AI in Quality of Life Research: Opportunities Across the Research Lifecycle

Newsletter 2026

EORTC
Quality of Life Group

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Dear readers,

I am pleased to return with the latest edition of the European Organisation for Research and Treatment of Cancer Quality of Life Group (EORTC QLG) newsletter. This year's newsletter touches on a topic that has gained unprecedented interest: artificial intelligence (AI). This year's focus theme, entitled 'AI in Quality of Life Research: Opportunities Across the Research Lifecycle', specifically addresses AI's usefulness in the development, validation, clinical and research applications of patient-reported outcome measures (PROMs), including health-related quality of life (HRQoL) assessment.

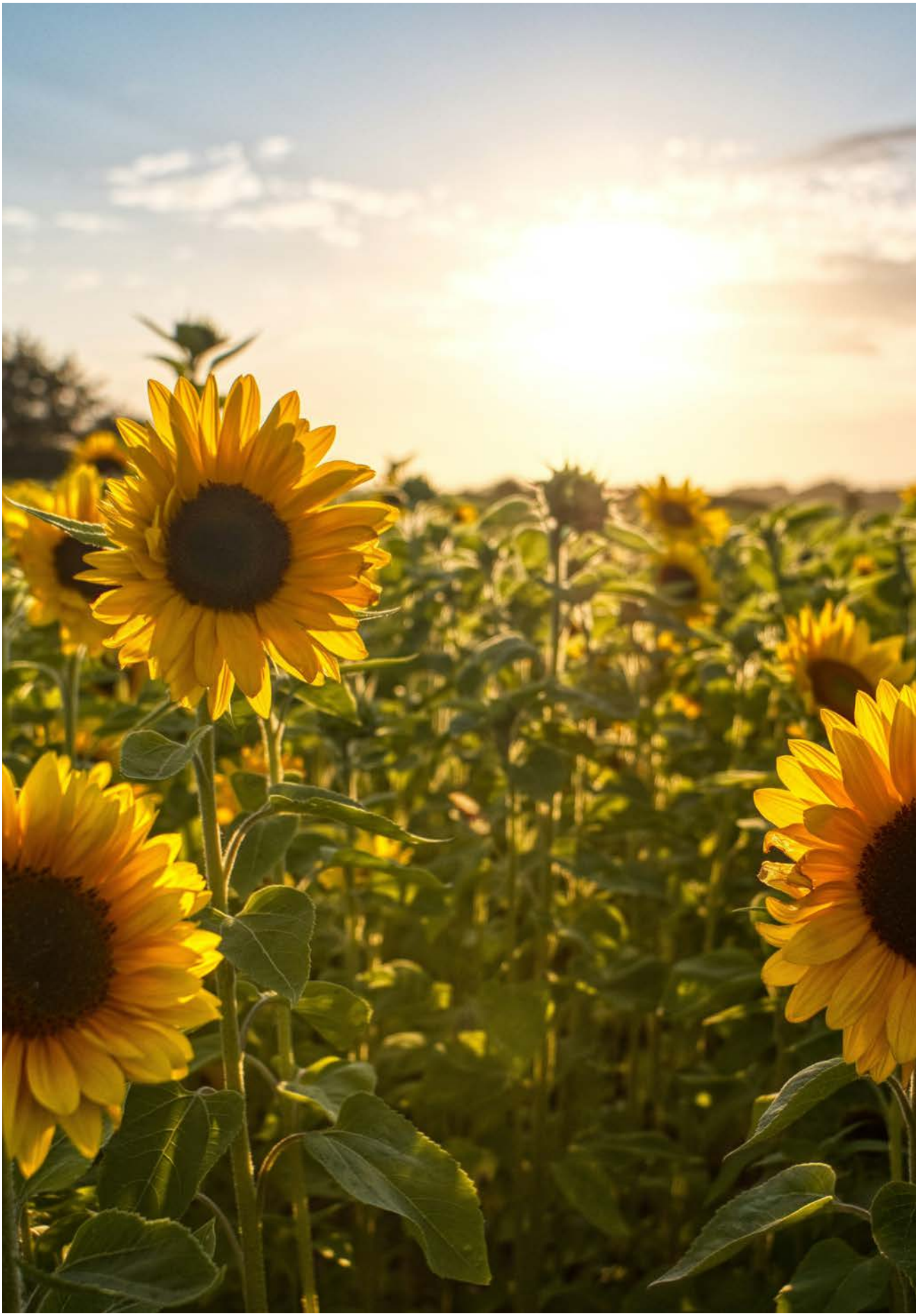
Rest assured: AI will not replace PROMs and the call to listen to the patient's voice. However, AI is expected to facilitate questionnaire development, by detecting item redundancy, prioritising issues and improving their relevance to the lived experience of patient groups. AI will also enable smoother computerised adaptive testing and patient-reported outcome (PRO) analyses, and support various applications like the longitudinal monitoring of PROs in clinical practice, or predicting the course of PROs and anticipating complications from large databases. Nonetheless, if an AI framework is to be built within the EORTC QLG, its benefits should be paired with responsible methodological, ethical and organisational standards. The deployment and use of AI by the QLG should be based on clear and reliable strategies, be used by trained and competent personnel checking AI outputs at key steps, and be applied while always ensuring specific vigilance to avoid algorithm bias or exclusive dependence on technology. The 2026 newsletter will thus give an overview of the plenary session on AI in Quality of Life Research that took place at the latest QLG meeting. This selected editorial theme will inform readers on the EORTC Headquarters' (HQ) perspective on AI, reflect on the benefits and limitations of AI, and explore the diverse applications it may serve.

In addition, as usual in our newsletter, you will be kept up to date with the latest developments in QLG members' research activities. In particular, a number of questionnaires developed in the past by the EORTC QLG are being revised to keep pace with advances in oncology. So, in this newsletter, we also provide an opportunity to catch up on the ongoing revision of various modules.

Finally, a major event took place in early 2026: a one-day meeting involving past and present members of the QLG's Executive Committee (EC) to review the group's future direction, strategic objectives, and upcoming initiatives. The strategy summary in this newsletter will make you want to learn more.

Once again, this newsletter will highlight the group's creativity and dynamism, and you are sure to enjoy reading it.

Anne



GLOSSARY

AYA	Adolescents and Young Adults
CAT	Computerised Adaptive Testing
CAYAC	Children, Adolescents and Young Adults with Cancer
DOG	Each EORTC Disease-Oriented Group is focused on research into a specific tumour site, cancer type or patient demographic
EC	The QLG Executive Committee
ECI	An Early Career Investigator
EMA	European Medicines Agency
EMR	Electronic Medical Record
EORTC	The European Organisation for Research and Treatment of Cancer is a unique pan-European non-profit clinical cancer research organisation established in 1962
ePRO	An electronic Patient-Reported Outcome electronically collects information about a patient's health status that comes directly from the patient, without interpretation by a clinician or other observer
GRC	The QLG's Grant Review Committee
HCP	Healthcare Practitioner / Healthcare Professional
HQ	EORTC Headquarters, based in Brussels
HRQoL	Health-Related Quality of Life
ICI	Immune Checkpoint Inhibitor, a type of immunotherapy
LLM	A Large Language Model is an advanced neural network trained on vast datasets to understand, summarise, translate, and generate human-like text
PMDC	The QLG's Project and Module Development Committee
PRO	A Patient-Reported Outcome can be collected via pen and paper method or electronically, and provides information about a patient's health status that comes directly from the patient, without and prior to interpretation by a clinician or other observer
PROM	A Patient-Reported Outcome Measure is any questionnaire, survey or similar instrument that gathers information directly from patients about their health status, quality of life, and how they experience healthcare
QLD	EORTC Quality of Life Department at HQ supporting the QLG
QLG	The EORTC Quality of Life Group is a multi-professional, international group of researchers and clinicians working together to better understand the effects of cancer and its treatments on HRQoL for patients across diverse populations and cultures
QLQ-C30	EORTC's Quality of Life Questionnaire-Core 30
QoL	Quality of Life
QWG	The Qualitative Working Group was established to strengthen qualitative research across the QLG
RAG	Retrieval-Augmented Generation is an AI-based approach to improving LLMs that incorporates relevant information retrieved from external knowledge sources into the generation process
RCA	Responsiveness to Change Analysis evaluates an instrument's or system's ability to accurately detect significant changes over time
SAC	The Scientific Advisory Committee of EORTC gives independent advice to the EORTC Board and to the Scientific Chairs Council on the activities, scientific output, overall priorities and strategies of EORTC
WISP	The Write In three Symptoms/Problems instrument is an open-ended question allowing patients to report and rate the severity of up to three additional symptoms or problems not covered by EORTC questionnaires

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IT'S THE JOURNEY....

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Dear friends,

It's tempting to start my chair's message with the same lines as the year before, and I have to admit that we're still in good shape. With our portfolio, revenues and membership all growing, we're doing pretty well. But that doesn't mean that we should lean back. One of the major strengths of the current Executive Committee (EC) is that we are a bunch of very optimistic people, who enjoy our work for the QLG and with each other. At the same time, our weakness is that we are a bunch of very optimistic people, who might overlook opportunities or ignore threats that are coming our way.

We recently concluded that we had to get out of our comfort zone and look the beast in the eye. But, how? The classic pitfall is to develop a 'strategy' in splendid isolation and spread the word from the top down. Discussing our 'strategy' from the bottom up with more than 1,000 members didn't make sense either, though. So, we decided to follow a stepwise process starting with a limited group of people. Under the inspiring leadership of one of our most senior and esteemed members, Mirjam Sprangers, and together with the members of our Advisory Board and EORTC leadership, during a Strategy Meeting in Brussels in January 2026 we took a thorough and sometimes painful in-depth look into our own behaviour. A summary of that meeting and the plans that emerged can be found in the article by Kelly de Ligt and me in the next pages of this issue.

