



EORTC Quality of Life Group Autumn Meeting

September 25th- 27th, 2024
Innsbruck, Austria

DRAFT PROGRAMME



MEETING VENUE Haus der Begegnung

Innsbruck, Austria
Rennweg 12, 6020 Innsbruck
<https://hdb.dibk.at/de/Startseite>



Wednesday 25th September 2024

10.00 – 12.00 Workshop (PMDC) - Developing a questionnaire: PMDC's tips and tricks (FORUM)
14.00 – 19.00 EC Meeting (one Lunch Break)

Thursday 26th September 2024

8.00 Registration

08.45-09.30 WELCOME SESSION (FORUM)

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

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

09.30-10.30 PMDC session (open to all) (FORUM)

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

Simone Oerlemans (s.oerlemans@iknl.nl)

10.30-11.00 Coffee/Tea Break

11.00-12.00 PARALLEL SESSIONS (1)

1.1. Immune Checkpoint Inhibitors (phase I/II) (EXTRA)

Anna Haire (anna.haire@kcl.ac.uk)

Mieke Van Hemelrijck

(Mieke.vanhemelrijck@kcl.ac.uk)

Marieke van Leeuwen

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

1.2. Hereditary Cancer Predisposition Syndrome Module (SEMINARRAUM I)

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

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

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

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

Morten Aa. Petersen

(Morten.Aagaard.Petersen@regionh.dk)

Mogens Groenvold (Mogens.Groenvold@regionh.dk)

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

1.4. Rare Cancer Project/Sarcoma module (SEMINARRAUM IV)

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

Olga Husson (o.husson@nki.nl)

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

Tom Bootsma (t.bootsma@erasmusmc.nl)

Bibian Been (b.been@nki.nl)

1.5. Gastrointestinal modules (QLQ-PAN26, QLQ-STO22 update, QLQ-CR29 update, Metastatic anal cancer) (SEMINARRAUM III)

Deborah Fitzsimmons (D.Fitzsimmons@swansea.ac.uk)
Alexandra Gilbert (A.Gilbert@leeds.ac.uk)
Samantha Sodergren (S.C.Sodergren@soton.ac.uk)
Vassilis Vassiliou (vasilis.vassiliou@bococ.org.cy)

1.6. Development of an interpretation guideline for the EORTC PRO measures (FORUM)

Monika Sztankay (monika.sztankay@tirol-kliniken.at)
Daniela Krepper (daniela.krepper@i-med.ac.at)

1.7. Comparison of the EORTC QLU-C10D with generic utility instruments and development of a comprehensive manual for its use - final session (SEMINARRAUM II)

Eva Gamper (eva.gamper@tirol-kliniken.at)
Simone Seyringer (simone@curbs.at)

1.8. Satellite meeting Communication module (KAMINZIMMER)

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

12.00-12.15 Coffee/Tea Break

12.15-13.15 PARALLEL SESSIONS (2)

2.1. Renal Cell Cancer Module: Preparation of Phase III and Bladder Cancer (phase I/II) (EXTRA)

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)

2.2. Satisfaction with cancer care (SEMINARRAUM IV)

Anne Bredart (anne.bredart@curie.fr)

2.3. Update of the EORTC QOL Reference Value Manual and Database (SAAL)

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)

2.4. EORTC QLU-C10D: Country utilities - overview and project closing (SEMINARRAUM III)

Georg Kemmler (georg.kemmler@tirol-kliniken.at)
Jens Lehmann (jens.lehmann@i-med.ac.at)
Jonas Dreher (jonas.dreher@i-med.ac.at)

2.5. Establishing Thresholds for Clinical Importance for EORTC Modules (FORUM)

Johannes Giesinger (johannes.giesinger@i-med.ac.at)
Anna Thurner (anna.thurner@i-med.ac.at)

2.6. Advanced Melanoma (phase I/II) (SEMINARRAUM I)

Mees Egeler (m.egeler@nki.nl)
Lonneke van de Poll (L.vandePoll@iknl.nl)

13.15 -14.15 Lunch

14.15-15.15 PARALLEL SESSIONS (3)

3.1. EMBED (SEMINARRAUM I)

Hugo Vachon (Hugo.vachon@eortc.org)
Anna Haire (anna.haire@kcl.ac.uk)
Mieke Van Hemelrijck (Mieke.vanhemelrijck@kcl.ac.uk)

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

Jammbe Musoro (jammbe.musoro@eortc.org)
Corneel Coens (corneel.coens@eortc.org)
Luigi Lim (luigi.lim@eortc.org)
Henning Flechtner (hans-henning.flechtner@med.ovgu.de)

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

Lotte van der Weijst (lotte.vanderweijst@eortc.org)
Anne Esser (anne.esser@eortc.org)
Ahu Alanya (ahu.alanya@eortc.org)

3.4. Update of the ophthalmic cancer module (QLQ-OPTxx) (KAMINZIMMER)

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

3.5. ECI fellowship: Health-related quality of life within sexual and gender minority cancer population & commissioned call project: Addressing neutrality and inclusivity in EORTC Quality of Life Measures: Updating gendered language (SEMINARRAUM IV)

Tom Bootsma (t.bootsma@erasmusmc.nl)
Olga Husson (o.husson@nki.nl)
Monica Pinto (m.pinto@istitutotumori.na.it)

3.6. Development of a Module to Assess the Patients' Financial Burden Related to Cancer Treatment – "Financial Toxicity" (EXTRA)

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

3.7. Bone metastases, spinal cord compression, skin cancer and breast ductal carcinoma in situ module development (SEMINARRAUM III)

