



ISOQOL 33rd Annual Conference

Final Program Oral/Brief/Poster Presentations

18-21 October 2026
Prague Czech Republic

Monday, 19 October

10:05 AM - 10:45 AM

Monday Poster Session 101

Zenit

(1001) Health care providers' experiences with patient-reported outcomes in clinical practice: A thematic analysis of open-ended survey responses across two Danish health regions

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

NEW INVESTIGATOR POSTER AWARD FINALIST

(1003) The WOUND-Q: Development and U.S. FDA Qualification as a Medical Device Development Tool

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

OUTSTANDING POSTER AWARD FINALIST

(1005) A Conceptual Model of Psychosis Associated with Alzheimer's Disease

Sarah Donelson, Bristol Myers Squibb, Princeton, New Jersey, United States

OUTSTANDING POSTER AWARD FINALIST

(1008) Implementing patient-reported outcome measures and shared decision-making in pediatric physical therapy using the KLIK Physiotherapy portal: A process evaluation

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

STUDENT POSTER AWARD FINALIST

(1011) Bridging the Gap Between Promise and Practice: Barriers and Opportunities for Patient-Reported Outcome Measures in the Australian Cystic Fibrosis Data Registry

Rasa Ruseckaite, Monash University, Melbourne, Australia

OUTSTANDING POSTER AWARD FINALIST

(1013) From Identification to Consensus: Developing a Generic Core Patient-Reported Outcome Set for Neuro-RDs Using a Delphi Study

Tom Steenberg, MSc., Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, Netherlands

(1015) Comparing free-text and structured item collection for comprehensive symptom assessment in cancer patients

Amylou Dueck, PhD, Mayo Clinic, Scottsdale, Arizona, United States

(1017) Development of a Patient Reported Outcome Measure for Care Following Childbirth Related Perineal Trauma: early findings from item generation phase

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

(1019) Development of the Pediatric Eating and Feeding Behaviors Measure: Building an integrated, longitudinally adaptable framework for early childhood feeding assessment

Constance Mara, PhD, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, United States

(1021) Spurious baseline dependency of the minimal important change is due to skewness and ceiling effects

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

(1023) Understanding individualized thresholds of treatment success in common hand and wrist conditions: a cohort study

Eva Lindner, Department of Plastic, Reconstructive and Hand Surgery, Erasmus MC, Rotterdam, Netherlands

ISOQOL 33rd Annual Conference | Final Program Oral/Brief/Poster Presentations

Presenting authors indicated. The full author listing is available on the conference mobile app under the specific session. Last updated on 8 October 2026. For the most updated version of the final program, reference the mobile app.

(1025) Health-Related Quality of Life in Kidney Failure: How do potential transplant candidates and recipients compare to the Canadian general population?

Giuliano Panizza, HBSc, Ajmera Transplant Centre, University Health Network, Toronto, Ontario, Canada

(1027) Bridging Clinical Adoption, Patient Engagement, and Local Adaptation in Early Multi-Site Implementation of a Digital PRO Platform in Breast Cancer Care

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

(1031) Validation of the MACrO2 Patient-Reported Outcome (PRO) Measure in Treatment-Refractory MAC Lung Disease (TR-MAC-LD)

Donald Bushnell, MA, Thermo Fisher Scientific, Waltham, Massachusetts, United States

(1033) Departing from PRO compliance standards: A framework for high-frequency patient monitoring data

Alexandra Kalpadaki-Smith, Evinova, Barcelona, Spain

(1035) Psychometric evaluation of a novel patient-reported Dengue Virus Daily Diary (DENV-DD) measuring illness intensity

Verity Smith, PhD, Adelphi Values Ltd., Patient Centered Outcomes, Bollington, United Kingdom

(1037) Robustness of the ROSALI algorithm to violations of the unidimensionality assumption: a simulation study

Angèle Boisbras, Master's Student, UMR Inserm 1246 SPHERE, Nantes, France

(1039) Performance of a residual-based algorithm aiming at identifying response shift at the item level using Rasch models – A simulation study

Yseulys Dubuy, Nantes University - UMR 1246 SPHERE, Nantes, France

(1041) A method to establish threshold on group level for meaningful treatment effect

Jakob Bjorner, MD PhD, IQVIA, Copenhagen, Denmark

(1043) Personality and Occupational Status as Determinants of Mental Health in Hong Kong Adults: A Cross-Sectional Study

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

(1049) Better communities, better quality of life? Examining the link between age-friendly communities and older persons' quality of life

Ava Mehdi pour, PhD, Trinity Western University, Langley, British Columbia, Canada

(1053) Intensive Blood Pressure Control after Endovascular Thrombectomy Worsens Health-Related Quality of Life: Insights from the ENCHANTED2/MT Trial

Renjun Gu, Assistant researcher, Neurovascular Center, Changhai Hospital, Naval Medical University; Department of Social Medicine of School of Public Health, and Department of Pharmacy of the First Affiliated Hospital, Zhejiang University School of Medicine, Shanghai/Hangzhou City, China

(1055) Exploring Perceptions of Body Image in Adolescents with Lower Limb Differences

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

(1057) Improving quality of life after orthopaedic trauma through social drivers of health screening and Community Health Worker integration: A pilot study

Caryn Lindsey, DSW, MSW, Cedars-Sinai Department of Orthopaedic Surgery, Los Angeles, California, United States

(1059) Validity of patient-reported vision as a proxy for measured visual acuity: evidence from population-based cohort studies

Ellen Elsman, Ophthalmology, Amsterdam UMC location Vrije Universiteit Amsterdam, Amsterdam, Netherlands

(1061) Qualitative Assessment of Health-Related Quality of Life Impacts Associated with Transfusion-Dependent β -Thalassemia (TDT) in Children and Adolescents in the United States and United Kingdom: The VISIBLE Study

Jennifer Drahos, PhD MPH, Vertex Pharmaceuticals Incorporated, Boston, Massachusetts, United States

(1063) Witnessing Code Blues: A Qualitative Study of Bystander Patients' Lived Experiences and Emotional Well-Being

Jingrong Yu, MBBS, National University of Singapore, Yong Loo Lin School of Medicine, Singapore, Singapore

(1065) Evaluating the feasibility of discrete choice experiments to value EQ-TIPS-5L health states in children aged 0-4 years: a qualitative study

Ling Jie Cheng, PhD, MPH, BSN (Hons), RN, National Perinatal Epidemiology Unit, Nuffield Department of Women's and Reproductive Health, University of Oxford, Oxford, United Kingdom

(1069) Anchor-based minimal important change thresholds for health-related quality of life measures in patients with chronic non-cancer pain - a systematic review and meta-analysis of generic measurement instrument studies

Daniel Broholm, PhD fellow, MSc in physiotherapy, Department of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Campusvej 55, Odense, Denmark

(1071) Operational and Design Drivers of ePRO Data Completeness Across Therapeutic Areas

Lindsay Hughes, PhD, IQVIA, New York, New York, United States

(1073) Kidney Disease as an Influencing Factor of Quality of Life in Women with Cervical Cancer

Julissa Luvian-Morales, MICAELA Program, Instituto Nacional de Cancerología (INCan), Mexico

(1075) Content and construct validity of smartphone-based, patient-centered study endpoints for trials in chronic retinal conditions and glaucoma

Jan H. Terheyden, MD, University Hospital Bonn, Department of Ophthalmology, Bonn, Germany

(1077) Using Generative AI Models for Analyzing Anxiety, Fear, and Misinformation in Discourse Data from Cancer Patients who experienced anti-helminth drugs including fenbendazole

Minsu Kim, Hallym University of Korea, Chuncheon, South Korea

(1079) Productivity Impairment and Health-Related Quality of Life (HRQoL) in Inflammatory Bowel Disease: Evidence from a Canadian Cohort

Ana Fuhrmann, PhD, University of Calgary, Calgary, Alberta, Canada

(1081) Are our measures abelist?

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

(1083) Planned Qualitative Exploration of the Lived Experience of Hemodiafiltration in US Adult Patients

Le Hong Ngoc Pham, MS, Fresenius Medical Care, Bad Homburg, Germany

(1085) Different Dimensions of Apathy and Motivation in People with Parkinson's Disease (PD).

Louis-François Chénier-André, R.N., BSc Nursing, MSc Digital Health Innovation (student), McGill University, Montreal, Quebec, Canada

Monday, 19 October

10:05 AM - 10:45 AM

Monday Poster Session 101

Zenit

(1087) Convergence, Divergence, and Incremental Validity of Patient-Reported Outcomes and Performance-Based Measures of Physical Function in Sarcopenia

Jin-Shei Lai, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

(1089) Challenges with Conducting Interviews in people living with Amyotrophic Lateral Sclerosis: Practical Considerations and Proposed Solutions

Anne Skalicky, MPH, Thermo Fisher Scientific, Seattle, Washington, United States

(1091) The impact of different definitions and approaches for time-to-deterioration of patient-reported outcomes in advanced oncology trials

Jessica Roydhouse, PhD, Menzies Institute for Medical Research, University of Tasmania, Hobart, Australia

Monday, 19 October

1:45 PM - 3:15 PM

Concurrent Oral Sessions

Oral Session 101: Supportive Interventions for Cancer

Virgo & Leo

Session Chair: Christina Ramsenthaler, PhD, Switzerland

1:50 PM - 2:07 PM (101.1) The (dis-)agreement between Patient Reported Outcomes (PROs) and Proxy-/Observer-Reported Outcomes for the Assessment of Health-Related Quality of Life in Pediatric Oncology

Chiara Vetrano, M.Sc., Medical University Innsbruck, Department of Psychiatry, Psychotherapy, Psychosomatics, and Medical Psychology, Innsbruck, Austria

2:07 PM - 2:24 PM (101.2) Pilot study of a virtual reality intervention targeting distress and anxiety symptoms in patients with primary brain tumors: Final analysis of a phase 2 clinical trial

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

2:24 PM - 2:41 PM (101.3) “Everyone keeps telling me it’s ok and that it doesn’t matter.... but it does to me.” The conversations we are not having in cancer care.

Claudia Rutherford, University of Sydney, Sydney, Australia

2:41 PM - 2:58 PM (101.4) Are we reaching the right patients? Factors influencing referral to supportive care in a comprehensive cancer center

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

2:58 PM - 3:15 PM (101.5) Online symptom reporting post curative breast cancer treatment improves quality of life - results of CANVAS project (CANCer SurVeillance And Support) funded by Yorkshire Cancer Research

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

Oral Session 102: Patient Experience of Care

Taurus & Aquarius

Session Chair: Sara Ahmed, PhD, Canada

1:50 PM - 2:07 PM (102.1) Evaluation of the experience in hospitals’ ambulatory care: ‘Continued Care Patient Reported Experience Measure’ (CC-PREM) questionnaire

Clara Amat-Fernandez, MS, MPH, Hospital del Mar Research Institute, Barcelona, Spain
[STUDENT ORAL PRESENTATION AWARD FINALIST](#)

2:07 PM - 2:24 PM (102.2) Development of the MatNeoPREM conceptual framework describing patient experience of maternity and neonatal care in England

Sarah Smith, PhD, London School of Hygiene & Tropical Medicine (LSHTM), London, United Kingdom

2:24 PM - 2:41 PM (102.3) Uncovering hidden differences in home care experiences to guide equitable quality improvement

Ava Mehdipour, Trinity Western University, Langley, British Columbia, Canada

2:41 PM - 2:58 PM (102.4) Parent-reported differences in pediatric inpatient experiences

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

2:58 PM - 3:15 PM (102.5) The relationship between hospital harm and person-centred quality indicators (PC-QIs) in the inpatient setting

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

Monday, 19 October

1:45 PM - 3:15 PM

Concurrent Oral Sessions

Oral Session 103: PROs in Routine Care

Meridian

Session Chair: Jessica Roydhouse, PhD, Australia

1:50 PM - 2:07 PM (103.1) Patient-Reported Outcome Measures Assessment through Telephone Data Collection - Reflections and Opportunities from Low and Middle-Income Country, Pakistan

Laila Akbar Ladak, PhD, MScN, BScN, RN, The Aga Khan University, Karachi, Pakistan

2:07 PM - 2:24 PM (103.2) From core outcome set to clinical practice: implementing electronic PROMs in spinal cord injury rehabilitation

Sara Ahmed, McGill University, Montreal, Quebec, Canada

2:24 PM - 2:41 PM (103.3) Implementation of CMS-Mandated Patient-Reported Outcome Performance Measures for Arthroplasty Across a Large Health System: Lesson Learned

Nicholas Berlin, MD, MPH, MS, Brigham and Women's Hospital, Boston, Massachusetts, United States

2:41 PM - 2:58 PM (103.4) Integrating high-frequency PROMs into electronic health records: Clinical implementation, initial results and perspectives across different medical domains

Martin Dugas, Prof. Dr., Heidelberg University Hospital, Heidelberg, Germany

2:58 PM - 3:15 PM (103.5) From clinical trial to clinical practice: A multi-case study approach to understanding institutional experiences of adopting ePROMs

Kate Absolom, PhD, Associate Professor of Applied Health Research, Leeds Institute of Medical Research/Leeds Institute of Health Services Research, University of Leeds, Leeds, United Kingdom

Oral Session 104: Addressing Inequality

Kepler

Session Chair: David Mott, PhD, United Kingdom

1:50 PM - 2:07 PM (104.1) Social inequalities in Oncological Patient Experience in Europe: the EUonQoL project

Amanda Miranda-Martins, Predoctoral Student, Hospital del Mar Research Institute, Barcelona, Spain

2:07 PM - 2:24 PM (104.2) Socioeconomic inequalities in health-related quality of life in patients with myelodysplastic syndromes

