



ISOQOL 31st Annual Conference

Final Program Oral/Brief/Poster Presentations

13-16 October 2024
Cologne, Germany

Monday, 14 October

10:05 AM - 10:45 AM

Monday Poster Session I

Saal Heumarkt II

(1001) Developing a PROM to measure outcomes and experience of care in youth receiving gender-affirming treatment: GENDER-Q Youth

Anne Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada

OUTSTANDING POSTER AWARD FINALIST

(1003) Electronic Symptom Monitoring During Metastatic Cancer Treatment: Does it work better for some patients than for others (AFT-39)?

Allison Deal, MS, UNC Lineberger Comprehensive Cancer Center, Chapel Hill, North Carolina, United States

OUTSTANDING POSTER AWARD FINALIST

(1005) Psychometric evaluation of the HFDD, PROMIS SD SF 8b and MENQOL for vasomotor symptoms associated with menopause: validity, reliability, responsiveness, and identification of within-individual change thresholds

Andrew Trigg, Bayer plc, Reading, United Kingdom

OUTSTANDING POSTER AWARD FINALIST

(1007) Patient-Reported Outcome Measures to Inform Measurement-based Care for Youth Living with Mental Health Concerns: A mixed method study.

Kalpna Thapa Bajgain, MPH, MSc, University of Calgary, Calgary, Alberta, Canada

NEW INVESTIGATOR POSTER AWARD FINALIST

(1009) Assessing real-world use of ePRO patient engagement metrics

Mariia Zagumennova, MBA, Varian, a Siemens Healthineers Company, Helsinki, Finland

(1011) PROcoach: Development of an e-learning course on the use of EORTC patient-reported outcome measures in clinical practice

Monika Sztankay, PhD, University Hospital of Psychiatry II & Medical University Innsbruck, Innsbruck, Austria

(1013) Developing a novel outcome measure to assess the impact of amyotrophic lateral sclerosis (ALS) on health-related quality of life (HRQoL): A study protocol

Jill Carlton, PhD, University of Sheffield, Sheffield, United Kingdom

(1015) Translation and content validation of the German versions of the Long COVID Symptom and Impact Tools

Katharina Piontek, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

(1017) Shared decision making in pediatric physiotherapy: a qualitative study among adolescents, parents and therapists

Selina Limmen, MSc, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands, Amsterdam, Netherlands

(1019) User-Centered and Co-Design Approaches for Developing Electronic Patient-Reported Outcomes (ePROs): a Scoping Review Protocol

Elizabeth Kwong, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, United States

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(1021) The steroid symptom questionnaire for multiple myeloma (SSQ-MM): a multi-centre validation study

Margaret-Ann Tait, Sydney Nursing School, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

(1023) Cancer Survivors Definitions of Spirituality and Quality of Life: A Qualitative Approach

Jenny Firkins, PhD, RN, Oregon Health & Science University, Portland, Oregon, United States

(1025) Real-life experience of ePROs and Symptom Monitoring in the Radiotherapy workflow: Impact of new MR-guided treatments on Prostate Cancer Patients' Quality of Life

Pia Krause Møller, RN, MPH, PhD, Odense University Hospital, Odense C, Denmark

(1027) The impact of prostate cancer ADT and EBRT follow-up treatment on patient-reported quality of life – results from the EUPROMS 2.0 follow-up study

Lionne Venderbos, Department of Urology, Erasmus MC Cancer Institute, Erasmus University Medical Center Rotterdam, Rotterdam, Netherlands

(1029) Exploring the impact of physical exercise regimens on health-related quality of life following esophageal or gastric cancer surgery: a systematic review and meta-analysis of randomized controlled trials.

Kenneth Färnqvist, Karolinska Institute, Stockholm, Sweden

(1031) Validation of the Steroid PRO in international gastroenterology, respiratory, and dermatology departments: Assessing the impact of steroids on patient health-related quality of life.

Martina Zagaria, Oxford University Innovation, Oxford, United Kingdom

(1033) Stigma and quality of life in patients with Parkinson's disease

Carmen Rodríguez-Blázquez, Dr, CIBER-ISCIII G85296226, Madrid, Spain

(1035) Suitable assessment formats for patients unable to complete patient-reported outcome measures (PROMs): a scoping review

~~Ellen Elsmann, PhD, Amsterdam UMC, Department of Ophthalmology, Amsterdam, Netherlands~~

(1037) Impact of using home-based rehabilitation on health-related quality of life: a pilot study

Tetsuya Sano, Doctor of Philosophy, Seirei Christopher University, Hamamatsu, Japan

(1039) Empowering patients with COPD: Completing a PRO for palliative care before outpatient consultations promotes open and profound discussions.

Cecilie Lindstrom Egholm, PhD, Department of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark

(1041) Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) Use in Clinical Trials Based on Clinicaltrials.gov Data

Lauren Rogak Shapiro, MA, Mayo Clinic, Department of Quantitative Health Sciences, Scottsdale, Arizona, United States

(1043) Analyzing Citation Patterns of New Investigators Special Interest Group Members

Jae-Yung Kwon, University of Victoria, Victoria, British Columbia, Canada

(1045) Can machine translation match human expertise? Quantifying the performance of Large Language Models in the translation of patient-reported outcome measures (PROMs)

Chris Sidey-Gibbons, Department of Symptom Research, The University of Texas MD Anderson Cancer Center, Houston, Texas, United States

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(1047) Shortness of breath on the day of discharge: An early alert for post-discharge complications in patients undergoing lung cancer surgery

Xing Wei, Department of Thoracic Surgery, Sichuan Clinical Research Center for Cancer, Sichuan Cancer Hospital & Institute, Sichuan Cancer Center, Affiliated Cancer Hospital of the University of Electronic Science and Technology of China, Sichuan Cancer Center, Sic, Chengdu, China

(1049) Definition of patient-reported urinary incontinence following radical prostatectomy for localized prostate cancer

Víctor Zamora, PhD, Health Services Research Unit, IMIM (Hospital del Mar Research Institute), Barcelona, Spain

(1051) A simultaneous assessment of multiple sources of Differential Item Functioning and Response Shift in health-related quality of life of cancer survivors

Myriam Blanchin, PhD, Nantes Université, Université de Tours, INSERM, UMR1246 SPHERE "methods in Patient-centered outcomes and HEalth ResEarch", Nantes, France

(1053) Is the single-item walking measure from a multi-item questionnaire valid in patients with cancer?

Jingyu Zhang, State Key Laboratory of Ultrasound in Medicine and Engineering, College of Biomedical Engineering, Chongqing Medical University, Chongqing, China., Chongqing, China

(1055) Generating items for an osteoarthritis-specific patient-reported outcome measure using natural language processing

Ayse Kuspinar, PT, PhD, McMaster University, Hamilton, Ontario, Canada

(1057) Sociodemographic predictors of mobility decline among community-dwelling older Canadians: A six-year CLSA longitudinal analysis

Oluwagbohunmi (Olu) Awosoga, PhD MBA, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada

(1059) Beyond English: Bridging the Gap for Finnish QOL Measures with a Hungarian Lifeline

Melinda Johnson, MA, Linguistics, Lionbridge Technologies, Cary, North Carolina, United States

(1061) Developing Methods of Cognitive Interviewing for Measures of Health-related Quality of Life for Young Children: A 'Solution-Focussed' Approach

Victoria Gale, MA, University of Sheffield, Sheffield, United Kingdom

(1063) How do we know if a concept is salient to the patient experience? A review of qualitative interview and analysis techniques in concept elicitation studies

Natalie Aldhouse, Clarivate, London, United Kingdom

(1065) Psychometric Evaluation and Computerized Adaptive Testing Simulations of Age-Related Macular Degeneration Quality Of Life Item Banks

Ecosse Lamoureux, Singapore Eye Research Institute, Singapore National Eye Centre, Singapore, Singapore

(1067) Methodological considerations to support meaningful qualitative assessment of stigma

Verity Smith, Adelphi Values, Bollington, United Kingdom

(1069) What is "Recovery"? Patient-Centered Recommendations for Complex Terminology in PROs

Tim Poepsel, PhD, RWS, St. Louis, Missouri, United States

(1071) Directionality of associations between pain, sleep and inflammation: a systematic literature review

Brandon Becker, Bristol Myers Squibb, Princeton, New Jersey, United States

(1073) Exploring Mental Health Profiles in Japanese Older Populations: Insights from a Flourishing

Junko Sakano, Ph.D., Okayama Prefectural University, Okayama, Japan

(1075) Changes in the General Public's Concept of Quality of Life Over Time in Three National Surveys: Part 2: Conceptual Structure

Yoshimi Suzukamo, Ritsumeikan University, Kyoto, Japan

(1077) Change in the General Public's Concept of Quality of Life Over Time in Three National Surveys: Part 1: Awareness and Concept

Kikuko Miyazaki, PhD, Kyoto University, Kyoto, Japan

(1079) The ISOQOL Dictionary: To Update or Not to Update? That is the Question!

Nancy Mayo, B.Sc.(PT), M.Sc., Ph.D., McGill University, Montreal, Quebec, Canada

(1081) Time is now to consider how we measure person-centred care – the role of patient-reported outcomes

Claudia Rutherford, PhD, Faculty of Medicine and Health, University of Sydney, Sydney, Australia

(1083) The argument-based approach to validation: Assumptions, contexts and equitable health outcomes

Melanie Hawkins, PhD, Swinburne University of Technology, Melbourne, Australia

(1085) Applicability of the DISABKIDS-37 Generic Measure scores for Brazil

Claudia Benedita Santos, PhD, Ribeirão Preto College of Nursing. University of São Paulo, Ribeirão Preto, Brazil

(1087) Symptom clusters of upper limb related to surgical complications in breast cancer survivors: A cross-sectional study

Ling Wang, school of nursing, Fudan university, Shanghai, China

(1089) Is the Neuro-QOL V2.0 Cognitive Function – Short Form unidimensional in patients with primary brain tumors?

Tito Mendoza, PhD, MS, MEd, Office of Patient-Centered Outcomes Research, CCR, National Cancer Institute, National Institute of Health, Bethesda, Maryland, United States

Monday, 14 October

2:00 PM - 3:15 PM

Concurrent Oral Sessions

Oral Session 101: Cancer Implementation

Salon 14 Köln

Session Chair: Madeline Pe, PhD, Belgium

2:05 PM - 2:22 PM (101.1) Promoting implementation of patient-reported outcomes in institutions caring for vulnerable and underserved cancer populations

Anne Schuster, The Ohio State University, Columbus, Ohio, United States

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

2:22 PM - 2:39 PM (101.2) Barriers and Facilitators to Health Information Technology (HIT)-Assisted Patient-Reported Outcome Data Collection in Black Women with Breast Cancer Seeking Care at Community Cancer Centers

Amanda Higgins, MPH, Brigham and Women's Hospital Department of Surgery, Boston, Massachusetts, United States

2:39 PM - 2:56 PM (101.3) Differences in barriers to using Patient-Reported Outcome Measures in clinical practice between clinicians who use them and those who do not: Findings from an international EORTC cross-sectional survey (RP-2380)

Jens Lehmann, PhD, University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

2:56 PM - 3:13 PM (101.4) A pan-European project to develop and implement a digitally supported solution to patient-centred cancer care

Kate Absolom, PhD, University Academic Fellow, Leeds Institute of Medical Research/Leeds Institute of Health Services Research, University of Leeds, Leeds, United Kingdom

Oral Session 102: Caregivers and Patient Support I

Salon 16 Königswinter

Session Chair: Nancy Mayo, PhD, Canada

2:05 PM - 2:22 PM (102.1) Implementation and effectiveness evaluation of the iPeer2Peer program for adolescent thoracic transplant recipients

Samantha Anthony, PhD, The Hospital for Sick Children Research Institute, Toronto, Ontario, Canada

2:22 PM - 2:39 PM (102.2) Burden Through Different Lenses: How Care Recipient Self-Perceived Burden Differs from Proxy-Reported Caregiver Burden

Maja Kuharic, MPharm, Msc, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

2:39 PM - 2:56 PM (102.3) Changes are needed to adequately assess health-related quality of life (HRQoL) in informal carers of children with rare progressive life-limiting conditions: key learnings from a collaborative workshop

Jill Carlton, PhD, University of Sheffield, Sheffield, United Kingdom

2:56 PM - 3:13 PM (102.4) Personalized Endpoints in Clinical Development: Inventory-facilitated Goal Setting Enhances the Implementation of Goal Attainment Scaling

Gunes Sevinc, Ph.D, Ardea Outcomes, Halifax, Nova Scotia, Canada

Monday, 14 October

2:00 PM - 3:15 PM

Concurrent Oral Sessions

Oral Session 103: Cognitive Debriefing and Qualitative Research

Salon 17 Darmstadt

Session Chair: Sonya Eremenco, MA, United States

2:05 PM - 2:22 PM (103.1) Using cognitive debriefing interviews to optimize measurement of health-related quality of life among adolescents and adults with hereditary angioedema - a rare disease

Lynne Broderick, MPH, QualityMetric, an IQVIA business, Johnston, Rhode Island, United States

2:22 PM - 2:39 PM (103.2) Exploring the feasibility of conducting cognitive debrief of clinical outcome assessments through surveys or mixed methods approaches

Owen Cooper, DPpsych, IQVIA, London, United Kingdom

2:39 PM - 2:56 PM (103.3) Representing people's experiences of cancer and its treatment (ResPECT) : an international study and novel platform to generate actionable insights to reduce the global burden of cancer.

