



EORTC Quality of Life Group Spring Meeting

March 21st - 22nd, 2024
Rome, Italy



MEETING VENUE

Centro Congressi „Roma Eventi – Fontana di Trevi“

Piazza della Pilotta, 4 – 00187 Roma
(Italy)

www.roma-eventi.com



Wednesday 20th March 2024

14.00- 19.00 EC Meeting (one Lunch Break)

Thursday 21st March 2024

8.00 Registration

08.45-09.30 WELCOME SESSION (LOYOLA Auditorium)

Welcome from:

EORTC QLG Chair - Jaap Reijneveld
(JC.Reijneveld@amsterdamumc.nl)

QoL Department - Madeline Pe
(madeline.pe@eortc.org)

Dagmara Kulis (dagmara.kulis@eortc.org)

Local Organizer – Anna Costantini
(drssa.costantini@gmail.com)

09.30-11.00 PMDC session (open to all) (LOYOLA Auditorium)

Bernhard Holzner (Bernhard.holzner@tirol-
kliniken.at)

Simone Oerlemans (s.oerlemans@iknl.nl)

11.00-11.30 Coffee/Tea Break + ECI Mentor- Mentees Meeting (MANZONI & ARIOSTO)

11.30-12.30 PARALLEL SESSIONS (1)

1.1. Renal Cell Cancer Module: Preparation of Phase III and Bladder Cancer (phase I/II) (MARINETTI) Lisa

Wintner (lisa.wintner@tirol-kliniken.at)

Franziska Gross (franziska.gross@i-med.ac.at)

Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)

Elke Rammant (elke.rammant@ugent.be)

Mieke Van Hemelrijck (Mieke.vanhemelrijck@kcl.ac.uk)

Marieke van Leeuwen

(marieke.van.leeuwen.mvl@gmail.com)

1.2. CODAGLIO 2.0: Combining clinical trial datasets in glioma patients to answer clinically relevant questions about patients' health-related quality of life

(TRILUSSA)

Johan Koekkoek (j.a.f.koekkoek@lumc.nl)

Ogechuckwu Edeh-Asogwa (o.a.edeh-asogwa@lumc.nl)

1.3. Hereditary Cancer Predisposition Syndrome

Module (MONTALE)

Anne Oberguggenberger (anne.oberguggenberger@i-med.ac.at)

Vasilis Vasiliou (vasilis.vasiliou@bococ.org.cy)

Veronika Engele (veronika.engele@i-med.ac.at)

1.4. Computer Adaptive Testing Projects/Comparative evaluation of the computer adaptive EORTC quality of life measures (ALFIERI)

Morten Aa. Petersen

(Morten.Aagaard.Petersen@regionh.dk)

Mogens Groenvold (Mogens.Groenvold@regionh.dk)

Johannes Giesinger (johannes.giesinger@i-med.ac.at)

1.5. Update of the EORTC QOL Reference Value Manual and Database (ALIGHIERI)

Monika Sztankay (monika.sztankay@tirol-kliniken.at)

Susanne Singer (singers@uni-mainz.de)

Matthias Büttner (matbuett@uni-mainz.de)

Andrea Csipak (andrea.csipak@uni-mainz.de)

Daniela Krepper (daniela.krepper@i-med.ac.at)

Melanie Schranz (melanie.schranz@uni-mainz.de)

1.6. Sarcoma Module/Rare Cancer Project (BELLI)

Tom Bootsma (t.bootsma@nki.nl)

Catarina Simões Padilla (c.simoes@nki.nl)

Olga Husson (o.husson@nki.nl)

Winette van der Graaf (w.vd.graaf@nki.nl)

1.7. Cancer Clinical Trials Pooling of Quality-of-Life Data(CATAPULT)/ Prospective Minimal important Difference (pMID) Projects (LEOPARDI)

Jamme Musoro (jammbe.musoro@eortc.org)

Corneel Coens (corneel.coens@eortc.org)

Luigi Lim (luigi.lim@eortc.org)

1.8. Survivorship Module (LOYOLA Auditorium)

Louis Fox (Louis.fox@kcl.ac.uk)

Lonneke van de Pol (L.vandePoll@iknl.nl)

12.30-12.45 Coffee/Tea Break (MANZONI & ARIOSTO)

12.45-13.45 PARALLEL SESSIONS (2)