Francesco Sparano, MSc, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

2:24 PM - 2:41 PM (104.3) Financial Hardship and Financial Management in Dementia Caregiving: A Qualitative Thematic Content Analysis

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

2:41 PM - 2:58 PM (104.4) Network for Equity in psychosocial oncology addressing Underserved populationS: an inters-x-tional approach (NEXUS) - the co-creation of a sustainable national community and platform for inclusive, equity-driven research

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

2:58 PM - 3:15 PM (104.5) Who Decides What to Measure? Establishing a Canadian Council for Equitable Person-Centred Health Measurement

Sandra Munro, PaCER, The University of Calgary, Calgary, Alberta, Canada

(1002) Evaluation of the Added Predictive Value of Patient-Reported Symptoms for Chemotherapy Toxicity–Related Unplanned Admission in Routine Gastrointestinal Cancer Care

Jason Liu, The University of Texas MD Anderson Cancer Center, Houston, Texas, United States

NEW INVESTIGATOR POSTER AWARD FINALIST

(1004) Assembling a generic parent-reported outcome measure set for parents of children with chronic conditions

Esmée van Zon, MA MSc, Vrije Universiteit Amsterdam, Amsterdam, Netherlands

OUTSTANDING POSTER AWARD FINALIST

(1014) Validating the Afrikaans for the Western Cape DASH Questionnaire for Use in South Africa's Public Healthcare Sector

Susan de Klerk, B OT, DHT, M OT, PhD OT, Stellenbosch University, Cape Town, South Africa

(1016) How important are the back-translation review and cognitive debriefing interview steps in linguistic validation of PROMs: A CLEFT-Q example

Trisia Bretkopf, MSc, Department of Pediatrics, McMaster University, Hamilton, Ontario, Canada

(1018) Translation and harmonization of the NS-SIM-PRO: ensuring cross-cultural equivalence in measuring swelling impact in nephrotic syndrome

Lillian Savic, MBA, FACITtrans, Ponte Vedra, Florida, United States

(1020) Tired of being tired? Translating fatigue descriptors in the PROMIS® Fatigue Item Bank for use in India

Emily Parks-Vernizzi, MBA, FACITtrans, Ponte Vedra, Florida, United States

(1022) Relating patient-perceived concept relevance and meaningful change to a multidimensional clinician-reported outcome (ClinRO) measure in cutaneous lupus erythematosus (CLE)

Mona L. Martin, RN, MPS, PPD Evidera Patient-Centered Research, Thermo Fisher Scientific, Waltham, Massachusetts, United States

(1024) Comparison of overall side effect impact summary measures in a cross-sectional survey

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

(1026) A scoping review of outcome and outcome measure sets for individuals with spinal cord injury, stroke and traumatic brain injury

Snigdha Widge, MSc in Rehabilitation Science, University of Alberta, Edmonton, Alberta, Canada

(1028) Methodological considerations for developing a photograph guide to support clinician assessment for use in dermatological clinical trials

Dale Chandler, Adelphi Values Ltd, Bollington, United Kingdom

(1030) Assessing the Measurement Structure of the Dermatology Life Quality Index (DLQI) using nonparametric item response theory, Mokken Scale Analysis

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

(1034) Development of a Conceptual Model and Proposed Decision Support Tool to Support EHR-Integrated Shared Decision-Making in Relapsed/Refractory Multiple Myeloma (RRMM)

Kimberly A. Webster, MA, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

(1036) Cross-Cultural Translatability and Conceptual Equivalence of Shame-Related Terms in PROs

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

(1038) How do qualitative studies conceptualise acceptability of surgical interventions? A qualitative evidence synthesis

Sophie James, BSc, MSc, University of York, York, United Kingdom

(1040) Development of a new measure of care worker quality of life: the ASCK-WELL scale

Fiona Lerigo, PhD, London School of Hygiene and Tropical Medicine, London, United Kingdom

(1042) Prepare-NS Developed a Core Set of Clinical Outcome Assessments for Use across the Lifespan in Nephrotic Syndrome Clinical Trials

Devin Peipert, University of Birmingham, Birmingham, United Kingdom

(1044) Biopsychosocial burden and care needs in older long-term cancer survivors: Description of the study design and response patterns in a stratified cancer registry-based mixed-methods study with population-based comparison cohorts (SurvAge)

Annika Waldmann, Prof. Dr., Institute for Social Medicine and Epidemiology, University of Lübeck, Lübeck, Germany

(1046) Comparison of Patient Reported Outcome Domains for Predicting Survival and Disease Progression in Cancer

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

(1048) Exploring the relationships between patient-reported and performance-based cognitive outcomes after CAR-T therapy

Carlos Litovich, MPH, DrPH, Medical College of Wisconsin, Milwaukee, Wisconsin, United States

(1052) Development of the interviewer competency and compliance evaluation tool (ICCET) for quality assurance in semi-structured health research interviews

Dorsa Khazaei, MSc, Kielo Research, London, United Kingdom

(1054) Digital Engagement after a Bipolar Disorder Diagnosis: A Qualitative Study of Digital Health Experiences and Expectations among Newly Diagnosed Outpatients

Simon Sørderbo Nielsen, MSc in Social Anthropology, AmbuFlex, Gødstrup Hospital, Central Denmark Region, Herning, Denmark

(1056) “You Feel Like You Have to Make the Effort, Even if You Don’t Understand Everything”: Spanish-Speaking Patient Experiences of Language Barriers Across the Surgical Care Continuum

Gezzer Ortega, MD, MPH, Center for Surgery and Public Health, Mass General Brigham, Harvard Medical School, Boston, Massachusetts, United States

(1058) A systematic review to identify and appraise outcome measures used in lichen sclerosis research

Natalie VJ Aldhouse, MSc, Centre of Evidence Based Dermatology, University of Nottingham, Nottingham, United Kingdom

(1060) Age- and Treatment-Specific Patient-Reported Outcomes in Moyamoya Disease: A Systematic Review

Eun-sun Jang, Master's Student, Hallym University, Chuncheon, South Korea

(1062) How is health-related quality of life impacted following lumbar spinal fusion surgery?: an analysis of the patient rehabilitation experience

Nicole Peters, MPT, Western University, London, Ontario, Canada

(1064) RUTISS-Diary and RUTISS-65: Development of two new patient-reported outcome measures for recurrent urinary tract infection

David Churchman, PhD, Inspired Health Outcomes, Witney, United Kingdom

(1066) Development of a Novel Patient-Reported Outcome (PRO) Measure for Congenital Adrenal Hyperplasia (CAH): the CAH Symptom and Impact Survey (CAHSIS)

Cory Saucier, MPH, IQVIA, Providence, Rhode Island, United States

(1072) Psychometric Properties of the Traditional Chinese Life Functioning Questionnaire (LFQ) in Adolescent and Young Adult (AYA) Survivors of Cancer

Yin Ting Cheung, PhD, The Chinese University of Hong Kong, Hong Kong, Hong Kong

(1076) Co-Designing a Measurement-Based Care System within a School-Based Mental Health Classroom

Erin McCabe, PhD, MScPT, BSc, University of Alberta, Edmonton, Alberta, Canada

(1080) Developing a Patient-Reported Outcome Measure for Caesarean Scar Disorder (CSDi): A Qualitative Interview Study

Georgina Forshall, BA, MA, MRes, Leeds Beckett University, Leeds, United Kingdom

(1084) Validation of the Steroid Symptom Questionnaire – Multiple Myeloma (SSQ-MM) in patients with immune thrombocytopenia and autoimmune hemolytic anemia: a multinational psychometric validation study

Helena Ditzel, MD, PhD, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark

(1086) Methodological Issues, Strategies, and Considerations in Interviewing Children and Adolescents: An Obesity Case Study

Amy Clark, PhD, Evidera, PPD, Thermo Fisher Scientific, London, United Kingdom

(1088) ePRO-Derived Pain Phenotypes Map Peripheral-to-Central Sensitization in Diffuse Adenomyosis

Shizhu Li, Chongqing Medical University, Chongqing, China

(1090) Empower patients through knowledge: Co-developing a Tip Sheet focused on explaining patient-reported outcome measures (PROMs) to patients

Veronika Kiryanova, APERSU Patient Engagement Network, Calgary, Alberta, Canada

(1092) Changes in health-related quality of life in parents of adolescents: a four year longitudinal study from Norway

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

Monday, 19 October

4:05 PM - 5:35 PM

Concurrent Oral Sessions

Oral Session 106: Literacy and Language

Virgo & Leo

Session Chair: Sonya Eremenco, MA, United States

4:10 PM - 4:27 PM (106.1) Towards inclusive PROMs: Adapting Dutch PROMIS item banks to improve comprehensibility for adults with low literacy skills

Lisa Stikvoort, MSc, Amsterdam UMC, Amsterdam, Netherlands

STUDENT ORAL PRESENTATION AWARD FINALIST

4:27 PM - 4:44 PM (106.2) Towards inclusive PROMs: Designing accessible PROM lay-outs for people with severe (speech)motor impairments who use AAC methods and people with low literacy

Juliet Hondtong, MA, Amsterdam UMC, Amsterdam, Netherlands

4:44 PM - 5:01 PM (106.3) Towards inclusive PROMs: Identifying accessibility barriers and facilitators in the digital PROM patient journey for adults with low literacy skills

Lisa Stikvoort, MSc, Amsterdam UMC, Amsterdam, Netherlands

5:01 PM - 5:18 PM (106.4) Associations of health literacy with EQ-5D-5L and EQ-HWB-9 outcomes in a general population sample

Stevanus Pangestu, Ph.D., EuroQol Research Foundation, Rotterdam, Netherlands

5:18 PM - 5:35 PM (106.5) Readability of Lower Extremity Lymphedema Patient-Reported Outcome Measures: Identifying Item-writing Conventions That Drive Reading Difficulty

Serenity Bennett, BS, BA, Harvard Medical School, Cambridge, Massachusetts, United States

Oral Session 107: Engagement of Young People

Taurus & Aquarius

Session Chair: Abigail Rader, MS, United States

4:10 PM - 4:27 PM (107.1) Illness perceptions and beliefs about medicines as longitudinal predictors of adherence and outcomes in paediatric asthma

Sebastian Perry-Pasten, MSc, Health Services Research Group, Hospital del Mar Research Institute, Barcelona, Spain

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

4:27 PM - 4:44 PM (107.2) Psychometric properties of MyCommunication-Children: a new measure for communicative participation.

Eline Alons, PhD, Amsterdam UMC, Amsterdam, the Netherlands

4:44 PM - 5:01 PM (107.3) Adapting an online PROM portal for paediatric physiotherapy: a co-design process

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

5:01 PM - 5:18 PM (107.4) Selecting Patient-Reported Outcome Measures to Support Shared Decision Making in Psychomotor Therapy in Youth Mental Health Care in the Netherlands

Albertine de Haan, MA, Windesheim University of Applied Sciences, Zwolle, Netherlands

5:18 PM - 5:35 PM (107.5) Go Check- Increasing awareness of gynaecological cancer and early detection in students: pilot study of a university-based educational and behaviour change intervention.

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

Monday, 19 October

4:05 PM - 5:35 PM

Concurrent Oral Sessions

Oral Session 108: Caregiver Burden

Tycho

Session Chair: Richard Sawatzky, PhD RN, Canada

4:10 PM - 4:27 PM (108.1) A program to empower informal caregivers

Pedro Ferreira, PhD, CEISUC/CIBB, Coimbra, Portugal

4:27 PM - 4:44 PM (108.2) Exploring Stress, Resilience, and Health-related Quality of Life among Parents of Children with Congenital Heart Disease Following Surgery: A Descriptive Qualitative Study

Dr Laila Ladak, Senior Author/ Supervisor, Aga Khan University, School of Nursing and Midwifery, Karachi, Pakistan

4:44 PM - 5:01 PM (108.3) Care recipient self-perceived burden: experience, healthcare decision-making, and clinical implications from a multi-stakeholder qualitative study

Maja Kuharic, Northwestern University, Chicago, Illinois, United States

5:01 PM - 5:18 PM (108.4) Designing qualitative interview studies for populations living with dementia and their caregivers

Natasha Ramachandran, BSc, MSc, PPD Evidera Thermo Fisher Scientific, London, United Kingdom

5:18 PM - 5:35 PM (108.5) Development and Psychometric Validation of the TF-Col: A Patient- and Caregiver-Reported Measure of Financial Toxicity in Oncology

Julio César Sánchez-Arévalo, Psychologist; M.Sc. in Clinical Epidemiology, National University of Colombia, Bogotá, Colombia

Oral Session 109: Analytical Methods

Kepler

Session Chair: Carrie Houts, PhD, United States

4:10 PM - 4:27 PM (109.1) Evaluating the Ordinal Sensitivity of Ecological Indices: Reflective versus Formative Weighting

Zonggui Li, Ph.D., University of Maryland Baltimore School of Pharmacy, Baltimore, Maryland, United States

4:27 PM - 4:44 PM (109.2) LonGRMTTree: A tree-based longitudinal item response theory model for testing response shift in patient-reported outcome measures

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

4:44 PM - 5:01 PM (109.3) Performance of repeated-measures versus multilevel correlations in longitudinal psychometric data: A simulation study

Marie-Jeanne Holveck, PhD Maths and Life Science, SeeingTheta, Saumur, France

5:01 PM - 5:18 PM (109.4) The Recurrent Event Joint Survival Model: Correcting Fundamental Flaws in the Existing PRO-Based TTD Framework for Oncology

Daniel Serrano, PhD, The Psychometrics Team, Ltd., London, United Kingdom

5:18 PM - 5:35 PM (109.5) Ecological Momentary Assessments Show No Relationship between Physical Activity and Fatigue in People with Post-COVID Syndrome

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

(1006) The General Impact of Caregiving for Patients Diagnosed with Cancer in the Arab World: A Scoping Review

Ohoud Aljaloud, PhD Candidate, School of Nursing and Midwifery, Queen's University Belfast, Belfast, United Kingdom

OUTSTANDING POSTER AWARD FINALIST

(1009) Bayesian Estimation of Meaningful Change Thresholds for Patient-Reported Outcomes in Small Samples: A Simulation Study Using Published Data from CNS Disorders

Mariam Bayram, PhD, SeeingTheta, Saumur, France

NEW INVESTIGATOR POSTER AWARD FINALIST

(1010) Artificial Intelligence Agents for Patient-Reported Outcome Management in Clinical Settings: A Systematic Review

Jinah Sim, Ph.D, The Catholic University of Korea, Seoul, South Korea

OUTSTANDING POSTER AWARD FINALIST

(1012) Investigating systematic discrepancies in patient-reported and performance-based physical functioning through a common metric: a focus on the Post-COVID syndrome

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

STUDENT POSTER AWARD FINALIST

(2013) Optimizing HRQL Assessment in Cancer-Associated Cachexia: Comparative Performance and Survival Relevance of QLQ-C30/QLQ-CAX24 and FAACT in Cervical Cancer

Julissa Luvián-Morales, PhD, Modelo Integral para la Atención del Cáncer Cervicouterino Localmente Avanzado y Avanzado (MICAELA), Instituto Nacional de Cancerología (INCan), Mexico City, Mexico

(2015) Developing and evaluating a diabetes self-management intervention for people with severe mental illness: Management of multimorbidity and impacts on quality of life.

