

### **ISOQOL 32nd Annual Conference**

Final Program Oral/Poster Presentations

22-25 October 2025 Milwaukee, Wisconsin, USA

## (1001) Refining well-being measures for Sweden's ageing population: Through a cognitive testing approach

Marie-Louise Möllerberg, PhD, Malmö university, Malmö, Sweden

#### **OUTSTANDING POSTER AWARD FINALIST**

# (1002) Patient-Reported Outcome (PRO) Consortium's Chronic Heart Failure (CHF) Working Group: Collaboration on qualitative research to support qualification of a step count-based measure to evaluate physical activity in persons with CHF

Maria Mattera, MPH, Critical Path Institute, Tucson, Arizona, United States

#### **OUTSTANDING POSTER AWARD FINALIST**

### (1003) Symptom Severity and Quality of Life Among Long Term Metastatic Breast Cancer Survivors

Chloe Hery, Ph.D., The Ohio State University College of Medicine, Columbus, Ohio, United States

#### NEW INVESTIGATOR POSTER AWARD FINALIST

# (1004) Using self-reported measures to assess financial toxicity in cellular therapy patients with hematologic diseases in a US setting: A scoping review

Sarah Reed-Thryselius, MPH, Medical College of Wisconsin, Milwaukee, Wisconsin, United States

#### STUDENT POSTER AWARD FINALIST

# (1013) Assessing HIV treatment related worries and stigma: Psychometric properties of a novel, brief patient-reported outcome measure

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

# (1015) Patient-reported and transfusion-related outcomes in alpha- and beta-transfusion-dependent thalassemia: A multi-region real-world survey

Christina Chamberlain, Agios Pharmaceuticals, Cambridge, Massachusetts, United States

# (1017) Using a Multiple-Case Study Design to Explore the Experiences of Caregivers of Children with Rare Disease: Lessons Learned from a Study in Leukocyte Adhesion Deficiency, Type 1 (LAD-I)

Meaghan O'Connor, MTS, MPH, IQVIA, Providence, Rhode Island, United States

#### (1019) Clinical Symptom Profiles for People with Multiple Sclerosis

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

# (1021) Idiopathic multicentric Castleman disease symptom burden study (ISBUS): Emerging findings and insights

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

# (1023) Promoting professional well-being through resilience and self-care: A qualitative study Sabrina Figueiredo, PhD, The George Washington University, Washington, District Of Columbia, United States

# (1025) Intraclass Correlation Coefficients in Multilevel Structural Validation of Intensively Collected Questionnaires: A Targeted Literature Review

Dara O'Neill, IQVIA, Barcelona, Spain

### (1027) Mind mapping: an accessible solution for qualitative data collection and visual data summarization and dissemination

Kirsten Glynn, MPH, LUNGevity, Boston, Massachusetts, United States

### (1029) Incorporating Qualitative Data as Evidence into Rare Disease Clinical Development Programs: Leveraging the Rare Disease Clinical Outcome Consortium

Asha Hareendran, PhD, University of Bedfordshire, London, United Kingdom

### (1031) Migration inconsistencies in electronic Quality of Life (QOL) instruments in clinical trials Lindsay Hughes, IQVIA, New York, New York, United States

# (1033) Patient-reported walking difficulty predicting the post-discharge overall function in patients with lung cancer undergoing minimally invasive surgery

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

# (1035) Imputing item-level missingness in PRO data using continuous-time Markov models: a simulation study

Shizhu Li, Phd, Chongging Medical University, Chongging, China

#### (1037) Semantic analysis of the multidimensional health locus of control

Joel Alcantara, DC, PhD, The International Chiropractic Pediatric Association, San Jose, California, United States

# (1039) Development of a tree-based graded response model R package to test for differential item functioning in patient-reported outcome measures

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

# (1041) Derivation of a preference-based value set for the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) to allow calculation of Mental Well-being Adjusted Life Years (MWALYS)

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

# (1043) Patient-Reported Outcome Measures for Addiction Treatment: Development of a Digital Health Platform using a Patient-Centered Approach

Yolanda Pardo, PhD, Universitat Autònoma de Barcelona, Barcelona, Spain

### (1047) Mapping the Edmonton Symptom Assessment System-revised (ESAS-r) to the EQ-5D-5L in Patients with Cancer

Fatima Al Sayah, PhD, University of Alberta, Edmonton, Alberta, Canada

# (1049) Barriers and Facilitators to Implementation of Breast Cancer Digital Care Companion App in Community Oncology Settings

Amanda Higgins, MPH, Brigham and Woman's Hospital, Boston, Massachusetts, United States

### (1051) The Impact of Clinical Trial Participation on Quality of Life in Families Affected by Rare Disease

Aidan Leffler, University of Washington, Bellevue, Washington, United States

# (1053) Prognostic value of health-related quality of life for major adverse cardiovascular events in myocardial infarction patients: A systematic review of prognostic models.

Raghad AL-Kafawin, MD, MPH, University of leeds, Leeds, United Kingdom

# (1055) Advancing Reliable Measurement in Cognitive Aging and Decision-making Ability (ARMCADA): A pilot study on financial decision-making ability measures

Elizabeth Dworak, Northwestern University, Feinberg School of Medicine, Chicago, Illinois, United States

# (1057) Patient-reported outcome measures used for differences of sex development: readability analysis and content mapping

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

# (1059) Assessing linguistic and cultural appropriateness of patient-reported outcome measures (PROMs) for people with a migration background

Ellen Elsman, Amsterdam UMC, location University of Amsterdam, Epidemiology and Data Science, Amsterdam, The Netherlands, Amsterdam, Netherlands

### Oral Session 101: QOL in Population Health

Regency CD

Session Chair: Fatima Al Sayah, PhD, Canada

# 1:50 PM - 2:06 PM (101.1) Exploring Variability in EQ VAS scores: A Systematic Review and Meta-regression of Population Health Studies

Ling Jie Cheng, PhD, MPH, BSN (Hons), RN, National Perinatal Epidemiology Unit, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom

#### NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

# 2:06 PM - 2:22 PM (101.2) Holistic Health in Crisis: Identifying Key Health Issues and Behaviors Across 29 Nations

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

# 2:22 PM - 2:38 PM (101.3) Measuring What Matters in Primary Care: Health-Related Quality of Life and Its Predictors Among Users of Public Primary Care Clinics in Singapore Using the EQ-5D-5L

Ling Jie Cheng, PhD, MPH, BSN (Hons), RN, National Perinatal Epidemiology Unit, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom

# 2:38 PM - 2:54 PM (101.4) Exploring the Use of Health-Related Quality of Life Measures in Africa: A systematic scoping reviefayedw

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

# 2:54 PM - 3:10 PM (101.5) Financial toxicity and health: Results from a U.S. nationally representative survey

Oyiza Usman, M.D., Medical College of Wisconsin, Milwaukee, Wisconsin, United States

#### Oral Session 102: Hematology

**Executive A** 

Session Chair: Fabio Efficace, PhD, Rome

# 1:50 PM - 2:06 PM (102.1) Update of the EORTC Multiple Myeloma module (QLQ-MY20): Results from qualitative interviews with patients and healthcare professionals

Kim Cocks, PhD, Adelphi Values Ltd, Bollington, United Kingdom

# 2:06 PM - 2:22 PM (102.2) Association between patient-reported adverse events (AEs) and health-related quality of life (HRQoL) in chronic myeloid leukemia (CML) – Analysis of PRO-CTCAE and PROMIS Global Health measures

Kelly Schoenbeck, MD, University of California San Francisco, Division of Hematology and Oncology, San Francisco, California, United States

# 2:22 PM - 2:38 PM (102.3) Steroid-toxicity in newly diagnosed patients with multiple myeloma treated with a limited dexamethasone regimen; results from the NMSG REST study

Lene Kongsgaard Nielsen, PhD MD, Quality of Life Research Center, Odense University Hospital, Odense, Denmark

# 2:38 PM - 2:54 PM (102.4) Patient Reported Outcome Data for Daratumumab Treatment Readiness in Multiple Myeloma; Assessing the Feasibility

Tine Rosenberg, Cand scient, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark

# 2:54 PM - 3:10 PM (102.5) Qualitative research to understand the burden of disease and concept relevance of the PROMIS-Fatigue for patients with sickle cell disease

Phoebe Wright, PharmD, MS, Agios, Seattle, Washington, United States

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### Oral Session 103: Physical Function Assessment

**Executive B** 

Session Chair: Aaron Kaat, PhD, United States

## 1:50 PM - 2:06 PM (103.1) Linking the Physical-Performance Test to the PROMIS physical function metric: results from a prospective multicenter study

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 ORAL PRESENTATION AWARD FINALIST

2:06 PM - 2:22 PM (103.2) Embedded cognitive debriefing to assess content validity of physical function performance outcome measures in a multi-condition validation study Courtney Hurt, MSW, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

# 2:22 PM - 2:38 PM (103.3) Can patient-reported and performance-based physical function measures similarly predict mortality?