Chris Gibbons, PhD, MD Anderson Cancer Center, Houston, Texas, United States

2:56 PM - 3:13 PM (103.4) Virtual qualitative health research with youth about sensitive topics: A framework to prioritize participant and research team safety during data generation

Shelby Kennedy, MHK, McMaster University, Hamilton, Ontario, Canada

Oral Session 104: EQ Measures

Salon 21 Mannheim

Session Chair: Philip A. Powell, PhD, United Kingdom

2:05 PM - 2:22 PM (104.1) Evaluating differential item functioning of the EQ-5D in acute ischemic stroke: Results from the AcT Trial

Olayinka Arimoro, University of Calgary, Calgary, Alberta, Canada

2:22 PM - 2:39 PM (104.2) Assessing Psychometric Properties of EQ-5D-5L and ICECAP-A in Patients with Chronic Depression in the UK

Yan Feng, PhD, Queen Mary University of London, London, United Kingdom

2:39 PM - 2:56 PM (104.3) What does EQ VAS measure: analysis of general population survey data informed by established models of self-rated health

You-Shan Feng, Medical University Tübingen, Tübingen, Germany

Oral Session 105: Assessing Mental Health

Salon 22 Titisee

Session Chair: John Devin Peipert, PhD, United States

2:05 PM - 2:22 PM (105.1) European general population reference data for the PROMIS depression metric and major depression scales

Laili Riazy, PhD, Department of Psychosomatic Medicine, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin and Humboldt-Universität zu Berlin, Berlin, Germany

2:22 PM - 2:39 PM (105.2) Establishing score equivalence between self-rating instruments for depression and anxiety in patients with immune-mediated inflammatory disease

Muditha Bodawatte Gedara, BSc in Statistics; MSc in Statistics, University of Manitoba, Winnipeg, Manitoba, Canada

2:39 PM - 2:56 PM (105.3) Agreement of standardized depression estimates from major depression measures - a meta-analysis on common metric validity

Mia Grote, B.Sc., Center for Patient-Centered Outcomes Research (CPCOR), Charité, Berlin, Germany

2:56 PM - 3:13 PM (105.4) Do Somatic Symptoms Confound the Patient Health Questionnaire – 9 Depression Scores in Patients with Decompensated Cirrhosis?

Maria Edelen, Ph.D., Brigham and Women's Hospital, Boston, Massachusetts, United States

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2:00 PM - 3:15 PM

Concurrent Oral Sessions

Oral Session 106: PROMS in Clinical Practice I

Saal Maritim I

Session Chair: Mogens Groenvold, MD PhD, Denmark

2:05 PM - 2:22 PM (106.1) Personalized communication for promoting implementation of Patient Reported Outcome Measures in clinical practice: Insights from health communication and digital sciences

Kelly de Ligt, PhD, Netherlands Cancer Institute - Antoni van Leeuwenhoek, Amsterdam, Netherlands

STUDENT ORAL PRESENTATION AWARD FINALIST

2:22 PM - 2:39 PM (106.2) A Resource Toolkit for Clinical Coordinators to Support the Sustained Use of PROMs into Recovery Planning for Community Mental Health

Angela Wolff, PhD, RN, Associate Professor, School of Nursing, Trinity Western University, Langley, British Columbia, Canada

2:39 PM - 2:56 PM (106.3) Evaluation of PROM implementation in clinical practice: a qualitative study with clinicians

Hedy van Oers, PhD, Amsterdam UMC, Amsterdam, Netherlands

2:56 PM - 3:13 PM (106.4) The Use of Patient Reported Outcome Measures in Oncology Clinical Practice across Australia and New Zealand

Ashika Maharaj, TU Delft, The Hague, Netherlands

Monday, 14 October

3:30 PM - 4:10 PM

Monday Poster Session II

Saal Heumarkt II

(1002) Quality of Life assessment in women with Gestational Diabetes Mellitus – pilot testing of a disease-specific measure in a German outpatient sample

Klara Greffin, Dr., University of Greifswald, Greifswald, Germany

OUTSTANDING POSTER AWARD FINALIST

(1004) PROfound interpretation: The European Organisation for Research and Treatment of Cancer's PRO Interpretation Guideline

Monika Sztankay, PhD, University Hospital of Psychiatry II & Medical University Innsbruck (Innrain 52, ATU57495455), Innsbruck, Austria

OUTSTANDING POSTER AWARD FINALIST

(1006) Health-related quality of life measures in predictive modelling for oncology: A systematic review

Thijs van der Heijden, MSc, Department of Psychosocial Research and Epidemiology, Netherlands Cancer Institute, Amsterdam, Netherlands

OUTSTANDING POSTER AWARD FINALIST

(1008) Sex differences in diabetes distress and general well-being among adults with type 1 diabetes: Insights from a population-based registry study

Ingvild Hernar, RN, PhD, Department of Internal Medicine, Haukeland University Hospital, Bergen, Norway

NEW INVESTIGATOR POSTER AWARD FINALIST

(1010) The association of cannabinoid combinations with patient-reported pain improvements in patients with chronic pain prescribed medicinal cannabis.

Margaret-Ann Tait, Sydney Nursing School, Faculty of Medicine and Health, University of Sydney, Sydney, Australia

STUDENT POSTER AWARD FINALIST

(1012) Trajectories of patient-reported outcomes after oesophageal cancer surgery - a population-based study

Kenneth Färnqvist, Karolinska Institute, Stockholm, Sweden

STUDENT POSTER AWARD FINALIST

(1014) Improving research on cannabis and quality of life in cancer patients: Development of the Cannabis Literacy Toolkit and Cannabis Use Questionnaire

Kathleen Yost, PhD, Mayo Clinic, Rochester, Minnesota, United States

(1016) Response pattern and its relation of age in electronic patient reported outcomes (ePROs) of surgery-related symptoms

Hongfan Yu, PhD., State Key Laboratory of Ultrasound in Medicine and Engineering, College of Biomedical Engineering, Chongqing Medical University, Chongqing, China

(1018) Constructing a Checklist for Optimal Pain-Anchor Correlation Selection in Lung Surgery MCID Estimation: A Simulation study

Wei Xu, College of Public Health, Chongqing Medical University, Chongqing, China

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Monday Poster Session II

Saal Heumarkt II

(1020) Screening for cognitive impairment in routine clinical oncology practice: a pilot study using Patient Reported Outcome Measures and online cognitive testing in melanoma and breast cancer patients

Kelly de Lig, PhD, Netherlands Cancer Institute - Antoni van Leeuwenhoek, Amsterdam, Netherlands

(1022) Sustainable use of electronic patient-reported outcome assessment in routine cancer care: Results from a scoping review and follow-up survey

Niclas Hubel, MSc, University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(1024) Human factors research to inform the usability and optimize the health care provider interface of a remote patient monitoring solution for oncology clinical trials

Madalina Sucala, PhD, Evinova, New York, New York, United States

(1026) New Zealand first-person narratives confirm how using a quality of life PROM targets relevant mental health recovery issues.

Melissa Rowthorn, PhD, Auckland University of Technology (AUT), Auckland, New Zealand

(1028) The mediating role of coping in the relationship between perceived health status and psychological wellbeing in recurrent urinary tract infection: A structural equation model

David Churchman, BSc, MSc, PhD, InSpired Health Outcomes Ltd, Witney, United Kingdom

(1030) Implementation of PROMs and PREMs in routine clinical practice: Standardized evaluation of their impact on patients and healthcare professionals.

Clara Amat-Fernandez, Hospital del Mar Research Institute, Barcelona, Spain

(1032) Association of maternal depression with perinatal outcomes in pregnant women with allergic rhinitis : a retrospective cohort analysis

Xing Wei, PhD, Sichuang, China

(1034) The lived experience of patients with atopic dermatitis and with alopecia areata – results of a qualitative study

Toni Maria Janke, University Medical Center Hamburg-Eppendorf (UKE), Institute for Health Services Research in Dermatology and Nursing (IVDP), Hamburg, Germany

(1036) Disease and treatment experience of children with cancer in China: From the perspective of parents

Renjun Gu, Department of Social Medicine, School of Public Health, Zhejiang University School of Medicine, Hangzhou City, China

(1038) Impact of remote monitoring with patient-reported outcomes on symptom deterioration during cancer treatment in the PRO-TECT Trial (AFT-39)

Jennifer Jansen, MPH, University of North Carolina, Lineberger Comprehensive Cancer Center, Chapel Hill, North Carolina, United States

(1040) Exploring the patient experience of advanced and/or metastatic hepatocellular carcinoma: a multi-stage study

Sally Lanar, ICON plc, Lyon, France

(1042) Living with a prostate cancer patient: Real world evidence from the unprecedented Europa Uomo Prostate cancer Partners in Europe Research (EU-ProPER) study

Lionne Venderbos, Department of Urology, Erasmus MC Cancer Institute, Erasmus University Medical Center Rotterdam, Rotterdam, Netherlands

Monday, 14 October

3:30 PM - 4:10 PM

Monday Poster Session II

Saal Heumarkt II

(1044) Postoperative quality of life in thoracic surgery patients using electronic patient-reports outcomes

Elizabeth Kwong, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, United States

(1046) Rasch analysis of the Community Wellbeing Index: A multicountry validation study

Maria João Forjaz, PhD, Institute of Health Carlos III, National Center of Epidemiology, Q2827015E, Madrid, Spain

(1048) An Analysis of Participants and PROMs Used to Inform Clinical Practice Guidelines for Hip and Knee Osteoarthritis

Tina Mai, BS, Department of Orthopaedic Surgery, University of California - San Francisco, San Francisco, California, United States

(1050) Cross-cultural adaptation and psychometric validation of the Chichewa (Malawi) PedsQLTM 4.0 Generic Core Scales child self-report and PedsQLTM 4.0 GCS teen self-report.

Lucky Gift Ngwira, PhD, Health Economics and Policy Unit, Kamuzu University of Health Sciences, Blantyre, Malawi

(1052) Assessing Sleep Problems in Australian Children: A Psychometric Evaluation of the generic health related quality of life instruments compared to the Sleep Disturbances Scale for Children (SDSC)

Renee Jones, Health Economics Unit, Centre for Health Policy, The University of Melbourne, Melbourne, VIC, Australia, Melbourne, Australia

(1054) Psychometric Properties of the PedsQL 4.0TM Generic Module (PedsQL-GM) to Measure Health-related Quality of Life (hrQoL) in Pediatric Out-patients after Thermal Injuries

Clara Herta Spiller, Department of Pediatric Surgery, University Hospital Dresden - Technical University of Dresden, Dresden, Germany

(1056) Quality of Life in Infants and Toddlers with Dermatological Conditions – Validation of the German Version of the InToDermQoL Questionnaire

Neuza da Silva Burger, Ph.D., Institute for Health Services Research in Dermatology and Nursing, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1058) Impact of self-reported symptomatic adverse events on health-related quality of life in patients receiving treatment for Mycobacterium avium complex pulmonary disease

Emily Henkle, PhD, MPH, OHSU-PSU School of Public Health, Portland, Oregon, United States

(1060) Clinical Relevance in the context of patient-reported outcome data. A qualitative study to enrich the definition from a multi-professional experts' perspective.

Ines Rathgeber, M.A. B.Sc., Medical University of Innsbruck, Innsbruck, Austria

(1062) Establishing the minimal subgroup size for the group-based trajectory modeling - A simulation study

Qiuling Shi, MD PhD, Chongqing Medical University, Chongqing, China

(1064) Is number of items in a scale or number of timepoints more important for precise estimation of mean change from baseline? (NCCTG N08CB, Alliance A152306)

Brie Noble, Mayo Clinic, Scottsdale, Arizona, United States

(1066) Sensitivity of Study Results to Patient-Reported Data Collected Through Backup Phone Calls (NCCTG N1048 [Alliance])

Gina L. Mazza, PhD, Mayo Clinic, Scottsdale, Arizona, United States

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Monday Poster Session II

Saal Heumarkt II

(1068) Which modes of assessment for patient-reported outcomes are used in cancer randomized clinical trials? A protocol for a systematic scoping review of data collection methods

Jens Lehmann, PhD, University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(1070) DEVELOPMENT AND VALIDATION OF GENDER-Q SCALES MEASURING HEALTH-RELATED QUALITY OF LIFE IN INDIVIDUALS SEEKING GENDER-AFFIRMING CARE: AN INTERNATIONAL STUDY

Manraj Kaur, PhD, Harvard Medical School, Brigham and Women's Hospital, Boston, Massachusetts, United States

(1074) How do children understand and respond to the Child Health Utility 9 Dimensions (CHU9D)? A think-aloud study in 6-12 year olds.