Jan Boehnke, PhD, School of Health Sciences, University of Dundee, Dundee, United Kingdom

(2017) Associations Between Health-Related Quality of Life and Presenteeism in a Canadian Working Population

Sol Yates, BA / MSc Economics, University of Manchester, Manchester, United Kingdom

(2019) Cardiovascular health as a precursor to collective well-being: a cross-lagged, county-level analysis

Jiangyuan Zhu, MD, MPH, NYU Langone Health, Guangzhou, China

(2021) Semantic network analysis of the Seattle Angina Questionnaire using large language model embeddings

Henry Michael, BPharm, MSc, PhD, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

(2023) Capturing the full patient experience with gene therapies: a disease-agnostic conceptual model to inform PRO measure development

Elizabeth Hribal, Humanity, Boston, Massachusetts, United States

(2025) Stigmatisation of patients with ME/CFS and post-COVID in healthcare: Qualitative findings from the StiMECO study

Marielle Donié, Universitätsklinikum Hamburg-Eppendorf Institut für Versorgungsforschung in der Dermatologie und bei Pflegeberufen, Hamburg, Germany

(2027) Efficient Application of the Oxford Hip Score for Patient-Centred Decision Support in Primary Care: Towards a Simplified PROM-Based Decision Aid

Burraq Imran, bmbs, University of Exeter Medical School, Exeter, United Kingdom

(2029) Standardizing Goal Attainment Scale Appraisal for Personalized Outcome Assessment: A Preliminary Study Comparing Artificial Intelligence and Expert Ratings

Chere Chapman, MHSc, MBA, Ardea Outcomes, Halifax, Nova Scotia, Canada

(2031) Development of an EORTC Health-Related Quality of Life Questionnaire for Renal Cell Cancer Patients: Phases 1-2

Lisa Wintner, PhD, University Clinic of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(2033) Time-dynamic versus time-static prediction models for impaired health-related quality of life in breast cancer: A methodological comparison using international harmonized data from the EORTC BALANCE database

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

(2035) Beyond Efficiency: Examining the Benefits and Risks of Artificial Intelligence Adoption in Patient-Centered Outcomes Research

Jessica Smith, MA, OPEN Health Group, New York, New York, United States

(2037) Challenges and opportunities in the communication of PRO tolerability data in early phase studies

Emma Martin, Adelphi Values PCO, Bollington, United Kingdom

(2039) Development and Psychometric Evaluation of the Nurses' Workplace Support Scale

Oluwagbohunmi Awosoga, University of Lethbridge, Lethbridge, Alberta, Canada

(2041) Validation of new self-reported measures to capture tobacco and nicotine product use behavior from users and their relatives in Japan

Emilie Clerc, MA, Philip Morris Products S.A., Neuchâtel, Switzerland

(2043) Using patient-reported data to improve outcome analysis in the Australia & New Zealand Bariatric Surgery Registry

Alyssa Budin, PhD, Monash University, Melbourne, Australia

(2049) Beyond Noticeable Change: Caregivers' Judgments of Meaningful Communication Improvement in Angelman Syndrome

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

(2051) Building the Validity Argument Before Measurement: A Five-Level Framework Integrating ECD, Kane's Interpretive Argument, and COSMIN Standards

Julio César Sánchez-Arévalo, Psychologist; M.Sc. in Clinical Epidemiology, National University of Colombia, Bogotá, Colombia

(2053) The Patient Benefit Index for Topical Treatment – longitudinal validation study in patients with psoriasis

Lisa Lebherz, MSc, University Medical Center Hamburg-Eppendorf, Institute for Health Services Research in Dermatology and Nursing (IVDP), Hamburg, Germany

(2055) Patient-reported inter- and intradialytic symptoms in hemodialysis and hemodiafiltration patients - analysis from the CONVINC trial

Ngoc Pham, MSc Psychology, Fresenius Medical Care, Bad Homburg, Germany

(2057) Face and content validity of a single-item global indicator of cancer treatment burden: Evidence from cognitive interviews

Andreia Ferreira Moura, PhD, EORTC, Brussels, Belgium

(2059) In-silico development, refinement, and structural validation of a pilot patient-reported outcome measure using AI generative psychometrics to assess the lived experience of people with co-occurring hyperacusis and tinnitus

Nathan Clarke, PhD, Adelphi Values Ltd, Macclesfield, United Kingdom

(2061) Evaluating Robust Distribution-Based Estimates to Inform Meaningful Within-Person Change Thresholds for Highly Skewed Digital Measures: A Simulation Study Using Cough Frequency Data

Aleksandra Sjöström-Bujacz, PhD, Patient-Centered Solutions, IQVIA, Stockholm, Sweden

(2065) What matters most to patients with rheumatoid arthritis? A qualitative study exploring unmet needs and contemporary treatment priorities

Elizabeth Collins, PhD, COA, Clarivate, London, United Kingdom

(2067) Identifying Patient-Reported Outcome Measures for Socio-Emotional Wellness in Children Aged 8-12: A Systematic Review

Erin McCabe, PhD, MScPT, BSc, Department of Physical Therapy, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada

(2069) motional Distress as the Primary Pathway Linking Sleep Disturbance to Health-Related Quality of Life: Integrated Subjective and Objective Evidence

Jingyu Zhang, Chongqing Medical University, Chongqing, China

(2071) Changes in anxiety and depression symptoms among healthcare workers in comprehensive cancer centres during the COVID-19 pandemic

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

(2075) Developing and Validating Standardized Patient Global Impression Scales: Qualitative Insights Into an Adaptable Framework

Dhaniel Fantinati, IQVIA Inc., São Paulo, Brazil, São Paulo, Brazil

(2077) Associations Between Somatic Symptom Burden and Personality in the General Adult Population

Hajime Iwasa, PhD, Fukushima Medical University, Fukushima-shi, Japan

(2079) Reinventing Well-being Measurements for Older Persons: Psychometric Evaluation of the Older Persons' Well-being Scale (OPWELLS)

Jeanette Melin, PhD, Linnaeus University, Kalmar, Sweden

(2081) Patient-Reported Tolerability (PRT) in Industry Sponsored Oncology Clinical Trials: Current Practices and Regulatory Implications

Ellen Adamian, BSc MSc, Kyowa Kirin International, Marlow, United Kingdom

(2083) Development of a Dutch Value Set for the PROMIS Preference Score (PROPr)

Ellen Elsman, Epidemiology & Data Science, Amsterdam UMC, Amsterdam, Netherlands

(2085) Patient-reported outcomes at 90 days after stroke among midlife stroke survivors compared to older stroke survivors: a population-based study

Lynda Lisabeth, PhD, MPH, University of Michigan, Ann Arbor, Michigan, United States

Tuesday, 20 October

9:35 AM - 10:15 AM

Tuesday Poster Session 201

Zenit

(2087) Making PROMs Accessible: Equipping Leaders to Support Sustainable Practice Change

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

(2089) Methodological considerations in the design and conduct of a large international in-trial qualitative interview study to generate in-depth patient experience data

Elizabeth Gargon, PhD, Patient-Centered Outcomes, Adelphi Values, Bollington, United Kingdom

Tuesday, 20 October

10:20 AM – 11:35 AM

Concurrent Symposium Sessions

Symposium 1

Meridian

"Your Dad Scored a 30 on a Fatigue Scale-What Should He Do Next?" Making PROM Scores Actionable

Moderator: Bellinda King-Kallimanis, PhD, LUNgevity Foundation, Bethesda, Maryland, United States

(S1.1) Are your symptoms to do with your tumour or side effects? Evaluating changes in a curative cancer setting

Alexandra Gilbert, University of Leeds, Leeds, United Kingdom

(S1.2) You may have gotten worse, maybe? Evaluating change in progressive diseases.

Fraser Bocell, MEd PhD, Critical Path Institute, Silver Spring, Maryland, United States

(S1.3) PROMS for Screening in Clinical Care: Does this patient need support for cognitive dysfunction?

Theresa Coles, PhD, Duke University School of Medicine, Durham, North Carolina, United States

Symposium 2

Virgo & Leo

A need to grow up: Optimising and prioritising children and young people's PRO assessment in cancer clinical trials and practice

Moderator & Discussant: Martha Grootenhuys, Princess Maxima Center for Pediatric Oncology, Utrecht, Netherlands

(S2.1) Barriers and facilitators for the use of PROMs in pediatric clinical trials – results of a scoping review and a mixed-methods study

Franziska Helmberg, University Hospital of Psychiatry II, Department of Psychiatry, Psychotherapy, Psychosomatics and Medical Psychology, Medical University of Innsbruck, Innsbruck, Austria

(S2.2) Methodological resources to support implementation of patient reported outcomes in paediatric cancer clinical trials: scoping review

Kelly LA van Bindsbergen, PhD, Princess Máxima Center for pediatric oncology, Utrecht, the Netherlands

(S2.3) Using electronic PROs/ObsROs in pediatric clinical trials – Lessons learned from the MONALISA project

Annalena Endres, University Hospital of Psychiatry II, Department of Psychiatry, Psychotherapy, Psychosomatics and Medical Psychology, Medical University of Innsbruck, Innsbruck, Austria

(S2.4) Advancing patient-reported outcome measures in pediatric oncology: A PROM Facility to benchmark pediatric quality of life cancer module scores for clinical trials and patient-centered care

Kelly LA van Bindsbergen, PhD, Princess Máxima Center for pediatric oncology, Utrecht, the Netherlands

(S2.5) Validation of an adult generic quality of life measure, the EORTC QLQ-C30, for use in adolescents: A route to improving access to clinical trials.

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

Symposium 3

Taurus & Aquarius

Challenges and triumphs of multi-national generic patient reported outcome (PRO) measure development

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

(S3.1) Patient and Public Involvement and Engagement (PPIE) Guidelines Worldwide and Their Relationship to Quality of Life Research

Amy Cizik, PhD MPH, University of Utah, Salt Lake City, Utah, United States

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Tuesday, 20 October

10:20 AM – 11:35 AM

Concurrent Symposium Sessions

(S3.2) Current guidelines on qualitative research for instrument development

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

(S3.3) Reflections from the development of the EQ Health and Wellbeing 9 (EQ-HWB-9)

Ole Marten, PhD, School of Public Health, Department of Health Economics and Health Care Management, Bielefeld University, Bielefeld, Germany

(S3.4) Reflections from the multinational development of the experimental EuroQoL Toddler and Infant Populations (EQ-TIPS) measure of Health-Related Quality of Life

Maria Belizan, MSc, Institute for Clinical Effectiveness and Health Policy (IECS), Buenos Aires, Argentina

Symposium 4

Kepler

Empowering Patients: Advancing Communication of Patient-Reported Outcome Trial Results for Shared Decision-Making

Moderator: Melanie Calvert, Centre for Patient Reported Outcomes Research, NIHR Birmingham Biomedical Research Centre, University of Birmingham, Birmingham, United Kingdom

Discussant: Patricia A. Spears, BS, Research Patient Advocate FASCO, University of North Carolina Lineberger Comprehensive Cancer Center Chapel Hill, North Carolina, United States

(S4.1) Communicating Clinical Trial Information About Cancer Drug Products to Patients and Health Care Professionals- the Current State of Play: Review of Patient-Reported Outcome Messaging

Sarah Knight, BSc (Hons) MSc, Clarivate, Oxford, United Kingdom

(S4.2) Communication of PRO Results in Oncology Product Labeling – A Regulatory Perspective

Vishal Bhatnagar, MD, US Food and Drug Administration, Silver Spring, Maryland, United States

(S4.3) SISAQOL-IMI Recommendations: Visualisation and presentation of PRO results from cancer clinical trials

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

(S4.4) Adaptive Patient-Reported Outcome Messaging Across Stakeholder Literacy Levels: A Qualitative and AI-Assisted Framework

Saeid Shahraz, MD PhD, Gilead Sciences, Foster City, California, United States

Symposium 5

Tycho

Meaningful score regions: Concepts, methods and pitfalls

Moderator: Dara O'Neill, PhD, IQVIA, Barcelona, Spain

(S5.1) Meaningful score regions: Concepts and context for an emerging regulatory approach to COA interpretability

Dara O'Neill, PhD, IQVIA, Barcelona, Spain

(S5.2) Why ROC-analysis should not be used to identify meaningful score regions, but instead item response theory should be used

