfew on most weekends so we stayed home all through these days. We are slowly testing the normality nowadays.”

### Anna Constantini and Eva Mazzotti, Italy

“We recently published an experimental study in Italy: Italian validation of COVID-19 Peritraumatic Distress Index and preliminary data in a sample of general population (Riv Psichiatr 2020; 55(3): 145-151).

After we did this study, I organised a helpline for cancer patients in my hospital.

I also acted as Scientific Director of a Distance Learning Course for the Italian National Institute of Health. The course was about COVID-19 and Psycho-Oncology: Skills to be Integrated into Clinical Practice.”

### Colin Johnson, UK

“In the lockdown, I’ve been getting my daily exercise, and writing (creatively, I hope).”

#### Say Hello

*She looked round at me. ‘What?’ Her eyes were wide, mouth open.  
‘Nice day isn’t it?’  
She nodded. ‘Yeah.’ She looked around.  
‘Yeah, it is.’  
I’d seen her coming along the path. Looking down, shoulders forward, feet scuffing the sand, like a question mark on roller skates.  
‘Good to see you,’ I called as we walked our ways.  
Looking back, I see her back is straighter. Her step springs. She looks around, her ponytail jerks and bobs.  
She turns her face towards another solitary walker, raises her hand as they cross.*

### Sam Sodgeren, UK

“I have been working with Anne-Sophie Darlington on COVID-19-related research projects including the SHARE Study, which involves a longitudinal survey of parents with children with life-threatening or life-limiting conditions. It asks how they are coping, what support and information they require, and how they are making decisions during this pandemic. I have been involved in the analysis of responses and have been preparing reports to disseminate to charities (such as Children with Cancer and Leukemia – CCLG).

In my capacity as a Health Psychologist, I have volunteered my support to the British Psychological Society’s Health Psychology

Exchange, a collaborative of over 100 health psychology and mental health professionals, the aim of which is to ensure all health and social care professionals have access to health psychology knowledge and skills during COVID-19. The group have provided behavioural science input for public health advice, psychological support to workforces and rapid reviews of evidence for councils and the government. I was specifically involved in a 4-day rapid review of uptake and engagement with COVID-19 track and trace apps (SCOPING REVIEW OF MOBILE PHONE APP UPTAKE AND ENGAGEMENT TO INFORM DIGITAL CONTACT TRACING TOOLS FOR COVID-19 – Link: <https://doi.org/10.31234/osf.io/qe9b6>).



### John Ramage, UK

“Well, I had the virus in early March but recovered despite my advanced age.

I have been busy with COVID-19 trials in our hospital. We have recruited at least 60 patients into the RECOVERY trial which is the largest treatment trial in the world on COVID-19 infection. We are actively investigating the psychological aspects of COVID-19 in health care workers and are also setting up a trial for prevention of infection in health care workers.

We are working on the data of our Phase 3 pancreatic module and working on a possible pseudomyxoma peritonei module in between doing phone clinics with patients with cancer.”

### Ali Alkan, Turkey

“We have been passing through a tough period of life; experiencing deep impacts of the pandemic both on our lives and also on our oncology practice.

Although we arranged our practices to care only for patients with active disease, there are still new cases. Trying to treat them has been like skating on thin ice. Since March, the uncertainty of the pandemic has led me to think about life, goals, motivators, etc. In addition, I have felt closer to death. Actually, due to our oncology practice, we are already familiar with death. But, I noticed the importance of “hope” in those situations. After their first outpatient clinic visit, the patients ask for the progress of the disease. Most of them ask a clear, desperate question: “Can I get rid of this disease?” Since the first case in my country, besides the fear of getting infected, I have wondered if we are going to be able to get rid of this pandemic. Unfortunately, the uncertainty of the COVID-19 pandemic is still ongoing and its psychosocial impacts continue. Hope is important: I hope we can get more hopeful in the following weeks. I hope you are all staying safe and healthy through these unusual times.”