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

2:38 PM - 2:54 PM (103.4) The Northwestern University Clinical Outcome Assessment Team (NUCOAT) Project: Overview of Development of Cross-Cutting Physical Function Measures for Regulatory Use in Sarcopenia and Rare Disorders

Maja Kuharic, PhD, Msc, MPharm, Northwestern University, Chicago, Illinois, United States

2:54 PM - 3:10 PM (103.5) Identifying patients with delayed physical function recovery after solid organ transplantation using supervised cluster analysis of longitudinal PROMIS□ Physical Function scores

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

#### Oral Session 104: PROM Development & Validation

**Executive CD** 

Session Chair: Philip Powell, PhD, United Kingdom

1:50 PM - 2:06 PM (104.1) The caregiver experience in amyotrophic lateral sclerosis (ALS): a mixed-methods study to examine the lived experience of caring for people living with ALS and to develop a novel ALS Caregiver Impact Questionnaire (ALS-CIQ)

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

2:06 PM - 2:22 PM (104.2) Developing a person-centered measure for contraceptive side effects

Amelia Mackenzie, PhD, ScM, FHI 360, Annapolis, Maryland, United States

2:22 PM - 2:38 PM (104.3) Validation of a novel patient-reported outcome instrument assessing atopic dermatitis-associated xerosis in patients with skin of color

Christopher Hartford, Regeneron Pharmaceutical Inc., Tarrytown, New York, United States

2:38 PM - 2:54 PM (104.4) Psychometric properties of cognition bolt-ons for the EQ-5D-3L and EQ-5D-5L: a systematic review

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

2:54 PM - 3:10 PM (104.5) Development of a Nontuberculous Mycobacterial Symptom Scale (NTM-SS): Psychometric Analysis and Proposed Scale

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

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### 3:20 PM - 4:00 PM

### (1005) Expansion of the Rare Disease Clinical Outcome Assessment (COA) Resource, a Tool to Aid in COA-derived Endpoint Selection

Lindsey Murray, PhD, Critical Path Institute, Tucson, Arizona, United States

#### **OUTSTANDING POSTER AWARD FINALIST**

# (1006) Building better patient recruitment strategies: What the FDA recommends and how researchers are listening

Amanda Roussel, Adelphi Values Patient-Centered Outcomes, Boston, Massachusetts, United States

#### NEW INVESTIGATOR POSTER AWARD FINALIST

# (1007) Comparing Linking Approaches for Patient Reported Outcomes under Non-Normal Distribution: A Monte Carlo Simulation Study

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

#### STUDENT POSTER AWARD FINALIST

# (1008) Characterizing disease-related stigma and treatment-related stigma among people with HIV: insights from BEYOND

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

#### **OUTSTANDING POSTER AWARD FINALIST**

### (1014) Ascertainment of Minimal Clinically Important Differences in the Chronic Prostatitis Symptom Index

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

# (1016) Enhancing health-related quality of life for care partners of individuals with traumatic brain injury: A randomized controlled trial of the CareQOL mobile health intervention

Noelle Carlozzi, PhD, University of Michigan, Ann Arbor, Michigan, United States

# (1018) Consumer perspectives towards patient reported measures in clinical quality registries Rasa Ruseckaite, PhD, Monash University, Melbourne, Australia

# (1020) Meaningful within-patient change of PROMIS-Fatigue in patients with cancer cachexia in the phase 2 ponsegromab study

Jarjieh Fang, Pfizer, New York, New York, United States

### (1022) Lessons learned from the development and implementation of an electronic patientreported outcomes platform (MyPRO) in a Toronto community health clinic serving racialized immigrant and refugee women

Kirsten Wade, MPH, Syneos Health, Morrisville, North Carolina, United States

# (1024) Mediating effects of diabetes distress on glycemic level and health-related quality of life among patients with type 2 diabetes mellitus: a cross-sectional study

Huayu Li, Department of Social Medicine of School of Public Health, and Department of Pharmacy of the First Affiliated Hospital, Zhejiang University School of Medicine, China

# (1026) Regional influences on quality of life in leukaemia patients: uncovering key predictors for personalised care.

Sam Salek, PhD RPh FFPM/FRCP GFMD MCMS FRPS FESCP, University of Hertfordshire, Hatfield, United Kingdom

### (1028) Assessing CFA model fit criteria in data conditions resembling clinical trials: A simulation study

Brandon Foster, PhD, Lumanity, Boston, Massachusetts, United States

### (1032) Psychometric Properties of the Subcutaneous Administration Assessment Questionnaire (SQAAQ)

Chisom Kanu, RPh, PhD, Eli Lilly and Company, Indianapolis, Indiana, United States

# (1034) Association between socio-economic status and health-related quality of life in patients with relapsed/refractory multiple myeloma treated in countries with universal healthcare system and the mediating role of financial difficulties

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

# (1036) From Data Overload to Insight: Interactive visualisation of PRO-CTCAE Data with an R Shiny Tool

Kim Cocks, PhD, Adelphi Values, Manchester, United Kingdom

# (1038) Implementation Strategies for Electronic Patient-Reported Outcomes (ePRO)-Based Cancer Symptom Management in Chinese Primary Care Settings

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

# (1040) Contribution of patient-reported versus clinician-reported outcomes to core domain sets and differences in expert and patient voting patterns across these domains.

Zachary Hopkins, MD, University of Utah Health, Salt Lake City, Utah, United States

# (1042) Cross-Cultural Adaptation and Psychometric Validation of the Danish and Norwegian Versions of the Steroid Symptom Questionnaire for Multiple Myeloma (SSQ-MM)

Tine Rosenberg, Cand scient, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark, Odense, Denmark

# (1044) Validation of the Treatment-Induced Neuropathy Assessment Scale (TNAS) in Chinese Cancer Patients: a prospective cohort study

Fan Li, Chongqing Medical University, Chongqing, China

# (1046) Needs and health-related quality of life domains relevant to people in Europe undergoing cancer treatment: A systematic review of qualitative research

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

# (1048) Impact of fruits and vegetable intake on HRQoL: Results from a randomized trial comparing produce prescription delivery modes

Corneliu Bolbocean, University of Oxford, Oxford, Arkansas, United Kingdom

### (1050) Optimizing Color Schemes for Graphs: Enhancing Accessibility and Inclusivity

Matthew O'Brien, Adelphi Values, Boston, Massachusetts, United States

# (1052) Adaptation of Goal Attainment Scaling for Prader Willi Syndrome (PWS): Development of a Goal Inventory for Standardized Implementation

Gunes Sevinc, Ph.D., M.Sc., B.Sc., Ardea Outcomes, Vancouver, British Columbia, Canada

# (1054) Understanding health-related quality of life and experience of care in individuals with face transplantation

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

### (1056) Scientific best practices in electronic clinical outcome assessments: a literature review from past to present

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

# (1058) Design and Implementation of an Optimized ePRO System for Thoracic Surgery Patients (Recovery Monitor): a study protocol

Gita Mody, MD, MPH, UNC School of Medicine, Chapel Hill, North Carolina, United States

# (1060) Characterizing Variability in Patient Global Impression of Change (PGIC) and Severity (PGIS) Measures: Towards Standardization of PRO Design to Improve Development, Comparability, Translatability, and the Patient Experience

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

# (1062) Perceived stress, coping strategies and associated factors among Colombian undergraduate health science students

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

# (1064) Quality of Life and Return to Duty and Combat Readiness Among Obese Active-Duty and Retired Military Personnel with Low Back Pain and other Spine Conditions: A Scoping Review Amy Cizik, PhD, MPH, University of Utah, Salt Lake City, Utah, United States

# (1066) An "argument-based" approach to validity applied to an endocrine therapy measure of "medication usage"

Kyra Kapsaskis, BA, UNC - Chapel Hill, Chapel Hill, North Carolina, United States

# (1068) Quality of Life in the Early Period After Allogeneic Hematopoietic Stem Cell Transplantation: Dynamics and the Impact of GVHD

