

*The Journey of Quality of Life Research:  
A Path Towards Personalized Medicine*

**FINAL PROGRAM**



**BUDAPEST** 

*International Society for Quality of Life Research*

**19<sup>th</sup> ANNUAL CONFERENCE**

October 24-27, 2012

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*Welcome to the 19<sup>th</sup> Annual Conference of the  
International Society for Quality of Life Research  
24-27 October, 2012*

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## **Contact Information**

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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

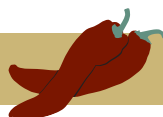
## Wednesday, 24 October

9:30 am - 12:30 pm	Morning Workshops (WK01 - WK07)*	See page 18 for details
2:00 pm - 5:00 pm	Afternoon Workshops (WK08-WK13)*	See page 18 for details
5:00 pm - 6:30 pm	IAC Symposium <i>Perspectives on Mixed Methods to Assess Content Validity of a Patient Reported Outcome</i>	Corso Room
6:30 pm - 7:00 pm	Future of ISOQOL Reception	Budapest Ballroom
7:00 pm - 9:00 pm	Welcome Reception	Budapest Ballroom

## Thursday, 25 October

7:30 am - 8:15 am	Communications Committee Meeting	Margit Room
8:30 am - 10:15 am	Welcome Plenary <i>Comparative Effectiveness Research (CER) and Patient-Centered Outcomes Research</i>	Budapest Ballroom
10:15 am - 11:00 am	Exhibits Open and Refreshment Break	
10:30 am - 12:00 pm	<b>Concurrent Oral Sessions</b>	
	Oral Session 101: <i>Societal Health Outcome Evaluation</i>	Margit Room
	Oral Session 102: <i>Patient Reported Outcomes in Cancer Trials</i>	Corso Room
	Oral Session 103: <i>Utility Measures</i>	Lánchid Room
	Oral Session 104: <i>Quality of Life Evaluation in Cancer and Chronic Illness</i>	Budapest Ballroom
12:15 pm - 1:15 pm	<b>Luncheon Roundtables*</b>	
	<i>RT01: Quality of Life and Health Economics - Future Directions for the Use of QALYS</i>	Erzsébet Ballroom
	<i>RT02: Clinicians' Perspectives on the Interpretation and Application of PROs and ePROs</i>	Erzsébet Ballroom
	<i>RT03: Application of Mixed Methods to Quality of Life Research</i>	Erzsébet Ballroom
	<i>RT04: Innovations in Modern Psychometrics</i>	Erzsébet Ballroom
	<i>RT05: Industry Perspectives on Quality of Life Evaluation</i>	Erzsébet Ballroom
	<i>NIRT1: CVs, Resumes, and Cover Letters, Oh My!</i>	Árpád Room
1:30 pm - 3:00 pm	Plenary Session <i>From Clinical Trials to Clinical Practice: Towards Bridging the Gap</i>	Budapest Ballroom
3:00 pm - 4:00 pm	Exhibits Open and Refreshment Break	
3:00 pm - 4:00 pm	Poster Presentations (1000s)	Erzsébet Ballroom
4:00 pm - 5:30 pm	<b>Concurrent Oral Sessions</b>	
	Oral Session 105: <i>Patient and Health Outcomes in Chronic Conditions</i>	Margit Room
	Oral Session 106: <i>Utility Measures</i>	Lánchid Room
	Oral Session 107: <i>Outcome Evaluation in Cancer</i>	Buda Room
	Oral Session 108: <i>Psychosocial and Health Interventions</i>	Corso Room
	Oral Session 109: <i>Symptom Monitoring in Clinical Research and Practice</i>	Pest Room
6:00 pm - 7:00 pm	Mentor/Mentee Reception	Corso Room
6:00 pm - 7:30 pm	Psychometric SIG Presentation <i>ISOQOL Recommends Minimum Standards for Patient-Reported Outcomes Measures for use in Patient-Centered Outcomes Research</i>	Margit Room
6:00 pm - 7:30 pm	Translation & Cultural Adaptation (TCA) SIG Presentation <i>One Language: Benefits of a Universal Translation Approach</i> <i>Impact of Culture in PRO Data</i>	Lánchid Room

\*Ticket Required

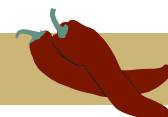




# Schedule at a Glance

## Friday, 26 October

7:00 am - 8:45 am	Child Health SIG Business Meeting	Margit Room
7:00 am - 8:45 am	Response Shift SIG Presentation <i>Advancing the Response Shift Research Road Map: Developing the Next International Collaboration</i>	Lánchid Room
7:30 am - 8:45 am	Industry Advisory Committee (IAC) Meeting	Árpád Room
8:00 am - 8:45 am	2013 Annual Conference Planning Committee Meeting	Corso Room
9:00 am - 10:30 am	ISOQOL Business Meeting and Awards Presentation	Budapest Ballroom
10:30 am - 11:00 am	Exhibits Open and Refreshment Break	Breakout Lobby
10:45 am - 12:15 pm	<b>Concurrent Oral Sessions</b>	
	Oral Session 201: <i>Health Outcome Evaluation and Development</i>	Margit Room
	Oral Session 202: <i>Trials and Intervention Evaluation</i>	Corso Room
	Oral Session 203: <i>Analysis and Interpretation of Outcomes</i>	Lánchid Room
	Oral Session 204: <i>Mental Health and Patient Outcomes</i>	Budapest Ballroom
12:15 pm - 1:15 pm	Lunch on your own	
1:15 pm - 2:15 pm	Poster Presentations (2000s)	Erzsébet Ballroom
2:15 pm - 2:45 pm	Special Presentation <i>Patient Advocates in Cancer Research: A European Patients' Perspective</i>	Budapest Ballroom
2:45 pm - 4:00 pm	Plenary Session <i>Innovations in eHealth</i>	Budapest Ballroom
4:00 pm - 4:30 pm	Exhibits Open and Refreshment Break	Breakout Lobby
4:30 pm - 6:00 pm	<b>Concurrent Oral Sessions</b>	
	Oral Session 205: <i>Quality of Life Measure Development</i>	Lánchid Room
	Oral Session 206: <i>Patient Reported Outcomes in Clinical Practice</i>	Budapest Ballroom
	Oral Session 207: <i>Outcome Measure Development</i>	Margit Room
	Oral Session 208: <i>Health Outcomes in Children</i>	Corso Room
6:15 pm - 7:45 pm	QoL in Clinical Practice SIG Presentation <i>Do Patient Reported Outcome Guidelines for Routine Clinical Practice Matter? Government, Industry and Patient Perspectives</i>	Lánchid Room
6:15 pm - 7:45 pm	New Investigator SIG Presentation <i>Tricks of the Trade: Advice for New Investigators in QOL Research II</i>	Margit Room



# Schedule at a Glance

## Saturday 27 October

8:00 am - 8:45 am	Membership Committee Meeting	Lánchid Room
9:00 am - 10:30 am	Plenary Session <i>Paving the Path Towards Personalized Medicine</i>	Budapest Ballroom
10:30 am - 11:00 am	Exhibits Open and Refreshment Break	Breakout Lobby
10:45 am - 12:15 pm	<b>Concurrent Oral Sessions</b>	
	Oral Session 301: <i>Outcome Measure Development</i>	Margit Room
	Oral Session 302: <i>Personalized Medicine</i>	Lánchid Room
	Oral Session 303: <i>Response Shift</i>	Corso Room
	Oral Session 304: <i>Health Outcomes in Children</i>	Budapest Ballroom
12:30 pm - 1:30 pm	<b>Luncheon Roundtables*</b>	
	RT06: <i>How to Do a Peer Review</i>	Erzsébet Ballroom
	RT07: <i>Cancer Survivorship</i>	Erzsébet Ballroom
	RT08: <i>What are American Funding Agencies Looking For? Priorities for Funding</i>	Erzsébet Ballroom
	RT09: <i>Patient Engagement in the European Context</i>	Erzsébet Ballroom
	RT10: <i>Genetics</i>	István Room
	NIRT2: <i>Interview Tips and Strategies</i>	Árpád Room
1:45 pm - 3:15 pm	<b>Concurrent Symposia Sessions</b>	
	Symposium 1: <i>Implementing Patient-Reported Outcomes in Clinical Practice: An Expert Panel Discussion of Current Knowledge and Unanswered Questions</i>	Buda Room
	Symposium 2: <i>Are Generic Preference-Based Measures Valid in Mental Health? A Mixed Methods Enquiry</i>	Pest Room
	Symposium 3: <i>Response Shift Detection in Secondary Data Analysis: Findings and Implementation Guidelines</i>	Margit Room
	Symposium 4: <i>Patient-centered Approach to Adverse Event Reporting: the US National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events</i>	Lánchid Room
	Symposium 5: <i>Conceptual and Methodological Advances and Research Priorities for Child HRQOL</i>	Corso Room
3:15 pm - 4:15 pm	Poster Presentations (3000s)	Erzsébet Ballroom
3:15 pm - 4:15 pm	Exhibits Open and Refreshment Break	Breakout Lobby
4:15 pm - 5:45 pm	<b>Concurrent Oral Sessions</b>	
	Oral Session 305: <i>Symptom Monitoring in Clinical Research and Practice</i>	Buda Room
	Oral Session 306: <i>Caregiver Quality of Life and Health Evaluation</i>	Margit Room
	Oral Session 307: <i>Psychometric Approaches</i>	Lánchid Room
	Oral Session 308: <i>Mental Health Evaluation</i>	Corso Room
	Oral Session 309: <i>Psychometric Approaches</i>	Pest Room
7:00 pm - 10:00 pm	Closing Dinner* <i>Danube River Cruise</i>	

\*Ticket Required

### Registration Desk Hours

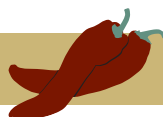
Tuesday, 23 October:	2:00 pm – 5:00 pm
Wednesday, 24 October:	7:00 am – 5:00 pm
Thursday, 25 October:	7:00 am – 5:00 pm
Friday, 26 October:	7:00 am – 5:00 pm
Saturday, 27 October:	8:00 am – 2:00 pm

### Continental Breakfast

Continental Breakfast will be available near the ISOQOL Registration Desk at the following times:	
Wednesday, 24 October:	8:00 am – 9:00 am
Thursday, 25 October:	7:30 am – 8:30 am
Friday, 26 October:	8:00 am – 9:00 am
Saturday, 27 October:	8:00 am – 9:00 am

### Poster Hall Hours

The Poster Hall will be open from Thursday, 25 October – Saturday, 27 October from 7:00 am – 8:00 pm. Poster Hall will be open only to Luncheon Roundtable ticket holders from 12:00 pm – 1:30 pm on Thursday and Saturday for Luncheon Roundtable Sessions.



# Welcome from the Committee Chairs



*Sara Ahmed, PhD*



*Fabio Efficace, PhD*

## Üdvözöllek Magyarországon!

As the Program co-chairs, it is our pleasure to invite you to the ISOQOL 19<sup>th</sup> Annual Conference in Budapest, Hungary.

This year's conference will draw attendance from leading researchers, health professionals, and patient advocates from all over the world. Speakers representing industry, government policy makers, as well as academic scholars and researchers from the health and patient reported outcome arena will present and discuss the latest topics in health care and quality of life.

The theme for this year's conference is The Journey of Quality of Life Research: A Path Towards Personalized Medicine. Once again, with input from our members and planning committee we've planned a conference focused on three main areas: comparative effectiveness and patient-centered outcomes research, personalized medicine, and innovations in ehealth. Plenary speakers will share their expertise and innovative projects on topics that cover each of these areas. This year we have aimed to bring to the forefront the central role that patients and advocacy groups play in shaping future clinical and research endeavors.

Given the success of the roundtables last year we have brought these back again, and we've added additional new topics. Attendees will have the opportunity to engage with a small group of their peers to discuss a particular topic in health-related quality of life research.

Throughout this conference, we invite you to stay engaged, keep us proactive and help us shape the future of quality of life research. In addition to taking in the rich scientific content, don't forget to join in the fun during the many social events, including the Future of ISOQOL Reception, Welcome Reception, Mentor/Mentee Reception, and of course the Closing Dinner, a dinner cruise on the Danube River.

We welcome all attendees and look forward to seeing you. Thank you for sharing your passion and enthusiasm for quality of life research and for helping us make this year's conference a success!

Have a wonderful conference,

Sara Ahmed and Fabio Efficace  
Co-chairs, Scientific Program Committee



# ISOQOL Leadership

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United States

## Past President



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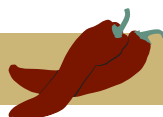
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Rebecca Brandt, CAE



Meetings and Membership Manager  
Heather Vitale

## Co-Editors of *Quality of Life Research Journal*

Dennis Revicki, PhD, United States  
Carolyn Schwartz, ScD, United States





# Scientific Program Committee

## Scientific Program Committee Co-Chairs

Sara Ahmed, PhD, Canada  
Fabio Efficace, PhD, Italy

## Workshop Abstract Reviewers

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Monika Bullinger, PhD, Germany  
Henrica C.W. de Vet, PhD, The Netherlands  
Joanne Greenhalgh, PhD, United Kingdom  
Marc Jacobs, MSc, The Netherlands  
Ana A. Popielnicki, BA, United States  
Dennis Revicki, PhD, United States  
Ana Maria Rodriguez, MSc BSc PT, Canada  
Julie G. Trudel, PhD, Canada

## Symposium Abstract Reviewers

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Joanne Greenhalgh, PhD, United Kingdom  
Cynthia Gross, PhD, United States  
Marc Jacobs, MSc, The Netherlands  
Cicely Kerr, MSc PhD, United Kingdom  
Josephine M. Norquist, MS, United States  
Ana A. Popielnicki, BA, United States  
Julie G. Trudel, PhD, Canada  
Tracey A. Young, PhD MSc BSc CStat, United Kingdom

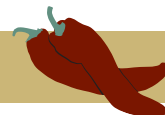
## Oral and Poster Presentation Abstract Reviewers

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Rick Berzon, DrPH, United States  
Steven I. Blum, MBA, United States  
Joan J. Branin, PhD, United States  
Michael Brundage, MD, Canada  
Monika Bullinger, PhD, Germany  
Henrica C.W. de Vet, PhD, The Netherlands  
Fabio Efficace, PhD, Italy  
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Hwee-Lin Wee, PhD, Singapore  
Carlos King Ho Wong, MPhil, BSc, Hong Kong, SAR China  
Kathleen J. Yost, PhD, United States  
Tracey A. Young, PhD, MSc, BSc, CStat, United Kingdom  
Susan E. Yount, PhD, United States

## Publicity Committee

Yash J. Jalundhwala, United States (Co-Chair)  
Ana Maria Rodriguez, MSc BSc PT, Canada (Co-Chair)

*Special thank you to Lazslo Gulacsi and Márta Péntek of Corvinus University, Budapest, Hungary for providing a local perspective to the planning process.*



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# General Information

The Journey of Quality of Life Research – A Path Towards Personalized Medicine has been selected as the theme of ISOQOL's 19<sup>th</sup> Annual Conference.

## Hotel Information

The ISOQOL Annual Conference will take place at the Budapest Marriott Hotel.

### Budapest Marriott Hotel

Apáczai Csere János utca 4  
Budapest, 1052 Hungary  
+36 1 486-5000

## Registration

Conference registration fees include access to plenary sessions, scientific research presentations, such as concurrent oral sessions, symposia sessions and poster sessions; and also Special Interest Group (SIG) presentations. Registration fees also include continental breakfast and refreshment breaks on Thursday, Friday, and Saturday, and light refreshments at the Welcome Reception on Wednesday evening. A ticket is required for all workshops, luncheon roundtables, and for the closing dinner. Tickets may be available for purchase at the registration desk.

### Registration Desk Hours:

Tuesday, 23 October, 2:00 pm – 5:00 pm  
Wednesday, 24 October, 7:00 am – 5:00 pm  
Thursday, 25 October, 7:00 am – 5:00 pm  
Friday, 26 October, 7:00 am – 5:00 pm  
Saturday, 27 October, 7:00 am – 5:00 pm

*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 14 September will not be eligible for a refund.*

## Employment Services Program

Once again, ISOQOL will offer the Employment Services program. This program allows institutions to post job opportunities, and qualified applicants looking for employment to post his/her resume during the conference. Resumes may be inserted free of charge. Look for the Employment Services Program table near the Registration Desk and add job announcements and resumes to the appropriate notebooks.

## Highlighted Events

### Future of ISOQOL Reception

In order to celebrate and engage the future of ISOQOL, we would especially like to invite students, new investigators, and first time attendees to join us at the Future of ISOQOL Reception. This event takes place immediately prior to the ISOQOL Welcome Reception.

### Welcome Reception

The Scientific Program Planning Committee Co-Chairs would like you to join us at the ISOQOL Welcome Reception. Start off the conference by visiting with old friends and networking with new friends and colleagues. Light refreshments will be available.

## Mentor/Mentee Reception

The goal of the ISOQOL Mentoring Program is to promote career development and provide networking opportunities for New Investigators 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. **Preregistration is required as the Mentors and Mentees have been matched prior to the Annual Conference.**

## ISOQOL Business Meeting and Awards Presentation

The ISOQOL Business Meeting and Awards Presentation will take place on Friday, 26 October from 9:00 am – 10:30 am. 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.

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

### 2012 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.

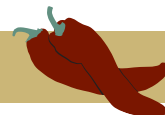
### New Investigator and Student Presentation Awards

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.*





# ISOQOL Committees and 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!

### Communications Committee

**Chair:** Deborah Miller, PhD, United States

*The purpose of the Communications Committee is to inform the membership about board activities, educational activities, ISOQOL and regional conferences, and other activities of existing and new members; to provide a forum for debate and to devise an attractive, readable, and newsworthy Newsletter. This committee includes two subcommittees: the Newsletter Subcommittee and the Website Task Force.*

**Meeting on Thursday, 25 October, 7:30 am – 8:15 am**  
MARGIT ROOM

### 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.*

**Meeting on Friday, 26 October, 7:30 am – 8:45 am**  
ÁRPÁD ROOM

*Don't miss the IAC Symposium on Wednesday!*

### 2013 Annual Conference Planning Committee

**2013 Co-Chairs:** David Eton, PhD, United States and Simon Pickard, PhD, United States

*The Scientific Program Planning Committee Co-Chairs will be hosting a brief meeting on Friday morning to discuss topics and themes for the 2013 Annual Conference. Whether you would like to offer suggestions for 2013 planning or volunteer to assist in the program planning process, we welcome you to join us.*

**Meeting on Friday, 26 October, 8:00 am – 8:45 am**  
CORSO ROOM

### Membership Committee

**Chair:** Joanne Greenhalgh, PhD, United Kingdom

*The purpose of the Membership Committee is to identify, develop, and implement strategies to retain existing ISOQOL members. This is achieved through measurement of members' needs and priorities and working with other leaders and committees to develop and implement plans to address these needs. This committee also strives to identify, develop, and implement strategies to attract new ISOQOL members. This is achieved through working with other leaders and committees to identify potential opportunities to identify and attract new members and to develop and implement strategies to engage potential new members. This includes outreach or educational activities.*

**Meeting on Saturday, 27 October, 8:00 am – 8:45 am**  
LÁNCHID ROOM

## Special Interest Groups

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.

Join us at the SIG meetings for presentations and discussion.