### Helle Pappot, Denmark

“During the COVID-19 pandemic many research projects have been on hold and I have spent most of my time working as a clinician. But based on science, public information and my own experience during the pandemic, co-authors and I have given a viewpoint on telemedicine and COVID-19: <https://www.liebertpub.com/doi/pdf/10.1089/tmj.2020.0099>

Social isolation, which to some extent might be decreased using telemedicine, seems to be an important issue especially among young cancer patients. We are at present performing a qualitative research project on COVID-19 and social isolation in AYAs with cancer.

At the beginning of June we released an app for all Danish AYAs with cancer. Although the app is not designed for COVID-19, it boasts among other features a community for social connection – a research project will be based on the EORTC QLQ-C30 measure for quality of life during use of the app.

On the private side my husband and I used the time in social isolation to start building an orangery in our garden!!!!”



PICTURE 1



PICTURE 2

### Naomi Kiyota, Japan

“Our Japan team has been holding web meetings for QOL research in Japan. In March, we invited Jammbe Musoro from EORTC HQ and he gave a lecture to us via ZOOM about MID.

(see picture 1)

We continue to do QOL research despite the COVID-19 pandemic!!

We hope you all are safe and healthy and we look forward to seeing you all after recovery from this pandemic.” (see picture 2)

**Jaap C. Reijneveld, Netherlands**

"The COVID-19 pandemic hit the Netherlands quite hard, although the situation here in Amsterdam was not as grim as in some other countries' cities. Our government communicated a so-called intelligent lockdown, trying to garner more support for the proposed measures by having everybody think that it could have been worse, and that our administration was smarter than others..."

For me and my family, it was quite a tough time though. Our three kids (5, 9 and 11 years old) were at home full-time as of 16 March, and with us both having jobs (a neurologist and a primary school teacher) that require our presence at work despite the lockdown, life was a challenge. Those first weeks, the only things we did were work, eat, sleep, and homeschool our children. So our Wi-Fi was challenged to the edge, and at some point all three kids were meeting through Google Classroom and Google Meet, while I was calling patients and my partner was Zooming with his own school class of 23 eight-year-olds. But at least we were allowed to go out every now and then, and our kids were allowed to play with other kids, as long as it was outside.

As of 11 May, things returned at least a little bit to normal. Our kids now attend school in an almost normal way, although the parents are not allowed to enter the school buildings. They also returned to their field hockey training schedule, piano and violin lessons, and even the swimming lessons (obligatory in our city consisting of so many canals) were started up. But of course, they all come with restrictions, and lots of our usual fun activities, such as parties, dinners with friends, and visiting theatres and museums, are not possible for the coming weeks. Let alone vacations, etc. But these are all so-called first-world problems.

Fortunately, we were not hit by the virus, nor were any of our family members or friends, but we have seen the downside of all the measures in several ways, sometimes wondering if the measures were a bit too extensive and doing more harm than good. I personally think that the loss of health for many people suffering from diseases other than COVID-19 will eventually be larger than that caused by the virus, never mind the loss of health (and quality of life) due to the upcoming economic crisis. Anyway, let's see what happens.

I miss you all!"

**Marion Eckert, Australia**

"This year, the International Year of the Nurse and Midwife, we have all been impacted by COVID 19.

In the midst of the COVID-19 global pandemic the critical role nurses and midwives play has come to the fore. In a world beset by challenges on the twin fronts of health care and economic stability, nurses and midwives are on the front line securing the health of citizens globally; a fact that could perhaps not be more pertinent in the WHO-designated Year of the Nurse and Midwife. A year that would have seen celebration and fanfare is now witnessing unprecedented unity from the community in recognising the value nurses and midwives play in health security. Whilst we know that the pandemic will pass, and that life will resume some normality, current challenges exist in preparing for the unknown that is life in the wake of COVID-19 while safely and professionally navigating this current time of great uncertainty.

In all clouds, however, shines a silver lining, and no coordinated media campaign could more clearly communicate the importance of the nurse and midwife, in particular the utterly crucial role these modern-day heroes play in supporting humanity when many other systems fail."

The Rosemary Bryant AO Research Centre said thanks via Zoom to nurses and midwives across the world:



**Pernilla Lagergren, Sweden**

"In Sweden we have not had a total lockdown but a lot of restrictions and recommendations. One is of course that those who can work from home are recommended to. So in my research group most people have been working from home and we have had all meetings online using Zoom or Teams. It works very well, I would say. To make it more social we have coffee breaks and after-work drinks regularly.