Julie Ratcliffe, PhD, Health and Social Care Economics Group, Caring Futures Institute, Flinders University, Adelaide, Australia

(1076) Using a timeline activity in concept elicitation interviews with youth: Methods and lessons learned from an interpretive descriptive study to develop a patient-reported outcome measure (GENDER-Q Youth)

Shelby Kennedy, MHK, McMaster University, Hamilton, Ontario, Canada

(1078) Gaining information from lack of measurement invariance and restoring causal inference in randomized controlled-trials including patient-reported outcome measures: a Rasch-based simulation study

Corentin Choisy, M.Sc, Nantes Université, Université de Tours, INSERM, UMR1246 SPHERE "methodS in Patient-centered outcomes and HEalth ResEarch", Nantes, France

(1080) A "one size fits all" model of developing and implementing patient-reported outcomes in clinical practice – the AmbuFlex model

Liv Schougaard, AmbuFlex, Centre for Patient-Reported Outcomes, Gødstrup Hospital, Herning, Denmark

(1084) Response shift analysis at the item level among multiple groups using Rasch models: a simulation study

Myriam Blanchin, PhD, Nantes Université, Université de Tours, INSERM, UMR1246 SPHERE "methodS in Patient-centered outcomes and HEalth ResEarch", Nantes, France

(1086) Effect of present state bias on minimal important change estimates; a simulation study

Berend Terluin, MD PhD, Amsterdam University Medical Center, Amsterdam, the Netherlands

(1088) Implementation of the Dermatology Life Quality Index (DLQI) in Routine Clinical Practice: A Systematic Review

Sam Salek, PhD, School of Life and Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom

(1090) Trajectory of anxiety following kidney transplantation

Ana Samudio, Ajmera Transplant Centre and Division of Nephrology, University Health Network, University of Toronto, Toronto, Ontario, Canada

(1092) Systematic Review of Generic PROMs in Switzerland

Thanh Elsener, Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland

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Monday Poster Session II

Saal Heumarkt II

(1094) Adverse Health Outcomes Three Years after Radical Prostatectomy Compared with Men in the General Population: A Study from the Cancer Registry of Norway

Mona Nilsson, Cancer Registry of Norway, Norwegian Institute of Public Health, Oslo, Norway

Monday, 14 October

4:25 PM - 5:40 PM

Concurrent Oral Sessions

Oral Session 107: Cancer: Measures I

Saal Maritim I

Session Chair: Galina Velikova, MD PhD FRCP, United Kingdom

4:30 PM - 4:47 PM (107.1) Development of an EORTC quality of life questionnaire specific to adolescents and young adults with cancer: Measuring what matters most to this unique patient group

Samantha Sodergren, BSc, PhD, University of Southampton, Southampton, United Kingdom

4:47 PM - 5:04 PM (107.2) Delphi study to inform PRO measure selection for electronic symptom and quality of life monitoring of patients following CAR-T cell therapy

Sarah Hughes, PhD, MHSc, Centre for Patient Reported Outcome Research, University of Birmingham, Birmingham, United Kingdom

5:04 PM - 5:21 PM (107.3) Selecting immune checkpoint inhibitor toxicities from item libraries for use in electronic patient-reported symptom monitoring systems

Claudia Rutherford, University of Sydney, Sydney, Australia

5:21 PM - 5:38 PM (107.4) An international field study for the reliability and validity of the EORTC Communication Questionnaire EORTC QLQ-COMU26

Juan Ignacio Arraras, Hospital Universitario de Navarra, Pamplona, Spain

Oral Session 108: COVID-19

Salon 16 Königswinter

Session Chair: Christine Blome, PhD, Germany

4:30 PM - 4:47 PM (108.1) Concluding the Global Impact: Insights from an International Survey of 30 Countries on COVID-19

Daniel Fong, PhD, The University of Hong Kong, Hong Kong, Hong Kong

4:47 PM - 5:04 PM (108.2) Change in Fatigue over Two Years in People with Post-Covid Syndrome

Nancy Mayo, B.Sc.(PT), M.Sc., Ph.D., McGill University, Montreal, Quebec, Canada

5:04 PM - 5:21 PM (108.3) Emerging priorities and concerns in the wake of the COVID-19 pandemic: Qualitative and quantitative findings from a United States national survey

Richard L. Skolasky, Sc.D., Johns Hopkins University School of Medicine, Baltimore, Maryland, United States

Oral Session 109: Guidelines and Good Practices

Salon 17 Darmstadt

Session Chair: Jan Boehnke, United Kingdom

4:30 PM - 4:47 PM (109.1) New COSMIN guidance for researchers to help improve the selection of measurement instruments

Wieneke Mokkink, PhD, Amsterdam UMC, Amsterdam, Netherlands

4:47 PM - 5:04 PM (109.2) A Qualitative Meta-synthesis on Response Shift

Kara Schick-Makaroff, PhD RN, University of Alberta, Edmonton, Alberta, Canada

5:04 PM - 5:21 PM (109.3) Improving standards for Patient and Public Involvement and Engagement in Health Research

Christel McMullan, PhD, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom

5:21 PM - 5:38 PM (109.4) Expert Consensus on Implementing Patient-Reported Outcomes in Telehealth: Findings from an International Delphi Study

Elizabeth Unni, PhD, Touro College of Pharmacy, New York, New York, United States

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Monday, 14 October

4:25 PM - 5:40 PM

Concurrent Oral Sessions

Oral Session 110: Nephrology and Urology

Salon 21 Mannheim

Session Chair: Christian Apfelbacher, PhD, Germany

4:30 PM - 4:47 PM (110.1) Remote symptom monitoring with patient-reported outcome measures in outpatients with chronic kidney disease (PROKID): a multicentre randomised controlled pragmatic non-inferiority study

Birgith Grove, RN;MHS,PhD, AmbuFlex- Centre for Patient-Reported Outcome, Herning, Denmark

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

4:47 PM - 5:04 PM (110.2) Assessment of Psychometric Properties of a Dialysis-Related Symptom Questionnaire based on the CONVINCE study

Ngoc Pham, Fresenius Medical Care, Bad Homburg, Germany

5:04 PM - 5:21 PM (110.3) Self-Efficacy and Social Support Assessments Predict Health-Related Quality of Life in Dialysis Patients over Time

Krister Cromm, Fresenius Medical Care, Bad Homburg, Germany

5:21 PM - 5:38 PM (110.4) Using Delphi methodology in the development of a new pain-specific patient-reported outcome measure for women with pelvic floor disorders

Sheymonti Hoque, Bachelor of Health Sciences (Honours), Monash University, Melbourne, Australia

Oral Session 111: Patient Perspective

Salon 22 Titisee

Session Chair: Kate Absolom, PhD, United Kingdom

4:30 PM - 4:47 PM (111.1) Examining the association between patient-reported outcomes and physical activity metrics in patients with HR+/HER2 advanced breast cancer treated with palbociclib plus endocrine therapy or endocrine therapy alone

Mari Oba S, Dr, National center of neurology and psychiatry, Tokyo, Japan

4:47 PM - 5:04 PM (111.2) Understanding Frailty Risks Among Older Adults with Cancer: Insights from Patient Narratives

Jae-Yung Kwon, University of Victoria, Victoria, British Columbia, Canada

5:04 PM - 5:21 PM (111.3) What patients want to know about physical function impacted by anti-cancer treatment

Rebecca Fillipo, Duke University School of Medicine, Durham, North Carolina, United States

5:21 PM - 5:38 PM (111.4) Living with Postural Orthostatic Tachycardia Syndrome: the Patient Experience

Katherine Kim, MPH, Regeneron Pharmaceuticals, Inc., Sleepy Hollow, New York, United States

Monday, 14 October

4:25 PM - 5:40 PM

Concurrent Oral Sessions

Oral Session 112: PROMS and PREMS in Pediatric Care I

Salon 14 Köln

Session Chair: Monika Bullinger, PhD, Germany

4:30 PM - 4:47 PM (112.1) Studying Implementation of Measurement-Based Care in Child and Adolescent Mental Health Services

Erin McCabe, MScPT, PhD, School of Public Policy, University of Calgary, Calgary, Alberta, Canada

STUDENT ORAL PRESENTATION AWARD FINALIST

4:47 PM - 5:04 PM (112.2) Adapting a precision mental wellness tool for Inuit children in the Canadian arctic

Nancy Young, BScPT MSc PhD, CHEO Research Institute, Ottawa, Ontario, Canada

5:04 PM - 5:21 PM (112.3) Development of a Core PRO(M) set in Pediatric Physiotherapy

Selina Limmen, MSc, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands, Amsterdam, Netherlands

5:21 PM - 5:38 PM (112.4) Engaging children in Shared-Decision Making: Making sense of PROM outcomes

Michiel Luijten, PhD, Amsterdam UMC, Amsterdam, Netherlands

Tuesday, 15 October

9:35 AM - 10:15 AM

Tuesday Poster Session I

Saal Heumarkt II

(2001) Validation of the EORTC Sexual Health questionnaire (SHQ-22) in a Danish AYA population during a cancer trajectory

Line Bentsen, Ph.D.-student, MD, Department of Oncology, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

(2003) Patients' acceptability of a patient-reported outcome measure in cardiac rehabilitation (The PRO-Heart-DK) – a mixed methods study using the Theoretical Framework of Acceptability

Cecilie Lindström Egholm, MScPH, Ph.D., REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital, Nyborg, Denmark; Department of Clinical Research, University of Southern Denmark, Odense, Denmark, Nyborg, Denmark

(2005) Home-based accommodations made by caregivers of those with Duchenne muscular dystrophy (DMD): a cross-sectional survey

Ivana F Audhya, Sarepta Therapeutics, Cambridge, Massachusetts, United States

(2007) Humanistic burden among caregivers of individuals living with sickle cell disease with recurrent vaso-occlusive crises and transfusion-dependent β -thalassemia: a qualitative assessment

Lauren Lilly, PharmD, PhD, Vertex Pharmaceuticals Incorporated, Boston, Massachusetts, United States

(2009) Patient-Reported Experiences (PREMs) after a hospital admission

Montserrat Ferrer, MD, PhD, Hospital del Mar Research Institute, Barcelona, Spain

(2011) Patient Reported Outcomes used in Pediatric Physiotherapy: A Literature Review

Selina Limmen, MSc, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands, Amsterdam, Netherlands

(2013) YOGA FOR PATIENTS UNDERGOING RADIOTHERAPY AND THEIR SPOUSAL CAREGIVERS: RESULTS OF A 3-ARM RANDOMIZED CONTROLLED TRIAL

Kathrin Milbury, PhD, The University of Texas MD Anderson Cancer Center, Houston, Texas, United States

(2015) Development of a conceptual framework to inform selection of patient reported outcomes linked to chimeric antigen receptor T-cell therapies (CAR-T) in patients with haematological malignancies

Foram Khatsuria, MPH, University of Birmingham, Birmingham, United Kingdom

(2017) Patient and caregiver experiences with head and neck squamous cell carcinoma: insights from a US social media listening study

Shirley Huang, Pfizer Inc., Bothell, Washington, United States

(2019) Evaluation and Adaptation of The FACE-Q Patient-Reported Outcome Measure for Retinoblastoma Patients

Farheen Khan, BSc (Hons), The Hospital for Sick Children, Toronto, Ontario, Canada

(2021) A systematic review comparing the psychometric properties of computer adaptive tests (CAT) and static patient-reported outcome measures in cancer patients

Carrie-Anne Ng, PhD, GradDipHlthSc, BHumSc, Centre for Health Economics Research and Evaluation, Faculty of Health, University of Technology Sydney, Sydney, Australia

(2023) Factors Contributing to a Clinically Meaningful Decline in BREAST-Q Score Following Breast Cancer Surgery

Eden Marco, BSc, University of Toronto Faculty of Medicine, Toronto, Ontario, Canada

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Tuesday Poster Session I

Saal Heumarkt II

(2025) Long-term sexual health of men on active surveillance for low-risk prostate cancer – results of the Movember GAP3 consortium.

Lionne Venderbos, Department of Urology, Erasmus MC Cancer Institute, Erasmus University Medical Center Rotterdam, Rotterdam, Netherlands

(2027) Health-Related Quality of Life Assessment in Renal Cell Cancer: Navigating the Maze of Measures. A Scoping Review.

Lisa Wintner, University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(2029) Response shift results of quantitative research using patient-reported outcome measures: A meta-regression analysis.

