

October 9-12, 2013 MIAMI, FLORIDA, USA



# **Final Program**



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# Welcome to the 20<sup>th</sup> Annual Conference of the International Society for Quality of Life Research

Energizing the Science of Quality of Life Research: Where Have We Been and Where Can We Go? October 9-12, 2013

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**ISOQOL Mission Statement:** To advance the scientific study of health-related quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations.



### **SCHEDULE AT A GLANCE**

Wednesday, October	9	
9:00 am - 12:00 pm	Morning Workshops (WK01 - WK03)*	See Page 14
1:00 pm - 4:00 pm	Afternoon Workshops (WK04 - WK07)*	See Page 15
4:30 pm - 6:00 pm	IAC Symposium Innovations for Patient Engagement in Health Outcomes Development, Selection and Measurement: Opportunities and Limitations	Escorial/Alhambra Room
6:00 pm - 7:30 pm	Welcome Reception	Versailles Ballroom
Thursday, October 1	0	
7:30 am - 8:45 am	Child Health SIG Meeting	Balmoral Room
7:30 am - 8:45 am	Psychometrics SIG Meeting	Sandringham/Windsor Room
7:45 am - 8:45 am	Industry Advisory Committee (IAC) Meeting	Michelangelo Room
9:00 am - 10:30 am	Plenary New Horizons in Quality of Life Research	Versailles Ballroom
10:30 am - 11:15 am	Poster Session 1	Biscayne Ballroom
10:30 am - 11:15 am	Exhibits Open	Mezzanine East
11:15 am - 12:45 pm	Plenary <i>Cutting Edge Research in Quality of Life</i>	Versailles Ballroom
12:45 pm - 1:45 pm	Lunch on Your Own	
12:45 pm - 1:45 pm	New Investigator Roundtable Career Topic: Networking and Interviews	Hibiscus Isle Room, Lobby Level
12:45 pm - 1:45 pm	Quality of Life Research Journal Associate Editor Meeting	Raphael Room
12:45 pm - 1:45 pm	SIG Leader Meeting	Michelangelo Room
2:00 pm - 3:30 pm	Concurrent Oral Sessions	
	Oral Session 101: Positive Psychology/Life Satisfaction	Balmoral Room
	Oral Session 102: Response Shift	Windsor Room
	Oral Session 103: Cancer Clinical Trials Issues	Sandringham Room
	Oral Session 104: Patient-Reported Outcomes Measure Development and Evaluation	Escorial/Alhambra Room
3:30 pm - 4:00 pm	Exhibits Open and Afternoon Break	Mezzanine East
4:00 pm - 5:30 pm	Concurrent Symposium Sessions	
	Symposium 1: The Application of PROMIS <sup>®</sup> in Real-World Settings: Advancing Patient-Centered Research and Care	Sandringham/Windsor Room
	Symposium 2: Patient and Public Engagement in Health Research	Raphael/Michelangelo Room
	Symposium 3: Genes, Cells and Symptom Clusters - What's the Story?	Escorial/Alhambra Room
6:00 pm - 7:30 pm	Mentor/Mentee Reception Featuring the New Investigator SIG Tricks of the Trade	Versailles Ballroom

\* Ticket Required

#### **Registration Desk Hours**

Tuesday, October 8:	4:00 pm – 7:00 pm
Wednesday, October 9:	7:00 am - 6:00 pm
Thursday, October 10:	7:00 am – 5:00 pm
Friday, October 11:	7:00 am - 5:00 pm
Saturday, October 12:	8:00 am – 4:00 pm

#### Poster Hall Hours

All Poster presentations will take place in the **Biscayne Ballroom**. The Biscayne Ballroom will be open daily from **7:00 am – 7:00 pm** from Thursday, October 10 – Saturday, October 12.

## **SCHEDULE AT A GLANCE**

Friday, October 11		
7:30 am - 8:45 am	2014 Annual Conference Planning Meeting	Escorial/Alhambra Room
7:30 am - 8:45 am	New Investigator SIG Meeting	Balmoral Room
7:30 am - 8:45 am	QOL in Clinical Practice SIG Meeting	Sandringham/Windsor Room
9:00 am - 10:30 am	Plenary Accentuate the Positive: The Sunny Side of Quality of Life Research	Versailles Ballroom
10:30 am - 11:15 am	Poster Session 2	Biscayne Ballroom
10:30 am - 11:15 am	Exhibits Open	Mezzanine East
11:15 am - 12:45 pm	Concurrent Symposium Sessions	
	Symposium 4: Tools for Assessing Religiousness and Spirituality in Health Research	Sandringham/Windsor Room
	Symposium 5: The Impact of Missing Data on Response Shift Detection: A Comparison Across Methods	Escorial/Alhambra Room
	Symposium 6: New Developments in Valuing Health: Directions for the EQ-5D	Raphael/Michelangelo Room
12:45 pm - 1:45 pm	Lunch on Your Own	
12:45 pm - 1:45 pm	Task Force Meeting ISOQOL Best Practices for PROs in Randomized Clinical Trials	Hibiscus Isle Room, Lobby Level
2:00 pm - 3:30 pm	Concurrent Oral Sessions	
	Oral Session 201: Quality of Life in Children	Balmoral Room
	Oral Session 202: Concepts and Frameworks	Escorial/Alhambra Room
	Oral Session 203: Statistical Methods	Raphael/Michelangelo Room
	Oral Session 204: Personalized Medicine	Sandringham Room
	Oral Session 205: Quality of Care Experience	Windsor Room
3:30 pm - 4:00 pm	Exhibits Open and Afternoon Break	Mezzanine East
4:00 pm - 5:30 pm	Concurrent Oral Sessions	
	Oral Session 206: Health Utilities	Balmoral Room
	Oral Session 207: Patient-Reported Outcome Measure Development and Evaluation	Escorial/Alhambra Room
	Oral Session 208: Itemized Response Theory/Item Banking	Raphael/Michelangelo Room
	Oral Session 209: Responsiveness of Quality of Life Measures	Sandringham Room
	Oral Session 210: Caregiver Health	Windsor Room
5:45 pm - 6:30 pm	Translation & Cultural Adaptation (TCA) SIG Meeting	Escorial/Alhambra Room
5:45 pm - 6:30 pm	Ibero America SIG Meeting	Balmoral Room
5:45 pm - 6:30 pm	Response Shift SIG Meeting	Sandringham Room
5:45 pm - 6:30 pm	Patient Engagement SIG Meeting	Windsor Room





### **SCHEDULE AT A GLANCE**



Saturday, October 12	2	
8:30 am - 10:00 am	Business Meeting and Awards Presentation	Versailles Ballroom
10:00 am - 10:45 am	Poster Session 3	Biscayne Ballroom
10:00 am - 10:45 am	Exhibits Open	Mezzanine East
10:45 am - 12:15 pm	Concurrent Oral Sessions	
	Oral Session 301: Longitudinal Follow Up in Cancer	Balmoral Room
	Oral Session 302: Quality of Life and Health Evaluation	Escorial/Alhambra Room
	Oral Session 303: Methods and Psychometric Approaches	Raphael/Michelangelo Room
	Oral Session 304: eHealth/Health Technology	Sandringham Room
	Oral Session 305: To Thine Own Self Be True:	Windsor Room
	Quality of Life of Researchers and Practitioners	
12:15 pm - 1:15 pm	Lunch on Your Own	
1:30 pm - 3:00 pm	Concurrent Oral Sessions	
	Oral Session 306: Quality of Life in Children: Methodological Issues	Balmoral Room
	Oral Session 307: Health Evaluation/Performance Measures	Escorial/Alhambra Room
	Oral Session 308: Symptoms and Quality of Life in Cancer	Raphael/Michelangelo Room
	Oral Session 309: Body Image/Sexual Function	Sandringham Room
	Oral Session 310: Respiratory Disease	Windsor Room
3:00 pm - 3:30 pm	Exhibits Open and Afternoon Break	Mezzanine East
3:30 pm - 5:00 pm	Plenary	Versailles Ballroom
- •	Twenty Years of ISOQOL - A Celebration	
7:00 pm - 10:00 pm	Closing Dinner*	Bubba Gump Shrimp Co. Bayside Marketplace

\* Ticket Required

#### **Registration Desk Hours**

Tuesday, October 8:	4:00 pm – 7:00 pm
Wednesday, October 9:	7:00 am – 6:00 pm
Thursday, October 10:	7:00 am – 5:00 pm
Friday, October 11:	7:00 am – 5:00 pm
Saturday, October 12:	8:00 am - 4:00 pm

#### **Poster Hall Hours**

All Poster presentations will take place in the **Biscayne Ballroom**. The Biscayne Ballroom will be open daily from **7:00 am – 7:00 pm** from Thursday, October 10 – Saturday, October 12.

# WELCOME FROM THE PROGRAM CHAIRS

Buenos Días and Welcome to Beautiful Miami, Florida!

We are pleased that you are able to join us for the 20<sup>th</sup> anniversary of ISOQOL's Annual Conference. This year's theme is "Energizing the Science of Quality of Life Research: Where Have We Been and Where Can We Go?"

We have designed this year's program with an eye toward stimulating new thought in quality of life science as well as highlighting some of the top rated research by our own members based on peer review. Invited speakers from within and outside our ranks will engage us on such diverse topics as life span science, cognitive reserve, multiple intelligences, and positive psychology and well-being. We are especially privileged to have Dr. Mihaly Csikszentmihalyi, one of the world's most important researchers of positive psychology, address us on the concept of Flow and its implications for quality of life. We have also selected three of the most highly-rated abstracts from open submission for presentation at a "Cutting Edge" plenary, a session to be hosted by the current and incoming president.



Simon and David enjoying some fun in the sun during a break from the abstract selection meeting.

Importantly, the 20<sup>th</sup> Annual Conference represents a milestone in the history of ISOQOL, so we have chosen to mark the occasion with a celebration in the final plenary session on Saturday afternoon. We hope that you will join us along with the past presidents of ISOQOL for an enjoyable look back at our accomplishments and a look ahead at what the future might hold for the society and the field of quality of life research.

If you have been a regular attendee of the annual conference over the past few years, you will note a few changes this year. To facilitate more podium presentations in the concurrent sessions, we have increased the number of presentations per session from 4 to 5. While this change requires a slight reduction in overall presentation time, it allows more authors an opportunity to present their work orally. Furthermore, in response to feedback we have received about the lack of adequate networking time, we have elected to build in some open time in the program. Hence, we hope that you will take advantage of the open lunch hour to network with colleagues, both old and new.

As time permits, we invite you to take in the many sights, sounds, and attractions of Greater Miami. You can enjoy the eternal summer with beach and water activities like snorkeling, kayaking, and stand up paddle boarding; swim with dolphins at the Miami Seaquarium or interact with the exotic animals at Jungle Island; immerse yourself in Cuban culture on Calle Ocho in Little Havana, or venture to South Beach to tour the Art Deco Historic District.

Of course, the annual conference would not be complete without a little bit of fun to accompany the science. On Wednesday evening, we welcome you in true Miami fashion with an introduction to Latin dance and music at the Welcome Reception. Saturday at ISOQOL is "Beach Shirt Day" and we invite you to attend all sessions adorned in your favorite floral print. And don't forget the Closing Dinner, where we will bring you a little 'Seafood and Salsa' courtesy of the Bubba Gump Shrimp Company. Bring your dancing shoes and loosen up those hips…that's all we've got to say about that!

We thank you for attending and hope that you will enjoy this celebration of science and camaraderie!



David Eton, PhD Co-chair, Scientific Program Committee



Simon Pickard, PhD Co-chair, Scientific Program Committee



### **ISOQOL LEADERSHIP**



President Bryce Reeve, PhD, United States



**President-Elect** Galina Velikova, MD, United Kingdom



Secretary-Treasurer William Lenderking, PhD, United States

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### Co-Editors-In-Chief of Quality of Life Research Journal



Dennis Revicki, PhD, United States



Carolyn E. Schwartz, ScD, United States

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**Meetings and** Membership Manager Heather Vitale



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# SCIENTIFIC PROGRAM COMMITTEE

### Scientific Program Committee

Co-Chair: David Eton, PhD, United States Co-Chair: Simon Pickard, PhD, United States

#### **Developing Country Scholarship Committee**

Chair: Gloria Juarez, PhD RN MSN, United States Education Committee Chair: Joan Branin, PhD, United States Doris Mwesigire, MD, Uganda Kathy Wyrwich, PhD, United States

#### Mentor/Mentee Reception

Chair: Elena Andresen, PhD, United States

#### Student/New Investigator Presentation Award

Chair: Roxanne Jensen, PhD, United States Special thank you to the Presentation Award judges

#### Workshop Abstract Reviewers

Workshop Chair: Nancy E. Mayo, PhD, Canada Education Committee Chair: Joan Branin, PhD, United States Jameson Hirsch, PhD, United States Marc Jacobs, MSc, The Netherlands Puja Joshi, MSc, United Kingdom Ana A. Popielnicki, BA, United States Ana Maria Rodriguez, PhD MSc BSc PT, Canada Rick Sawatzky, PhD RN, Canada Carolyn E. Schwartz, ScD, United States

#### Symposium Abstract Reviewers

Steven Blum, MBA MA, United States Elizabeth J. Gibbons, MSc, United Kingdom Jameson K. Hirsch, PhD, United States Marc Jacobs, MSc, The Netherlands Roxanne Jensen, PhD, United States Gloria Juarez, PhD RN MSN, United States Cicely Kerr, MSc PhD, United Kingdom Jin-Shei Lai, PhD, United States Cindy L.K. Lam, MD, Hong Kong, SAR China Muirne CS Paap, The Netherlands Ana A. Popielnicki, BA, United States Ana Maria Rodriguez, PhD MSc BSc PT, Canada Carolyn E. Schwartz, ScD, United States Carlos King Ho Wong, PhD MPhil BSc, Hong Kong, SAR China Tracey Young, PhD MSc BSc CStat, United Kingdom

#### Oral and Poster Presentation Abstract Reviewers

Sara Ahmed, PhD, Canada Antonia V. Bennett, PhD, United States Rick Berzon, DrPH, United States Steven Blum, MBA MA, United States Stefan J. Cano, PhD CPsychol AFBPsS, United Kingdom Divine Ewane Ediebah, MSc, Belgium Fabio Efficace, PhD, Italy Willem Eijzenga, MSc, The Netherlands Pranav Gandhi, PhD, United States Elizabeth J. Gibbons, MSc, United Kingdom Daniela C. Goncalves, United Kingdom Joanne Greenhalgh, PhD, United Kingdom Melissa Henry, Canada Jameson K. Hirsch, PhD, United States Patricia Holch, PhD, United Kingdom I-Chan Huang, PhD, United States Marc Jacobs, MSc, The Netherlands Gloria Juarez, PhD RN MSN, United States Cicely Kerr, MSc PhD, United Kingdom Youngmee Kim, PhD, United States Cindy L.K. Lam, MD, Hong Kong, SAR China Minghui Li, MS, United States Ana G. Magallanes, PhD, Mexico Oren Meyers, PhD, United States Sandra A. Mitchell, PhD CRNP AOCN, United States Michael Molla, PhD, United States Josephine M. Norquist, MS, United States Muirne CS Paap, The Netherlands Nalin Payakachat, BPharm MS PhD, United States Ana A. Popielnicki, BA, United States Andrea Pusic, MD MHS FRCSC, United States Maria-Jose Santana, PhD, Canada Silke Schmidt, PhD, Germany Carolyn E. Schwartz, ScD, United States Elizabeth J. Unni, PhD, United States Galina Velikova, MD, United Kingdom Mathilde Verdam, The Netherlands Valerie Williams, PhD, United States Vasoontara Yiengprugsawan, Thailand/Australia Huivong Zhang, MD, Peoples Republic of China



### **GENERAL INFORMATION**

#### **Conference Theme**

Energizing the Science of Quality of Life Research: Where Have We Been and Where Can We Go?

#### **Hotel Information**

The ISOQOL 20th Annual Conference will take place at the **InterContinental Miami Hotel.** 

#### InterContinental Miami Hotel

100 Chopin Plaza, Miami, Florida, 33131 Telephone: +1(305) 577-1000 www.icmiamihotel.com

A full service Fed Ex Office is located inside the InterContinental Miami. The Fed Ex Office is located on the Lobby Level near Starbucks.

#### **Registration Desk**

All registration transactions will be completed in US dollars. In addition to cash and checks, ISOQOL accepts MasterCard, Visa, American Express, and Discover credit cards.

#### **REGISTRATION DESK HOURS**

Tuesday, October 8:	4:00 pm – 7:00 pm
Wednesday, October 9:	7:00 am – 6:00 pm
Thursday, October 10:	7:00 am – 5:00 pm
Friday, October 11:	7:00 am – 5:00 pm
Saturday, October 12:	8:00 am – 4:00 pm

#### **Ticketed Events**

A ticket is required for all workshops and the Closing Dinner. Tickets are available at the Registration Desk while supplies last, through Friday, October 11 at 11:30 am.

#### **Cancellation Policy**

ISOQOL reserves the right to cancel any event due to lack of enrollment or other factors. In the event of a cancellation, registered participants will be notified by e-mail and will have the option to exchange their ticket for an available alternative, or to receive a complete refund.

All registration cancellations by participants must be received in writing and all refunds will be paid after the conference. Cancellations received after September 16 will not be eligible for a refund.

#### **Session Recording**

Session content is copyright-protected by ISOQOL. Recording of any session without the consent of ISOQOL is prohibited. Any recording done with consent of ISOQOL is for personal use only and cannot be reproduced or distributed.

#### **Certificates of Attendance**

Certificates of Attendance have been included in the registration materials. If you register onsite, you can request a certificate from the Registration Desk staff.

#### **Certificates of Presentation**

Certificates of Presentation have been created for presenters that have requested a certificate on the registration form. If you did not request a certificate in advance, you can request a certificate by sending an e-mail to the Executive Office at info@isoqol.org. Certificates requested during the conference will be distributed following the conclusion of the conference.

Oral presentation certificates will be available from the oral session chair. Poster presenters can pick up their presentation certificate at the Registration Desk starting on Friday afternoon.

#### **Poster Hall Hours**

All Poster presentations will take place in the **Biscayne Ballroom**. The Biscayne Ballroom will be open daily from **7:00 am – 7:00 pm** from Thursday, October 10 – Saturday, October 12.

# FIND! ATTRACT! RECRUIT!

- Don't Forget to Place Your Resume in the JOB BOOK located at the ISOQOL information table.
- Post Employment Opportunities & Resumes on ISOQOL's Online Job Board (resume postings are free!)