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

(S5.3) Using mixed methods vignette studies to estimate meaningful score regions

Jakob Bjorner, MD PhD, IQVIA, Copenhagen, Denmark

(S5.4) Interpreting treatment effects against meaningful score regions considering two sources of uncertainty

Andrew Trigg, Bayer plc, Reading, United Kingdom

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Tuesday, 20 October

1:20 PM – 2:50 PM

Concurrent Oral Brief Sessions

Oral Brief 201: Cancer

Meridian

Session Chair: Claudia Rutherford, PhD, Australia

1:25 PM - 1:33 PM (B201.1) Ecological momentary assessment in patients with lung and renal cell cancer: feasibility and dynamic networks of fatigue, affect, and pain

Belle H. de Rooij, The Netherlands Comprehensive Cancer Organization, Utrecht, the Netherlands., Eindhoven, Netherlands

1:33 PM - 1:41 PM (B201.2) PROfound Impact: Standardizing EORTC Patient-Reported Outcome Data Interpretation for Oncology Practice and Research

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

1:41 PM - 1:49 PM (B201.3) Completeness of patient-reported outcome reporting in randomized controlled trials (RCTs) of hematologic malignancies according to CONSORT-PRO recommendations: analysis of 143 RCTs published between 2015 and 2025

Fabio Efficace, Italian Group for Adult Hematologic Diseases (GIMEMA), Data Center and Health Outcomes Research Unit, Rome, Italy

1:49 PM - 1:57 PM (B201.4) Barriers and facilitators to the completion of Patient Reported Outcome Measures (PROMs) in cancer clinical trials: A multi-perspective interview study

Andreia Ferreira Moura, PhD, EORTC, Brussels, Belgium

1:57 PM - 2:05 PM (B201.5) Trajectory of patient-reported functioning leading up to death in advanced cancer patients receiving treatment in the AFT-39 PRO-TECT cluster-randomized clinical trial

Brenda Ginos, MS, Mayo Clinic, Department of Quantitative Health Sciences, Scottsdale, Arizona, United States

2:05 PM - 2:13 PM (B201.7) Longitudinal trajectories of patient reported cognitive function among adult transplant and cellular therapy recipients in the United States

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

2:13 PM - 2:21 PM (B201.8) Methods for assessing time spent with severe symptom burden during treatment (ACCRU RU011201I)

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

2:21 PM - 2:29 PM (B201.9) Cancer-Related Worry as a Psychosocial Pathway Associated With Long-Term Quality of Life in Hodgkin Lymphoma Survivors

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

2:29 PM - 2:37 PM (B201.10) PATIENT-REPORTED OUTCOME TRAJECTORIES ALIGNED TO TIME BEFORE DEATH IN TERMINAL CANCER PATIENTS IN KOREA

Jung Hye Kwon, Chung-Ang University Gwangmyeong Hospital, Gwangmyeong-si, South Korea

Oral Brief 202: Health Economics

Virgo & Leo

Session Chair: Oliver Rivero-Arias, DPhil, United Kingdom

1:25 PM - 1:33 PM (B202.1) Using routinely collected EQ-5D-5L to evaluate Workers' Compensation Board programs and predict return-to-work outcomes

Hilary Short, MSc, University of Alberta, Edmonton, Alberta, Canada

Tuesday, 20 October

1:20 PM – 2:50 PM Concurrent Oral Brief Sessions

1:33 PM - 1:41 PM (B202.2) Are Preference-based Cancer-specific Measures more sensitive than Generic Measures? A comparison of EQ-5D-5L, SF-6Dv2, FACT-8D and QLU-C10D in Gastrointestinal Cancers

Xin Zhang, PhD, Saw Swee Hock School of Public Health, National University of Singapore, Singapore, Singapore

1:41 PM - 1:49 PM (B202.3) Psychometric Evaluation of the EQ-TIPS in Infants and Toddlers in Argentina: A Comparative Study of 3L and 5L Versions

Maria Belizan, MSc, Institute for Clinical Effectiveness and Health Policy (IECS), Buenos Aires, Argentina

1:49 PM - 1:57 PM (B202.4) Heterogeneity in patient preferences towards treatment for coronary artery disease: a latent class analysis of a discrete choice experiment

Tolu Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada

1:57 PM - 2:05 PM (B202.5) Extending Health-Related Quality of Life Valuation to Adolescents: Can 16–17-Year-Olds Meaningfully Complete EQ-VT Time Trade-Off Tasks?

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

2:05 PM - 2:13 PM (B202.6) Health-related quality of life in people with multiple sclerosis, what matters most? Exploring preference heterogeneity using a discrete choice experiment in Italy

Edoardo Donarelli, PhD Student, Department of Psychology, University of Turin, Turin, Italy

2:13 PM - 2:21 PM (B202.7) Educational Inequalities in Quality-Adjusted Life Expectancy in Quebec: Decomposition by HRQoL Dimensions

Thomas Poder, PhD, Laval University, Québec City, Quebec, Canada

2:21 PM - 2:29 PM (B202.8) Content validity of the EQ-HWB-9, EQ-5D-5L, and six bolt-ons in older adults

Hilary Short, MSc, University of Alberta, Edmonton, Alberta, Canada

2:29 PM - 2:37 PM (B202.9) A Concurrent Multi-Country EQ-5D-Y-3L Valuation Study in Asia: A Hybrid Latent Class Approach with Larger cTTO Designs

Annushiah Vasan Thakumar, PhD, School of Pharmacy, Taylor's University, Subang Jaya, Malaysia

2:37 PM - 2:45 PM (B202.10) Measuring psychosocial domains of quality of life

Pedro Ferreira, PhD, CEISUC/CIBB, Coimbra, Portugal

Oral Brief 203: Rare Conditions

Taurus & Aquarius

Session Chair: Lee Aiyegbusi, MBChB PhD, United Kingdom

1:25 PM - 1:33 PM (B203.1) Recommendations for the use of Clinical Outcome Assessments in Rare Disease Drug Development

Samantha Cruz Rivera, Dr, CPROR, University of Birmingham, Birmingham, United Kingdom

1:33 PM - 1:41 PM (B203.2) A targeted guidance and case study review of patient reported outcomes in regulatory evaluation of advanced therapies

Devin Peipert, University of Birmingham, Birmingham, United Kingdom

1:41 PM - 1:49 PM (B203.3) Quality of Life Endpoints in Mesothelioma Trials: A Systematic Review

Lotte van der Weijst, PhD, EORTC, Brussels, Belgium

2:05 PM - 2:13 PM (B203.6) COS4TAND: The landscape of outcomes and outcome measures in Tuberous Sclerosis Complex - a survey study and scoping review

Floortje Hosman, MSc, Amsterdam UMC, Amsterdam, Netherlands

Tuesday, 20 October

1:20 PM – 2:50 PM Concurrent Oral Brief Sessions

1:49 PM - 1:57 PM (B203.4) COS4TAND: Outcomes that matter for persons with Tuberous Sclerosis Complex - a qualitative study

Floortje Hosman, MSc, Amsterdam UMC, Amsterdam, Netherlands

1:57 PM - 2:05 PM (B203.5) Cross-sectional comparison of patient-reported symptoms and health-related quality of life at different stages of chronic nontuberculous mycobacterial pulmonary disease (NTM-PD)

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

2:13 PM - 2:21 PM (B203.7) Qualitative Assessment of Health-Related Quality of Life Impacts Associated with Sickle Cell Disease and Recurrent Vaso-occlusive Crises in Children and Adolescents in the US and UK: The VISIBLE Study

Jennifer Drahos, PhD, MPH, Vertex Pharmaceuticals Incorporated, Boston, Massachusetts, United States

2:21 PM - 2:29 PM (B203.8) A Conceptual Framework for Respiratory Symptom Burden and Health-Related Quality of Life among School-aged Children and Adolescents born with Esophageal Atresia

Leah Frain, Doctor of Nursing Practice, Boston Children's Hospital, Boston, Massachusetts, United States

2:29 PM - 2:37 PM (B203.9) Family Psychosocial Risk, Communication and Psychological Outcomes in Families with Multiple Endocrine Neoplasia (MEN)

Daniel Zwerus, PhD Candidate and Psychologist, University Medical Center Utrecht, Utrecht, Netherlands

2:37 PM - 2:45 PM (B203.10) The lived experience of β -thalassemia: Fatigue, pain, and the overlooked burden of iron chelation therapy

Sarah Wilding, Modus Outcomes, Cambridge, Massachusetts, United States

Oral Brief 204: Routine Use of PROMS

Kepler

Session Chair: Anne Schuster, PhD MHS, United States

1:25 PM - 1:33 PM (B204.1) Daily assessment of quality of life in metastatic colorectal cancer: Feasibility and interim outcomes

Claire Conley, PhD, Georgetown University, Washington, District Of Columbia, United States

1:33 PM - 1:41 PM (B204.2) Practical application of the PROM-cycle: Selection, validation and implementation of PROMs in pediatric physiotherapy

Dorinde Korteling, PhD, Amsterdam UMC, Amsterdam, Netherlands

1:41 PM - 1:49 PM (B204.3) Taking paediatric care further: PedsQL 4.0TM Generic Module for routine and comprehensive health-related quality of life (HRQoL) assessment

Christina Pählig, M.A. Sociology, Universitätsklinikum Dresden, Dresden, Germany

1:49 PM - 1:57 PM (B204.4) Understanding why patients do not complete digital PROMs in cancer care: A Qualitative Study

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

1:57 PM - 2:05 PM (B204.5) Clinical application and use of outcome measures in neurorehabilitation programs across Alberta, Canada: a province-wide environmental scan

Ahlam Zidan, PT, MSc., PhD, Department of Physical Therapy, University of Alberta, Edmonton, Alberta, Canada

2:05 PM - 2:13 PM (B204.6) The Feasibility of Implementing Electronic Patient-Reported Outcome Measures (ePROMs) in Cardiac Rehabilitation.

Bitu Hojjatpanahmontazeri, MD. Master's student, Faculty of Medicine and Health Sciences, McGill University, Montreal, Quebec, Canada

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1:20 PM – 2:50 PM Concurrent Oral Brief Sessions

2:13 PM - 2:21 PM (B204.7) Perspectives of clinical and administrative staff on collecting patient-reported outcome measures in routine radiation oncology care

Claire Morton, MD, Brigham and Women's Hospital, Boston, Massachusetts, United States

2:21 PM - 2:29 PM (B204.8) Using Patient Reported Outcome Measures to identify melanoma patients with a high risk for emotional distress

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

2:29 PM - 2:37 PM (B204.10) Implementation and responsiveness of the German GENDER-Q in routine care for gender-affirming chest surgery

Maximilian Jacobi, MD, University Hospital Schleswig-Holstein, Lübeck, Germany

Oral Brief 205: Instrument Evaluation

Tycho

Session Chair: Melanie Hawkins, PhD, Australia

1:25 PM - 1:33 PM (B205.1) Qualitative research to evaluate varying item stem formulations of the PROMIS/Neuro-QoL™ Physical Function Measure for Multiple Sclerosis (PROMISnq Short Form v2.0 - Physical Function - Multiple Sclerosis 15a (PROMISnq PFMS-15a))

Sonya Eremenco, Critical Path Institute, Tucson, Arizona, United States

1:33 PM - 1:41 PM (B205.2) Minimal important change of QLU-C10D, PROPr and EQ-5D-5L in cancer patients

Antje Förster, Medical Doctor, Department of Psychosomatic Medicine, Center for Internal Medicine and Dermatology, Charité – University Medicine Berlin, Berlin, Germany

1:41 PM - 1:49 PM (B205.3) International phase IV field study to validate the European Organisation for Research and Treatment of Cancer questionnaire for assessing the health-related quality of life of cancer survivors: the EORTC QLQ-SURV100

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

1:49 PM - 1:57 PM (B205.4) Is the Functional Assessment of Chronic Illness Therapy—Fatigue (FACIT-F) a unidimensional or multi-faceted instrument? Evidence from publicly available data

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

1:57 PM - 2:05 PM (B205.5) Validation of the Coping Inventory for Stressful Situations – Short Form (CISS 21) in the General Dutch Population: Comparing Three and Four Factor Models and Concurrent Validity with Perceived Stress and Emotion Regulation

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

2:05 PM - 2:13 PM (B205.6) A Multidimensional Item Response Theory Analysis of the Seattle Angina Questionnaire: Measurement Precision, Differential Item Functioning, and Potential for Item Reduction

Oluwagbohunmi Awosoga, University of Lethbridge, Lethbridge, Alberta, Canada

2:13 PM - 2:21 PM (B205.7) Differential item functioning trends in clinical outcome assessment (COA) research over the past five years: An exploratory literature review

Tilly Stott, MPH, Mapi Research Trust, Lyon, France

2:21 PM - 2:29 PM (B205.8) A Comparison of Computerised Adaptive Testing and Multi-stage Adaptive Testing for the Seven Emotions Scale

Zhengkun Hou, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangzhou, China

Tuesday, 20 October

1:20 PM – 2:50 PM

Concurrent Oral Brief Sessions

2:29 PM - 2:37 PM (B205.9) Developing a mixture computerised adaptive test to enhance fairness in health measurement

Richard Sawatzky, PhD, RN, Trinity Western University, Langley, British Columbia, Canada

2:37 PM - 2:45 PM (B205.10) Comparing Three Patient-Reported Physical Functioning Measures in an International Cohort of Cancer Survivors

Brie Noble, BS in Statistics, Mayo Clinic, Scottsdale, Arizona, United States

(2014) Beyond the Interview: Can Online Surveys Support Cognitive Debriefing?