Veronique Sebillé, Nantes Université, Université de Tours, CHU Nantes, INSERM, methodS in Patient-centered outcomes and HEalth ResEarch, SPHERE, F-44000 Nantes, France

(2031) Comparative effectiveness of treatments for massive rotator cuff injuries

Victor Zamora, PhD, Health Services Research Group, Hospital del Mar Research Institute, Barcelona, Spain

(2033) The role of cognitive appraisal processes in self-reported pain after orthopaedic surgery: Associations with opioid-addiction risk

Richard L. Skolasky, ScD, Johns Hopkins University, Baltimore, Maryland, United States

(2035) The Continued Care Patient-Reported Experience Measure (CC-PREM)

Yolanda Pardo, PhD, Hospital del Mar Research Institute, CIBER de Epidemiología y Salud Pública (CIBERESP), Universitat Autònoma de Barcelona, Barcelona, Spain

(2037) Differing perspectives on patient self-efficacy for vascular surgery patients and caregivers results in increased caregiver strain: a mixed-methods study

Cassidy Chester, University of Utah, Salt Lake City, Utah, United States

(2039) Improving work-related quality of life through self-care knowledge, skills, and attitudes: A cross-sectional study

Sabrina Figueiredo, PhD, The George Washington University, Washington, District Of Columbia, United States

(2041) Using the PROMIS Itch Questionnaire to describe itch in survivors of burn injury: A Burn Model System National Database Study

Dagmar Amtmann, PhD, University of Washington, Seattle, Washington, United States

(2043) Use of nudges in relation to health-related QOL in a convalescent rehabilitation ward

Ryota Izumi, Ph.D, Seirei Christopher University, Hamamatsu, Japan

(2045) Evaluating Four Approaches to Measuring Physical Function in Cancer: Results of the Integrating 4 Methods to Evaluate Physical Function (In4M) Study

Amylou Dueck, PhD, Department of Quantitative Health Sciences, Mayo Clinic, Phoenix, Arizona, USA, Phoenix, Arizona, United States

(2047) Data collection and analysis in longitudinal qualitative research (LQR) to understand change over time

Sally Lanar, ICON plc, Insights, Evidence and Value, Lyon, France

(2049) A linguistic comparison of twelve Arabic versions of the Diabetes Treatment Satisfaction Questionnaire (DTSQs version): exploring the feasibility of regional rather than country-specific questionnaires

Rana Almbark, Health Psychology Research Ltd, Egham, United Kingdom

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Tuesday Poster Session I

Saal Heumarkt II

(2051) Developing accessible methods for capturing well-being outcomes in community support settings: testing the use of Moodscope cards with vulnerable families

Caroline Potter, DPhil, University of Oxford (Nuffield Department of Primary Care Health Sciences), NIHR Applied Research Collaboration Oxford and Thames Valley, Oxford, United Kingdom

(2053) Translatability Assessment of the Fluid Overload from Nephrotic Syndrome Measure

Bárbara Pérez, MA, FACITrans, Malaga, Spain

(2055) Development and evaluation of a Spanish-language pregnancy-specific patient-reported outcome measure (PROM) of trust in clinician

Maria Edelen, PhD, Brigham and Women's Hospital/ Harvard Medical School, Boston, Massachusetts, United States

(2057) Translation and Linguistic Validation of the PROMIS-57 and PROMIS Pediatric-49 Profiles in Hausa

Jiyoung Son, MA, Northwestern University, Chicago, Illinois, United States

(2059) Beyond Native Speakers: Rethinking Back-Translator Qualifications for Diverse QOL Research

Melinda Johnson, MA, Linguistics, Lionbridge Technologies, Cary, North Carolina, United States

(2061) Differences between Healthcare Managers' and Nurses' Perceptions of Service Climate in a Canadian Healthcare System

Oluwagbohunmi (Olu) Awosoga, PhD, MBA, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada

(2063) Translation, linguistic and content validation of the German version of the Holm and Cordoba UTI score (HCUTI): A patient-reported outcome measure to assess symptoms and impact of uncomplicated urinary tract infections in women

Katharina Piontek, Institute of Social Medicine and Health System Research, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

(2065) Measurement properties of Patient-reported Outcome Measures for acute bronchitis and acute cough: a systematic review

Theresa Donhauser, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

(2067) Macedonian Translation and Cross-Cultural Adaptation of the Inhaler Technique Questionnaire (InTeQ)

Dijana Miceva, MScPhm, PhD student, Division of Pharmacy, Faculty of Medical Sciences, Goce Delcev University, Stip, Krste Misirkov Str., No. 10-A, P.O. Box 201, 2000 Stip, North Macedonia; Shtip, Macedonia

(2069) Factorial validity of the DISABKIDS Diabetes Mellitus Specific module (DSM-10): an international collaborative study

Claudia Benedita Santos, PhD, Ribeirão Preto College of Nursing, University of São Paulo, Ribeirão Preto, Brazil

(2071) Agreement Between Patient and Proxy Assessments of Health-Related Quality of Life After Stroke Using the EQ-5D-5L

Misa Takegami, PhD, MPH, Department of Public Health and Health Policy, Graduate School of Medicine, The University of Tokyo, Bunkyo-ku, Japan

(2073) Patient perceptions of treatments for muscle-invasive bladder cancer: insights from a US social media listening study

Vanessa Shih, Pfizer Inc., Bothell, Washington, United States

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Tuesday Poster Session I

Saal Heumarkt II

(2075) Health-related quality of life in parents of adolescents assessed over a four-years period (2019, 2121 and 2023)

Gudrun Rohde, RN PhD, University of Agder and Sorlandet Hospital, Kristiansand, Norway

(2077) PROMIS®, Neuro-QoL and NIH Toolbox® PRO: Challenges in multilingual translation of item banks with overlapping items

Helena Correia, Northwestern University, Feinberg School of Medicine, Dept. Medical Social Sciences, Chicago, Illinois, United States

(2079) Development and Validation of the Kidney Symptom Burden Questionnaire (KSB-Q)

Nicola Anderson, PhD, Centre for Patient Reported Outcomes Research, Institute for Applied Health Research, University of Birmingham, Birmingham, United Kingdom

(2081) Reevaluating "Depressed": Unravelling Linguistic and Cultural Complexity in Clinical Outcome Assessments

Tim Poepsel, MS, PhD, RWS, St. Louis, Missouri, United States

Tuesday, 15 October

1:45 PM - 2:55 PM

Concurrent Oral Briefs

Oral Brief Session 201: Adaptive Testing and Scoring

Salon 16 Königswinter

Session Chair: Morten Petersen, MScI, Denmark

1:50 PM - 1:58 PM (B201.1) Developing Content for a Diabetes-Specific Quality of Life Item Bank and Computerized Adaptive Testing System (DiabCAT)

Ecosse Lamoureux, PhD, Duke-NUS Medical School, Singapore, Singapore

1:58 PM - 2:06 PM (B201.2) A literature review exploring whether meaningful change threshold estimates for patient-reported outcome (PRO) measures vary depending on baseline severity

Joel Sims, MSc, Adelphi Values, Bollington, United Kingdom

2:06 PM - 2:14 PM (B201.3) Crosswalk between PROMIS computer adaptive tests and numerical rating scales in cancer patients: Anxiety, Depression, Pain interference, Physical function

Minji Lee, PhD, Mayo Clinic, Rochester, Minnesota, United States

2:14 PM - 2:22 PM (B201.4) Parameter uncertainties in mapping algorithms: A case study of mapping PedsQL Generic Core Scales to EQ-5D-Y-3L among children with neurofibromatosis type 1

Jiabi Wen, School of Public Health, University of Alberta, Edmonton, Alberta, Canada

2:22 PM - 2:30 PM (B201.5) Linking algorithms based on the PROMIS Wave 1 sample can be used to translate SF-36 PF-10 scores to the PROMIS Physical Function metric in independent clinical samples

Audrey Yuki Brinker, Center for Patient-Centered Outcomes Research (CPCOR), Department of Psychosomatic Medicine, Charité – Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

2:30 PM - 2:38 PM (B201.6) Initial Findings from the StandardizingPF Project: A Prospective Multicenter Psychometric Study to Calibrate Patient-Reported and Performance Outcome Measures of General Physical Function to a Common Scale

Gregor Liegl, Center for Patient-Centered Outcomes Research (CPCOR), Department of Psychosomatic Medicine, Charité – Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

2:38 PM - 2:46 PM (B201.7) Impact of informed starting values on longitudinal computer adaptive tests in HRQOL assessments.

Michael Bass, Northwestern University, Chicago, Illinois, United States

2:46 PM - 2:54 PM (B201.8) An automated pipeline for analysis of PRO-CTCAE free-text responses with application to the ACCRU RU011201I clinical trial

Patrick W Johnson, Mayo Clinic, Department of Quantitative Health Sciences, Jacksonville, Florida, United States

Oral Brief Session 202: Implementation and Quality Improvement

Salon 17 Darmstadt

Session Chair: Andrea Pusic, MD MHS FRCSC, United States

1:50 PM - 1:58 PM (B202.1) Reporting patient reported outcome measures for quality improvement purposes

Rasa Ruseckaite, PhD, Monash University, Melbourne, Australia

1:58 PM - 2:06 PM (B202.2) Implementation of a national PROM for general palliative care – experiences from a feasibility trial

Cecilie Lindstrom Egholm, PhD, REHPA, the Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital, Nyborg, Denmark

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Concurrent Oral Briefs

2:06 PM - 2:14 PM (B202.3) Lessons learned from using Patient Reported Outcome (PRO) as intervention during cancer treatment in Denmark – possible reasons for lacking effect

Helle Pappot, MD DMSc Professor, Rigshospitalet, University Hospital of Copenhagen, Copenhagen, Denmark

2:14 PM - 2:22 PM (B202.4) Measurement systems including PROMs and PREMs to support value-based healthcare decision-making: an environmental scan.

Pierre-Henri Roux-Levy, Université de Sherbrooke, Chicoutimi, Quebec, Canada

2:22 PM - 2:30 PM (B202.5) Evaluating Hospital Surgical Quality with Patient-Reported Shared Decision Making

Jason Liu, MD, MS, Brigham and Women's Hospital, Boston, Massachusetts, United States

2:30 PM - 2:38 PM (B202.6) Standardising Patient-Reported Outcomes in Prostate Cancer: Insights from the PIONEER Consortium

Charlotte Moss, Translational Oncology and Urology Research, King's College London, London, United Kingdom

2:38 PM - 2:46 PM (B202.7) Leveraging SMS for patient-reported data collection

Samuel Llewellyn, MPH, Vitaccess, London, United Kingdom

Oral Brief Session 203: Measure Development and Evaluation

Salon 14 Köln

Session Chair: Claire Piccinin, Belgium

1:50 PM - 1:58 PM (B203.1) Development of an easy-read version of the Brain Injury associated Visual Impairment Impact Questionnaire (BIVI-IQ)

Lauren R Hepworth, University of Liverpool, Liverpool, United Kingdom

1:58 PM - 2:06 PM (B203.2) The development of a multidimensional, multilevel and intersectional measure of structural racism to predict HRQoL outcomes

Ester Villalonga Olives, University of Maryland School of Pharmacy, Baltimore, Maryland, United States

2:06 PM - 2:14 PM (B203.3) Meaningful communication change in individuals with neurodevelopmental disorders: A person-centered approach to interpretation of the Observer-Reported Communication Ability (ORCA) measure in clinical trials

Abigail Rader, MS, Duke University Department of Population Health Sciences, Durham, North Carolina, United States

2:14 PM - 2:22 PM (B203.4) Patient-reported outcome measures for acute rhinosinusitis in adults and children: A systematic review of instruments and measurement properties

Christian Apfelbacher, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

2:22 PM - 2:30 PM (B203.5) Improving high resolution diagnostics in pain disorders: Development of an adaptive instrument for measuring momentary pain catastrophizing.

Alexander Obbarius, PD Dr., Center for Patient Centered Outcomes Research, Department of Psychosomatic Medicine, Center for Internal Medicine and Dermatology, Charité – Universitätsmedizin Berlin, Berlin, Germany

2:30 PM - 2:38 PM (B203.6) Validity evidence of the Patient Activation Measure (PAM-13) in stroke

Ava Mehdipour, PhD, McMaster University, Toronto, Ontario, Canada

2:38 PM - 2:46 PM (B203.7) Content validity and meaningful change thresholds of Patient Global Impression of Severity (PGI-S) and Change (PGI-C) measures in non-small cell lung cancer: A qualitative patient interview study

Rohini Sen, AbbVie, Inc., North Chicago, Illinois, United States

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Concurrent Oral Briefs

2:46 PM - 2:54 PM (B203.8) Measuring the quality of life of people with cancer and cancer survivors in Europe: Development of the EUonQoL-Kit.