VISIT: http://jobs.isoqol.org



# BrightOutcome is pleased to announce the launch of:

# **PROmeasure**<sup>™</sup>

Electronic Patient Reported Outcomes (ePRO) survey administration, data capture, and reporting for healthcare providers and researchers.



- Affordable and turn-key HIPAA-compliant SaaS ePRO solution
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  - PROMIS<sup>®</sup> Short Forms, Item Banks, and Profiles
  - DSM-5 Section III Online Assessment Measures
  - FACIT<sup>®</sup> Measurement System
  - RAND<sup>®</sup> Health Surveys
  - And many more!
- Ideal for small to medium-sized PRO studies and practices

# Stop by the BrightOutcome booth at ISOQOL 2013, or visit www.brightoutcome.com to schedule a demo!

ISOQOL members receive discounted pricing on PROmeasure<sup>™</sup> before January 1st!

#### Welcome Reception

Wednesday, October 9, 6:00 pm – 7:30 pm Versailles Ballroom

The Scientific Program Planning Committee Co-Chairs would like you to join them at the ISOQOL Welcome Reception. Start off the conference by visiting with old friends and networking with new friends and colleagues. In true Miami style, we will have a salsa dance demonstration. Enjoy the show and maybe pick up a few dance moves to show off at the Closing Dinner. A cash bar will be available. (US dollars only)

#### **Mentor/Mentee Reception**

Thursday, October 10, 6:00 pm – 7:30 pm Versailles Ballroom

The goal of the ISOQOL Mentoring Program is to promote career development and provide networking opportunities for New Investigators and Students within the Society. Individuals interested in serving as a Mentor have been paired up with New Investigators that have signed up for the program. This reception provides a forum for the exchange of knowledge in a relaxed atmosphere.

The evening will begin with a presentation from the New Investigator SIG's *Tricks of the Trade: Advice for New Investigators in Quality of Life Research* series and segue into small group discussion with matched mentors and mentees. Refreshments will be provided.

# TRICKS OF THE TRADE: ADVICE FOR NEW INVESTIGATORS IN QUALITY OF LIFE RESEARCH

New investigators have many questions about how to develop a successful and fulfilling career in QOL research. A multidisciplinary panel consisting of two senior ISOQOL members and the recipient of the 2012 ISOQOL Emerging Leader Award, will talk personally about their own career development within QOL research; they will give advice to new investigators beginning to work in this field; and they will share their views about the future of QOL research.

#### Panelists:

**Donald Patrick, PhD MSPH,** University of Washington, Seattle, WA, United States

Karen Sousa, PhD, University of Colorado, Denver, CO, United States

**Melanie Calvert, PhD,** The University of Birmingham, United Kingdom

#### Industry Advisory Committee Symposium

INNOVATIONS FOR PATIENT ENGAGEMENT IN HEALTH OUTCOMES DEVELOPMENT, SELECTION AND MEASUREMENT: OPPORTUNITIES AND LIMITATIONS Wednesday, October 9, 4:30 pm – 6:00 pm Escorial/Alhambra Room

Recently, discussions have taken place at several venues (PRO Consortium Workshop, ISPOR, PCORI) on how to best include the patient perspective in health outcome development and measurement using new methodologies or innovations. The purpose of this symposium is to build upon these discussions by highlighting concrete examples of currently available and emerging innovations (e.g., patient panels, social media, patient forums, etc.) and discussing their strengths and challenges. The symposium will include a panel discussion to consider how to use these innovations in scientifically meaningful and productive ways that represent advancements in the field of health outcomes research and to develop a research agenda for their evaluation.

#### Panelists:

Alicyn Campbell, PhD, Genentech, United States Dennis Revicki, PhD, Evidera, United States Doug Rivers, PhD, You Gov, United States Tom Simon, Director, I CARE, Inc., United States

Moderator:

Heather Gelhorn, PhD, Evidera, United States

#### New Investigator SIG Roundtable Discussion

#### CAREER TOPIC: NETWORKING AND INTERVIEWS

Thursday, October 10, 12:45 pm – 1:45 pm Hibiscus Isle Room, Lobby Level

The New Investigator SIG invites you to join the discussion on networking and interviews. Attendees will learn from each other's experience and provide useful tips on networking as part of their job search. Interview strategies will also be discussed - how to get an interview; and how to be successful by preparing, learning to handle difficult questions, etc. A senior researcher with an established career in the field of quality of life research will be there to address questions and give specific advice. Additional material will be provided to all participants.

The roundtable is open to all new investigators, with a maximum of 20 participants. Lunch will not be provided.

### **HIGHLIGHTED EVENTS**

#### ISOQOL Business Meeting and Award Presentation

Saturday, October 12, 8:30 am – 10:00 am Versailles Ballroom

The first portion of the event will focus on the business of the Society including the official leadership transition. The second portion of the event will be the presentation of the ISOQOL Awards.

ISOQOL will present the following awards at the Business Meeting and Award Presentation:

#### 2013 PRESIDENT'S AWARD

The President's Award is awarded to an individual who has advanced HRQOL research and has made outstanding contributions to the Society in one or more of the following areas: education of professionals, patients or lay individuals about HRQOL's value; promotion or execution of HRQOL or other scholarly activities; and facilitating or furthering policy initiatives that have an impact on HRQOL. The awardee is selected by the Executive Committee and endorsed by the Board of Directors.

#### EMERGING LEADER AWARD - IN HONOR OF DONNA LAMPING

The Emerging Leader Award was established in 2011 to honor and commemorate Past-President Donna Lamping's contribution to the leadership of the Society. It will be awarded to an ISOQOL member who has shown exceptional leadership skills and potential.

#### NEW INVESTIGATOR AND STUDENT PRESENTATION AWARDS

These awards recognize the best overall oral and poster presentations made by full time students and investigators in the early stages of their career in HRQOL research. Finalists are selected based upon the scores and reviews received during the abstract submission stage.

#### OUTSTANDING ARTICLE OF THE YEAR AWARD

This award recognizes the single best article dedicated to HRQOL research published in *Quality of Life Research* journal during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQOL research methods or theory.

**Outstanding Poster Abstract Awards** recognize the year's top posters. The posters with the highest evaluations during the review process will be recognized with a ribbon posted on their poster board. These awards will be on display in the poster area and not formally presented at the Business Meeting and Award Presentation.

#### **Closing Dinner**

Saturday, October 12, 7:00 pm – 10:00 pm Bubba Gump Shrimp Co, Bayside Marketplace, Miami

The Closing Dinner will be held at a casual, seafood restaurant, Bubba Gump Shrimp Co, located in the Bayside Marketplace. Outdoor seating is available to enjoy the Miami weather. After dinner, a live Latin band will perform, and space will be available for dancing.

The restaurant is just a ten minute walk from the InterContinental Miami Hotel, but you can order a Monkey Shuttle in advance if you want to save your energy for salsa dancing! Monkey Shuttle information is available at the Registration Desk.

Tickets are required for this event and will be available for purchase at the Registration Desk through Friday at 11:30 am – or while supplies last. Ticket price includes buffet dinner, welcome drinks and dancing. Cash bar will be available. (Credit card or US dollars only)

Meet in the InterContinental Lobby at 6:45 pm to join a group to walk to Bayside Marketplace together.

# **DEVELOPING COUNTRY SCHOLARSHIPS**

### Congratulations to the 2013 Developing Country Scholarship Recipients:

Yu Changhe, MSc, Student, Liaoning University of Traditional Chinese Medicine, China

**Divine Ewane Ediebah**, **MSc**, Research Fellow in Biostatistics, EORTC HQ, Belgium

Yash Jalundhwala, MSc, Doctoral Candidate and Research Assistant, University of Illinois at Chicago, United States

Vasoontara Yiengprugsawan, PhD, Postdoctoral Research Fellow, Thai Health Risk Transition Project; Thailand/Australia





# **ISOQOL COMMITTEES & SPECIAL INTEREST GROUPS (SIGS)**

#### **Committees**

ISOQOL members are encouraged to serve on committees and subcommittees. The following committees will be meeting at the Annual Conference this year. Please join us!

#### INDUSTRY ADVISORY COMMITTEE (IAC)

Chair: Josephine Norquist, MS, United States

The purpose of the Industry Advisory Committee is to increase participation of the pharmaceutical and device industry in ISOQOL activities through spearheading scientific and methodological initiatives such as leading workshops, organizing symposia, supporting fundraising, authoring papers. The committee also chairs meetings related to scientific and methodological topics of joint interest to industry and ISOQOL.

#### **Industry Advisory Committee Meeting**

Thursday, October 10, 7:45 am – 8:45 am Michelangelo Room Don't miss the IAC Symposium on Wednesday!

#### 2014 ANNUAL CONFERENCE PLANNING COMMITTEE

2014 Co-Chairs: Jordi Alonso, MD PhD, Spain Susan Bartlett, PhD, Canada

The Scientific Program Planning Committee Co-Chairs will be hosting a brief meeting on Friday morning to discuss topics and themes for the 2014 Annual Conference in Berlin, Germany. Whether you would like to offer suggestions for 2014 planning or volunteer to assist in the program planning process, we welcome you to join us.

#### **2014 Planning Committee Meeting**

Friday, October 11, 7:30 am – 8:45 am Escorial/Alhambra Room

# BEST PRACTICES FOR PROS IN RANDOMIZED CLINICAL TRIALS TASK FORCE

Oversight Executive: Jane Blazeby, MD, United Kingdom Michael Brundage, MD, Canada Melanie Calvert, PhD, United Kingdom Dennis Revicki, PhD, United States

Building on the success of the ISOQOL Reporting Guidelines Task Force and ISOQOL's role in the development of the CONSORT PRO Extension, the Task Force is working on the development of best practices documentation for patient-reported outcomes (PROs) in randomized clinical trials (RCTs). The Task Force has two teams – the Protocol Checklist Development Team and the CONSORT PRO Guidance Implementation Tools Team.

#### **Task Force Meeting**

Friday, October 11, 12:45 pm – 1:45 pm Hibiscus Isle Room, Lobby Level

#### **Special Interest Groups (SIGS)**

Special Interest Groups (SIGs) have been established to facilitate communications between researchers with specific interests, ranging from methodology to applications of quality of life in particular populations. SIGs offer all ISOQOL members a unique network of researchers who share similar interests within the health related quality of life research field.

Board Liaison to SIGs: Maria-Jose Santana, PhD, Canada

#### CHILD HEALTH

Chair: Katherine Bevans, PhD, United States

Primary interests are to stimulate excellent child healthrelated quality of life research (C-HRQoL), to increase awareness among the general ISOQOL membership of the importance of early health and the potential of child health concepts and methodological practices to foster improvements in health across the lifespan. Such methods/ practices include non-patient observer reports/studies; integration of data from multiple reporters: cognitive interviewing methods; adaptations of instruments for respondents with low literacy, attentional and other respondent problems; and long term effects of health promotion interventions.

#### **Child Health SIG Meeting**

Thursday, October 10, 7:30 am – 8:45 am Balmoral Room

#### **IBERO AMERICA**

Chairs: Alfonso Urzúa, PhD, Chile Diana Camargo, MSc, Colombia

The Ibero America SIG is open to any ISOQOL member residing in an Ibero American country. The SIG holds meetings on targeted issues pertaining to health-related quality of life research.

#### **Ibero America SIG Meeting**

Friday, October 11, 5:45 pm – 6:30 pm Balmoral Room

#### **Special Interest Groups (SIGS)**

#### NEW INVESTIGATORS

Chairs: Antonia V. Bennett, PhD, United States Katerina Papageorgiou, MSc, The Netherlands

The New Investigators SIG is targeted at people new to QOL research. We welcome students, post docs, and anyone who has been working in QOL research for five years or less. We aim to:

- Create a network for investigators new to the field of QOL
- Facilitate discussions, both theoretical and practical
- Help solve common problems at early stages of one's career

#### New Investigator SIG Meeting

Friday, October 11, 7:30 am - 8:45 am Balmoral Room

#### New Investigator Roundtable Discussion

*Career Topic: Networking and Interviewing* Thursday, October 10, 12:45 pm - 1:45 pm Hibiscus Isle Room, Lobby Level

#### PATIENT ENGAGEMENT

Chairs: Sam Salek, BSc RPh PhD FFPM, United Kingdom Rick Sawatzky, PhD RN, Canada

The purpose of the Patient Engagement SIG is to place greater emphasis on patients' voice in relation to ISOQOL activities and work with patient advocacy organizations and partners. The Patient Engagement SIG will work closely with the QOL in Clinical Practice SIG to achieve these goals.

#### Patient Engagement SIG Meeting

Friday, October 11, 5:45 pm - 6:30 pm Windsor Room

#### **PSYCHOMETRICS**

Chairs: Stefan J. Cano, PhD CPsychol AFBPsS, United Kingdom; Lori McLeod, PhD, United States

The goals of the Psychometrics SIG are to: 1) advance the science of HRQOL research through the application of psychometric methods; and 2) educate researchers and clinicians on the appropriate use of psychometric methods. The field of psychometrics plays a critical role in HRQOL research. Psychometrics plays a key role alongside qualitative methods to develop and evaluate HRQOL measures. Further, structural equation models provide an incredible methodology for looking at associations among HRQOL variables or to model change over time when there are multiple endpoints or mediating/moderating factors.

#### **Psychometrics SIG Meeting**

Thursday, October 10, 7:30 am – 8:45 am Sandringham/Windsor Room

#### QUALITY OF LIFE IN CLINICAL PRACTICE

Chairs: Kirstie Haywood, DrPhil BSc, United Kingdom; Colleen Norris, PhD, Canada

The QOL in Clinical Practice Interest Group was formed by researchers and clinicians who are interested in using health-related quality of life (QOL) assessment to improve clinical practice. This focus includes using QOL assessment to manage individual patients as well as using QOL data for medical decision-making.

#### **QOL in Clinical Practice SIG Meeting**

Friday, October 11, 7:30 am – 8:45 am Sandringham/Windsor Room

#### **RESPONSE SHIFT**

Chairs: Leah McClimans, PhD, United States; Ruth Barclay-Goddard, PhD MHSc BMR (PT), Canada

The purpose of the response shift interest group is to bring together investigators and clinicians who are interested in the influence of response shift (a change in an individual's values, internal standards, and conceptualization of QOL) on QOL assessments. The ultimate objective is to better understand when and why response shift occurs such that healthcare professionals and researchers using patient reported outcomes across various disciplines can recognize and account for response shift.

#### **Response Shift SIG Meeting**

Friday, October 11, 5:45 pm – 6:30 pm Sandringham Room

#### TRANSLATION & CULTURAL ADAPTATION (TCA)

Chairs: Sonya Eremenco, MA, United States Mona Martin, RN MPA, United States

The overall objectives of the TCA SIG are to identify and advance research into practices and outcomes of translation and cultural adaptation of patient-reported outcome instruments; to provide an evidence database on translation and cultural adaptation of PROs; and to promote visibility of cross cultural issues in development and use of PROs in ISOQOL.

#### **TCA SIG Meeting**

Friday, October 11, 5:45 pm – 6:30 pm Escorial/Alhambra Room

Can't meet with us in person? Visit the SIG page on the ISOQOL website to connect with SIG leaders and join the discussion on the listservs.



### **WORKSHOPS**

Workshop tickets will be available for purchase at the Registration Desk as space permits.

#### **Morning Workshops**

#### Wednesday, October 9; 9:00 am - 12:00 pm

# (WK01) An Introduction to Health-Related Quality of Life Assessment

#### Sandringham Room

Heather Gelhorn, PhD and Kathy Wyrwich, PhD, Evidera, United States

This workshop will serve as a broad introduction to health-related quality of life (HRQOL) assessment and the value, rationale, and process for incorporating HRQOL into outcomes research.

Participants will learn about the rationale and value of incorporating HRQOL into outcomes research through an understanding of the definition and history of HRQOL assessment, and of the types of HRQOL measures. Participants will also learn about the development process for HRQOL instruments, including qualitative and psychometric evaluation, and at the workshop's conclusion will be able to navigate the HRQOL landscape through exposure to major sources of HRQOL instruments, discussion of regulatory considerations and modern modes of administration. Level: Basic

#### (WK02) Everything You Wanted to Know About Rasch Measurement Theory But Were Too Afraid to Ask - Part 1

#### Windsor Room

Stefan Cano, PhD CPsychol AFBPsS and Jeremy C. Hobart, PhD, Peninsula Schools of Medicine and Dentistry, United Kingdom

Are you wrestling with Rasch Measurement Theory? Struggling with the statistics? Muddled by the math? Are you like we were: wannabe psychometricians trying to get into modern psychometric methods, but who have attended other workshops and left feeling none-the-wiser? Then this is the Rasch Measurement Theory workshop for you. In reality the basic principles are very simple. So, we have put together a straightforward, non-technical, non-mathematical approach to Rasch Measurement Theory that will help you begin to access the fantastically powerful and illuminating information it has to offer.

In this workshop we will describe: the role of quality of life and other types of health rating scales as outcome measures; the basic principles underlying traditional psychometric methods, their limitations and drivers for modern methods; the principles underpinning modern psychometric methods; the similarities and difference between traditional and modern psychometric methods; the similarities and important differences between Rasch Measurement Theory and Item Response Theory. We will provide multiple examples of the applications of Rasch Measurement Theory to scale evaluation, scale modification, new scale development, head-to-head scale comparisons, item banking, and the all-important issue of determining clinically significant change. Also, new to this year's ISOQOL, we will be tackling the thorny issues of sample size, construct theories and what really should count as content validity from a Rasch Measurement Theory perspective. This workshop will also provide a hands-on instruction in using the Rasch Measurement Model (RUMM2030) software package in order to analyze data for internal construct validity; reliability; category probability curves; differential item functioning; and scaling characteristics.

Attendees should bring their laptops to the session to fully benefit from the hands on data analysis exercise. Level: Basic

#### (WK03) Discrete Choice Experiments: Enhancing PRO Beyond QALYs

#### **Balmoral Room**

#### Benjamin M. Craig, PhD, Moffitt Cancer Center, United States

Unlike in the United Kingdom and Canada, the United States does not have a provincial or national health care system. Its citizens are health consumers who require a more patient-centered approach to the summary of healthrelated quality of life (HRQOL) evidence, including patientreported outcomes (PROs). Preference-based measures, such as quality-adjusted life years (QALYs), are largely uninformative for such consumers. Instead, most patients faced with a difficult decision want to be able to phone a friend, ask the audience, or learn "what would you do in my situation." Discrete Choice Experiments (DCE) enhance PRO by summarizing outcomes in terms that health consumers understand.