Amy Howerter, PhD, Clinical Outcomes Solutions, Tucson, Arizona, United States

(2016) Simultaneous versus Staged Bilateral Total Knee Arthroplasty: A Comparative Study of Generic and Knee-Specific Patient-Reported Outcome Improvements

Xin Zhang, PhD, Saw Swee Hock School of Public Health, National University of Singapore, Singapore, Singapore

(2018) Measuring What Matters: Cross-country Validation of the WHO-5 Well-being Index for People Living with Chronic Conditions in the OECD PaRIS Patient Questionnaire (PaRIS-PQ)

Ian Porter, PhD, University of Exeter, Exeter, United Kingdom

(2020) Non-compensatory differential item functioning (NCDIF) of the Dermatology Life Quality Index (DLQI) across 13 European countries.

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

(2022) A Modular Approach to Quality-of-Life Measurement in Breast Cancer: Enabling Flexible, Low-Burden Assessment Across Treatment Phases

Shizhu Li, Chongqing Medical University, Chongqing, China

(2024) Rethinking Visualization of Known-Groups Validity: Graphical Approaches for Non-Standard Sample Sizes and Distributions

Nikola Markiewicz, SeeingTheta, Saumur, France

(2026) Using Mixed Methods to Assess the Impact of a Community Paramedicine Program for Intermediate Acuity Care on Self-reported Treatment Burden

Jennifer Ridgeway, PhD, Mayo Clinic, Rochester, Minnesota, United States

(2028) Responsiveness and minimal important change of the Dutch Adult Strabismus-20 Questionnaire (Dutch-AS-20)

Ellen Elsman, PhD, Amsterdam UMC, location Vrije Universiteit Amsterdam, Ophthalmology, Amsterdam, Netherlands

(2030) How much is too much? Acceptable PROM response burden in chronic conditions: A scoping review

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

(2032) Development of a PROMs Panel for Older Adults Following Hospital Discharge Based on the 4Ms Framework

Claire Morton, MD, MPP, Mass General Brigham, Boston, Massachusetts, United States

(2034) High-frequency ePRO monitoring characterizes perioperative symptom trajectories with hrHPV-associated cervical lesions

Ru Meng, Ph.D, Shanxi Key Laboratory of Cervical Disease Research, Jincheng People's Hospital, Jincheng, China

(2036) Association of a patient reported experience measure and clinical interventions during labor and childbirth

Rachel Breman, University of MD, Baltimore School of Nursing, Baltimore, Maryland, United States

(2038) What Outcomes Matter to Patients with Neuro-RDs? A Qualitative Study to Identify Patient-Reported Outcomes for Drug Repurposing Trials and Care.

Tom Steenbergen, MSc., Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, Netherlands

(2042) A Systematic Review of Goal Inventories to Standardize Implementation of Goal Attainment Scaling

Rebecca Metcalfe, PhD, Ardea Outcomes, Toronto, Ontario, Canada

(2044) The Association Between Self-stigma of Mental Illness and Quality of Life of Adults Living with Depression in Saudi Arabia: A Cross-Sectional Study.

Refah H. Alqahtani, MSc, RN, University of Dundee, Dundee, United Kingdom

(2046) Identifying and Prioritising Patient-Reported Outcomes for Psychomotor Therapy in Youth Mental Health Care in the Netherlands: a multi-phase qualitative co-creation study

Janet Moeijes, dr, Windesheim University of Applied Sciences, Zwolle, Netherlands

(2048) Developing measurement models of social connectedness and their associations with self-perceived health and sleep outcomes in Asian American populations

Zonggui Li, Ph.D., University of Maryland Baltimore School of Pharmacy, Baltimore, Maryland, United States

(2050) What matters to patients? Patient-identified priorities from free-text responses to patient-reported outcomes for clinical conversations in rehabilitation after cancer or cardiac arrest

Cecilie Lindström Egholm, , 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

(2054) Quality of life endpoints in EORTC clinical trials: a descriptive protocol review (2010-2026)

Anne Esser, Master, Quality of Life Department, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium

(2056) Evaluating Clinician-Reported Outcome Measures from the Patient Perspective: A Qualitative Study in Neurodegenerative Disease

Meagan Farrell, PhD, IQVIA, New York, New York, United States

(2058) Longitudinal EQ-5D-5L Trajectories and Their Association with Productivity Losses Following Miscarriage

Corneliu Bolbocean, Avera Research Institute, Sioux Falls, South Dakota, United States

(2062) Best practices for designing and electronically implementing event-driven diaries in clinical trials

Florence Mowlem, uMotif, London, United Kingdom

(2064) Usability and feasibility of an ePRO system linked to an electronic chemotherapy prescribing and patient management system: Preliminary findings from a UK oncology clinical setting

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

(2066) Development and validation of the EORTC-PRO-AE inventory: An international mixed-methods study to establish face and content validity

Alexandra Gilbert, Leeds Institute of Medical Research, University of Leeds, Leeds, United Kingdom

(2068) Triangulation or deduplication? Reconsidering multi-anchor synthesis of meaningful change thresholds using dominance analysis

Abi Williams, MSc, Adelphi Values, Macclesfield, United Kingdom

(2071) Experience as Strength: Education about Sexuality and Relationships for Women with Congenital Bleeding Disorders developed through Patient Engagement

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

(2072) Modelling sociodemographic determinants of health-related quality of life (HRQoL) loss among older adults in Spain using discrete beta regression

Ibtissame El Ferjani, Msc in Actuarial and Financial Sciences, University of Barcelona, Barcelona, Spain

(2074) A Data-Driven Framework for Optimizing Language Selection in Electronic Patient-Reported Outcome Studies

Jonathan Norman, YPrime, London, United Kingdom

(2076) What Matters Most? Ranked Patient Priorities for Quality of Life in Advanced Heart Failure

Hunter Groninger, MD, MedStar Health/Georgetown University, Washington, District Of Columbia, United States

(2078) Psychometric and impairment threshold evaluation of the Impact of Weight on Quality of Life-Lite Clinical Trials Version (IWQOL-Lite-CT) Physical Function (PF) score, in adults living with overweight or obesity

Milena Anatchkova, PPD Evidera Patient-Centered Research, Thermo Fisher Scientific, Waltham, Massachusetts, United States

(2080) Collective well-being as a direct determinant of individual cardiovascular outcomes

Jiangyuan Zhu, MD, MPH, NYU Langone Health, Guangzhou, China

(2082) Identifying Modifiable Behavioral Factors for Depression and Loneliness Using Explainable Artificial Intelligence: A Nationwide Study

Juyoun Jung, Ph.D., Division of Tourism & Wellness, Hankuk University of Foreign Studies, Seoul, South Korea

(2084) Construct Specificity and Instrument Sensitivity of PROMs for Quality of Life Assessment in Patients with Gestational Diabetes Mellitus (GDM): A Comparative Analysis of Known-Groups Validity

Klara Greffin, PhD, University of Greifswald, Greifswald, Germany

(2086) Does the choice of value set matter? Comparing five country tariffs for EQ-5D-5L population norms in Finland

Liisa Penttinen, MHS, PhD candidate, Finnish Institute for Health and Welfare, Helsinki, Finland

(2088) Integrating Large Language Models into Patient-Reported Outcome Development: A Human-in-the-Loop Framework

Constance Mara, PhD, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, United States

(2090) Making Evidence Usable: A Tailored, Theory-Informed Video to Support QOL Integration in Clinical Practice

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

(2092) Causal inference in observational comparative studies using PROs: A simulation study comparing Rasch Measurement and Classical Test Theories

Yseulys Dubuy, Nantes University - UMR 1246 SPHERE, Nantes, France

Tuesday, 20 October

3:40 PM – 5:10 PM

Concurrent Oral Sessions

Oral Session 206: Instrument Development

Taurus & Aquarius

Session Chair: Heather Gelhorn, PhD, United States

3:45 PM - 4:02 PM (206.1) Establishing the conceptual framework, content validity and face validity of the new APPRAISE patient-reported outcome measure to assess outcomes of prolapse, incontinence and mesh complication surgery

Mollie Price, PhD, Leeds Beckett University, Leeds, United Kingdom

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

4:02 PM - 4:19 PM (206.2) PROQuALS: A new Patient Reported Outcome Measure for Quality of Life in Amyotrophic Lateral Sclerosis

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

4:19 PM - 4:36 PM (206.3) The Patient-Specific Needs Evaluation (PSN): measuring information needs, treatment goals, and individualized thresholds of treatment success

Eva Lindner, Department of Plastic, Reconstructive and Hand Surgery, Erasmus MC, Rotterdam, Netherlands

4:36 PM - 4:53 PM (206.4) Validation of the Eating Drivers Diary (EDDY), a novel patient-reported outcome measure for use in clinical trials of medications for weight management

Lori McLeod, PhD, RTI Health Solutions, Research Triangle Park, North Carolina, United States

4:53 PM - 5:10 PM (206.5) Field-Testing a Bariatric-Specific Patient-Reported Outcome Measure for the Australia & New Zealand Bariatric Surgery Registry

Alyssa Budin, PhD, Monash University, Melbourne, Australia

Oral Session 207: Quality of Life Measurement in Young People

Virgo & Leo

Session Chair: Lotte Haverman, PhD, Netherlands

3:45 PM - 4:02 PM (207.1) The EORTC PRO measurement system for children with cancer

Chiara Vetrano, M.Sc., Medical University Innsbruck, Department of Psychiatry, Psychotherapy, Psychosomatics, and Medical Psychology, Innsbruck, Austria, Innsbruck, Austria

STUDENT ORAL PRESENTATION AWARD FINALIST

4:02 PM - 4:19 PM (207.2) Toward a core patient reported outcome measure (PROM) set for (genetic) intellectual disabilities: evaluating reliability, efficiency, and validity

Alannah Hijckema, MSC, Child and Adolescent Psychiatry & Psychosocial Care, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Department of Pediatrics, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Amsterdam, Netherlands

4:19 PM - 4:36 PM (207.3) Parent Proxy vs. Child Self-Report in the assessment of Health-related quality of life (HRQOL) using PedsQL 4.0: Agreement and Influencing Factors

Jurek Schultz, PD Dr. med. habil., Universitätsklinikum Dresden, Dresden, Germany

4:36 PM - 4:53 PM (207.4) Measuring "Life Impact" in Youth Mental Health: Clarifying Constructs and Strengthening Content Validity

Karolin Krause, PhD, Centre for Research in Epidemiology and Statistics (CRESS), Université Paris Cité / INSERM, Paris, France

4:53 PM - 5:10 PM (207.5) Exploring Health-Related Quality of Life and Care Burden in Parents of Boys and Men with Duchenne Muscular Dystrophy: A Mixed-Methods Study

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

Tuesday, 20 October

3:40 PM – 5:10 PM

Concurrent Oral Sessions

Oral Session 208: Meaningful Change

Meridian

Session Chair: Anne Skalicky, MPH, United States

3:45 PM - 4:02 PM (208.1) Qualitative research to determine meaningful change thresholds for patient-reported anchors in multiple sclerosis

Sonya Eremenco, Critical Path Institute, Tucson, Arizona, United States

4:02 PM - 4:19 PM (208.2) Seeing the whole picture: mixed-methods heat mapping for triangulating meaningful benefit

Christopher St Clair, PharmD, Clinical Outcomes Solutions, Fort Myers, Florida, United States

4:19 PM - 4:36 PM (208.3) An Evidential Framework for Evaluating Anchor Measures in Meaningful Change Research

Piper Fromy, Ph.D., SeeingTheta, Saumur, France

4:36 PM - 4:53 PM (208.4) Alternative methods for meaningful change: lessons learned from conducting a qualitative vignette-style approach to deriving meaningful change thresholds for the Kings Sarcoidosis Questionnaire Lung (KSQ-L)

Helen Kitchen, MSc, Clarivate, London, United Kingdom

4:53 PM - 5:10 PM (208.5) A Review of Vignette-Based Methods for Estimating Meaningful Score Differences

Kacylia Pistoia, SeeingTheta, Saumur, France

Oral Session 209: Wearable and Digital Technologies

Kepler

Session Chair: Karen Bailey, PhD, United Kingdom

3:45 PM - 4:02 PM (209.1) Digital health technology meets patient voice: a qualitative study to inform the meaningfulness and feasibility of actigraphy-derived digital endpoints

Sarah Bentley, Patient-Centered Outcomes, Adelphi Values Ltd, Bollington, Cheshire, United Kingdom

4:02 PM - 4:19 PM (209.2) Physical Activity and Sleep Patterns detected by Wearable-Device Signals and Future Health-Related Quality of Life Among Adult Survivors of Childhood Cancer

I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, Tennessee, United States

4:19 PM - 4:36 PM (209.3) Clinical Validation of Wearable Digital Biomarker Associations with Patient-Reported Outcomes in Post-COVID Fatigue: A 3-Month Longitudinal Study

Nana Yaw Aboagye, Newcastle University, Newcastle Upon Tyne, United Kingdom

4:36 PM - 4:53 PM (209.4) Predicting Symptom Severity in Childhood Cancer Survivors Using Digital Biomarkers from Wearable Devices: A Time-Lag Modeling Approach

I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, Tennessee, United States

4:53 PM - 5:10 PM (209.5) Leveraging Wearable Devices in Real-World Settings to Improve Physical Exercise Self-Efficacy in Black Prostate Cancer Survivors: A Feasibility Study

Emma Fortune, PhD, Mayo Clinic, Rochester, Minnesota, United States

Tuesday, 20 October

3:40 PM – 5:10 PM

Concurrent Oral Sessions

Oral Session 210: Quality of Life Measurement in Older People

Tycho

Session Chair: Richard Skolasky, ScD, United States

3:45 PM - 4:02 PM (210.1) Using network analysis to provide evidence for active living as a unified construct relevant to active aging