### Psychometric SIG Presentation

**Thursday, 25 October, 6:00 pm – 7:30 pm**  
MARGIT ROOM

**Psychometric SIG Co-Chairs:** Lori McLeod, PhD, United States and Bryce Reeve, PhD, United States

### ISOQOL Recommends Minimum Standards for Patient-Reported Outcomes Measures for use in Patient-Centered Outcomes Research

*Bryce B. Reeve, PhD, Lineberger Cancer Center & Dept of Health Policy & Management, The University of North Carolina at Chapel Hill, United States*

An essential aspect of patient-centered outcomes research (PCOR) is the integration of patient perspectives and experiences with clinical and biological data to evaluate treatment safety and effectiveness. A challenge for PCOR is capturing patient data in a way that best informs research, health care delivery, and policy decisions. This presentation will discuss ISOQOL recommendations for minimum standards for the use of a patient-reported outcome (PRO) measure in PCOR. This study was based on an extensive literature review and survey among ISOQOL members. Support was indicated for the attributes of conceptual and measurement model, reliability, validity (content validity, construct validity, responsiveness), interpretability of scores, translations, and response burden. The identification of these standards is a first step towards enabling PCOR to achieve its goals of improving the effectiveness and efficiency of healthcare delivery. Next steps are to identify best practices for selecting or deriving sound and decision-relevant PROMs for use in prospective PCOR.

### Translation and Cultural Adaptation (TCA) SIG Presentation

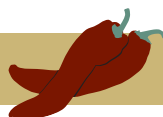
**Thursday, 25 October, 6:00 pm – 7:30 pm**  
LÁNCHID ROOM

**Translation and Cultural Adaptation SIG Co-Chairs:** Katrin Conway, MA, France and Donald Patrick, PhD, United States

### One Language: Benefits of a Universal Translation Approach

*Helena Correia, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, United States*

This presentation focuses on the universal approach to translation and its relevance to the translation and cultural adaptation of Patient Reported Outcome (PRO) measures in today's world. Combining qualitative and quantitative methods contributes to ensuring conceptual and measurement equivalence of PROs and item banks in particular. Issues and recommendations are based on the Spanish, Dutch, and Portuguese translations of the Patient-Reported Outcome Measurement Information System (PROMIS®), and the results of calibration testing with a diverse Spanish-speaking sample in the US.





# ISOQOL Committees and Special Interest Groups (SIGs)

## **(TCA) SIG, Cont.**

### **Impact of Culture in PRO Data**

*Ari Gnanasakthy, Head, Patient Reported Outcomes, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States*

Some concepts (e.g. anger and distress), attitude to disease (e.g. eating disorders, depression, HIV), literacy level of respondents and the respondents' willingness to provide information freely may impact the quality of PRO data in multi-regional clinical trials. Multi-regional trials are rarely powered to assess the impact of regional or cultural variations in PRO data. Study design based on prior knowledge of such issues and analysis plans adjusting for cultural variations are essential for the interpretation of PRO data from multi-regional clinical trials.

## **Child Health SIG Meeting**

**Friday, 26 October, 7:00 am – 8:45 am**

MARGIT ROOM

**Child Health SIG Co-Chairs:** Anne Riley, PhD, United States and Christopher Forrest, PhD, United States; Katherine Bevans, PhD, United States

### **Child Health Interest Group 2012 Budapest Meeting Plan**

- Introductions and sharing of current research activities
- Update on CHIG activities and discussion of next year's plan
- Discussion of Top Priorities for Child HRQOL Research -Results of the International eDelphi and Next Steps for CHIG
- Conclusion – Action Items for 2013

Two rounds of an emailed Delphi process were carried out in which an international group of child HRQOL clinical and academic researchers from 21 countries identified the top priorities for future research. The initial response identified over 100 topics and organized into 6 categories: Clinical, Developmental, Family/Social, Cognitive/Mental Health, Theory, and Methods Innovation. Within each category, respondents rated the priority for each suggested topic.

At the SIG meeting we will discuss ongoing activity in the topics with the highest priority ratings and discuss opportunities for developing and funding new initiatives.

Examples of these topics include, 'Defining clinically meaningful change in health;' 'Evaluating the usefulness of Pediatric PROs in tailoring treatments to individual children's needs.' 'Developing practical methods for maintaining consistency in measurement in longitudinal studies.' 'Determining how family functioning impacts child-reported HRQOL.'

We will identify the topics that appear to have the most potential for the CHIG to engage the largest number of CHIG members and that has realistic opportunities for support. We envision that the CHIG can contribute to the advancement of measurement science and clinical applications, promoting children's health as well as positively impacting health across the lifecourse.

## **Response Shift SIG Meeting**

**Friday, 26 October, 7:00 am – 8:45 am**

LÁNCHID ROOM

**Response Shift SIG Co-Chairs:** Sara Ahmed, PhD, Canada, and Lena Ring, PhD, Sweden

**Advancing the Response Shift Research Road Map:  
Developing the Next International Collaboration**

## **Quality of Life in Clinical Practice SIG Meeting**

**Friday, 26 October, 6:15 pm – 7:45 pm**

LÁNCHID ROOM

## **QOL in Clinical Practice SIG, Cont.**

**Quality of Life in Clinical Practice SIG Co-Chairs:** Kirstie Haywood, DPHiL BSc, United Kingdom, and Colleen Norris, PhD, Canada

### **Do Patient Reported Outcome Guidelines for Routine Clinical Practice Matter? Government, Industry and Patient Perspectives**

*Organized by:* Kirstie Haywood, DPHiL BSc, Royal College of Nursing Institute, University of Warwick, United Kingdom; Colleen Norris, PhD, University of Alberta, Canada; and Sam Salek, BSc RPh PhD FFPM, Centre for Socioeconomic Research, Cardiff University, United Kingdom

The FDA in North America has produced very clear and robust guidelines for the development and application of patient-reported outcome measures (PROMs) to support drug labeling claims. Increasingly, PROM scores are used to inform treatment guidelines in routine clinical practice settings. For example, in certain disciplines, such as rheumatology and dermatology, patients' are required to achieve pre-specified PROM scores before biologic therapies can be prescribed. However, European-based PRO guidance is lacking and the position of regularity authorities and industry is unclear.

The application of appropriate and relevant PROMs in routine clinical practice contributes towards clinical decision-making and has the potential to enhance patient-centered care. Until recently there has been very little consideration of the needs and values of patients with regards to PROM completion and data use. We will explore the patient perspective of PROMs in clinical practice. What do patients think of available PROMs? What do they need to enable them to become active users of PROM-related data to support their decision-making? We will also explore the potential for patients to be involved as active collaborators in the PROM research process, and their contribution towards enhancing PROM relevance.

## **New Investigator SIG Meeting**

**Friday, 26 October, 6:15 pm – 7:45 pm**

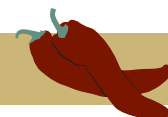
MARGIT ROOM

**New Investigator SIG Co-Chairs:** Antonia Bennett, PhD, United States, and Bellinda King-Kallimanis, PhD, Ireland

### **Tricks of the Trade: Advice for New Investigators in QOL Research II**

In light of the success of the first 'Tricks of the Trade' symposium in Denver 2011, the New Investigators SIG has convened it again, by bringing together another multidisciplinary panel of international senior members of ISOQOL to speak about their career experiences. This year, panelists will provide their perspectives on the following topics: (1) their background in QOL research; (2) their advice for people entering the field today; and (3) what the future holds for QOL research. The format of the symposium will be short individual presentations that will allow for a lively discussion between panelists and the audience. While the intended audience of this panel is new investigators, last years' panel was popular with other ISOQOL members as well, and their attendance added to the dynamic question and answer component of the symposium. All are welcome to attend the symposium.

**Panelists:** **John E. Brazier, PhD**, University of Sheffield, United Kingdom; **Juan J. Dapuelto, MD, PhD**, Facultad de Medicina, Universidad de la República, Uruguay; **Dennis Revicki, PhD**, United BioSource Corporation, Center for Health Outcomes Research, United States; **Mirjam AG Sprangers, PhD**, Academic Medical Center, The Netherlands



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## See UBC experts speak at the following workshops:

### *An Introduction to Health-Related Quality of Life Assessment*

[Heather Gelhorn](#), PhD, Research Scientist

[Kathleen Wyrwich](#), PhD, Senior Research Leader

**Wednesday, October 24, 9:30 am - 12:30 pm**

### *Interpretation of PRO Data within Clinical Trials*

[Kathleen Wyrwich](#), PhD, Senior Research Leader

[William Lenderking](#), PhD, Senior Research Leader

**Wednesday, October 24, 2:00 - 5:00 pm**

## Also hear UBC experts present on:

### *Is Rasch Model Analysis Applicable in Small Sample Pilot Studies for Assessing Preliminary Item Characteristics: An Example Using Data from PROMIS Pain Behavior Item Bank*

[Wen-Hung Chen](#), PhD, Research Scientist

[William Lenderking](#), PhD, Senior Research Leader

[Dennis Revicki](#), PhD, Senior VP Outcomes Research

### *PROMIS Version 2 Pain Quality Item Bank Discriminates between Neuropathic and Other Types of Pain*

[Dennis Revicki](#), PhD, Senior VP Outcomes Research

### *The Relationship between Pediatric Asthma Control, Excessive Daytime Sleepiness, and Health-related Quality of Life*

[Dennis Revicki](#), PhD, Senior VP Outcomes Research

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Under the scientific direction of PRO expert, Dr. David Cella since 1994, FACIT.org licenses the well-known FACIT system of QOL questionnaires, and FACITtrans provides translation and cross cultural assessment expertise to the HSR community. As the preferred translator for the PROMIS, NeuroQOL, Toolbox, and PROCTCAE item banking initiatives, FACITtrans has unparalleled experience in providing translation services to the federally-sponsored investigator.



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# Plenary Speakers

## Comparative Effectiveness Research (CER) and Patient-Centered Outcomes Research

Thursday, 25 October; 8:30 am – 10:15 am

Plenary Session Sponsored by 



**Ethan Basch, MD, MSc**  
Associate Attending Physician,  
Memorial Sloan-Kettering Cancer Center  
Chair, Patient-Centeredness Workgroup,  
Methodology Committee of the Patient-Centered  
Outcomes Research Institute (PCORI)

Dr. Basch is a medical oncologist and outcomes researcher at Memorial Sloan-Kettering Cancer Center who directs a program focused on patient-reported outcomes, clinical informatics, comparative effectiveness, and product safety evaluation. Studies by his group have determined that patient self-reporting of adverse events can improve data accuracy and comprehensiveness compared to clinician reporting. Building on this work, he leads the National Cancer Institute's PRO-CTCAE initiative to develop a standardized patient-centered approach to adverse event reporting in clinical trials. His group also designs patient-reported symptom endpoint models for use in drug approval and labeling, and runs a technology core supporting patient-reported data capture in over 25 multi-center studies. He serves as a federally-appointed member of the Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI) for which he chairs the Patient-Centeredness Workgroup. He also chairs the Health Outcomes Committee of the NCI cooperative group, the Alliance for Clinical Trials in Oncology, which oversees the group's activities in quality of life, health economics, and comparative effectiveness research. In the American Society of Clinical Oncology (ASCO), he is immediate past Chair of the Clinical Practice Guidelines Committee and a member of the Comparative Effectiveness Research Task Force and Rapid Learning System Advisory Group, and liaison to the Quality of Care Committee. He received his MD from Harvard Medical School, MSc in Epidemiology from the Harvard School of Public Health, internal medicine residency at Massachusetts General Hospital, and oncology fellowship at Memorial Sloan Kettering Cancer Center. The overall goal of Dr. Basch's work is to improve our understanding of, and the quality of, patients' experiences with illness and care.



**Andrew Vallance-Owen MBA FRCS Ed**  
Chairman, UK Department of Health's PROMs  
Stakeholder Group

Vallance-Owen's career within the British Medical Association, BMA, started as Provincial Medical Secretary for the north of England followed by promotion to the post of BMA Scottish Secretary. Latterly he moved to London to become Head of Central Services and International Affairs, a role which also developed into Head of Policy Development.

His experience spans the broad management spectrum in medicine with hands on experience of management, industrial relations, negotiating, political lobbying, public speaking and media communications. He has also developed a specific interest in measurement of clinical outcome, clinical audit and professional accountability over the last 20 years and has published on those subjects.

He became Medical Director of BUPA Hospitals in 1994 and, in 1995, became BUPA's Group Medical Director (Chief Medical Officer) where he has furthered his interests in the quality of health care, clinical audit and outcomes. He retired from Bupa on 30 March this year.

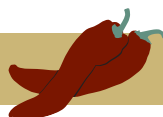
Vallance-Owen established the first programme for the routine measurement of patient reported outcomes in Bupa's hospitals in the UK in 1998. A PROMs programme has since been started by the National Health Service and Vallance-Owen chairs the Department of Health's PROMs Stakeholder Group.



**Albert W. Wu, MD MPH**  
Professor, Health Policy and Management,  
Johns Hopkins Bloomberg School of Public Health

Albert W. Wu is Professor of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health, with joint appointments in Epidemiology, International Health, Medicine and Surgery. He received BA and MD degrees from Cornell University, and completed an Internal Medicine residency at the Mount Sinai Hospital and UC San Diego. He was a Robert Wood Johnson Clinical Scholar at UCSF and received an MPH from UC Berkeley. His research and teaching focus on patient outcomes and quality of care. He was the first to measure the quality of life impact of antiretroviral therapy in HIV clinical trials. He developed the MOS-HIV health survey, as well as numerous other questionnaires to measure quality of life, adherence, satisfaction, attitudes and behaviors. He was co-founder and director of the outcomes research committee of the AIDS Clinical Trials Group of the NIH, and President of the International Society for Quality of Life. He advises many US and international organizations on assessment methods. He is director of the Johns Hopkins Center for Health Services and Outcomes Research and director of the AHRQ-funded DEcIDE center for patient centered outcomes research. He is a PROMIS investigator, and co-developer of PatientViewpoint, a patient portal to link patient reported outcomes to electronic health records. He leads a series of courses on health outcome assessment, patient safety, quality of care and comparative effectiveness. He has authored over 300 peer review publications, was a member of the Institute of Medicine committee on identifying and preventing medication errors, and Senior Advisor to the World Health Organization. He maintains a clinical practice in general internal medicine.

*Session Chaired by: Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands*






# Plenary Speakers

## From Clinical Trials to Clinical Practice: Bridging Towards the Gap

Thursday, 25 October; 1:30 pm – 3:00 pm

Plenary Session Sponsored by  EORTC Quality of Life



### Michael Brundage, MD

Director, Division of Cancer Care and Epidemiology, Cancer Research Institute at Queen's University, Ontario, Canada  
Member of the CONSORT PRO 2012 Executive and ISOQOL Reporting Guidelines Task Force

Dr. Michael Brundage is currently a Professor of Oncology and of Community Health and Epidemiology at Queen's University. Michael's research and teaching interests link epidemiological methods in clinical trials with clinical practice, including major research programs in applied health-related quality of life research, and in the evaluation of quality of care. His current research interests include health services research related to appropriate access to quality care in radiotherapy, as well as clinical trials methodology and quality of life outcomes in clinical practice. He is currently supported by a senior research chair from Cancer Care Ontario, Canada.

He is presently Director of the Division of Cancer Care and Epidemiology research unit at the Queen's Cancer Research Institute at Kingston, and has a clinical practice at the Cancer Centre of Southeastern Ontario at the Kingston General Hospital. He was formerly the medical director of the CCSEO radiation oncology program, and uses this experience in creating a health services research agenda that is integrated with the needs of the Provincial health delivery programs. He serves on the Canadian Cancer Society Research Institute Advisory Committee on Research, co-chairs the NCIC CTG quality of life research committee, serves on the Board of the International Society for Quality of Life Research, and co-chairs the Prostate Cancer Disease Pathway Management Program at Cancer Care Ontario.



### Paul Jacobsen, PhD

Associate Center Director for Population Science at H. Lee Moffitt Cancer Center & Research Institute; and Professor of Psychology and Oncologic Sciences, University of South Florida, Tampa, FL, United States

Dr. Jacobsen received his doctoral degree in Psychology (Clinical) from Michigan State University and completed post-doctoral training in psychosocial oncology at Memorial Sloan-Kettering Cancer Center. In 1994, he was recruited to Moffitt Cancer Center in Tampa, Florida to direct the clinical and research programs in psychosocial oncology and palliative care. He is currently Associate Center Director for Population Science at Moffitt and Professor of Psychology and Oncologic Sciences at the University of South Florida. Dr. Jacobsen's research focuses on quality of life and quality of care in oncology. He has authored more than 200 journal articles on these topics and been the recipient of multiple grants from the National Cancer Institute (US) and the American Cancer Society in support of his research.



### Holger J. Schünemann, MD, PhD, MSc, FRCP(C)

Chair, Department of Clinical Epidemiology & Biostatistics; Michael Gent Chair in Healthcare Research; and Professor, Departments of Clinical Epidemiology & Biostatistics and of Medicine, McMaster University Health Sciences Centre, Hamilton, ON, Canada

Dr. Schünemann is chair of the Department of Clinical Epidemiology and Biostatistics at McMaster University. He trained in Medicine (M.D. in 1993) epidemiology (Ph.D. in 2000), preventive medicine/public health and internal medicine (2000). He authored over 300 peer reviewed publications many of them focusing on topics in health related quality of life, utility assessment, guideline methodology and systematic reviews. He is editor of BMC Health and Quality of Life Outcomes, one of the leading journals in quality of life research, co-chair of the GRADE working group, and a member of several committees of World Health Organization (WHO).

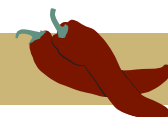
*Session Chaired by: Melanie Calvert, PhD, University of Birmingham, United Kingdom; and Member of the CONSORT PRO 2012 Executive and ISOQOL Reporting Guidelines Task Force*  
*Fabio Efficace, PhD, Head, Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy*



**2012 ISOQOL  
President's Award Recipient**



**Diane L. Fairclough, DrPH  
University of Colorado, Denver**



# Plenary Speakers

## Innovations in eHealth

Friday, 26 October; 2:45 pm – 4:00 pm

Plenary Session Sponsored by  **UBC**  
United BioSource Corporation



### Paul Wicks, PhD

Director, Research and Development,  
PatientsLikeMe, United Kingdom

Paul Wicks, PhD, is the director of research and development (R&D) at PatientsLikeMe. An internationally recognized expert in psychological aspects of neurodegenerative conditions, Dr. Wicks is responsible for shaping the scientific and medical validity of the PatientsLikeMe platform. As R&D director, he leads a team of experts charged with conducting scientific research that generates insights from the personal health data shared by patient members.

Under Dr. Wicks' direction, the PatientsLikeMe R&D team has produced over fifteen peer-reviewed publications, which have appeared in major scientific journals such as *Nature Biotechnology*, *Clinical Investigation*, *Journal of Medical Internet Research*, and *European Journal of Neurology*. Highlights include an innovative patient-led trial of lithium use in ALS, a survey of off-label drug use, and development of patient-reported outcome measures for people with multiple sclerosis. In addition to working with elite research organizations, including Johns Hopkins, Oxford University, and ALS Untangled, the R&D team also provides professional services to the company's commercial partners.

Prior to joining PatientsLikeMe, Dr. Wicks worked directly with patients from around the world, studying cognition in rare forms of ALS and the psychological consequences of Parkinson's disease. Those research findings have also been published in numerous peer-reviewed journals. A frequent conference presenter on the power of personalized medicine in improving health outcomes, Dr. Wicks was awarded "TR35 Humanitarian of the Year" by MIT's Technology Review magazine and recognized as one of Britain's 50 "New Radicals" by The Observer and NESTA.