This workshop will cover DCEs for health valuation, including paired comparison and partial rank tasks, such as best-worst scaling. The workshop will further discuss differences between DCE and traditional valuation approaches for standardized instruments (e.g., time tradeoff EQ-5D, standard gambles of SF-6D) and conclude with an econometric overview of QALYs, such as its constant proportionality assumptions. As a hands-on exercise, attendees will be arranged in groups and asked to design a DCE of a PRO instrument demonstrating a key advantage that sets DCE apart from more complex institutional approaches: anyone can design and run a proper DCE. Level: Advanced

#### Afternoon Workshops

Wednesday, October 9; 1:00 pm - 4:00 pm

#### (WK04) The Development and Validation of Clinician-Reported Outcome Instruments: The Application of Methods from Patient-Reported Outcomes

Sandringham Room

**Sophi Tatlock, MA,** Adelphi Values, United Kingdom; **Helen Kitchen, MSc,** The University of Manchester, United Kingdom; **Rob Arbuckle, MSc,** Adelphi Values, United Kingdom

This workshop will give attendees a sound understanding of the application of Patient-Reported Outcome (PRO) development and validation methods to the development and validation of Clinician-Reported Outcomes (ClinRO) to regulatory standards. Specifically, aspects of PRO methods that can be applied without change, those that may be adapted, and methods specific to or of increased importance for ClinROs will be outlined. Drawing on examples and including several interactive exercises, all stages of instrument development and validation will be discussed. Specifically, attendees will code clinician interview transcripts and group example clinician and patient quotes by domain. The group will then generate items based on those quotes, highlighting differences in item wording for clinicians and patients. Cognitive debriefing with clinicians and patients will be discussed, with similarities and differences compared. The value of observing or recording clinician-patient interactions and associated ethical issues will be discussed. Specific considerations for psychometric validation of ClinROs, including inter-rater reliability and developing cutpoints through Receiver Operating Characteristic (ROC) analysis will be explored. Finally, specific considerations for implementing ClinROs in clinical trials and other large scale studies will be discussed alongside the challenges of using measures developed for use in clinical practice as trial endpoints, and vice versa. Level: Basic

#### (WK05) Everything You Wanted to Know About Rasch Measurement Theory But Were Too Afraid to Ask -Part 2

#### Windsor Room

Stefan Cano, PhD CPsychol AFBPsS and Jeremy C. Hobart, PhD, Peninsula Schools of Medicine and Dentistry, United Kingdom

Please see the description of WK02 for more information. Enrollment in (WK02) Everything You Wanted to Know About Rasch Measurement Theory But Were Too Afraid to Ask - Part 1 is not required, but it is recommended. Level: Advanced

#### (WK06) Making QALY Instruments From PROs: Methods for Developing Preference Based Measures of Health from Existing Measures

#### Balmoral Room

Brendan Mulhern, Mres; John E. Brazier, PhD; Tracey Young, PhD and Simon Palfreyman, PhD, University of Sheffield, United Kingdom

Recent years have seen increasing reliance on a few generic preference-based measures of health (e.g. EQ-5D, HUI3, or SF-6D) for calculating Quality Adjusted Life Years (QALYs) for economic evaluation. However, generic measures may not be used in key clinical studies. This may be due to a desire to reduce patient burden or a view that generic instruments are not valid for the condition or responsive to the effects of treatment. For these reasons there is interest in developing new preference-based measures of health. This workshop focuses on the estimation of the preference-based indices from existing generic and condition specific measures of health related quality of life. We will cover in detail the derivation of health states from existing measures using psychometric methods. We will also describe in detail both new and existing methods of health state valuation that can be used to derive the preference-based index that is used in the calculation of QALYs. New valuation methods covered include Discrete Choice Experiments incorporating duration and a hybrid Time Trade Off method used to value EQ-5D-5L. This workshop offers a practical introduction to the use of psychometric methods in the development and refinement of health state classifications, and the use of a range of valuation methods. It will also examine the policy implications of using different descriptive systems to derive preferencebased measures. It assumes a basic knowledge of HRQOL measurement and OALYs. Level: Advanced



### **WORKSHOPS**

#### Afternoon Workshops

Wednesday, October 9; 1:00 pm - 4:00 pm

#### (WK07) Using Patient-Reported Outcome Measures to Improve Care in Chronically Ill Patients Presented in Spanish

#### Michelangelo Room

Maria-Jose Santana, PhD, University of Calgary, Canada; Iuan I. Dapueto. MD PhD. Universidad de la República. Montevideo, Uruguay; and Jose (Chema) Maria Valderas, MD PhD MPH, University of Oxford, United Kingdom The use of patient-reported outcome measures (PROMs) in routine clinical care improves clinical practice by ensuring the treatment plans and evaluations focus on the patient rather than on the disease. The routine use of PROMs can improve patient-clinician communication, communication among healthcare professionals, communication among family members and patients, improve adherence, support quality improvement efforts, improve patient satisfaction, improve provider satisfaction, monitor the progress of patients, enhance patient engagement and improve patient outcomes. This workshop will include discussion on how PROMs affect patient-clinician communication, patient engagement and management and shared decision making; how to interpret HRQL information; how to make it actionable, overcoming barriers, and customizing the approach to the setting. Examples from different settings, pediatrics versus adult or cancer care versus surgery and the inclusion of testimonials from doctors, nurses and patients/patient relatives, will be explored.

Attendees should bring their laptops to the session. Workshop will be presented in Spanish. Level: Basic

# **Congratulations to the Presentation Award Finalists**

#### **Student Oral Presentation Finalists**

*Jo Brett, United Kingdom,* Oral Session 205: Quality of Care Experience

*Sophie Cleanthous, MSc, BSc, United Kingdom,* Oral Session 104: Patient-Reported Outcomes Measure Development and Evaluation

*Kim Nicolaije, The Netherlands,* Oral Session 204: Personalized Medicine

#### New Investigator Oral Presentation Finalists

*Zeeshan Butt, PhD, United States,* Oral Session 207: Patient-Reported Outcomes Measure Development and Evaluation

*Brendan Mulhern, United Kingdom* Oral Session 206: Health Utilities

*Ester Villalonga, PhD, United States,* Oral Session 201: Quality of Life in Children

#### **Student Poster Presentation Finalists**

*Amin Abdul-Galeel Amro, RN, MSN, Norway,* Poster Session 1, Number 1072

*Amélie Anota, France,* Poster Session 2, Number 2013

Aaron C. Roberts, United States, Poster Session 1, Number 1001

#### New Investigator Poster Presentation Finalists

*Hyewon Chung, Korea,* Poster Session 1, Number 1056

*Eva-Maria Gamper, Austria,* Poster Session 1, Number1025

Jiseon Kim, United States, Poster Session 1, Number 1029

Winners will be announced at the ISOQOL Business Meeting and Awards Presentation on Saturday, October 12.

#### New Horizons in Quality of Life Research

Thursday, October 10; 9:00 am – 10:30 am

#### Christopher B. Forrest, MD PhD

The Children's Hospital of Philadelphia University of Pennsylvania Philadelphia, PA, United States



Christopher B. Forrest, MD PhD is a Professor of Pediatrics and Health Care Management at the University of Pennsylvania and Children's Hospital of Philadelphia. His research unit focuses on the theory and measurement of health across the life course, value in pediatric

healthcare, and delivery system transformation. He leads a federally funded Pediatric Quality Measures Program Center of Excellence and a national program in pediatric learning health systems (which are dedicated to advancing the health of children through research, quality improvement, and informatics). He chairs the NIH's Patient-Reported Outcome Measurement Information System's (PROMIS)<sup>®</sup> Executive Committee and serves on the Steering Committee for the National Children Study's Health Measurement Network. Dr. Forrest received his BA and MD degrees at Boston University as part of a dualdegree program, and completed a PhD in Outcomes Research at Johns Hopkins School of Public Health.

#### Carolyn E. Schwartz, ScD

DeltaQuest Foundation, Inc Tufts University School of Medicine Concord, MA, United States



Carolyn E. Schwartz, ScD is President and Chief Scientist at DeltaQuest Foundation in Concord, MA, USA, and Adjunct Research Professor of Medicine and Orthopaedics at the Tufts University School of Medicine. A specialist in outcomes research and measurement development, her

interdisciplinary and methodological research focuses on understanding what patients can do to have an impact on the course of their disease and their well-being. Her work has spanned a number of medical conditions, patientreported outcome tools development, and the theoretical and methodological foundations of response shift phenomena in longitudinal quality-of-life research. A longstanding member of ISOQOL, she has served as Co-Editorin-Chief of *Quality of Life Research* since 2009. Kirsi Tirri, PhD MTh

Department of Teacher Education University of Helsinki Helsinki, Finland



Kirsi Tirri, PhD MTh is a Professor of Education and Research Director at the Department of Teacher Education at the University of Helsinki, Finland. She is also a visiting scholar with the Stanford Center on Adolescence, USA. Dr. Tirri has been the President of ECHA (European Council for

High Ability) for the years 2008-2012. She is the President of the SIG International Studies at AERA (American Educational Research Association). Her research interests include moral and religious education, gifted education, teacher education and cross-cultural studies. She has published 12 monographs and numerous journal articles related to these fields. She has led the Finnish team in many national and international research projects.

Session chaired by **Katherine Bevans, PhD,** Children's Hospital of Philadelphia, PA, United States and **Simon Pickard, PhD**, University of Illinois at Chicago, IL, United States

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### **PLENARY SPEAKERS**

#### Cutting Edge Research in Quality of Life

Thursday, October 10; 11:15 am – 12:45 pm Plenary session sponsored by Genentech

#### Lena Wettergren, PhD

Karolinska Institutet Stockholm, Sweden



Lena Wettergren, PhD (2002), is an associate professor in Nursing at the Karolinska Institutet; she has a clinical background in cancer care and is specialized in psychosocial oncology. From 2009 to 2011 she was head of the Division of Nursing at the Karolinska Institutet and

holds several academic appointments within research and research education. She is now an associate professor and co-leads a research group investigating quality of life and health in persons with long-lasting conditions. Cancer survivorship has been focused in several studies with a growing emphasis on fertility and sexual concerns among young cancer survivors. In 2004 to 2006 she held a post doc position at Uppsala University in a research group focusing on childhood cancer, and has since conducted extensive research within the field.

#### INTERNET-BASED FOCUS GROUP DISCUSSIONS ARE FEASIBLE FOR INVESTIGATION OF SENSITIVE ISSUES AMONG YOUNG CANCER SURVIVORS

Internet-based focus group discussions constitute a novel form of data assessment that enables interaction with a population spread over a large geographic area. During three months we successfully conducted 40 group discussions on sensitive issues, intimacy and sexuality, in adolescents and young adults.

### Michael A. Kallen, PhD MPH

Northwestern University Chicago, IL, United States



Michael A. Kallen, PhD, MPH, is a Research Associate Professor in the Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, USA. His doctorate from the University of Arizona (Tucson, AZ) is in Educational Psychology; his specialization

was in classical and modern test theory and applied psychometrics. Dr. Kallen has served as PI and CI on numerous NIH, AHRQ, CDC, and VA HSR&D grants and contracts, and his research has focused on the psychometric evaluation of health-related quality of life. He has, for example, developed, adapted, and evaluated instruments measuring attitudes, beliefs, and diseasespecific quality of life among HIV patients and has developed new culturally-specific measures to assess health beliefs and practices. Dr. Kallen is interested in extending differential item functioning (DIF) analyses to include studies on the impact of DIF on scores and in exploring new methods to evaluate essential unidimensionality incorporating assessments of the scoring impact of multidimensionality.

#### SO MUCH DIF, SO LITTLE DIFFERENCE: IDENTIFIED DIF AND ITS IMPACT ON MEASURE SCORES

To test the property of "measurement equivalence" in outcome measures, studies often evaluate whether persons who possess a same trait level but come from different demographic and clinical subgroups answer items differently (i.e.,differential item function or DIF). However, when standard criteria identify DIF items, the overall impact of DIF on scores may be trivial. DIF studies should consider not just the statistical identification of DIF but also its practical impact on obtained scores.

### **PLENARY SPEAKERS**

#### Cutting Edge Research in Quality of Life, Continued

Thursday, October 10; 11:15 am – 12:45 pm Plenary session sponsored by Genentech

#### Jordi Alonso, MD MPH

Director, Epidemiology & Public Health Program IMIM-Hospital del Mar Medical Research Institute Barcelona, Spain



Jordi Alonso, doctor of medicine, specialist in family and community medicine, preventive medicine and public health, is director of the program of Epidemiology and Public Health at the IMIM-Mar Hospital Medical Research Institute. He is a professor of public health at the Pompeu

Fabra University (Barcelona), and an associate professor at the Johns Hopkins University. His research focuses on the measurement of perceived health and evaluation of the need for and effectiveness of health services, especially in the area of mental health. He is a regional coordinator of the WHO World Mental Health (WMH) Surveys Initiative, and editor of the book "Burdens of Mental Disorders" based on that large international study. Dr. Alonso has served on several steering committees including those of the Spanish Society of Epidemiology (SEE) and the International Society for Quality of Life Research (ISOQOL). In 2005, he received the Professional Excellence award by the Council of Medicine Colleges of Catalonia.

#### DOES DISABILITY MEDIATE THE IMPACT OF COMMON MENTAL AND PHYSICAL CONDITIONS ON PERCEIVED HEALTH?

Despite the fact that many conceptual models of perceived health have been proposed, very few of them have been empirically tested. In this study, we used path analysis to test models of perceived health using data from more than 50,000 adults from 22 countries.

Session chaired by **Bryce Reeve, PhD,** ISOQOL President, University of North Carolina at Chapel Hill, United States; and **Galina Velikova, MD,** ISOQOL President-Elect, University of Leeds, United Kingdom

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#### Accentuate the Positive: The Sunny Side of Quality of Life Research

Friday, October 11; 9:00 am – 10:30 am Plenary Session Sponsored by Evidera

#### Mihaly Csikszentmihalyi, PhD

C.S. and D.J. Davidson Professor of Psychology and Management, Director of Quality of Life Research Center, Claremont Graduate University, Claremont, CA, United States



Mihaly Csikszentmihalyi, PhD is the C.S. and D.J. Davidson Professor of Psychology at the School of Behavioral and Organizational Sciences, and the Peter F. Drucker Graduate School of Management, at Claremont Graduate University; and co-Director of the Quality of Life Research Center. He is a

Fellow of several scientific societies, The National Academy of Education, and a member of the Hungarian Academy of Sciences.

In addition to the hugely influential *Flow: The Psychology of Optimal Experience*, he is the author of thirteen other books translated into 23 different languages, and some 245 research articles on optimal development, creativity, and well-being.

#### Crystal L. Park, PhD

Professor of Psychology Director, Health Psychology Graduate Certificate Program University of Connecticut, Storrs, CT, United States



Crystal Park, PhD is a Professor of Psychology and Director of the Health Psychology graduate certificate program at the University of Connecticut, Storrs. Dr. Park has an extensive record of research in the area of post-traumatic growth and psychological adjustment after cancer,

including investigation of the religious and non-religious pathways to growth and meaning making in cancer survivors. She also has experience in measure development and currently has an NCCAM-funded R01 to develop a questionnaire to measure the key dimensions of an effective yoga intervention.

Session chaired by **David Eton, PhD**, Mayo Clinic, Rochester, MN, United States and **John Salsman, PhD**, Northwestern University, Chicago, IL, United States

#### **Twenty Years of ISOQOL – A Celebration**

Saturday, October 12; 3:30 pm – 5:00 pm

2013 marks the 20<sup>th</sup> anniversary of the ISOQOL Annual Conference. ISOQOL will celebrate this in the final plenary session by bringing together past presidents of ISOQOL on one stage to reflect on past achievements, rejoice in camaraderie, and provide insight into the future of the Society. Session co-chairs will moderate a stimulating and fun Q&A, with live microphones provided for audience engagement.

#### **ISOQOL PAST PRESIDENTS**

Donald L. Patrick, PhD MSPH, United States, 1993-1994 Robert Kaplan, PhD, United States, 1994-1996 Monika Bullinger, PhD, Germany, 1996-1998 Sharon Wood-Dauphinee, PhD, Canada, 1998-2000 Ivan Barofsky, PhD, United States, 2000-2001\* David Osoba, MD, Canada, 2001-2002\* Mirjam AG Sprangers, PhD, The Netherlands, 2002-2003\* Albert W. Wu, MD MPH, United States, 2003-2004\* David Feeny, PhD, United States, 2004-2005\* Peter Fayers, PhD, United Kingdom, 2005-2006\* Madeleine T. King, PhD, Australia, 2006-2007\*

Donna L. Lamping, PhD, United Kingdom, 2007-2008

Neil K. Aaronson, PhD, The Netherlands, 2008-2009

Diane L. Fairclough, DrPH, United States, 2009-2010\*

Carol M. Moinpour, PhD, United States, 2010-2011\*

Bryce B. Reeve, PhD, United States, 2011-2013\*

Session chaired by **Juan J. Dapueto, MD PhD**, Universidad de la República, Montevideo, Uruguay and **Dennis Revicki, PhD**, Evidera, Bethesda, MD, United States

\*Attending the Plenary Session

### Thursday, October 10, 4:00 pm – 5:30 pm

#### Symposium 1: The Application of PROMIS® in Real-World Settings: Advancing Patient-Centered Research and Care

#### Sandringham/Windsor Room

Moderator: Katherine B. Bevans, PhD, Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine, Philadelphia, PA, United States

# Discussant: Jim Witter, MD PhD, National Institutes of Health, Bethesda, MD, United States

The Patient Reported Outcome Measurement Information System (PROMIS®) initiative has led to the creation of patient-reported outcomes (PRO) measures that assess a broad range of patient-relevant domains. Many PROMIS® tools are currently being validated for use in specific populations and applied in clinical research studies. The next step for these measures involves testing their use in clinical practice. Several projects funded through the Patient-Centered Outcomes Research Institute (PCORI) focus on the refinement and use of PROMIS® measures in real-world settings. This symposium is comprised of three presentations that examine how PROMIS® instruments can be used to simultaneously impact clinical care, inform patient decision-making, and measure outcomes to gauge the effectiveness of clinical interventions.

Presenters will describe: (1) the PROMIS® instrument maturity model that guides the selection and implementation of PROMIS® tools in clinical practice and research; (2) an innovative approach for ensuring that PRO measures used in clinical research and care are selected in accordance with patient priorities; and (3) an application of PROMIS® tools in the clinical care of patients with rheumatoid arthritis, gastrointestinal disorders, and substance use disorders. International leaders in the PRO and patient-centered research movements will facilitate discussion about ways that PROMIS® is advancing patientcentered care and outcomes research.