We have stopped the RCT that we are running and rearranged ongoing data collections. I have not been working clinically but have close contacts with people who are and have been amazed by their hard work. I am pleased that so many people are taking responsibility and working together towards an end to this pandemic. I think we have all learned a lot from this extremely unusual situation."

And last but not least, the QLG Executive Committee has been keeping things ticking over by having all their meetings remotely too:



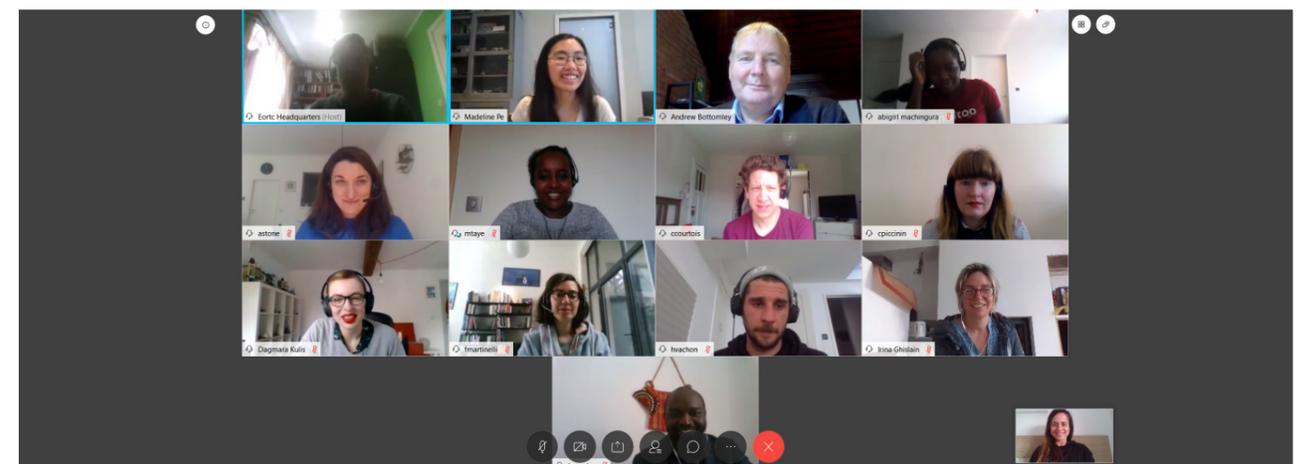
Thanks to all the QLG heroes continuing their work during the pandemic. We will all be together again soon!



**QLD under lockdown**

Cheryl Whittaker, Assistant Editor, Lancaster, UK

Going from an open-plan office to full-time homeworking has had its challenges, but those in the Quality of Life Department at EORTC HQ have done very well to respond to them. If anything, it's brought them closer together as a team: at the start of each lockdown department meeting, a different member has prepared a story about themselves and how they came to be in Belgium and work for EORTC.



But what else have they been up to? Let's ask a few of them:



**Dagmara Kuliś**

In the pre-pandemic times, I would wake up at 5:20 am and leave at 6:10 am to arrive at the office at 7:40 am – if everything was running smoothly. A 1.5h one-way trip means 3h of commuting a day.

So while the virus took away a lot of things, it also gave me 3h of extra time every day. What have I done with all that time?

Slept. Went for walks and runs, which meant discovering totally new bits of my town and the area. Biked a few hundred kilometres. Did many hours of workouts in the garden and Zoom classes that my gym was offering. Built three Lego houses. Finished six jigsaws with between 1,000 and 2,000 pieces each. Won countless Scrabble games against my husband. And, above all, worked a lot, because after a quiet week or two at the beginning of the lockdown, work really picked up again.





**Francesca Martinelli**

Working at home has been lonely but also productive – especially since my partner and I have separate “offices”. For a lot of things it is easier to focus if there are not many people around (the office I usually work in is open plan).

pyjamas; I have found out that sometimes it's best to set your Skype to “Do not Disturb” – otherwise some time-consuming tasks will take even more time; I have overcome my fear of technology and successfully organised WebEX calls and meetings (thanks to Monika Turek for the training!); and, on the side, I have managed to create a sourdough starter, something that I wanted to do for a long time but I never managed before.