Galina Velikova, Leeds Institute of Medical Research at St James', University of Leeds, Leeds, United Kingdom

Oral Brief Session 204: Mixed Conditions

Saal Maritim I

Session Chair: Sandra Nolte, PhD, Australia

1:50 PM - 1:58 PM (B204.1) Integrating Electronic Patient-Reported Outcome Measures in Routine Gender-Affirming Surgical Care at an Academic Center: Identifying Obstacles and Opportunities

Manraj Kaur, PhD, Harvard Medical School, Brigham and Women's Hospital, Boston, Massachusetts, United States

1:58 PM - 2:06 PM (B204.2) Exit interviews exploring the impact of vasomotor symptoms associated with menopause on mood and work/productivity: experiences of women in Phase 3 trials (OASIS 1 and 2)

Claudia Haberland, Bayer AG, Berlin, Germany

2:06 PM - 2:14 PM (B204.3) Socio-demographic diversity of the impact of dermatological diseases: Results from the patient-initiated Global Research on the Impact of Dermatological Disease (GRIDD) study

Neuza da Silva Burger, Ph.D., Institute for Health Services Research in Dermatology and Nursing (IVDP), University Medical Center Hamburg-Eppendorf (UKE), Hamburg, Germany

2:14 PM - 2:22 PM (B204.4) PROM4RARE: the final core patient reported outcome set for individuals with genetic intellectual disability

Nadia van Silfhout, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands, Amsterdam, Netherlands

2:22 PM - 2:30 PM (B204.5) The Impact of a Graded Care Model for Miscarriage on Quality of Life Outcomes in the UK

Corneliu Bolbocean, University of Arkansas for Medical Sciences, Little Rock, Arkansas, United States

2:30 PM - 2:38 PM (B204.6) Eliciting preferences of people living with diabetes using the Hypo-RESOLVE-QoL-8D to determine the impact of hypoglycaemia to inform economic evaluation

Donna Rowen, PhD, University of Sheffield, Sheffield, United Kingdom

2:38 PM - 2:46 PM (B204.7) Family Reported Outcome Measure (FROM-16) in Dermatology: Health Outcome Assessment Beyond PROs

Sam Salek, School of Life Medicinal Sciences, University of Hertfordshire, Professor of Pharmacoepidemiology, Hertfordshire, United Kingdom

2:46 PM - 2:54 PM (B204.8) What does quality of life mean for children living with medical complexity and neurological impairment?

Andrea Johnson, PhD, University of Toronto, Toronto, Ontario, Canada

Tuesday, 15 October

1:45 PM - 2:55 PM

Concurrent Oral Briefs

Oral Brief Session 205: Patient Engagement

Salon 21 Mannheim

Session Chair: Maria-Jose Santana, PhD, Canada

1:50 PM - 1:58 PM (B205.1) Quality of Life in a Crisis: Exploring Self-management and the Quality of Life of people living with psychosis

Rachel Milte, PhD, Flinders University, Adelaide, Australia

1:58 PM - 2:06 PM (B205.2) Amplifying the patient's voice: using patient reported data to inform remote monitoring by health care providers for improved treatment outcomes

Madalina Sucala, PhD, Evinova, New York, New York, United States

2:06 PM - 2:14 PM (B205.3) Collaborative redesign of a patient-reported oncology intake questionnaire using a modified Delphi technique: Maximizing the value of high-volume patient-reported data

Paige Barwick, Dana-Farber Cancer Institute, Boston, Massachusetts, United States

2:14 PM - 2:22 PM (B205.4) Patient and Public Involvement in Quality of Life research: lessons learned from collaborating with cancer patients and informal caregivers in the consensus process of the EUonQoL-Kit

Merel Engelaar, Netherlands Institute for Health Services Research (Nivel), Utrecht, Netherlands

2:22 PM - 2:30 PM (B205.5) When the self doesn't want help: implications of ego-syntonic diagnoses for concepts of normalcy and patient-centered care.

Mikael Andersén, PhD Student, Lic. Psychologist, Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

2:30 PM - 2:38 PM (B205.6) Patient Engagement in Quality of Life Research: A Scoping Review of Systematic Reviews

Natasha Anne Roberts, PhD, University of Queensland Centre for Clinical Research, Brisbane, Australia

2:38 PM - 2:46 PM (B205.7) Enhancing Patient-Centric Care: The Role of PROMs Utilizing SRS-30 in Scoliosis Management

Maria Santana, PhD, University of Calgary, Calgary, Alberta, Canada

2:46 PM - 2:54 PM (B205.8) Towards Targeted Engagement: What Are the Most Important Reasons Informing People's Decision to Attend Cancer Screening in England?

Damian Lewis, MSc Psychology, MSc Clinical Psychology, York Health Economic Consortium (YHEC), York, United Kingdom

Oral Brief Session 206: Population Health Assessment

Salon 22 Titisee

Session Chair: Jakob Bjorner, MD PhD, Denmark

1:50 PM - 1:58 PM (B206.1) Neighborhood socioeconomic disadvantage and geographic disparities in global health

Yadi Li, Cleveland Clinic, MEd, Cleveland, Ohio, United States

1:58 PM - 2:06 PM (B206.2) 'Decolonizing health': Perception and development of a conceptual health framework among children and adolescents in sub-Saharan Africa and its content comparison with the EQ-5D-Y

Lucky Gift Ngwira, PhD, Health Economics and Policy Unit, Kamuzu University of Health Sciences, Blantyre, Malawi

2:06 PM - 2:14 PM (B206.3) Estimating Quality-Adjusted Life Expectancy in Alberta, Canada

Arto Ohinmaa, Alberta PROMs & EQ-5D Research & Support Unit (APERSU), School of Public Health, University of Alberta, Edmonton, Alberta, Canada

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Concurrent Oral Briefs

2:14 PM - 2:22 PM (B206.4) OECD Patient-Reported Indicators Survey (PaRIS) in Canada: Determinants of quality of life and satisfaction of care

Vanessa Vaillancourt, Université de Sherbrooke, Chicoutimi, Quebec, Canada

2:22 PM - 2:30 PM (B206.5) POPS II Feasibility & Methodology: Population Norms and Inequality Indicators based on EQ-5D-5L in General Population Surveys (England and Spain)

You-Shan Feng, Medical University Tübingen, Tübingen, Germany

2:30 PM - 2:38 PM (B206.6) Wellbeing in Latin America: Who are the most vulnerable in Argentina, Chile, Ecuador and Peru?

María-José Mendoza-Jiménez, Erasmus University Rotterdam, Rotterdam, Netherlands

2:38 PM - 2:46 PM (B206.7) Enhancing Population Health Assessment: Insights from the EuroQol Data Assessment of Population Health Needs and Instrument Evaluation (EQ-DAPHNIE) Pilot Study

Mathieu Janssen, PhD, EuroQol Research Foundation, Rotterdam, Netherlands

2:46 PM - 2:54 PM (B206.8) A MIMIC Model Approach to Examining Differential Responses to Questions on Health Literacy among Hispanics living in the United States (U.S.)

Jennifer Contreras, MPH, University of Maryland School of Pharmacy, Baltimore, Maryland, United States

Tuesday, 15 October

3:10 PM - 3:50 PM

Tuesday Poster Session II

Saal Heumarkt II

(2002) Prevalence and sociodemographic correlates of mental health symptoms among young Canadians during the COVID-19 pandemic: A cross-sectional study

Ogochukwu Kelechi Onyeso, MSc, PhD(c), Faculty of Health Sciences, University of Lethbridge, Alberta, Canada, Lethbridge, Alberta, Canada

(2004) Content validation of the German version of the PROMIS 29+2 v2.1 in patients with post COVID-19 condition

Christian Apfelbacher, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

(2006) Routine, comprehensive measuring of health-related Quality of Life (hrQoL) in pediatric surgery outpatient settings with PedsQL 4.0 Generic Module (PedsQL-GM) and Family Impact Module (PedsQL-FIM) to prepare for hrQoL-based patient management

Jurek Schultz, Dr. med., Department of Pediatric Surgery, University Hospital Dresden - Technical University of Dresden, Dresden, Germany

(2008) Development and Refinement of a Mobile Health Intervention for Symptom Management and Psychosocial Support to Enhance Health-Related Quality of Life Outcomes in Ethnically-Diverse Black Prostate Cancer Survivors

Motolani Adedipe, DPh, MSc, PhD, University Of Oklahoma, Oklahoma City, Oklahoma, United States

(2010) Association between alert notification intensity during early study participation and time to study discontinuation in the AFT-39 PRO-TECT cluster-randomized clinical trial

Brenda Ginos, MS, Alliance Statistics and Data Management Center, Mayo Clinic, Scottsdale, Arizona, United States

(2012) PROpatient: A registry-based randomised controlled trial of symptom monitoring, using patient-reported outcome measures and centralised care coordination, to improve quality of life in patients with upper gastrointestinal cancers.

Liane Ioannou, PhD, Monash University, Melbourne, Australia

(2014) Understanding the concepts underlying the measurement of patient-reported tolerability

Aude ROBOREL de CLIMENS, PhD, IQVIA, Paris, France

(2016) Facilitators and Barriers to Implementation of the Community-Powered Cancer Management Program in the Chinese Context: A qualitative Study of Stakeholders' Perspectives

Jingyu Zhang, State Key Laboratory of Ultrasound in Medicine and Engineering, College of Biomedical Engineering, Chongqing Medical University, Chongqing, China., Chongqing, China

(2018) Predictors of perioperative quality of life and survival of patients with non-small cell lung cancer

Ryuta Fukai, Shonan Kamakura General Hospital, Kamakura, Japan

(2020) Trajectories of anxiety experienced by parents of children with a physical illness

Melissa Elgie, MSc, University of Waterloo, Waterloo, Ontario, Canada

(2022) Oxford Brain Health Clinic: health-related quality of life assessment among initial sample

Caroline Potter, DPhil, University of Oxford (Nuffield Department of Primary Care Health Sciences), NIHR Applied Research Collaboration Oxford and Thames Valley, Oxford, United Kingdom

(2024) Socioeconomic barriers to incorporating the patient perspective into chronic kidney disease management and research

Clara Amat-Fernandez, Hospital del Mar Research Institute, Barcelona, Spain

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Tuesday, 15 October

3:10 PM - 3:50 PM

Tuesday Poster Session II

Saal Heumarkt II

(2026) Deciphering Fatigue in patients receiving hemodialysis: How is peri-/intradialytic fatigue related to overall fatigue burden?

Anna Schappert, MD, Department of Psychosomatic Medicine, Center of Internal Medicine and Dermatology, Charité Universitätsmedizin Berlin, Berlin, Germany

(2028) Measurement properties of the Inflammatory Rasch-built Overall Disability Scale (I-RODS) in patients with Guillain-Barré Syndrome

Farah Pelouto, MSc, Department of Neurology, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands, Rotterdam, Netherlands

(2030) Uses of the ICECAP measure of capability in adults with neurological health conditions: a scoping review

Ruth Barclay, PhD, College of Rehabilitation Sciences, University of Manitoba, Winnipeg, Manitoba, Canada

(2032) Changes in physical, mental, and social health of adults with sickle cell disease following allogeneic stem cell transplantation: a mixed-methods, prospective cohort study

Maud van Muilekom, PhD, Emma Children's Hospital, Amsterdam UMC, Amsterdam, Netherlands

(2034) The influence of the cost-of-living crisis, self-efficacy, and religiosity on quality-of-life for patients with sickle cell disease

Judith Eberhardt, PhD, Teesside University, Middlesbrough, United Kingdom

(2036) Quantifying the impact of symptoms on health-related quality of life in idiopathic multicentric Castleman disease: Protocol for a novel outcome measure

Philip Powell, PhD, University of Sheffield, Sheffield, United Kingdom

(2038) The impact of haemophilia on sexual functioning in Dutch men

Tessa van Gastel, MSc, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands., Amsterdam, Netherlands

(2040) Evaluation of a simulated longitudinal testing method of digital healthcare tools in a routine oncology setting.

Ciara Dwan, ACMA; BSc, Accountancy, Evinova, Manchester, United Kingdom

(2042) Translation and psychometric validation of the Chinese Version of the Health Screening Tool Self-administered Geriatric-8 (S-G8) questionnaire for older patients with cancer

Hongfan Yu, PHD, ChongQing Medical University, Chongqing, China

(2044) Modular Patient-Reported Outcome Measurement Approach Supported by EORTC QLQ-C30 Domain and Summary Score Correlation Analyses in Breast Cancer Patients

Greta Marie de Waal, PhD, Signant Health, Potchefstroom, South Africa

(2046) A systematic approach using forest plots with multiple anchors to estimate meaningful change for a new patient-reported functional measure in narcolepsy

Helen Doll, Clinical Outcomes Solutions, Folkestone, United Kingdom

(2048) Missing data considerations for patient reported outcome measures in randomized controlled trials

Josephine M Norquist, BARDS-PaCES, Merck & Co. Inc, Rahway, New Jersey, United States

(2050) Identifying meaningful aspects of worst skin pain in cutaneous lupus erythematosus for assessment using a skin pain numeric rating scale

Josephine Park, EMD Serono Research & Development Institute, Inc., Billerica, MA, USA, an affiliate of Merck KGaA, Billerica, Massachusetts, United States

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Tuesday, 15 October

3:10 PM - 3:50 PM

Tuesday Poster Session II

Saal Heumarkt II

(2052) Investigation of Variability in Severity Response Set Composition across PROs: Data for increasing consistency, face validity, and comprehensibility in instrument development

Tim Poepsel, PhD, RWS, St. Louis, Missouri, United States

(2054) Interpreting Scores Using PRO Stories: New Shareware Supports Bookmarking and Idioscale Judgement

Karon Cook, PhD, Retired, Nacogdoches, Texas, Texas, United States

(2056) Longitudinal validity of the Hyperhidrosis Quality of Life Index (HidroQoL ©) in a phase IIIb clinical trial population with hyperhidrosis: responsiveness and meaningful score interpretation

Theresa Donhauser, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

(2058) Structural validity and reliability in daily data: recommendations based on findings from a simulated intensively longitudinal dataset

Christina Daskalopoulou, PhD, IQVIA, Athens, Greece

(2060) How is cognitive behavioural therapy (CBT) intended to support quality of life for people on dialysis with depressive symptoms? A realist analysis.