### Jon Stamford, PhD

PARKINSON'S MOVEMENT, an initiative of the  
Cure Parkinson's Trust, United Kingdom

Dr. Jon Stamford is a neuroscientist with a double interest in Parkinson's. As well as leading a research laboratory investigating the neurochemistry of Parkinson's for more than a decade, Dr. Stamford also has young onset Parkinson's disease. Dr. Stamford has published three neuroscience books and more than 200 research publications (reviews, papers, abstracts) in an academic career lasting 23 years. He holds an honorary readership at the University of Leicester, is a scientific and advocate communications coordinator with the Cure Parkinson's Trust and a member of the program committee for WPC 2013 in Montreal. Dr. Stamford is interested in patient empowerment and patient-reported outcomes. Dr. Stamford also writes a humorous and influential weekly blog "Slice of Life" about life with young onset Parkinson's.



### Martha Grootenhuis, PhD

Head Research Psychosocial Department, Emma  
Children's Hospital, Academic Medical Center,  
The Netherlands

Martha Grootenhuis is an internationally recognized leader in the field of pediatric psycho-oncology. She is the Head of Research and Co-Director of the Pediatric Psychology Department in the Emma Children's Hospital, Amsterdam. Prof Grootenhuis founded the SIOP Pediatric Psycho-Oncology Committee and is a registered health psychologist. She is a multidisciplinary project leader, consultant and tutor for psychologists, pediatricians, and students. Prof Grootenhuis' academic accomplishments are reflected by her numerous publications. She has published 117 peer reviewed articles in leading international journals. She has extensive experience coordinating randomised controlled trials of psychosocial cognitive behavioural interventions with children with chronic diseases, and developing web-based interventions for young cancer survivors and their parents. These interventions reveal the depth and extent of the translation of research into clinical practice. The research team from the Emma Childrens Hospital was the first in the world to successfully implement an electronic patient reported outcome into a busy pediatric clinic environment.

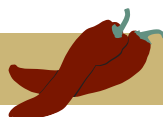
Session Chaired by: Sara Ahmed, PhD, McGill University, Montreal, Canada and Bernhard Holzner, PhD BE, Clinical Psychologist, University Hospital, Innsbruck, Austria

## Congratulations to the 2012 Outstanding Article of the Year!

### *Patterns of reporting health-related quality of life outcomes in randomized clinical trials: implications for clinicians and quality of life researchers*

Brundage M, Bass B, Davidson J, Queenan J, Bezjak  
A, Ringash J, Wilkinson A, Feldman-Stewart D.

Published in the *Quality of Life Research Journal*  
Qual Life Res (2011) 20:653–664. DOI 10.1007/  
s11136-010-9793-3





# Plenary Speakers

## Paving the Path Towards Personalized Medicine

Saturday, 27 October; 9:00 am – 10:30 am

Plenary Session Sponsored by **Genentech**



### **Per Hall, MD, PhD**

Professor of Radiation Epidemiology at the Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden

Dr. Hall is a medical oncologist by training. He started working at the Department of Oncology, Karolinska Hospital, Stockholm, in 1984. In 1991 he defended his thesis on the adverse effects of radioiodine. Dr Hall created and headed the Hereditary Breast Cancer Unit that started in 1995. During the 16 years he spent at the hospital he devoted most of his to breast cancer.

In 2000 he moved to the Karolinska Institute and took up a full time position as a cancer epidemiologist. Since 2009 he has headed a European Commission funded study, Collaborative Oncological Gene-environment Study (COGS), where the aim is to identify genetic determinants of breast, prostate and ovarian cancer. The consortium includes more than 140 groups spread over the world. In 2009 he received a donation from the Swedish Rausing family that made it possible to initiate Karma study which will include 100,000 women with the overall aim of reducing the incidence of breast cancer. The total budget for these two projects is approximately \$30 million.



### **Donald E. Morisky, ScD ScM MPH**

Professor, Department of Community Health Sciences, UCLA School of Public Health, Los Angeles, CA, United States

Dr. Morisky received his doctoral degree in health education and behavioral sciences from the Johns Hopkins School of Hygiene and Public Health in 1981. He has worked with epidemiologists, physicians, nurses, and community members designing and implementing research studies aimed at developing tools to understand factors associated with poor adherence and why patients stop taking their medicines. His research team at the Johns Hopkins Medical University published the Morisky, Green and Levine self-reported adherence measure in 1986. Updated adherence measures include the MMAS-4 which is used primarily in the medical office environment where the clinician/health care provider can interact with the patient and provide reinforcement and educational counseling based on responses. The recent MMAS-8 published in 2008 has a higher level of internal consistency and higher concurrent and predictive validity. Dr. Morisky has published over 160 peer reviewed journal articles focusing on program evaluation and assessment of socio-structural interventions and incorporation of successful components into the health care delivery system. He has served as a consultant with the World Health organization, United Nations Family Planning Association, UNICEF, and the USAID. He is on the editorial board of the American Journal of Health Behavior, AIDS Behavior, and Health Education and Behavior. He has conducted research in the Philippines, Taiwan and China and speaks many of these languages and dialects.



### **William E. Narrow, MD MPH**

Research Director, DSM-5 Task Force, American Psychiatric Association, United States

Dr. William Narrow is Associate Director of the Division of Research at the American Psychiatric Association and Research Director of the DSM-5 Task Force. He received a bachelor's degree with majors in biology and sociology from Boston University, a medical degree from Temple University, and a master's degree in public health from the Johns Hopkins University. Dr. Narrow's research focuses on the epidemiology of mental disorders. He is particularly interested in disability, estimation of need for mental health services, and child and adolescent mental disorders. Dr. Narrow has participated in several collaborative research projects, including the DSM-5 Field Trials and the editorial board for development of the Diagnostic Interview Schedule for Children (DISC-IV). He is also an editor of the journal *Social Psychiatry and Psychiatric Epidemiology*.

*Session Chaired by: Juan J. Dapuerto, MD, PhD, Professor, Director Dept. Medical Psychology, Facultad de Medicina, Universidad de la República, Montevideo, Uruguay and Mirjam AG Sprangers, PhD, Academic Medical Center, Amsterdam, The Netherlands*

## *Congratulations to the 2012 Scholarship Recipients*

### **New Investigator and Student Scholarships**

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

**Lotte Haverman, MSc, Emma Children's Hospital -  
Academic Medical Centre, The Netherlands**

**Bellinda King-Kallimanis, PhD, TILDA, Trinity College  
Dublin, Ireland**

### **Developing Country Scholarships**

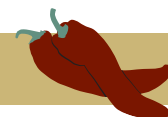
**Joshua C. Gandi, RN, RPN, HND, BSc, MSc,  
University of Jos, Emerging Alliance Researchers (ERA), Nigeria**

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

**Shahnaz Shahrbanian, McGill University, Canada**

**Paulos Teckle, PhD, Canadian Centre for Applied Research  
in Cancer, UBC, Canada**

*A special thank you to all who have supported the ISOQOL  
Scholarship Funds for helping to make these awards possible.*



# Program Schedule

## Wednesday, 24 October 2012

**Registration Desk** 7:00 am – 5:00 pm  
FUNCTION LOBBY

**Continental Breakfast** 8:00 am – 9:00 am  
BREAKOUT LOBBY

### Workshops

**Morning Workshops** 9:30 am – 12:30 pm

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

ISTVÁN ROOM

Heather Gelhorn, PhD, and Kathy Wyrwich, PhD, United BioSource Corporation, Bethesda, MD, United States

**(WK02) Improving Adherence through Effective Patient-Physician Communication and Personalized Medicine**

LÁNCHID A ROOM

Carla Dias Barbosa, MSc, Senior Research Manager, Mapi Consultancy, Lyon, France; and Benoit Arnould, PhD, Managing Director, Mapi Consultancy, Lyon, France

**(WK03) Step by Step Development of a Patient Reported Outcomes (PRO) Instrument with Good Content Validity**

LÁNCHID B ROOM

Emuella Flood, Director, Patient Reported Outcomes, Oxford Outcomes, an ICON plc Company, Bethesda, MD, United States; Cicely Kerr, MSc PhD, Senior Outcomes Researcher, Patient Reported Outcomes, Oxford Outcomes, an ICON plc Company, Oxford, United Kingdom; and Sarah Acaster, MSc, Director, Patient Reported Outcomes, Oxford Outcomes, an ICON plc Company, San Francisco, CA, United States

**(WK04) An Interactive Overview of Using Computer-Assisted Qualitative Data Analysis Software (CAQDAS) in Health Outcomes Research**

MARGIT A ROOM

Helen Kitchen and Christopher Marshall, Adelphi Values, Cheshire, United Kingdom

**(WK05) Improving the Reporting of Patient Reported Outcomes in Clinical Trials**

MARGIT B ROOM

Melanie Calvert, PhD, Reader in Epidemiology, MRC Midland Hub for Trials Methodology Research, School of Health and Population Sciences, University of Birmingham, United Kingdom; Jane Blazeby, MD, Professor of Surgery, Director MRC ConDuCT Hub for Trials Methodology Research, University of Bristol & University Hospitals Bristol NHS Foundation Trust, United Kingdom; Michael Brundage, MD, Director, Division of Cancer Care and Epidemiology, Cancer Research Institute at Queen's University, Ontario, Canada, Members of the CONSORT PRO 2012 Executive and ISOQOL Reporting Guidelines Task Force

**(WK06) Bayesian Item Response Theory Modeling: A Hands-On Tutorial on Dealing with Excessive Missing Item Response Data**

CORSO A ROOM

Yuelin Li, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY, United States

**(WK07) Interpreting Utility (Preference-Based) Measures of Health-Related Quality of Life**

CORSO B ROOM

David Feeny, PhD, Professor Emeritus University of Alberta and Health Utilities Incorporated, Portland, OR, United States; Maria Jose Santana, PhD, University of Calgary, Calgary, AB, Canada; and John R. Horsman, BA, Health Utilities Incorporated, Dundas, ON, Canada

### Afternoon Workshops

2:00 pm – 5:00 pm

**(WK08) Are You Developing your Patient-Reported Outcome Measures Correctly? Things You Need to Know to Develop One Successfully!**

ISTVÁN ROOM

Kristina Fitzgerald, MPH, Genentech, San Francisco, CA, United States; Stacie Hudgens, MA, and Somali Misra Burgess, PhD, Adelphi Values, Boston, MA, United States

**(WK09) Assessing Health Outcomes in a Global Clinical Research Setting: Challenges and Solutions to Manage Cultural Variability**

LÁNCHID A ROOM

Antoine Regnault, PhD, Benoit Arnould, PhD, and Caroline Anfray, Mapi Institute, Lyon, France

**(WK10) Developing a Researchable Question and Beyond**

LÁNCHID B ROOM

Nancy E. Mayo, PhD, McGill University and McGill University Health Centre Research Institute, Montreal, QC, Canada

**(WK11) FDA and EMA PRO Labels—The Anatomy of Three Success Stories**

ÁRPÁD ROOM

Jeff Sloan, PhD, Mayo Clinic, Rochester, MN, United States; Ari Gnanasakthy, MSc MBA, Head, Patient Reported Outcomes, Novartis Pharmaceuticals, East Hanover, NJ, United States; and third speaker to be confirmed

Organized by Diana Rofail, Principal Patient-Reported Outcomes, Roche; Yasuhiro Torigoe, Principal Patient-Reported Outcomes, Genentech/Roche, and Stacey Yager, Lead Patient-Reported Outcomes Scientist, Genentech

**(WK12) Making Quality Adjusted Life Year Instruments from Patient Reported Outcomes: Methods for Developing Preference-based Measures of Health from Existing Measures**

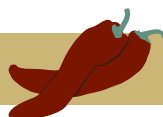
MARGIT A ROOM

Tracey A. Young, PhD MSc BSc CStat; John E. Brazier, PhD; Brendan Mulhern; and Donna Rowen, PhD, University of Sheffield, Sheffield, Yorkshire, United Kingdom

**(WK13) Interpretation of PRO Data within Clinical Trials**

MARGIT B ROOM

Sarah Acaster, MSc, Oxford Outcomes, San Francisco, CA, United States; Kathleen Wyrwich, PhD, United BioSource Corporation, Bethesda, MD, United States; Josephine M. Norquist, MS, Merck, Sharp & Dohme, Corp., a Subsidiary of Merck & Co., Inc., North Wales, PA United States; William Lenderking, PhD, United BioSource Corporation, Bethesda, MD, United States





# Program Schedule

## Wednesday, 24 October 2012

**IAC Symposium** 5:00 pm – 6:30 pm  
CORSÓ ROOM

**Perspectives on Mixed Methods to Assess Content Validity of a Patient Reported Outcome**

*Organized by the ISOQOL Industry Advisory Committee (IAC)*

**Stephen Joel Coons, PhD**, Executive Director, PRO Consortium, Critical Path Institute, United States; **Stacie Hudgens, MA**, Vice President, Global Lead - Healthcare Analytics, Adelphi Values, United States; **Josephine M. Norquist, MS**, Patient Reported Outcomes Specialist, Merck Sharp & Dohme Corp., United States; **Kathleen Wyrwich, PhD**, Senior Research Leader, United BioSource Corporation, United States; Moderated by **William Lenderking, PhD**, Senior Research Scientist, United BioSource Corporation, United States

**Future of ISOQOL Reception** 6:30 pm – 7:00 pm  
BUDAPEST BALLROOM

In order to celebrate and engage the future of ISOQOL, we would especially like to invite students, new investigators, and first time attendees to join us at the Future of ISOQOL Reception.

**Welcome Reception** 7:00 pm – 9:00 pm  
BUDAPEST BALLROOM

The Scientific Program Planning Committee Co-Chairs would like you to join us at the ISOQOL Welcome Reception. Start off the conference by visiting with old friends and networking with new friends and colleagues. Light refreshments will be available.

## Thursday, 25 October 2012

**Registration Desk** 7:00 am – 5:00 pm  
FUNCTION LOBBY

**Poster Hall Open** 7:00 am – 8:00 pm  
ERZSÉBET BALLROOM

**Continental Breakfast** 7:30 am – 8:30 am  
BREAKOUT LOBBY

**Communications Committee Meeting** 7:30 am – 8:15 am  
MARGIT ROOM

**Welcome Plenary Session** 8:30 am – 10:15 am  
BUDAPEST BALLROOM

**Comparative Effectiveness Research (CER) and Patient-Centered Outcomes Research**

**Ethan Basch, MD MSc**, Associate Attending Physician, Memorial Sloan-Kettering Cancer Center, United States; **Andrew Vallance-Owen, MBA FRCS Ed**, Chairman, UK Department of Health's PROMs Stakeholder Group, United Kingdom; **Albert W. Wu, MD MPH**, Professor, Johns Hopkins Bloomberg School of Public Health, United States

**Exhibits Open and Refreshment Break** 10:15 am – 11:00 am  
BREAKOUT LOBBY

**Concurrent Oral Sessions** 10:30 am – 12:00 pm  
(101) *Societal Health Outcome Evaluation*  
MARGIT ROOM

(102) *Patient Reported Outcomes in Cancer Trials*  
CORSÓ ROOM

(103) *Utility Measures*  
LÁNCHID ROOM

(104) *Quality of Life Evaluation in Cancer and Chronic Illness*  
BUDAPEST BALLROOM

**Luncheon Roundtables** 12:15 pm – 1:15 pm  
ERZSÉBET BALLROOM

(RT01) *Quality of Life and Health Economics – Future Directions for the Use of QALYS*

(RT02) *Clinicians' Perspectives on the Interpretation and Application of PROs and ePROs*

(RT03) *Application of Mixed Methods to Quality of Life Research*

(RT04) *Innovations in Modern Psychometrics*

(RT05) *Industry Perspectives on Quality of Life Evaluation*

(NIRT1) *CVs, Resumes, and Cover Letters, Oh My!*  
ÁRPÁD ROOM

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international

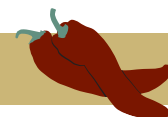
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# Program Schedule

## Thursday, 25 October 2012

**Plenary Session** 1:30 pm – 3:00 pm  
BUDAPEST BALLROOM

**From Clinical Trials to Clinical Practice: Towards Bridging the Gap**

**Michael Brundage, MD**, Director, Division of Cancer Care and Epidemiology, Cancer Research Institute at Queen's University, Ontario, Canada Member of the CONSORT PRO 2012 Executive and ISOQOL Reporting Guidelines Task Force; **Paul Jacobsen, PhD**, Associate Center Director for Population Science at H. Lee Moffitt Cancer Center & Research Institute; and Professor of Psychology and Oncologic Sciences, University of South Florida, United States; **Holger J. Schönemann, MD, PhD, MSc, FRCP(C)**, Chair, Department of Clinical Epidemiology & Biostatistics; Michael Gent Chair in Healthcare Research; and Professor, Departments of Clinical Epidemiology & Biostatistics and of Medicine, McMaster University Health Sciences Centre, Canada

**Exhibits Open and Refreshment Break** 3:00 pm – 4:00 pm  
BREAKOUT LOBBY

**Poster Presentations (1000s)** 3:00 pm – 4:00 pm  
ERZSÉBET BALLROOM

**Concurrent Oral Sessions** 4:00 pm - 5:30 pm  
**(105) Patient and Health Outcomes in Chronic Conditions**  
MARGIT ROOM

**(106) Utility Measures**  
LÁNCHID ROOM

**(107) Outcome Evaluation in Cancer**  
BUDAPEST BALLROOM – BUDA ROOM

**(108) Psychosocial and Health Interventions**  
CORSO ROOM

**(109) Symptom Monitoring in Clinical Research and Practice**  
BUDAPEST BALLROOM – PEST ROOM

**Mentor/Mentee Reception** 6:00 pm – 7:00 pm  
CORSO ROOM

**Psychometric SIG Presentation** 6:00 pm – 7:30 pm  
MARGIT ROOM

**ISOQOL Recommends Minimum Standards for Patient-Reported Outcomes Measures for use in Patient-Centered Outcomes Research**

**Bryce B. Reeve, PhD**, Lineberger Cancer Center & Dept of Health Policy & Management, The University of North Carolina at Chapel Hill, United States

**Translation and Cultural Adaptation (TCA) SIG Presentation** 6:00 pm – 7:30 pm  
LÁNCHID ROOM

**One Language: Benefits of a Universal Translation Approach**  
**Helena Correia**, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, United States

**Impact of Culture in PRO Data**  
**Ari Gnanasakthy, MSc MBA**, Head, Patient Reported Outcomes, Novartis Pharmaceuticals Corporation, United States

## Friday, 26 October 2012

**Registration Desk** 7:00 am – 5:00 pm  
FUNCTION LOBBY

**Poster Hall Open** 7:00 am – 8:00 pm  
ERZSÉBET BALLROOM

**Continental Breakfast** 8:00 am – 9:00 am  
BREAKOUT LOBBY

**Child Health SIG Business Meeting** 7:00 am – 8:45 am  
MARGIT ROOM

**Response Shift SIG Presentation** 7:00 am – 8:45 am

**Advancing the Response Shift Research Road Map: Developing the Next International Collaboration**  
LÁNCHID ROOM

**Industry Advisory Committee (IAC) Meeting** 7:30 am – 8:45 am  
ÁRPÁD ROOM

**2013 Annual Conference Planning Committee Meeting** 8:00 am – 8:45 am  
CORSO ROOM

**ISOQOL Business Meeting and Awards Presentation** 9:00 am – 10:30 am  
BUDAPEST BALLROOM

**Exhibits Open and Refreshment Break** 10:30 am – 11:00 am  
BREAKOUT LOBBY

**Concurrent Oral Sessions** 10:45 am – 12:15 pm  
**(201) Health Outcome Evaluation and Development**  
MARGIT ROOM

**(202) Trials and Intervention Evaluation**  
CORSO ROOM

**(203) Analysis and Interpretation of Outcomes**  
LÁNCHID ROOM

**(204) Mental Health and Patient Outcomes**  
BUDAPEST BALLROOM

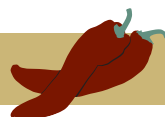
**Lunch on your Own** 12:15 pm – 1:15 pm