#### INDIVIDUAL PRESENTATIONS

#### **PROMIS® Instruments: Ready for the Big Time**

Carole A. Tucker PhD, Temple University, Philadelphia, PA, United States

#### **Developing Methods to Identify Child Health Outcome Priorities**

Katherine B. Bevans, PhD, Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine, Philadelphia, PA, United States

#### Integrating Patient-Centered Outcomes in Arthritis Clinical Care

Clifton O. Bingham III, MD, Johns Hopkins University, Baltimore, MD, United States

# Symposium 2: Patient and Public Engagement in Health Research

#### Raphael/Michelangelo Room

On behalf of the ISOQOL Patient Engagement and Quality of Life in Clinical Practice Special Interest Groups

The last decade has seen a growing interest in the active involvement of patients and the public in health-related and social-care research. This symposium will consider the desirability, rewards and challenges for patient and public engagement in health research more generally and PROs research more specifically, drawing on evidence of the benefits and challenges for patients and the public working in partnership with researchers.

Although collaborative patient and public engagement has developed in many areas of health research, it has been relatively absent in the PROs field. The development of PROs has followed a well-trodden methodological path, with patients contributing as research subjects to the content of many PROMs. However, the potential for more collaborative forms of patient and public engagement in different aspects of PROs research requires substantial exploration and methodological development in the future. This symposium will highlight the on-going effort to integrate patients and the public as collaborative researchers in health-related research, the developing evidence-base for these activities, and the relevance to PROs research.

This symposium will address the challenges of more collaborative forms of patient and public engagement with patients as research partners in the research process, not just as those individuals who are consulted or as subjects, from whom data are sourced, to ensure the acceptability, relevance, and quality of research. By reference to a new approach to patient and public engagement in Canada, the symposium will illustrate the impact of patient engagement researchers (PERs) and the experience of both PERs and their collaborators in driving collaborative investigations.

The majority of the symposium will focus on an interactive discussion, both among the panel members and between

Continued on next page...



## **CONCURRENT SYMPOSIA SESSIONS**

### Thursday, October 10, 4:00 pm - 5:30 pm

the panel and the audience. At the end of the symposium, attendees will have an improved awareness of processes, challenges, and rewards from enhanced patient and public engagement in health research, and key issues in the field requiring additional study.

#### PANEL DISCUSSANTS AND PRESENTERS

Kirstie L Haywood, DPhil; Sophie Staniszewska, DPhil (Oxon); and Joanne Brett, MSc, Royal College of Nursing Research Institute, Warwick Medical School, United Kingdom; Sam Salek, PhD, Cardiff University, United Kingdom; Svetlana Shklarov, MD; Nancy Marlett, PhD; and Colin Penman, University of Calgary, Canada; Colleen Norris, PhD, University of Alberta, Canada; Maria J. Santana, PhD, University of Calgary, Canada

#### Symposium 3: Genes, Cells and Symptom Clusters -What's the Story?

#### Escorial/Alhambra Room

Moderator: Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), University of Sydney, Sydney, Australia

Discussant: Donald Patrick, PhD MSPH, Seattle Quality of Life Group, Seattle, WA, United States

Tantalizing evidence is emerging of "symptom clusters" in cancer. A common cause could point to more effective treatment of symptoms via the underlying cause. As individualized medicine emerges as the new treatment paradigm, informed by genetic profiling, it is both timely and important to explore possible causal pathways between biological parameters (such as gene expression, DNA methylation, genotypes and cytokines) and patientreported outcomes including symptoms and other aspects of quality of life (QOL), not only in cancer but in all health conditions.

The symposium will start with a brief exposition of a conceptual model of potential biological pathways, genetic and biomolecular variants, characteristics of the afflicted person and his/her environment (social and medical), symptom experience, treatment (benefits and harms), and QOL (health-related and more broadly). Three speakers will then present cutting-edge knowledge about potential biological pathways (e.g. inflammatory, immunologic), and other genetic and biomolecular linkages. The session will end with a panel discussion of future research directions.

#### INDIVIDUAL PRESENTATIONS

#### A Conceptual Framework for Linking Biological Mechanisms to Symptom Clusters

Donald Patrick, PhD MSPH, Seattle Quality of Life Group, Seattle, WA, United States

#### Inflammatory Response-Related Development of Sickness Symptoms During Aggressive Cancer Therapy

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

#### **Pre-Clinical Biological Basis**

Annemeike Kavelaars, PhD, MD Anderson Cancer Center, Houston, TX, United States

#### Studying the Biological Underpinnings of Quality of Life: Update on the GeneQol Consortium Activities

Mirjam AG Sprangers, PhD, Academic Medical Center, University of Amsterdam, The Netherlands

### HEALTH UTILITIES INDEX<sup>®</sup> (HUI<sup>®</sup>) for <u>Your Multi-National</u> <u>Clinical Trials</u> Leading world instrument for

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# **CONCURRENT SYMPOSIA SESSIONS**

### Friday, October 11, 11:15 am - 12:45 pm

# Symposium 4: Tools for Assessing Religiousness and Spirituality in Health Research

#### Sandringham/Windsor Room

Moderator: John M. Salsman, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

Religiousness and spirituality are increasingly shown to be related to myriad aspects of health and well-being. There has been growing interest in the links among religion, spirituality and health outcomes which has catalyzed research in the field and stimulated a deeper exploration of religion and spirituality. As researchers increasingly include these variables, they face a bewildering array of methods and measures. The proliferation has led to a number of surveys which vary widely in psychometric quality and conceptual validity. During this panel, researchers will identify important considerations in the measurement of religion and spirituality, as well as considerations when designing a study to measure religion and spirituality. The panel will use specific health issues as exemplars of how to identify quality assessment tools. We will discuss specific assessment tools and provide specific criteria for evaluating their appropriateness in particular studies. By using empirically validated information, the panel will discuss the religion and spirituality variables that are particularly pertinent to the health issue.

By the end of this panel, researchers and clinicians will have better knowledge of quality assessment tools for use in research and clinical practice and they will have the means to assess the qualities of new or unfamiliar assessment tools that they wish to integrate into their future studies.

Continued on next page...



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#### Friday, October 11, 11:15 am - 12:45 pm

#### INDIVIDUAL PRESENTATIONS

#### Current Challenges and Suggested Solutions for Assessing Religion and Spirituality in Pain

Amy B. Wachholtz, PhD MDiv , University of Massachusetts Medical School, United States

# Current Challenges and Suggested Solutions for Assessing Religion/Spirituality in Cancer

John M. Salsman, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

#### Measuring Religious and Spiritual Constructs in the Context of Cardiovascular Health and Illness

Crystal L. Park, PhD, University of Connecticut, United States

#### Symposium 5: Response Shift Detection in Incomplete Longitudinal Quality of Life Outcomes Data

Escorial/Alhambra Room

On behalf of the Response Shift Special Interest Group of ISOQOL

Moderator: Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, MA, United States

Discussant: Diane Fairclough, DrPH, University of Colorado, Denver, CO, United States

Missing data due to attrition or item non-response are often encountered in longitudinal quality-of-life (QOL) research, resulting in biased estimates and loss of power. Notable recent advances characterize patterns of and methods to handle missing data. While missing data present challenges to all outcome research applications, their impact on response shift (RS) detection is relatively unknown. Recent work by Sajobi and colleagues has suggested that missing data problems can not only obfuscate RS detection, but also that missing data methods are not equally able to accommodate this challenge. This symposium will investigate the impact of missing data

The RS detection methods investigated include: (1) *Relative importance analysis* based on discriminate function and logistic regression analysis to detect reprioritization RS; (2) *Item-response theory-based* (IRT) to detect recalibration, reprioritization, and reconceptualization RS; and (3) Oort's *structural equation modeling* (SEM) to detect recalibration, reprioritization, and reconceptualization RS. Four longitudinal health-related QOL datasets: (a) stroke

caregivers; (b) multiple sclerosis; (c) cancer; (d) chronic disease. Tested missing-data techniques included case-wise deletion, available-case analysis, single imputation, and multiple imputation methods.

Tests based on relative importance measures in the strokecaregiver sample were sensitive to the type and amount of missing data and imputation method, with multiple imputation showing the largest effect. In the multiple sclerosis sample, the findings were robust across all tested imputation methods. Similarly, the IRT algorithm developed for RS detection yielded consistent and stable results across sub-samples, regardless of whether performed on complete or available case data. The attrition-based multigroup SEM enabled detection of measurement bias and true change across measurements (i.e. RS), and between groups of patients with different attrition rates. It revealed a reconceptualization response shift in pain measurement which did not alter the substantive conclusions about symptoms and functional status.

Results suggest that missing data imputation techniques generate similar findings across relative importance methods, and that IRT- and SEM-based analyses are robust to missing data. This symposium will provide a rich forum for discussing future directions for this untapped research area.

#### INDIVIDUAL PRESENTATIONS

A Comparison of Imputation Methods for Response Shift Detection in a Stroke Caregiver Population Tolulope Sajobi, PhD, University of Calgary, Calgary, Canada

#### Using Attrition-Based Multi-Group Structural Equation Modeling to Assess Response Shift and True Change in Multivariate Longitudinal Health-Related Quality of Life Data

Mathilde Verdam, MSc, Academic Medical Centre, University of Amsterdam, The Netherlands

#### Item Response Theory Models for Response Shift Detection with Missing Data in Patient-Reported Outcomes in Longitudinal Clinical Studies Veronique Sebille, ScD, University of Nantes, France

Identifying reprioritization response shift in multiple sclerosis: The impact of missing data imputation method on response shift detection

Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, MA, United States

## **CONCURRENT SYMPOSIA SESSIONS**

### Friday, October 11, 11:15 am – 12:45 pm

#### Symposium 6: New Developments in Valuing Health: Directions for the EQ-5D

#### Raphael/Michelangelo Room

Moderator: Paul Kind, MS, University of Leeds, Leeds, United Kingdom

EQ-5D is a generic classification of health-related quality of life that is widely used around the world for monitoring population health status, evaluating HRQL as an endpoint in clinical trials, informing health care resource allocation, and increasingly, as a performance management tool in healthcare systems. The descriptive system consists of five domains: mobility, self-care, usual activities, pain/ discomfort, and anxiety/depression, each with three response options: no problems, some problems, and extreme problems. Scoring systems have been developed that enable EQ-5D health states to be represented as a single index. With the goal of further refining the measure, the EuroQol Group has recently developed a descriptive system with 5 levels (EQ-5D-5L), an crosswalk to obtain interim values for the EQ-5D-5L derived from existing 3L value sets, and developed a protocol to guide international valuation studies. The aims of this symposium are: (1) to provide an overview of the EQ-5D-3L and best practices for valuation studies; (2) to describe the development of the EQ-5D-5L descriptive system and crosswalk; (3) to explain the international protocol and present results from the Canadian EQ-5D-5L valuation study.

#### INDIVIDUAL PRESENTATIONS

# Overview of the EQ-5D-3L and New Directions for Valuation

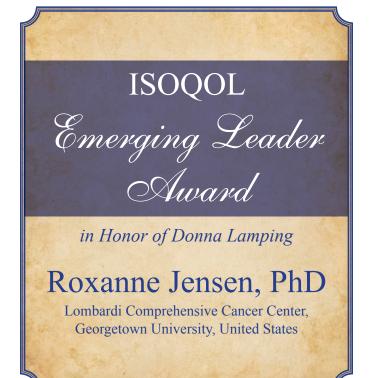
Paul Kind, MS, University of Leeds, Leeds, United Kingdom

# Recent Developments in EQ-5D Measures and Valuation

Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States

# The EQ-5D-5L International Protocol and the Canadian Experience

Feng Xie, BSc(Pharm) MSc PhD, McMaster University, Hamilton, ON, Canada





### Thursday, October 10, 2:00 pm – 3:30 pm

# Oral Session 101: Positive Psychology/Life Satisfaction

Session Chair: David Eton, PhD, United States Balmoral Room

(101.1) A Pilot Study of Salutogenic Cafe Which Improves Sense of Coherence in a Work Place Shin-ichiro Sasahara, University of Tsukuba, Tsukuba-City, Japan

# (101.2) Positive Mental Health Among People with Psoriasis

Eva Langeland, Bergen University College, Bergen, Norway

#### (101.3) Cognitive Judgment Towards Eudaimonia Through Basic Needs Satisfaction

Tadashi Hirai, PhD, The University of Tokyo, Tokyo, Japan

#### (101.4) Positive Mental Health, Coping and Health-Related Quality of Life Among Adolescents at High School

Ragnhild Sollesnes, Bergen University College, Bergen, Norway

# (101.5) Satisfaction with Life and Marital Satisfaction in Couples With and Without Children

Jocelyne M.R. Clench-Aas, PhD, Norwegian Institute of Public Health, Oslo, Norway

#### Oral Session 102: Response Shift

Session Chair: Leah McClimans, PhD, United States Windsor Room

#### (102.1) Response Shift in Dermatology: A New Approach of Telling Recall Bias from Scale Recalibration

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

### (102.2) Relative Weight Analysis for Response Shift Detection in Longitudinal Health-Related Quality of Life

Tolulope T. Sajobi, PhD, University of Calgary, Calgary, Canada

# (102.3) Response Shift in QoL: People Living with Dialysis

Barbara A. Elliott, PhD, Medical School-University of Minnesota, Duluth, MN, United States

#### (102.4) Response Shift and Transformative Learning – Do Rehabilitation Professionals Use These Concepts of Change in Their Clinical Practice?

Ruth Barclay-Goddard, PhD MHSc BMR (PT), University of Manitoba, Winnipeg, Canada

#### **Oral Session 103: Cancer Clinical Trials Issues**

Session Chair: Melanie Calvert, PhD, United Kingdom Sandringham Room

#### (103.1) Patient-Reported Outcomes in Randomized Controlled Trials of Genitourinary Cancers. Methodological Quality and Impact on Clinical-Decision-Making

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy

#### (103.2) Concordance of Patient-Reported (PROs) and Clinical Outcomes in Randomized Controlled Trials (RCTs) of Cancer Treatment. Evidence from 192 RCTs in Patients with Solid Tumors

Jonathan R. Rees, MSc PhD MRCS, University of Bristol, Clifton, United Kingdom

### (103.3) Use of PRO Data from Clinical Trials to Inform Cancer Care: An International Perspective

Julie Rouette, Queen's University, Trois-Rivieres, Canada

(103.4) Concordance Between Clinician-Rated Adverse Symptom Events and Patient Grading Using the Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE): Application of a Bayesian Graded Item Response Model Thomas M. Atkinson, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY, United States

#### (103.5) Analyzing Patient-Reported Outcome (PRO) Endpoints in Advanced Cancer Clinical Trials: Responder Analysis Versus Mixed Model for Repeated Measures (MMRM) Illustrated with Results from the AURELIA Ovarian Cancer Trial

Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Sydney, Australia

### Thursday, October 10, 2:00 pm – 3:30 pm

#### Oral Session 104: Patient-Reported Outcomes Measure Development and Evaluation

Session Chair: I-Chan Huang, PhD, United States Escorial/Alhambra Room

#### (104.1) Assessing the Translatability of a New Patient-Reported Outcome Measure for Major Depressive Disorder

Mona L. Martin, RN MPA, Health Research Associates, Inc., Mountlake Terrace, WA, United States

#### (104.2) Development of a Clinical Outcome Assessment for Autism Spectrum Disorder

Linda S. Deal, MS, Shire, Wayne, PA, United States

#### (104.3) Development and Validation of a New Patient-Reported Instrument of Uncertainty in Systematic Lupus Erythematosus (SLE) and Rheumatoid Arthritus (RA)

Sophie Cleanthous, MSc BSc, University College London, London, United Kingdom

STUDENT PRESENTATION AWARD FINALIST

#### (104.4) Development of a Composite Thyroid-Specific Quality of Life Scale for a Randomized Clinical Trial Among Hypothyroid Patients with Chronic Autoimmune Thyroiditis, Based on the ThyPRO Questionnaire

Kristian Winther, MD, Odense University Hospital, Odense, Denmark

#### (104.5) Validation of the Final Version of the Hyperhidrosis Quality of Life Index (HidroQoL©) Paul Kamudoni, Cardiff University, United Kingdom





#### Friday, October 11, 2:00 pm - 3:30 pm

#### Oral Session 201: Quality of Life in Children

Session Chair: Anne Riley, PhD, United States Balmoral Room

# (201.1) Health-Related Quality of Life and HIV Stigma in Children Living with HIV in Sweden

Lise-Lott Rydström, PhD-candidate, Karolinska Institutet, Sweden, Huddinge, Sweden

(201.2) The Use of Creative Exercises to Maximize Content Drawn from Concept Elicitation Interviews used to Develop Symptom and Health-Related Quality of Life Measures in Pediatric Populations with Chronic Disease

Rob Arbuckle, Adelphi Values, Cheshire, United Kingdom

#### (201.3) Health-Related Quality of Life of Children with Immigrant Backgrounds: Towards a New Pattern in Europe?

Ester Villalonga, PhD, Harvard School of Public Health, Boston, MA, United States

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

#### (201.4) Factors Influencing Quality of Life in Children with Epilepsy: A Structural Equation Modeling Approach

Nora Fayed, University Health Network, Hamilton, Canada

#### (201.5) Developing a Disease Specific Quality of Life Measure for Children with Osteogenesis Imperfecta

Wendy O. Baird, PhD, University of Sheffield, Sheffield, United Kingdom

#### **Oral Session 202: Concepts and Frameworks**

Session Chair: Cindy Gross, PhD, United States Escorial/Alhambra Room

#### (202.1) Development of a Measure of Patient-Reported Experiences and Outcomes of Patient Safety in General Practices in England: The PREOS-PC Instrument

Jose M. Valderas, MD PhD MPH, University of Oxford, Oxford, United Kingdom

#### (202.2) On the Conceptual Structure of the Chemotherapy-Induced Peripheral Neuropathy Scale of the EORTC Quality of Life Questionnaire (QLQ-CIPN20)

Jacobien Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

#### (202.3) Finalizing a Measurement Framework of Burden of Treatment in Complex Patients with Chronic Conditions

David T. Eton, PhD, Mayo Clinic, Rochester, MN, United States

#### (202.4) What's Important to Patients Following Fragility Hip Fracture? A Qualitative Exploration of Outcomes

Kirstie L. Haywood, DPHiL BSc, Warwick Medical School, Coventry, United Kingdom

(202.5) Examining the ICF Framework as a Model of the Cross-Sectional Relationship Between Chronic Disease and Quality of Life at Middle and Older Ages Eithne Sexton, Royal College of Surgeons in Ireland, Dublin, Ireland

#### **Oral Session 203: Statistical Methods**

Session Chair: Diane Fairclough, DrPH, United States Raphael/Michelangelo Room

#### (203.1) Development of a Crosswalk Between Measures of Work Role Limitations

Milena D. Anatchkova, PhD, University of Massachusetts Medical School, Worcester, MA, United States

#### (203.2) Mortality Bias in Quality of Life Scores Between Cancer Patients With and Without Follow-up Surveys

Ryan M. McCabe, Cancer Treatment Centers of America, United States

#### (203.3) Sample Size Determination Using Type I Error and Power When Conducting a Confirmatory Factor Analysis (CFA): A Simulation Study

Emmanuelle Anthoine, University of Nantes, Nantes, France

#### (203.4) Auxiliary Item Score Information to Deal with Missing Data in Longitudinal Patient-Reported Outcomes

Iris Eekhout, VU University Medical Center, Amsterdam, The Netherlands

Continued on next page...