It's nice to have a plan but, as said, we do not function in splendid isolation. The next step was to ask for comments and input from our members. We circulated the plan and put it on the agenda of our Business Meeting in Berlin in spring 2026. We asked for our members' opinions, particularly on prioritisation and their willingness to participate in the various so-called pillars of the plan. In the meantime, we assigned specific EC functions to every pillar and restructured the agenda of our meetings accordingly. This will facilitate us in keeping track of the progress made, and taking action if we don't.

Actually, and this 'actually' is the most important observation, it will be an ongoing process, evaluating and adapting our strategy on a regular basis. For that purpose, we will organise such a Strategy Meeting in parallel with our Scientific Audit Committee review every 3 years from now on. Because the journey is more important than the destination.

In the meantime, enjoy reading this wonderful newsletter.

Jaap

STRATEGY SUMMARY

MISSIONS, VISIONS AND PILLARS: A RECAP OF THE QLG STRATEGY MEETING

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On 30 January, the Quality of Life Group (QLG) Executive Committee (EC) invited members of EORTC Headquarters (HQ), the Quality of Life Department (QLD), and past EC officers to the HQ in Brussels. The aim was to update the QLG's strategy for the upcoming years.

LIVING UP TO THE SCIENTIFIC AUDIT COMMITTEE (SAC) RECOMMENDATIONS

Our starting point was the most recent SAC recommendations. Back in 2022, the SAC recommended that we take more leadership in health-related quality of life (HRQoL) analysis within and beyond EORTC; intensify collaborations with the EORTC disease-oriented groups (DOGs) on interpretation and reporting of HRQoL and clinically relevant questions; and increase the involvement of oncologists in the QLG. Most of these recommendations have been addressed since then, for instance by initiatives like SISAQOL-IMI (aimed at establishing international standards on how to analyse, interpret and report PRO data gathered in cancer clinical trials); REQUALIFY (aimed at updating the guidelines based on recent publications and initiatives on best practices in implementing, assessing and interpreting QoL data in cancer clinical trials); the DOG QoL liaisons programme; and through constant interaction within the EORTC Scientific Chair Council in which our QLG chair participates. However, educational and practical bridging between DOGs and the QLG still needs attention.

More recently, in 2025 the SAC recommended that we look beyond global QoL into specific symptoms and even explore expansion of our activities into interventional symptom management trials; further extend our collaboration with the Older Adult Council; and initiate an introductory session for new QLG members during our twice-yearly meetings. While some of these recommendations have already been addressed, for instance by the Elderly Functional Index (ELFI) project (development and validation of a composite patient-reported measure for assessing multidimensional functioning derived from the QLQ-C30 core questionnaire) and the 2026 EORTC QLG cancer clinical trial grant call, others require a stronger collaboration with the DOGs. From autumn 2026 onwards, the QLG meetings will feature a 'newbie' meeting.

ADAPTING TO THE CONSTANTLY CHANGING LANDSCAPE AND MANAGING OUR GROWTH

Apart from paying attention to the valuable recommendations of the regular SAC reviews, we also assessed our key strengths and weaknesses. Without a doubt, the modular measurement strategy has always been the core strength of the QLG. It offers measurement precision for a wide range of research

FIFTY YEARS OF QLG

In 2030, the QLG celebrates its 50th anniversary. When redefining the QLG strategy, we looked back at the QLG's history to understand our strengths and weaknesses. We have summarised this history in a manuscript, which will act as a signpost to our reason for existence, activities and reach. This manuscript includes major developments like the design of the modular measurement strategy and efforts to enhance the relevance and usability of our measures in cancer clinical trials, research and practice. Importantly, as the cancer care landscape becomes increasingly complex, we describe ongoing developments within the group and across the broader research landscape that call for a clear strategic direction. The manuscript was published in the European Journal of Cancer in July 2026.

objectives, populations and contexts, while prioritising a biopsychosocial scope, cross-cultural development and rigorous methods. However, in order to keep pace with the rapidly evolving treatment regimens evaluated in trials, constant refining and updating is needed, and we need to remain agile in our processes facilitating this.

Additionally, the group grew from fifty in the year 2000 to over a thousand active and corresponding members combined in 2025. While we have a strong collaborative and sharing culture within the group and the global network to the group, members might no longer know each other at this scale, which demands a rethinking of communication and collaboration processes. Additionally, collaboration at this scale carries the risk that processes become slow or rigid, and focus gets lost.

REDEFINING OUR STRATEGIC PILLARS TO INCREASE OUR IMPACT

Based on all of the above, we redefined some of the strategic pillars, which traditionally encapsulate the QLG's key focus areas. Pillars focusing on innovation & research, people management, leadership & funding, and internal collaboration largely stayed the same, though we tried to 'sharpen the saw' in a continuous effort to stay as transparent and responsive as possible, despite our growth. In comparison to the pillars defined in 2022, we focused more on areas where policy and reimbursement decisions are imminent. We redefined the pillar 'Communication & Awareness Raising' to 'Policy, Stakeholder Management & Global Outreach' to establish strategic partnerships in these areas. See *Figure 1* for an overview of all pillars; the 2026 strategy meeting report will be published later this year.

Figure 1: QLG strategic pillars

GROWING INTERNATIONALISATION

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Great news: the Berlin spring meeting in April 2026 was the best-attended meeting in our group's history – 259 registrations from 35 countries, with 234 attending in person.

GROWING INTERNATIONALISATION

This spring, 42 participants joined from outside Europe, with interest rising particularly in South Korea and Canada. That said, there remains a clustering of attendees from Central and Western European countries – a reflection of long-standing research traditions and expertise (see *Figure 1*). This isn't a drawback, but it's something to keep in mind. Our upcoming meetings in **Zagreb** and **Oslo** offer excellent opportunities to strengthen connections with new research communities.

SUSTAINABILITY GOALS

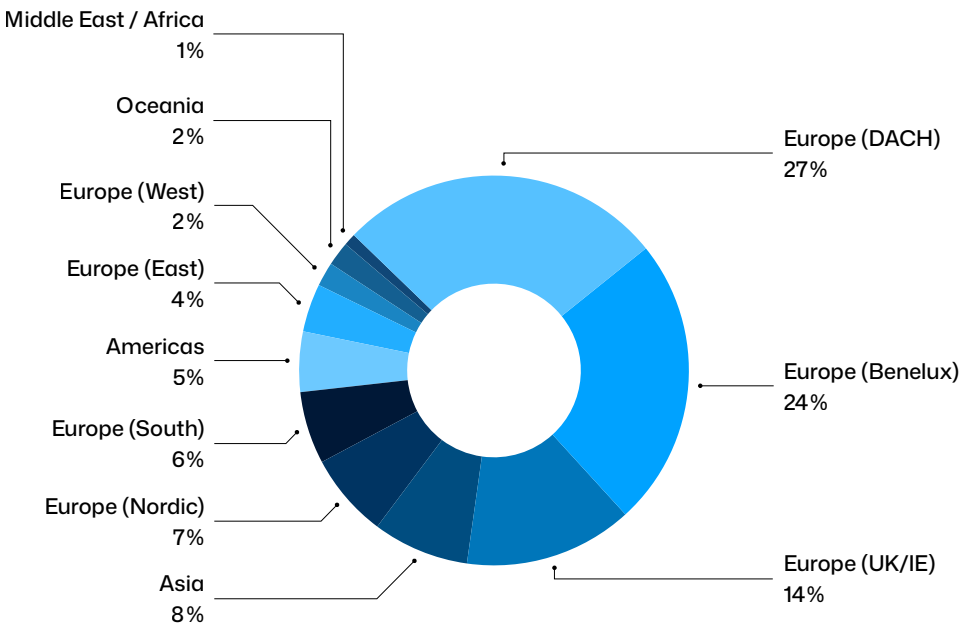
Internationalisation comes at a cost: **per capita CO_2 emissions are rising**, driven largely by an increase in long-distance flights. Our goal of reducing conference-related emissions remains in place – and we'll need creative solutions going forward.

YOUR INPUT MATTERS

Have questions or concerns? Please don't hesitate to reach out at any time: secretary@eortc-qlg.org

Martin

Figure 1: Participants – spring meeting, Berlin
Regions and numbers of registrations, also shown as a percentage of attendees



THE QLD: HOW WE WORK

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In the 2023 newsletter, we introduced the new structure of the Quality of Life Department (QLD) and all the team members. Although we give a short update from the department at each QLG meeting, there is never enough time to go into detail of what the different teams do on a daily basis. This is why, three years later, we would like to go through the QLD structure again and show you the breadth of work done by the QLD staff.

Starting from the top, there have been no changes – Madeline Pe as Head and Dagmara Kuliś as Associate Head are responsible for the QLD, its functioning within the Headquarters' (HQ) structure and with the QLG. They do this with Monika Turek's support as Executive Assistant, but these days she is also busy with organising events, coordinating educational resources and many other things.

Dagmara also leads the QoL Tools Team, which is responsible for various aspects of a questionnaire's lifecycle, from its development to translations and then use by academics and commercial entities. The QoL Tools Team takes good care of the Item Library too, making sure it is up to date when it comes to content and IT solutions.

Next, the New Technologies and Research Projects Team coordinates research activities on relatively novel topics, such as wearables and computerised adaptive tests (CAT), ensuring they fit into EORTC's structure. Led by Hugo Vachon, the team is involved in projects such as EMBED (investigation of the feasibility of using mobile devices for the assessment of HRQoL and physical activity in adult cancer patients undergoing treatment); ILDETECT (development and evaluation of a predictive algorithm for the early detection of interstitial lung disease (ILD)); and the development and implementation of the EORTC CAT Core. Hugo also supervises all QLD fellows.