**Poster Presentations (2000s)** 1:15 pm – 2:15 pm  
ERZSÉBET BALLROOM

**Special Presentation on Patient Advocacy** 2:15 pm – 2:45 pm  
BUDAPEST BALLROOM

**Patient Advocates in Cancer Research: A European Patients' Perspectives**

**Jan Geissler**, President of EUPATI - The European Patients' Academy on Therapeutic Innovation, Germany



# Program Schedule

**Friday, 26 October 2012**

## Plenary Session

BUDAPEST BALLROOM

### Innovations in eHealth

**Paul Wicks, PhD**, Director, Research and Development, PatientsLikeMe, United Kingdom; **Jon Stamford, PhD**, PARKINSON'S MOVEMENT, an initiative of the Cure Parkinson's Trust, United Kingdom; **Martha Grootenhuys, PhD**, Head Research Psychosocial Department Emma Children's Hospital, Academic Medical Center, The Netherlands

**2:45 pm – 4:00 pm**

## Exhibits Open and Refreshment Break

BREAKOUT LOBBY

**4:00 pm – 4:30 pm**

## Concurrent Oral Sessions

**4:30 pm - 6:00 pm**

**(205) Quality of Life Measure Development**

LÁNCID ROOM

**(206) Patient Reported Outcomes in Clinical Practice**

BUDAPEST BALLROOM

**(207) Outcome Measure Development**

MARGIT ROOM

**(208) Health Outcomes in Children**

CORSO ROOM

## Quality of Life in Clinical Practice SIG Presentation

LÁNCID ROOM

**Do Patient Reported Outcome Guidelines for Routine Clinical Practice Matter? Government, Industry and Patient Perspectives**

**6:15 pm – 7:45 pm**

## New Investigator SIG Presentation

MARGIT ROOM

**Tricks of the Trade: Advice for New Investigators in Quality of Life Research II**

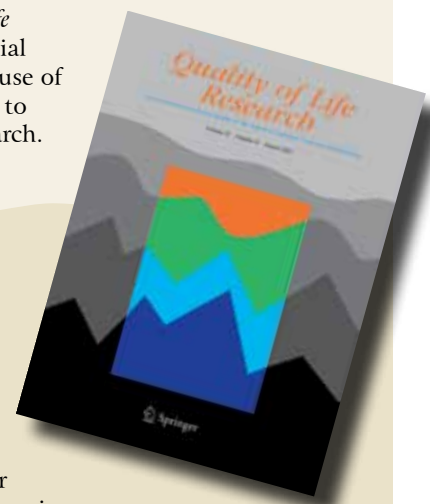
**John E. Brazier, PhD**, University of Sheffield, United Kingdom; **Juan J. Dapuelto, MD, PhD**, Facultad de Medicina, Universidad de la República, Uruguay; **Dennis Revicki, PhD**, United BioSource Corporation, Center for Health Outcomes Research, United States; **Mirjam AG Sprangers, PhD**, Academic Medical Center, The Netherlands

**6:15 pm – 7:45 pm**

# Call for Papers

The Editors of *Quality of Life Research* are planning a special series to highlight effective use of quantitative methodologies to improve quality of life research. We are seeking papers that exemplify excellent science on various methodologies or topics, including but not limited to:

- Application of linear growth curve models for analyzing clinical trial data
- Application of bifactor models for examining general and specific factor structures within QOL domains
- Methods for handling missing data in statistical analyses of prospective QOL data
- Applications of unidimensional and multidimensional item response theory (IRT) models for analyses of health outcome data
- Applying differential item functioning (DIF) testing to evaluate measurement equivalence of QOL measures.
- Dyadic data analysis in QOL research
- Application of structural equation modeling (SEM) for evaluating construct validity of QOL measures or examining relationships among QOL variables.
- Using latent class analysis (cluster analysis) or latent profile analysis to identify classes (clusters or profiles) of individuals with similar (or different) QOL profiles and underlying factors associated with these classes (clusters or profiles).



To participate in this call, please submit a **letter of intent** with draft title, contact information and institution for all co-authors, and abstract (250 word maximum). A subset of these letters of intent will be invited for full manuscript. We expect to publish 4-6 manuscripts.

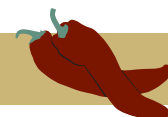
Anticipated timeline:

Letter of Intent	February 1, 2013
Manuscripts invited based on screening of letters of intent	March 1, 2013
Manuscripts due	June 3, 2013
Anticipated publication of special section	Fall 2013

Please email to:

Carolyn Schwartz ([carolyn.schwartz@deltaquest.org](mailto:carolyn.schwartz@deltaquest.org)) and Dennis Revicki ([dennis.revicki@unitedbiosource.com](mailto:dennis.revicki@unitedbiosource.com)).

Deadline for submission of Letter of Intent: February 1, 2013





# Program Schedule

## Saturday, 27 October 2012

**Registration Desk** 8:00 am – 2:00 pm  
FUNCTION LOBBY

**Poster Hall Open** 7:00 am – 8:00 pm  
ERZSÉBET BALLROOM

**Continental Breakfast** 8:00 am – 9:00 am  
BREAKOUT LOBBY

**Membership Committee Meeting** 8:00 am – 8:45 am  
LÁNCHID ROOM

**Plenary Session** 9:00 am – 10:30 am  
BUDAPEST BALLROOM

**Paving the Path Towards Personalized Medicine**  
**Per Hall, MD, PhD, Professor of Radiation Epidemiology at the Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden; Donald E. Morisky, ScD ScM MPH, Professor, Department of Community Health Sciences, UCLA School of Public Health, United States; William E. Narrow, MD MPH, Research Director, DSM-5 Task Force, American Psychiatric Association, United States**

**Exhibits Open and Refreshment Break** 10:30 am – 11:00 am  
BREAKOUT LOBBY

### Concurrent Oral Sessions 10:45 am – 12:15 pm

**(301) Outcome Measure Development**  
MARGIT ROOM

**(302) Personalized Medicine**  
LÁNCHID ROOM

**(303) Response Shift**  
CORSO ROOM

**(304) Health Outcomes in Children**  
BUDAPEST BALLROOM

**Luncheon Roundtables** 12:30 pm – 1:30 pm  
ERZSÉBET BALLROOM

**(RT06) How to Do a Peer Review**

**(RT07) Cancer Survivorship**

**(RT08) What are American Funding Agencies Looking For? Priorities for Funding**

**(RT09) Patient Engagement in the European Context**

**(RT10) Genetics**  
ISTVAN ROOM

**(NIRT2) Interview Tips and Strategies**  
ÁRPÁD ROOM

### Concurrent Symposia Sessions 1:45 pm – 3:15 pm

**(Symposium 1) Implementing Patient-Reported Outcomes in Clinical Practice: An Expert Panel Discussion of Current Knowledge and Unanswered Questions**  
BUDAPEST BALLROOM – BUDA ROOM

**(Symposium 2) Are Generic Preference-Based Measures Valid in Mental Health? A Mixed Methods Enquiry**  
BUDAPEST BALLROOM – PEST ROOM

**(Symposium 3) Response Shift Detection in Secondary Data Analysis: Findings and Implementation Guidelines**  
MARGIT ROOM

**(Symposium 4) Patient-Centered Approach to Adverse Event Reporting: The US National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events**  
LÁNCHID ROOM

**(Symposium 5) Conceptual and Methodological Advances and Research Priorities for Child HRQOL**  
CORSO ROOM

**Exhibits Open and Refreshment Break** 3:15 pm – 4:15 pm  
BREAKOUT LOBBY

**Poster Presentations (3000s)** 3:15 pm – 4:15 pm  
ERZSÉBET BALLROOM

### Concurrent Oral Sessions 4:15 pm - 5:45 pm

**(305) Symptom Monitoring in Clinical Research and Practice**  
BUDAPEST BALLROOM – BUDA ROOM

**(306) Caregiver Quality of Life and Health Evaluation**  
MARGIT ROOM

**(307) Psychometric Approaches**  
LÁNCHID ROOM

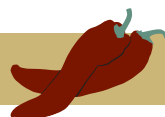
**(308) Mental Health Evaluation**  
CORSO ROOM

**(309) Psychometric Approaches**  
BUDAPEST BALLROOM – PEST ROOM

### Closing Dinner 7:00 pm – 10:00 pm

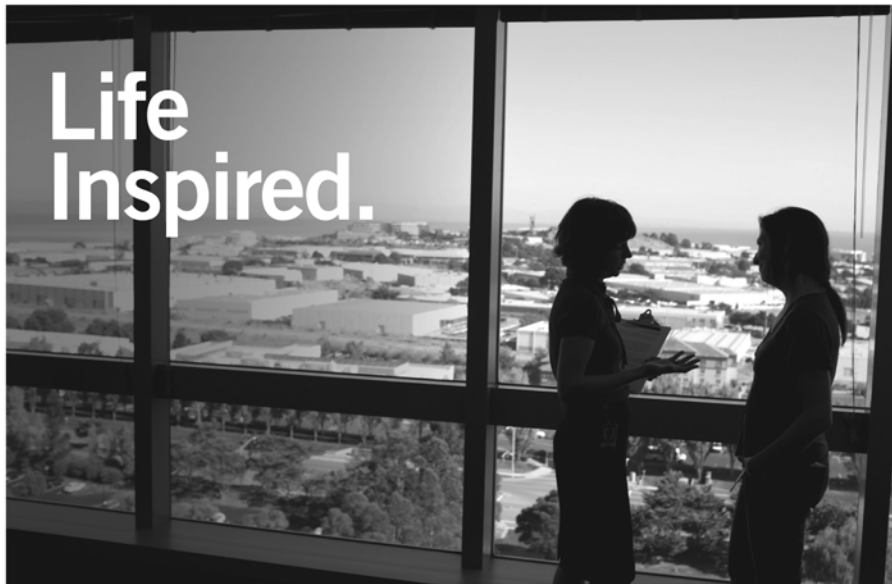
DANUBE RIVER CRUISE

Information on boat launch location will be available at the Registration Desk.





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## Patient-Reported Outcomes Career Opportunities

We're passionate and rigorous about our science. For more than 30 years, Genentech has been at the forefront of the biotechnology industry, using innovative science to develop breakthrough medicines that improve the lives of people with serious or life-threatening diseases. We're also passionate about our people, our most important asset.

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# Concurrent Oral Sessions

Thursday, 25 October, 10:30 am – 12:00 pm

## Oral Session 101: Societal Health Outcome Evaluation

Populations and Healthcare Policy Track

Session Chair: Antonia V. Bennett, PhD, United States  
MARGIT ROOM

### (101.1) From deindustrialization to individual health-related quality of life: multilevel evidence of contextual predictors, mediators and modulators across French regions, 2003

Etienne Audureau, Assistance Publique-Hôpitaux de Paris, Université Paris-Descartes, France; Stéphane Rican, Space, Health and Territories Laboratory, University of Paris Ouest-Nanterre, France; Joël Coste, Assistance Publique-Hôpitaux de Paris, Université Paris-Descartes, France

### (101.2) Individual and Household Characteristics Associated with Adult Longitudinal Health Status Assessment: Regional Rural Injury Study-III (RRIS-III)

Colleen M. Renier, BS, Essentia Institute of Rural Health; Susan G. Gerberich, Environmental Health Sciences, University of Minnesota, Minneapolis, MN; Andrew D. Ryan, Environmental Health Sciences, University of Minnesota, Minneapolis, MN; Bruce H. Alexander, Environmental Health Sciences, University of Minnesota, Minneapolis, MN; Timothy R. Church, Environmental Health Sciences, University of Minnesota, Minneapolis, MN; Patricia M. McGovern, University of Minnesota, United States; Ann S. Masten, United States; Steven J. Mongin, Environmental Health Sciences, University of Minnesota, Minneapolis, MN

### (101.3) Using Time to Symptomatic Recovery as an Outcome Measure for Para-operative Pain Study

Qiuling Shi, PhD, University of Texas MD Anderson Cancer Center; Xin Shelley Wang, MD MPH, UT MD Anderson Cancer Center; Elizabeth A. David, UT MD Anderson Cancer Center; Ara A. Vaporciyan, UT MD Anderson Cancer Center; Charles S. Cleeland, PhD, UT-MD Anderson Cancer Center

### (101.4) Hopelessness and health-related quality of life: Results from Japanese General Social Surveys 2010

Misa Takegami, National Cerebral and Cardiovascular Center, Japan; Yōsuke Yamamoto, Kyoto University, Japan; Noriko Iwai, Osaka University of Commerce, Japan

### (101.5) Quality of life of homeless patients suffering from severe mental health disorder in France

Cécile Fortanier, PhD, Assistance Publique Hôpitaux de Marseille - EA 3279, France; Vincent Girard, Assistance Publique Hôpitaux de Marseille - EA 3279; Aurélie Tinland, Assistance Publique Hôpitaux de Marseille; Benjamin Videau, Assistance Publique Hôpitaux de Marseille - EA 3279; Fanny Olive, Assistance Publique Hôpitaux de Marseille; Guillaume Suderie, ORSMIP; Amandine Albisson, ORSMIP; Achille Djiena, F2RSM; Christian Laval, Assistance Publique Hôpitaux de Marseille - EA 3279; Pascal Auquier, PhD, Laboratoire de Santé Publique, France

## Oral Session 102: Patient Reported Outcomes in Cancer Trials

Comparative Effectiveness Research Track

Session Chair: Carolyn C. Gotay, PhD, Canada  
CORSO ROOM

### (102.1) Value Added of Patient-Reported Data to Clinician Reported Toxicity Data: Preliminary Analysis of 3DCRT vs IMRT on RTOG 0126 Prostate Cancer Trial High Dose Arm

Deborah W. Bruner, RN PhD FAAN, Emory University, United States; Daniel Hunt, PhD, American College of Radiology; Jeff M. Michalski, MD, Washington University in St. Louis; Walter Bosch, PhD, Washington University in St. Louis; Yan Yan, MD MS, American College of Radiology; James M. Galvin, DSc, Thomas Jefferson University-Jefferson Medical College; Jean-Paul Bahary, MD FRCP, Centre Hospitalier de L'Université de Montreal, Canada; Gerard C. Morton, MD, University of Toronto-Odetta Cancer Centre; Matthew B. Parliament, MD, University of Alberta; Howard Sandler, MD, Cedars-Sinai Medical Center

### (102.2) A Systematic Review in Health-Related Quality of Life Reporting in Small-Cell Lung Cancer Clinical Trials: An Examination into the Added Value of Health-Related Quality of Life Findings

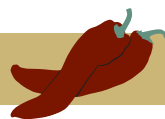
Efstathios Zikos, MSc MA EORTC HQ, Belgium; Corneel Coens, MSc EORTC HQ, Belgium; Irina Ghislain, MSc EORTC, Quality of Life Department; Divine Ewane Ediebah, MSc, EORTC HQ, Belgium; Elisabeth Sloan, EORTC HQ; Chantal Quinten, MSc, EORTC, Belgium; Michael Koller, PhD, Center for Clinical Studies, Germany; Jan P. Van Meerbeek, PhD, Ghent University Hospital, Respiratory Medicine-Thoracic Oncology; Henning H. Flechtner, PhD, Otto-von-Guericke University (KKJP), Germany; Roger Stupp, MD, 7Department of Oncology of the Riviera/Chablais, Switzerland

### (102.3) Patient-reported satisfaction with reconstructed breasts in the long-term survivorship period: Comparison of autologous and non-autologous breast reconstruction

Amie M. Scott, MPH, Memorial Sloan-Kettering Cancer Center; Adelyn L. Ho, MD MPH, University of British Columbia, Canada; Anne Klassen, D Phil, McMaster University, Canada; Stefan Cano, BSc PhD, Peninsula College of Medicine & Dentistry, United Kingdom; Nancy VanLaeken, The University of British Columbia; Peter Cordeiro, Memorial Sloan Kettering Cancer Center; Andrea Pusic, MD MHS FRCSC, Memorial Sloan Kettering Cancer Center, United States

### (102.4) Health-related quality of life following breast reconstruction after mastectomy: a large multi-centre cohort study of patient-reported outcomes for different surgical techniques

John Browne, PhD, University College Cork, Ireland; Ranjeet Jeevan, Royal College of Surgeons of England; David Cromwell, London School of Hygiene and Tropical Medicine, United Kingdom; Jerome Pereira, James Paget University Hospitals NHS Foundation Trust; Chris Caddy, Sheffield Teaching Hospitals NHS Foundation Trust; Carmel Sheppard, Portsmouth Hospitals NHS Trust; Kimberley Greenaway, NHS Information Centre for Health and Social Care; Jan Van Der Meulen, London School of Hygiene and Tropical Medicine



# Concurrent Oral Sessions

Thursday, 25 October, 10:30 am – 12:00 pm

## Oral Session 103: Utility Measures

Methods and Theory Track

Session Chair: David Feeny, PhD, United States

LÁNCHID ROOM

### (103.1) Revaluating the SF-6D Using Ordinal Methods for Eliciting Preferences

Richard Norman, MSc, University of Technology, Sydney, Australia; John E. Brazier, PhD, Univ of Sheffield, United Kingdom; Rosalie Viney, PhD, Centre for Health Economics Research & Evaluation, Australia; Leonie Burgess, University of Technology, Sydney, Australia; Paula Cronin, University of Technology, Sydney, Australia; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; Julie Ratcliffe, University of Flinders; Deborah Street, University of Technology, Sydney, Australia

### (103.2) Mapping the Childhood Health Assessment Questionnaire to the Health Utilities Index Mark 2 and Mark 3 in Children with Juvenile Idiopathic Arthritis

Kit Simpson, Medical University of South Carolina; James W. Shaw, Abbott Laboratories, United States

### (103.3) Mapping responses on the Functional Assessment of Cancer Therapy-General (FACT-G) to the HUI2 and HUI3

Paulos Teckle, PhD, Canadian Centre for Applied Research in Cancer, Canada; Peacock Stuart, BC Cancer Agency; Kim Van Der Hoek, BC Cancer Agency, Canada

### (103.4) EQ-5D and SF-6D performance in different patient groups

Pedro L. Ferreira, PhD, University of Coimbra, Portugal; Lara N. Ferreira, PhD, University of the Algarve-ESGHT, Portugal; Luis N. Pereira, University of the Algarve-ESGHT; CIEO

## Oral Session 104: Quality of Life Evaluation in Cancer and Chronic Illness

Populations and Healthcare Policy Track

Session Chair: Maria-Jose Santana, PhD, Canada

BUDAPEST BALLROOM

### (104.1) Defining Chronic Cancer: Patient Experiences and Self-Management Needs

Simon A. Pini, The University of Leeds, United Kingdom; Clare Harley, PhD, University of Leeds, United Kingdom; Kiera Bartlett, University of Sheffield, United Kingdom; Galina Velikova, MD, University of Leeds, United Kingdom