Katrin Micklitz, DPhil, Independent, Berlin, Germany

(2062) Measurement Properties of Patient-Reported Outcome Measures for Heart conditions: A COSMIN Systematic Review

Theresa Munyombwe, PhD, University of Leeds, Leeds, United Kingdom

(2064) Exploring Eight PROMIS® Profile Domain Scores and an Overall Health Score based on Multidimensional Item Response Theory (MIRT)

Xiaodan Tang, PhD, Northwestern University, Chicago, Illinois, United States

Lihua Yao, PhD, Northwestern University, Chicago, Illinois, United States

(2066) Synthesising validity evidence to form a validity argument: an application of modern validity theory in the Australian prison context

Scott Gill, BSc(Hons), Swinburne University of Technology, Melbourne, Australia

(2068) Frequency of common symptoms immediately after kidney and liver transplantation

Ana Samudio, Ajmera Transplant Centre and Division of Nephrology, University Health Network, University of Toronto, Toronto, Ontario, Canada

(2070) A patient-centered perspective on non-muscle invasive bladder cancer treatment: insights from a US social media listening study

Vanessa Shih, Pfizer Inc., Bothell, Washington, United States

(2072) The effect of disease modifying therapies on fatigue in multiple sclerosis

Samantha Cruz Rivera, Dr, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom

(2074) The Health-Related Quality of Life of Drug-resistant Tuberculosis Patients who are on Treatment in Botswana

Mooketsi Molefi, BMedSci, MBChB, MSCE, GH&L Fellowship, University of Botswana, Gaborone, Botswana

(2076) An International Field Test Study of LIMB-Q Kids: A new Patient-Reported Outcome Measure

Harpreet Chhina, PhD, University of British Columbia, Vancouver, British Columbia, Canada

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Tuesday, 15 October

4:00 PM - 5:15 PM

Concurrent Oral Sessions

Oral Session 207: Assessment in Pediatrics

Salon 16 Königswinter

Session Chair: Michiel Luijten, PhD, Netherlands

4:05 PM - 4:22 PM (207.1) Early Childhood Mental Health: Multidimensional Modeling for Assessment and Cluster Analysis for Profile Identification

Lihua Yao, Ph.D., Northwestern University, Chicago, Illinois, United States

4:22 PM - 4:39 PM (207.2) Who Should Value Health-Related Quality of Life in Children? Results from a Dual Country Survey

Philip Powell, PhD, University of Sheffield, Sheffield, United Kingdom

4:39 PM - 4:56 PM (207.3) The Preparing a clinical outcome assessment set for Nephrotic Syndrome (Prepare-NS) Project: A Core Set of Clinical Outcome Assessments and Endpoints for Nephrotic Syndrome Related to Rare Kidney Diseases

John Peiper, PhD, Northwestern University, Chicago, Illinois, United States

4:56 PM - 5:13 PM (207.4) Can Young Children Participate Meaningfully in Cognitive Interviews of Health-related Quality of Life Measures? An Exploration of Feasibility and a Novel Analytic Approach

Victoria Gale, MA, University of Sheffield, Sheffield, United Kingdom

Oral Session 208: Cancer: Measures II

Saal Maritim I

Session Chair: TBD

4:05 PM - 4:22 PM (208.1) Development and evaluation of the non-muscle invasive bladder cancer symptom index (NMIBC-SI)

Margaret-Ann Tait, Sydney Nursing School, Faculty of Medicine and Health, University of Sydney, Sydney, Australia

4:22 PM - 4:39 PM (208.2) Using prior information to individualise start item selection for the EORTC CAT Core

Morten Petersen, Palliative Care Research Unit, Department of Geriatrics and Palliative Medicine GP, Bispebjerg og Frederiksberg Hospital, Copenhagen NV, Denmark

4:39 PM - 4:56 PM (208.3) Development of EORTC quality of life questionnaire for metastatic breast cancer patients (EORTC QLQ-MBR44)

Galina Velikova, MD PhD FRCP, University of Leeds, Leeds, United Kingdom

4:56 PM - 5:13 PM (208.4) Cross-cultural validation of the COmprehensive Score for financial Toxicity (COST) in Australian cancer care

Claudia Rutherford, Susan Wakil School of Nursing and Midwifery, The University of Sydney, Sydney, Australia

Oral Session 209: Cancer: Treatment I

Salon 14 Köln

Session Chair: Michael Brundage, MD, Canada

4:05 PM - 4:22 PM (209.1) Trajectories of quality of life in breast cancer survivors during the first 6 months of treatment: A latent transition analysis

Eva Boomstra, Department of Psychosocial Research and Epidemiology, Netherlands Cancer Institute, Amsterdam, Netherlands

4:22 PM - 4:39 PM (209.2) Health-related quality of life and response shift effect of diffuse large B-cell lymphoma French relapse-free patients one year after diagnosis included in prospective real-life REALYSA cohort

Amelie Anota, PhD, Department of Clinical Research and Innovation and Department of Human and Social Sciences, Centre Léon Bérard, Lyon, France

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Tuesday, 15 October

4:00 PM - 5:15 PM

Concurrent Oral Sessions

4:39 PM - 4:56 PM (209.3) The Agreement of PSA-Lung and QLQ-LC29 in Assessing Symptom Burden and Physical Functioning Following Lung Cancer Surgery

Qiuling Shi, MD PhD, Chongqing Medical University, Chongqing, China

4:56 PM - 5:13 PM (209.4) Testing for Measurement Invariance of the Brief Fatigue Inventory in CNS Cancer Patients: A Comparison of Photon and Proton Radiotherapy

Heather Gunn, PhD, Mayo Clinic, Scottsdale, Arizona, United States

Oral Session 210: Clinical Research in Pediatrics

Salon 17 Darmstadt

Session Chair: Lotte Haverman, PhD, Netherlands

4:05 PM - 4:22 PM (210.1) Qualitative Descriptive Case Study of the Duchenne Muscular Dystrophy Clinical Research Partnership and Development of the FOCUS Model

Jennifer Davis, PhD, George Washington University, Washington, District Of Columbia, United States

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

4:22 PM - 4:39 PM (210.2) PROs in pediatric immunotherapy: Longitudinal self- and proxy-reported symptoms in children treated with CAR T cells for advanced leukemia

Allison Barz Leahy, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, United States

4:39 PM - 4:56 PM (210.3) Continuity of Symptoms of Mental Illness in Youth with Chronic Physical Illness and their Siblings

Dominique Basque, MA, PhD Candidate, University of Waterloo, Waterloo, Ontario, Canada

4:56 PM - 5:13 PM (210.4) Comparative analysis of limitations in activities, participation, and quality of life in Nepalese children with visual impairment

Ellen Elsman, PhD, Amsterdam UMC, Department of Ophthalmology, Amsterdam, Netherlands

Oral Session 211: Measurement Considerations I

Salon 21 Mannheim

Session Chair: Kevin Weinfurt, PhD, United States

4:05 PM - 4:22 PM (211.1) Tree-based item-response theory model for evaluating sample heterogeneity in patient-reported outcome measures: A web-based R Shiny implementation

Olayinka Arimoro, University of Calgary, Calgary, Alberta, Canada

STUDENT ORAL PRESENTATION AWARD FINALIST

4:22 PM - 4:39 PM (211.2) Are social determinants of health associated with measurement bias?

Ava Mehdipour, PhD, McMaster University, Toronto, Ontario, Canada

4:39 PM - 4:56 PM (211.3) Using Bifactor Exploratory Structural Equation Modeling to Test for a Continuum Structure of Reversible Cognitive Frailty

Henry Michael, BPharm, MSc, Division of Experimental Medicine, McGill University, Montreal, Quebec, Canada

4:56 PM - 5:13 PM (211.4) When Methods Align and Misalign: The Impact of Sample Size and Bootstrapping on the Use of CFA and IRT in Psychometric Validation of Patient-Reported Outcomes Measures

Hoan Do, Ph.D, Clinical Outcomes Solutions, Tucson, Arizona, United States

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Tuesday, 15 October

4:00 PM - 5:15 PM

Concurrent Oral Sessions

Oral Session 212: Measurement in Older Populations

Salon 22 Titisee

Session Chair: Stacie Hudgens, MA, United States

4:05 PM - 4:22 PM (212.1) Redefining Burden Assessment in Caregiving Dyads: Development and Validation of the Care-Recipient Self-Perceived and Proxy-Reported Caregiver Burden (CARE-SPB) Scale

Maja Kuharic, MPharm, Msc, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

4:22 PM - 4:39 PM (212.2) Older adults' dementia worry, self-reported cognition, and control beliefs about cognitive aging: A mixed methods study

Emily Bratlee-Whitaker, PhD, RN, RTI Health Solutions, Patient-Centered Outcomes Assessment, Research Triangle Park, North Carolina, United States

4:39 PM - 4:56 PM (212.3) ARMCADA- Advancing Reliable Measurement in Cognitive Aging and Decision-making Ability: Identification, Synthesis, and Validation of End-of-Life Decision-making Measures

Berivan Ece, PhD, Northwestern University, Chicago, Illinois, United States

4:56 PM - 5:13 PM (212.4) Proxy-reporting of quality of life for older people receiving aged care services: a psychometric validation study

Jyoti Khadka, PhD, Health and Social Care Economics Group, Caring Futures Institute, Flinders University, Adelaide, Australia

Wednesday, 16 October

9:30 AM - 10:10 AM

Wednesday Poster Session I

Saal Heumarkt II

(3001) Research on Depressed HPV positive individuals in a Chinese high incidence area

Yang Pu, Chongqing College of Traditional Chinese Medicine ; School of Public Health, Chongqing Medical University, Chongqing, China

(3003) Excess weight leads to a better health-related quality of life in outpatients with cancer

Xing Wei, Department of Thoracic Surgery, Sichuan Cancer Hospital, School of Medicine, University of Electronic Science and Technology of China, Chengdu, China

(3005) Surgeon's Prediction of Patients' Postoperative 1-year SANE Score Following Rotator Cuff Repair Surgery

Sarah Harris, BSc Eng, Pan Am Clinic Foundation, Winnipeg, Manitoba, Canada

(3007) Measuring informal carer health-related quality of life in motor neuron disease: A systematic review of the content validity of self-report instruments using COSMIN

Jill Carlton, PhD, University of Sheffield, Sheffield, United Kingdom

(3009) Pregnancy status and neonatal outcomes of pregnant women with allergic rhinitis in different seasons: a retrospective cohort study

Hongfan Yu, MS, State Key Laboratory of Ultrasound in Medicine and Engineering, College of Biomedical Engineering, Chongqing Medical University, Si Chuan, China

(3011) A Heterogeneity Analysis of Preference-Based Health-Related Quality of Life Outcomes in Individuals Born Very Preterm and Very Low Birthweight Adults: An Individual Participant Data Meta-Analysis

Corneliu Bolbocean, University of Arkansas for Medical Sciences, Little Rock, Arkansas, United States

(3013) Implementation of the iBLAD-app in Clinical Care to Improve Symptom Monitoring and Self-Management and facilitate Peer-to-Peer Advice

Lærke K. Tolstrup, PhD, Odense University Hospital, Odense, Denmark

(3015) Symptom Burden of Patients with Cancer in Community

Jingyu Zhang, State Key Laboratory of Ultrasound in Medicine and Engineering, College of Biomedical Engineering, Chongqing Medical University, Chongqing, China., Chongqing, China

(3017) Design of the Cancer Symptom Rating Questionnaire (CancerSRQ).