Overall, the homeworking experience has been positive. But now I have had enough. I hope now that the measures have been lifted people will keep on acting responsibly, so that we will all be able to go back to normal life as soon as possible.



In these months, I have learnt that I shout when I am on a call and I am wearing my headphones; I have had calls and meetings in my normal clothes and in



**Madeline Pe**

Life in lockdown for me means no need to wake up at 5am, and no 4-hour round-trip commute to work!

So what am I doing with the extra free time? Sleeping more, having a proper breakfast in the morning (and not having to eat my breakfast on the train!).

But I'm definitely missing seeing friends face to face. Hooray for video “apero” calls to help us all keep in touch, but nothing can replace being together in person.

During the lockdown, our town was so quiet that the ducks decided to have a stroll in the main square.



**Anne Stone**

Working through the pandemic has brought some challenges, but on the whole, I have personally appreciated the joys of working from home. I have taken advantage of missing the usual crowded metro trip in the morning and have been getting up early before work to exercise, which puts me in a good frame of mind for the day!

Of course, it was a shame to miss the Group meeting in Cyprus as I was looking forward to meeting some of the members for the first time.

We decided early on to set up a weekly coffee call to replicate some social office chat. The idea was that everyone in the department was welcome (...apart from Andrew!). Not the same thing as in real life, of course, but it definitely helped to see some friendly faces.



**Claire Piccinin**

To be very honest, the past few months have been a difficult time for me and my family, as we lost my father-in-law due to complications related to COVID-19 at the end of May. He was in

the hospital for more than two months and in the ICU in a medically induced coma for much of that time, where he experienced many ups and downs throughout his treatment. He received excellent care and we had the opportunity to say goodbye to him in person, for which I am very grateful. I was also very lucky to have the support of my dear QLD and QLG colleagues, family members, and friends, which helped immensely.

On a more positive note, I have loved the transition to full-time homeworking. Not having to do the daily commute has meant that I gain a couple of hours every day, which has been incredible for my work-life balance. I've been able to devote more time to my hobbies (in particular, origami, drawing, and baking), spend more time outside, and I feel much more energised overall. I've really enjoyed reconnecting with old friends and finding creative ways to keep in touch, which has made the physical distance more manageable. In terms of work, the added flexibility and shaking up of some of our usual daily commitments has paved the way for exciting new research ideas and allowed more time for fostering new international collaboration. Although I miss the ability to travel and it feels strange to not be spending my summer holidays at home in Canada, this experience has helped me refine my goals and has served as an important reminder of what really matters in life.



# EORTC QLG Meeting Naples, September 2019

Abigirl Machingura, Quality of Life Department, EORTC HQ, Brussels, Belgium

The Quality of Life Group's autumn meeting 2019 was held in Naples, Italy in the Royal Continental Hotel. The meeting location was amazing and the view from the hotel was spectacular. It was very well located just in front of the Borgo dei Pescatori in Santa Lucia. With a stunning view over the Gulf of Naples, it was a good spot for dinner and an evening stroll. A great view of the sea, castle, boats, mountains and the moon. And at night it was bustling with plenty of restaurants, trattorias, and pizzerias.

ever-growing list and progress of questionnaires and modules developed and proposed. At the end of the day, we visited Naples' National Archaeological Museum. I was stunned by the beautiful Roman artefacts, mosaics, marbles and much more from Greek, Roman and Renaissance times. We then had a networking dinner at Le Arcate Restaurant, where we embraced the entire Gulf of Naples from the terrace and enjoyed impeccable service, high-quality food, and extraordinary moments including a performance from a local music band.

On the last day of the meeting, I attended some of the parallel sessions. I met and interacted with old and new QLG members during the coffee and lunch breaks. The meeting ended with a plenary session. On the social side, we took a city walk to the Royal Palace of Naples and other small museums. All the arrangements were perfect, thanks to Monica Pinto, and I enjoyed every part of it. I also learned more about Quality of Life in oncology and how the QoL tools are made. It was my first time attending a QLG meeting and I would not want to miss another one.

