



QLG Virtual Group Meeting September 16th-17th, 2021

Thursday 16th September 2021

(CET time)

8.45-9.00 Log in

09.00-09.20 WELCOME SESSION

Welcome from:

EORTC QLG Chair - Anne-Sophie Darlington
(a.darlington@soton.ac.uk)

QoL Department - Andrew Bottomley
(andrew.bottomley@eortc.org)

09.20-10.40 PMDC session (open to all)

Sally Wheelwright (s.j.wheelwright@soton.ac.uk)
Bernhard Holzner (Bernhard.holzner@tirol-kliniken.at)
Francesca Martinelli (Francesca.martinelli@eortc.org)
Lucia Senna (lucia.senna@eortc.org)
Mirjam Renovanz (Mirjam.Renovanz@med.uni-tuebingen.de)

10.40-10.50 Coffee/Tea Break

10.50-11.50 PARALLEL SESSIONS (1)

1.1. Cancer Clinical Trials Pooling of Quality-of-Life Data (CATAPULT)/ Minimal important Difference (MID) Projects

Corneel Coens (corneel.coens@eortc.org)
Jammbe Musoro (jammbe.musoro@eortc.org)
Andrew Bottomley (andrew.bottomley@eortc.org)
Henning Flechtner (henning.flechtner@med.ovgu.de)

1.2. QLU-C10D validation and manual development

Eva-Maria Gamper (eva.gamper@tirol-kliniken.at)
Micha Pilz (micha.pilz@i-med.ac.at)

1.3. Breast Cancer Module Update and Male Breast Cancer Module Development/ Metastatic Breast Cancer Module Development (1)

Vesna Bjelic-Radicic (vesna.bjelic-radicic@helios-gesundheit.de)
Sina-Maria Schafer (sina-maria.schafer@helios-gesundheit.de)
Luisa Zoe Probst (LuisaZoe.probst@helios-gesundheit.de)
Christopher Bedding (c.m.bedding1@leeds.ac.uk)
Galina Velikova (G.Velikova@leeds.ac.uk)
Melanie Beauvois (melanie.beauvois@eortc.org)

1.4. Bladder Cancer Modules Update and Renal Cell Cancer Module

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

Marieke van Leeuwen (m.v.leeuwen@nki.nl)
Elke Rammant (elke.n.rammant@kcl.ac.uk)
Louis Fox (louis.fox@kcl.ac.uk)
Bernhard Holzner (Bernhard.holzner@tirol-kliniken.at)
Lisa Wintner (lisa.wintner@tirol-kliniken.at)
Timo Kachel (timo.kachel@tirol-kliniken.at)

1.5. Sarcoma Module Development

Olga Husson (o.husson@nki.nl)
Winette van der Graaf (w.vd.graaf@nki.nl)
Dide den Hollander (D.denHollander@radboudumc.nl)
Tom Bootsma (t.bootsma@nki.nl)

1.6. Computer Adaptive Testing Projects/Comparative evaluation of the computer adaptive EORTC quality of life measures

Mogens Grønvold (mogens.groenvold@regionh.dk)
Morten Aa. Petersen (morten.aagard.petersen@regionh.dk)
Johannes Giesinger (johannes.giesinger@i-med.ac.at)

1.7. Hereditary Cancer predisposition Syndrome module

Anne Oberguggenberger (anne.oberguggenberger@i-med.ac.at)
Monika Sztankay (monika.sztankay@tirol-kliniken.at)
Vasilis Vasiliou (vasilis.vasiliou@bococ.org.cy)

11.50-12.50 PARALLEL SESSIONS (2)

2.1. Fertility Module

Joachim Weis (joachim.weis@uniklinik-freiburg.de)
Andrea Kiemen (andrea.kiemen@uniklinik-freiburg.de)

2.2. Development of a Module to Assess the Patients' Financial Burden Related to Cancer Treatment – “Financial Toxicity” – Phase I