### Friday, October 11, 2:00 pm – 3:30 pm

#### (203.5) Power and Sample Size Determination for the Group Comparison of PROs in IRT: Impact of a Misspecification of the Parameters

Myriam Blanchin, University of Nantes, France

#### **Oral Session 204: Personalized Medicine**

Session Chair: Mirjam AG Sprangers, PhD, The Netherlands Sandringham Room

#### (204.1) Profiling Chronic Myeloid Leukemia Patients Reporting Intentional and Unintentional Non-Adherence to Lifelong Therapy with Tyrosine Kinase Inhibitors

Francesco Cottone, PhD, GIMEMA (Italian Group for Adult Hematologic Diseases), Rome, Italy

(204.2) The Impact of an Automatically Generated Survivorship Care Plan on Patient-Reported Outcomes: Results of a Pragmatic Cluster Randomized Controlled Trial (ROGY Care) Among Endometrial Cancer Patients

Kim Nicolaije, Tilburg University, Tilburg, The Netherlands STUDENT PRESENTATION AWARD FINALIST

#### (204.3) Using Cluster Analysis to Generate Outcome Variables for Gene-Symptom Association Study in Cancer Patients

*Qiuling Shi, PhD, University of Texas M.D. Anderson Cancer Center, Houston, TX, United States* 

(204.4) A Randomized Trial of the Psychosocial Aspects of Hereditary Cancer (PAHC) Questionnaire in Cancer Genetic Counseling: Effect on Counselees' Levels of Psychosocial Distress

Willem Eijzenga, MSc, The Netherlands Cancer Institute, Amsterdam, The Netherlands

#### (204.5) Impact of Rapid Genetic Counseling and Testing on Health-Related Quality of Life in Breast Cancer Patients: Findings from a RCT

Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

#### Oral Session 205: Quality of Care Experience

Session Chair: San Keller, PhD, United States Windsor Room

(205.1) Measuring Cancer Care Quality: The Impact of Patient and Stakeholder Input on Survey Design

Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States

# (205.2) Patient-Reported Experience of Fracture of the Proximal Femur in Patients Over 65 Years

Jo Brett, University of Warwick, Oxfordshire, United Kingdom STUDENT PRESENTATION AWARD FINALIST

#### (205.3) Measuring Cancer Care Quality: Psychometric Properties of an Instrument for Assessing Patient Experience with Cancer Care

Christian Evensen, MS, American Institutes for Research, Chapel Hill, NC, United States

#### (205.4) The Development of a Patient-Centered Experience/Outcomes of Care Questionnaire for People with Chronic Conditions

Monica Hadi, PhD candidate, University of Oxford, Oxford, United Kingdom

#### (205.5) A Multi-Centre Study of Patient Experiences with Acute and Post-Acute Injury Care

Niklas JH Bobrovitz, BHSc(h), University of Calgary, Calgary, Canada



#### Friday, October 11, 4:00 pm - 5:30 pm

#### **Oral Session 206: Health Utilities**

Session Chair: Pedro Ferreira, PhD, Portugal Balmoral Room

#### (206.1) Validation of the CAT-5D-QOL Multi-Attribute Health Utility (MAHU) Score

Jacek Kopec, PhD, Arthritis Research Centre of Canada, Richmond, Canada

# (206.2) Valuation of Health Outcomes Measured Using the PROMIS<sup>®</sup>-29

Benjamin M. Craig, PhD, Moffitt Cancer Center, Tampa, FL, United States

(206.3) Improving the Measurement of QALYs in Multiple Sclerosis: Developing a Patient-Reported Health Descriptive System for Use in Deriving Quality-Adjusted Life-Years (QALYs) for Multiple Sclerosis

Elizabeth Goodwin, University of Exeter Medical School, Exeter, United Kingdom

(206.4) Developing an EQ-5D-5L Value Set for England

Brendan Mulhern, University of Sheffield, Sheffield, United Kingdom

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

#### (206.5) Health Utilities and Caregiver Spillover Effects Associated with Sleep Problems in Children with Autism Spectrum Disorders

J. Mick Tilford, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

#### Oral Session 207: Patient-Reported Outcomes Measure Development and Evaluation

Session Chair: Susan Bartlett, PhD, Canada Escorial/Alhambra Room

#### (207.1) Psychometric Properties of a Brief, Clinically-Relevant Measure of Pain in Patients with Hepatocellular Carcinoma

Zeeshan Butt, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

#### (207.2) The Diabetic Peripheral Neuropathic Pain Impact (DPNPI) Measure - Qualitative and Conceptual Development of a Patient-Reported Outcome Measure (PRO)

Steven I. Blum, MBA MA, Forest Laboratories, North Bellmore, NY, United States

# (207.3) Development and Psychometric Evaluation of the FACE-Q Aging Appraisal Scale

Vivek Panchapakesan, MD FRCSC, McMaster University, Toronto, Canada

#### (207.4) Development and Evaluation of a Physical Limitation Scale for Chinese Coronary Heart Disease Patients

Changhe Yu, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### (207.5) Development of a Patient-Reported Treatment Satisfaction Measure for Hyperfunctional Lines in the Upper Face

Selena R. Daniels, PharmD, Allergan, Inc., Irvine, CA, United States

#### Oral Session 208: Item Response Theory/ Item Banking

Session Chair: Georg Kemmler, PhD, Austria Raphael/Michelangelo Room

#### (208.1) Transition from EORTC QLQ-C30 to "EORTC QLQ-CAT" – Results and Experiences from the Development of CAT for 10 HRQOL Domains

Morten Aa Petersen, MSCi, Bispedjerg Hospital, Copenhagen, Denmark

#### (208.2) Correspondence Between the New RAND Impact of Asthma on Quality of Life Item Bank and the Marks Asthma Quality of Life Questionnaire

Maria O. Edelen, PhD, RAND Corporation, Boston, MA, United States

#### (208.3) A Multilevel Item Response Theory Analysis of the Relationship Between Environmental Factors and Lived Health of Institutionalized Persons in Spain

Cristina N. Bostan, University of Lucerne and Swiss Paraplegic Research, Nottwil, Switzerland

Continued on next page...

### Friday, October 11, 4:00 pm - 5:30 pm

#### (208.4) Withdrawn

#### (208.5) PROsetta Stone<sup>®</sup>: A Method and Common Metric to Link PRO Measures for Comparative Effectiveness Research (CER)

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

#### Oral Session 209: Responsiveness of Quality of Life Measures

Session Chair: Neil K. Aaronson, PhD, The Netherlands Sandringham Room

#### (209.1) Using the EORTC QLQ-C30: What Score Represents a Change in Patients' Supportive Care Needs?

Claire Snyder, PhD, Johns Hopkins, Baltimore, MD, United States

# (209.2) Minimal Important Difference Established for PROMIS<sup>®</sup> Pain Interference

Jiseon Kim, University of Washington, Seattle, WA, United States

#### (209.3) Responsiveness and Minimal Important Difference of the Rheumatoid Arthritis-Work Instability Scale (RA-WIS)

Arijit Ganguli, PhD MBA, AbbVie, Inc., North Waukegan, IL, United States

#### (209.4) Validation for Pediatric Patient-Reported Outcomes Measurement Information System (PROMIS)<sup>®</sup> in Asthmatic Children: A Responsiveness Study

I-Chan Huang, PhD, University of Florida, Gainesville, FL, United States

#### (209.5) Responsiveness to Change for the Brazilian Scale of Oral Health Outcomes for 5-Year-Old Children (SOHO-5)

Jenny Abanto, University of Sao Paulo, Sao Paulo, Brazil

#### **Oral Session 210: Caregiver Health**

Session Chair: Karen Sousa, PhD, United States Windsor Room

#### (210.1) Dyadic Effects of Social Support and Loneliness on Quality of Life of Cancer Patients and Their Family Caregivers

Youngmee Kim, PhD, University of Miami, Coral Gables, FL, United States

#### (210.2) Bereaved Family Caregivers' Unmet Needs Predict Grief Severity

Aurelie Lucette, University of Miami, Coral Gables, FL, United States

#### (210.3) Relationship Between Child Health-related Quality of Life and SF6D Scores for Children with Autism and Their Caregivers

Nalin Payakachat, BPharm MS PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

#### (210.4) Validation of the Final Version of the Family Reported Outcome Measure (FROM-16)©

Catherine J. Golics, MPharm, Cardiff University, Cardiff, United Kingdom

# (210.5) A Longitudinal View of Caregiver Emotional Vitality

Skye P. Barbic, PhD candidate, OT, McGill University, Montreal, Canada



### Saturday, October 12, 10:45 am - 12:15 pm

#### Oral Session 301: Longitudinal Follow Up in Cancer

Session Chair: Sandra Mitchell, PhD CRNP AOCN, United States Balmoral Room

#### (301.1) Baseline Quality of Life as Prognostic Factor of Relative Survival in Elderly Patients with Colorectal Cancer: A Population-Based Study

Evelyne Fournier, MPH, Doubs and Belfort Cancer Registry, University Hospital of Besançon, Besançon, France

#### (301.2) Long-Term Quality of Life in Breast Cancer Patients According to Sentinel Lymph Node Biopsy or Axillary Lymph Node Dissection: A Multicenter Cohort Study with 6 Years Follow-Up

Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges Francois Leclerc, Dijon, Burgundy, France

#### (301.3) Relationship Between Survival Time and Quality of Life in Terminal Cancer Patients Receiving Palliative Care Intervention

Kikuko Miyazaki, PhD, Kyoto University, Kyoto, Japan

#### (301.4) Quality of Life (QoL) for Prostate Cancer after Prostatectomy, Brachytherapy and External Beam Radiotherapy with a Follow-up of 5 years

Monica Avila Pacheco, MPH, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

#### (301.5) Quality of Life in a Urinary Bladder Cancer Cohort with Patients from Seven Spanish Hospitals

Stefanie Schmidt, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

# Oral Session 302: Quality of Life and Health Evaluation

Session Chair: Juan Dapueto, MD PhD, Uruguay Escorial/Alhambra Room

#### (302.1) Health-Related Quality of Life in Kidney Donors from the Last Five Decades: Results from the RELIVE Study

Cynthia Gross, PhD, University of Minnesota, Minneapolis, MN, United States

#### (302.2) Health-Related Quality of Life Associated with Imbalanced Body Constitution

Cindy L.K. Lam, MD, The University of Hong Kong, Hong Kong SAR, Peoples Republic of China

#### (302.3) Firefighters' Quality of Life and Emergency-Related Factors - Cross-National Data

Doris Kehl, University of Greifswald, Germany

# (302.4) The Cognitive Basis of the Visual Analog Scale (VAS)

Ivan Barofsky, PhD, The Quality of Life Institute, East Sandwich, MA, United States

#### (302.5) Patient-Reported Outcomes in Medicare Beneficiaries with Less Common Cancers: Population-Based Surveillance Using the SEER-MHOS Data Linkage.

Steven B. Clauser, PhD, National Cancer Institute, Rockville, MD, United States

# 2013 ISOQOL President's Award



Peter Fayers, PhD Retired, University of Aberdeen, United Kingdom

#### Saturday, October 12, 10:45 am - 12:15 pm

#### Oral Session 303: Methods and Psychometric Approaches

Session Chair: Caroline Terwee, PhD, The Netherlands Raphael/Michelangelo Room

#### (303.1) Which Paradigm for Evaluating Patient-Reported Outcome Instruments? A Comparison of Classical Test Theory, Item Response Theory, and Rasch Measurement Theory

Jennifer Petrillo, PhD, Novartis, East Hanover, NJ, United States

#### (303.2) Assessment of the Relative Precision of the NEI VFQ-25 and a Modified, Rasch-Scored NEI VFQ in Clinical Trial Data for Patients with Diabetic Macular Edema (DME)

Stefan J. Cano, PhD CPsychol AFBPsS, Plymouth University Peninsula Schools of Medicine & Dentistry, Plymouth, United Kingdom

#### (303.3) A Simple Ratio-Based Approach for Power and Sample Size Determination in Rasch Family Models

Jean-Benoit Hardouin, PhD ScD, University of Nantes, Nantes, France

#### (303.4) Use of Latent Growth Modeling to Evaluate Construct Validity in Longitudinal Studies

Lauren Nelson, RTI Health Solutions, Research Triangle Park, NC, United States

# (303.5) Self-Reported Cognitive Concerns and Abilities: Two Sides of One Coin?

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

#### Oral Session 304: eHealth / Health Technology

Session Chair: Carol M. Monipour, PhD, United States Sandringham Room

(304.1) Mode Equivalence and Acceptability of Web-, Interactive Voice Response System, and Paper-based Administration of US National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Antonia V. Bennett, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

#### (304.2) Developing a Tool to Measure the Effects of Using Health-Related Websites (The e-Health Impact Questionnaire)

Laura Kelly, University of Oxford, Oxford, United Kingdom

(304.3) Empowering Individuals to Manage their Health: Evaluating Individual Preferences and Willingness to Adopt Health Information Technologies Sara Ahmed, PhD, McGill University, Montreal, Canada

#### (304.4) A Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care

Roxanne E. Jensen, PhD, Georgetown University, Washington, DC, United States

(304.5) Development and Implementation of a Clinical Trial Management System for Pragmatic Multi-Center Trials, Optimized for Electronic Data Capture and Patient-Reported Outcomes, with Minimal Interference with Routine Clinical Practice

Per Cramon, MD, Copenhagen University Hospital, Copenhagen, Denmark

#### Oral Session 305: To Thine Own Self Be True: Quality of Life Among Researchers and Practitioners

Session Chair: Simon Pickard, PhD, United States Windsor Room

#### (305.1) Lifestyle Behaviors as Predictors of Bad Quality of Life in Thai Resident Physicians

Anawin Sanguankeo, Johns Hopkins University, Bangkok, Thailand

#### (305.2) Is There Any Difference on Quality of Life Between Hospital Doctor and Practitioner?

Sho Matsui, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, Japan

#### (305.3) Withdrawn

#### (305.4) Burnout and Quality of Life Among Health Sciences Research Faculty

Jeff Sloan, PhD, Mayo Clinic, Rochester, MN, United States

#### (305.5) Mexican Professors' Quality of Life in Comparison with Other Occupations

Fernando Arias-Galicia, Sr., Morelos State University, Cuernavaca, Mexico



#### Saturday, October 12, 1:30 pm - 3:00 pm

#### Oral Session 306: Quality of Life in Children: Methodological Issues

Session Chair: Jin-Shei Lai, PhD, United States Balmoral Room

#### (306.1) A Mixed Methods Approach to Studying Quality of Life in Children with Leukemia

Tha'er G. Momani, PhD(c), RN, St. Jude Children's Research Hospital, Memphis, TN, United States

# (306.2) Child HRQoL Assessment and the Kidscreen Instrument - Does Recall Time Matter?

Solveig Petersen, Umea University, Umea, Sweden

#### (306.3) The Application of a Mixed Methodology to Compare Three Legacy Pediatric Generic Health-Related Quality of Life Instruments Among Medicaid Population

Pranav Gandhi, PhD, South College, Knoxville, TN, United States

#### (306.4) How Do Aboriginal Children and Youth Interpret Health Questions?

Nancy L. Young, PhD, Laurentian University, Sudbury, Canada

#### (306.5) Design and User Acceptance of a New Computer-Adaptive Test for the Assessment of Quality of Life in Children – The Kids-CAT Project

Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany

#### Oral Session 307: Health Evaluation/Performance Measures

Session Chair: Jose (Chema) Valderas, MD PhD MPH, United Kingdom Escorial/Alhambra Room

#### (307.1) Self-Reported Measures of General Perception of Health, Psychological Well-Being and Risk Factors at Work Helped to Defined Promotion and Preventive Mental Health Interventions

Juan J. Dapueto, MD PhD, Universidad de la República, Montevideo, Uruguay

#### (307.2) Incorporating Patient-Reported Outcome Measures into the Electronic Health Record for Research: Application Using the Patient Health Questionnaire (PHQ-9)

Sandra D. Griffith, PhD, Cleveland Clinic, Cleveland, OH, United States

#### (307.3) The Effect of Baseline Patient Characteristics on Outcomes of Varicose Vein Surgery

Wei-Han Cheng, University of Illinois at Chicago, United States

#### (307.4) Using Baseline Patient Self-Rating of Health to Predict the Outcomes of Hip Replacement Surgery Vash Lalundhwala, University of Illinois at Chicago, Chicago, IL

Yash J. Jalundhwala, University of Illinois at Chicago, Chicago, IL, United States

#### (307.5) Comparing the Impact of Clinical Governance Policies in Different Countries: The Example of the English PROMs Programme

Maria B. Boyce, University College Cork, Cork, Ireland

# Oral Session 308: Symptoms and Quality of Life in Cancer

Session Chair: Jeff Sloan, PhD, United States Raphael/Michelangelo Room

#### (308.1) Decisional Conflict in Women with Hereditary Risk After a Breast Cancer Diagnosis

Marlene H. Frost, PhD, Mayo Clinic, Rochester, MN, United States

#### (308.2) Relationship Between Symptoms, Psychosocial Factors and Health-Related Quality of Life in Hematopoietic Stem Cell Transplant Survivors

Kelly Kenzik, PhD, University of Florida College of Medicine, Gainesville, FL, United States

# (308.3) Review of Self-Report Symptom Measures in Pediatric Oncology Research

Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

#### (308.4) Hispanic Cancer Survivor Preferences for a New eHealth Symptom Management Application "MAESTRA": Results from User-Centered Design Focus Groups

David Victorson, PhD, Northwestern University Feinberg School of Medicine, Evanston, IL, United States

Continued on next page...