Then, under Ahu Alanya's supervision, the QoL Support Team provides oversight and scientific advice on the inclusion of QoL in EORTC-led studies. In collaboration with the EORTC study teams, the Support Team's work includes development of QoL endpoints, support in drafting the QoL sections of the protocol, and providing training on the use of QoL endpoints in clinical trials. The team also participates as QoL experts in cross-functional meetings, supports grant proposal development, maintains EORTC guidelines and procedures, oversees electronic patient-reported outcome (ePRO) implementation with data managers, and ensures ongoing communication with DOGs and QoL liaisons.

In addition, Lotte van der Weijst leads the Team for QLG-Funded Activities. This team supports all QLG-funded projects and research activities from conceptualisation to completion. The team also supports the Project and Module Development Committee (PMDC) and Grant Review Committee (GRC) as well as QLG expert working groups. They also facilitate the involvement of QLG members in EU-funded projects.

And finally, as well as the teams within the QLD, we are also closely connected to other departments within HQ. This is through involvement in studies with multi-department teams (e.g., Statistics and Medical Departments) and QoL activities that are handled by other departments, like Communications, Services or Contracts.

Pernille Tine Jensen
3 September 1964 – 30 January 2026

REMEMBERING PERNILLE

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Pernille became a member of the EORTC QLG about 30 years ago, and from the very beginning she left a lasting mark. She was deeply involved in the development of gynaecological cancer modules, including cervical, endometrial and ovarian cancer. But for Pernille, the QLG was never just a professional collaboration – it was her extended family.

She was loved, respected and admired, yet also known for her strength and high expectations. Pernille never chose the easy way. She was exceptionally thorough, uncompromising in her standards, and she expected the same dedication from all of us. She did not shy away from difficult conversations – on the contrary, she faced them directly, always with the intention of improving the work and lifting the group. We sometimes called her a 'badass', and it was said with both affection and deep respect. She always pushed us – and herself – to aim higher.

Pernille was the one who invited me into the group. I still remember my first meeting in Pamplona in 2009, when the idea of a vulvar cancer module was just beginning to take shape. She approached every task with care and precision, and she inspired those around her to do the same. Nothing in her work was left to chance – everything was carefully considered and executed with great attention to detail.

Her work meant everything to her. Even in her final weeks, she remained fully engaged. We sat together and edited the vulva cancer module Phase 1–3 article just two weeks before her passing. She was mentally sharp, focused and completely present. It is hard to describe how much that time means to me now. Everything she did was ultimately for the benefit of patients, and improving quality of life for women with gynaecological cancers was her greatest passion.

Besides being a dedicated QLG member, Pernille was a gynaecological oncology surgeon and a professor in robotic surgery in the Department of Gynaecology at Aarhus University Hospital, Denmark.

She was ambitious, honest and deeply inclusive, and today the gynaecological oncology group within the QLG has grown into a strong international collaboration of experts from across Europe and beyond. She was a true role model – an outstanding clinician and scientist – but also a person of great warmth. Being with her was inspiring; you felt lifted, challenged and supported all at once.

She also brought a unique personal touch to the group as she was known for her sense of style – elegant, confident and unforgettable. We all remember her arriving at meetings with her famously large suitcase, always prepared, always herself.

In short, Pernille was someone to admire and to love. I feel an immense gratitude for having known her, for everything she taught me and for the friendship we shared. We have lost an exceptional colleague, a brilliant researcher and a remarkable human being. I have lost a close and very dear friend.

Her spirit will continue to live on – in our work, in our standards, and in all of us who had the privilege of knowing her.

QLG MEETING IN COPENHAGEN, AUTUMN 2025

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It was a true pleasure and honour to host the EORTC QLG meeting on 25 and 26 September 2025 in our beautiful city of Copenhagen. The venue reflected Copenhagen's modern architectural style. We felt that it provided a well-organised and professional setting for the event, and that the AC Bella Sky Hotel offered excellent facilities for both plenary and parallel sessions, as well as the dining experience on the Thursday night.

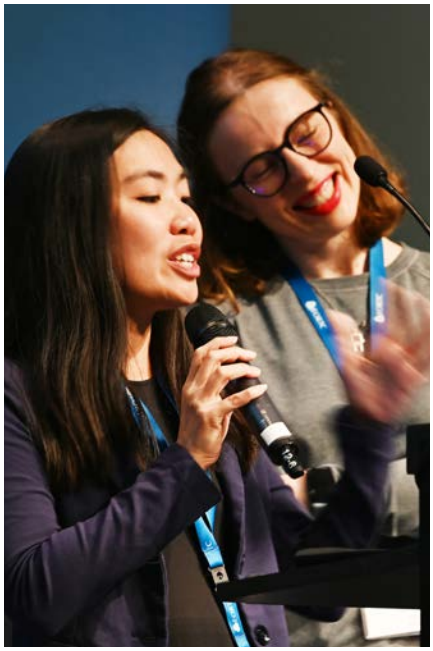
We cannot take credit for the coincidence that we had thousands of beekeepers attending another conference at the same venue, but we had some fun looking at their exhibition about beekeeping facilities, equipment and honey production, and being reminded that there are many other important topics that can make people travel across the globe.

The meeting opened on Thursday with a warm welcome from the QLG Chair and the QLD leaders, and concluded on Friday with insightful presentations and discussions emphasising the importance of strengthening collaboration and research on QoL in a global context. We particularly valued the inspiring presentations from non-European regions, emphasising the need to think about how we can transform our work and thinking into a more global perspective.

As always, the meeting offered a valuable opportunity to share project updates, exchange ideas and reflect on our collective future as a QLG community – while also providing a welcome chance to reconnect with colleagues and friends.

We hope our colleagues also had time to explore Copenhagen and its surroundings and enjoy some of its many attractions.


THANK YOU




Welcome to Copenhagen

QLG MEETING IN BERLIN, SPRING 2026

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The spring 2026 meeting of the EORTC QLG, held from 16 to 17 April in Berlin, brought members together for two days of engaging scientific exchange and genuine connection.

Beautiful sunny spring weather set the tone for a meeting that felt particularly welcoming. Hosted by Matthias Rose, Felix Fischer, Alizé Rogge and Claudia Weber, and situated in the heart of Berlin, the venue created an atmosphere where it was easy to approach one another, exchange ideas, and truly get to know colleagues across the group and the globe.

The programme showcased the diverse fields the QLG is actively engaged in, ranging from clinical research and ePROs to the development of questionnaire modules for clinical trials. It highlighted not only the breadth of ongoing work, but also the group's continuous efforts to innovate and adapt to emerging challenges in QoL research. A particularly thought-provoking highlight was the plenary session 'AI in Quality of Life Research: Opportunities Across the Research Lifecycle', which sparked lively discussion around both the challenges and possibilities of artificial intelligence in oncology research, and features as the focus theme of this issue.

Beyond the scientific programme, the social event at Spreespeicher Berlin, set along the river that once divided East and West, offered a memorable evening of conversation, dancing and connection.

Leaving Berlin, there was a shared sense of momentum and community, and we now look forward to continuing these conversations in Zagreb, Croatia, in autumn 2026.


EORTC
Quality of Life Group

The QLG – Berlin, 2026

EORTC'S QLG QUALITATIVE WORKING GROUP (QWG): UNITING QUALITATIVE ENTHUSIASTS

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The Qualitative Working Group (QWG) was launched in October 2025 to strengthen qualitative research across the QLG and thus create a community of practice.

"The EORTC QWG is a space dedicated to valuing, revisiting and learning from the rich narratives collected across QLG studies."

VISION

'There is a wealth of qualitative data collected within the QLG. We aim to create a collaborative space where researchers can support one another in making the most of these data,' explains Andreia Moura, cofounder of the QWG, alongside Sam Sodergren, Senior Research Fellow and member of the QLG EC. 'We see this as a community of practice,' adds Sam, 'bringing together a group of people who share a passion for qualitative research and who are keen to learn from one another, exchange experiences, and continually improve their work through regular interaction.'

SEED

Face-to-face meetings are ideal moments for connecting, and even brief coffee-break conversations can spark ideas. Sam recalls her first conversation with Andreia at the spring 2025 meeting in Rotterdam: 'The most rewarding aspect of my work is listening to patients' stories.' And when Andreia responded with 'Do our qualitative projects ever generate any "left-over data"?', the seed for the QWG was planted: a space dedicated to valuing, revisiting and learning from the rich narratives collected across QLG studies.

ACTIONS

Since its launch, the QWG has actively engaged members. By April 2026, the group had run six sessions with nearly 20 participants. Topics included:

- Developing interview guides
- Integrating qualitative methods into clinical trials
- Conducting and publishing mixed-methods studies

The group also hosted its first guest speaker, Professor Karen O'Reilly (Emeritus Professor of Sociology at Loughborough University, England), who has 25 years of qualitative research experience. Her session was both insightful and inspiring, highlighted by her reflection: 'My most profound quote was silence.'

Following her talk, Dr Zsuzsanna Iyizoba-Ebozue (Clinical Oncologist and Researcher at Leeds Teaching Hospital, England) shared further

The QWG members together at the QLG Berlin meeting in spring 2026

reflections, observing how 'qualitative insights give life to the numbers,' and 'qualitative research makes scientific data human again.'

OUTPUTS

The group's first output is a mixed-methods study exploring the experiences of patients with anal cancer: an in-depth analysis of data collected for the rare cancer module, developed in collaboration with study coordinator Catarina Simões Padilla and the Netherlands Cancer Institute [1].

FUTURE

The QWG is designed for its members, and their feedback shapes its direction. A key request has been increased collaboration on proposals and publications to showcase the rich qualitative data generated during module development.

COMMUNITY RESPONSE

Participants have expressed strong enthusiasm for strengthening qualitative research within the QLG. As one member shared, 'It's a real treasure trove, what we have with qualitative data.' Another concluded, 'Let's live up to our motto: giving a voice to patients.'