2.1. Common Data Model for EORTC QoL Modules (MARINETTI)

Charlotte Moss (charlotte.moss@kcl.ac.uk)

Mieke Van Hemelrijck

(Mieke.vanhemelrijck@kcl.ac.uk)

2.2. Reworking the QLQ guidelines for assessing Quality of Life in EORTC clinical trials – updating and rewriting by incorporating cutting-edge advice on PROs and input from relevant QLQ projects (REQUALIFY) (15') (TRILUSSA)

Lotte van der Weijst (lotte.vanderweijst@eortc.org)

Ahu Alanya (ahu.alanya@eortc.org)

2.3. Big data strategies in breast cancer (BALANCE): risk prognosis for clinically relevant impairments of health related quality of life (MONTALE)

Thijs van der Heijden (t.vd.heijden@nki.nl)

Niclas Hubel (niclas.hubel@i-med.ac.at)

Lonneke van de Poll (l.vd.poll@nki.nl)

Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)

2.4. Investigating the Equivalence of the EORTC QLQ-C30 and the QLQ-F17 (ALFIERI)

Michael Koller (michael.koller@ukr.de)

Florian Zeman (florian.zeman@ukr.de)

2.5. Development of an interpretation guideline for the EORTC PRO measures (ALIGHIERI)

Monika Sztankay (monika.sztankay@tirol-kliniken.at)

Daniela Krepper (daniela.krepper@i-med.ac.at)

2.6. Sexual Health Projects and Ovarian Cancer Update (BELLI)

Eva Greimel (elfriede.greimel@medunigraz.at)

Claudia Schmalz (schmalz@onco.uni-kiel.de)

Anne Oberguggenberger

(anne.oberguggenberger@tirol-kliniken.at)

Vesna Bjelic-Radistic (vesna.bjelic-radistic@helios-gesundheit.de)

Veronika Engele (veronika.engele@tirol-kliniken.at)

Nora Nevries (nora.nevries@helios-gesundheit.de)

2.7. Understanding the long-term implications of rare brain tumours on health-related quality of life: A European cross-sectional study (LEOPARDI)

Florien Boele (F.Boele@leeds.ac.uk)

Se Frances (umsfmfr@leeds.ac.uk)

2.8. Communication Module (LOYOLA Auditorium)

Juan Ignacio Arraras (jiarraras@correo.cop.es)

13.45 -14.45 Lunch (MANZONI & ARIOSTO)

14.45-15.45 PARALLEL SESSIONS (3)

3.1. EMBED (MARINETTI)

Hugo Vachon (Hugo.vachon@eortc.org)

Louis Fox (Louis.fox@kcl.ac.uk)

Mieke Van Hemelrijck

(Mieke.vanhemelrijck@kcl.ac.uk)

3.2. Haematological QOL Modules (TRILUSSA)

Charalampia Kyriakou (Charalampia.kyriakou1@nhs.net)

Eleanor Scouler (eleanor.scouler@adelphivalues.com)

Katie Forde (katie.forde@adelphivalues.com)

Kim Cocks (kim.cocks@adelphivalues.com)

Simone Oerlemans (s.oerlemans@iknl.nl)

3.3. Establishing Thresholds for Clinical Importance for EORTC Modules (MONTALE)

Johannes Giesinger (johannes.giesinger@i-med.ac.at)

Micha Pilz (micha.pilz@i-med.ac.at)

Anna Thurner (anna.thurner@i-med.ac.at)

3.4. An Educational Programme for Quality of Life in Oncology (ALFIERI)

Michael Koller (michael.koller@ukr.de)
Sally Wheelwright (S.Wheelwright@sussex.ac.uk)

3.5. Development of an EORTC QOL e-Learning course - Phase II (ALIGHIERI)

Heike Schmidt (heike.schmidt2@uk-halle.de)
Monika Sztankay (monika.sztankay@tirol-kliniken.at)
Thomas Nordhausen (thomas.nordhausen@uk-halle.de)
Ines Rathgeber (ines.rathgeber@i-med.ac.at)

3.6. Ophthalmic Cancer Module Update (BELLI)

Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)
Anne Brédart (anne.bredart@curie.fr)
Veronika Engele (veronika.engele@i-med.ac.at)
Anita Müller (anita.muller@curie.fr)