### (104.2) Patients with chronic diseases quality of life, moral expectations and consensual platform

Estelle Boetti, MA, Public Health Nord University Hospital, France; Auquier Pascal, MD PhD, Laboratoire de Sante Publique, France; Le Coz Pierre, Medical Philosophy, La Timone University Hospital of Marseille, France

### (104.3) Measure-ABLE: Ensuring that health outcome and performance measures are accessible and valid for people with disabilities and chronic medical conditions

Susan Magasi, Northwestern University, United States; Mark Harniss, University of Washington, United States

### (104.4) Quality of Life (QoL) and symptoms in patients with myelodysplastic syndromes (MDS). Investigating the role of transfusion dependency in an International study

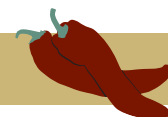
Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Italy; Gianluca Gaidano, Amedeo Avogadro University of Eastern Piedmont, Novara, Italy; Reinhard Stauder, Innsbruck University Hospital, Innsbruck, Austria; Giovanni Caocci, University of Cagliari, Cagliari, Italy; Maria Teresa Voso, University of Rome "Cattolica S. Cuore", Rome, Italy; David Bowen, St James's University Hospital, Leeds, UK.; Dominik Selleslag, AZ Saint-Jan AV, Department of Hematology, Brugge, Belgium; Anna Angela Di Tucci, Hospital "Businco", Department of Hematology, Cagliari, Italy; Monica Lunghi, Amedeo Avogadro University of Eastern Piedmont, Italy; Massimo Breccia, Sapienza University, Rome, Italy

## Advancing Health Outcomes Research Methods and Clinical Applications

### A Publication of the International Society for Quality of Life Research

Edited by  
William R. Lenderking, PhD  
& Dennis A. Revicki, PhD

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# Concurrent Oral Sessions

Thursday, 25 October, 4:00 pm – 5:30 pm

## Oral Session 105: Patient and Health Outcomes in Chronic Conditions

Clinical Practice Track

Session Chair: Diane L. Fairclough, DrPH, United States  
MARGIT ROOM

### (105.1) Health-related quality of life does not differ between short-, long- and very long-term cancer survivors in the Swedish general population

Anna Wikman, Karolinska Institutet, Sweden; Therese Djarv, MD PhD, Karolinska Institutet, Sweden; Mohammed A. Johar, BSc(Hons) MSc, Karolinska Institutet, Sweden; Pernilla Lagergren, PhD RN, Karolinska Institute, Dept. of Molecular Med, Sweden

### (105.2) Health-related quality of life in persons treated for active and latent tuberculosis, versus persons screened but not treated for tuberculosis from diagnosis through six months of follow-up

Melissa Bauer, McGill University, Montreal Chest Institute, Canada; Christina Greenaway, Sir Mortimer B. Davis—Jewish General Hospital; Marek Lalli, Montreal Chest Institute, Canada; Allison Leavens, Montreal Chest Institute, Canada; Ashley Wayne, Montreal Chest Institute, Canada; Bilkis Vissandjee, Faculty of Nursing, Université de Montréal, Canada; Andrea Benedetti, Montreal Chest Institute, Canada; Richard Menzies, Montreal Chest Institute, Canada; Kevin Schwartzman, Montreal Chest Institute, Canada

### (105.3) Risk factors for weight loss and influence of nutritional symptoms among patients surviving five years after oesophageal cancer surgery

Lena Martin, PhD, Karolinska Institutet, Sweden; Pernilla Lagergren, PhD RN, Karolinska Institute, Dept. of Molecular Med, Sweden

### (105.4) Health status and quality of life in long-term survivors of childhood leukaemia

Julie Berbis, Department of Public Health, Medicine University, France; Gérard Michel, Pediatric Haematology Departments, University Hospital of Marseille, France; Pierre Bordigoni, Pediatric Haematology Department, University Hospital of Nancy, France; Pascal Chastagner, Pediatric Haematology Department, University Hospital of Nancy, France; Nicolas Sirvent, Pediatric Haematology Department, University Hospital of Montpellier, France; François Demeocq, Pediatric Haematology Department, University Hospital ClermontFerrand, France; Justyna Kanold, Pediatric Haematology Department, University Hospital ClermontFerrand, France; Dominique Plantaz, Pediatric Haematology Department, University Hospital of Grenoble, France; Karine Baumstarck, France; Pascal Auquier, Public Health Department, University Hospital of Marseille, France, France

### (105.5) Maximizing the Effects of Asthma Interventions: Predictors of Perceived Asthma Control

Owis J. Eilayyan, McGill University, Canada; Sara Ahmed, PhD, McGill University, Canada; Amede Gogovor, McGill University, Canada



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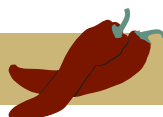
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# Concurrent Oral Sessions

Thursday, 25 October, 4:00 pm – 5:30 pm

## Oral Session 106: Utility Measures

Methods and Theory Track

Session Chair: Simon Pickard, PhD, United States  
LÁNCID ROOM

### (106.1) Appropriate mapping functions in HRQL: a series of models mapping from FACT-G to EQ-5D

Tracey A. Young, PhD MSc BSc CStat, University of Sheffield, United Kingdom; Donna Rowen, PhD, University of Sheffield, United Kingdom; Clara Mukuria, PhD, University of Sheffield, United Kingdom; John E. Brazier, PhD, Univ of Sheffield, United Kingdom; Louise Longworth, Jr., Health Economics Research Group, Brunel University

### (106.2) Comparison of the EQ-5D-5L and the EQ-5D-3L in a Spanish urological cancer sample

Oriol Cunillera Puertolas, MSc, Fundació IMIM, Spain; Carlos G. Forero, PhD, IMIM, Spain; Stefanie Schmidt, IMIM (Hospital del Mar Medical Research Institute), Spain; Juan M. Cabasés, Universidad Pública de Navarra; Juan M. Ramos Goñi, Servicio Canario de Salud, Spain; Iñigo Gorostiza, Basurto University Hospital – Osakidetza; Luis Rajmil, PhD, Agència d'Informació Avaluació i Qualitat en Salut (AIAQS), Spain; Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Spain; Montserrat Ferrer, MD PhD MPU, Institut Municipal d'Investigació Mèdica (IMIM), Spain

### (106.3) Evidence from four countries on the validity of the discrete choice model in quantifying health-states for the new EQ-5D-5L

Paul F.M. Krabbe, PhD, University of Groningen, Dept. of Epidemiology, Netherlands; Nancy Devlin, PhD, Office for Health Economics, United Kingdom; Elly Stolk, Erasmus University Rotterdam, Netherlands; Koonal Shah, Office of Health Economics; Mark Oppe, Erasmus University Rotterdam, Netherlands; Ben Van Hout, University of Sheffield; Simon Pickard, PhD, University of Illinois at Chicago, College of Pharmacy, United States; Feng Xie, MSc, National University of Singapore, Singapore

### (106.4) Australian algorithms for the EQ-5D-3L and EQ-5D-5L

Richard Norman, MSc, University of Technology, Sydney, Australia; Rosalie Viney, PhD, Centre for Health Economics Research & Evaluation, Australia; John E. Brazier, PhD, Univ of Sheffield, United Kingdom; Paula Cronin, University of Technology, Sydney, Australia; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; Julie Ratcliffe, University of Flinders; Deborah Street, University of Technology, Sydney, Australia

## Oral Session 107: Outcome Evaluation in Cancer

Clinical Practice Track

Session Chair: Madeleine T. King, PhD, Australia  
BUDAPEST BALLROOM – BUDA ROOM

### (107.1) Breast Reconstruction and Radiation: An analysis of quality of life and satisfaction among patients undergoing implant reconstruction

Claudia R. Albornoz, Memorial Sloan-Kettering Cancer Center, United States; Evan Matros, MD, Plastic Surgery Department, Memorial Sloan Kettering Cancer Center, United States; Andrea Pusic, MD MHS FRCSC, Memorial Sloan Kettering Cancer Ctr; Anne Klassen, D Phil, McMaster University, Canada; Stefan Cano, BSc PhD, Peninsula College of Medicine & Dentistry, United Kingdom; Colleen McCarthy, MD MS, Memorial Sloan Kettering Cancer Center; Joseph J. Disa, Memorial Sloan-Kettering Cancer Center; Babak J. Mehrara, Memorial Sloan Kettering Cancer Center; Peter Cordeiro, Memorial Sloan Kettering Cancer Center

### (107.2) Quality of Life And Satisfaction Among Prostate Cancer Patients Followed Through A Disease-Specific Survivorship Clinic

Scott Gilbert, University of Florida, Department of Urology; Rodney Dunn, MS, University of Michigan Dept of Urology; Daniela Wittmann, University of Michigan; Jeffrey S. Montgomery, University of Michigan; John M. Hollingsworth, University of Michigan, Department of Urology, United States; Brent Hollenbeck, MD MS, University of Michigan; John T. Wei, MD, University of Michigan, United States; James Montie, University of Michigan, United States

### (107.3) Spiritual Well-Being in Lung Cancer Survivors

Marlene H. Frost, PhD, Mayo Clinic; Paul J. Novotny, Mayo Clinic-Rochester, United States; Mary E. Johnson, Mayo Clinic; Matthew M. Clark, Mayo Clinic; Jeff Sloan, PhD, Mayo Clinic, United States; Ping Yang, Mayo Clinic, United States

### (107.4) Identifying and Characterizing Trajectories of QOL in Persons with Advanced Cancer: Important Contributors to decreasing QOL in People with Cancer

Ana Maria Rodriguez, MSc BSc PT, McGill University, Canada; Nancy E. Mayo, PhD, McGill University, Royal Victoria Hospital, Canada

## Oral Session 108: Psychosocial and Health Interventions

Comparative Effectiveness Research Track

Session Chair: Ivan Barofsky, PhD, United States  
CORSO ROOM

### (108.1) Efficacy of cognitive behavioral therapy and physical exercise in alleviating treatment-induced menopausal symptoms in women with breast cancer: Final results of a randomized controlled trial

Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Netherlands; Saskia F.A. Duijts, The Netherlands Cancer Institute/VU University Medical Center; Marc Van Beurden, The Netherlands Cancer Institute; Martijn M. Stuiver, The Netherlands Cancer Institute, Netherlands; Jacobien Kieffer, PhD, The Netherlands Cancer Institute, Department of Psychosocial Research, Netherlands; Myra S. Hunter, King's College London; Hester S.A. Oldenburg, The Netherlands Cancer Institute

### (108.2) Empowerment Partnership in Coping System (EPICS) Index: Measuring Treatment Impacts and Quality of Life in Chronic Illness

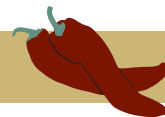
Joshua C. Gandi, RN RPN HND BSc MSc, University of Jos, Nigeria; Paul S. Wai, University of Jos, Nigeria

### (108.3) Quality of Life Outcomes of a Randomized Counseling Trial for Cervical Cancer Survivors

Lari Wenzel, PhD, University of California, Irvine; Kathryn Osann, Ph.D., University of California, Irvine, United States; Susie Hsieh, University of California, Irvine; Nissa Chantana, University of California, Irvine; Sandra Sappington, University of California, Irvine; Diana Marquez, University of California, Irvine; Edward Nelson, University of California, Irvine, United States

### (108.4) Effectiveness of a Patient Empowerment Programme for Chinese Patients with Diabetes Mellitus

Cindy L.K. Lam, MD, The University of Hong Kong, Peoples Republic of China; T.P. Elegance Lam, PhD, The University of Hong Kong, Hong Kong; William C. Wong, the University of Hong Kong



# Concurrent Oral Sessions

Thursday, 25 October, 4:00 pm – 5:30 pm

## Oral Session 109: Symptom Monitoring in Clinical Research and Practice

Clinical Practice Track

Session Chair: Roxanne E. Jensen, PhD, United States  
BUDAPEST BALLROOM – PEST ROOM

### (109.1) The Myotonic Dystrophy Type-1 Health Index (MDHI): A Reliable Outcome Measure for Clinical Trials and Patient Monitoring

Chad Heatwole, Rita Bode, Northwestern University; Jeanne Dekdebrun, The University of Rochester; Nuran Dilek, The University of Rochester; Nicholas Johnson, The University of Rochester; Elezabeth Luebhe, The University of Rochester; William Martens, The University of Rochester; Charles Thornton, The University of Rochester; Richard Moxley, III, The University of Rochester

### (109.2) Asking the right questions to get the right answers: Using cognitive interviews to review the acceptability, comprehension and clinical meaningfulness of patient self-report adverse event items in oncology patients

Patricia Holch, PhD, University Of Leeds, United Kingdom; Lorraine Warrington, University of Leeds; Lucy Ziegler, University of Leeds, United Kingdom; Ceri Hector, University of Leeds, United Kingdom; Ada Keding, University of Leeds, United Kingdom; Leon Bamforth, University of Leeds, United Kingdom; Clare Harley, PhD, University of Leeds, United Kingdom; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Ethan Basch, MD MSc, Memorial Sloan-Kettering Cancer Center; Galina Velikova, MD, University of Leeds, United Kingdom

### (109.3) Validity and utility of the M. D. Anderson Symptom Inventory (MDASI) among prostate cancer patients: Data from E2Z02: Symptom Outcomes and Practice Patterns (SOAPP)

Tito R. Mendoza, PhD, Univ. of Texas M.D. Anderson Cancer Ctr.; Fengmin Zhao, Dana-Farber Cancer Institute, Boston, MA; Linda J. Patrick-Miller, University of Chicago Center for Clinical Cancer Genetics, Chicago, IL; Charles S. Cleeland, PhD, UT-MD Anderson Cancer Center; Lynne I. Wagner, Northwestern University, Chicago, IL; Michael Fisch, University of Texas M.D. Anderson Cancer Center, Houston, TX, United States

### (109.4) Symptom Frequency, Severity and Interference Represent Non-Overlapping Attributes of Symptomatic Treatment Toxicity in Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Thomas Atkinson, Memorial Sloan-Kettering Cancer Center, United States; Amylou C. Dueck, PhD, Mayo Clinic, United States; Yuelin Li, PhD, Memorial Sloan-Kettering Cancer Ctr., United States; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Lauren Rogak, Memorial Sloan-Kettering Cancer Center; Laura Sit, George Mason University; Antonia V. Bennett, PhD, Memorial Sloan-Kettering Cancer Center; Tito R. Mendoza, PhD, Univ. of Texas M.D. Anderson Cancer Ctr.; Steven B. Clauser, PhD, National Cancer Institute; Ethan Basch, MD MSc, Memorial Sloan-Kettering Cancer Center, United States

### (109.5) Validation of the Distress Thermometer for Parents with a Chronically Ill Child

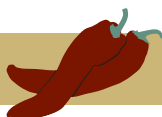
Lotte Haverman, MSc, Emma Children's Hospital - Academic Medical Centre, Netherlands; Hedy Van Oers, Emma Children's Hospital/Academic Medical Center; Perrine Limperg, Emma Children's Hospital/Academic Medical Center, Netherlands; Bregje Houtzager, MA, Pediatric Psych, Netherlands; Jaap Huisman, VU medical centre; Anne-Sophie Darlington, PhD, University of Southampton School of Medicine, United Kingdom; Heleen Maurice-Stam, MSc, Emma's Children's Hosp, Academic Medical Ctr, Netherlands; Martha Grootenhuis, PhD, Academic Medical Center, The Netherlands

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# Concurrent Oral Sessions

Friday, 26 October 2012, 10:45 am – 12:15 pm

## Oral Session 201: Health Outcome Evaluation and Development

*Methods and Theory Track*

Session Chair: Ana Maria Rodriguez, PhD c, MSc, BSc PT, Canada  
MARGIT ROOM

### (201.1) Patient reported outcome measures: Including people with low literacy skills and/or learning disabilities

Deepa Jahagirdar, Healthcare Improvement Scotland, United Kingdom; Thilo Kroll, University of Dundee; Karen Ritchie, Healthcare Improvement Scotland; Sally Wyke, University of Glasgow, United Kingdom

### (201.2) A New Measurement System to Evaluate Environmental Barriers and Facilitators to Community Participation

Jin-Shei Lai, PhD, Northwestern University; Allen W. Heinemann, Northwestern University, United States; Noelle Carozzi, University of Michigan; Sofia Garcia, PhD, Northwestern University; David Gray, Washington University; Elizabeth Hahn, MA, Northwestern University; Joy Hammel, University of Illinois; Susan Magasi, Northwestern University, United States; David Tulsky, PhD, University of Michigan; Patrick Semik, Rehabilitation Institute of Chicago, United States

### (201.3) Systematic evaluation of disease-specific health-related quality of life instruments for patients with shoulder pathology

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

### (201.4) Evaluation of a newly developed questionnaire to measure motivation for self-care among people living with type 2 diabetes (T2DM): The Motivation for Exercise and Diet Questionnaire (MED-Q)

Shana B. Traina, Janssen Global Services; Susan D. Mathias, MPH, Health Outcomes Solutions; Hilary H. Colwell, Health Outcomes Solutions; Ross Crosby, PhD, Neuropsychiatric Research Institute

### (201.5) Understanding meaning from measurement in movement disorder clinical trials: Rasch analysis of the Parkinson's Disease Dyskinesia Scale (PDYS-26)

Jennifer Petrillo, PhD, Novartis, United States

## Oral Session 202: Trials and Intervention Evaluation

*Comparative Effectiveness Research Track*

Session Chair: Galina Velikova BMBS(MD) PhD FRCP, United Kingdom

CORSO ROOM

### (202.1) Joint modeling of longitudinal health-related quality of life data and overall survival

Divine Ewane Ediebah, MSc, EORTC HQ, Belgium; Corneel Coens, MSc, EORTC HQ, Belgium; Efstathios Zikos, MSc, MA, EORTC HQ, Belgium; Chantal Quinten, MSc, EORTC, Belgium; Jolie Ringash, MD, The Princess Margaret Hospital, Canada; Carolyn C. Gotay, PhD, UBC School Pop & Pub Health, Canada; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; David Osoba, FRCPC, QOL Consulting, Canada; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; Henning H. Flechtner, PhD, Otto-von-Guericke University (KKJP), Germany; Martin Taphoorn, PhD, Medical Centre Haaglanden, Neurology, The Hague, The Netherlands; J. Schmucker von Koch, PhD, University of Regensburg, Medical Ethics, Regensburg, Germany; Joachim Weis, PhD, University of Freiburg, Psychooncology, Freiburg, Germany; Charles S. Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, United States; E.F. Smit, PhD, Free University Hospital, Dept. of Pulmonology, Amsterdam, the Netherlands; Andrew Bottomley, PhD, EORTC, Quality of Life, Brussels, Belgium on behalf of the Lung Cancer Cooperative Group, Quality of Life Department and Patient Reported Outcome and Behavioral Evidence (PROBE)

### (202.2) Is 'In-Trial' Quality of Life guidance lacking? A Systematic Review Employing Qualitative Content Analysis

Derek G. Kyte, MSc MACP MMACP, University of Birmingham, United Kingdom; Heather Draper, University of Birmingham; Jonathan Ives, University of Birmingham; Clive Liles, University of Birmingham, United Kingdom; Adrian Gheorghe, University of Birmingham; Melanie Calvert, PhD, The University of Birmingham, United Kingdom

### (202.3) Core outcome sets and the COMET (Core Outcome Measures in Effectiveness Trials) Initiative; improving the efficiency and value of the research process