INTERESTED IN JOINING THE QWG?

The group welcomes all qualitative and non-qualitative but enthusiastic minds! To get involved, please contact the organisers: Andreia.moura@eortc.org and S.C.Sodergren@soton.ac.uk

References

1. Moura AF, Padilla CS, Vorbach SM, et al. (2026). Quality of Life and Healthcare Experiences of Patients with Anal Cancer: A Mixed-Methods Study. *Current Oncology* **33**(5): 266. DOI: https://doi.org/10.3390/curroncol33050266

EMPOWERING EARLY CAREER INVESTIGATORS

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Taking on the role of Early Career Investigator (ECI) Chair within the EORTC QLG is both a privilege and a commitment. I feel very thankful to be able to represent and support a vibrant and growing community of early career researchers dedicated to advancing QoL research in oncology.

The strength of the ECI community has become increasingly visible in recent years, and it is inspiring to witness its continued growth. Since the autumn 2025 meeting in Copenhagen, ECI membership has increased by 19%, now consisting of over 500 members across 46 countries. This momentum reflects not only rising interest, but also the trust that early career researchers place in this network.

With growth come both opportunities and challenges. A central characteristic of the QLG is its strong collaborative network, which forms the backbone of its scientific and professional achievements. For ECIs, becoming part of this network can be transformative, but only if connections are actively fostered. Our goal is therefore clear: to bring people together, encourage collaboration, and support ECIs in becoming not only colleagues but long-term collaborators and peers.

To guide this effort, we have developed the NEXUS strategy: a framework centred on connection, exchange and development. At its core, NEXUS aims to strengthen community building while supporting scientific excellence and career progression. Creating meaningful connections is not a passive process; it requires structured opportunities and continuous engagement.

We currently offer two on-site meetings per year alongside two to three online workshops, providing multiple opportunities for engagement. Recent online workshops have addressed diverse and forward-looking topics, such as “Hey chatbot, how am I feeling today?” (Felix Fischer, Charité Medical University Berlin), “From Barriers to Breakthroughs: Exploring Quality of Life in Cancer Clinical Research” (Saskia Litière, EORTC Scientific Director), and “Bringing Perspectives: The Need for Academia–Regulators–HTA Collaboration in Cancer Clinical Trials” (Maria Teixeira and Madeline Pe, EORTC QLD).

Beyond structured events, we actively seek to understand and support our community. Annual surveys allow us to capture the evolving needs of ECIs and shape our initiatives accordingly. We also circulate ongoing project support requests to increase visibility, foster collaboration and enable members to actively contribute to research initiatives.

The on-site ECI sessions during QLG meetings are particularly valuable. The sessions aim to provide a platform for ECIs to present their work, especially projects supported through EORTC QLG fellowships and visiting fellowships, through short pitches. They also offer opportunities to meet grant recipients and engage with inspiring speakers from EORTC HQ, helping ECIs better understand the broader strategic context of the organisation.

Looking ahead, my vision for the ECI community is centred on building long-lasting relationships. Careers in research are rarely linear: they evolve through different stages, challenges and opportunities. A strong professional network can provide continuity and support throughout these transitions. Ultimately, the success of the ECI group lies in its people: their openness to collaborate, willingness to support one another, and commitment to advancing QoL research in cancer within EORTC. My goal as Chair is to nurture this environment and ensure that every ECI finds a place within this growing and dynamic network.

NEW COMMISSIONED CALLS FOR 2026

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The QLG commissioned call process supports the strategic development of the EORTC QLG research portfolio. Commissioned calls are designed to strengthen the overall research programme, increase the visibility and uptake of QLG projects and measures, and foster collaboration across the membership.

Commissioned calls are priority-driven projects developed and endorsed by the QLG EC and are open to all members. They offer opportunities to contribute to high-impact, group-wide research questions and methodologies, while also supporting early career development and cross-project synergies.

Applicants are encouraged to submit short outlines aligned with ongoing or forthcoming commissioned calls. Feed-in and spin-off projects are particularly welcome, provided that applicants demonstrate clear strategic alignment with the existing QLG portfolio. Researchers are encouraged to engage early with Principal Investigators of active projects to explore complementarities, avoid overlap and enhance coherence across initiatives. This alignment should be clearly described in the strategic section of the application.

A recent development is that commissioned call grant applications now follow a fast-track procedure, allowing submissions at any time. This aims to improve responsiveness to emerging research needs while making efficient use of limited financial resources.

In addition to ongoing commissioned call projects a new commissioned call will be launched in 2026 following the plenary session themed 'Artificial Intelligence in Quality of Life Research: Opportunities Across the Research Lifecycle'. Active members of the QLG will be informed directly once the call opens.

STATUS OF CURRENT COMMISSIONED CALLS

Year	Project	Status
2020	Improving completion and standard of data collection and use in trials: setting standards for the next generation (Madeline Pe)	Ongoing
2020	Update of the EORTC QLQ reference values manual (Monika Sztankay & Susanne Singer)	Ongoing
2020	Measurement strategies for assessment of health-related quality of life outcomes in cancer patients with progressive disease (Florien Boele & Johan Koekkoek)	Ongoing
2020	Investigating the equivalence of the EORTC QLQ-C30 and the QLQ-F17 (Michael Koller)	Completed
2021	Development of recommendations for the use of the EORTC QLQ-C30 summary score in cancer clinical trials and clinical practice (Mogens Grønvold, Johan Koekkoek & Martin Taphoorn)	Ongoing
2021	Item Library Guidelines (Alexandra Gilbert)	Ongoing
2022	EORTC Quality of Life Group Education – Creation of a Curriculum in QoL in Oncology (Michael Koller & Sally Wheelwright)	Ongoing
2022	Facilitating the representation of EORTC QoL Modules and items in common data models (Mieke Van Hemelrijck)	Sustainability application under review
2023	Addressing neutrality and inclusivity in EORTC Quality of Life Measures: Updating gendered language (Olga Husson, Monica Pinto & Tom Bootsma)	Ongoing
2023	Time Frame Flexibility for Item Library Items (Alexandra Gilbert & Olga Husson)	Ongoing
2023	Navigating Acceptability: Evaluating patients' perceived assessment burden of PROMs in oncology (NAVIGATE) (Bernhard Holzner & Lotte van der Weijst)	Ongoing
2024	Developing a scientific strategy for the QLU-C10D: what is important for the EORTC QLG to move forward with the QLU-C10D?' (Eva Gamper & Janos Pitter)	To be submitted
2024	Potential Impact of Open-Label Bias on Patient-Reported Outcome Endpoints in Cancer Clinical Trials (Madeline Pe, Johannes Giesinger & Tihana Gašpert)	Under Review
2024	Towards an EORTC QLG Measurement System for Use in Clinical Practice (Bernhard Holzner & Sally Wheelwright)	To be submitted
2025	Making EORTC questionnaires accessible (Susanne Singer & Tihana Gašpert)	To be submitted
2025	Enhancing Cultural Sensitivity and Global Collaboration in EORTC QoL Research (Winette van der Graaf, Sandra Nolte, Jean-Marc Bourque, Rahul Krishnatry)	To be submitted

A LIFE-COURSE APPROACH TO HRQOL ASSESSMENT

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For over a decade now, we have been working towards a comprehensive, life-course approach to HRQoL assessment in oncology. In 2013, Anne-Sophie Darlington initiated discussions on addressing the unmet needs of adolescents and young adults (AYAs) with cancer. This led to the development of the EORTC QLQ-AYA30 [1], the first cancer-specific HRQoL questionnaire specifically tailored to AYAs aged 14-39, now available in multiple languages (currently 17) and about to start large-scale international validation (Phase 4). The EORTC QLQ-AYA30 measures HRQoL across the following domains: activity limitations and life disruptions, worry about cancer and the future, self-esteem, relationships, and positive changes, alongside nine single items.

Building on this, we expanded our efforts into the younger paediatric populations. Started in 2020, one of our projects focuses on developing an HRQoL questionnaire for children aged 8-14. In its early phases, we combined insights from systematic literature reviews with insights from interviews with children aged 8-14, parents and healthcare professionals (HCPs), ensuring the voices of the patients are heard. A little later in 2022 we launched another project addressing children younger than 8. For this, we developed and incorporated innovative, play-based interview methods adapted to this age group. Given the clinical necessity, an additional project was started in 2025 with the aim of developing EORTC-led consensus guidelines in cooperation with key stakeholders on how to deal with the dilemma of simultaneous PRO and proxy ratings in paediatric oncology.

Together, our initiatives aim to establish a unified measurement framework, allowing for a life-course approach to HRQoL assessment. This is particularly relevant for tracking patient outcomes longitudinally, even as individuals transition from childhood into adulthood. Alongside working on these projects, we have been able to establish a strong international network of collaborators that continuously informs and strengthens our work (see *Figure 1*). This collaborative approach, as well as our methods of involving the patients themselves, ensures that our work is closely aligned with scientific, clinical and patient perspectives.

Figure 1: EORTC QLG Children, Adolescents and Young Adults with Cancer (CAYAC) projects across the globe

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QLQ-ICI MODULE: PHASES 1 & 2

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Immune checkpoint inhibitors (ICIs) are an immunotherapy that work by blocking cell signalling pathways that regulate the immune system and which are exploited by cancer. They are being increasingly used in oncological practice. At present the EMA has authorised licences for 15 types of ICIs, for 109 different clinical circumstances spanning 19 diverse cancer types. The use of ICIs is likely to continue increasing as more clinical trial results are published.

SIDE EFFECTS

The side effects associated with ICI treatment are diverse. Potential side effects involve many bodily systems; they can include effects on the skin, hormonal system, joints, digestive system, lungs, cardiovascular system and nervous system. The side effects are highly variable in nature from patient to patient, giving ICIs a broad and somewhat unpredictable side effects profile that can be distressing for patients, and must be monitored and managed by oncologists.