Gabriela Lampart, Jagiellonian University Medical College, Doctoral School of Medical and Health Sciences, Krakow, Poland, Kraków, Poland

# (1070) Design and Implementation of Data Quality Controls in the EQ-DAPHNIE Study: Insights from the Pilot Phase and 15-Country Analysis

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

# (1072) Development and Content Validation of a Survey Instrument to Assess Physician Attitudes Toward Real-World Evidence in U.S. Cancer Care Using Modified COSMIN Methodology

Sabrina Figueiredo, PhD, Mac, George Washington University School of Medicine and Health Sciences, Washington, District Of Columbia, United States

### Oral Session 106: Head Neck & Lung

**Regency CD** 

Session Chair: Kathleen Yost, PhD, United States

4:10 PM - 4:26 PM (106.1) Beyond Treatment Costs: Financial Hardship, Symptom Burden, and Long-term Complications in Head and Neck Cancer Survivors

Eden Brauer, UCLA, Los Angeles, California, United States

**4:26 PM - 4:42 PM** (106.2) Network Analysis of Symptom Clusters in Head and Neck Cancers Xiaodan Tang, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

4:42 PM - 4:58 PM (106.3) Experience of symptoms related to dysarthria in patients with nasopharyngeal carcinoma during radiotherapy: A descriptive qualitative study Fan Li, Chongging General Hospital, Chong Qing, China

4:58 PM - 5:14 PM (106.4) Development and Validation of the Postoperative Recovery Assessment in Lung Cancer (PRA\_Lung): A Modular Patient-Reported Outcome Measure Cheng Lei, Ph.D, Sichuan Cancer Hospital and Institute, Chengdu, China

5:14 PM - 5:30 PM (106.5) Reliability and validity tests of the ISA Lung Symptom Scale reported by patients undergoing immunotherapy for lung cancer
Jingyu Zhang, ChongQing Medical University, Chong Qing, China

### Oral Session 107: PROMs in Clinical Practice

**Executive A** 

Session Chair: Norah Crossnohere, PhD, United States

4:10 PM - 4:26 PM (107.1) Bridging the gap: A conceptual framework for integrating Patient Reported Outcome Measures throughout the process of Shared Decision Making in clinical care Anouk Groenewegen, MSc, Department of Child and Adolescent Psychiatry and Psychosocial Care, Amsterdam UMC, University of Amsterdam, Emma Children's Hospital, Amsterdam, Netherlands

### STUDENT ORAL PRESENTATION AWARD FINALIST

4:26 PM - 4:42 PM (107.2) Integrating PROMs into chronic disease management: A qualitative examination of patient and clinician views on PROM acceptability and timing Claudia Rutherford, PhD. University of Sydney, Sydney, New South Wales, Australia

4:42 PM - 4:58 PM (107.3) Patient education on patient-reported outcome measure completion in clinical care settings: a scoping review

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

4:58 PM - 5:14 PM (107.4) Evaluating patient reported outcome measures (PROM) implementation initiatives in cancer care organizations: A systematic review and recommendations for standardizing terminology

Angela Stover, PhD, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, United States

5:14 PM - 5:30 PM (107.5) Developing PROM-GRIP: a reporting guideline for the integration or use of PROMs in clinical practice

Ellen Elsman, PhD, Department of Child and Adolescent Psychiatry and Psychosocial Care, Amsterdam UMC, Emma Children's Hospital, Amsterdam, Netherlands

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

### Oral Session 108: COAs in Clinical Trials

**Executive B** 

Session Chair: Kevin Weinfurt, PhD. United States

4:10 PM - 4:26 PM (108.1) Consensus-Based Recommendations for Designing, Analyzing, Interpreting, and Presenting Patient-Reported Outcomes in Cancer Clinical Trials Kate Sandberg, AbbVie Inc., North Chicago, Illinois, United States

4:26 PM - 4:42 PM (108.2) How are digital COA endpoints defined? Some examples from current efforts in drug development

Konstantina Skaltsa, IQVIA, Barcelona, Spain

4:42 PM - 4:58 PM (108.3) Stakeholder perspectives on possible open-label bias of patientreported outcome results from cancer randomized controlled trials: the IMPROvE Project Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Data Center and Health Outcomes Research Unit, Rome, Italy

4:58 PM - 5:14 PM (108.4) Perceived Burden of Completing Patient-Reported Outcome Measures: Qualitative Interviews with Oncology Clinical Trial Participants

Ashley Geiger, PhD, Takeda Development Center Americas, Inc., Lexington, Massachusetts, United States

5:14 PM - 5:30 PM (108.5) Meaningful tolerability endpoints to capture the dynamics of sideeffect experience of cancer treatment

Konstantina Skaltsa, PhD, IQVIA, Barcelona, Spain

#### Oral Session 109: Older Adults

**Executive CD** 

Session Chair: Amy Cizik, PhD MPH, United States

(109.1) A gender disaggregated growth curve analysis of mobility decline 4:10 PM - 4:26 PM and its sociodemographic correlates among community-dwelling older Nigerians

Ogochukwu Kelechi Onyeso, PhD, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada

4:26 PM - 4:42 PM (109.2) Comparing age-specific and generic well-being scales: A systematic review and content analysis for older adults

Marie-Louise Möllerberg, PhD. Malmö university, Malmö, Sweden

4:42 PM - 4:58 PM (109.3) Comparative performance of the EQ-5D-5L and PROMIS-10 in the elderly: Data from the EQ-DAPHNIE project in five countries

Fatima Al Sayah, Alberta PROMs and EQ-5D Research and Support Unit (APERSU) School of Public Health, University of Alberta, Edmonton, Alberta, Canada

4:58 PM - 5:14 PM (109.4) A pilot study of emotion and non-cognitive measures of decisionmaking ability in older adults within ARMCADA

Elizabeth M. Dworak, PhD, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

5:14 PM - 5:30 PM (109.5) Fear of falling as a personality-mediated experience: older adults' adaptation and identity in a shifting embodied world

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

### Concurrent Oral Sessions

### Oral Session 110: Mental Health

Milwaukee

Session Chair: David Churchman, PhD MSc, United Kingdom

### 4:10 PM - 4:26 PM (110.1) Prioritizing the Health and Well-Being of Frontline Healthcare Professionals in Canada

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

4:26 PM - 4:42 PM (110.2) Leveraging artificial intelligence (AI) for implementation of patient-reported outcome measures (PROMs) systems in mental health care

Amber Bailey, MHS, Sheppard Pratt, Baltimore, Maryland, United States

4:42 PM - 4:58 PM (110.3) Assessing ADHD in Psychiatric Care: Standardized Assessment and a Novel ADHD Assessment, Developed by Clinicians with Generative Al

Amber Bailey, MHS, Sheppard Pratt, Baltimore, Maryland, United States

4:58 PM - 5:14 PM (110.4) Valbenazine improves the impacts and symptoms of tardive dyskinesia: topline results from the phase 4 KINECT-PRO study

Morgan Bron, MS, PharmD, Neurocrine Biosciences, Inc., San Diego, California, United States

5:14 PM - 5:30 PM (110.5) Association between concerns about AI in healthcare and self-reported anxiety among cancer survivors

Maria Rincon, PhD MPH, National Cancer Institute, Rockville, Maryland, United States

9:35 AM - 10:15 AM

# (1009) Can Al contribute to the development of a conceptual model of the patient experience? A feasibility assessment.

Elizabeth Collins, PhD, Clarivate, London, United Kingdom

#### NEW INVESTIGATOR POSTER AWARD FINALIST

# (1010) Meaningful change in adult attention-deficit/hyperactivity disorder (ADHD): Using vignettes to estimate thresholds for meaningful improvement and deterioration in scores on the Adult ADHD Investigator Symptom Rating Scale (AISRS)

Dorothee Oberdhan, PhD, Otsuka Pharmaceutical Development & Commercialization, Inc., Rockville, Maryland, United States

#### **OUTSTANDING POSTER AWARD FINALIST**

# (1011) Differential item functioning of the PROMIS sleep disturbance – short form 8a across levels of health literacy in a community sample of adults

Rowida Mohamed, PhD, Pritzker School of Medicine, The University of Chicago, Chicago, Illinois, United States

#### **OUTSTANDING POSTER AWARD FINALIST**

(1012) Artificial intelligence meets clinical trial design: A test case in predicting patient achievement of minimal significant difference using conditional generative adversarial networks Siddharth Kakked, MBBS, MPH, OPEN Health, Falmouth, Maine, United States