Jane Blazeby, MD, University of Bristol, United Kingdom; Doug G. Altman, University of Oxford, United Kingdom; Mike Clarke, Queen's University Belfast; Elizabeth A. Gargon, University of Liverpool, United Kingdom; Paula R. Williamson, University of Liverpool, United Kingdom

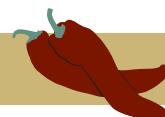
### (202.4) Patient satisfaction with participation, adverse events and hospitalizations in phase II/III NCCTG clinical trials: Was it worth it? (N0392)

Cynthia Chauhan, MSW, Mayo Clinic Breast SPORE; Jeff Sloan, PhD, Mayo Clinic, United States; Pamela Atherton, Mayo Clinic; Amylou C. Dueck, PhD, Mayo Clinic, United States

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# Concurrent Oral Sessions

Friday, 26 October 2012, 10:45 am – 12:15 pm

## Oral Session 203: Analysis and Interpretation of Outcomes

Methods and Theory Track

Session Chair: Bellinda L. King-Kallimanis, PhD, Ireland  
LÁNCHID ROOM

### (203.1) Matched health-related quality of life reference mean scores as a proxy for “true baseline” when assessing recovery

Mohammed A. Johar, B.Sc.(Hons), M.Sc., Karolinska Institutet, Sweden; Therese Djarv, MD PhD, Karolinska Institutet, Sweden; Pernilla Lagergren, PhD RN, Karolinska Institute, Dept. of Molecular Med, Sweden

### (203.2) Analysis of the Spanish PROMIS Pain Behavior Item Bank for Language Related DIF

Leo Morales, MD, Group Hlth Research Institute; Sylvia H. Paz, PhD, UCLA; Karen L. Spritzer, UCLA; Ronald D. Hays, PhD, UCLA  
David Geffen

### (203.3) Power and sample size determination for the group comparison of PROs in IRT: robustness of a method based on the Cramer-Rao bound

Myriam Blanchin, University of Nantes, France; Jean-Benoit Hardouin, PhD, University of Nantes - EA4275, France; Alice Guilleux, University of Nantes - EA 4275; Véronique Sébille, University of Nantes, France

### (203.4) Beyond age and gender adjustment when using Quality of Life reference data: a propensity score matching approach

Francesco Cottone, PhD, GIMEMA (Italian Group for Adult Hematologic Diseases), Italy; Gary Collins, PhD, Univ of Oxford, Ctr for Statistics in Med, United Kingdom; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Italy

## Oral Session 204: Mental Health and Patient Outcomes

Methods and Theory Track

Session Chair: Susan J. Bartlett, PhD, Canada  
BUDAPEST BALLROOM

### (204.1) Cognitive Reserve: An important emerging construct for quality-of-life research

Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., United States; Brian R. Quaranto, DeltaQuest Foundation; Ralph HB Benedict, Dept. Neurology, Jacobs Neurol. Instit., Univ. of Buffalo; Erin Snook, Department of Kinesiology, University of Massachusetts Amherst; Timothy Vollmer, Dept. Neurology, Univ. Colorado Denver, Rocky Mountain MS Ctr; Bruce D. Rapkin, PhD, Yeshiva University

### (204.2) The Challenge of Translating the Picture Naming Subtest of the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)

Elisabeth Rendu, MAPI Institute, France; Brian Harel, CogState; Athena Nomikos, Cogstate; Angela Caveney, University of Michigan; Catherine Acquadro, MD, MAPI Research Trust, France; Caroline Anfray, MAPI Institute, France

### (204.3) Trajectories and predictors of the course of mental health in persons with spinal cord injury

Christel M. Van Leeuwen, PhD, Center of Excellence for Rehabilitation Center De Hoogstraat; Trynke Hoekstra, VU University Medical Center Amsterdam; Casper F. Van Koppenhagen, Rehabilitation Center De Hoogstraat; Sonja De Groot, Reade, centre for rehabilitation and rheumatology; Marcel Post, PhD, Institute for Rehabilitation Research, Netherlands

### (204.4) The Effects of Stroke on Depression: A Functional Outcome of Patients with Ischemic Stroke

Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Hai Ying, Department of Neurology, Affiliated Hospital of Liaoning University of TCM, Peoples Republic of China; Yu Li, Department of Neurology, Affiliated Hospital of Liaoning University of TCM, Peoples Republic of China; Yu Xiu, department of neurology, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yuan Dongchao, department of neurology, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Qi Wencheng, department of neurology, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lu Yujuan; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China



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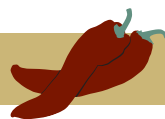
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If you are interested in learning more about this position, please send a letter or email of inquiry to David J. Vanness, Health Services and Outcomes Research Search Committee Chair, Department of Population Health Sciences, 610 Walnut Street, 785 WARF, Madison, WI 53726 ([dvanness@wisc.edu](mailto:dvanness@wisc.edu)).

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# Concurrent Oral Sessions

Friday, 26 October 2012, 4:30 pm – 6:00 pm

## Oral Session 205: Quality of Life Measure Development

Populations and Healthcare Policy Track

Session Chair: Cicely Kerr, MSc PhD, United Kingdom  
LÁNCHID ROOM

### (205.1) Testing the generalisability of the EORTC QLQ-C30 core questionnaire across primary cancer sites using multi-group confirmatory factor analysis

Daniel S. J. Costa, PhD, Psycho-oncology Co-operative Research Group (PoCoG), Australia; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Netherlands; Peter Fayers, PhD, Aberdeen Medical School, United Kingdom; Julie F. Pallant, PhD, School of Rural Health, Univ of Melbourne, Australia; Galina Velikova, MD, University of Leeds, United Kingdom; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; The MAUCa Consortium, Psycho-oncology Research Group

### (205.2) Metric properties of the Bladder Cancer Index proposed for patients with Bladder Cancer

Angels Pont, Hlth Svcs Research Unit, Spain; Yolanda Pardo, Institut de Recerca Hospital del Mar (IMIM); Stefanie Schmidt, IMIM (Hospital del Mar Medical Research Institute), Spain; Ricard Riel, Institut Català de la Salut; Montserrat Ferrer, MD PhD MPU, Institut Municipal d'Investigació Medica (IMIM), Spain

### (205.3) The WHOQOL-OLD Module: Psychometric Properties of the Turkish National Data Pool

Erhan Eser, MD, Celal Bayar University, School of Medicine, Dept. Public Health, Turkey; Sultan Eser, MOH, Izmir Cancer Registry, Turkey

### (205.4) Cross-cultural development of an EORTC measure to assess quality of life (QoL) in patients with chronic myeloid leukemia (CML)

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Italy; Massimo Breccia, Sapienza University, Rome, Italy; Susanne Saussele, Universität Heidelberg, Mannheim, Germany; Ute Kossak-Roth, Universität Heidelberg, Mannheim, Germany; Annarita Cardoni, Italy; Giovanni Caocci, University of Cagliari, Cagliari, Italy; Weichu Chie, National Taiwan University, Taipei, Taiwan; Adel Naeem, University of Baghdad, Baghdad, Iraq; Ourania Nicolatou-Galitis, University of Athens, Greece; Kim Cocks, University of York, York, UK; Marco Vignetti, Health Outcomes Research Unit, GIMEMA Data Center, Rome, Italy; Michele Baccarani, University of Bologna, Bologna, Italy; Franco Mandelli, Health Outcomes Research Unit, GIMEMA Data Center, Rome, Italy; Mirjam Sprangers, PhD, University of Amsterdam, Amsterdam, The Netherlands

## Oral Session 206: Patient Reported Outcomes in Clinical Practice

Clinical Practice Track

Session Chair: Tito R. Mendoza, PhD, United States  
BUDAPEST BALLROOM

### (206.1) Threshold for determining clinically relevant urinary incontinence using the Incontinence Symptom Index (ISI) in a population-based cohort

Anne M. Suskind, MD, University of Michigan, United States; Rodney Dunn, MS, University of Michigan Dept of Urology; Daniel M. Morgan, University of Michigan; John O. L. DeLancey, University of Michigan; John T. Wei, MD, University of Michigan, United States

### (206.2) Does feedback of patient-reported outcomes to healthcare professionals result in an improvement in patient outcomes? A systematic review and meta-analysis

Maria B. Boyce, MA, University College Cork, Ireland; John Browne, PhD, University College Cork, Ireland

### (206.3) A systematic review and narrative review of qualitative studies about the use of PROs in clinical practice

Daniela C. Gonçalves, University of Oxford, United Kingdom; Elizabeth J. Gibbons, MSc, University of Oxford, United Kingdom; Raymond Fitzpatrick, PhD, Univ of Oxford, Dept of Public Hlth, United Kingdom; Jose M. Valderas, MD PhD MPH, University of Oxford, United Kingdom

### (206.4) The Norwegian study in RENEWING HEALTH: Development, implementation and evaluation of an intervention with an electronic diabetes diary - the Few Touch Application (FTA) - with and without health counseling. A randomized controlled trial

Lis Ribu, PhD, Oslo and Akershus University College, Norway; Eirik Arsand, Norwegian Centre for Integrated Care and Telemedicine, Norway; Astrid Torbjornsen; Heidi Holmen; Astrid Grotland

## Oral Session 207: Outcome Measure Development

Methods and Theory Track

Session Chair: Sharon Wood-Dauphinee, PhD, Canada  
MARGIT ROOM

### (207.1) The development of an EORTC Communication questionnaire: first steps

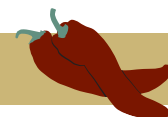
Juan Ignacio Arraras, PhD, Spain; Karin Kuljanic Vlastic, University Hospital Center Rijeka, Croatia; Monika J. Sztankay, Innsbruck Medical University, Austria; Lisa M. Wintner, Department of Psychiatry and Psychotherapy, Innsbruck Medical University, Austria; Anna Costantini, Sant'Andrea Hospital, Sapienza University of Rome, Italy; Wei-Chu Chie, PhD, Inst of Epidemiology and Preventive Medicine, Nat'l Taiwan Univ, Taiwan; Astrid Helene Liavaag, Sorlandets Sykehus, Norway; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; Anne Bredart, PhD, Institut Curie, France; Maria Arnott, EORTC

### (207.2) Assessing validity without a conceptual model? The Neck Disability Index as an example

Luc Ailliet, VU Medical Center, Department of Epidemiology and Biostatistics; Sidney M. Rubinstein, VU Medical Center, Department of Epidemiology and Biostatistics; Dirk L. Knol, Department of Epidemiology and Biostatistics, VU University Medical Center; Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center, Netherlands; Maurits W. Van Tulder, Department of Health Sciences, Faculty of Earth and Life Sciences, VU University; Caroline B. Terwee, PhD, VU University Medical Center, Department of Epidemiology and Biostatistics, The Netherlands

### (207.3) Development and Evaluation of Environmental Factor Candidate Items for Persons with Stroke, Traumatic Brain Injury and Spinal Cord Injury

Allen W. Heinemann, Northwestern University, United States; Jin-Shei Lai, PhD, Northwestern University; Noelle Carlozzi, University of Michigan; Joy Hammel, University of Illinois; Sofia Garcia, PhD, Northwestern University; David Gray, Washington University; Elizabeth Hahn, MA, Northwestern University; Susan Magasi, Northwestern University, United States; David Tulsy, PhD, University of Michigan; Allan Kozlowski, Rehabilitation Institute of Chicago, United States





# Concurrent Oral Sessions

**Friday, 26 October 2012, 4:30 pm – 6:00 pm**

## **(207.4) Comparing transition and static measures of Patient enablement instruments (PEI)**

Wong Wendy, PhD, *The University of Hong Kong, Hong Kong*; Cindy L.K. Lam, MD, *The University of Hong Kong, Peoples Republic of China*

## **(207.5) Evaluation of a More Comprehensive Survey Item Bank for Standardizing Disease-Specific Impact Comparisons across Chronic Conditions**

John E. Ware, Jr., PhD, *Univ of MA Medical School*; Rick Guyer, JWRC Incorporated; Magdalena Harrington, JWRC Incorporated; Mikel Strom, JWRC Incorporated; Rosemarie Boulanger, JWRC Incorporated

## **Oral Session 208: Health Outcomes in Children**

*Populations and Healthcare Policy Track*

Session Chair: Anne Riley, PhD, United States

CORSO ROOM

## **(208.1) Identification of Subjective Adverse Event Terms to Inform the Development of a Child Self-Report Measure for use in Oncology Trials**

Bryce B. Reeve, PhD, *University of North Carolina at Chapel Hill, United States*; Jessica C. Lyons, MS, *University of North Carolina at Chapel Hill*; Catriona Mowbray, PhD BSN RN CPN, *Children's National Medical Center*; Justin Baker, *St. Jude Children's Research Hospital*; David Freyer, *Children's Hospital Los Angeles*; Stuart Gold, *University of North Carolina at Chapel Hill School of Medicine*; Mary C. Hooke, PhD RN PCNS CPON, *University of Minnesota School of Nursing*; Steven Joffe, MD MPH, *Dana-Farber Cancer Institute/Boston Children's Hospital*; Janice Withycombe, *Palmetto Health Children's Hospital*; Pamela Hinds, PhD RN FAAN, *Children's National Medical Center*

## **(208.2) Content Comparison of the Qualitative Data Informing the CLEFT-Q to Generic Instruments (Peds-QL 4.0, CHQ, KINDL) using the ICF-CY Classification**

Karen W.Y. Wong, MD MSc FRCSC, *Hospital for Sick Children, Canada*; Nora Fayed, *University Health Network, Canada*; Christopher R. Forrest, MD, *The Hospital For Sick Children, Canada*; Tim Goodacre, *Oxford Radcliffe Hospitals, Oxford, UK*; Andrea Pusic, MD MHS FRCSC, *Memorial Sloan Kettering Cancer Ctr; Arun Gosain, Rainbow Babies and Children's Hospital, Cleveland, USA*; Olaf Kraus de Camargo, *McMaster University*; Stefan Cano, BSc PhD, *Peninsula College of Medicine & Dentistry, United Kingdom*; Anne Klassen, PhD, *McMaster University, Canada*

## **(208.3) Simultaneous cross-cultural development of a condition-specific instrument to assess quality of life (QOL) in short stature youth**

Monika Bullinger, PhD, *Inst for Medical Psychology, Hamburg Univ, Germany*; Julia Hannah Quitmann, *University Medical Center Hamburg-Eppendorf, Germany*; Michael Power, PhD, *Edinburgh University, United Kingdom*; John E. Chaplin, PhD AFBPS, *University of Gothenburg*; Emmanuelle Mimoun, *University of Toulouse*; Michael Herdmann, *IMIM University, Insight Consulting and Research*; Hartmut Wollmann, *Pfizer Ltd.*; Andreas Pleil, PhD, *Pfizer, Inc.*

## **(208.4) A Life Course Approach to Measurement of Global Health**

Christopher B. Forrest, MD PhD, *University of Pennsylvania, School of Medicine, United States*; Katherine Bevans, PhD, *Children's Hospital of Philadelphia*; Ramya Pratiwadi, *Children's Hospital of Philadelphia*; JeanHee Moon, *Children's Hospital of Philadelphia*; Jin-Shei Lai, PhD, *Northwestern University*; Carole A. Tucker, PhD, *Temple University*

**Saturday, 27 October 2012, 10:45 am – 12:15 pm**

## **Oral Session 301: Outcome Measure Development**

*Methods and Theory Track*

Session Chair: Bryce B. Reeve, PhD, United States

MARGIT ROOM

## **(301.1) Numeracy and Valuations in Quality of Life Assessment (QOLA)**

Ivan Barofsky, PhD, *The Quality of Life Institute, United States*

## **(301.2) A systematic review of the use and validation of health-related quality of life instruments in patients with cancer cachexia**

Sally J. Wheelwright, *University of Southampton, United Kingdom*; Anne-Sophie Darlington, PhD, *University of Southampton School of Medicine, United Kingdom*; Jane B. Hopkinson, *University of Cardiff*; Deborah Fitzsimmons, *Swansea University, United Kingdom*; Alice White, *University of Southampton*; Colin Johnson, MChir, *Dept of Surgery, United Kingdom*

## **(301.3) International validation of the WHOQOL-SRPB: a study of older adults**

Suzanne Skevington, PhD, *University of Bath, United Kingdom*; Juliana Moratelli, *United Kingdom*; Laura Smith, *University of Bath*; Ramona Lucas, PhD MD MPH, *University of Barcelona, Psychology School, Spain*; Marcelo P. Fleck, PhD, *Hospital de Clinicas de Porto Alegre, Brazil*; Tal Narkiss, *Ben-Gurion University of the Negev*; Laura Schwartzmann, MD, *Interdisciplinary Ctr of Childhood & Poverty, Uruguay*

## **(301.4) Qualitative Development of the PROMIS® Pediatric Subjective Well-Being (SWB) Item Banks**

Janine Devine, *University Medical Center Hamburg-Eppendorf, Germany*; Katherine Bevans, PhD, *Children's Hospital of Philadelphia*; Anne Riley, *Johns Hopkins University, United States*; JeanHee Moon, *Children's Hospital of Philadelphia*; John M. Salsman, PhD, *Northwestern University*; Christopher B. Forrest, MD PhD, *University of Pennsylvania, School of Medicine, United States*; Ulrike Ravens-Sieberer, *University Medical Center of Hamburg, Germany*

## **Oral Session 302: Personalized Medicine**

*Clinical Practice Track*

Session Chair: Cynthia Gross, PhD, United States

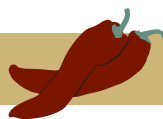
LANCHID ROOM

## **(302.1) Are Condition-Specific Measures Necessary to the Practice of Personalized Medicine?**

San Keller, PhD, *American Institutes for Research*; Manshu Yang, *American Institutes for Research*; Christian Evensen, *American Institutes for Research*; Marsha Treadwell, *Children's Hospital and Research Center at Oakland*

## **(302.2) Relationship between genetic markers and quality of life (QOL) in stage III colon cancer (CC) patients (pts) prior to adjuvant treatment (N0147).**

Jeff Sloan, PhD, *Mayo Clinic, United States*; Qian Shi, *Mayo Clinic*; Adam Lee, *Mayo Clinic*; Robert Diasio, *Mayo Clinic*; Emily Pavay, *Mayo Clinic*; Dan Sargent, *Mayo Clinic*; Richard Goldberg, *Ohio State*; Michelle Mahoney, *Mayo Clinic*; Steven Alberts, *Mayo Clinic*





# Concurrent Oral Sessions

Saturday, 27 October 2012, 10:45 am – 12:15 pm

## (302.3) Screening for psychosocial problems in onco-genetics: Development and evaluation of a screening checklist

Willem Eijzenga, MSc, NKI/AVL; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Netherlands; Daniela E.E. Hahn, NKI-AVL; Irma Kluijft, Amsterdam Medical Center, Netherlands; Margreet G.E.M. Ausems, University Medical Center Utrecht; Grace N. Sidharta, NKI-AVL; Eveline M.A. Bleiker, NKI-AVL

## (302.4) Concept Relevance for Components of the ENSEMBLE MDS 1.0 Questionnaire Battery

Mona L. Martin, RN MPA, Health Research Associates, Inc.; Kelly McCarrier, PhD MPH, Health Research Associates, Inc.; Michael Scanlon, Health Research Associates, Inc; Matthew Wolfe, Health Research Associates, Inc.; Rosirene Paczkowski, Eli Lilly and Company, United States; Don P. Buesching, PhD, Eli Lilly & Company

## Oral Session 303: Response Shift

Methods and Theory Track

Session Chair:

CORSO ROOM

### (303.1) Impact of Response Shift on time to quality of life scores deterioration in breast cancer patients: is it time to move for QoL RECIST criterion?