Edward Chow (Edward.Chow@sunnybrook.ca)
Milena Gojsevic (mgojsevic@uwaterloo.ca)
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Vasilis Vasilou (Vasilis.Vasilou@bococ.org.cy)
Pierluigi Bonomo (bonomopierlu@gmail.com)
Shing Fung Lee (leesf@nuhs.edu.sg)
Henry Wong (henrywong3011@gmail.com)
Vesna Bjelic-Radisic (Vesna.Bjelic-Radisic@helios-gesundheit.de)

15.15 – 15.30 Coffee/Tea Break

15.30-17.00 PARALLEL SESSIONS (4)

4.1. Common Data Model for EORTC QoL Modules (SEMINARRAUM II)

Charlotte Moss (charlotte.moss@kcl.ac.uk)
Mieke Van Hemelrijck
(Mieke.vanhemelrijck@kcl.ac.uk)

4.2. Male Breast Cancer and Metastatic Breast Cancer Module Development/ Follow-up in Early and Locally Advanced Breast Cancer Patients Module Development (SEMINARRAUM IV)

Vesna Bjelic-Radistic (vesna.bjelic-radistic@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)

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

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)

4.4. Children, Adolescents and Young Adults with Cancer (CAYAC) (SAAL)

Anne-Sophie Darlington (a.darlington@soton.ac.uk)
David Riedl (david.riedl@tirol-kliniken.at)
Samantha Sodergren (S.C.Sodergren@soton.ac.uk)
Chiara Vetrano (chiara.vetrano@i-med.ac.at)
Kirsty Way (K.M.Way@soton.ac.uk)

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

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)
Bonnie Pacheco (bonnie.pacheco@eortc.org)
Hayat Hamzeh (h.h.hamzeh@leeds.ac.uk)

4.6. Improving Compliance Rates in EORTC Cancer Clinical Trials (SEMINARRAUM I)

Madeline Pe (madeline.pe@eortc.org)
Johan Koekkoek (J.A.F.Koekkoek@lumc.nl)
Abigail Machingura (abigail.machingura@eortc.org)
Lotte van der Weijst (lotte.vanderweijst@eortc.org)

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

Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)
Elke Rammant (elke.rammant@ugent.be)
Lisa Wintner (lisa.wintner@tirol-kliniken.at)
Jens Lehmann (jens.lehmann@i-med.ac.at)

4.8. EORTC Haematological QOL Modules (KAMINZIMMER)

Charalampia Kyriakou
(charalampia.kyriakou1@nhs.net)
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Celine Broekhuizen (c.broekhuizen@IKNL.NL)
Kim Cocks (Kim.Cocks@adelphivalues.com)
Eleanor Scouler (eleanor.scouler@adelphivalues.com)
Katie Forde (katie.forde@adelphivalues.com)

17.00 – 18.00 ECI Session (FORUM)

Friday 27th September 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 (FORUM)

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

5.2. Development and evaluation of an e-learning programme on EORTC Quality of Life measures, in clinical practice and Creation of a Curriculum in QOL in Oncology (SAAL)

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)
Sally Wheelwright (Wheelwright@sussex.ac.uk)
Michael Koller (Michael.Koller@klinik.uni-regensburg.de)

5.3. Thyroid Cancer (SEMINARRAUM IV)

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

5.4. CODAGLIO 2.0: Combining clinical trial datasets in glioma patients to answer clinically relevant questions about patients' health-related quality of life/ Development of recommendations for the use of the EORTC QLQ-C30 summary score in cancer clinical trials and clinical practice (SEMINARRAUM III)

Johan Koekkoek (j.a.f.koekkoek@lumc.nl)
Ogechuckwu Edeh-Asogwa (o.a.edeh-asogwa@lumc.nl)
Martin Taphoorn (m.j.b.taphoorn@lumc.nl)
Mogens Groenvold (mold@sund.ku.dk)
Josien Scheepens (j.c.c.scheepens@lumc.nl)

5.5 Vulva module, Ovarian module update, Sexual health module (EXTRA)

Pernille Jensen (pernille_jensen@dadlnet.dk)
Anne Oberguggenberger (anne.oberguggenberger@i-med.ac.at)
Veronika Engele (veronika.engele@i-med.ac.at)
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Nora Nevries (nora.nevries@helios-gesundheit.de)

10.00– 10.15 **Coffee/Tea Break**

10.15 - 11.15 **PMDC (open to all)**
(FORUM)

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

11.15– 11.30 **Coffee/Tea Break**

11.30 - 13.30 **QLG BUSINESS**
MEETING (Closed session; active members
only) (FORUM)

Jaap Reijneveld (jc.reijneveld@vumc.nl)
Karin Kuljanic (kuljanickarin@gmail.com)
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Jens Lehmann (jens.lehmann@i-med.ac.at)

13.30– 14.30 **Lunch**

14.30-16.30 **PLENARY SESSION (FORUM)**

- Item Library – Claire Piccinin
- Common Data Model – Peter Prinsen
- Reference Values Database – Monika Sztankay
- PROMs – Jens Lehmann

16.30 **Closing**

Social Events

Thursday, 26th September

Banquet at Villa Blanka
<https://www.villablanka.com/>
followed by a party with DJ

Option for a joint walk to the location (about 1.3 km, 30 minutes from the meeting venue). Don't forget to bring comfortable shoes.

Friday, 27th September

Dinner at Seegrube
<https://nordkette.com/>

Mountain station with a view over Innsbruck with a Railway and cable car ride up the mountain.

Local Organisational Committee:

Bernhard Holzner (Bernhard.holzner@tirol-kliniken.at)
Franziska Gross (franziska.gross@i-med.ac.at)

EORTC QLG Meeting Organisational Committee:

Karin Kuljanic
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