Michelle Taylor, PhD, DClinPsy, Health Psychology Research Limited, Egham, United Kingdom

(3019) A systematic review of Quality of Life (QoL) issues for patients with metastatic or recurrent/persistent anal cancer

Samantha Sodergren, PhD, University of Southampton, Southampton, United Kingdom

(3021) Understanding oncological and sexual function outcomes with sexual organ preserving cystectomy in women with bladder cancer-a systematic review

Rebecca Martin, MSc, The Royal Marsden NHS FT, London, United Kingdom

(3025) Capturing patients' overall experience of HER2-mutation-positive non-small-cell lung cancer in a clinical trial: a qualitative interview substudy

Heiko Zettl, PhD, Boehringer Ingelheim International GmbH, Binger Straße 173, 55216 Ingelheim am Rhein, Germany

(3027) Utility Atlas for Non-small Cell Lung Cancer Patients in China

Luying Wang, PhD, China Pharmaceutical University, Nanjing, China

(3029) Symptom burden in adults with hematological cancer participating in community-based exercise

Joanna F. Parkinson, BKin, MSc, Nova Scotia Health Authority, Halifax, Nova Scotia, Canada

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(3031) Safety of arthroscopic rotator cuff repair: standardized documentation, complication risks, and quality of life in a Swiss multicenter cohort study

LAURENT Audigé, DVM PhD, University Hospital Basel, Basel, Switzerland

(3033) Patients' self-reported experiences with symptoms associated with Sjögren's disease: findings from a systematic review of qualitative and quantitative studies

Brandon Becker, Bristol Myers Squibb, Princeton, New Jersey, United States

(3035) Measurement properties of the (Rasch-)Fatigue Severity Scale in patients with Guillain-Barré Syndrome

Farah Pelouto, MSc, Department of Neurology, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands, Rotterdam, Netherlands

(3037) The determinants of dropping out of remote Patient-Reported Outcome (PRO)-based follow-up among patients with epilepsy: a prospective cohort study

Liv Marit Valen Schougaard, MsciH, PhD, AmbuFlex, Centre for Patient-Reported Outcomes, Gødstrup Hospital, Denmark, Herning, Denmark

(3039) The patient experience in amyotrophic lateral sclerosis: a literature review to explore signs, symptoms, and impacts and to evaluate associated clinical outcome assessments

William Nowell, Regeneron Pharmaceuticals, Inc., Tarrytown, New York, United States

(3041) Instruments measuring (health-related) quality of life in people with multiple sclerosis: a systematic review following COSMIN guidelines

Andrea Giordano, Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy

(3043) Understanding Patients' Preferences for Intravitreal Treatment Options in Diabetic Macular Edema: Insights from a Discrete Choice Experiment and Willingness-to-Pay Analysis

Hanfei Wang, MMed, Beijing University of Chinese Medicine, Beijing, China

(3045) How patient-centered is the gynaecological care provided for patients with Genitourinary Syndrome of Menopause in Switzerland? A survey on the implementation of Patient-Centered Care

Theresa Donhauser, Otto-von-Guericke-University Magdeburg, Magdeburg, Germany

(3047) The association of Alcohol consumption and mental health over four years: A bivariate Latent Change score Model

Henriette Markwart, Dr., University Medicine Greifswald, Institute for Community Medicine, Department of Methods of Community Medicine, Greifswald, Germany

(3049) Rasch Validation of the Arabic Version of Patient-Reported Outcome Measurement Information System (PROMIS) Cognitive Function-Abilities

Rehab Alhasani, PT, PhD, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia

(3051) Validation of The Patient-Reported Outcomes Measurement Information System® (PROMIS®)-16 using a Nationally Representative Probability-based Sample

Maria Edelen, Ph.D., Brigham and Women's Hospital, Boston, Massachusetts, United States

(3053) Digital Storytelling (DST) in Health Research: Amplifying Patient Voices to Improve Quality of Life and Person-Centred Care

Sandra Zelinsky, University of Calgary, Calgary, Alberta, Canada

(3055) Graphical presentation of anchor- and distribution-based estimates of meaningful change

Helen Doll, MSc DPhil, Clinical Outcomes Solutions, Folkestone, United Kingdom

Wednesday, 16 October

9:30 AM - 10:10 AM

Wednesday Poster Session I

Saal Heumarkt II

(3057) Using online crowdsourcing platforms for the development and validation of PROMs: An example from the WOUND-Q study

Anne Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada

(3059) Development of a conceptual model of the patient experience of disease activity in cutaneous lupus erythematosus

Josephine Park, MPH, MBA, EMD Serono Research & Development Institute, Inc., Billerica, MA, USA, an affiliate of Merck KGaA, Billerica, Massachusetts, United States

(3061) Validation of a questionnaire on COVID-19 vaccine health literacy according to classic psychometric and Rasch analyses

Carmen Rodríguez-Blázquez, Dr, CIBER-ISCIII G85296226, Madrid, Spain

(3063) Content validity and feasibility of the Severe Asthma Questionnaire among people with severe asthma in Singapore: interview study

Christian Apfelbacher, MSc PhD, Otto von Guericke University, Magdeburg, Germany

(3065) Development and validation of therapy outcome measures for inducible laryngeal obstruction and chronic cough.

Siobhan Ludlow, Speech Sciences undergraduate degree and current doctoral fellow, Manchester University NHS Foundation Trust, Manchester, United Kingdom

(3067) Addressing quality-of-life after paediatric liver transplantation. Co-designing practice change to improve outcomes.

Kathe Holmes, Bachelor of Nursing, Postgraduate Diploma Advanced Clinical Nursing Paediatric Intensive Care, Master of Health Management, Royal Children's Hospital, Melbourne, Australia

(3069) Patient Reported Outcomes for psychomotor therapy in adult mental health care in the Netherlands: a multi-method qualitative study

Albertine de Haan, MA, Research Group Human Movement, Health and Well-being at Windesheim University of Applied Sciences; PhD student at Radboud University Medical Center, Zwolle, Netherlands

(3071) A Systematic Review on the Minimally Important Change for the PHQ-9 Depression Scale

Yoshitake Takebayashi, Ph.D, Fukushima Medical University, Fukushima, Japan

(3073) Identifying measures of decision-making ability and functional outcomes in older adults as part of the ARMCADA study: results from a scoping review

Berivan Ece, PhD, Northwestern University, Chicago, Illinois, United States

(3075) Initial Development of a patient-reported outcome tool for assessing anxiety in patients with HPV infection

Wei Xu, Chongqing Medical University, Chongqing, China

(3077) Physical function recovery following kidney transplantation

Jad Fadlallah, MEng, HBSoc, University Health Network, Toronto, Ontario, Canada

(3079) Enhancing COA Implementation in Clinical Trials with the COA Endpoint Manual

Chris Buckley, MSc, Parexel, London, United Kingdom

(1072) Evaluating Health-Related Quality of Life in Children: Selecting the value-set for the EQ-5D-Y-3L.

Diana Khanna, PhD Student (Health Econ), Health and Social Care Economics Group, Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, Australia

Wednesday, 16 October

10:20 AM - 11:35 AM

Concurrent Oral Sessions

Oral Session 301: Cancer Applications

Salon 16 Königswinter

Session Chair: Kim Cocks, PhD, United Kingdom

10:25 AM - 10:42 AM (301.1) User-Centered Design Evaluation of an Electronic Patient-Reported Outcome (ePRO) System to Improve Health-Related Quality of Life for Thoracic Surgery Patients

Elizabeth Kwong, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, United States

10:42 AM - 10:59 AM (301.2) Time to Worsening of Patient Reported Outcomes. Recommendations for Best Practice in Oncology

Joel Sims, MSc, Adelphi Values, Bollington, United Kingdom

10:59 AM - 11:16 AM (301.3) Using group-based multi-trajectory modeling to identify heterogeneity of symptom burden in lung cancer patients after surgery

Yang Pu, Chongqing College of Traditional Chinese Medicine ; School of Public Health, Chongqing Medical University, Chongqing, China

11:16 AM - 11:33 AM (301.4) The Mediating Role of PRO in the Functional Recovery of Lung Cancer Patients across Different Surgical Approaches: A Multicenter Prospective Cohort Study

Qiuling Shi, Chongqing medical university, Chongqing, China

Oral Session 302: Caregivers and Patient Support II

Salon 17 Darmstadt

Session Chair: Michelle Carty, PhD, United States

10:25 AM - 10:42 AM (302.1) Supporting Patients with Advanced Cancer and their Spouses in Parenting Minor Children: Results of a Randomized Controlled Trial

Kathrin Milbury, PhD, The University of Texas MD Anderson Cancer Center, Houston, Texas, United States

10:42 AM - 10:59 AM (302.2) Development of two conceptual models to describe the patient and caregiver reported impacts of living with X-linked myotubular myopathy (XLMTM)

Sam Llewellyn, MPH, Vitaccess, London, United Kingdom

10:59 AM - 11:16 AM (302.3) Conceptual models can be used to identify suitable proxy conditions in terms of health-related quality of life: results and findings from a case study in alopecia areata

Alice Biggane, Pfizer, London, United Kingdom

11:16 AM - 11:33 AM (302.4) Symptom severity and parenting concerns among patients with advanced cancer who parent minor children

Meagan Whisenant, PhD, APRN, The University of Texas MD Anderson Cancer Center, Houston, Texas, United States

Oral Session 303: Neurological Diseases

Salon 21 Mannheim

Session Chair: R. J. Wirth, PhD, United States

10:25 AM - 10:42 AM (303.1) Variables predicting migraine interictal burden (IIB): Additional Insights from a Random Forests Machine Learning Analysis

William Lenderking, PhD, Evidera, Harvard, Massachusetts, United States

10:42 AM - 10:59 AM (303.2) Changing the Paradigm for the Management of Facial Pain and Pressure: Development and accuracy of a patient-reported case finding tool for use in specialty clinics

Hui-Jie Lee, Department of Biostatistics and Bioinformatics, Duke University School of Medicine, Durham, North Carolina, United States

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10:20 AM - 11:35 AM

Concurrent Oral Sessions

10:59 AM - 11:16 AM (303.3) Assessing the Interaction of Race and Neighborhood Deprivation as Social Determinants of Health Measures on Quality of Life among MS Patients.

Deborah Miller, PhD, Mellen Center, Cleveland Clinic, Cleveland, Ohio, United States

11:16 AM - 11:33 AM (303.4) Mood not Fatigue affects Measures of Gait Quality and Walking Capacity

Helen Dawes, phd, University of Exeter, Exeter, United Kingdom

Oral Session 304: PROMS and PREMS in Pediatric Care II

Salon 22 Titisee

Session Chair: Nancy L. Young, BScPT MSc PhD, Canada

10:25 AM - 10:42 AM (304.1) The Voxe ePROM platform in pediatric clinical care: Findings from an implementation-effectiveness evaluation

Samantha Anthony, PhD, The Hospital for Sick Children Research Institute, Toronto, Ontario, Canada

10:42 AM - 10:59 AM (304.2) Patient and Family's Perspective of Measurement-Based Care in Child and Adolescent Mental Health Services

Bishnu Bajgain, University of Calgary, Calgary, Alberta, Canada

10:59 AM - 11:16 AM (304.3) Can routine collection of a paediatric patient reported outcome measure strengthen children's voice in clinical decision making? Co-design of the P-PROM ROCK trial

Renee Jones, MPH, Melbourne Health Economics, University of Melbourne, Melbourne, Australia

11:16 AM - 11:33 AM (304.4) A symptom monitoring and reporting program to improve health-related quality of life for children with cancer

Jin-Shei Lai, Northwestern University, Chicago, Illinois, United States

Oral Session 305: PROMS in Clinical Practice II

Salon 14 Köln

Session Chair: Monika Sztankay, PhD, Austria

10:25 AM - 10:42 AM (305.1) Making the 10-item PROMIS® Global Health Measure Clinically Useful: A "Screen-to-CAT" Approach

David Cella, PhD, Northwestern University, Chicago, Illinois, United States

10:42 AM - 10:59 AM (305.2) Patient preferences in visualization of PROMs: a qualitative study

Anouk Groenewegen, MSc, Department of Child and Adolescent Psychiatry and Psychosocial Care, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Amsterdam, Netherlands

10:59 AM - 11:16 AM (305.3) Comprehension and preferences for quality of life visualizations among patients who received a hematopoietic cell transplant, their caregivers, and healthcare team members: a randomized observational study

Rachel Cusatis, PhD, Medical College of Wisconsin, Milwaukee, Wisconsin, United States

11:16 AM - 11:33 AM (305.4) The use and implementation of patient-reported outcome and experience measures (PROMS/PREMs) in integrated care settings – a bridge between health and social care?