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# **CONCURRENT ORAL SESSIONS**

### Saturday, October 12, 1:30 pm – 3:00 pm

# (308.5) Component Causes of QOL Trajectories in People with Advanced Cancer

Ana Maria Rodriguez, PhD MSc BS PT, McGill University, Montreal, Canada

#### Oral Session 309: Body Image/Sexual Function

Session Chair: Peter Fayers, PhD, United Kingdom Sandringham Room

#### (309.1) Do Existing Questionnaires for Sexual Dysfunction Measure Items Relevant to Patients with HIV and HCV?

Marcelo Watanabe, Medicine School of ABC, Sao Paolo, Brazil

# (309.2) Conceptual Model for the PROMIS<sup>®</sup> Sexual Function and Satisfaction Measure

Kathryn E. Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States

#### (309.3) Assessing Quality of Life in Patients Awaiting Delayed Breast Reconstruction

Helen C. Miller, BS, Memorial Sloan-Kettering Cancer Center, Great Falls, MT, United States

#### (309.4) Reasons for Sexual Inactivity in a U.S. National Survey of Adults

*Kevin P. Weinfurt, PhD, Duke Clinical Research Institute, Durham, NC, United States* 

#### (309.5) Quality of Life and the Impact of Altered Facial Appearance in Head and Neck Cancer Patient Populations: A Qualitative Study

Jessica L. Lawson, MSc, Yeshiva University, New York, NY, United States

#### **Oral Session 310: Respiratory Diseases**

Session Chair: Sara Ahmed, PhD, Canada Windsor Room

#### (310.1) Psychometric Performance of the Asthma Symptom Diary (ASD) in Adult and Adolescent Subjects with Persistent Asthma

Gary Globe, Amgen Inc., United States

#### (310.2) Validation of the RAND Impact of Asthma on Quality of Life Item Bank Short-Forms

Cathy Sherbourne, The RAND Corporation, Santa Monica, CA, United States

#### (310.3) Selecting Relevant PROMIS® Item Banks for Patients with Chronic Obstructive Pulmonary Disease: An Interview Study

Muirne CS Paap, University of Twente, Enschede, The Netherlands

#### (310.4) The Psychometric Development of an Item Bank and Short Forms that Assess the Impact of Asthma on Quality of Life

Brian D. Stucky, RAND Corporation, Santa Monica, CA, United States

#### (310.5) Evaluating Predictors of Perceived Asthma Control to Maximize the Impact of Interventions in Primary Care

Owis J. Eilayyan, McGill University, Montreal, Canada

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Scientific Communications

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access through evidence



### Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

#### eHealth/ePROs

#### (1001) Behind the Scenes: A Review of Instruments Used in Electronic Patient-Reported Outcomes Systems

Aaron C. Roberts, Georgetown University, Washington, DC, United States

STUDENT PRESENTATION AWARD FINALIST

#### (1002) Update of the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID): Inclusion of e-PRO Information

Katrin Conway, MA, Mapi Research Trust, Lyon, France

(1003) Online Platform to Accelerate Patient Involvement in Open Instrument Development Shimon Rura, PatientsLikeMe, Cambridge, MA, United States

#### (1004) Cheap PRO Collection on the Web with Low Response Rates vs Expensive Paper Forms with High Rates: Do We Have to Choose?

Niels Henrik Hjollund, Aarhus University Hospital, Herning, Denmark

#### **Patient-Reported Outcomes in Clinical Practice**

#### (1006) The Use of Individualized Measurement Instruments in the Process of Goal Setting: A Systematic Review

Anna Beurskens, PhD, Zuyd University of Applied Sciences, Heerlen, The Netherlands

#### **Conceptual Issues/Frameworks**

# (1009) Empowerment: An Individual Characteristic of Health-Related Quality of Life?

Jane Kass-Wolff, University of Colorado Anschutz Medical Campus, United States

#### (1010) Improving Patient Safety: A Framework to Assess Patient-Reported Adverse Outcomes

Barbara M. Okoniewska, University of Calgary, Canada

#### (1011) Understanding Health Care Needs of People With Chronic Conditions: Patient Experiences, Outcomes and Quality of Life

Monica Hadi, PhD candidate, University of Oxford, Oxford, United Kingdom

(1012) Differences in the Perception of Quality of Life Domains Between Hospital and Community Patients with Pressure Ulcers

Simon J. Palfreyman, PhD, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom

#### (1013) Framework to Assess the Effects of Using Patient-Reported Measures in Chronic-Care Management

Maria-Jose Santana, PhD, University of Calgary, Calgary, Canada

#### **Guidelines and Guidance**

# (1014) The Role of Measurement in Establishing Evidence-Based Medicine

Leah M. McClimans, PhD, University of South Carolina, Columbia, SC, United States

#### (1015) PRO Trial Protocols: The Current State of Play

Melanie Calvert, PhD, The University of Birmingham, Birmingham, United Kingdom

(1016) Issues for Consideration When Migrating PRO Measures to an Electronic Platform for Asian Languages Valeska Kantzer, Health Research Associates, Seattle, WA, United States

#### (1017) CLEFT-Q: Cross-Cultural and Age-Related Similarities in Developing a Patient-Reported Outcome Instrument for Children with a Cleft Lip and/or Palate

Karen W.Y. Wong, MD MSc FRCSC, Hospital for Sick Children, Toronto, Canada

🍯 Outstanding Poster Abstract Award

### Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

#### Translation and Cultural Adaptation

(1018) Transformation of Retrospectively Worded Questionnaire Items into Momentary Wording Using Cognitive Interviewing

Stine Birk Nissen, University of Copenhagen, København, Denmark

#### (1019) Lost in Translation: Translatability of Psychiatric Terms - The Example of the Mini-International Neuropsychiatric Interview (M.I.N.I.) Caroline Anfray, Mapi, Lyon, France

(1020) Translation of Oswestry Disability Index in to Tamil with Cross Cultural Adaptation and Evaluation of Reliability and Validity

Joshua I. Vincent, PT MPT, The University of Western Ontario, London, Canada

#### (1021) New Concepts for Back Translation Review: The EORTC's Perspective

Dagmara Kulis, EORTC, Brussels, Belgium

# (1022) Trans Cultural Adaptation of PROMIS<sup>®</sup> Social Function Item Banks to Portuguese

Carlos Henrique Martins Silva, Sr., Universidade Federal de Uberlândia - FAMED, Brazil

#### (1023) Measuring Physical Functioning in the Elderly Population: Adaptation and Validation of the Late-Life Function and Disability Instrument (LLFDI) to the Portuguese Culture

Luis Manuel Cavalheiro, PhD, Centre for Health Studies and Research of the University of Coimbra, Coimbra, Portugal

#### Item Bank/Computer Adaptive Testing (CAT)

#### (1024) Validation of the Dutch-Flemish PROMIS<sup>®</sup> Physical Functioning Item Bank in Patients with Chronic Pain

Martine H.P. Crins, Reade | Amsterdam Rehabilitation Research Center, Amsterdam, The Netherlands

#### (1025) Development and Calibration of an Item Bank for the EORTC Role Functioning Computer Adaptive Test (EORTC RF-CAT)

Eva-Maria Gamper, Innsbruck Medical University, Innsbruck, Austria

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

#### **Non-IRT Measures**

#### (1026) Applying Partial Least Square Regression to Further Explore Concept Structure and Interviewee Profiles in Qualitative Research

Fatoumata Fofana, Mapi and University of Nantes, Lyon, France

(1027) Propensity Score Matching and Age-Gender Adjustment Methods for Quality of Life Comparisons Between Non-Randomized Groups: The Influence of Sample Size on Bias Reduction

Francesco Cottone, PhD, GIMEMA (Italian Group for Adult Hematologic Diseases), Rome, Italy

#### **Psychometrics**

# (1028) Applying Multilevel IRT Modeling for Analyzing Longitudinal Data

Rosalie Gorter, VU University Medical Centre, Amsterdam, The Netherlands

#### (1029) Validation of CESD-20 and PHQ-9 Crosswalks to PROMIS® Depression in Multiple Sclerosis

Jiseon Kim, University of Washington, Seattle, United States NEW INVESTIGATOR PRESENTATION AWARD FINALIST

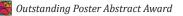
#### (1031) Testing for Unidimensionality Using the Principal Component Analysis (PCA)/T-Test Protocol in Rasch Analysis: A Cautionary Note

Peter Hagell, Kristianstad University, Kristianstad, Sweden

#### (1033) Quality of Life after Brain Injury and the QOLIBRI Overall Scale: A Brief Index

Nicole Von Steinbuchel, PhD, University of Goettingen, Goettingen, Germany





#### Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

#### Utilities

#### (1034) Valuation of Child Health-Related Quality of Life in the United States

Benjamin M. Craig, PhD, Moffitt Cancer Center, Tampa, FL, United States

#### (1035) Predicting Health Utilities for Children with Autism Spectrum Disorders

Nalin Payakachat, BPharm MS PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

#### (1036) Assessing the Burden of Illness from Cervical Dystonia Using TWSTRS Scores and Health Utilities: Meta-Analysis of Baseline Patient-Level Clinical Trial Data

Jerome Dinet, PhD, Ipsen, France

#### **Patient Populations**

(1037) Subjective Health Complaints and Quality of Life in Patients with Acute Intermittent Porphyria Janice Andersen, University of Bergen, Bergen, Norway

#### (1038) The 'Wound-QoL' – Development of a Short Quality of Life Questionnaire on the Basis of Three Established Wound-Specific Instruments

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

#### (1039) Developing the Eating Behavior Scale for Diabetes (EBSD): A Brief Screening Instrument for Disordered Eating in Diabetes

Brendan Mulhern, University of Sheffield, Sheffield, United Kingdom

#### (1040) Health-Related Quality of Life of People Living with Methicillin-Resistant Staphylococcus Aureus

Lars E. Eriksson, PhD, Karolinska Institutet, Huddinge, Sweden

#### (1041) What Matters to Children with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME)? A Qualitative Exploration of Important Outcomes

Kirstie L. Haywood, DPHiL BSc, Warwick Medical School, Coventry, United Kingdom

#### Caregivers

(1042) Addressing the Needs of Cancer Patients and Caregivers through Multi-Disciplinary Psychosocial Interventions

Pamela J. Atherton, MS, Mayo Clinic, Rochester, MN, United States

#### (1044) The Influence of Culture on Quality of Life of Hispanic Family Caregivers of Patients with Advanced Cancer

Gloria Juarez, PhD RN MSN, City of Hope, Duarte, CA, United States

#### (1045) Caregiver Burden, Self Efficacy, and Quality of Life Among Hispanic Working Caregivers

Joan J. Branin, PhD, University of La Verne, Pasadena, CA, United States

#### Children

#### (1046) Quality Of Life (QOL) Questionnaire for Children and Mothers

Rika Hayashida, MS, University of Nagasaki, Siebold, Japan

# (1047) Health-Related Quality of Life in Children with Urea Cycle Disorders

Natalie M. Gallant, UCLA, Los Angeles, CA, United States

#### (1049) Parent Prognostic Outlook throughout the Pediatric Hematopoietic Stem Cell Transplant (HSCT) Course

Christina K. Ullrich, MD MPH, Dana-Farber Cancer Institute, Boston, MA, United States

#### (1050) Health-Related Quality of Life in Children Under Active Treatment for Cancer: State of the Science

Tha'er G. Momani, PhD(c) RN, St. Jude Children's Research Hospital, Memphis, TN, United States

#### (1051) Super Marrow: A Psychotherapeutic Resource to Prepare Oneself for the Illness Process

Maribel P. Doro, PhD, Clinical Hospital, Curitiba, Brazil

### Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

#### Aging/Dementia

(1052) The Association of Poor Medication Adherence and Drug-Related Problems with Health Status of Community-Dwelling Asian Elderly: An Interim Analysis

McVin Hua Heng Cheen, Singapore General Hospital, Singapore, Singapore

#### (1053) The Relationships Among Health Status, Service Coordination, and Patient-Reported Outcomes in Medicaid Long Term Care Program

Zheng Li, MPH, University of Florida, Gainesville, FL, United States

# (1054) Apolipoprotein E and Quality of Life in the Arizona ApoE Cohort

Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States

#### (1055) Better Response Rate to EQ5D Questionnaire Using Script for Telephone Interview, in Low Income Older People in Brazil

Monica A C T Cintra, MD, National Institute of Cardiology Brazil, Rio de Janeiro, Brazil

#### Mental Health

(1056) Assessing Measurement Invariance of Three Depression Measures Between Neurologic and Community Samples

Hyewon Chung, Chungnam National University, Daejeon, Korea NEW INVESTIGATOR PRESENTATION AWARD FINALIST

#### (1057) Quality of Life in Mood Disorders: A WHOQOL – BREF Comparison with the Brazilian Normative Values

Ana Flavia da Silva Lima, PhD, UFRGS, Porto Alegre, Brazil

#### (1058) Valuations of Depression: Discrepancies Between Individuals With and Without Depression.

Katerina Papageorgiou, MSc, University Medical Center Groningen, Groningen, The Netherlands

#### (1059) The Impact of Hazardous Jobs on Mental Health and Well Being Among Working Thai Adults

Vasoontara Yiengprugsawan, The Australian National University, Acton, Canberra ACT, Australia

#### (1060) Psychotic and Non-Psychotic Depression: Are There Differences in Symptom Intensity and Quality of Life Among Hospitalized Patients?

Neusa Sica da Rocha, MD, Federal University of Rio Grande Du Sul, Porto Alegre, Brazil

#### (1061) Myth or Reality: Are Head and Neck Cancer Patients At Increased Risk for Suicidal Thoughts and Gestures? – Preliminary Results

Melissa Henry, McGill University, Montreal, Canada

#### (1062) QOL Measures in Mood Disorders: A Brazilian Sample Assessment and Comparison Between Models.

Sandro R P S Miguel, MD, Institute for Health Technology Assessment, Porto Alegre - Rio Grande Do Sul, Brazil

# (1063) Quality of Life Among Non-Depressed and Depressed Older Adults

Liv Halvorsrud, Oslo and Akershus University College of Applied Science, Oslo, Norway

#### **Respiratory Disease**

#### (1064) Predictors of Mental and Physical Quality of Life in Patients with COPD

Randi Andenas, PhD, Oslo and Akershus University College, Oslo, Norway

#### (1065) Illness Perception Among People with COPD

Christine R. Borge, Institute of Health and Society, Sofiemyr, Norway



Outstanding Poster Abstract Award

### Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

#### Cardiovascular/Stroke

#### (1067) Overlap Between TCM-SAQ and SAQ on Patients with Stable Angina Pectoris and Phlegm and Blood-Stasis Syndrome

Jin Wu, Liaoning University of Traditional Chinese Medicine, Shenyang Peoples Republic of China

#### (1068) The Further Validation of a Syndrome-Specific Instruction to Assess QoL for Angina Treated by Traditional Chinese Medicine (TCM-SAQ): The Ability to Detect Change

Huiyong Zhang, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### (1069) The Effect of Disease Severity on Quality of Life for Patients with Angina

Lv Meijun, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### Kidney/Liver/Gastrointestinal

# **(1072)** Symptom Clusters Predict Mortality Among Dialysis Patients in Norway

Amin Amro, RN MSN, Oslo University Hospital, Oslo, Norway STUDENT PRESENTATION AWARD FINALIST

#### (1073) Cost-Effectiveness of Three Types of Dialysis Modalities in Mexicans with End-Stage Renal Disease

Luxana Reynaga-Ornelas, Universidad de Guanajuato, Guanajuato, Mexico

#### (1074) Digestive Functions May Differently Affect Quality of Life According to Each Sasang Constitution in Korea

Eunsu Jang, Korea Institution of Oriental Medicine, Daejeon, Korea

#### **Musculoskeletal**

#### (1075) Emotional Support Contributes to Outcomes Following Distal Radius Fractures

Joy MacDermid, PhD, McMaster University, Hamilton, ON, Canada

(1077) Psychometric Properties of the Dutch Short Musculoskeletal Function Assessment Questionnaire (SMFA) in Patients with a Fracture of the Upper or Lower Extremity

Marleen Van Son, MSc, Tilburg University, Tilburg, The Netherlands

(1078) Patients with a Single Fracture of the Upper or Lower Extremity Have Worse Health Status and Quality of Life Six Months Post-Injury Compared to Their Pre-Injury Status

Marleen Van Son, MSc, Tilburg University, Tilburg, The Netherlands

#### (1079) Baseline Predictors of Work Instability in Patients with Work-Related Upper Extremity Disorders (WRUED)

Vanitha Arumugam, PT MPT, University of Western Ontario, London, Canada

#### (1080) Can Expectancy, Credibility, Hope, Optimism and Pessimism be Distinguished in Total Hip and Total Knee Arthroplasty Patients in a Meaningful Way?