Previous work showed that existing questionnaires to assess HRQoL in these patients do not cover the extent of the side effects. This has led to an effort within the QLG to develop a strategy to measure HRQoL in patients receiving ICIs.

> "Previous work showed that existing questionnaires to assess HRQoL in patients receiving ICIs do not cover the extent of the side effects."

PHASES 1 & 2

Phase 1 of this work drew upon 17 qualitative and 66 quantitative studies, and 89 reviews published in the literature, to produce a list of HRQoL issues potentially relevant to this patient group. Then, 40 patients and 16 clinicians were interviewed to see if anything further could be added to the list. The final list was shown to 127 cancer patients of different cancer types (and from nine different countries), who provided relevance and importance scoring for every issue on the list.

In Phase 2, data from Phase 1 were discussed in meetings of the module development group – a multidisciplinary team of experts in medical oncology and PROM development. The data were used to make decisions on which issues to formulate into questionnaire items for a preliminary ICI questionnaire. Phase 2 is now concluded, producing a preliminary item list containing 42 issues relevant to ICI patients. Of these, 30 issues showed particular 'strength' and were already present in the QLG Item Library. These 30 issues have been selected for a 'core' list, which is now available for use from the Item Library (as custom questionnaire IL453). The team was delighted to be able to present this work at the ESMO Congress in late 2025.

NEXT STEPS

In the next project phase, the team aims to enrol a larger patient sample across more research sites, and use a more elaborate study design, to evaluate all 42 items and ensure that the ICI measure is concise, representative and specific to issues caused by ICI treatment. The team aims to produce a measure that is comparable across patients with different cancer types, and compatible with existing questionnaire modules developed by the QLG, thereby upgrading these tools for a future in which ICIs are a staple of oncology practice.

QLQ-OV28 UPDATE: PHASES 1 & 2

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Ovarian cancer is the eighth most common cancer among women worldwide. The five-year survival rate is 90.0% for early-stage disease and 30.2% for advanced disease.

RESPONDING TO THE CHANGING TREATMENT LANDSCAPE

The introduction of new treatment options, such as PARP inhibitors, immunotherapy and bevacizumab, has led to longer recurrence-free intervals and more long-term survivors. However, these therapies have also introduced new side effects that are not adequately addressed by the EORTC QLQ-OV28, which was developed back in 1997. There is therefore a strong clinical and research need to update the questionnaire to reflect contemporary treatments and their impact on QoL. The necessity of updating the EORTC QLQ-OV28 was discussed within the EORTC QLG and the EORTC Gynaecological Cancer Group (GCG), as well as with EORTC HQ. The idea of initiating the update was well received, and the QLG EC advocated for a grant to fund Phases 1 and 2 of the QLQ-OV28 module update in 2022, the aim of which was to investigate whether the QLQ-OV28 needs to be updated, and if so, whether additional scales/items covering new QoL issues could be generated to supplement or integrate into the existing module.

PHASE 1

The focus was on identifying QoL issues relevant to ovarian cancer patients, particularly those related to new treatment options and long-term survival. This involved a systematic literature search and review of questionnaires, investigator brochures, focus groups and research group meetings (Phase 1).

A total of 697 potentially relevant records, comprising 24 different questionnaires used to assess QoL issues in ovarian cancer patients in various studies, were extracted from the literature (*Figure 1*).

Figure 1: Literature search

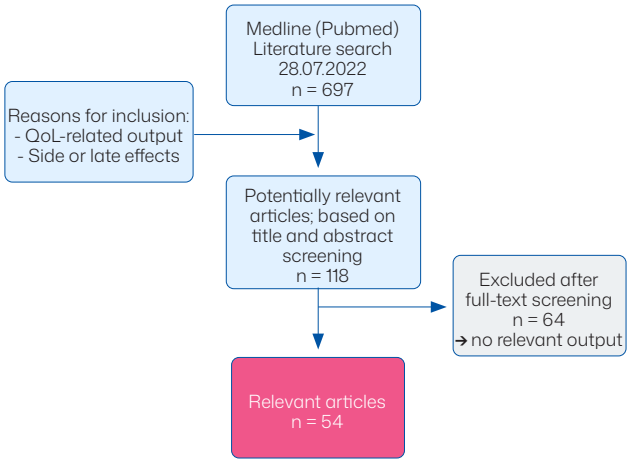
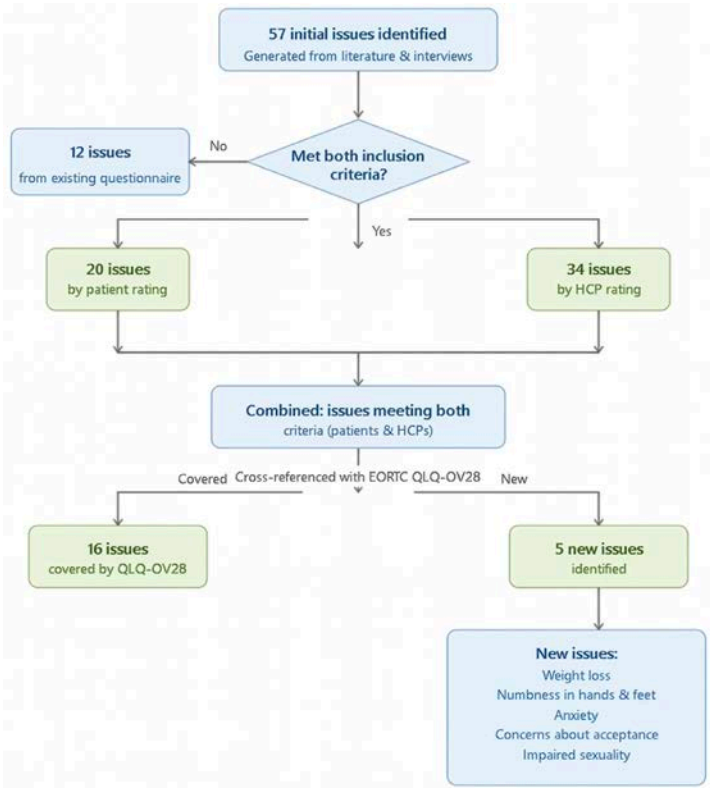


Figure 2: Development issue list and item list



The mixed-methods approach identified 57 QoL-related issues in ovarian cancer patients (*Figure 2*). This list of issues was then used to conduct interviews with 58 patients (from seven centres/countries) and 31 HCPs (from six study centres/countries) who rated each issue according to its relevance using a four-point response format – 'not at all', 'a little', 'quite a bit', 'very much' – and 'priority' (yes/no). Issues were added to the list if the ratings of patients and/or HCPs fulfilled the following criteria:

- relevance rating of at least 2 (on a scale of 1 to 4) and
- priority rating of at least 30%.

PHASE 2

Of the initial 57 issues, 20 (as rated by patients) and 34 (as rated by HCPs) met both inclusion criteria. Sixteen of these were covered by the existing QLQ-OV28 questionnaire, while five new issues were identified: weight loss; numbness in the hands and feet; anxiety; concerns about acceptance of their condition; and impaired sexual functioning. Twelve issues from the existing QLQ-OV28 questionnaire did not meet all the inclusion criteria (*Figure 2*). In Phase 2, these issues were translated into items and used to create a preliminary 39-item questionnaire to assess quality of life (QoL) in ovarian cancer patients. The provisional Phase 2 questionnaire/module was reviewed by the EORTC QLD translation team in February 2026.

NEXT STEPS

The results of Phases 1 and 2 suggest that the QLQ-OV28 module currently in use does not sufficiently address all the relevant QoL issues for patients with ovarian cancer. A preliminary questionnaire comprising 39 items will be tested for comprehensibility, completeness and psychometric properties in Phase 3 of the EORTC module development process. The report of Phases 1 and 2 is under review by the QLG PMDC, and with the completion of Phases 1-2 in accordance with the EORTC module development manual, the ovarian cancer group is now ready to start Phases 3a and 3b of the module development.

With thanks to Nora Sophie Nevries and Jennifer Steinmetz, Study Coordinators for the QLQ-OV28 update.

QLQ-STO22 UPDATE: GLOBAL COLLABORATION

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The EORTC QLG developed the QLQ-STO22 as a disease-specific module to assess HRQoL in patients with gastric cancer. Since its validation in the early 2000s, advances in treatment and shifts in patient populations have highlighted the need to update this instrument to ensure its continued relevance.

A key limitation of the original QLQ-STO22 is the absence of patient and HCP input from East Asia, where gastric cancer is most prevalent. In addition, evolving treatment approaches, including multimodal therapies and systemic treatments, have introduced new QoL issues and concerns that are not fully captured by the original module. A systematic review and qualitative interviews with patients and HCPs identified important gaps, including issues related to eating patterns, neuropathy, and concerns about future health.

To address these limitations, the update of the QLQ-STO22 is being conducted in line with the standard EORTC module development framework. Phases 1 and 2 have been completed. In Phase 2, items covering eating small amounts, neuropathy, and flatulence (n=5) were added; items covering thinking about illness and worry about future health (n=2) were removed; and items were also revised (n=7). Therefore, the module preliminary item list now includes 25 items. The project is currently in Phase 3, focusing on pre-testing and preliminary psychometric evaluation of the updated module.

In Phase 3a, patients with gastric cancer complete the updated module alongside the EORTC QLQ-C30 and the EORTC Write In three Symptoms/Problems (WISP) instrument. Using 'think aloud' interviews and structured debriefing, patients provide feedback on the clarity, relevance and acceptability of each item. Phase 3b extends this work to a larger international cohort, enabling quantitative evaluation of the module's structure and reliability through psychometric analysis.