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

4:02 PM - 4:19 PM (210.2) Patient-reported outcomes and associated factors among older people living with HIV/AIDS

Renjun Gu, Assistant researcher, Neurovascular Center, Changhai Hospital, Naval Medical University; Department of Social Medicine of School of Public Health, and Department of Pharmacy of the First Affiliated Hospital, Zhejiang University School of Medicine, Shanghai/Hangzhou City, China

4:19 PM - 4:36 PM (210.3) Gender-disaggregated longitudinal associations between health behaviours and life satisfaction in community-dwelling older adults: a six-year growth curve analysis of the CLSA

Oluwagbohunmi Awosoga, University of Lethbridge, Lethbridge, Alberta, Canada

4:36 PM - 4:53 PM (210.4) Physical functioning after treatment for breast cancer and the impact of age

Victoria Robins, MSc, BSc Hons, PGCert, University of Leeds, Leeds, United Kingdom

4:53 PM - 5:10 PM (210.5) Do non-responders of a geriatric screening questionnaire face lower one-year survival compared to responders? A retrospective cohort study

Kathrine Hønholt Carlson, RN, MSc, AmbuFlex, Centre for Patient-reported Outcomes, Gødstrup Hospital, Herning, Denmark

Wednesday, 21 October

8:00 AM – 9:15 AM

Concurrent Symposium Sessions

Symposium 6

Meridian

Demystifying the FDA Patient-Focused Drug Development (PFDD) rationale table: An overview and applications of the argument-based approach to validity to support COAs as fit-for-purpose measures

Moderator: Carrie R. Houts, PhD, Vector Psychometric Group, Lakewood, Ohio, United States

Discussant: RJ Wirth, Vector Psychometric Group, Chapel Hill, North Carolina, United States

(S6.1) An introduction to the argument-based approach to validity

Kevin Weinfurt, PhD, Duke University School of Medicine, Durham, North Carolina, United States

(S6.2) Example of applying an argument-based validity approach to a patient-reported outcome (PRO) measure: The PROMIS Physical Functioning Short Form 10a in osteoarthritis

Rikki Mangrum, MLS, Vector Psychometric Group, LLC, Chapel Hill, North Carolina, United States

(S6.3) An example of a clinician-reported outcome measure and supporting its fit-for-purpose via an argument-based rationale: The Functional Mobility Screen (FMS) as a measure of functional mobility in adults living with osteoarthritis.

Carrie R. Houts, PhD, Vector Psychometric Group, Lakewood, Ohio, United States

(S6.4) Digitally-derived measures and how to construct an appropriate rationale: A sensor-based activity measure in osteoarthritis

Cheryl Coon, PhD, Critical Path Institute, Tucson, Arizona, United States

Symposium 7

Virgo & Leo

Implementing SISAQOL-IMI (Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints) guidelines: Recommendations and Resources

Moderator: Kim Cocks, PhD, Adelphi Values, Cheshire, United Kingdom

(S7.1) Driving Change in PRO Methodology: SISAQOL-IMI Recommendations and Available Resources for Implementation

Madeline Pe, PhD, European Organisation for Research and Treatment of Cancer, Belgium

(S7.2) SISAQOL-IMI recommendations for improving analysis and communication of PRO endpoints in cancer clinical trials: Showcasing three practice-changing recommendations

Antoine Regnault, PhD, Modus Outcomes, a THREAD Company, Lyon, France

(S7.3) Score interpretation thresholds for Patient-Reported Outcomes: SISAQOL-IMI recommendations for harmonization, application, and interpretation

Johannes Geisinger, Medical University of Innsbruck, Innsbruck, Austria

Symposium 8

Taurus & Aquarius

Introducing the EQ-5D Bolt-on Toolbox: The EuroQol Group's new approach to the development, valuation and use of bolt-ons to the EQ-5D-5L

Moderator: Brendan Mulhern, PhD, University of Technology Sydney, Sydney, New South Wales, Australia

(S8.1) Introduction to the EQ-5D Bolt-on Toolbox

Fanni Rencz, MD MSc PhD DSc, Corvinus University of Budapest, Department of Health Policy & EuroQol Research Foundation, Budapest, Hungary

(S8.2) Developing cognition bolt-ons for the EQ-5D Bolt-on Toolbox

Brendan Mulhern, PhD, University of Technology Sydney, Sydney, New South Wales, Australia

ISOQOL 33rd Annual Conference | Final Program Oral/Brief/Poster Presentations
Presenting authors indicated. The full author listing is available on the conference mobile app under the specific session. Last updated on 8 October 2026. For the most updated version of the final program, reference the mobile app.

Wednesday, 21 October

8:00 AM – 9:15 AM

Concurrent Symposium Sessions

(S8.3) Development and testing of hearing and vision EQ-5D bolt-ons

Nadine Henderson, MSc, Office of Health Economics, London, United Kingdom

(S8.4) Expanding the EQ-5D-5L in dermatology with the addition of EQ-5D Bolt-on Toolbox dimensions

Katy Gallop, MSc, Acaster Lloyd Consulting, London, United Kingdom

(S8.5) Exploring non-preference Scoring Approaches for EQ-5D-5L Bolt-ons using psychometric methods: A case study of the Skin bolt-ons

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

(S8.6) Valuation of bolt-ons – ensuring consistency of EQ-5D-5L value sets with and without bolt-ons using measurement correlation

Kim Rand, PhD, Maths in Health B.V., Klimmen, the Netherlands

Symposium 9

Kepler

Bridging the Validation Gap: From Digital Measures to Fit for Purpose Clinical Outcome Assessments

Moderator: Aleksandra Sjöström-Bujacz, PhD, IQVIA, Stockholm, Sweden

(S9.1) Navigating clinical validation of digital measures: Common challenges and emerging needs

Aleksandra Sjöström-Bujacz, PhD, IQVIA, Stockholm, Sweden

(S9.2) AI-driven Cognitive Endpoints for Alzheimer's Disease Drug Development

Jelena Curcic, Novartis, Biomedical Research, Basel, Switzerland

(S9.3) From technically valid to clinically valid digital mobility outcomes: the Mobilise-D framework

Joren Buekers, ISGlobal, Barcelona, Spain

(S9.4) Digital clinical outcome measures – similarities and differences to 'traditional' outcome measures: a regulatory perspective

Andreas Kirisits, AGES – Austrian Agency for Health and Food Safety / BASG – Austrian Federal Office for Safety in Health Care, Vienna, Austria

Symposium 10

Tycho

Patient-Reported Outcomes: Measurable for What?

Moderator: Leah McClimans, University of South Carolina, Columbia, South Carolina, United States

(S10.1) Tin opener or dial? The implications of ongoing coordination between questionnaire and construct for the use of PROMs in clinical practice

Joanne Greenhalgh, Bsc(Hons) MPH PhD, University of Leeds, Leeds, United Kingdom

(S10.2) The Role of Values in Mental Health Measurement at the Clinic

Sebastian Rodriguez Duque, PhD, University of Cambridge, Cambridge, United Kingdom

(S10.3) Making Data Listen: Co-creative Data Analysis and the Future of the "Empower Flower"

Rebecca L. Jackson, PhD, Durham University, Durham, United Kingdom

(S10.4) Measuring patient-reported outcomes over time: Asking questions to move PROM development and validation from cross-sectional to longitudinal considerations

Jan Boehnke, PhD, School of Health Sciences, University of Dundee, Dundee, United Kingdom

(3013) Navigating the Unknown: Post-Diagnostic Support Needs of Informal Carers in Amyotrophic Lateral Sclerosis – An Interview Study

Jill Carlton, University of Sheffield, Sheffield, United Kingdom

(3015) Measuring What Matters: Cross-country Validation of PROMIS Global Health for People Living with Chronic Conditions in the OECD PaRIS Patient Questionnaire (PaRIS-PQ)

Ian Porter, PhD, University of Exeter, Exeter, United Kingdom

(3017) Barriers and facilitators from stakeholder interviews for implementing Dutch-Flemish PROMIS measures in pediatric oncology care

Anne Westerweel, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands

(3019) Understanding the experience of fatigue: Evaluating the adequacy of the Dutch Multifactor Fatigue Scale for OHCA survivors

Nadja Buch Petersson, RN, MSc, PhD student, Department of Cardiology, Odense University Hospital, Odense, Denmark

(3021) Psychometric evaluation of summary scores for the EORTC CAT Core

Morten Petersen, M.Sc., Palliative Care Research Unit, Department of Geriatrics and Palliative Medicine, Copenhagen University Hospital, Bispebjerg & Frederiksberg, Copenhagen, Denmark

(3023) Translating Caregiver-Defined Meaningful Communication Changes from Qualitative Interviews into Score Differences on the ORCA Measure Using Item Response Theory

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

(3025) Content validity of the Evaluating Respiratory Symptoms in COPD measure in patients with recent COPD exacerbations

Paivi Miskala, MSPH, PhD, AstraZeneca, Gaithersburg, Maryland, United States

(3027) Behavior Change Strategies to Support Participant Adherence and Retention in Longitudinal Digital Studies: A Targeted Review

Hanna Skrobanski, BSc, MSc, PhD, Vitaccess, London, United Kingdom

(3029) PROMIS-29 as a Valid and Comparable Patient-Reported Outcome Measure to the SF-36 in Turkish Dialysis Patients

Saynab Atiye, Fresenius Medical Care, Bad Homburg, Germany

(3033) Factors associated with health-related quality of life in rectal cancer survivors after stoma closure

Tatjana Gazibara, MD, PhD, University of Belgrade Faculty of Medicine, Belgrade, Serbia

(3035) Profiles Contributing to Older Persons Active Living Related Quality of Life (OPALrQOL)

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

(3037) Feasibility, Reliability, and Known-Group Validity of the experimental EQ-TIPS-5L EV3.0 for Assessing Health-Related Quality of Life in Japanese Infants and Toddlers

Emi Kamono, MMS, National Center for Child Health and Development, Setagaya, Japan

(3039) Using an Individualized Measurement Framework to Identify Activity-Connections Among Older Persons – PGAI (Person-Generated Activity Index)

Natasha Hassija, Ph.D. Student, McGill University, Montreal, Quebec, Canada

(3041) PROcoach: The European Organisation for Research and Treatment of Cancer e-learning course on the use of patient-reported outcome measures in clinical practice

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

(3043) Measuring Caregiver Quality of Life in Juvenile Idiopathic Arthritis: Validating the CarerQoL Instrument

Ana Fuhrmann, PhD, University of Calgary, Calgary, Alberta, Canada

(3045) A New Health-Related Quality of Life PROM for Adenomyosis: Findings from a Qualitative Concept Elicitation Study

Georgina Forshall, Leeds Beckett University, Leeds, United Kingdom

(3047) Quality of life in dysmenorrhea patients

Jelena Dotlic, MD, PhD, Ass. Prof., Clinic of Obstetrics and Gynecology, University Clinical Center of Serbia, Medical Faculty University of Belgrade, Belgrade, Serbia

(3053) Stakeholder Perspectives on Assessment Modes of PROMs in Cancer Clinical Trials: A qualitative Study

Claudia Seidl, M.A., Health Outcome Research Unit (HORU) at the University Hospital of Psychiatry II, Medical University of Innsbruck, Innsbruck, Austria

(3055) ICF Content Coverage of Lower Extremity Lymphedema Patient-Reported Outcome Measures: A Systematic Domain Mapping Analysis

Serenity Bennett, BS, BA, Harvard Medical School, Boston, Massachusetts, United States

(3057) Matching the question to the method: the link between missing data methods, estimands and what the results mean for PROs

Emma Martin, PhD, Adelphi Values PCO, Bollington, United Kingdom

(3061) Approach to Comparing PROMIS-29 and SF-36 in Adults receiving Hemodialysis: A measurement equivalence study

Le Hong Ngoc Pham, MS, Fresenius Medical Care, Bad Homburg, Germany

(3063) Structural validity and dimension performance of the experimental EQ-TIPS health-related quality of life measure: a combined CFA and IRT approach

You-Shan Feng, Institute for Clinical Epidemiology and Applied Biometry, Medical University[YF1.1] Tübingen, Tübingen, Germany

(3065) Spillover effects on informal and family caregivers' utility: a systematic literature review

David Mott, PhD, Office of Health Economics, London, United Kingdom

(3067) When Training Breaks, Data Breaks: Associations Between eCOA Training Timing, Quality, and Accuracy with Downstream Compliance

Lindsay Hughes, PhD, IQVIA, New York, New York, United States

(3069) Content Validity of Patient-Reported Outcome and Performance Outcome Measures Among Participants with Cachexia and Cancer

Jarjeh Fang, BS, MPH, Pfizer, New York City, New York, United States

(3071) Preventing online survey fraud in healthcare research: Emerging AI-generated eligibility challenges and importance of recruiting legitimate participants

Elizabeth Collins, PhD, Clarivate, London, United Kingdom

Wednesday, 21 October

9:20 AM - 10:00 AM

Wednesday Poster Session 301

Zenit

(3073) Age, Gender, and Education Differences Associated with PROMIS® Mental and Physical Health Summary Scores

Jiwon Kim, Northwestern University, Chicago, Illinois, United States

(3075) Agreement Between Patient and Proxy Assessments of Health-Related Quality of Life After Stroke Using EQ-5D-5L

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

(3077) Patient perspectives on the eHealth Literacy Questionnaire (eHLQ) and three subscales of the Health Literacy Questionnaire (HLQ): A qualitative content validity study in patients with bipolar disorder

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

(3079) Beyond words: A comparative analysis of human versus AI approaches to patient-reported outcome translation and cultural adaptation

Angie Lee, MBA, IQVIA, Seattle, Washington, United States

(3081) Applying the Ophelia Approach in Pediatric Epilepsy Services: A Methodological Pathway from Health Literacy Profiling to Co Design.