Zeinab Hamidou, Centre Georges Francois Leclerc, France; Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges Francois Leclerc, France; Francis Guillemin, MD, PhD, Ecole de sante publique - Lorraine University, France; Thierry Conroy, Centre Alexis Vautrin, France; Michel Velten, Epidemiology and public health laboratory, College of Medicine, Strasbourg, France; Damien Jolly, University Hospital of Reims; Sylvain Causeret, Centre Georges François Leclerc; Jean Cuisenier, Centre Georges François Leclerc; Mariette Mercier, Cellular and molecular biology laboratory, University Hospital of Besançon; Franck Bonnetain, PhD, Centre Georges Francois Leclerc, France

### (303.2) Understanding response shift in multiple sclerosis patients: application of Random Forest method

Mohamed Boucekine, Self-perceived Health Assessment Research Unit, France; Anderson Loundou, EA3279, Self-perceived Health Assessment Research Unit, Marseille, France; Rima L'Mouaci, Timone University Hospital, France; Patricia Minaya Flores, MA, Laboratoire de Sante Publique EA3279, France; Helmut Butzkueven, MS Unit, Melbourne, Victoria, Australia; Karine Baumstarck, France; Badih Ghattas, Département de Mathématiques, Faculté des Sciences de Luminy, Marseille, France; Pascal Auquier, PhD, Laboratoire de Sante Publique, France

### (303.3) Assessing the Measurement Invariance of Quality of Life Across Age and Aging Perceptions: a MIMIC Modeling Approach

Bellinda L. King-Kallimanis, PhD, TILDA, Trinity College Dublin, Ireland; Roxanne E. Jensen, PhD, Georgetown University; George Savva, Trinity College Dublin, Ireland; Rose Anne Kenny, Trinity College Dublin, Ireland

### (303.4) Identifying individuals with inflammatory bowel disease who experienced response shift: A latent class analysis

Richard Sawatzky, PhD RN, Trinity Western University, Canada; Anne M. Gadermann, PhD, University of British Columbia, Canada; Pamela A. Ratner, PhD RN FCAHS, University of British Columbia, School of Nursing, Canada; Bruno Zumbo, University of British Columbia, Canada; Lisa M. Lix, PhD, School of Public Health, University of Saskatchewan, Canada

### (303.5) Examining response shift and true change in self-reported physical and mental health status in homeless and vulnerably housed individuals

Anne M. Gadermann, PhD, University of British Columbia, Canada; Richard Sawatzky, PhD RN, Trinity Western University, Canada; Anita Palepu, University of British Columbia; Anita Hubley, University of British Columbia, Canada; Bruno Zumbo, University of British Columbia, Canada; Tim Aubry, University of Ottawa, Canada; Stephen Hwang, MD MPH, St. Michael's Hospital, Canada

## Oral Session 304: Health Outcomes in Children

Methods and Theory Track

Session Chair: Christopher B. Forrest, MD, PhD, United States  
BUDAPEST BALLROOM

### (304.1) Weight Status, Quality of life and Cigarette Smoking among Adolescents in Washington State

Hongmei Wang, PhD, Social Medicine and Family Medicine, Zhejiang University, China, United States; Janice F. Bell, Department of Health Services, University of Washington; Todd C. Edwards, PhD, University of Washington, United States; Yi Huang, Department of Health Services, University of Washington; Donald Patrick, PhD MSPH, Seattle Quality of Life Group

### (304.2) Comprehensive assessment of Health-related quality of life measures amongst Hungarian children and adolescents living with cancer, diabetes or juvenile rheumatoid arthritis

Dalma Hosszú, PhD Candidate, University of Pécs Institute of Psychology; Bátor Tábor Foundation, Hungary; Szabolcs Török, Semmelweis University, Institute of Mental Health, Budapest, Hungary; Gyöngyi Kökönyei, Eötvös Loránd University, Faculty of Education and Psychology, Budapest, Hungary; Andrea Békési, Bátor Tábor Foundation, Budapest, Hungary, Hungary; KIDSCREEN Group, University Clinic Hamburg-Eppendorf, Hamburg, Germany

### (304.3) Trajectories of overweight and indicators of health-related quality of life and well-being in 5-7 year old children; the 'Be active, eat right' study

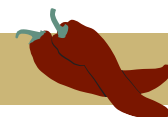
Hein Raat, MD, PhD, MBA, Erasmus MC - Univ Medical Ctr Rotterdam, Netherlands; Amy Van Grieken, MSc, University Medical Center Rotterdam, Netherlands

### (304.4) Linking child and adolescent quality of life scales in youth with epilepsy

Nora Fayed, University Health Network, Canada; David Streiner, Baycrest; Gabriel Ronen, McMaster University; Aileen M. Davis, PhD, Toronto Western Research Institute and University of Toronto, Toronto, Canada, Canada

### (304.5) The relationships between pediatric asthma control, excessive daytime sleepiness, and health-related quality of life

I-Chan Huang, PhD, University of Florida; Zheng Li, University of Florida, United States; Lindsay Thompson, University of Florida; Sanjeev Tuli, University of Florida; Dennis Revicki, PhD, United BioSource Corporation; Elizabeth Shenkman, PhD, Univ of Florida College of Medicine



# Concurrent Oral Sessions

Saturday, 27 October 2012, 4:15 pm – 5:45 pm

## Oral Session 305: Symptom Monitoring in Clinical Research and Practice

Methods and Theory Track

Session Chair: Nancy E. Mayo, PhD, Canada  
BUDAPEST BALLROOM – BUDA ROOM

### (305.1) The psychometric development of multiple asthma quality of life item banks

Brian D. Stucky, RAND Corporation, United States; Cathy Sherbourne, PhD, The RAND Corporation; Maria Orlando Edelen, PhD, RAND Corp.; Nicole K. Eberhart, RAND Corporation; Marielena Lara-Greenberg, RAND Corporation

### (305.2) Minimally Important Difference (MID) in Scores on the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 15 for Palliative (QLQ-C15-PAL)

Kikuko Miyazaki, PhD, Schl of Pblc Hlth - Kyoto University, Japan; Yoshimi Suzukamo, PhD, Tohoku Univ, Dept of Physical Med & Rehab, Japan; Kojiro Shimoizuma, Dept. of Biomedical Sciences, College of Life Sciences, Ritsumeikan University, Japan; Shozo Ohsumi, National Hospital Organization Shikoku Cancer Center, Japan; Mari Saito, Yokohama City University Medical Center; Takeo Nakayama, MD PhD, Kyoto University School of Public Health, Japan

### (305.3) PROMIS Version 2 pain quality item bank discriminates between neuropathic and other types of pain

Dagmar Amtmann, PhD, University of Washington; Cindy Nowinski, MD PhD, Northwestern University; David Cella, PhD, Northwestern University; Rana Salem, University of Washington; Dennis Revicki, PhD, United BioSource Corporation; Fred Wolfe, National Data Bank for Rheumatic Diseases; Kaleb Michaud, National Data Bank for Rheumatic Diseases; Robert L. Askew, BA, UT - M.D. Anderson Cancer Center

### (305.4) Assessing the Association of Cancer-Related Fatigue Thresholds on the Piper Fatigue Scale-12 with Sexual Functioning in a Population-Based Cohort of Breast Cancer Survivors: A HEAL Study

Angela M. Stover, University of North Carolina - Chapel Hill, United States; Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, United States; Barbara Piper, University of Arizona; Catherine M. Alfano, National Cancer Institute; Ashley Wilder Smith, PhD, National Cancer Institute; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Leslie Bernstein, City of Hope National Medical Center; Katherine B. Baumgartner, University of Louisville; Anne McTiernan, Fred Hutchinson Cancer Research Center; Rachel Ballard-Barbash, National Cancer Institute

## Oral Session 306: Caregiver Quality of Life and Health Evaluation

Clinical Practice Track

Session Chair: Carol M. Moinpour, PhD, United States  
MARGIT ROOM

### (306.1) Experienced burden of informal care among caregivers in the Netherlands

Renske Hoefman, Erasmus University Rotterdam; Job Van Exel, Erasmus University Rotterdam, Netherlands; Werner Brouwer, Erasmus University Rotterdam

### (306.2) Quality of Life Among Parents of Children with Autism Spectrum Disorders: A Comparison of Generic Instruments

Nalin Payakachat, BPharm MS PhD, Univ of Arkansas for Med Sci; Renske Hoefman, Erasmus University Rotterdam; Erica Kovacs, Columbia University Medical Center Division of Child and Adolescent Psychiatry; Job Van Exel, Erasmus University Rotterdam, Netherlands; Jeffery M. Pyne, University of Arkansas for Medical Science College of Medicine; Karen A. Kuhlthau, PhD, Center for Child and Adolescent Health Policy; John Tilford, Univ of Arkansas for Medical Sciences; Werner Brouwer, Erasmus University Rotterdam

### (306.3) Health status of informal caregivers of cancer and prostate cancer patients in Europe

Amir Goren, PhD, Kantar Health, United States; Isabelle Gilloteau, Bristol-Myers Squibb, United States; Ave Mori, Bristol-Myers Squibb; Marco DiBonaventura, Kantar Health

### (306.5) Detecting Response Shift in a Longitudinal Study of Stroke Caregivers

Lisa M. Lix, PhD, School of Public Health, University of Saskatchewan, Canada; Tolulope T. Sajobi, PhD, University of Saskatchewan, Canada; Richard Sawatzky, PhD RN, Trinity Western University, Canada; Juxin Liu, University of Saskatchewan, Canada; Nancy E. Mayo, PhD, McGill University, Royal Victoria Hospital, Canada

## Oral Session 307: Psychometric Approaches

Methods and Theory Track

Session Chair: Mogens Groenvold, MD, PhD, Denmark  
LÄNCHID ROOM

### (307.1) Spatio-temporal Rasch analysis of quality of life outcomes in the French general population. Measurement invariance and group comparisons

Jean-Benoit Hardouin, PhD, University of Nantes - EA4275, France; Etienne Audureau, Assistance Publique-Hôpitaux de Paris, Université Paris-Descartes, France; Alain Leplège, University of Paris Diderot, France; Joël Coste, Assistance Publique-Hôpitaux de Paris, Université Paris-Descartes, France

### (307.2) The Evaluation of the Patient Rated Elbow Evaluation using Rasch analysis

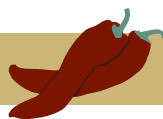
Joshua I. Vincent, MPT, The University of Western Ontario, Canada; Joy MacDermid, PhD, McMaster University, Canada; Ruby Grewal, University of Western Ontario, Canada

### (307.3) Is Rasch Model Analysis Applicable in Small Sample Pilot Studies for Assessing Preliminary Item Characteristics: An Example Using Data from PROMIS Pain Behavior Item Bank

Wen-Hung Chen, PhD, United BioSource Corporation; William Lenderking, PhD, United BioSource Corporation; Ying Jin, United BioSource Corporation; Dennis Revicki, PhD, United BioSource Corporation, United States

### (307.4) Rasch Measurement: A Mixed Methods Approach for Assessing Content Validity

Stacie Hudgens, MA, Adelphi Values; Patrick Marquis, MD, MAPI Values



# Concurrent Oral Sessions

Saturday, 27 October 2012, 4:15 pm – 5:45 pm

## Oral Session 308: Mental Health Evaluation

Populations and Healthcare Policy Track

Session Chair: David T. Eton, PhD, United States

CORSO ROOM

### (308.1) Mindfulness: A Systematic Review of Measures of an Emergent PRO

Tachwan Park, University of Minnesota; Maryanne Reilly-Spong, University of Minnesota; Cynthia Gross, PhD, Univ of MN, Pharmacy & Nursing, United States

### (308.2) How is depression valued when it co-occurs with a somatic condition? Pilot study using in depth interviews

Katerina Papageorgiou, MSc, University Medical Center Groningen, Netherlands; Karin Vermeulen, PhD, University Medical Center Groningen, Netherlands; Maya J. Schroevers, University Medical Center Groningen; Fenna RM Leijten, Rotterdam Erasmus Medical Center, Netherlands; Erik Buskens, University Medical Center Groningen; Adelita V. Ranchor, University Medical Center Groningen, The Netherlands

### (308.3) Screening accuracy of the Center for Epidemiologic Studies Depression Scale (CES-D): A systematic review with meta-analysis

Gemma Vilagut, MSc, Institut Municipal d'Investigació Mèdica, Spain; Carlos G. Forero, PhD, IMIM, Spain; Gabriela Barbaglia, IMIM-Research Institute Hospital del Mar; Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Spain

### (308.4) An IRT mixture model to correct prevalence bias from censored binary indicators: Application to lifetime mental health comorbidity in the ESEMeD surveys

Carlos G. Forero, PhD, IMIM, Spain; Josue Almansa, Utrecht University; Gemma Vilagut, MSc, Institut Municipal d'Investigació Mèdica, Spain; Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Spain

## Oral Session 309: Psychometric Approaches

Methods and Theory Track

Session Chair: Richard Sawatzky, PhD RN, Canada

BUDAPEST BALLROOM – PEST ROOM

### (309.1) Empirical evaluation of multivariate meta-analysis for multiple outcomes of QOL measurement using simulated data

Kazuo Yamaoka, PhD, Teikyo University, Graduate School of Public Health, Japan; Toshiro Tango, Center for Medical Statistics, Japan;

### (309.2) Does the choice of the minimal important difference for individual subjects affect the clinically relevant difference at the group level?

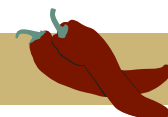
Georg Kemmler, PhD, Innsbruck Medical University, Austria; Johannes M. Giesinger, PhD, Innsbruck Medical University, Austria; Monika J. Sztankay, Innsbruck Medical University, Austria; Lisa M. Wintner, Department of Psychiatry and Psychotherapy, Innsbruck Medical University, Austria; Bernhard Holzner, PhD BE, Univ. Hospital, Innsbruck, Austria

### (309.3) Analysis of longitudinal Patient-Reported Outcomes with intermittent missing data (informative and non informative): comparison of score and Rasch-based methods

Elodie De Bock, Université de Nantes, France; Jean-Benoit Hardouin, PhD, University of Nantes - EA4275, France; Myriam Blanchin, University of Nantes, France; Tanguy Le Néel, Nantes University, France; Gildas Kubis, Nantes University; Etienne Dantan, Nantes University; Véronique Sébille, University of Nantes, France

### (309.4) Development and testing of standards for individualization of Patient Reported Outcome (PRO) measures using EMPRO

Jose M. Valderas, MD PhD MPH, University of Oxford, United Kingdom; Montserrat Ferrer, MD PhD MPU, Institut Municipal d'Investigació Mèdica (IMIM), Spain; Joan Mendivil, Bayer Healthcare; Olatz Garin, MPH, IMIM-Hospital del Mar Research Institute, Spain; Luis Rajmil, PhD, Agència d'Informació Avaluació i Qualitat en Salut (AIAQS), Spain; Michael Herdmann, IMIM University, Insight Consulting and Research; Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Spain; Daniela C. Gonçalves, University of Oxford, United Kingdom





# Concurrent Symposia Sessions

**Saturday, 27 October, 1:45 pm – 3:15 pm**

## **(Symposium 1) Implementing Patient-Reported Outcomes in Clinical Practice: An Expert Panel Discussion of Current Knowledge and Unanswered Questions** BUDAPEST BALLROOM – BUDA ROOM

*Claire F. Snyder, PhD, Johns Hopkins School of Medicine, Baltimore, MD, United States; Neil K. Aaronson, PhD, The Netherlands Cancer Institute & University of Amsterdam, Amsterdam, The Netherlands; Thomas E. Elliott, MD, Essentia Institute of Rural Health, Essentia Health, Duluth, Minnesota, United States; Joanne Greenhalgh, PhD, School of Sociology and Social Policy, University of Leeds, Leeds, United Kingdom; Michele Halyard, MD, Radiation Oncology, Mayo Clinic, Scottsdale, AZ, United States; Rachel Hess, MD, MS, Center for Research on Health Care, University of Pittsburgh, Pittsburgh, PA, United States; Deborah M. Miller, PhD, Mellen Neurology, Cleveland Clinic, Cleveland, OH, United States; Bryce B. Reeve, PhD, Lineberger Comprehensive Cancer Care & Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Maria-Jose Santana, PhD, University of Calgary, Calgary, AB, Canada*

To assist researchers and clinicians interested in using PROs in clinical practice, a working group of 10 experts developed a User's Guide. This User's Guide covers the goals and challenges of implementing PROs in clinical practice; determining the who, where, and when for PRO administration; identifying the methods and modes of administering PRO questionnaires; developing processes for reporting the results; providing information to support interpretation and actions in response to the PRO results; and evaluating the impact of the PRO intervention on the practice. A unifying framework was employed across all sections of the User's Guide, with each section addressing (1) options for consideration, (2) resources required for each option, and (3) each option's relative advantages and disadvantages. During this panel discussion, the User's Guide authors will highlight the key considerations regarding each of the issues described above. Half the time will focus on interactive discussion, both among the panel members and between the panel and the audience. At the end of the session, attendees will have a clear understanding of the steps involved in implementing PROs in clinical practice, options for designing each step, the trade-offs among the options, and the key issues in the field requiring additional study.

## **(Symposium 2) Are Generic Preference-Based Measures Valid in Mental Health? A Mixed Methods Enquiry** BUDAPEST BALLROOM – PEST ROOM

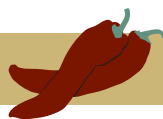
*John Brazier, PhD, School of Health and Related Research, University of Sheffield, Sheffield, United Kingdom; Brendan Mulhern, MRes, School of Health and Related Research, University of Sheffield, Sheffield, United Kingdom; Jordi Alonso, PhD, Health Services Research Unit, IMIM-Institut de Recerca Hospital del Mar, Barcelona, Spain, and CIBER en Epidemiología u Salud Pública (CIBERESP), Barcelona, Spain; Janice Connell, BSc (Hons), School of Health and Related Research, University of Sheffield, Sheffield, United Kingdom; Dianna Papaioannou, MSc, School of Health and Related Research, University of Sheffield, Sheffield, United Kingdom; Gemma Vilagut, BSc (Hon), Health services Research Unit, IMIM-Institut de Recerca Hospital del Mar, Barcelona, Spain, and CIBER en Epidemiología u Salud Pública (CIBERESP), Barcelona, Spain*

The last decade has seen increasing use of generic preference-based measures such as EQ-5D and SF-6D. It is claimed that these are applicable to all patient groups, and this has support in many physical conditions. However research in mental health is more limited. This symposium describes four studies from a programme of mixed methods work to examine the validity of EQ-5D and SF-6D in mental health. The first is the European survey of mental health which investigates how these instruments describe the impact of mental health. The second is a systematic review investigating the psychometric performance of the measures across five conditions. The next session describes new psychometric analyses using seven data sets. This is followed by a report on qualitative evidence from mental health service users on how their condition impacts their quality of life. The final session brings together this evidence to address the validity of these measures in mental health. It concludes that these measures may be valid for use in mood disorders, but evidence suggests they are not suitable in psychosis. There may also be a place for a new generic measure focused on health related quality of life in people with mental health problems.