A major strength of this project is its global and collaborative approach. The study is conducted in partnership with the EORTC Gastrointestinal Tract Cancer Group (GITCG), the Asian Clinical Trials Network for Cancer Project (ATLAS) conducted by National Cancer Center Japan, and the Japan Clinical Oncology Group (JCOG) Stomach Cancer Study Group (SCSG). The inclusion of patients from Asia and other regions ensures that the updated module reflects diverse clinical and cultural contexts.

Updating the QLQ-STO22 is crucial to maintaining the relevance of PROs in gastric cancer research and care. The revised module – provisionally referred to as QLQ-STO25 – is expected to better capture the impact of modern treatments and improve the assessment of patient experience across diverse populations. Importantly, this project has enabled closer collaboration with Asian research networks, particularly through ATLAS and JCOG, facilitating the inclusion of patient perspectives from regions with the highest disease burden. In this context, the study represents an important step towards more globally representative and culturally relevant PRO measures. Ultimately, this work aims to support more patient-centred clinical research and care worldwide.

Please contact the study coordinator Ms Amy Din if you are interested in collaborating: A.E.Din@soton.ac.uk

PATSAT-C33 AND OUT-PATSAT7: NOW VALIDATED

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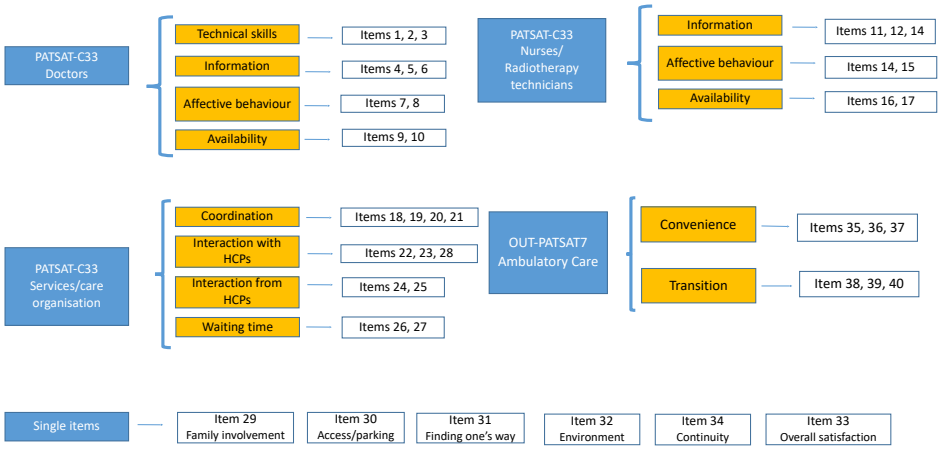
Advances in cancer care require ongoing monitoring of patient satisfaction using rigorous questionnaires. The EORTC QLG has cross-culturally developed a 33-item patient satisfaction core questionnaire (PATSAT-C33) to be used in any hospital cancer care settings, and a 7-item outpatient satisfaction module (OUT-PATSAT7) to address specific ambulatory care aspects.

VALIDATION STEPS

Within the QLG, we performed an international prospective study aimed to validate these questionnaires. Patients affected with any cancer site or stage enrolled in diverse cancer settings from 20 institutions, 12 countries and 5 geographic/cultural areas completed the PATSAT-C33 (N=675) and, when outpatients, the OUT-PATSAT7 (N=526). A subset completed a two-week retest or a one-year responsiveness-to-change analysis (RCA) second assessment. Full item completion was high (85% & 88%); 83% patients took ≤20 minutes to complete both questionnaires (40 items). Confirmatory factor analyses evidenced an acceptable fit of the PATSAT-C33 and OUT-PATSAT7 items on 13 multi-item scales and 6 single-item specific scales (*Figure 1*). Internal consistency, test-retest reliability, convergent-divergent validity, known-group comparisons and RCA evidenced satisfactory results. We concluded that this study supports the psychometric robustness of the PATSAT-C33 and OUT-PATSAT7 [1].

Figure 1: PATSAT-C33 and OUT-PATSAT7 multi-item scales and single items



FURTHER ASSESSMENT

Secondary analyses of these data provided relevant clinical information. On the cross-sectional assessment, patients without comorbidity were significantly less satisfied with most care domains; cancer care in day hospitals and treatment toxicities predicted less satisfaction with the domains of doctors' care and organisation of services [2]. On the one-year prospective assessment, among noteworthy results, patients who received supportive care over the one-year follow-up presented a lower decrease in satisfaction with doctors' care and a higher increase in satisfaction with care organisation compared with those who did not receive such care [3]. These results call for reinforcing initiatives to prepare patients for cancer care especially when never attending hospitals before, and to ensure multi-disciplinary and more continuous and coordinated care services.

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MEASURING HRQOL IN PROGRESSIVE DISEASE

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"Missing data is a major problem in treatment trials focusing on patients with progressive disease."

Cancer patients with progressive disease face limited survival, as well as an increasing symptom burden. This makes evaluating HRQoL outcomes on top of survival of the utmost importance, as it allows investigators to determine the net clinical benefit of a treatment strategy. Nevertheless, missing data is a major problem in treatment trials focusing on patients with progressive disease, complicating data analyses and impeding the value of the information obtained. To improve current standards, we aim to develop guidelines on the design, collection and analysis of HRQoL data in cancer clinical trials in the progressive disease setting.

This is being done in multiple steps: the first one involving the investigation of patient preferences on what they regard as important HRQoL research objectives, their preferred timing, frequency and method of assessment, and, finally, barriers and facilitators to completion of PRO questionnaires. For this, we are performing a systematic review, extracting data from 253 articles that have been included. In parallel, we are doing semi-structured interviews with patients, proxies and HCPs, having reached the 95% recruitment target in May 2026. For this, we would like to thank our collaborators from six different centres who have participated in the enrolment and interviewing of patients, as well as the patients and proxies who have agreed and taken the time to participate in our study.

Next, another systematic review is being performed, currently in the full-text screening phase, this time looking into alternative strategies to PROs to measure HRQoL. We defined alternative strategies as assisted completion, electronic assessment by the patient, proxy assessment, clinician-reported data, and/or data obtained with wearables. We will also look into the reliability of substitute data generated by alternative strategies in a re-analysis of the data from three different clinical trials, including two EORTC trials. Finally, these data will also be used in an additional analysis to determine how HRQoL data are best analysed in the progressive disease research setting, evaluating different mechanisms of handling missing data. The statistical analysis plan is in development. We are confident that we will be able to formulate a comprehensive set of recommendations on the design, collection and analysis of HRQoL data in cancer clinical trials in the progressive disease setting in the coming years. We would like to thank all of our collaborators and are looking forward to publishing the first results of our study.

23-24 March 2027 | The Square, Brussels, Belgium

Taking place on 23–24 March 2027 in Brussels, Belgium, the EORTC Summit 2027 will bring together the international cancer research community to help rethink how research is designed – and how better outcomes are achieved.

The Summit provides a focused platform to engage with key stakeholders across disciplines – clinicians, methodologists, patient advocates, and regulators – to address what clinical research must rethink: trial design and methodology; AI, data and emerging tools; patient-centred endpoints and quality of life; and regulatory barriers and research feasibility in Europe.

Through high-level plenary sessions, interactive discussions, and abstract submissions (30 September–4 November 2026), the Summit will highlight emerging priorities, offer a forward-looking perspective on how clinical trials in Europe are evolving, and strengthen collaboration across EORTC and the wider research community.

We encourage QLG members to seize this opportunity to submit an abstract and showcase their work on PROs and HRQoL to a broad, influential audience shaping the future of cancer research.

More info: https://event.eortc.org/summit/

The 7th EORTC Quality of Life in Cancer Clinical Trials Conference, on 13 and 14 May 2027 in Madrid, Spain, will provide an in-depth exploration of the latest methodological and practical advances in health-related quality of life (HRQoL) and patient-reported outcome (PRO) research.

The programme spans topics such as HRQoL measurement strategies and interpretation of PRO scores, as well as innovative approaches such as item libraries, computerised adaptive testing, and AI applications in patient experience reporting. Over the two days of the conference, attendees will also hear about the integration of PROs into clinical trials, regulatory and health technology assessment (HTA) decision-making, implementation in routine clinical practice, and global perspectives on HRQoL assessment and patient advocacy involvement.

Designed for both experts and emerging researchers, the conference is a must-attend for anyone seeking to stay at the forefront of Quality of Life (QoL) science and to strengthen the impact of patient-centred outcomes in oncology research.

More info: https://www.eortc.org/event/eortc-quality-of-life-conference-2027/

AI IN QUALITY OF LIFE RESEARCH: OPPORTUNITIES ACROSS THE RESEARCH LIFECYCLE

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Artificial intelligence (AI) is rapidly entering health research, healthcare delivery and everyday clinical practice. Quality of Life (QoL) research is no exception. As a field situated at the intersection of patient experience, clinical decision-making, health systems and policy, QoL research may be particularly shaped by both the opportunities and the risks that AI introduces. The 2026 focus section of the QLG Newsletter explores what AI could mean for QoL research across the full research lifecycle, from concept development to implementation in clinical practice.

At the QLG spring meeting in Berlin, AI was the focus of a dedicated plenary session entitled 'AI in Quality of Life Research: Opportunities Across the Research Lifecycle'. The aim of this session was not to showcase technological innovation for its own sake, but to create a shared space for critical reflection. AI tools, particularly large language models (LLMs) and related data-driven approaches, are already being used by many researchers, often in an exploratory and decentralised manner. The key question for QoL research is therefore no longer whether AI will be used, but how it should be used responsibly, rigorously, and in ways that genuinely strengthen the patient voice. This includes identifying not only where AI adds value, but also where it falls short, and what safeguards must be in place before it can be trusted in clinical research and practice.