*Tsjitske M. Haanstra, MSc, VU University Medical Centre, Amsterdam, The Netherlands* 

### Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

#### **Cancer Symptoms and Quality of Life**

#### (1081) Using Structural Equation Modeling to Detect Response Shift and True Change in Quality of Life Score of Palliative Care Patients

Yoshimi Suzukamo, PhD, Tohoku University, Sendai, Japan

#### (1082) Incorporating Quality of Life Data into Surgical Decision-Making and Treatment Strategies: A Literature Review and Recommendations

Juliane Bingener, Mayo Clinic, Rochester, MN, United States

#### (1083) Prediction of Survival by Preoperative Health-Related Quality of Life Scores in a Prospective Cohort of Elderly Oncosurgical Patients

Maren Schmidt, Charité Universitaetsmedizin Berlin, Berlin, Germany

#### (1084) Are Health-Related Quality of Life Decrements After Breast Cancer Diagnosis Time-Limited for Women Ages 65 and Older? - A Matched Comparative Study of Medicare Beneficiaries

Angela M. Stover, University of North Carolina at Chapel Hill, Durham, NC, United States

(1085) Impact of Response Shift on the Assessment of Health-Related Quality of Life in Breast Cancer Patients After Surgery

Kazuhiro Nakamura, Ritsumeikan University, Japan

(1086) Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) in NCCTG (Alliance) N1031 (Randomized Phase II Study of Two Doses of Pixantrone in Patients with Metastatic Breast Cancer)

Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States

#### (1087) Concordance Between Symptomatic Adverse Event Ratings by Clinicians and Patients: A Systematic Review

Thomas M. Atkinson, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY, United States

#### (1088) Incorporating Patient-Reported Outcomes in a Phase I Clinical Trial

Jeff Sloan, PhD, Mayo Clinic, Rochester, MN, United States

(1089) How Change in Comorbidity Influences Health-Related Quality of Life in Patients after Esophageal Cancer Surgery: A Prospective Population-Based Study Lovisa Backemar, Karolinska Intsitutet, Stockholm, Sweden

**(1090) A Review of Health-Related Quality of Life Assessment in EORTC Cancer Clinical Trials** *Efstathios Zikos, MSc MA, EORTC HQ, Brussels, Belgium* 

#### (1091) Initial Quality of life Deficit in Patient-Reported Outcome is Related to Cancer Stage: A Mayo Clinic Esophageal Adenocarcinoma and Barrett's Esophagus Registry Consortium Study

Terence T. Sio, MD MS, Mayo Clinic, Rochester, MN, United States

#### (1092) A Prospective Assessment of Aspects of Emotional Functioning Following Oesophageal Cancer Surgery

Ylva V. Hellstadius, PhD student, Molecular Medicine and Surgery, Stockholm, Sweden

#### (1093) Patient-Proxy Agreement of Health-Related Quality of Life (HRQOL) Measurements in Low-Grade Glioma Patients

Divine Ewane Ediebah, MSc, EORTC HQ, Brussels, Belgium



#### Poster Session 2: Friday, October 11, 10:30 am - 11:15 am

#### eHealth/ePROs

(2001) How Much of a Difference Makes a Difference? Steps Toward Standardized Criteria for Cognitive Assessment of Paper to Electronic Equivalence for PROs

Mona L. Martin, RN MPA, Health Research Associates, Inc., Mountlake Terrace, WA, United States

#### (2002) Implementing New Clinical Outcome Assessment Instruments on Alternative Data Collection Modes: The Electronic Implementation Assessment and Migration Process

Sonya Eremenco, MA, Evidera, Bethesda, MD, United States

#### (2003) AmbuFlex/Epilepsy – Implementation of Patient-Reported Outcomes in Epilepsy Clinics

Liv Marit Valen Schougaard, VestKronik, Regional Hospital West Jutland, Herning, Denmark

#### (2004) Short-Term Findings from The Norwegian (RCT) Study of Renewing Health: A Low-Intensity and Low-Cost Mobile Health Intervention with Health Counseling

Astrid CV Torbjørnsen, Oslo and Akershus University College of Applied Sciences, Oslo, Norway

#### (2005) Increasing Symptom Management Self Efficacy Using a Novel eHealth Tool for Men with Clinically Localized Prostate Cancer

David Victorson, PhD, Northwestern University Feinberg School of Medicine, Evanston, IL, United States

#### **Patient-Reported Outcomes in Clinical Practice**

(2006) Interpretation of Patient-Reported Outcome Results in Routine Clinical Oncology Practice: A Literature Review of Presentation Considerations Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

### (2007) Oncologists' Preferences for Presentation of PRO Data in Randomized Clinical Trial (RCT) Publications: A Quantitative Assessment

Michael Brundage, MD, Queen's University, Kingston, Canada

(2008) Development and Feasibility of a Web-Based Question Prompt Sheet Aimed to Increase the Discussion of Health Related Quality of Life Topics in the Initial Follow-up Consultation after Esophageal Cancer Surgery

Marc Jacobs, Academic Medical Center, Amsterdam, The Netherlands

(2009) Professional's Experiences of Using Patient-Reported Outcome Measures as Quality Improvement Tools - A Systematic Review of Qualitative Research Maria B. Boyce, University College Cork, Cork, Ireland

#### **Conceptual Issues/Frameworks**

(2010) A Qualitative Study to Develop a Conceptual Framework to Understand the Health Concerns of Patients Who Undergo Facial Surgery for Skin Cancer Erica H. Lee, MD, Memorial Sloan-Kettering Cancer Center, New York, NY, United States

#### (2011) Thematic Analysis of Patient-Reported Experiences with Acute and Post-Acute Injury Care Niklas JH Bobrovitz, BHSc(h), University of Calgary, Calgary, Canada

# Minimally Important Differences/Clinical Significance

#### (2013) QoLR: An R package for the Longitudinal Analysis of Health-Related Quality of Life in Oncology

Amélie Anota, Quality of Life in Oncology Platform, France, Besançon, France

STUDENT PRESENTATION AWARD FINALIST

### (2014) Clinical Significance in Self-Rated HRQoL Among Survivors after Childhood Cancer

Anna Jervaeus, Karolinska Institutet, Huddinge, Sweden

#### (2015) Ferrans & Powers Quality of Life Index – Wound Version: A Study about Responsiveness Alciclea dos Santos Oliveira, MS, Beneficencia Portuguesa

Hospital/ Sao Paulo, Sao Paulo, Brazil

#### Poster Session 2: Friday, October 11, 10:30 am - 11:15 am

#### **Guidelines and Guidance**

#### (2016) Stakeholder Perspectives on the PRO Guidance

Ari Gnanasakthy, MSc MBA, Novartis Pharmaceuticals, East Hanover, NJ, United States

#### (2017) Development of Guidelines for Measurement of Patient-Reported Outcomes in Clinical Trials of Hematological Treatments

Sam Salek, BSc RPh PhD FFPM, Cardiff University, Cardiff, United Kingdom

#### **Translation and Cultural Adaptation**

#### (2018) Translation and Psychometric Testing of the Chinese Version of Measure Yourself Medical Outcome Profile (MYMOP)

Fan Zhang, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

# (2019) Face Validation and Translatability Assessment of Patient Questionnaires

Matthew Talbert, Corporate Translations, Chicago, IL, United States

#### (2021) Portuguese Translation and Cross-Cultural Adaptation of the PROMIS<sup>®</sup> Anxiety and Depression Items Bank

Carlos Henrique Martins Silva, Sr., Universidade Federal de Uberlândia - FAMED, Brazil

#### (2022) Cross-Cultural Adaptation and Validation of the Portuguese Version of the Dougados Functional Index (DFI)

Rui Soles Goncalves, PhD, Centre for Health Studies and Research of the University of Coimbra, Coimbra, Portugal

#### Non-IRT Measures

#### (2023) A Mixed Method Approach to Saturation: Applying Partial Least Square Regression to Qualitative Data

Fatoumata Fofana, Mapi and University of Nantes, Lyon, France

(2024) Longitudinal Quality of Life Assessment in Cancer Trials: Should Data Be Treated as Continuous or Ordinal?

Dagmara Kulis, EORTC, Brussels, Belgium

#### **Psychometrics**

#### (2025) Precision Where You Need It? - Comparing Different Computerized Adaptive Tests for Depression Screening

Matthias Rose, MD PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany

#### (2028) Validity of the Singapore Short Form 12 Version 2

Maudrene LS Tan, MSc, National University of Singapore, Singapore

#### (2029) Online Analyses of PRO Using CTT and IRT Methods for Validating, Analyzing Scales or for Planning Studies

Jean-Benoit Hardouin, PhD ScD, University of Nantes, Nantes, France

#### (2031) The Vulvar Discomfort Domain of the PROMIS<sup>®</sup> Sexual Function and Satisfaction Measure

Kathryn E. Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States

# (2032) Psychometric Evaluation of the Swedish MRSA Stigma Scale

Maria H. Lindberg, Karolinska Institutet, Huddinge, Sweden



#### Poster Session 2: Friday, October 11, 10:30 am - 11:15 am

#### Utilities

#### (2033) Metric Properties of the Spanish Version of the Patient-Oriented Prostate Utility Scale (PORPUS)

Monica Avila Pacheco, MPH, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

#### (2034) Comparison of Three Utility Measures Using Item Response Theory in Stroke Patients

Ryota Izumi, MS, Niigata University of Health and Welfare, Niigata-Shi, Japan

#### (2035) Preferences for EQ-5D Health States Among Patients Undergoing Knee Replacement Surgery

Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States

(2036) How Better is EQ-5D-5L Compared to EQ-5D-3L?

Pedro L. Ferreira, PhD, University of Coimbra, Coimbra, Portugal

#### **Patient Populations**

#### (2037) A Review of the Impact of Long-Term Armed Conflict on Health-Related Quality of Life

Yara M. Asi, University of Central Florida, Oviedo, FL, United States

#### (2038) Assessment of the Quality of Life in Chinese Myasthenia Gravis Patients with Ocular, Mild and Moderate Groups

Huiyong Zhang, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

 (2039) Perceptions of Treatment Benefit and Quality of Life in Adults with Growth Hormone
 (GH) Deficiency Replaced with GH: An International Surveillance Study from the KIMS Database

Andreas Pleil, PhD, Pfizer, Inc., San Diego, CA, United States

#### (2040) Factors Associated with Quality of Life Among HIV Patients Attending an Urban Clinic in a Resource Limited Setting-Uganda

Doris M. Mwesigire, MD, Makerere University, Kampala, Uganda

#### (2041) Gender Differences on Perceived Health in Multiple Sclerosis Detected Using Regression Shrinkage, Not Using Conventional Methods

Nancy E. Mayo, PhD, McGill University Health Centre, Montreal, Canada

Caregivers

#### (2042) Dementia with Lewy Bodies: The Caregivers' Quality of Life

Maria Alves Barbosa, Nursing Faculty of Federal University of Goiás, Goiania, Brazil

#### (2044) A Novel Approach for Measuring Outcomes in Infants and Young Children—Using the Eyes and Ears of Caregivers

Todd C. Edwards, PhD, University of Washington, Seattle, WA, United States

#### (2045) The Effects of an Early Intervention on Maternal Confidence in Mothers of Moderately and Late Preterm Infants- A Randomized Controlled Trial

Ingrid Helen Ravn, Pub.H.RN. MSN PhD, Oslo and Akershus University College, Oslo, Norway

#### Children

(2046) The HIV Stigma Scale for Children – Validity and Reliability of the Swedish Version Maria Wiklander, PhD, Karolinska Institutet, Huddinge, Sweden

(2048) Measurement Properties of the Adolescent Quality of Life Mental Health Scale (AQOL-MHS) Ligia M. Chavez, PhD, University of Puerto Rico, San Juan, Puerto Rico

#### (2049) Quality of Life and Anxiety Evaluation in Normal-Weight, Overweight and Obese Children

Paula M. Castelo, Professor, UNIFESP, Diadema, Brazil

# (2050) Mental Health of Indigenous School Children in Northern Chile

Alejandra Caqueo-Urízar, PhD, Universidad de Tarapacá, Arica-Chile, Arica, Chile

#### (2051) I Feel I Mean Something for Someone

Lisbeth G. Kvarme, PhD, Oslo and Akershus University College, Oslo, Norway

🔏 Outstanding Poster Abstract Award

#### Poster Session 2: Friday, October 11, 10:30 am - 11:15 am

#### Aging/Dementia

#### (2052) Health Status Profiles of Community-Dwelling Elderly Using Self-Reported Health Indicators: A Latent Class Analysis

Charis Wei Ling Ng, BA MPH, Health Services & Outcomes Research (HSOR), NHG, Singapore

#### (2053) Physical Component of SF-12 Predicts Mortality in Seniors. Evidences from the SABE Study Sao Paulo – Brazil

Jair Licio Ferreira Santos, PhD, University of Sao Paulo, Ribeirao Preto, Brazil

# (2054) Health Related of Quality of Life (HRQOL) of the Elderly: SABE Study – Brazil

Keila C. Trindade Da Cruz, Brasília University, Lago Sul –Brasília, DF, Brazil

#### (2055) Determinants of Health Related Quality of Life Among Community Dwelling Elderly in Singapore

Pradeep Paul George, Health Services & Outcomes Research (HSOR), NHG Singapore

#### Mental Health

#### (2056) The Effects of a Biography-Based Intervention on Quality of Life and Depression in Late Life

Daniela Knuth, PhD, University of Greifswald, Greifswald, Germany

#### (2057) Predictors of Quality of Life and Perceived Stress Among People with Chronic Illness

Hideaki Tanaka, Florida International University School of Public Health, Miami, FL, United States

#### (2059) The Association of Middle-Of-The-Night Awakening (MOTN) with Quality of Life and Work Productivity Among Patients With/ Without Psychiatric Disorders

Jill Bell, Oxford Outcomes, Purdue Pharma LP, United States

# (2060) Multiple Psychiatric Readmissions and Quality of Life of Patients with Severe Mental Illness

Lucas P. Alves, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil

#### (2061) Are There Differences in Quality of Life Using the EUROHIS-QOL 8-Item in Psychiatric Inpatients Comparing Those with Readmissions with Those With No Readmissions on 12 Months Follow-Up?

Fernanda LC Baeza, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil

#### (2062) Electroconvulsive Therapy Increases Quality of Life as Much as Standard Therapy in Severely Depressive Inpatients

Lucas P. Alves, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil

#### Cardiovascular/Stroke

#### (2063) Patient-Reported Outcomes in Long-Term Conditions: A Cohort Survey in England

Michele Peters, PhD, University of Oxford, Oxford, United Kingdom

#### (2064) Do One Comprehensive Question Equal to a Corresponding Dimension with Several Items? A Study of Seattle Angina Questionnaire (SAQ)

Changhe Yu, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### (2065) Influence of Resting Heart Rate on the Angina Patients' Quality of Life

Yang Mingqian, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### (2066) The Influence of Disease-Related Risk Factors on Angina Patients as Shown in Seattle Angina Questionnaire (SAQ)

Chen Zhihui, MD, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### (2067) Health-Related Quality of Life (HRQoL) in Abdominal Aortic Aneurysm (AAA) Patients

Yaping Ai, Hong Kong

#### (2068) Looking at the Quality of Life of Artificial Cardiac Pacemaker Patients in Goiânia, Brazil

Virginia V. Brasil, PhD, Nursing Faculty of the Federal University of Goias, Goiânia, Brazil

Outstanding Poster Abstract Award



#### Poster Session 2: Friday, October 11, 10:30 am - 11:15 am

#### **Diabetes**

#### (2070) Sense of Coherence is a Predictor of Lifestyle Change in Subjects at Risk for Type 2 Diabetes

Vegard Nilsen, MD, Sorlandet Hospital and University of Bergen, Kristiansand, Norway

#### (2071) Motivation for Diet Change Among Persons with Type 2 Diabetes

Heidi Holmen, Oslo and Akershus University College of Applied Science, Oslo, Norway

#### (2073) Sample Size Requirements of Three Psychosocial Distress Measures in Patients with Type 2 Diabetes Mellitus

Hwee-Lin Wee, PhD, National University of Singapore, Singapore

#### Kidney/Liver/Gastrointestinal

#### (2074) Quality of Life in Coeliac Disease: The Qualitative Development of a New Patient-Reported Outcome Measure

Helen Crocker, University of Oxford, Headington, Oxford, United Kingdom

(2075) Monitoring the National Specific Plan "Improving Quality of Life in Chronic Disease Patients": The Example of End-Stage Renal Disease Serge Briançon, MD, Nancy University, Vandoeuvre Les Nancy, France

#### (2076) Development and Content Validation of a New Patient Questionnaire for Studies in Patients with Chronic Hepatitis C Virus (HCV): The HCV Symptom and Impact Questionnaire (HCV-SIQv3)

Louise Humphrey, Adelphi Values, Bicester, United Kingdom

#### **Musculoskeletal**

(2077) Patient-Reported Outcome Measures (PROMs) and Fragility Hip Fracture: A Systematic Review of Quality and Acceptability

Jo Brett, University of Warwick, Oxfordshire, United Kingdom

#### (2079) Evaluating the Longitudinal Construct Validity of the Health Utilities Indices Mark 2 and Mark 3 Over Recovery from Hip Fracture

David Feeny, PhD, University of Alberta, Portland, OR, United States

Pain

#### (2080) Health-Related Quality of Life in Patients Treated with Chronic Pain in Bogata

Martin Romero, MD PhD(c), Fundacion Salutia, Bogota, Colombia

# (2081) How Do Patients with Different Conditions Describe Their Pain?

Donald M. Bushnell, III, MA, Health Research Associates, Inc., Mountlake Terrace, WA, United States



#### Poster Session 2: Friday, October 11, 10:30 am - 11:15 am

#### **Cancer Symptoms and Quality of Life**

#### (2082) Feasibility and Value of Daily Symptom Reporting in Patients Undergoing Hematopoietic Cell Transplantation

William A. Wood, MD MPH, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

#### (2083) Exploratory Study of Health-Related Quality of Life in a Phase I Trial Studying Idarubicin-Loaded Beads for Chimioembolization of Hepatocellular Carcinoma

Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges Francois Leclerc, Dijon, Burgundy, France

#### (2084) Number of HRQOL Symptoms for Cancer Patients Impacts Functioning and Global Health Levels

Swetha B. Nutakki, MS, Cancer Treatment Centers of America, Zion, IL, United States

# (2085) Quality of Life in a Prostate Cancer Cohort with Patients from Seven Spanish Hospitals

Stefanie Schmidt, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

#### (2086) Health-Related Quality of Life (HRQoL) Following Surgical Treatment for Penile Cancer

Jacobien Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

#### (2087) Social Support and Coping Among Hispanic and Non-Hispanic Women Participating in a Randomized Counseling Trial for Cervical Cancer Survivors

Lari Wenzel, PhD, University of California, Irvine, CA, United States

#### (2089) Evolution of Quality of Life of Elderly Patients With Colorectal Cancer: A Cohort Population-based Study

Evelyne Fournier, MPH, Doubs and Belfort Territory Cancer Registry, France

#### (2090) Head and Neck Cancer in Elderly Population: Quality of Life Evaluation

Pedro L. Ferreira, PhD, University of Coimbra, Coimbra, Portugal

# (2091) Does Quality of Life Predict Malnutrition in Head and Neck Cancer Patients?

Ewa Silander, MD RD, Sahlgrenska University Hospital, Goteborg, Sweden

#### (2092) The Relationships of Reduction in Pain with Other Symptoms for Cancer Patients Treated with Stereotactic Body Radiation Therapy

*Tito R. Mendoza, PhD, University of Texas M.D. Anderson Cancer Center, Houston, TX, United States* 

#### (2093) Patient-Reported Outcome Measures for People with Skin Cancer: A Structured Review

Elizabeth J. Gibbons, MSc, University of Oxford, Oxford, United Kingdom



#### Poster Session 3: Saturday, October 12, 10:00 am - 10:45 am

#### eHealth/ePROs

#### (3001) Web-Based QOL Monitoring of Cancer Patients Undergoing Chemotherapy

Georg Kemmler, PhD, Innsbruck Medical University, Innsbruck, Austria

#### (3002) A Qualitative Study of Cancer Patients' Views of the Usability of Computerized Versions of the EORTC-QLQ-C30 and the SEIQOL-DW

Lena Ring, PhD, Medical Products Agency (MPA) and Uppsala University, Uppsala, Sweden