Nicola Anderson, RN MSc PhD, University of Birmingham, Birmingham, United Kingdom

(3002) Gender gap of Quality of Life (QOL) changes difference by Covid-19 panic for people from other country living in Japan

Rika Hayashida, University of Nagasaki, Siebold, Nishisonogi-gun, Nagasaki, Japan

(3004) Content comparison of computerised adaptive testing (CAT) and patient-reported outcome measures used to assess pain in patients with cancer

Carrie-Anne Ng, PhD, GradDipHlthSc, BHumSc, Centre for Health Economics Research and Evaluation, Faculty of Health, University of Technology Sydney, Sydney, Australia

(3006) Higher Resilience and Social Support Enhance Mental Health Among Metastatic Breast Cancer Survivors

Michelle Naughton, Ph.D., M.P.H., The Ohio State University Comprehensive Cancer Center, Columbus, Ohio, United States

(3008) Predictors of health-related quality of life among Colombian head and neck cancer patients

Martha J Rodriguez, MSc, Universidad Santo Tomás, Bucaramanga, Colombia

(3010) Cognitive appraisals, resilience, coping modes and quality of life among adolescent and young adult cancer survivors

Renjun Gu, School of Public Health, Zhejiang University, Hangzhou City, China

(3012) Quality of Life Assessment in Patients with Cardiogenic Shock eligible for Extracorporeal Membrane Oxygenation (ECMO): A Scoping Review

Margaret Carlson, MPH, University of Utah, Salt Lake City, Utah, United States

(3014) Onset of physical-mental multimorbidity in children with a physical illness

Melissa Elgie, MSc, University of Waterloo, Waterloo, Ontario, Canada

(3016) The Influence of Disability on Trajectories of Health-related Quality of Life in Youth with Chronic Physical Illness

Dominique Basque, MA, PhD Candidate, University of Waterloo, Waterloo, Ontario, Canada

(3018) Challenges in the establishment of minimal important changes (MIC) for outcomes by patients undergoing an arthroscopic rotator cuff repair in Switzerland

Thomas Stojanov, University Hospital Basel, Basel, Switzerland

(3020) Satisfied with the worst health outcomes or unsatisfied with the best? Explaining the divergence between good patient-reported outcomes and low satisfaction and vice versa among knee arthroplasty patients

Lukas Schöner, TU Berlin, Berlin, Germany

(3022) PROMs Assessing HRQOL In Patients With Immune-mediated Polyneuropathy (GBS And CIDP): A Systematic Review Of Measurement Properties

Farah Pelouto, MSc, Department of Neurology, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands, Rotterdam, Netherlands

(3024) Comparison of the EQ-5D-Y and the CHU-9D instruments in a general child population: Based on self-reports and proxy-reports

Yan Li, Pharmacoeconomics, School of International Pharmaceutical Business, China Pharmaceutical University, Nanjing, China

(3026) QuALity of Life In Goldenhar SyNdrome (ALIGN); Building a conceptual framework for a Patient Reported Outcome Measure (PROM) for Goldenhar syndrome in children and adults.

Patricia (Trish) Holch, PhD, Leeds Beckett University, Leeds, United Kingdom

(3028) Health-related quality of life after SARS-CoV-2 infection and reinfection: Findings from a multinational representative survey of the European working-age population

Christine Blome, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(3030) Assessing the psychometric performance of a new condition-specific preference-weighted measure, VILL-UI, and EQ-5D-5L in patients with age-related macular degeneration: A MACUSTAR Study Report

Donna Rowen, PhD, University of Sheffield, Sheffield, United Kingdom

(3032) PSYCHOMETRIC EVALUATION OF THE GLYCOGEN STORAGE DISEASE FUNCTIONAL ASSESSMENT DIARY (GSD FAD)

Adrian Jewett, Humanity, Long Beach, California, United States

(3034) The impact of a bleeding disorder on the daily life in Dutch women

Tessa van Gastel, MSc, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands., Amsterdam, Netherlands

(3036) Inclusion of Patient-Reported Outcome Endpoints in the Summary of Product Characteristics for Non-oncology Drugs Approved by the European Medicines Agency (2018-2022)

Courtney Levy, BSc, RTI Health Solutions, Manchester, United Kingdom

(3038) Fostering collaborative engagement when valuing health-related quality of life

Philip Powell, PhD, University of Sheffield, Sheffield, United Kingdom

(3040) Exploration of the patient experience through user analytics from a patient-reported outcome measure digital solution.

Cara Arizmendi, PhD, AstraZeneca, Durham, North Carolina, United States

(3042) Patient reported outcome (PRO) results in oncology trials: potential for collecting sufficient data

Anja Reinartz, Dr., Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen, Cologne, Germany

(3044) Use of qualitative methods to inform meaningful within-patient change in oncology

Minji Lee, PhD, Mayo Clinic, Rochester, Minnesota, United States

(3046) Introduction and validation of the Open Symptom Framework: a public domain modular framework for patient-reported measurement of symptoms related to cancer and its treatment

Chris Gibbons, PhD, MD Anderson Cancer Center, Houston, Texas, United States

(3048) The EORTC Reference Values Database: Scope, rational and design of a dynamic user interface to calculate reference values of EORTC quality of life questionnaire data

Daniela Krepper, University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(3050) Seeing is Believing: Exploring Interpretation Accuracy of PRO Data Visualisations by Patients, Healthcare Professionals, and other Stakeholders

Lisa Wintner, University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(3052) The gap between statistical and clinical significance: time to pay attention on clinical relevance in patient-reported outcomes measures of insomnia

Zong-Shi Qin, MD, PhD, Peking University Clinical Research Institute, Beijing, China

(3054) Innovative assessment of holistic health: integrating Traditional Chinese Medicine and multidimensional multistage adaptive testing

Zhengkun Hou, the First affiliated hospital of Guangzhou University of Chinese Medicine, Guangzhou, China

(3056) Do subpopulation variables moderate linking relationships? An investigation of physical function and substance use severity PROM crosswalks with mixed effects modelling

Benjamin Schalet, PhD, Amsterdam UMC, Amsterdam, Netherlands

(3058) The Dutch version of the PROMIS® Sexual Function and Satisfaction Measures for individuals with haemophilia and the potential role of artificial intelligence in the translation process

Lorynn Teela, PhD, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands, Amsterdam, Netherlands

(3060) Defining key terms for patient-reported outcome measures used for screening or case finding

Kathleen Yost, PhD, Mayo Clinic, Rochester, Minnesota, United States

(3062) PROM4RARE: patient reported outcomes used for individuals with genetic intellectual disability - a scoping review

Nadia van Silfhout, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands, Amsterdam, Netherlands

(3064) The measurement quality of PROMS used in Dermatology

Sandrine Herbelet, PhD, Ghent University, Ghent, Belgium

(3066) Using vignettes to generate and collect validity evidence based on the consequences of testing for the Health Literacy Questionnaire (HLQ) in Australian prisons

Scott Gill, BSc(Hons), Swinburne University of Technology, Melbourne, Australia

(3068) Psychometric comparison of patient reported summary scores for EQ-5D (EQ-PRSM)

M.F. Bas Janssen, PhD, Senior scientist, EuroQol Research Foundation, Rotterdam, Netherlands

(3070) Factorial validity of the of the DISABKIDS-37 Generic questionnaire for Brazil

Claudia Benedita Santos, PhD, Ribeirão Preto College of Nursing. University of São Paulo, Ribeirão Preto, Brazil

(3072) A scoping review of development and dynamics of use for local versions of the Medical Outcome Survey of HIV(MOS-HIV) tool in assessing health-related quality of life among HIV patients in sub-Saharan Africa

Mooketsi Molefi, MD, MSCE, University of Botswana, Gaborone, Botswana

Wednesday, 16 October

4:15 PM - 5:30 PM

Concurrent Oral Sessions

Oral Session 306: Cancer Treatment II

Saal Maritim I

Session Chair: Ashley Wilder Smith, PhD MPH, United States

4:20 PM - 4:37 PM (306.1) Benchmarking quality of care using Patient-Reported Outcome data of patients with colorectal cancer: Results of a nationwide cohort study

Lonneke van de Poll-Franse, PhD, Netherlands Cancer Institute, Amsterdam, Netherlands

4:37 PM - 4:54 PM (306.2) Feasibility and utility of a Fitbit activity tracker to measure physical activity among patients with (hematologic) cancer during the initial six months post-diagnosis.

Simone Oerlemans, PhD, Netherlands Comprehensive Cancer Organisation, Utrecht, Netherlands

4:54 PM - 5:11 PM (306.3) Global response score correlates with quality of life in cutaneous T-cell lymphoma

Niloufer Khan, MD, MSCE, City of Hope, Duarte, California, United States

Oral Session 307: Childhood Cancer Survivors

Salon 14 Köln

Session Chair: Jens Lehmann, PhD, Austria

4:20 PM - 4:37 PM (307.1) Predicting health-related quality-of-life (HRQOL) in adult survivors of childhood cancer: insights from symptom network analysis

I-Chan Huang, PhD, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, Memphis, Tennessee, United States

4:37 PM - 4:54 PM (307.2) Mapping the quality of life challenges after cancer as a young person: an umbrella review and future directions

Samantha Sodergren, PhD, University of Southampton, Southampton, United Kingdom

4:54 PM - 5:11 PM (307.3) Evaluating Clinically Significant Symptoms for Survivors of Childhood Cancer: A Global Healthcare Provider Survey

Jaesung Choi, Ph.D, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, Memphis, Tennessee, United States

5:11 PM - 5:28 PM (307.4) Comparison of symptoms between adult survivors of childhood cancer and the U.S. general population using the modified Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Madeline Horan, PhD, Wake Forest University School of Medicine, Winston-Salem, North Carolina, United States

Wednesday, 16 October

4:15 PM - 5:30 PM

Concurrent Oral Sessions

Oral Session 308: HIV/AIDS

Salon 16 Königswinter

Session Chair: Martin Duracinsky, MD PhD, France

4:20 PM - 4:37 PM (308.1) Gender differences in patient-reported outcomes among people living with HIV switching to an oral dual therapy: PROBI study

Tristan Alain, Health Economics Clinical Trial Center (URC-ECO), AP-HP, Hôpital Hôtel-Dieu, 75004, Paris, France, Paris, France

4:37 PM - 4:54 PM (308.2) Health-related quality of life among older people living with HIV/AIDS: a qualitative study applied response shift revised model

Renjun Gu, School of Public Health, Zhejiang University, Hangzhou City, China

4:54 PM - 5:11 PM (308.3) Mediators of HIV-related stigma and patient-reported outcomes measures among people with HIV

Irina Kolobova, ViiV Healthcare, Durham, North Carolina, United States

5:11 PM - 5:28 PM (308.4) The development of a web-based flexible and secure electronic PRO solution for HIV care and prevention, designed for broad clinic adoption.

Duncan Short, PhD, ViiV Healthcare, London, United Kingdom

Oral Session 309: Measurement Considerations II

Salon 17 Darmstadt

Session Chair: Kathrin Fischer, MSc PhD, Germany

4:20 PM - 4:37 PM (309.1) Self- management in sleep apnea patients: are they up for the job?

Regine Grytnes, PhD, AmbuFlex - Centre for Patient Reported Outcomes, Gødstup Hospital, Herning, Denmark

4:37 PM - 4:54 PM (309.2) Patient-relevance of visual function decline in intermediate age-related macular degeneration – a MACUSTAR study report

Jan Henrik Terheyden, MD, University Hospital Bonn, Department of Ophthalmology, Bonn, Germany

4:54 PM - 5:11 PM (309.3) Uncovering the story within the story: A scoping review of response shift in qualitative research

Richard L. Skolasky, Sc.D., Johns Hopkins University School of Medicine, Baltimore, Maryland, United States

Oral Session 310: QOL in Older Populations

Salon 21 Mannheim

Session Chair: Elizabeth J. Unni, PhD, United States

4:20 PM - 4:37 PM (310.1) Interdependencies between Care Experience and Quality of Life Outcomes in Aged Care: An Empirical Investigation.

Jia Song, Flinders University, Adelaide, Australia

4:37 PM - 4:54 PM (310.2) Exploring Dominant Quality of Life Dimensions of Older People Living in Continuing Care Facilities at Different Levels of Health Resources

Carla Carnaghan, PhD, University of Lethbridge, Lethbridge, Alberta, Canada

4:54 PM - 5:11 PM (310.3) Active Living Related Quality of Life in Older Persons and the Built Environment

Ezinne Ekediegwu, B.M.R (Hons.), M.Sc(Hons.), Nnamdi Azikiwe University, Nigeria. McGill University, Canada, Montreal, Quebec, Canada

5:11 PM - 5:28 PM (310.4) Capacities Leading to Active Living: Does Sex and Age Matter?

Natasha Hassija, Ph.D. Candidate in Rehabilitation Sciences, School of Physical and Occupational Therapy, McGill University, Canada, Montreal, Quebec, Canada

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Presenting authors indicated. The full author listing is available on the conference mobile app under the specific session. Last updated on 18 September 2024. For the most updated version of the final program, reference the mobile app.

Wednesday, 16 October

4:15 PM - 5:30 PM

Concurrent Oral Sessions

Oral Session 311: Use of AI in PRO Research

Salon 22 Titisee

Session Chair: Emily Parks-Vernizzi, MBA, United States

4:20 PM - 4:37 PM (311.1) Artificial Intelligence in GPT-4 Can Interpret Cancer Patients' Prognosis Awareness without Training: A Zero-Shot Learning Task

Yuelin Li, PhD, Department of Psychiatry & Behavioral Sciences; Department of Epidemiology and Biostatistics, Memorial Sloan Kettering Cancer Center, New York, New York, United States

4:37 PM - 4:54 PM (311.2) Do artificial intelligence tools have a future in qualitative analysis within patient-focused healthcare research?

Verity Smith, PhD, Adelphi Values, Patient Centred Outcomes, Bollington, United Kingdom

4:54 PM - 5:11 PM (311.3) Combining Natural Language Processing with Patient-Reported Outcome Measures scores to gain insight into the impact of pandemic regulations on the mental health of children

Michiel Luijten, PhD, Amsterdam UMC, Amsterdam, Netherlands