#### STUDENT POSTER AWARD FINALIST

# (2013) Reliability of "baseline" scores for traumatically injured patients: advantages of using the Patient-Reported Measurement Information System (PROMIS) domains

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

# (2015) Comparison of the EQ-5D-5L cognition bolt-on and EQ-HWB cognition items: Results from EQ-DAPHNIE data in China and Japan

Fatima Al Sayah, PhD, University of Alberta, Edmonton, Alberta, Canada

### (2017) Symptom burden after dialysis initiation and associations with hospitalizations

Devin Peipert, PhD, University of Birmingham, Birmingham, Illinois, United Kingdom

# (2019) Administering in-trial interviews using an Al chatbot: results of a proof of principle experiment

Bill Byrom, PhD, Signant Health, Nottingham, United Kingdom

# (2021) Psychometric Validation of the Weight and Emotions Scale (WES) in Adults with Obesity or with Overweight and Obesity-related Complications

Chisom Kanu, RPh, PhD, Eli Lilly & Company, Indianapolis, Indiana, United States

# (2023) Psychometric properties of Dutch-Flemish PROMIS Sleep measures in Dutch childhood cancer patients receiving follow-up care

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

# (2025) Impact of transfusion dependent alpha- and beta-thalassemia on adult patients' health-related quality of life and work productivity: A multi-region real-world survey

Christina Chamberlain, Agios Pharmaceuticals, Cambridge, Massachusetts, United States

#### 9:35 AM - 10:15 AM

(2027) Capturing the Impact of Facioscapulohumeral Muscular Dystrophy (FSHD) on Healthrelated Quality of Life (HRQoL): a systematic review of the reliability and validity of existing selfreport instruments using COSMIN

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

### (2031) Cognitive Assessment in Schizophrenia: A Landscape Review of Instruments and Core Domains

Angela Stroupe, MA, Parexel, Boston, Massachusetts, United States

# (2033) Subgroup or principal stratum analysis? A comparison and guidance for use of the principal stratum framework for COA endpoints

Konstantina Skaltsa, PhD, IQVIA, Barcelona, Spain

# (2035) Mapping Treatment-Induced Adverse Events against HRQoL Questionnaires in Non-Small Cell Lung Cancer: Evaluation of the EORTC QLQ-C30 and QLQ-LC29

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

### (2037) Physical functioning measures by PROs on MDASI-Lung and 6-minute walk test during first year after chemoradiation and immunotherapy for NSCLC.

Shu-En Shen, The University of Texas MD Anderson Cancer Center, Houston, Texas, United States

### (2039) Impact of Diabetes on Patient-Reported Outcomes After Lung Resection: A Prospective Cohort Study

Wei Dai, Sichuan Cancer Hospital and Institute, Chengdu, China

# (2041) Dynamic Screening Nutritional Risk Index on Treatment Tolerance and Hospitalization Costs in Cancer Patient: A 3-Year Longitudinal Cohort Study Title page

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

# **(2043) Meaningful changes in physical function and pain in patients with knee osteoarthritis** Xiaodan Tang, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

# (2045) Meaningful within-patient change of PROMIS-Physical Function in patients with cancer cachexia in the phase 2 ponsegromab study

Jarjieh Fang, Pfizer, New York, New York, United States

# (2047) Evaluation of digital readiness in pulmonary hypertension: a study on health technology implementation and professional insights

Frances Varian, MBChB, MRCP(UK), University of Sheffield, Sheffield, United Kingdom

# (2049) Study on Perioperative Symptom Trajectories in HPV-Infected Patients Based on Patient-Reported Outcomes

Dengfeng Chen, Chongqing Medical University, Chongqing, China

# (2051) Linguistic and cross-cultural validation of the BODY-Q modules included in the Obesity ICHOM Set for their use in the Spanish and Catalan population

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

# (2053) Meaningful within-patient change assessment of the Quality of Life-Bronchiectasis Questionnaire Respiratory Symptom score (QOL-B RSS)

John Fastenau, Insmed Incorporated, Bridgewater, New Jersey, United States

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9:35 AM - 10:15 AM

Friday Poster Session 201

Regency AB

# (2055) Methodological considerations for developing an Investigator Global Assessment (IGA) for use in dermatological studies

Sarah Bentley, Adelphi Values Ltd, United Kingdom

(2057) Future of Linguistic Validation: Will Machine Translation replace or augment LingVal? Willie Muehlhausen, SAFIRA, Cloughjordan, Ireland

### (2059) GenAl in Action: A Study on the Efficacy of Al Comparative Review Output

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

# (2061) Title: Searching Smarter: Using Linguistics to Improve Symptom Reporting for Children with Cancer

Stacey Crane, PhD RN CPON, University of Texas Health Science Center at Houston, Houston, Texas, United States

1:30 PM - 3:00 PM

Concurrent Oral Sessions

### Oral Session 201: Pancreatic Cancer

Regency CD

Session Chair: Anne Marie Lunde Husebø, PhD, Norway

1:35 PM - 1:51 PM (201.1) Patient-reported outcomes (PROs) in the pragmatic comparative effectiveness trial of surgical versus nonsurgical management for patients with malignant bowel obstruction (S1316)

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

1:51 PM - 2:07 PM (201.2) Patient-Reported Health Status Predicts Survival in Pancreatic Cancer: A Prospective Multicenter Cohort Study

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

2:07 PM - 2:23 PM (201.3) Tai Chi Game Theory of Psychological Resilience in Pancreatic Cancer Patients: Based on Grounded Theory

Wen Zhou, State Key Laboratory of Ultrasound in Medicine and Engineering, Chongqing Medical University, Chongqing, China

2:23 PM - 2:39 PM (201.4) Pain Trajectory between Survival and Death Groups after Pancreatic Cancer Diagnosis: a Multicenter Longitudinal Cohort Study

Wen Zhou, State Key Laboratory of Ultrasound in Medicine and Engineering, Chongqing Medical University, Chongqing, China

2:39 PM - 2:55 PM (201.5) Investigating the Mediating Effects within the Causal Chain of "FUAS Treatment—Pain Symptom Trajectory—Quality of Life" in Advanced Pancreatic Cancer Patients

Qiuling Shi, Chongqing medical university, Dr, Chongqing, China

#### Oral Session 202: Methods: DIF, Response Shift & Missing Data

**Executive A** 

Session Chair: Lori McLeod, PhD, United States

1:35 PM - 1:51 PM (202.2) Response Shift in Patient-Reported Outcome Assessment among Older People Living with HIV/AIDS

Huayu Li, Department of Social Medicine of School of Public Health, and Department of Pharmacy of the First Affiliated Hospital, Zhejiang University School of Medicine, China

1:51 PM - 2:07 PM (202.3) A tree-based graded response theory model to test for differential item functioning in patient-reported outcome measures

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

2:07 PM - 2:23 PM (202.4) Evaluation of demographic DIF in the PROMIS and EORTC cognitive function measures in a nationally representative US sample

Miranda Kapfhammer, Medical College of Wisconsin, Milwaukee, Wisconsin, United States

2:23 PM - 2:39 PM (202.5) Predictors of missing instruments in a postoperative lung cancer cohort

Shizhu Li, Chongging Medical University, China

Oral Session 203: Decision Making in Diagnosis Treatment & Monitoring

**Executive B** 

Session Chair: Kathrin Fischer, PhD, Germany

1:35 PM - 1:51 PM (203.1) Implementation of PROMIS Global Health as a Screener to Trigger Construct-Specific PROs in Clinical Care: a mixed methods study of patients' perspectives

Brittany Lapin, PhD MPH, Cleveland Clinic, Cleveland, Ohio, United States

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### 1:30 PM - 3:00 PM

#### **Concurrent Oral Sessions**

### 1:51 PM - 2:07 PM (203.2) Assessment of patient needs and treatment benefits - a scoping review on the Patient Benefit Index (PBI)

Stefanos Boudouroglou-Walter, M.Sc., University Medical Center Hamburg-Eppendorf, Hamburg, Germany

# 2:07 PM - 2:23 PM (203.3) Psychometric properties of CHOICEs-22, a patient reported experience measure of shared decision-making in perinatal care

Rachel Breman, PhD, MSN, MPH, RN, University of MD, Baltimore School of Nursing, Baltimore, Maryland, United States

### 2:23 PM - 2:39 PM (203.4) Framework for patient-reported measurement of diagnostic excellence

Vadim Dukhanin, MD, MHS, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, United States

# 2:39 PM - 2:55 PM (203.5) Impact of demographics, information access, and patient involvement in treatment decision-making on quality of life in leukaemia: insights from a global survey.