Merete Tschamper, PHD, University lecturer, Oslo, Norway

(3083) Co-designing digital clinical outcomes assessment system for stroke trials: Insights about priorities, barriers, and facilitators for stroke survivors

Veronika Kiryanova, PhD, PaCER, University of Calgary, Calgary, Alberta, Canada

(3085) Changes in Quality-Adjusted Life Expectancy in Quebec, 2016–2024: A Decomposition of Mortality and Morbidity Contributions

Thomas Poder, PhD, Laval University, Québec City, Quebec, Canada

(3087) Psychometric properties and outcomes of the PROMIS® Sexual Function and Satisfaction Measures in individuals with congenital bleeding disorders

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

(3089) Recruiting Hard-to-Reach People: Challenges, Strategies and Determinants of Health for People on Dialysis with Depressive Symptoms Considering Cognitive Behavioral Therapy

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

(3091) Association between patient-reported outcomes and patient-reported experience in European oncology care: The EuonQoL project

Sebastian Perry-Pasten, Hospital del Mar Research Institute, Barcelona, Spain

(3014) Construct Validity and Responsiveness of the EQ-HWB-9 in Patients with Gastric, Pancreatic, and Colorectal Cancer

Xin Zhang, PhD, National University of Singapore, Singapore, Singapore

(3016) Developing a novel patient-reported outcome measure to capture patient-centered functional outcomes before and after treatment for urinary incontinence, pelvic organ prolapse and surgical complications

Rasa Ruseckaite, Monash University, Melbourne, Australia

(3018) Weight-Related Quality of Life and Associated Factors Among Adolescents in Zhejiang Province, China Based on the Wilson-Cleary Model

Renjun Gu, Zhejiang University, Hangzhou, China

(3020) The development and validation of computerized adaptive test of TaiDa symptom checklist for psychiatric patients

Ay Woan Pan, PhD, School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan

(3022) Testing the Valderas and Alonso Model-Based Classification of Patient-Reported Outcome Measures: Evidence from the OECD PaRIS Survey

Ian Porter, PhD, University of Exeter, Exeter, United Kingdom

(3024) Single-item measures of treatment-related side effect burden in cancer: a synthesis of current guidance and evidence

Tamara Jones, PhD, Person-Centred Research, Eastern Health Clinical School, Monash University, Melbourne, Australia

(3026) Towards inclusive PROMs: Adapting PROMIS item banks for adolescents and adults with severe (speech) motor impairments

Juliet Hondtong, MA, Amsterdam UMC, Amsterdam, Netherlands

(3028) Evaluating the ICHOM Standard Sets

Eline Alons, PhD, Amsterdam UMC, Amsterdam, Netherlands

(3030) Urinary Incontinence and Quality of Life among U.S. Women

Aaron Winn, PhD, MPP, University of Illinois Chicago, Chicago, Illinois, United States

(3032) Quality of Life in the Late Period After Allogeneic Hematopoietic Stem Cell Transplantation: Dynamics and the Impact of GVHD

Gabriela Lampart, MSc in Physiotherapy; MSc in Public Health, Jagiellonian University Medical College, Doctoral School of Medical and Health Sciences, Krakow, Poland, Kraków, Poland

(3034) Association Between EHMRG-7 Risk Score and Psychological Burden Among Patients with Heart Failure: An Analysis Using PROMIS Computer Adaptive Testing

Istvan Mucsi, Ajmera Transplant Centre and Division of Nephrology, University Health Network, Toronto, Ontario, Canada

(3036) Implementing and evaluating an adolescent and child measurement-based care program in Alberta's mental health care system (INSIGHT)

Maria J. Santana, University of Calgary, Calgary, Alberta, Canada

(3040) Expanding Item Response Theory-Based Patient-Reported Outcome Measures: PROMIS® Pediatric Mobility and Upper Extremity

Dorinde Korteling, PhD, Amsterdam UMC, Amsterdam, Netherlands

(3044) Emotional Burden and Unmet Information Needs in Relapsed/Refractory Multiple Myeloma

Serena Puglia, MSc, Data Center and Health Outcomes Research Unit, Italian Group for Adult Haematologic Diseases (GIMEMA), Rome, Italy

(3046) Cultural adaptation of the Japanese translation of the QOLVAD questionnaire for LVAD patients

Midori Miyatake, PhD, Division of Cardiovascular Surgery, Graduate School of Medicine, Tohoku University, Sendai, Japan

(3048) Psychosocial Impact of Multiple Endocrine Neoplasia (MEN) in Children and Their Family Members: a Qualitative Study

Daniel Zwerus, PhD Candidate and Psychologist, University Medical Center Utrecht, Utrecht, Netherlands

(3050) Self-Efficacy Predicts PROMIS Health-Related Quality of Life Outcomes in Turkish Dialysis Patients better than SF-36

Saynab Atiye, Fresenius Medical Care, Bad Homburg, Germany

(3054) Overcoming Screening Stigma Through the Patient Voice: Improving the Accuracy of Social Health Data Collection Through Multimedia Education

Caryn Lindsey, DSW, MSW, Cedars-Sinai Department of Orthopaedic Surgery, Los Angeles, California, United States

(3056) Durability and discordance between functional outcomes and patient satisfaction after lumbar surgery: a 2-year registry study

Ling Jie Cheng, PhD, MPH, BSN (Hons), RN, National Perinatal Epidemiology Unit, Nuffield Department of Women's and Reproductive Health, University of Oxford, Oxford, United Kingdom

(3058) How many timepoints are enough? Rethinking long-term PRO modelling in oncology

Konstantina Skaltsa, PhD, IQVIA, Barcelona, Spain

(3060) Health-Related Quality of Life (HRQoL) of Children and Adolescents with Type-I Diabetes Mellitus (T1DM): A Quantitative Cross-Sectional Analytical Study at a Tertiary Care Hospital in Karachi, Pakistan

Laila Akbar Ladak, PhD, MScN, BScN, RN, The Aga Khan University, Karachi, Pakistan

(3062) Development and Validation of a Methodology for Collecting Free-Text Health Narratives for PROM Inference

Ellie Choi, MBBS, National University Hospital, Singapore, Singapore, Singapore

(3064) Quality of life characteristics in children born prematurely with extremely low and very low birth weight in Armenia

Razmik Dunamalyan, Lecturer, Y SMU, Yerevan, Armenia

(3066) A review of the recommendations and best practices when using existing linguistically validated translations in immigrant populations

Hayley Simpson-Finch, IQVIA, Reading, United Kingdom

(3068) Mapping algorithms for predicting EQ-5D-5L utilities from the Abnormal Involuntary Movement Scale (AIMS) in Tardive Dyskinesia

Tom Booth, Acaster Lloyd, London, United Kingdom

(3072) Identifying Patient and Treatment Predictors of Clinically Significant Fatigue Following Radiotherapy for CNS Tumors

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

(3074) Exploring Conceptual Differences Between Adult and Pediatric Informal Caregiver Quality of Life: A Framework-Based Analysis of Existing Instruments

Manami Takai, PhD student, Keio university, Tokyo, Japan

(3076) Identifying barriers and enablers to PROMs use in Costa Rica: development of an implementation science-based instrument

Clara Amat-Fernandez, MPH, Health Services Research Group, Hospital del Mar Research Institute, Barcelona, Spain

(3078) Measuring What Matters Beyond Function: Implementing LIMB Q Kids for Longitudinal Outcome Assessment in Patients with Lower Limb Differences

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

(3082) Content Validity of Overall Severity and Overall Interference Items in PRO-CTCAE Format

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

(3084) Evaluation of a Rasch-based algorithm for detecting and adjusting for recalibration response shift in multiple-group PRO studies: a simulation study in a three-group setting

Bastien Perrot, PhD, UMR INSERM 1246 SPHERE, Nantes, France

(3086) Linguistic Validation and Cultural Adaptation of the Japanese Version of WOUND-Q: A Qualitative Study of Patients with Chronic Wounds

Erika Kusajima, MD, PhD, Hakodate Central General Hospital, Hakodate, Japan

(3090) From Readiness to Routine Practice: Training Implications Across Pre- and Implementation Stages of a Person-Centred Outcome Measure in Community Dementia Care

Susanne de Wolf-Linder, PhD, MSc Palliative Care, RN, ZHAW Zurich University of Applied Sciences, Winterthur, Switzerland

(3092) Are proxy-reporters capable of completing a core-patient reported outcome measure set on behalf of individuals with genetic intellectual disabilities?

Alannah Hijlkema, MSc, Amsterdam UMC, Amsterdam, Netherlands

(3094) Health-related quality of life before and after coronary artery bypass grafting in patients with severe coronary artery disease

Tatjana Gazibara, MD, PhD, University of Belgrade, Belgrade, Serbia

Wednesday, 21 October

3:25 PM – 4:55 PM

Concurrent Oral Sessions

Oral Session 301: Patient and Public Engagement

Meridian

Session Chair: Leonie Young, DUniv, Australia

3:30 PM - 3:47 PM (301.1) Patient-led solutions to PRO collection in research and clinical practice

Christel McMullan, University of Birmingham, Birmingham, United Kingdom

3:47 PM - 4:04 PM (301.2) Adaptation of a legacy discrimination scale for use in clinical HIV care through use of transdisciplinary community partner board and patient cognitive interviews

Rob Fredericksen, PhD MPH, University of Washington, Seattle, Washington, United States

4:04 PM - 4:21 PM (301.3) Patient and Public Involvement and Engagement of People with Dementia in Research: A Meta-synthesis and Qualitative Interview Study of Contributions, Barriers and Evaluation Approaches

Jörg Meisser, MScN, ZHAW Zurich University of Applied Sciences, Winterthur, Switzerland

4:21 PM - 4:38 PM (301.4) Beyond the “Void”: Community Leader Perspectives on Determinants of PRO Engagement in Community Oncology

Manraj Kaur, Harvard University; Mass General Brigham, Boston, Massachusetts, United States

4:38 PM - 4:55 PM (301.5) Creating a ‘true sense of ownership’: A case study exploring the value and impact of PPIE in PRO research

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

Oral Session 302: Registries and PROs

Virgo & Leo

Session Chair: Robert Klaassen, MD FRCPC, Canada

3:30 PM - 3:47 PM (302.2) Blood Cancer Voices PROgram: Developing sustainable PRO collection infrastructure embedded within national registries and clinical care

Claudia Rutherford, PhD, The University of Sydney, Sydney, Australia

3:47 PM - 4:04 PM (302.1) Methods for Population-Level PRO Monitoring: Early Results from Automated ePRO Collection with Patient-Mediated EMR Access in a Decentralized Registry

Lisa Charlton, PhD, Castor, Hermitage, Pennsylvania, United States

4:04 PM - 4:21 PM (302.3) Quality of life in older long-term cancer survivors – results of a large registry-based mixed-methods study

Annika Waldmann, Prof. Dr., Institute for Social Medicine and Epidemiology, University of Lübeck, Lübeck, Germany

4:21 PM - 4:38 PM (302.4) Patient-Reported Outcomes Following Primary Stress Urinary Incontinence Procedures: Real-World Insights from Registry Data

Rasa Ruseckaite, Monash University, Melbourne, Australia

4:38 PM - 4:55 PM (302.5) Trajectory of Health-Related Quality of Life (HRQoL) in Inflammatory Arthritis: Insights from Routine Care in the Rheum4U Precision Health Registry

Ana Fuhrmann, PhD, University of Calgary, Calgary, Alberta, Canada

Wednesday, 21 October

3:25 PM – 4:55 PM

Concurrent Oral Sessions

Oral Session 303: AI in PROMs Methods

Taurus & Aquarius

Session Chair: Bryce Reeve, PhD, United States

3:30 PM - 3:47 PM (303.1) PRO development for heterogeneous populations using AI-supported concept elicitation: The Symptom Burden Questionnaire™ for Multiple Long -Term Conditions

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

3:47 PM - 4:04 PM (303.2) Development of an agentic artificial intelligence chatbot for dynamic assessment of patient-reported symptoms

Amylou Dueck, PhD, Mayo Clinic, Scottsdale, Arizona, United States

4:04 PM - 4:21 PM (303.3) Validity of artificial intelligence in capturing patient natural language adverse events post ambulatory cancer surgery—Prospective, concurrent validation against PRO-CTCAE

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

4:21 PM - 4:38 PM (303.4) Accelerating Thematic Analysis for PRO Development using GDPR-aligned LLM: A Feasibility Study with Human Comparison

Shannon Keith, GlaxoSmithKline, Philadelphia, Pennsylvania, United States

4:38 PM - 4:55 PM (303.5) Exploring patient and public perceptions of artificial intelligence in healthcare and health research contexts

Nicolas Hall, BSc, Sprout Health Solutions, London, United Kingdom

Oral Session 304: Pain

Kepler

Session Chair: Richard Sawatzky, PhD RN, Canada

3:30 PM - 3:47 PM (304.1) Analysis of Variability in Pain Response Set Composition and Design to Support Standardization and Improved Patient Experience

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

3:47 PM - 4:04 PM (304.2) Detecting and quantifying differential item functioning in a pain item bank using GRMTree: Implications for equity in patient-reported outcome measurement

Henry Michael, BPharm, MSc, PhD, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

4:04 PM - 4:21 PM (304.3) Measuring What Matters: Digital Storytelling as an Arts Based Approach to Quality of Life Research in Chronic Pain

Sandra Munro, PaCER, The University of Calgary, Calgary, Alberta, Canada

4:21 PM - 4:38 PM (304.4) Added value of equitable people-centred health measurement: A comparison with conventional measurement modalities for pain

Mathilde Verdam, PhD, Leiden University, Institute of Psychology, Department of Methodology & Statistics, Amsterdam, Netherlands