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

2.3. Electronic Data capture in research and daily clinical practice/PRO measures for improving inter-rater reliability of CTCAE ratings – the CTCAEplusPRO project
Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)
Lisa Wintner (lisa.wintner@tirol-kliniken.at)

2.4. HTA/Utility Workgroup

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

2.5. Communication Module

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

**2.6. Association cognition and HRQOL in brain tumors/
Long-term implications of rare brain tumors / Ratings
from patients with primary brain tumors: the role of self-
awareness and cognitive functioning**

Jaap Reijneveld (j.reijneveld@amsterdamumc.nl)

Florien Boele (f.boele@leeds.ac.uk)

Se Frances (umsmfr@leeds.ac.uk)

Ivan Caramanna (i.caramanna@amsterdamumc.nl)

Martin Klein (m.klein@amsterdamumc.nl)

**2.7. Lymphoma and Chronic Leukemia Modules/Multiple
Myeloma (update of MY20)/Haematological malignancies
modules**

Lonneke van de Poll-Franse (L.vd.poll@nki.nl)

Fabio Efficace (f.efficace@gimema.it)

Simone Oerlemans (s.oerlemans@iknl.nl)

Charalampia Kyriakou (charalampia.kyriakou1@nhs.net)

Julia Scarisbrick (juliascarisbrick@doctors.org.uk)

Kevin Molloy (Kevin.Molloy@uhb.nhs.uk)

Kim Cocks (kim.cocks@adelphivalues.com)

Isobel McMillan (isobel.mcmillan@adelphivalues.com)

12.50-14.00 Lunch Break

14.00-15.00 PARALLEL SESSIONS (3)

3.1. Thyroid Cancer Module

Susanne Singer (singers@uni-mainz.de)

**3.2. Development of an Interpretation Guideline for the
EORTC PRO Measures**

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

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

3.3. Vulva Module Development

Pernille Jensen (Pernille_jensen@dadlnet.dk)

**3.4. QoL in Adolescents and Young Adults (AYA) with cancer/
Children with Cancer**

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)

3.5. QRECISt project

Amelie Anota (amelie.anota@lyon.unicancer.fr)

Emilie Charton (emilie.charton@lyon.unicancer.fr)

Corneel Cones (corneel.coens@eortc.org)

Madeline Pe (madeline.pe@eortc.org)

Abigirl Machingura (abigirl.machingura@eortc.org)

**3.6. Breast Cancer Module Update and Male Breast
Cancer Module Development/**

Metastatic Breast Cancer Module Development (2)

Vesna Bjelic-Radicic (vesna.bjelic-radicic@helios-
gesundheit.de)

Sina-Maria Schafer (sina-maria.schafer@helios-
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Galina Velikova (G.Velikova@leeds.ac.uk)

Melanie Beauvois (melanie.beauvois@eortc.org)

**3.7. An opportunity to Convert EORTC QoL Modules into
OMOP Standards for Big Data**

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

15.00 – 15.10 Coffee/Tea Break

15.10-16.10 PARALLEL SESSIONS (4)

**4.1. Late Toxicity and Long-term QoL in Head and Neck
Cancer Survivors**

Susanne Singer (singers@uni-mainz.de)

Kathy Taylor (kataylor@uni-mainz.de)

**4.2. Development and Evaluation of an e-learning
Programme on EORTC Quality of Life Measures in Clinical
Practice**

Heike Schmidt (heike.schmidt2@uk-halle.de)

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

4.3. Advanced Melanoma

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

Marieke van Leeuwen (m.v.leeuwen@nki.nl)

Mees Egeler (m.egeler@nki.nl)

4.4. Early Career Investigators

Emma Lidington (emma.lidington@rmh.nhs.uk)

Julia Lai-Kwon (juliak@gmail.com)

Rille Pihlak (rille.pihlak@gmail.com)

Anne-Sophie Darlington (a.darlington@soton.ac.uk)