Sam Salek, PhD RPh FFPM/FRCP GFMD MCMS FRPS FESCP, University of Hertfordshire, Hatfield, United Kingdom

### Oral Session 204: Cancer Symptom Assessment & Monitoring

**Executive CD** 

Session Chair: Maria Edelen, PhD, United States

1:35 PM - 1:51 PM (204.1) Enhancing quality of life through policy-driven integration of clinical pharmacists in cancer pain management: Evidence from the PharmaCAP Trial in Nepal Sunil Shrestha, BPharm, PharmD, PhD, Kathmandu Cancer Center, Bhaktapur, Nepal

#### NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

# 1:51 PM - 2:07 PM (204.2) ePRO Vision's Latest PROM-Al apps to Accelerate PROM Clinical Implementations

Xu Frank Wang, Master of Management, ePRO Vision (Beijing) Health Technology Co., Ltd., Beijing, China

# 2:07 PM - 2:23 PM (204.3) Development of a patient-reported outcome measure of postoperative recovery for lung cancer: a modular conceptual framework

Cheng Lei, Ph.D, Sichuan Cancer Hospital and Institute, Chengdu, China

# 2:23 PM - 2:39 PM (204.4) Time in Severe Symptom State With Eribulin Versus Paclitaxel in Patients With Locally Recurrent or Metastatic Breast Cancer (ACCRU RU011201I)

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

# 2:39 PM - 2:55 PM (204.5) Identifying Longitudinal Trajectories of Quality of Life and Associated Risk and Protective Factors Among Cancer Patients

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

#### Oral Session 205: Cancer: QOL Assessment

Milwaukee

Session Chair: Helen Parsons, PhD MPH, United States

# 1:35 PM - 1:51 PM (205.1) Evaluating the Association Between Insurance Type and Financial Toxicity in Patients with Cancer

Ada Lu, Fred Hutchinson Cancer Center, Seattle, Washington, United States

### STUDENT ORAL PRESENTATION AWARD FINALIST

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### 1:30 PM - 3:00 PM

### **Concurrent Oral Sessions**

1:51 PM - 2:07 PM (205.2) Assessing the Understanding of 'Quality of Life' Amongst Global Oncology Patients

Hayley Simpson-Finch, BA, IQVIA, Reading, United Kingdom

2:07 PM - 2:23 PM (205.3) Needs and health-related quality of life domains relevant to people in Europe with advanced cancer in palliative care: A systematic review of qualitative research Clara Amat-fernandez, Hospital del Mar Research Institute, Barcelona, Spain

2:23 PM - 2:39 PM (205.4) Quality of Life in Oncology: Psychometric properties of the EUonQoL-Kit static version

Olatz Garin, Hospital del Mar Research Institute, Barcelona, Spain

2:39 PM - 2:55 PM (205.5) Evaluating missing data imputation strategies for PRO-CTCAE composite average

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

### 3:05 PM - 3:45 PM

### (2014) A Qualitative Study to Understand the Supportive Care Needs of Adolescents with X-Linked Hypophosphatemia during the Transition to Adulthood

Angela Rylands, PhD, CPsychol, Kyowa Kirin Ltd, Marlow, United Kingdom

# (2018) Pre-testing items for a new pain-specific patient-reported outcome measure for pelvic floor surgery through patient and clinician feedback

Rasa Ruseckaite, PhD, Monash University, Melbourne, Australia

# (2020) Development of a conceptual model for cognitive impairment in a rare blood disorder, Thrombotic thrombocytopenic purpura

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

### (2022) Adaptation of the Pediatric Quality of Life Inventory 3.0 (PedsQL) Neuromuscular Module: Lessons from Kazakhstan

Ainur Bekitayeva, PhD-student, al-Farabi Kazakh National University, Almaty, Kazakhstan

## (2024) Real-world use of Vitaccess Real™ platform to assess quality of life impact with long-term use of Mucinex® in stable chronic bronchitis

Samuel Llewellyn, MD, Vitaccess, Charlotte, North Carolina, United Kingdom

# (2026) A comprehensive literature review of definitions and methods for assessing saturation of qualitative data

Miranda Lauher-Charest, BA, ScM, IQVIA Quality Metric, INC., Providence, Rhode Island, United States

### (2028) Translation and linguistic validation of the GENDER-Q into French for use in Canada

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

### (2030) Validation of a two-item version of the Perceived Health Competence Scale

Jacquelyn S. Pennings, Ph.D., Vanderbilt University Medical Center, Nashville, Tennessee, United States

# (2032) Assessing the content validity of the Familial Chylomicronemia Syndrome Symptoms and Impacts scale (FCS-SIS) in severe hypertriglyceridemia (sHTG)

Asia Sikora Kessler, PhD, Ionis Pharmaceuticals, Carlsbad, California, United States

# (2034) Evaluating the impact of missing data on scale reliability: A simulation study of a 10-Item HRQOL COA with varying item properties

Adrian Jewett, Lumanity, Los Angeles, California, United States

#### (2036) Developing a Dutch PROPr value set: study design and lessons learned

Ellen Elsman, PhD, Department of Child and Adolescent Psychiatry and Psychosocial Care, Amsterdam UMC, Emma Children's Hospital, Amsterdam, Netherlands

### (2038) How long is too long? Review of screenshots for electronic implementation of EORTC instruments

Dagmara Kulis, MA, EORTC, Brussels, Belgium

# (2040) EORTC item Q168: the psychometric performance of a single-item indicator of side-effect burden for people with cancer

Sandra Nolte, PhD, Person-Centred Research, Eastern Health Clinical School, Monash University, Melbourne, Australia

# (2042) Study protocol for electronic patient-reported outcomes in a decentralised phase IV crossover trial for pulmonary arterial hypertension

Frances Varian, MBChB, MRCP(UK), University of Sheffield, Sheffield, United Kingdom

### 3:05 PM - 3:45 PM

# (2044) Using Item Response theory for validity evidence using the DASS-21 with a rural population in the highlands of Peru

Fiorella Guerrero, PhD, Duke University, Durham, North Carolina, United States

# (2046) Results from a literature review on available methods for defining Meaningful Between-Group Difference (MBGD) to be applied to the Attention-Deficit/Hyperactivity Disorder (ADHD) Investigator Symptom Rating (AISRS) Scale

Dorothee Oberdhan, PhD, Otsuka Pharmaceutical Companies, Alexandria, Virginia, United States

### (2048) Measuring Health-Related Quality of Life using the EQ-5D-5L in the Lebanese Adult Population

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

# (2050) Reliability, Longitudinal Measurement Invariance, and Responsiveness of PROMs in a Japanese Web-Based Cognitive Behavioral Healthcare Intervention for Premenstrual Syndrome: A Secondary Analysis of a Randomized Controlled Trial

Yoshitake Takebayashi, PhD., Department Health Risk Communication, Fukushima Medical University School of Medicine, Fukushima, Japan

# (2052) Development and validation of a biliary tract cancer symptom scale for mortality prediction: A Longitudinal Cohort Study

Jian Li, Chongqing Medical Universiity, Chongqing, China

### (2054) Change over Time in PROMIS Global Health across Neurological Populations

Brittany Lapin, PhD MPH, Cleveland Clinic, Cleveland, Ohio, United States

# (2056) Evaluating the Effectiveness of an Electronic Data Collection Platform to Improve Patient Response Rates in a Canadian Orthopaedic Arthroscopic Surgery Registry

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

# (2058) The Future of Linguistic Validation is Now: Enhancing Reconciliation Process Compliance with GenAl

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

#### (2060) Patient activation is associated with positive attitudes toward pain medications

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

#### (2062) Functional constipation RCT: MIC/MCID application bias

Zhengkun Hou, Guangzhou University of Chinese Medicine, Guangzhou, China

# (2064) Financial Insecurity and Discrimination Are Associated with Patient-Reported Quality of Life in Patients with Lupus

Heather Gold, PhD, NYU Langone Health, New York, New York, United States

### (2066) Traditional Chinese Medicine Injections for Pain Relief in Cancer Patients: A Secondary Analysis of a Randomized Clinical Trial

Shizhu Li, Chongqing Medical University, Chongqing, China

3:50 PM - 5:20 PM

Concurrent Oral Sessions

### Oral Session 206: Qualitative Methods

**Regency CD** 

Session Chair: Kelly McCarrier, PhD MPH, United States

3:55 PM – 4:11 PM (206.1) Leveraging MAXQDA Al-Assist for Qualitative Workflows in Patient Experience Data