3.7. Vulva Module Development (LEOPARDI)

Pernille Jensen (Pernille_jensen@dadlnet.dk)

15.45 – 16.00 Coffee/Tea Break (MANZONI & ARIOSTO)

16.00-17.30 PARALLEL SESSIONS (4)

4.1. Immune Checkpoint Inhibitors (phase I/II) and Advanced Melanoma (phase I/II) (MARINETTI)

Louis Fox (Louis.fox@kcl.ac.uk)
Mieke Van Hemelrijck (Mieke.vanhemelrijck@kcl.ac.uk)
Marieke van Leeuwen (marieke.van.leeuwen.mvl@gmail.com)
Mees Egeler (m.egeler@nki.nl)
Lonneke van de Pol (L.vandePoll@iknl.nl)

4.2. Children, Adolescents and Young Adults with Cancer (CAYAC) (TRILUSSA)

Anne-Sophie Darlington (a.darlington@soton.ac.uk)
David Riedl (david.riedl@tirol-kliniken.at)
Samantha Sodergren (S.C.Sodergren@soton.ac.uk)
Maria Rothmund (maria-sophie.rothmund@tirol-kliniken.at)

4.3. Development of a Health-Related Quality of Life (HRQOL) Module for Keratinocyte Carcinoma – Phase I study// Development of Health-Related Quality of Life (HRQoL) Issues in Patients with Ductal Carcinoma In Situ (DCIS) – Phase I / II //Phase I update of the EORTC Quality of Life Bone Metastases Module: QLQ-BM22// Phase I study to develop a health-related quality of life module for patients with malignant spinal cord compression (MSSC) (MONTALE)

Pierluigi Bonomo (bonomopierlu@gmail.com)
Edward Chow (Edward.Chow@sunnybrook.ca)
Shing Fung Lee (leesf@nuhs.edu.sg)
Agata Rembielak (agata.rembielak@nhs.net)
Vasilis Vasilou (Vasilis.Vasilou@bococ.org.cy)
Henry Wong (henrywong3011@gmail.com)

4.4. Development of a Module to Assess the Patients' Financial Burden Related to Cancer Treatment – “Financial Toxicity” (ALFIERI)

Matthias Buettner (matbuett@uni-mainz.de)
Kathy Taylor (kataylor@uni-mainz.de)

4.5. Breast Cancer Module Update and Male Breast Cancer Module Development/ Metastatic Breast Cancer Module Development (ALIGHIERI)

Vesna Bjelic-Radasic (vesna.bjelic-radasic@helios-gesundheit.de)
Galina Velikova (G.Velikova@leeds.ac.uk)
Melanie Beauvois (melanie.beauvois@eortc.org)
Christopher Bedding (c.m.bedding1@leeds.ac.uk)
Nora Nevries (nora.nevries@helios-gesundheit.de)

4.6. Improving Compliance Rates in EORTC Cancer Clinical Trials / Measurement Strategies for Assessment of Health-related Quality of Life Outcomes in Cancer Patients with Progressive Disease (BELLI)

Madeline Pe (madeline.pe@eortc.org)
Linda Dirven (L.Dirven@lumc.nl)
Johan Koekkoek (J.A.F.Koekkoek@lumc.nl)
Abigail Machingura (abigail.machingura@eortc.org)
Lotte van der Weijst (lotte.vanderweijst@eortc.org)
Esther Zaloumis (e.a.m.zaloumis@lumc.nl)

4.7. Electronic PROs in Research and Daily Clinical Practice (CTCAEplusPRO, ePRO in trials & routine) (LEOPARDI)

Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)
Lisa Wintner (lisa.wintner@i-med.ac.at)
Jens Lehmann (jens.lehmann@i-med.ac.at)

Friday 22nd March 2024

08.00 Registration

08.30-10.00 PARALLEL SESSIONS (5)

5.1. Patient organisation vs Hospital Recruitment for QLQ studies and EORTC QLQ Patient Involvement Project (MARINETTI)

Saran Green (saran.green@kcl.ac.uk)
Elke Rammant (elke.rammant@ugent.be)
Mieke Van Hemelrijck (Mieke.vanhemelrijck@kcl.ac.uk)
Olga Husson (o.husson@nki.nl)
Winette van der Graaf (w.vd.graaf@nki.nl)
Emily Holthuis (e.holthuis@nki.nl)
Iryna Shakhnenko (iryna.shakhnenko@eortc.org)