Madeline Pe (madeline.pe@eortc.org)

Francesca Martinelli (francesca.martinelli@eortc.org)

Elke Rammant (elke.rammant@uzgent.be)

**4.5. Establishing Thresholds for Clinical Importance for EORTC
Modules**

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

**4.6. Implementation of smart devices to capture HRQoL
in cancer research**

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

Hugo Vachon (hugo.vachon@eortc.org)

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

Friday 17th September 2021

(CET time)

08.50-09.00 Log in

09.00-10.00 PARALLEL SESSIONS (5)

5.1. I-ADL in brain tumor patients/Update QLQ-BN20

Martin Taphoorn (m.taphoorn@haaglandenmc.nl)
Linda Dirven (l.dirven@lumc.nl)
Quirien Oort (q.oort@amsterdamumc.nl)

5.2. An International Field Study for the Reliability and Validity of the EORTC PATSAT-C33 Core Questionnaire and the EORTC OUT-PATSAT7 Module

Anne Bredart (anne.bredart@curie.fr)

5.3. Write-in-Symptoms-and-Problems Project

Mogens Grønvd (mold@sund.ku.dk)
Leslye Alejandra Rojas Concha
(leslye.alejandra.rojas.concha@regionh.dk)

5.4. Update of the EORTC QLQ Reference Value Manual

Monika Sztankay (monika.sztankay@tirol-kliniken.at)
Susanne Singer (singers@uni-mainz.de)

5.5. Development of a Cancer Survivorship Questionnaire

Marieke van Leeuwen (m.v.leeuwen@nki.nl)
Lonneke van de Poll-Franse (l.vd.poll@nki.nl)
Neil Aaronson (n.aaronson@nki.nl)

5.6. GI modules (Anal, Pancreatic, Peritoneal Malignancy & Stomac)/ Update of the EORTC QLQ-PAN26

Vasilis Vasilio (vasilis.vasilio@bococ.org.cy)
John Ramage (john.ramage@hhft.nhs.uk)
Deborah Fitzsimmons (D.Fitzsimmons@swansea.ac.uk)
Mitsumi Terada (mitterad@ncc.go.jp)
Samantha Sodergren (S.C.Sodergren@soton.ac.uk)
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Serdar Turhal (serdar.turhal@anadolusaglik.org)
Liv Kosnes (l.kosnes@swansea.ac.uk)

10.00– 10.10 Coffee/Tea Break

10.10– 12.10 QLG BUSINESS MEETING

(Closed session; active members only)

Andrew Bottomley (andrew.bottomley@eortc.org)
Anne-Sophie Darlington (a.darlington@soton.ac.uk)
Jaap Reijneveld (jc.reijneveld@vumc.nl)
Karin Kuljanic (kuljanickarin@gmail.com)
Mieke Van Hemelrijck (mieke.vanhemelrijck@kcl.ac.uk)
Martin Taphoorn (m.taphoorn@haaglandenmc.nl)
Sanne Schagen (s.schagen@nki.nl)

12.10 – 13.10 Lunch Break

13.10 - 14.10 PLENARY SESSION

13.10 The need to convert our QoL Modules into common datamodels for big data projects

Mieke Van Hemelrijck (mieke.vanhemelrijck@kcl.ac.uk)
Peter Prinsen (p.prinsen@iknl.nl)
Nicole Horevoorts (N.Horevoorts@iknl.nl)

13.15 Cutaneous T-cell and B-cell lymphomas

Kevin Molloy (Kevin.Molloy@uhb.nhs.uk)

13.30 PRO routine monitoring in childhood cancer

Bernhard Holzner (bernhard.holzner@tirol-kliniken.at)
Jens Lehmann (jens.lehmann@tirol-kliniken.at)

13.45 Spring Group Meeting Cyprus 2022 and Closing

Vasilis Vasilio (vasilis.vasilio@bococ.org.cy)

EORTC QLG Meeting Organizational Committee:

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