Trena Paulus, Ph.D., East Tennessee State University, JOHNSON CITY, Tennessee, United States

**4:11 PM - 4:27 PM** (206.2) Generative Al for qualitative analysis: speed at what cost? Anne Skalicky, MPH, Evidera, Seattle, Washington, United States

4:27 PM - 4:43 PM (206.3) Sentiment analysis of children's open-text survey responses during the pandemic: Using PROMs to assess differences in affective states

Michiel Luijten, PhD, Amsterdam UMC, Amsterdam, Netherlands

4:43 PM - 4:59 PM (206.4) Patient perspectives and experiences related to interviewing methodology for clinical outcomes assessment research

Jake Macey, MSc, Clarivate, Clinical Outcome Assessment, London, United Kingdom

4:59 PM – 5:15 PM (206.5) How low can you go? PROM developers' perspectives on the involvement of young children in concept elicitation and cognitive interviews in quality of life research

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

#### Oral Session 207: Pediatrics

**Executive A** 

Session Chair: Christina Zigler, PhD MSEd, United States

3:55 PM – 4:11 PM (207.1) Psychometric properties of Dutch-Flemish PROMIS Pediatric measures in the Dutch pediatric oncology population 8-17 years

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

4:11 PM - 4:27 PM (207.2) Health-related quality-of-life among pediatric sibling hematopoietic stem cell donors; findings from RDSafe and DonorKids QL studies

Galen Switzer, PhD, University of Pittsburgh, Pittsburgh, Pennsylvania, United States

4:27 PM - 4:43 PM (207.3) PROtocols matter: A systematised evaluation of adherence to Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) patient-reported outcome guidelines in interventional paediatric oncology trials.

Denise Connolly, MB BCh BAO, MCncrSc, The Hospital for Sick Children, Toronto, Ontario, Canada

4:43 PM - 4:59 PM (207.4) Development and Validation of the Observer-Reported Outcome for Children with Cancer (ObsRO-CC)

Hua-Yu Li, Department of Social Medicine, School of Public Health, Zhejiang University School of Medicine, Hangzhou, China

4:59 PM – 5:15 PM (207.5) Family members/partners of people with autism experience a major impact on quality of life as measured by the Family-Reported Outcome Measure (FROM-16)
Sam Salek, School of Life & Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom

### Oral Session 208: Translation & Cultural Adaptation

**Executive B** 

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

3:55 PM – 4:11 PM (208.1) Cross-cultural validation of the Dermatology Life Quality Index (DLQI) across 13 European languages

Sam Salek, RPh, PhD, University of Hertfordshire, Hatfield, United Kingdom

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#### **Concurrent Oral Sessions**

4:11 PM - 4:27 PM (208.2) Refining the Spanish version of the awareness and beliefs about cancer (ABC) instrument: Supporting valid assessment for cancer knowledge and screening interventions

Christopher M. Amissah, PhD, MPhil, University of Maryland School of Pharmacy, Baltimore, Maryland, United States

4:27 PM - 4:43 PM (208.3) Data and Methods to Support Translation of Critical COA Terminology in a Shifting Linguistic Validation Landscape: Improving Quality of Life in the Almediated Age

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

4:43 PM - 4:59 PM (208.4) Al-Augmented Translatability Assessments: Increasing Patient Voice in Outcomes through Efficient Recommendations for Cultural Adaptation of Original Assessment Items

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

4:59 PM – 5:15 PM (208.5) Assessing the Quality of Al-Generated Swahili Translations of the BREAST-Q: Enhancing PROM Accessibility in Low-Resource Settings

Oluchukwu Dele-Oni, BS, Geisel School of Medicine at Dartmouth, Hanover, New Hampshire, United States

### Oral Session 209: Cancer: Breast & Ovarian

**Executive CD** 

Session Chair: David Cella, PhD, United States

3:55 PM – 4:11 PM (209.1) A systematic review of Patient-Reported Outcome Measures (PROMs) to assess Health-Related Quality of Life (HRQoL) for breast cancer patients on adjuvant endocrine therapy: Application of the COSMIN guidelines

Rila Su, DrPH, M.D, PhD, Inner Mongolia People's Hospital, Hohhot, China

4:11 PM - 4:27 PM (209.2) Health-Related Quality of Life (HRQoL) Assessment using the Validated Mongolian FACT-ES among Mongolian Women with Breast Cancer (BC) on Adjuvant Endocrine Therapy (AET)

Rila Su, DrPH, M.D, PhD, Inner Mongolia People's Hospital, Hohhot, China

4:27 PM - 4:43 PM (209.3) Recovery from Breast Cancer Surgery: Implementation of the ICHOM Standard Order to Understand the Patient Perspective

Eva Roy, MD, Brigham and Women's Hospital, Boston, Massachusetts, United States

4:43 PM - 4:59 PM (209.4) Assessing Socioeconomic Disparities in Patient-Reported Outcome Measure Response Rates Among Ovarian Cancer Surgery Patients

Jason B. Liu, MD, MS, MD Anderson Cancer Center, Houston Texas, United States

4:59 PM – 5:15 PM (209.5) How does Surgical Complexity impact Health-Related Quality of Life in Patients with Ovarian Cancer?

Jason B. Liu, MD, MS, MD Anderson Cancer Center, Houston Texas, United States

### Oral Session 210: PROMs in Registries & Care

Milwaukee

Session Chair: Deborah Mattila, United States

3:55 PM – 4:11 PM (210.1) Implementation of patient-reported outcome measures in clinical registries worldwide

Rasa Ruseckaite, PhD, Monash University, Melbourne, Victoria, Australia

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### 3:50 PM - 5:20 PM

### **Concurrent Oral Sessions**

4:11 PM - 4:27 PM (210.2) Individual and Community-Level Social Determinants Associated with Representation in a Cellular Therapy Registry

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

4:27 PM - 4:43 PM (210.3) Barriers and facilitators to Patient Reported Outcome (PRO) collection. Interim findings from a mixed-methods, multi-site study

Devin Peipert, PhD, University of Birmingham, Birmingham, United Kingdom

**4:43 PM - 4:59 PM** (210.4) How do we ensure ePRO solutions meet accessibility standards? Florence Mowlem, BSc, MSc, PhD, uMotif, London, United Kingdom

4:59 PM – 5:15 PM (210.5) Evaluation of enrollment rates to PRO data collection in a large clinical registry in the US – the first 5 years

Idayat Akinola, MBBS, MPH, Medical College of Wisconsin, Milwaukee, Wisconsin, United States

#### 9:20 AM - 10:00 AM

### (3015) Evaluating agreement metrics used in analytical validation: A simulation study for a digital measure of step count

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

# (3017) Predictors in infancy of disease-specific quality of life in adolescents born with esophageal atresia - a nationwide prospective observational study in Sweden

Michaela Dellenmark-Blom, PhD, Associate Professor, Department of Pediatric Surgery, Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden, Institute of Clinical Sciences, Department of Pediatrics, Queen Silvia Children's Hospital, Gothenburg, Sweden

# (3019) Psychometric Validation of the Eating Behavior and Appetite Questionnaire (EBAQ) in Adults with Obesity or with Overweight and Obesity-related Complications

Chisom Kanu, RPh, PhD, Eli Lilly & Company, Indianapolis, Indiana, United States

#### (3021) Quality of life in the rural highlands of Peru

Fiorella Guerrero, PhD, Duke University, Durham, North Carolina, United States

# (3023) Understanding the natural history of cognitive impairment in people living with immune thrombotic thrombocytopenic purpura: qualitative perspectives of patients and their observers Laura Mkumba, MS, Duke University, Durham, North Carolina, United States

# (3025) Using the EORTC Item Library to assess patient-reported symptomatic adverse events: Development of the EORTC-PRO-AE inventory

Claire Piccinin, Quality of Life Department, EORTC, Brussels, Belgium

# (3027) Smart Pediatric Oncology Tracker of Symptoms (SPOTS): Design and Development of a Web-Based Interface for the Pediatric PRO-CTCAE

Stacey Crane, PhD RN CPON, University of Texas Health Science Center at Houston, Houston, Texas, United States

### (3029) Pre-Treatment Readiness Tool for Sarcoma

Marium Husain, MD, MPH, Ohio State University James Comprehensive Cancer Center, Columbus, Ohio, United States