On the day preceding the meeting, I attended a workshop held by Corneel Coens, Jammbe Musoro and Madeline Pe on “Implementing Quality of Life in clinical trials: Design & Analysis of QoL in EORTC clinical trials”. The workshop was mind blowing and was followed by a buzzing question and answer session. After the workshop, we took an evening walk along the beautiful seafront. Later in the evening, I attended the Executive Committee dinner – a much more formal affair, by the sea. I had the chance to meet QLG Committee members holding important jobs and still devoting a lot of their time to the Group. We enjoyed traditional Neapolitan foods that included fish and octopus and then were served with special Neapolitan pizza and desserts. It was a really lovely dinner as I got to meet and connect with very friendly members.



On the first day of the meeting, I attended the plenary session opened by EORTC QLG Chair, Professor Anne-Sophie Darlington, and Head of the EORTC Quality of Life Department, Dr Andrew Bottomley. I also attended the Project and Module Development Committee (PMDC) meeting for the status updates of the modules and some new projects proposed by QLG members. Later in the afternoon, I attended parallel sessions for the oral presentations of the ongoing projects and modules. I was blown away by the enthusiasm of the Group's



# HQ Quality of Life Department

## Head of Department

**Dr Andrew Bottomley**

e-mail: [andrew.bottomley@eortc.org](mailto:andrew.bottomley@eortc.org)

### Quality of Life Department Executive Assistant & Web Administrator

**Monika Turek**

Tel: +32 (0)2 774 1678

e-mail: [monika.turek@eortc.org](mailto:monika.turek@eortc.org)

### Quality of Life Officer

**Christopher Courtois**

Tel: +32 (0)2 774 1585

email: [christopher.courtois@eortc.org](mailto:christopher.courtois@eortc.org)

### Translation Team Leader

**Dagmara Kuliś**

Tel: +32 (0)2 774 1680

e-mail: [dagmara.kulis@eortc.org](mailto:dagmara.kulis@eortc.org)

### Translation Assistant

**Anne Stone**

Tel: +32 (0)2 774 1668

e-mail: [anne.stone@eortc.org](mailto:anne.stone@eortc.org)

### Quality of Life Specialist

**Francesca Martinelli**

Tel: +32 (0)2 774 1619

e-mail: [francesca.martinelli@eortc.org](mailto:francesca.martinelli@eortc.org)

### Quality of Life Specialist

**Dr Madeline Pe**

Tel: +32 (0)2 774 1544

e-mail: [madeline.pe@eortc.org](mailto:madeline.pe@eortc.org)

### Project Manager

**Mélanie Beauvois**

Tel: +32 (0)2 774 1867

e-mail: [melanie.beauvois@eortc.org](mailto:melanie.beauvois@eortc.org)

### Quality of Life Coordinator

**Irina Ghislain**

Tel: +32 (0)2 774 1057

e-mail: [irina.ghislain@eortc.org](mailto:irina.ghislain@eortc.org)

### Lead Biostatistician

**Corneel Coens**

Tel: +32 (0)2 774 1632

e-mail: [corneel.coens@eortc.org](mailto:corneel.coens@eortc.org)

### Biostatistician

**Dr Jammbe Musoro**

Tel: +32 (0)2 774 1539

e-mail: [jammbe.musoro@eortc.org](mailto:jammbe.musoro@eortc.org)

### Fellow

**Mekdes Taye**

Tel: +32 (0)2 774 1588

e-mail: [mekdes.taye@eortc.org](mailto:mekdes.taye@eortc.org)

### Fellow

**Abigail Machuringa**

Tel: +32 (0)2 774 1314

e-mail: [abigail.machuringa@eortc.org](mailto:abigail.machuringa@eortc.org)

### Item Library Researcher

**Claire Piccinin**

Tel: +32 (0)2 774 1592

e-mail: [claire.piccinin@eortc.org](mailto:claire.piccinin@eortc.org)

### CAT Researcher

**Hugo Vachon**

Tel: +32 (0)2 774 1313

e-mail: [hugo.vachon@eortc.org](mailto:hugo.vachon@eortc.org)