4:38 PM - 4:55 PM (304.5) Conceptual Ambiguity Of “Worst Pain Imaginable” In Patient-Reported Outcome (Pro) Pain Scales

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

Wednesday, 21 October

3:25 PM – 4:55 PM

Concurrent Oral Sessions

Oral Session 305: INDIV: Treatment Goals

Tycho

Session Chair: Devin Peipert, PhD, United Kingdom

3:30 PM - 3:47 PM (305.1) Longer Time in Control and Fewer Flare-Ups and Exacerbations: Qualitative Research with Patients to Characterise Asthma States and Define Treatment Goals

Katie Mellor, PhD, COA, Clarivate, London, United Kingdom

3:47 PM - 4:04 PM (305.2) Development and cognitive debriefing of the MACrO2 Patient Reported Outcome measure with a most bothersome symptom scoring approach in treatment-refractory MAC lung disease (TR-MAC-LD)

Larissa Stassek, MPH, PPD Evidera Patient-Centered Research, Part of Thermo Fisher Scientific, Waltham, Massachusetts, United States

4:04 PM - 4:21 PM (305.3) Using a Personalized Decision-Support Model for Predicting the Personal Meaningful Gain in Hand and Wrist Care: a Feasibility Study

Robbert Wouters, PhD, Depts. of Rehabilitation Medicine and Plastic, Reconstructive and Hand Surgery, Erasmus MC University Medical Center Rotterdam, Rotterdam, Netherlands

4:21 PM - 4:38 PM (305.4) Reducing Variability in Goal Attainment Scaling: Initial Reliability Testing of a Structured Goal Appraisal Framework

Gunes Sevinc, PhD, Ardea Outcomes, Vancouver, British Columbia, Canada

4:38 PM - 4:55 PM (305.5) Development of a Patient-Reported Outcomes Instrument on Patient Goals and Treatment Benefits in Post-COVID ("PBI-PoCO")

Katharina Hense, Dr., University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1) Enhancing Health-Related Quality of Life Assessment in Children with ADHD: Evaluating Cognition-related Bolt-On Items in EQ-5D-Y-3L and EQ-5D-Y-5L

Chenxi Yang, Msc, Department of Rehabilitation Sciences, Faculty of Health and Social Sciences, Hong Kong Polytechnic University, Kowloon, China (Hong Kong), Hong Kong, China

(2) Persistent Symptom Burden Related to ICI-Pneumonitis During the First Year of Survivorship After Chemoradiation for NSCLC

Xin Shelley Wang, MD, MPH, MD Anderson Cancer Center, Houston, Texas, United States

(3) Responsiveness and minimal important difference of the observer-reported outcome for children with cancer (ObsRO-CC)

Rui Zhou, Department of Social Medicine, School of Public Health, Zhejiang University School of Medicine, Hangzhou, China

(4) The Burden on Research Personnel During Longitudinal Data Collection of Patient-Reported Outcomes (PROs): A Convergent Mixed-Methods Study

Cheng Lei, Ph.D, The Affiliated Cancer Hospital of University of Electronic Science and Technology of China, Chengdu, China

(5) Perioperative Symptom Burden and Its Association with Postoperative Complications: Focus on Symptom Dynamics in Gynecologic Malignancies

Jingyu Zhang, PhD, Chongqing Medical University, Chongqing, China

(6) Opioid Use and Symptom Burden After Minimally Invasive Surgery for Early-Stage Non-Small Cell Lung Cancer: A Longitudinal, Propensity Score-Matched Study

Xing Wei, MD, Sichuan Cancer Hospital and Institute, Chengdu, China

(7) Quality of Life Assessment in Digital Mental Health Care for Rural Workers: Addressing Violence and Psychosocial Vulnerabilities in Brazil

Claudia Fegadolli, Doutora, Digital Health Hub of Universidade Federal de São Paulo, São Paulo, Brazil

(8) Engaging and Empowering Patients in Their Care Using Patient-Reported Outcomes

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

(9) APPLICATION OF THE LIFE QUALITY CRITERIA AS A STANDARD FOR THE HEALTH STATE COMPLEX EVALUATION OF IN THE EARLY AGE CHILDREN

Razmik Dunamalyan, Lecturer, Y SMU, Yerevan, Armenia

(10) The Use of a Quality of Life Assessment Instrument in the Implementation Process of Mental Health Actions at the Digital Health Hub of the University

Luciana Surjus, Ph. D., Fundação de Apoio à Universidade Federal de São Paulo, Santos, Brazil

(22) Relationship between number of medications and subjective well-being among older adults

Yuko Yoshida, Tokyo Metropolitan Institute for Geriatrics and Gerontology, Tokyo, Japan

(23) Correlation between individual patient-reported symptoms and overall symptom bother

Brenda Ginos, MS, Mayo Clinic, Department of Quantitative Health Sciences, Scottsdale, Arizona, United States

(25) Longitudinal Responsiveness of the Modular Quality of Life Assessment Tool for Breast Cancer (mQOL-BC) Across Multiple Treatment Modalities

Ru Meng, Ph.D, Shanxi Key Laboratory of Cervical Disease Research, Jincheng People's Hospital, Jincheng, China

(26) Crowdsourcing patient-reported outcomes in a diverse international sample using an online platform

Amylou C Dueck, PhD, Mayo Clinic, Scottsdale, Arizona, United States

(27) From Rights to Resilience: A Pragmatic Gap Analysis of Nigeria's Ageing Policies for Frailty Mitigation and Health-Related Quality of Life

Ifeoma Blessing Nwosu, MSc in orthopedic and sports Physiotherapy, Department of Medical Rehabilitation, Faculty of Health Science and Technology, College of Health Sciences, Nnamdi Azikiwe University Awka, Awka, Nigeria

(28) Country outweighs sex: Cross-national variation in self-reported well-being in Türkiye and the United States

Ege Şırlakoğlu, Independent Researcher, Eskişehir, Turkey

(29) Developer Deep Dive, A Reflection on AI Requirements in COA Measure Copyright Agreements

Melinda Johnson, RWS, Cary, North Carolina, United States

(30) Within-trial Qualitative Interviews: Regulatory Considerations and Case Example

Maile Diaz, MBA, Food and Drug Administration, Silver Spring, Maryland, United States

(31) Informing Active Living and Cognitive Health Policy Using the C3Q (Communicating Cognitive Concerns): Integrating Patient-Reported Evidence Into Decision-Making

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

(32) Representing all patient voices: Recommendations for increasing accessibility in remote interviews

Elizabeth Collins, PhD, Clarivate, London, United Kingdom

(35) A user-centered development and evaluation of an electronic outcome assessment system in stroke trials

Tolulope Sajobi, University of Calgary, Calgary, Alberta, Canada

(40) High Quality of Life, Low Wellbeing - A Hidden Paradox. Evidence from a General Population Study

Urszula Religioni, Prof., School of Public Health, Centre of Postgraduate Medical Education, Warsaw, Poland

(49) Comparative performance of humans versus GPT-5.3 in Assessing quality of PRO reporting in cancer trials using the CONSORT-PRO recommendations

Serena Puglia, MSc, Data Center and Health Outcomes Research Unit, Italian Group for Adult Haematologic Diseases (GIMEMA), Rome, Italy

(52) Using machine learning to capture patient-reported outcome data from semi-structured datasets in ophthalmology

Jan H. Terheyden, MD, University Hospital Bonn, Department of Ophthalmology, Bonn, Germany

(53) Magdeburg Urinary Tract Infection – Daily Impact Assessment Scale (MUTI-DIAS): psychometric validation of an outcome measurement instrument to assess the impact of uncomplicated urinary tract infection on daily activities in women

Katharina Piontek, Dr., Otto-von-Guericke University Magdeburg, Medical Faculty, Magdeburg, Germany

(56) Performance of Missing Data Handling Approaches for Perioperative Studies with Longitudinal Patient-Reported Outcomes: A simulation study using real-world data

Shizhu Li, PHD, Chongqing Medical University, Chongqing, China

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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 8 October 2026. For the most updated version of the final program, reference the mobile app.

(57) Regulatory Expectations for Qualitative Patient Experience Data: A Critical Review of Evolving Methodological Standards Across Selected Regulatory Agencies

Beth Gibson, PhD, RTI-HS, Manchester, United Kingdom

(58) Relationships between validated and flexible data capture metrics in Atopic Dermatitis

Sarah Villard, PhD, Folia Health, Boston, Massachusetts, United States

(60) Responsiveness of EQ-5D-5L Versus PROPr in Pregnant Women: A Longitudinal Cohort Study

Xiaodan Tang, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

(61) The specific challenge ePROMs pose for Implementation Research

Johannes Kögel, Dr.rer.soc., Otto von Guericke University Magdeburg, Magdeburg, Germany

(64) Visualizing response shift analysis results from Patient-Reported Outcomes data: an application using the Hospital Anxiety and Depression Scale (HADS) collected during the treatment phase of breast cancer

Angèle Boisbras, Master's Student, UMR Inserm 1246 SPHERE, Nantes, France

(65) Meeting Health Authority Standards Together: A New Open-Access Handbook for Psychometricians

Elisabeth Berger, Master's Degree, Seeing Theta, Paris, France

(66) Semantic analysis of the SOC-29 scale to measure sense of coherence.

Joel Alcantara, DC, PhD, ICPA, Los Gatos, California, United States

(68) Considerations for improving inclusivity and accuracy when generating evidence to support the development of sexual health patient-reported outcome measures

Laura Grant, Adelphi Values – Patient-Centered Outcomes, Bollington, United Kingdom

(69) AutoSocratic AI: Improving Data Fidelity and Reducing Recall Bias in Patient-Reported Outcome Measures

Olov Berg, University of California, Irvine, Newport Beach, California, United States

(73) The Study of Development and Attribute Evaluation of TCM Hepatobiliary Disease-Syndrome Scale

Zhengkun Hou, The First Affiliated Hospital, Guangzhou University of Traditional Chinese Medicine, Guangzhou, China

(74) Development and Psychometric Property Evaluation of the Traditional Chinese Medicine Syndrome Scale for Spleen and Stomach System Diseases

Zhengkun Hou, The First Affiliated Hospital, Guangzhou University of Traditional Chinese Medicine, Guangzhou, China

(83) Perioperative patient-reported outcome data produce larger anchor-based minimally important differences than postoperative data

Ling Jie Cheng, PhD, MPH, BSN (Hons), RN, National Perinatal Epidemiology Unit, Nuffield Department of Women's and Reproductive Health, University of Oxford, Oxford, United Kingdom

(84) Climate vulnerability and symptom presence in adult survivors of childhood cancer: Results from the Childhood Cancer Survivor Study

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

(85) Experiences of patients prescribed medicinal cannabis in Australia long-term: A qualitative study

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

(86) Designing for Sustainability: Lessons from a Patient Advisory Council Supporting Clinical Communication

Veronika Kiryanova, PhD, PaCER, University of Calgary, Calgary, Alberta, Canada

(88) Pediatric Dentistry: Development of a Gamified Digital Intervention to Support Oral Health-Related Quality of Life Assessment

Pedro Lopes Ferreira, CEISUC, Centre of Investigation in Technologies and Centre for Health Studies and Research of the University of Coimbra, PhD, Coimbra, Portugal

(89) Methodological considerations for conducting qualitative patient experience research with individuals affected by cognitive impairment.

Helen Reohorn, Adelphi Values, Macclesfield, United Kingdom

(90) PROMs utilized in contemporary hand surgery research are infrequently well-validated or interpreted with clearly defined clinical meaning values

Madeline Mueller, BS, MS, University of Missouri - Columbia, Columbia, Missouri, United States

(91) The Unknowns of Elective Hand Surgery from a Patient Perspective: Unmet Expectations Influence Patient Reported Outcomes

Madeline Mueller, University of Missouri - Columbia, Columbia, Missouri, United States

(92) Psychometric Evaluation of the Albanian EORTC QLQ-C30 and QLQ-BN20 in Patients with Primary Brain Tumors

Mitilda Gugu, Ph.D, University of Elbasan Aleksander Xhuvani, Elbasan, Albania

(93) Longitudinal Changes in Multidimensional Health-Related Quality of Life Following Outpatient Rehabilitation After Convalescent Ward Discharge: Divergent Trajectories of EQ-5D-5L and SF-12

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

(94) Patient-reported outcome use in orphan drug approvals and post-approval real-world evidence: a retrospective analysis, 2018-2025.

Erin Crutcher, MSG, MS HCDA, University of Southern California Mann School of Pharmacy and Pharmaceutical Sciences, Cypress, California, United States

(95) Effectiveness of Nudge Intervention Models in Convalescent Rehabilitation: A Longitudinal Study Focusing on ADL and HRQOL

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

(96) Baseline and Early Chemotherapy-Induced Symptom Changes Predict Overall Survival in Biliary Tract Cancer

Jingyu Zhang, Chongqing Medical University, Chongqing, China

(97) Feasibility of Electronic Patient-Reported Outcome Monitoring in Solid Tumor Daytime Chemotherapy: A Randomized Pilot Trial

Qiuling Shi, PhD in Epidemiology and Health Statistics, Chongqing Medical University, Chongqing, China

(98) Symptom Management in Gynecologic Malignancies: A Phase I Feasibility Study of a Digital Monitoring, Alerting, and Intervention Platform Using Patient-Reported Outcomes

Qiuling Shi, School of Public Health, Chongqing Medical University, Chongqing, China; State Key Laboratory of Ultrasound in Medicine and Engineering, Chongqing Medical University, Chongqing, China

(99) Development and Validation of a Generic Physical Functioning Module: A LEGO-Inspired Building Block for Modular PRO Assessment Across Cancer Populations

Qiuling Shi, Chongqing Medical University, Chongqing, China