# (3031) Test-retest reliability and concurrent validity of performance outcome measures in sarcopenia

Xiaodan Tang, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

# (3033) Equivalence of Paper-Based and Smartphone-Based Patient-Reported Outcomes Using the Perioperative Symptom Assessment of Lung Surgery (PSA-Lung): A Randomized Crossover Equivalence Study

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

# (3035) Validation and reliability of a Patient-Reported Outcome Tool for Assessing Anxiety in patients with HPV infection

Wenlin Wu, Chongqing Medical University, Chongqing, China

# (3037) A Virtual Focus Group Model for Qualitative Cognitive Debriefing of Patient-Reported Outcome Measures

Sara Shaunfield, PhD, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States

#### 9:20 AM - 10:00 AM

# (3039) Evaluating Construct Validity of the Patient-Reported Outcomes Measurement Information System 16-Item Profile in Total Laryngectomy Patients

Maria Edelen, PhD, RAND Corporation, Boston, Massachusetts, United States

### (3041) PRO-CTCAE Composite Average Validation in Prostate Cancer Phase 3 Trial

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

### (3045) Religeous beliefs and health outcomes: results from a population-based study in Japan

Yosuke Yamamoto, Department of Healthcare Epidemiology, Graduate School of Medicine, Kyoto University, Kyoto, Japan

### (3047) Assessing comprehensibility of Dutch patient-reported outcome measures (PROMs) for people with low literacy skills

Ellen Elsman, Amsterdam UMC, location University of Amsterdam, Epidemiology and Data Science, Amsterdam, The Netherlands, Amsterdam, Netherlands

### (3049) Development of a Modular Quality of Life Assessment Tool for Breast Cancer Patients Based on Patient-Reported Outcomes (PROs)

Xu Wei, Chongging Medical University, Chongging, China

# (3051) Did The Kids Understand? Translating Key Concepts in Norwegian PROMIS Pediatric and Proxy Measures

Abigail Boucher, FACITtrans, Chicago, Illinois, United States

### (3053) Cross-cultural adaptation of the EQ-TIPS into Chichewa (Malawi): preliminary findings

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

### (3055) Bivariate latent change score modeling of pain and physical function in osteoarthritis

Aaron Kaat, PhD, Northwestern University, Chicago, Illinois, United States

# (3057) Using a meaningful change item to support interpretations of meaningful score differences derived using traditional anchors

Alyssa Bamer, MPH, Clinical Outcomes Solutions, Tucson, Arizona, United States

# (3059) Statistical vs. Clinical Significance: Shifting the Focus to Clinical Relevance in Patient - Reported Outcome Measures of Functional Dyspepsia

Zhengkun Hou, Guangzhou University of Chinese Medicine, Guangzhou, China

# (3061) The impact of psychological wellness and caregiver quality of life on patient quality of life after CAR T cell therapy

Emma DuMez, BA, Medical College of Wisconsin, Milwaukee, Wisconsin, United States

# (3063) Simulation of screen-to-CAT algorithm for PROMIS anxiety and depression in solid organ transplant recipients

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

# (3065) Social communication assessment priorities of adults with traumatic brain injury and speech-language pathologists

Lindsey Byom, PhD, Viterbo University, LaCrosse, Wisconsin, United States

# (3067) Using multiple graphical approaches to support estimation of meaningful within patient change (MWPC) and meaningful score regions (MSRs)

Helen Doll, Clinical Outcomes Solutions, Folkestone, United Kingdom

Saturday Poster Session 301

Regency AB

# (3069) Reliability and validity of the Colombian version of Kidscreen-10 in school children and adolescents

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

**Concurrent Oral Sessions** 

### Oral Session 301: Meaningful Change Methodology

**Regency CD** 

Session Chair: Jessica Roydhouse, PhD, Australia

4:05 PM - 4:21 PM (301.1) What anchor correlation value should I use when deriving Meaningful Within Patient Change (MWPC) values

Kim Cocks, PhD, Adelphi Values, Manchester, United Kingdom

4:21 PM - 4:37 PM (301.2) Establishing Meaningful Change Thresholds Through Personalized Narratives and Tailored Definitions: A Feasibility Study in Patients with Cancer

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

4:37 PM - 4:53 PM (301.3) A Comparison of Minimally Important Difference Definitions for Quality of Life in Four Clinical Trials

Salene Jones, PhD, Fred Hutchinson Cancer Center, Seattle, Washington, United States

4:53 PM – 5:09 PM (301.4) Which of these response choices would reflect a meaningful change? Methods of asking about meaningful change in qualitative interviews outside of a clinical trial

Sonya Eremenco, MA, Critical Path Institute, Patient-Reported Outcome Consortium, Tucson, Arizona, United States

5:09 PM - 5:25 PM (301.5) The impact of severity prevalence on cut points estimated from receiver operating characteristic (ROC) curve analysis; implications for threshold and meaningful change estimation

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

### Oral Session 302: Application of AI in PRO Research

**Executive A** 

Session Chair: Katie Kunze, PhD, United States

4:05 PM - 4:21 PM (302.1) Predicting oncologic adverse events from patient-reported symptoms: Al models developed using data from a large national multicenter trial. Chris Gibbons, Oracle Health, Austin, Texas, United States

4:21 PM - 4:37 PM (302.2) Assessment of Treatment Response Through the Use of Personalized Endpoints: Using Artificial Intelligence to Assist Goal Attainment Scaling Gunes Sevinc, Ardea Outcomes, Halifax, Nova Scotia, Canada

4:37 PM – 4:53 PM (302.4) Exploring Al-Driven prediction of Patient-Reported Fatigue: Digital Biomarkers versus Quality-of-Life(QL) Scores.

Nana Abaogye, Newcastle University, Newcastle Upon Tyne, United Kingdom

4:53 PM - 5:09 PM (302.5) Patient perceptions toward the use of AI in clinical and research settings

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

### Oral Session 303: Neurology

**Executive B** 

Session Chair: TBD

4:05 PM - 4:21 PM (303.1) Understanding the experience of people living with amyotrophic lateral sclerosis: a qualitative study and conceptual model informed by patients, caregivers, and clinicians

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

4:21 PM - 4:37 PM (303.2) The trajectory of depression-related symptom clusters following stroke

Qi Zhang, Associate professor, Sun Yat-Sen University, Guangzhou, China

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### **Concurrent Oral Sessions**

4:37 PM - 4:53 PM (303.3) Major impact of Multiple Sclerosis on family members and partners: evidence using the Family Reported Outcome Measure (FROM-16)

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

4:53 PM – 5:09 PM (303.4) Developing a conceptual framework of health-related quality of life of informal carers in Amyotrophic Lateral Sclerosis (ALS)

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

5:09 PM - 5:25 PM (303.5) Minimally important differences (MIDs) and minimally important changes (MICs) were determined for the Vestibular Schwannoma Quality of Life (VSQOL) Index Kathleen Yost, PhD, Mayo Clinic, Rochester, Minnesota, United States

### Oral Session 304: Electronic Symptoms Surveillance

**Executive CD** 

Session Chair: Rachel Cusatis, PhD, United States

4:05 PM - 4:21 PM (304.1) Establishing optimal Cut-off Points for Remote Monitoring of Cancer Symptoms via ePROs in China's Primary Health Care Settings

Dai Wei, Sichuan Clinical Research Center for Cancer, Chengdu, China

4:21 PM - 4:37 PM (304.2) Defining Critical Symptom Profiles to Build ePRO-based Pathway for Patient Care During First Year After Chemoradiation and Immunotherapy for NSCLC Shu-en Shen, MS, MD Anderson Cancer Center, Houston, Texas, United States

4:37 PM - 4:53 PM (304.3) ePRO-MAI-CRC: Al-Powered Real-Time Symptom Monitoring and Proactive Triage for Home-Based Chemotherapy in Colorectal Cancer

Wei Xu, PhD, College of Public Health, Chongging Medical University, Chongging, China

4:53 PM – 5:09 PM (304.4) Dynamic Electronic Monitoring of Chemotherapy-Induced Neurotoxicity: Patterns and Clinical Impact in colorectal and breast Tumor Cohorts Wei Xu, PhD, College of Public Health, Chongging Medical University, Chongging, China

5:09 PM - 5:25 PM (304.5) Understanding response rates of electronic PROMs in clinical care: trends and characteristics

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

### Oral Session 305: Health Valuation & Utility Assessment

Milwaukee

Session Chair: Andria Joseph, United Kingdom

4:05 PM - 4:21 PM (305.1) Collaborative involvement in valuing health-related quality of life is underdeveloped: Novel insights and emerging recommendations

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

4:21 PM - 4:37 PM (305.2) Have relative preferences for different dimensions of health changed over time? Evidence from the UK using EQ-5D

Donna Rowen, PhD, Sheffield Centre for Health and Related Research, University of Sheffield, Sheffield, United Kingdom

4:37 PM - 4:53 PM (305.3) Assessing Health State Utilities Across Different Severity Levels of Friedreich Ataxia by the General Population

Kristen Deger, Evidera (Part of Thermo Fisher Scientific), Bethesda, Maryland, United States

4:53 PM – 5:09 PM (305.4) Are child patient reported-outcome measures used to inform assessments of health technologies and highly specialised technologies? A review of recent evidence in England

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### Saturday, 25 October

### 4:00 PM - 5:30 PM

### Concurrent Oral Sessions

Donna Rowen, PhD, Sheffield Centre for Health and Related Research, University of Sheffield, Sheffield, United Kingdom

5:09 PM - 5:25 PM (305.5) Impact of Severe Neonatal Complications on Long-Term Health-Related Quality of Life in Very Preterm and/or Very Low Birth Weight Survivors: Evidence from Meta-Analysis.