AI'S MANY ROLES IN QOL RESEARCH

A central theme of both the plenary and this focus section is that AI can enter QoL research in multiple ways. In one mode, AI functions as a tool: supporting translation, assisting qualitative analysis, generating summaries, or helping researchers navigate increasingly large and complex datasets. In another mode, AI becomes the object of research itself, with models developed, trained and evaluated to predict outcomes, monitor symptoms, or interact directly with patients. In addition, emerging approaches position AI as a measurement extension, augmenting existing methodologies rather than replacing them.

These complementary roles raise distinct methodological, ethical and governance challenges, but all require strong domain expertise and clear scientific framing.

Speakers at the plenary session on AI, held at the 2026 QLG spring meeting in Berlin. Plenary organised by Amy Thomas. From L-R: Felix Fischer, Kelly de Ligt, André Pfob, Mangyeong Lee, Vassilis Golfinopoulos, Laurent Boyer.

Importantly, AI does not reduce the need for QoL science – if anything, it reinforces it. Patient-reported outcome measures (PROMs) have been developed over decades to translate lived experience into structured, standardised and validated scores that enable comparability across patients, settings and time. However, patients' experience of illness does not always fit into predefined categories. Numerical scores, while robust, can lack context and may be difficult for patients and clinicians to interpret or act upon.

Recent advances in LLMs introduce the possibility of capturing more contextualised, narrative expressions of health, allowing patients to describe their experiences in their own words. In this sense, QoL research may increasingly move from scores towards stories. Rather than replacing PROMs, such approaches can be understood as extending measurement: combining the robustness and comparability of structured instruments with the depth, flexibility and interpretability of narrative data.

INTEGRATION CHALLENGES

However, integrating these approaches is not straightforward. AI-enabled QoL research often involves multiple interconnected stages: from extracting symptom information from patient narratives, to mapping these expressions onto standardised clinical concepts, to generating feedback or interventions for patients and clinicians. Each of these stages introduces distinct methodological challenges related to reliability, validity, reproducibility and safety. At the same time, the probabilistic nature of AI systems raises important questions about interpretability, bias and equity, as well as the risk that fluent outputs may obscure underlying uncertainty or misrepresentation of the patient experience.

A recurring message is that AI should augment – not automate away – patient-centred care, clinical judgement and QoL expertise. Maintaining the principle of direct patient reporting remains essential, particularly as systems move from supporting tasks towards more automated forms of analysis and decision-making. In this context, human-in-the-loop oversight is fundamental to ensuring that AI systems remain aligned with clinical standards and patient needs.

A SPRINGBOARD FOR FUTURE USE OF AI

The articles in this focus section reflect the breadth and depth of discussions at the Berlin plenary. They span organisational and governance considerations, conceptual and methodological challenges, innovations in measurement and data capture, advances in symptom monitoring and interpretation, and novel approaches to making QoL data more meaningful and actionable for patients and clinicians. A cross-cutting theme is the need to enhance

"This initiative reflects a clear recognition that innovation must remain firmly anchored in the core principles of QoL science."

not only the quantity of data collected, but also the interpretability, relevance and impact of these data in real-world settings.

This focus section is deliberately exploratory. It is intended to inspire, to surface critical questions, and to highlight concrete areas where AI may add value across the QoL research lifecycle, while also identifying points where caution is essential. It does not propose a definitive strategy for AI use within the QLG, nor does it aim to provide exhaustive methodological guidance. Rather, it represents a shared starting point: a snapshot of how QoL researchers are currently engaging with AI, and of the principles that may guide future work.

NEXT STEPS

Looking ahead, discussions within the QLG point to the need to move from individual, often fragmented initiatives towards a more coordinated, transparent and methodologically grounded approach to AI in QoL research. Building directly on the reflections from the Berlin plenary and the contributions in this focus section, the QLG has initiated a commissioned call on AI in QoL research. This next step aims to translate emerging ideas into a more structured effort to define shared priorities and clarify where and how AI can most meaningfully support QoL research across the full lifecycle.

At the same time, this initiative reflects a clear recognition that innovation must remain firmly anchored in the core principles of QoL science. In particular, it emphasises that AI should operate within, rather than redefine, the conceptual, methodological and psychometric foundations of the field, including the primacy of the patient perspective and the interpretability and validity of QoL measurement. In this way, the commissioned call represents a step towards integrating AI in a way that is deliberate, coordinated and aligned with the long-standing values of the field.

EORTC ACTIVITIES IN ARTIFICIAL INTELLIGENCE

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It is not uncommon these days for EORTC representatives to have discussions where someone claims that AI will take over <insert any clinical cancer research area here>; and, in the case of the QLG, that AI will replace the measurement of HRQoL and/or PROs.

The statement is meant to be provocative and of course brings into question how new technologies can change the field of clinical cancer research.

EORTC is actively exploring how AI can strengthen cancer clinical research while safeguarding scientific quality, patient centredness and data protection. A key question is not whether to use it, but to find out where it helps, where it fails, and what must be in place before it can be trusted. For instance, an essential aspect of the measurement of QoL is the direct reporting of patients on their actual health experience, without the interpretation of others – including any type of AI-based solutions.

EORTC is running several initiatives across departments to test how AI can support day-to-day activities. Currently, our clinical research support tools include AI assistance, and there is an EORTC AI working group piloting AI-powered agents for repetitive tasks and streamlining workflows. There is also exploratory work on an AI-powered 'protocol assistant' that can help teams generate, review and update protocol text more efficiently, so that teams can focus more time and effort on the scientific and operational decisions.

Because work here often involves sensitive clinical and operational information, EORTC also emphasises responsible and secure use. This means only authorised tools are allowed to be used for EORTC activities and information is not allowed to be shared in publicly available AI tools. As a general principle, the more we move from supported manual work to automation, the more oversight matters.

Finally, EORTC is convening strategic discussions on the use of AI in cancer clinical research at the EORTC Summit in 2027. The AI session will combine expert lectures and panel discussions, covering both emerging capabilities in data science and AI, as well as the practical questions of how to approach adoption responsibly, including regulatory, ethical and implementation considerations.

By combining core principles of EORTC, a stepwise approach in piloting various AI tools within HQ, and overall strategic discussions with key opinion leaders, EORTC is building a pragmatic AI agenda focused on measurable value, scientific robustness, reliable data, responsible use of technology and appropriate governance – all in support of fulfilling the overall mission of EORTC to increase QoL and survival rates of cancer patients through high-quality clinical cancer research.

The EORTC framework will be incorporated into the QLG's AI commissioned call to ensure alignment.

> "EORTC is building a pragmatic AI agenda focused on measurable value, scientific robustness, reliable data, responsible use of technology and appropriate governance."

GENERATIVE AI: WILL IT STRENGTHEN OR WEAKEN THE PATIENT VOICE?

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AI is rapidly transforming healthcare. Yet, despite decades of work establishing PROMs as essential indicators of treatment benefit, QoL, and patient-centred care, patient-reported data remain largely absent from current AI development.

This is the PRO paradox: PROMs are increasingly recognised as critical for healthcare decision-making, while AI systems continue to be trained primarily on biomedical, imaging, administrative and genomic data.

Generative AI offers an opportunity to address this gap. Conversational interfaces may make PROM collection more accessible for individuals who face literacy, language, cognitive or physical barriers, thereby expanding inclusivity. AI can also support the analysis of patient narratives, helping clinicians and researchers move beyond numerical scores alone. Rather than replacing questionnaires, AI may enrich them by combining structured measurement with qualitative insights that capture the context and meaning of patients' experiences.

This opens the door to hybrid quantitative–qualitative workflows in which validated PROM scores are complemented by AI-assisted interpretation of patient narratives. Such approaches could strengthen clinical decision-making while preserving the comparability and scientific robustness of established outcome measures.

However, these opportunities come with significant risks. Automation may encourage over-reliance on AI-generated outputs, potentially reducing clinical reflection and human judgement. Biases in training data can reinforce existing inequalities if vulnerable or underrepresented populations remain excluded from PROM collection. Furthermore, AI systems introduced primarily to increase efficiency may contribute to workflow pressure, standardisation, and even moral injury among HCPs if they are perceived as replacing rather than supporting clinical work.

To realise the benefits of AI while protecting patient-centred care, PROMs must become FAIR: Findable, Accessible, Interoperable, and Reusable. FAIR PROs provide the foundation for trustworthy AI by ensuring that patient-reported data are standardised, interoperable across systems, transparently documented, and reusable for research and clinical applications. Such infrastructures make it possible to integrate patient perspectives into AI development at scale while monitoring bias, representativeness and data quality.

The future of AI in QoL research is therefore not simply a technological question: it is a design choice. AI must be deliberately developed to strengthen – not marginalise – the patient voice, ensuring that innovation enhances patient-centred care rather than distancing healthcare from the experiences that matter most to patients.

FROM SCORES TO STORIES

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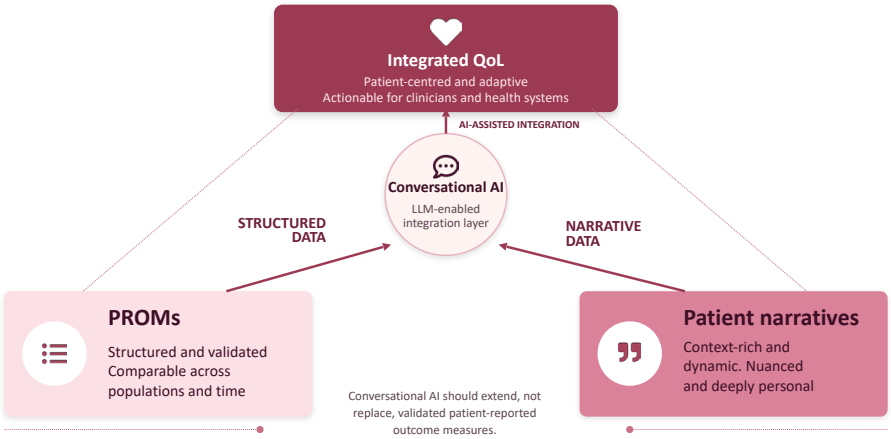
PROs are central to understanding QoL in cancer. Traditionally, these are captured through PROMs: structured questionnaires that translate complex experiences into numerical scores.