5.2. Thyroid Cancer Module and Late toxicity in thyroid cancer project (LoQoT) (TRILUSSA)

Susanne Singer (susanne.singer@uni-mainz.de)

5.3. Development of recommendations for the use of the EORTC QLQ-C30 summary score in cancer clinical trials and clinical practice (MONTALE)

Martin Taphoorn (m.j.b.taphoorn@lumc.nl)
Mogens Groenvold (mold@sund.ku.dk)
Josien Scheepens (j.c.c.scheepens@lumc.nl)

5.4. Gastrointestinal modules (QLQ-PAN26, QLQ-STO22 update, CR29 update, Metastatic anal cancer, Pelvic exenteration) (ALFIERI)

Vassilis Vassiliou (vassilis.vassiliou@bococ.org.cy)
Deborah Fitzsimmons (D.Fitzsimmons@swansea.ac.uk)
Mitsumi Terada (mitterad@ncc.go.jp)
Alexandra Gilbert (A.Gilbert@leeds.ac.uk)
Samantha Sodergren (S.C.Sodergren@soton.ac.uk)
Deena Harji (deena_harji@hotmail.com)

5.5. Item Library Projects: The development of guidelines. The assessment symptomatic patient-reported adverse events (ALIGHIERI)

Alex Gilbert (A.Gilbert@leeds.ac.uk)
Rose Peacock (R.Peacock@leeds.ac.uk)
Chris Bedding (c.bedding@leeds.ac.uk)
Claire Piccinin (claire.piccinin@eortc.org)

5.6. Satisfaction with cancer care (BELLI)

Anne Bredart (anne.bredart@curie.fr)
Amélie Anota (Amelie.ANOTA@lyon.unicancer.fr)

5.7. EORTC Fertility Module (LEOPARDI)

Joachim Weis (Joachim.weis@uniklinik-freiburg.de)
Nathalie Dammer (Nathalie.dammer@uniklinik-freiburg.de)

10.00– 10.15 Coffee/Tea Break (MANZONI & ARIOSTO)

10.15- 11.45 PMDC (open to all) (LOYOLA Auditorium)

Bernhard Holzner (Bernhard.holzner@tirol-kliniken.at)
Simone Oerlemans (s.oerlemans@iknl.nl)

11.45– 12.00 Coffee/Tea Break (MANZONI & ARIOSTO)

12.00-14.00 QLG BUSINESS MEETING (Closed session; active members only) (LOYOLA Auditorium)

Jaap Reijneveld (jc.reijneveld@vumc.nl)
Karin Kuljanic (kuljanickarin@gmail.com)
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Madeline Pe (madeline.pe@eortc.org)
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Andy Nordin (anordin@nhs.net)
Juan Ignacio Arraras (jiarraras@correo.cop.es)

14.00– 15.00 Lunch (MANZONI & ARIOSTO)

15.00-17.00 PLENARY SESSION (LOYOLA Auditorium)

Plenary Session Chairs: Jaap Reijneveld and MadelinePe

What are core outcome sets and how can they facilitate PROM collection?

Speaker – Steven MacLennan with introduction from Mieke Van Hemelrijck

EMA views on the relevance of patient preference methodology for benefit risk assessment

Speaker – Douwe Postmus (EMA) with introduction from Madeline Pe

Next steps in the use of the QLU-C10D -C10D: a personal view from an on-the ground health economics and QoL researcher

Speaker – Deborah Fitzsimmons with introduction from Jaap Reijneveld

Developing a scientific strategy for the QLU-C10D: what is important for the EORTC QLG to do to move forward with the QLU-C10D? (Commissioned call)

Speakers – Jaap Reijneveld and Mieke Van Hemelrijck

17.00 Closing (LOYOLA Auditorium)

Social Events

Thursday, 21st March

20.00 Group Photography
20.30 Dinner at the Parco dei Principi (Via Gerolamo Frescobaldi, 5, 00198 Roma)

Friday, 22nd March

20.30 Dinner at the Ristorante Flavio al Velavevodetto (Via di Monte Testaccio, 97, 00153 Roma)

Local Organizational Committee:

Anna Costantini (drssa.costantini@gmail.com)
Chiara Navarra (chiaranavarra@msc.com)



EORTC QLQ Meeting Organizational Committee:

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