#### (3003) Electronic Assessment of Health-Related Quality of Life Specific to HIV /AIDS: Reliability Study of PROQOL-HIV Questionnaire

Marcelo Watanabe, Medicine School of ABC, Sao Paolo, Brazil

#### (3004) Using iPads to Assess Health-Related Quality of Life in Clinical Kidney Nursing Practice

Kara L. Schick Makaroff, PhD RN, University of Alberta, Victoria, Canada

#### **Patient-Reported Outcomes in Clinical Practice**

#### (3006) Inconsistencies in Quality of Life Data Collection in Clinical Trials: A Potential Source of Bias? Interviews with Research Nurses and Trialists

Derek Kyte, MSc, University of Birmingham, Birmingham, United Kingdom

#### (3008) Which Health-Related Quality of Life Outcomes Should be Discussed During the Initial Follow-up Consultation After Surgery for Esophageal Cancer? Preliminary Findings of a Delphi Survey

Marc Jacobs, Academic Medical Center, Amsterdam, The Netherlands

#### **Conceptual Issues/Frameworks**

(3010) Patient-Reported Pain in Autosomal Dominant Polycystic Kidney Disease (ADPKD): Concept Stability Between Europe and United States (US) Focus Groups Jason C. Cole, PhD, Covance Market Access Services, Inc., United

Jason C. Cole, PhD, Covance Market Access Services, Inc., United States

#### (3012) Concept Relevance and Respondent Comprehension of the Component Scales of the ENSEMBLE MDS 2.0 Questionnaire Battery

Donald M. Bushnell, III, MA, Health Research Associates, Inc., Mountlake Terrace, WA, United States

# Minimally Important Differences/Clinical Significance

#### (3013) But What Does this Score Mean? A Clinical Standard Setting Method Applied to Outcomes in a Sample of Persons with MS

Karon Cook, PhD, Northwestern University, Chicago, IL, United States

#### (3014) Single-Item Assessment of Perceived Health in Neurological Disorders: Verbal Response Categories vs Visual Analog Scale

Peter Hagell, Kristianstad University, Kristianstad, Sweden

#### **Guidelines and Guidance**

(3016) Movers and Shakers: Who is Doing What with PRO-Related Topics as Online Keyword Search Queries Adam Wilbur, BrightOutcome, Inc., Chicago, IL, United States

(3017) Implementing the CONSORT Patient-Reported Outcome Extension in RCTs in Oncology: Understanding the Items that Influence Clinical Decision-making

Rhiannon C. Macefield, University of Bristol, Bristol, United Kingdom

(3018) Evaluation of the CONSORT Extension Recommendations for PRO Reporting in Clinical Trials: An International Survey of Oncologists

Julie Rouette, Queen's University, Trois-Rivieres, Canada

#### Poster Session 3: Saturday, October 12, 10:00 am - 10:45 am

#### **Translation and Cultural Adaptation**

#### (3019) Translatability of Response Sets Used in Patient Reported Outcomes and Best Practices for Development

Shawn McKown, MA, Corporate Translations, Inc., Chicago, IL, United States

#### (3020) Obstacles to the Development of Universal Spanish Translations of PRO Instruments

Caroline Anfray, Mapi, Lyon, France

# (3022) RIMAS: A Repository of Portuguese Validated PRO measures

Luis Manuel Cavalheiro, PhD, Centre for Health Studies and Research of the University of Coimbra, Coimbra, Portugal

#### Item Bank/Computer Adaptive Testing (CAT)

(3024) Validity of PROMIS<sup>®</sup> CATs, Short Forms and Global Health Items in Rheumatoid Arthritis

Susan J. Bartlett, PhD, McGill University, Montreal, Canada

#### (3025) Dimensionality of the PROMIS® Fatigue Item Bank in Patients with Fibromyalgia

Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States

#### **Psychometrics**

#### (3027) Development & Validation of the Oxford Participation & Activities Questionnaire: Exploring the Views of Relevant Stakeholders

Laura Kelly, University of Oxford, Oxford, United Kingdom

(3028) A Literature Review of the Variance in 'Interval Length' Between Administrations for Assessment of Test-Retest Reliability and Equivalence of PRO Measures

Diane J. Wild, MSc, ICON plc, Oxford, United Kingdom

#### (3030) Psychometric Properties of the PedsQL Multidimensional Fatigue Scale in Dutch Young Adults

Lotte Haverman, PhD, Emma Children's Hospital - Academic Medical Centre, Amsterdam, The Netherlands

#### (3031) See Patient Populations

(3032) Alternate Models for Correlated Clinical Data

Ana Maria Rodriguez, PhD MSc BS PT, McGill University, Montreal, Canada

#### **Utilities**

#### (3033) Health State (QALY) Values for Multiple Sclerosis: Improving the Quality of Information Used in Cost-Effectiveness Analyses of Treatments for MS

Annie J. Hawton, MSc, University of Exeter Medical School, Exeter, United Kingdom

#### (3035) Health-Related Quality of Life in Patients with Multiple Sclerosis in Colombia

Martin Romero, MD PhD(c), Fundacion Salutia, Bogota, Colombia

#### **Patient Populations**

#### (3031) Job Satisfaction of Public University Professors: Reflections in their Quality of Life

Virginia V. Brasil, PhD, Nursing Faculty of the Federal University of Goiás, Goiânia, Brazil

#### (3036) Content Validation of the QoLISSY Questionnaire (Quality of Life in Short Statured Youth) in American Children and Adolescents Based on the European Version

Andreas Pleil, PhD, Pfizer, Inc., San Diego, CA, United States

# (3038) Relationship Between Oral Health and Quality of Life of University Students

Ana G. Magallanes, PhD, Universidad Autónoma de Baja California, Tijuana, Mexico

#### (3039) Longitudinal Associations Between Oral Health Status and Quality of Life Among a National Cohort of Thai Adults

Vasoontara Yiengprugsawan, The Australian National University, Acton, Canberra ACT, Australia

#### (3040) The Associations of Oral Health-Related Quality of Life with Educational Level in Japanese Men and Women

Mariko Naito, DDS, PhD, Nagoya University Graduate School of Medicine, Nagoya, Japan



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#### Poster Session 3: Saturday, October 12, 10:00 am - 10:45 am

#### Caregivers

# (3041) A Protoype Emotional Vitality Measure for Caregivers

Skye P. Barbic, PhD candidate, OT, McGill University, Montreal, Canada

#### (3042) Validity and Reliability of the Family Reported Outcome Measure (FROM-16©) in Urology

Sam Salek, BSc RPh PhD FFPM, Cardiff University, Cardiff, United Kingdom

#### (3043) The Early-Onset Scoliosis 24 Item Questionnaire (EOSQ-24) Reflects Changes in Quality of Life and Parental Burden After Growing Rod Surgery

Hiroko Matsumoto, MA, Columbia University, New York, NY, United States

#### Children

#### (3045) Quality of Life in Children: Development and Application of Computer-Adaptive Testing in Routine Pediatric Care (KIDS-CAT)

Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany

#### (3046) Health-Related Quality of Life in Dutch Young Adults: Psychometric Properties of the PedsQL Generic Core Scales Young Adult Version

Lotte Haverman, PhD, Emma Children's Hospital - Academic Medical Centre, Amsterdam, The Netherlands

(3048) HRQOL and Pain Problems in Children Kristin Haraldstad, PhD, University of Agder, Kristiansand, Norway

#### (3049) Adolescents with High Frequency Use of OTC Analgesics May Have Reduced Quality of Life

Siv Skarstein, RN MPA, Oslo and Akershus University College, Oslo, Norway

#### (3051) Effect of Wearing an Orthodontic Appliance on Quality of Life Among Adolescents: Case-Control Study

Andréa Antônia Costa, Federal University of Minas Gerais, Brumadinho, Brazil

#### Aging/Dementia

#### (3052) Quality of Life of Elderly Participants of Health Promotion Group Activities

Lizete M A C Oliveira, PhD, Federal University of Goiás, Goiania, Brazil

#### (3053) Health Related Quality of Life in Elderly Men Participating in a Systematic 12 Week Strength Training Program

Gudrun Rohde, PhD, University of Agder, Kristiansand, Norway

(3054) How Does Chronic Disease Affect Quality of Life at Older Ages? A Systematic Review of the Evidence Based on Representative Population Samples Eithne Sexton, Royal College of Surgeons in Ireland, Dublin, Ireland

#### (3055) A Scoping Review: Transitioning into Retirement with Chronic Health Disorders Catherine P. Gelinas, University of Western Ontario, London, Canada

#### **Mental Health**

#### (3056) Validity and Reliability of the Japanese Mental Health Continuum-Short Form (MHC-SF)

Junko Sakano, Okayama Prefectual University, Soja, Okayama, Japan

# (3057) Negative Life Events and Related Life Satisfaction or Psychological Distress

Jocelyne M.R. Clench-Aas, PhD, Norwegian Institute of Public Health, Oslo, Norway

#### (3059) Addressing Challenges for Eliciting Concepts Among Adolescents with Attention Deficit Hyperactivity Disorder (ADHD) for Developing Patient-Reported Outcome (PRO) Tools

Juliana Setyawan, Shire Development LLC, United States

#### (3060) Asenapine Effect on Quality of Life in Patients Suffering from Bipolar I Disorder with Mixed Episodes

Christophe Sapin, Lundbeck SAS - Global Outcomes Research, Issy Les Moulineaux, France

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#### Poster Session 3: Saturday, October 12, 10:00 am - 10:45 am

#### (3061) Difficulties in Emotional Regulation and Quality of Life

Alfonso Urzua, PhD, Universidad Catolica del Norte, Antofagasta, Chile

#### (3062) Quality of Work Life Perception and Mental Health in Primary Care Physicians

Raquel Gonzalez-Baltazar, PhD, University of Guadalajara, Guadalajara, Jalisco, Mexico

#### **Respiratory Diseases**

(3063) Content Validity of the Asthma Symptom Diary (ASD) for Use in Adult and Adolescent Subjects with Persistent Asthma

Gary Globe, Amgen Inc., United States

(3064) Usability of the Asthma Symptom Diary (ASD) on the AM3® Device for Use in Adult and Adolescent Subjects with Persistent Asthma

Sonya Eremenco, MA, Evidera, Bethesda, MD, United States

(3065) Impact of Roflumilast on Dyspnea and Lung Function in Patients with Chronic Obstructive Pulmonary Disease: A Pooled Analysis of Four Clinical Trials

Shawn X. Sun, Forest Research Institute, United States

#### Cardiovascular/Stroke

#### (3067) The Feasibility of Blood Circulation by Removing Blood Stasis Method of Traditional Chinese Medicine Treatment of Stable Angina and the Evaluation of the Patient's Quality of Life

Chen Lijuan, MD, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

#### (3068) Benefits of a New Cardiac Rehabilitation Program Using Information and Communication Technologies for Patients with Cardiovascular Disease

Toshiko Yoshida, RN PHN PhD, Miyagi University School of Nursing, Kurokawa-gun, Miyagi, Japan

#### (3069) Self-Reported Health After Stroke – A Follow-Up Study with Multiple Measurements Over a 2-Year Period

Louise Pape, MHSc, University of Aarhus, Herning, Denmark

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#### Diabetes

(3070) Audit of Diabetes Dependent Quality of Life is a More Sensitive Measure of Health-Related Quality of Life Than the Diabetes Health Profile in Singapore Maudrene LS Tan, MSc, National University of Singapore, Singapore

#### Kidney/Liver/ Gastrointenstinal

#### (3073) Quality of Life of the Living Kidney Donors in France Before and After Surgery: A Surprisingly High Quality of Life

Serge Briançon, MD, Nancy University, Vandoeuvre Les Nancy, France

#### (3074) Using Internal Cross-Validation to Identify Response Shift Potential in People with Inflammatory Bowel Disease (IBD)

Nancy E. Mayo, PhD, McGill University Health Centre, Montreal, Canada

#### (3075) An Explanatory Model for Response Shift in the SF-36 in an Inflammatory Bowel Disease Cohort Richard Sawatzky, PhD RN, Trinity Western University, Langley,

Canada

#### **Musculoskeletal**

#### (3078) The Level of Agreement Between Child Self-Reports and Parent Proxy-Reports of Health-Related Quality of Life for Boys with Duchenne Muscular Dystrophy

Yoonjeong Lim, University of Florida, Gainesville, FL, United States



#### Poster Session 3: Saturday, October 12, 10:00 am - 10:45 am

#### Pain

(3079) Validation of the Dutch-Flemish PROMIS® Pain Behavior and Pain Interference Item Banks in Patients with Chronic Pain

Martine H.P. Crins, Reade | Amsterdam Rehabilitation Research Center, Amsterdam, The Netherlands

(3080) Pain Assessment Screening Tool and Outcomes Registry: A Department of Defense and PROMIS® Partnership to Improve Pain Management

Karon Cook, PhD, Northwestern University, Chicago, IL, United States

(3081) Exploratory and Confirmatory Factor Analysis of PROMIS® Pain Quality Version -2 Affective Items Dennis Revicki, PhD, Evidera, Bethesda, MD, United States

#### **Cancer Symptoms and Quality of Life**

(3082) HRQOL Functioning in Cancer Patients: Symptom Pathways Dominate Disease Progression Ryan M. McCabe, Cancer Treatment Centers of America, United States

(3083) Time to Health-Related Quality of Life Score Deterioration as a Modality of Longitudinal Analysis using Propensity Score Method to Deal with Missing Data: A Phase II Trial in Patients with Metastatic Non Pre-Treated Pancreatic Adenocarcinoma

Amélie Anota, Quality of Life in Oncology Platform, Besançon, France

(3084) Methods and Measures for Assessing the HRQoL of Long-Term Survivors of Testicular and Prostate Cancer Previously Participating in EORTC Phase III Clinical Trials

Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

(3085) Normative Data of the EORTC QLQ-C30 in Germany: A Population-Based Survey

Annika Waldmann, University of Luebeck, Luebeck, Germany

# (3086) Normative Data for the EORTC QLQ-HN35 in the General Swedish Population

Eva Hammerlid, MD PhD, Dept EMT-Head & Neck Surgery, Goteborg, Sweden

#### (3088) Young Cancer Survivors' Experiences and Thoughts on Intimate Relationships and Having Children

Jenny Nilsson, Karolinska Institutet, Huddinge, Sweden

#### (3089) Heterogeneity in Posttraumatic Stress and Posttraumatic Growth Among Hematopoietic Stem Cell Transplant Survivors

Kelly Kenzik, PhD, University of Florida College of Medicine, Gainesville, FL, United States

#### (3091) Quality of Life in Long-Term Adult Survivors of Allogeneic Bone Marrow Transplantation and Comparison with a Control Group

Maribel P. Doro, PhD, Clinical of Hospital, Curitiba, Brazil

(3092) Quality of Life (QoL) and Symptoms in Transfusion-Dependent Patients with Myelodysplastic Syndromes (MDS) Undergoing Oral Chelation Therapy Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy



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Twenty Years of ISOQOL — A Celebration Session Co-Chair: Dennis Revicki, PhD

#### <u>Workshop</u>

• An Introduction to Health-Related Quality of Life Assessment Heather Gelhorn, PhD and Kathleen Wyrwich, PhD

#### <u>Symposium</u>

 Innovative Methods for Incorporating the Patient Perspective into Health Outcomes Development and Measurement: Opportunities and Limitations Heather Gelhorn, PhD and Dennis Revicki, PhD

#### Oral Sessions

 Psychometric Performance of the Asthma Symptom Diary (ASD) in Adult and Adolescent Subjects with Persistent Asthma

Mattera MS, Wiklund I, Chen WH

 Responsiveness and Minimal Important Difference of the Rheumatoid Arthritis-Work Instability Scale (RA-WIS)

Revicki D, Safikhani S

#### Posters

- Addressing Challenges for Eliciting Concepts among Adolescents with Attention Deficit Hyperactivity Disorder (ADHD) for Developing Patient Reported Outcome Tools Steenrod A, Hareendran A, Pokrzywinski R
- Content Validity of the Asthma Symptom Diary (ASD) for Use in Adult and Adolescent Subjects with Persistent Asthma

Wiklund I, Mattera M, von Maltzahn R

- Implementing New Clinical Outcome Assessment Instruments on Alternative Data Collection Modes: The Electronic Implementation Assessment and Migration Process Eremenco S
- Usability of the Asthma Symptom Diary (ASD) on the AM3<sup>®</sup> Device for Use in Adult and Adolescent Subjects with Persistent Asthma

Eremenco S, Devine M, Wiklund I

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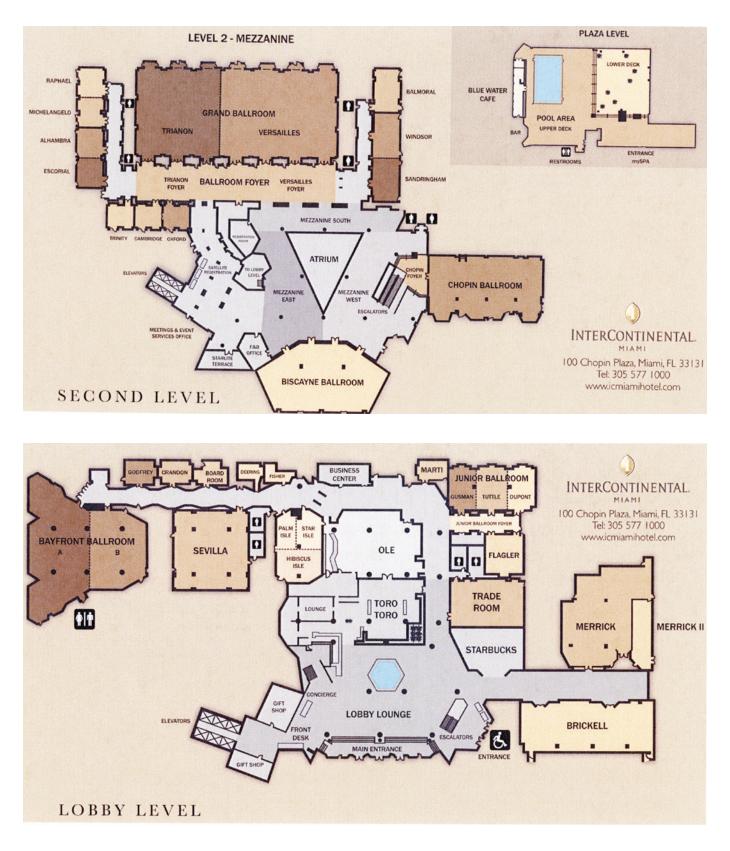


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# **NOTES**


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18 April 2014 Oral & Poster Abstracts

# Berlin, Germany 15–18 October, 2014