Corneliu Bolbocean, University of Oxford, Oxford, Arkansas, United Kingdom

#### Virtual Poster Hall

### (1) Association of Particulate Matter 2.5 Exposure and Health-related Quality of Life among 38,724 Patients in Massachusetts, United States

Chengbo Zeng, Ph.D., Brigham and Women's Hospital, Boston, Massachusetts, United States

### (2) Arabic Translation and Adaptation of the CVID\_QoL Questionnaire to Measure Health-Related Quality of Life of Adults with Common Variable Immune Deficiency

Salim Zridi, PhD Candidate, Laboratory of Clinical Immunology, Inflammation and Allergy (LICIA), Faculty of Medicine and Pharmacy, Hassan II University, Casablanca, Morocco, Benslimane, Morocco

### (3) Physical, mental and social functioning of children in pediatric physical therapy: mental health matters

Dorinde L. Korteling, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Meibergdreef 9, Amsterdam, The Netherlands

# (4) Child-caregiver agreement and test-retest reliability of nine PROMIS item banks in pediatric physical therapy

Dorinde L. Korteling, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Meibergdreef 9, Amsterdam, The Netherlands

# (5) Responsiveness of pediatric v2.0 and v3.0 PROMIS Pain Interference, Upper Extremity and Mobility

Dorinde L. Korteling, Amsterdam UMC location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Meibergdreef 9, Amsterdam, The Netherlands

### (6) Bridging the gap: Understanding child and caregiver discrepancies in patient-reported outcome measures

Aline Thorkelsson, Department of Psychology, University of Alberta, Undergraduate student, Edmonton, Alberta, Canada

# (7): Using an argument-based approach to validation to evaluate three PROMs for intensive outpatient child and adolescent mental health services

Erin McCabe, MScPT, PhD, Department of Physical Therapy, University of Alberta, Edmonton, Alberta, Canada

### (8) Key informant experiences with patient-reported outcome measures in child and adolescent mental health

Erin McCabe, MScPT, PhD, Department of Physical Therapy, University of Alberta, Edmonton, Alberta, Canada

# (9) Psychometric evaluation of the PROMIS SD SF 8b and ISI in women experiencing sleep disturbances associated with menopause: reliability, validity, and responsiveness Andrew Trigg, Bayer Plc, Reading, United Kingdom

# (10) Symptom prevalences and changes among gastrointestinal cancer patients receiving chemotherapy

Chengbo Zeng, Ph.D., Brigham and Women's Hospital, Boston, Massachusetts, United States

# (11) Bridging Technology and Trust: Leveraging AI and Health Behavior Theory to Combat Misinformation in African American Communities

Akorfa Adobor, MCW, Milwaukee, Wisconsin, United States

(12) How Al Can Help Sickle Cell Disease Management in African American Communities Akorfa Adobor, MCW, Milwaukee, Wisconsin, United States

#### Virtual Poster Hall

### (13) Estimating Meaningful Score Differences and Meaningful Score Regions for the PROMIS® Pediatric Asthma Impact Scale

Jing Yuan, PhD, Duke University, Durham, North Carolina, United States

(14) Patient preference information for HTA: A rapid review of HTA community perspectives Takako Kaneyasu, Kinugasa Research Organization, Ritsumeikan University, Kyoto, Japan

# (15) Exploring health-related quality of life and patient perceptions in persons with above-knee bone-anchored prostheses: a mixed methods study

Mayank Rehani, MSc, Division of Physical Medicine & Rehabilitation, Department of Medicine, Faculty of Medicine & Dentistry, University of Alberta, Edmonton, Alberta, Canada

# (16) A reconceptualization of Maslow: A chronic illness-informed framework for health-related quality of life

Angel Sheu, B.S., Anne Burnett Marion School of Medicine at Texas Christian University, Fort Worth, Texas, United States

# (17) How, for Whom, under What Circumstances, and Why is Mental Healthcare for Anxiety Supposed to Improve Well-being for People Receiving Dialysis?

Lori Suet Hang Lo, MSc, BScN, Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada

(18) Identifying and explaining variation in emotional well-being measurement bias Richard Sawatzky, PhD, RN, Trinity Western University, Langley, British Columbia, Canada

# (19) Quality-of-life discounting: A behavioral economics framework for understanding the underutilization of preventive health interventions

Angel Sheu, B.S., Anne Burnett Marion School of Medicine at Texas Christian University, Fort Worth, Texas, United States

# (20) Beyond the individual: Bronfenbrenner's ecological systems theory as a proxy for understanding pediatric health-related quality of life

Angel Sheu, B.S., Anne Burnett Marion School of Medicine at Texas Christian University, Fort Worth, Texas, United States

**(21) Mapping the Evidence for Outcomes in Telehealth Across Four Domains: A Scoping Review** Fatemeh Ehteshami, PhD student, university of western ontario, London, Ontario, Canada

### (22) To what extent do older adults differ in how they respond to questions about their physical and mental health?

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

### (23) Improving communication in primary care using a mixed-methods approach to creating datadriven personas

Jeanette Jackson, Health Quality Council of Alberta, Calgary, Alberta, Canada

### (24) The Association Between Self-stigma of Mental Illness and Quality of Life of Adults Living with Depression: A Systematic Review.

Refah Algahtani, University of Dundee, Dundee, United Kingdom

# (25) Assessing security in telemedical care from the patient's perspective: Further development of the SeCu questionnaire

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

### (26) Challenges in analysing the effect of treatment on PROs in cancer registry data

Emma Martin, MSc, AdelphiValues PCO, Macclesfield, United Kingdom

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#### Virtual Poster Hall

### (27) Key Domains Affected by Lower Limb Amputation: Patient and Healthcare Professional Perspectives

Justin-Pierre Lorange, M.D., Universite de Montreal, Montreal, Quebec, Canada

# (28) Grounded in Lived Experience: Community Voices Refine the Obesity-Specific Preference-Based Weight-Related Quality of Life (PB-WRQL) Prototype

Ana Moga, PT, MSc, PhD candidate, Faculty of Medicine, School of Physical Therapy, Rehabilitation Science, McGill University, Montreal, Quebec, Canada

# (29) Evaluating the PB-WRQL Prototype Against Generic Preference-Based HRQL Measures in People Living with Obesity

Ana Moga, PT, MSc, PhD candidate, Faculty of Medicine, School of Physical Therapy, Rehabilitation Science, McGill University, Montreal, Quebec, Canada

# (30) Measurement properties of PROMIS 29 v2.1 in German, French and Italian for Swiss population in a cross-sectional study

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

# (31) Translation and cultural adaptation of the FACE-Q Paralysis Module from English to Danish. Elena Takasugi Aagaard, Research Unit of Plastic Surgery, Odense University Hospital, Odense,

Denmark

# (32) A Mixed Methods Analysis Using Trial Data to Describe Patients with Glycogen Storage Disease Type Ia Who Met Baseline Expectations for Meaningful Change in Daily Cornstarch Intake Diane M. Turner-Bowker, PhD, Ultragenyx Pharmaceutical, Novato, California, United States

### (33) Evaluating Responsive Shift in Total Knee Arthroplasty Patients

Ademola Itiola, B.Pharm, MPH, MSc, School of Public Health, University of Alberta, Edmonton, Alberta, Canada

# (34) Child and family-important outcomes in pediatric randomized controlled trials over a 10-year period

Nora Fayed, PhD, MScOT, Queen's University, Kingston, Ontario, Canada