Yet, patients rarely experience illness in predefined categories. Living with cancer is dynamic, multidimensional and deeply personal. Structured questionnaires capture what researchers decide to ask, but may not always completely cover what matters most to patients in a given moment. As a result, important aspects of patient burden may remain underrepresented.

Recent advances in LLMs may offer a complementary approach. Conversational AI enables patients to describe experiences in their own words, while AI systems analyse narrative data at scale. These approaches aim to capture additional aspects of lived experience. Early empirical work suggests that combining narrative input with quantitative PROMs may provide a richer understanding of patient burden. Large international initiatives, such as the ResPECT project, are now exploring how conversational AI can be integrated into routine QoL assessment to better capture patient burden, support clinicians with actionable insights, and provide health systems with real-time, equity-sensitive intelligence for care planning and policy development.

Figure 1: Structured PROMs and patient narratives as complementary inputs to quality of life measurement



At the same time, important challenges remain. Unlike PROMs, conversational data lack inherent standardisation. Outputs may vary depending on model design, prompting strategies, language or clinical context. Reliability, comparability across settings, interpretability and bias therefore become central methodological questions. For now, conversational AI can be best understood not as a replacement for PROMs, but as a measurement extension (see *Figure 1*). PROMs provide robustness, standardisation and comparability; narrative AI may add scalability and contextual depth.

Looking ahead, QoL measurement may evolve towards integrated models that combine structured measurement with scalable narrative insight. In doing so, we may come closer to understanding not only how patients score, but how they truly experience cancer and its treatment.

MAKING PROMS MEANINGFUL: GIVING CONTEXT TO SCORES USING PERSONALISED NARRATIVES

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Imagine you are a patient and you completed the EORTC QLQ-C30 in your online patient portal. The next day, you have an appointment with your surgical oncologist, and she presents you with the scores. You see a '73' for a topic called 'physical functioning', which is highlighted in red. Both you and the doctor understand that there are some issues here. On the way back home, you are a bit puzzled: why did I score 73? Is that bad? What does this even mean? The context of what 73 means is missing.

CONTEXT IS ESSENTIAL

PROs are often presented in numbers and graphs that lack context and evaluability, and are therefore occasionally misinterpreted by patients and considered not very actionable by HCPs [1-3]. Importantly, effectively presenting PROs can promote patient activation, defined as having the knowledge, skills and confidence to manage one's health [4]. Promoting patient activation can significantly improve key aspects of cancer survivorship like self-management, coping with side effects, and adoption of healthy behaviours, with lasting effects [5-8].

Presenting personalised narratives alongside PROs could improve the presentation of PROs in an impactful way. Narratives are patients' written experiences with disease and treatment. Up to now, narratives have not yet been applied to PROs – although they were found to communicate information more effectively in persuasive health communication because they provide context to numerical information [9, 10]. Besides, when the narrative's main character resembles the patient, for instance by having the same age, gender and diagnosis, patients engage more deeply with narratives. This could even change a patient's behaviour, as they could mimic the behaviour described in the narrative [11, 12].

PILOTING AUTOMATION

To implement the up-scaling of personalised narratives in clinical practice, you need automation: it is simply not feasible to manually select or develop a narrative every time someone completes the EORTC QLQ-C30. LLMs offer the opportunity to automate the development of narratives that are in line with readers' characteristics. We piloted the automated development of personalised narratives by using a database of template sentences derived from interviews, that were tailored semi-automatically by inserting relevant information to create new, fluent narratives [13]. With rapid ongoing advancements in LLMs, simply feeding QLQ-C30 scores into GPTs like ChatGPT can create accurate, meaningful patient narratives that are appreciated by readers [unpublished work, submitted to Conference on Language Modeling].

THE QLG'S WEALTH OF DATA

The QLG offers a great platform to further develop personalised narratives. It is important that the narratives are developed from real patient content and are evaluated by real patients. In particular, as we expect that people from different cultures and language areas speak differently about their experiences with their disease and treatment, development and evaluation will ideally take place cross-culturally. The module development guidelines offer a structured method for this. Secondly, feeding real patient interviews into LLMs could train them to better mimic real patient stories and enable diverse but also controlled input. The QLG conducts many interviews during module development, of which the transcripts could be a highly valuable source of narratives.

BRIDGING THE GAP

The successful implementation of PROMs in routine clinical practice consists of several interlinked stages, including inviting patients to complete PROMs, patients completing the PROMs, interpreting and discussing PROs, and applying the PROs to patient management [14]. Hampering any one of these steps leads to the under-use of PROMs in clinical practice, in turn leading to patients missing out on benefits like improved patient–physician communication, quality of care and QoL [15, 16]. LLM-generated personalised narratives could bridge the gap between PROM scores and meaningful clinical conversations, securing the use of the QLQ-C30 in clinical practice.

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PRO-DRIVEN SYMPTOM MONITORING AND INTERVENTION: PROMISES AND CHALLENGES OF LLMS

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PROs are a cornerstone of patient-centred cancer care, yet the digital infrastructure has evolved only modestly. Most remain anchored in closed-ended items, fixed thresholds and pre-defined response pathways.

Such designs capture standardised data efficiently but leave limited room for contextual interpretation, individual variability and conversational depth in eliciting patient experience. LLMs are anticipated to help extend patient-centred symptom monitoring and management. However, their use in symptom monitoring and management requires careful consideration across three linked domains: symptom extraction from patient narratives; mapping to standardised terminology; and delivery of individualised health information.

At the extraction stage, LLMs can read unstructured clinical and patient narratives, recovering symptom information that coded systems often miss. Several studies have reported acceptable accuracy in extracting symptoms from clinical notes. Yet pre-trained biases and sparse patient context can cause symptoms to be missed or misinterpreted. 'Pain at chest' may indicate breast, pulmonary or chest-wall pathology depending on disease context, and LLMs can dismiss meaningful menstrual changes as routine physiology. Addressing these would require reassurance dialogue flows and electronic medical record (EMR) integration.

At the mapping stage, the stochastic nature of LLMs makes reproducibility inherently fragile regardless of extraction accuracy or contextual consistency. Identical prompts may yield 'headache', 'pain at head', or no output. Intermediate normalisation is essential, with embedding-based mapping to standardised symptom terminology. More fundamentally, descriptions of clinical terminologies were not built around how patients express symptoms. Therefore, a patient-derived ontology of real-world symptom expressions would be needed, usable as a future benchmark.

At intervention stage, the health information generated by LLMs is delivered directly to patients, so hallucination must be carefully avoided. Fine-tuning and retrieval-augmented generation (RAG) – an approach that incorporates relevant information retrieved from external knowledge sources into the generation process – are methods commonly considered to mitigate this risk. However, mitigating hallucination alone may not be enough. Effective symptom-level consultation requires follow-up questions that probe deeper based on individual symptom profiles and deliver appropriately tailored information. While current LLMs can reason at a differential diagnosis level, symptom care necessitates conversational guardrails to maintain clinical standards and safety.

Looking ahead, an agentic system will be required in which extraction, mapping and intervention work reciprocally. For now, human-in-the-loop oversight remains essential until that vision is reached. In parallel, substantial effort must go into collecting real-world qualitative data, both to capture the lived context of patients and to serve as nourishing input for LLMs. This raises the need for governance and platforms that can acquire and process such data at scale. Above all, clinically acceptable AI alone may not be enough, and achieving patient-centredness alongside it is equally important.

QUALITY OF LIFE RESEARCH IN THE AGE OF AI

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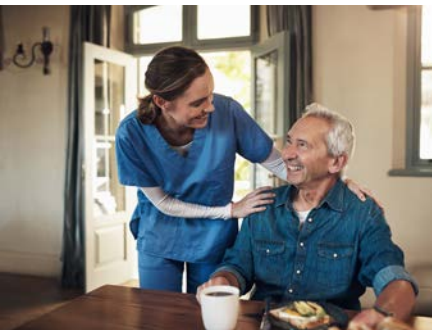
AI offers many novel approaches to a broad range of challenges that we face in medical research and clinical care.



Pattern recognition, for example, supports the analysis of imaging data, and natural language processing using LLMs can enable patients to better understand their health information by translating complex medical documents into accessible language. LLMs promise to enhance our understanding of patients' perspectives on their health as well.

Galatzer-Levy et al. [1] argue that the development of modern diagnostic tools based on LLMs can solve the conflict between rich but unscalable methods to understand a patient's perspective (e.g., patient interviews) and reductive but scalable tools to measure those (e.g., PROMs). They highlight that development of such innovative AI tools needs to address issues we typically face in PROM development as well – from the development of a precise translation of theoretical and clinical understanding of the constructs into a measurement tool, to the formal investigation of its measurement properties such as reliability, validity and measurement invariance across different populations.

From a different perspective, LLMs can help us to analyse the relationships between constructs, items and scales. Wulff & Mata [2] highlight how LLMs can be used to automatically identify common ground across PROMs measuring similar constructs. Hommel et al. [3] show that LLMs can be used to develop novel items for a given construct and that a substantial part of these automatically generated items are of similar quality to items carefully developed by experts.

These works provide valuable ideas for how LLMs can facilitate QoL research and highlight that our expertise as QoL researchers is crucial in the development of AI methods. The advent of these innovative methods calls for us to identify challenges, understand where LLMs can provide a promising scientific approach, and collaborate with AI experts to tackle them.

Although the way we measure a patient's own perspective on their health might look very different in the future, the underlying constructs and their relevance for patients are already well established. Most importantly, our role as advocates for patient-centred care and research will be more relevant than ever.

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