## **(Symposium 3) Response Shift Detection in Secondary Data Analysis: Findings and Implementation Guidelines** MARGIT ROOM

*Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, MA, United States; and Tufts University School of Medicine, Boston, MA, United States; Joel Finkelstein, MSc MD FRCS(C), Division of Orthopaedics, Sunnybrook Health Sciences Center and The University of Toronto, Toronto, Ontario Canada; Nancy E. Mayo, BSc(PT) MSc PhD, Department of Medicine, School of Physical and Occupational Therapy McGill University Division of Clinical Epidemiology Division of Geriatrics McGill University Health Center; Sara Ahmed, PhD, Faculty of Medicine, School of Physical Therapy, McGill University, Montreal, Quebec, Canada; Tolulope T. Sajobi, PhD, School of Public Health, University of Saskatchewan, Saskatoon, Saskatchewan, Canada*

Response shift studies often draw on existing data sources and implement secondary data analysis. This symposium will discuss the theoretical and methodological challenges facing secondary analyses. Drawing from work done in spinal surgery patients, primary care patients, and post-stroke caregivers, we will discuss key findings from studies using the then-test, trajectory analysis, structural equation modeling, and relative importance methods. We will discuss the impact of missing data on response shift detection, and provide a guidelines checklist for the optimal implementation of secondary analysis.



# Concurrent Symposia Sessions

**Saturday, 27 October, 1:45 pm – 3:15 pm**

**(Symposium 4) Patient-centered Approach to Adverse Event Reporting: the US National Cancer Institute's Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE; HHSN261201000043C and HHSN261201000063C)**  
LÁNCHID ROOM

*Sandra A. Mitchell, PhD CRNP; Outcomes Research Branch, National Cancer Institute, Bethesda, MD, United States; Amylou C. Dueck, PhD; Mayo Clinic, Scottsdale, AZ, United States; Galina Velikova, MD PhD; University of Leeds, St. James Institute of Oncology, Leeds, United Kingdom; Deepa Lalla, BPharm PhD; Health Outcomes, Genentech Inc., South San Francisco, CA, United States; Ethan Basch, MD; Memorial Sloan-Kettering Cancer Center, New York, NY, United States*

The US National Cancer Institute's Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) is an item bank of adverse symptom items for patient self-reporting in NCI-sponsored clinical trials. Items can be administered to patients using an online software system or an interactive voice response system. The items are intended to be complementary to the NCI's CTCAE, a lexicon of clinician-reported adverse event items required for use in all NCI-sponsored trials. This symposium will summarize the context for development of the PRO-CTCAE and describe current and potential future uses of PRO-CTCAE within the US and internationally. Specifically, this symposium will provide an overview of the PRO-CTCAE measurement system and will describe the development and psychometric testing of PRO-CTCAE items. The symposium will also illustrate a collaboration with partners in the pharmaceutical industry who are using the PRO-CTCAE, as well as highlight an ongoing effort in the UK to integrate patient self-reporting of adverse events using PRO-CTCAE and other descriptive items into routine cancer care. Lastly, this symposium will describe the use of PRO-CTCAE in clinical research, regulatory decision-making, and policy in the US.

**(Symposium 5) Conceptual and Methodological Advances and Research Priorities for Child HRQOL**  
CORSO ROOM

*Organizer and Corresponding Author: Anne W. Riley, PhD, Department of Population, Family & Reproductive Health, Johns Hopkins University Bloomberg School of Public Health, Baltimore, MD, United States*

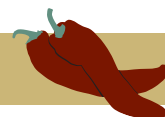
*Moderator and Discussant: Christopher B. Forrest, MD PhD, Department of General Pediatrics, Children's Hospital of Philadelphia, University of Pennsylvania, Philadelphia, PA, United States*

*Presenters: Katherine B. Bevans, PhD, Department of General Pediatrics, Children's Hospital of Philadelphia and University of Pennsylvania, United States; Samantha J. Anthony PhD MSW RSW, McMaster University, Hamilton, Ontario, Canada; Christiane Otto, University Medical Center Hamburg-Eppendorf, Department of Child and Adolescent Psychiatry, Hamburg, Germany; Anne W. Riley, PhD, Department of Population, Family & Reproductive Health, Johns Hopkins University Bloomberg School of Public Health, Baltimore, MD, United States*

This symposium is designed to characterize cutting edge research being conducted in the area of child and adolescent HRQOL and to report on an international Delphi process to identify the research priorities in child HRQOL. Four papers will be presented from an international group of researchers. Dr. Bevans will present on a newly developed mixed-method (qualitative-quantitative-qualitative) approach that will be illustrated using examples derived from the development and validation of 10 pediatric Patient Reported Outcome Measurement Information System (PROMIS) item banks. Dr. Anthony will report on a large qualitative study of children with cancer and child cancer survivors about their conceptualization of health. She will highlight where their concepts overlap with classic aspects of health assessed in HRQOL tools, as well as what is not captured by these instruments, including positive transformation experiences such as an enhanced sense of self, altered priorities and appreciation for life. Dr. Otto will speak about the process by which data from a number of large studies of child HRQOL in Europe were pooled to develop a new computer-adapted test (CAT) instrument, the KIDS-CAT, which has 5 domains: psychological well-being, physical well-being, autonomy and parent relations, social support and peers, and school. Finally, Dr. Riley will present the results of an international Delphi process by which research priorities were generated from members of the ISOQOL Child Health Interest Group as well as recently published authors of child HRQOL studies. Research topics were generated in round 1, rated by 69 respondents in round 2, and then refined. The top 20 research priorities will be discussed. Dr. Forrest, the discussant, will provide a brief integration and discuss next steps in stimulating new international collaborations and advancing research and clinical practice in child HRQOL.

**ISOQOL Emerging Leader Award  
in Honor of Donna Lamping**

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



Thursday, 25 October, 3:00 pm – 4:00 pm

## ERZSÉBET BALLROOM

### (1001) Assessing Health Related Quality of Life in Pediatric Brain tumor patients treated with proton radiotherapy: a comparison with a published brain tumor cohort

Karen A. Kuhlthau, PhD, Center for Child and Adolescent Health Policy; Sundeeep K. Bhat, Stanford/Kiaser Emergency Medicine Residency; Bow Yeap, Massachusetts General Hospital; Jennifer Delahaye, Massachusetts General Hospital; Thomas DeLaney, Massachusetts General Hospital; Shannon MacDonald, Massachusetts General Hospital; David Ebb, Massachusetts General Hospital; Paul Fisher, Lucile Packard Children's Hospital at Stanford; Nancy Tarbell, Massachusetts General Hospital; Torunn Yock, Massachusetts General Hospital

### (1002) Transition from pediatric to adult care: a qualitative meta-synthesis

Liv Fegran, University of Agder, Kristiansand, Norway, Norway

### (1003) The effects of survey administration modality on the assessment of child reported health

Katherine Bevans, PhD, Children's Hospital of Philadelphia; Ramya Pratiwadi, Children's Hospital of Philadelphia; Christopher B. Forrest, MD, PhD, University of Pennsylvania, School of Medicine, United States

### (1004) Qualitative Development of Child-Report Family Relationship Item Banks

Anne Riley, Johns Hopkins University, United States; Jeanne Landgraf, MA, HealthAct CHQ Inc.; Rachel E. Teneralli, MS, RD, Children's Hospital of Philadelphia, United States; Barbara H. Fiese, University of Illinois at Champaign Urbana; Lisa J. Meltzer, PhD, National Jewish Health; Katherine Bevans, PhD, Children's Hospital of Philadelphia; Anna K. Ettinger, Johns Hopkins Bloomberg School of Public Health; Christopher B. Forrest, MD, PhD, University of Pennsylvania, School of Medicine, United States

### (1006) New Card System Quality Of Life (QOL) Questionnaire For Children (Part 2)

Rika Hayashida, MS, Siebold Univ of Nagasaki, Japan; Megumi Masuyama, Nagasaki University Hospital, Japan; Aya Sakai, Isahaya City, Nagasaki, Japan; Michiko Kobayashi, MD PhD, Kwassui Women's College, Japan; Takashi Mandai, MD, Japanese Society of Quality of Life Research, Japan

### (1007) Psychometric properties of the KIDDY-KINDL for early kindergarten populations

Ester Villalonga, PhD, Medical Psychology and Medical Sociology, University Medical Centre, Göttingen, Germany; Claudia Witte, University Medical Centre, Germany; Erich Kastan, Medical Psychology and Medical Sociology, University Medical Centre, Göttingen; Christiane Kiese-Himmel, Medical Psychology and Medical Sociology, University Medical Centre, Göttingen; J.S. Gaier, Medical Psychology and Medical Sociology, University Medical Centre, Göttingen; Nicole Von Steinbuchel, PhD, University of Goettingen, Germany

### (1008) Headache and Health Related Quality of Life among Norwegian Children and Adolescents

Kristin Haraldstad, PhD, University of Agder, Norway; Sølvi Helseth, Oslo and Akershus University College

### (1009) Health-related quality of life and self-worth in 10-year old children with congenital hypothyroidism diagnosed by neonatal screening

Liesbeth Van Der Sluijs Veer, Emma Childrens Hospital; Marlies Kempers, University of Nijmegen; Tom Vulsma, Emma Childrens Hospital; Bob Last, Emma Childrens Hospital; Martha Grootenhuis, PhD, Academic Medical Center, Netherlands

### (1010) Assessing the impact of brain cancer in caregivers' quality of life (QoL)

Patricia Minaya Flores, MA, Laboratoire de Sante Publique EA3279, France; Olivier Chinot, Timone University Hospital, Department of Neurooncology, Marseille; Julie Berbis, Department of Public Health, Medicine University, France; Pascal Auquier, PhD, Laboratoire de Sante Publique, France

### (1011) Physical and mental health of family caregivers: findings from 60,569 adults in Thailand

Vasontara Yiengprugsawan, The Australian National University, Australia; Sam-ang Seubsman, Sukhothai Thammathirat Open University; Adrian Sleight, The Australian National University

### (1012) Impact of Culture on the Quality of Life of Mexican-American Family Caregivers of Patients with Advanced Cancer

Joan J. Branin, PhD, University of La Verne; Gloria Juarez, PhD RN MSN, City of Hope

### (1013) Development of 9 item quality of life assessment scale for caregivers of children with atopic dermatitis in Japan.

Yukihiro Ohya, MD PhD, Nat'l Ctr for Child Hlth & Dvlpmnt, Japan; Toshio Katsunuma, The Jikei University School of Medicine

### (1014) The role of metacognition and reflexivity in QoL: a philosophical analysis

Julien Blanc, Aix-Marseille University, France; Laurent Boyer, PhD, Aix-Marseille University, France; Pascal Auquier, PhD, Laboratoire de Sante Publique, France; Pierre Le Coz, Aix-Marseille Université, France

### (1015) Effect of facial emotion recognition on subjective psychosocial functioning in bipolar patients

Omer Aydemir, Celal Bayar University, Turkey; Cengiz Akkaya, Uludag University Dept. of Psychiatry Bursa Turkey, Turkey; Burak Uykur, Celal Bayar Uni. Dept. of Psychiatry Manisa Turkey; Almila Erol, Izmir Ataturk Training Hospital Dept. of Psychiatry Izmir Turkey

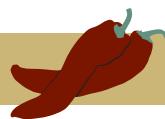
### (1016) Interpretation of response categories in patient-reported rating scales: a test-retest study among people with neurological disorders

Peter Hagell, Kristianstad University, Sweden; Ida Knutsson, Lund University; Karin Samuelson, Lund University

### (1017) Estimating the Portuguese EQ-5D value set using the TTO

Lara N. Ferreira, PhD, University of the Algarve-ESGHT, Portugal; Pedro L. Ferreira, PhD, University of Coimbra, Portugal; Luis N. Pereira, University of the Algarve-ESGHT; CIEO, Portugal

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Thursday, 25 October, 3:00 pm – 4:00 pm

**(1018) Inferior quality of life and psychological well-being in immigrant cancer survivors**

Phyllis Butow, PhD, University of Sydney, School of Psychology, Australia; Lynley Aldridge, University of Sydney, Australia; Melanie Bell, PhD MSc AB, University of Sydney, Australia; Ming Sze, University of Sydney; Maurice Eisenbruch, Monash University; Michael Jefford, Peter MacCallum Cancer Centre; Penelope Schofield, Peter MacCallum Cancer Centre; Afaf Girgis, University of New South Wales; David Goldstein, University of New South Wales; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia

**(1019) PHQ-9 Use in Clinical Practice**

Thomas E. Elliott, MD, Essentia Institute of Rural Health; Colleen M. Renier, BS, Essentia Institute of Rural Health; Jeanette A. Palcher, Essentia Institute of Rural Health

**(1020) Accentuate the Positive: Coping with the Burden of Treatment and Complex Self-care**

David T. Eton, PhD, Mayo Clinic, United States; Djenane R. Oliveira, Universidade Federal de Minas Gerais, Belo Horizonte, Brazil, Brazil; Jason S. Egginton, Mayo Clinic, Rochester, MN USA; Jennifer L. Ridgeway, Mayo Clinic, Rochester, MN USA; Laura Odell, Mayo Clinic, United States; Carl R. May, University of Southampton, United Kingdom; Victor M. Montori, Mayo Clinic, Rochester, MN USA

**🌱 (1021) Health Related Quality of Life: concerns about clinical practice integration and clinical utility**

Augusta Silveira, University Fernando Pessoa, Portugal; Joaquim Gonçalves, Polytechnic Institute of Cávado & Ave, Portugal; Ana Maria Almeida, Instituto Português de Oncologia, Portugal; Cláudia C. Ribeiro, Universidade Católica Portuguesa, Portugal; Lurdes Carvalho, Portuguese Oncology Institute, Porto, Portugal; Eurico Monteiro, Portuguese Oncology Institute, Portugal; Francisco Luis Pimentel, MD PhD, Universidade de Aveiro, Portugal; Teresa Sequeira, Portugal

**(1022) Communicating clinical and quality of life outcomes to patients before surgery for oesophageal cancer: what's most important?**

Rhiannon C. Macefield, University of Bristol, United Kingdom; Natalie Blencowe, University of Bristol; Marc Jacobs, MSc, Amsterdam Medical Center, Netherlands; Sara Brookes, University of Bristol; Mirjam AG Sprangers, PhD, Academic Medical Center, Netherlands; Jane Blazeby, MD, University of Bristol, United Kingdom

**(1023) Pediatrician's capability, willingness, and barriers of measuring patient-reported outcomes in clinical practice: A national survey in the United States**

I-Chan Huang, PhD, University of Florida; Onyekachukwu Osakwe, University of Florida; Lindsay Thompson, University of Florida; Darren DeWalt, MD MPH, University of North Carolina; Dennis Revicki, PhD, United BioSource Corporation; Elizabeth Shenkman, PhD, Univ of Florida College of Medicine

**(1024) A randomized controlled study on the effect of a group therapy for parents of youths with type 1 diabetes on Health-Related Quality of Life**

Elisabetta Petracci, Department of Statistics; Giulia Cavrini, Free University of Bolzano /Bozen, Italy; Laura Nardi, Department of Pediatrics; Stefano Zucchini, Department of Pediatrics; Elena Tomba, Department of Psychology University of Bologna; Silvana Grandi, Department of Psychology University of Bologna; Franco D'Alber-ton, Department of Pediatrics

**(1025) An EORTC Phase III trial of Adjuvant Whole-Brain Radiotherapy Versus Observation in patients with 1 to 3 Brain Metastases From Solid Tumors After Surgical Resection or Radiosurgery: Quality-of-Life Results**

Riccardo Soffietti, University of Torino and San Giovanni Battista Hospital, Neurology/Neuro-Oncology, Torino, Italy; Martin Kocher, University of Cologne, Radiation Oncology, Koeln, Germany; Mehmet Ufuk Abacioglu, Marmara University Hospital, Radiation Oncology, Istanbul, Turkey; Savador Villa, Hospital Germans Trias i Pujol ICO, Radiation Oncology, Barcelona, Spain; François Fauchon, Centre Haute Energie, Nice, France; Brigitta G. Baumert, Radiation-Oncology (MAASTRO), Maastricht University Medical Centre (MUMC), GROW (School for Oncology), Maastricht, Netherlands; Laura Fariselli, Fondazione Istituto Neurologico "Carlo Besta", Milano, Italy; Tzahala Tzuk-Shina, Rambam Medical Center, Haifa, Israel; Rolf-Dieter Kortmann, University Hospital, Leipzig, Germany; Christian Carrie, Department of Radiation Oncology, Centre Leon Bérard, Lyon, France; Mohamed Ben Hassell, Department of Radiotherapy, Centre Eugène Marquis-Rennes, Rennes, France; Mauri Kouri, Radiotherapy and Oncology, Helsinki University Central Hospital, Finland; Egils Valeinis, Neurosurgery Clinic, Pauls Stradins Clinical University Hospital, Riga, Latvia; Dirk van den Berge, Radiation Oncology Department, Univesitair Ziekenhuis Brussel, Belgium; Rolf-Peter Mueller, University of Cologne, Radiation Oncology, Koeln, Germany; Gloria Tridello, Azienda Ospedaliera Universitaria Verona, Verona, Italy; Laurence Collette, EORTC Headquarters, Brussels, Belgium; Andrew Bottomley, PhD, on behalf of the EORTC Radiation Oncology and Brain Groups EORTC Headquarters, Brussels, Belgium

**(1026) Effects of high intensity resistance training on quality of life in patients with prostate cancer treated with androgen deprivation therapy**

Sally Wilson, NHS, United Kingdom; Nicholas Stuart, Gwynedd Hospital; Samuele Marcora, University of Kent, United Kingdom

**(1027) Item Response Theory and Factor Analysis as mean to characterize occurrence of Response Shift for longitudinal quality of life study in breast cancer patients**

Amélie Anota, Plateform 'Quality of Life and Cancer', France; Caroline Bascoul-Mollevi, Biostatistic Unit, Montpellier, France; Francis Guillemin, Clinical epidemiology and evaluation department, Nancy; Thierry Conroy, Centre Alexis Vautrin, France; Michel Velten, Epidemiology and public health laboratory, College of Medicine, Strasbourg, France; Damien Jolly, University Hospital of Reims; Mariette Mercier, Cellular and molecular biology laboratory, University Hospital of Besançon; Sylvain Causeret, Centre Georges François Leclerc; Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges Francois Leclerc, France; Franck Bonnetain, PhD, Centre Georges Francois Leclerc, France

**🌱 (1028) IRT-scaled checklists of mental disorder symptoms for diagnosis and severity assessment at the patient's first contact**

Carlos G. Forero, PhD, IMIM, Spain; Genma Vilagut, MSc, Institut Municipal d'Investigacio Medica, Spain; Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Spain

**(1029) Development of an Item Bank Measuring Economic and Financial Quality of Life for Individuals with Disabilities**


David Tulskey, PhD, University of Michigan; Pamela A. Kisala, University of Michigan; Noelle Carozzi, University of Michigan; Jin-Shei Lai, PhD, Northwestern University; Allen W. Heinemann, Northwestern University, United States

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# Poster Sessions

Thursday, 25 October, 3:00 pm – 4:00 pm

 (1030) **Factors associated with asthma control and health-related quality of life in children: A path analysis**

Pranav Gandhi, PhD, South College, United States; Kelly Kenzik, MS, University of Florida; Lindsay Thompson, University of Florida; Sanjeev Tuli, University of Florida; Darren DeWalt, MD MPH, University of North Carolina; Elizabeth Shenkman, PhD, Univ of Florida College of Medicine; I-Chan Huang, PhD, University of Florida

 (1031) **Application of a Universal Translation Method to PROMIS® Pediatric Item Banks**

Janine Devine, University Medical Center Hamburg-Eppendorf, Germany; Philippa L. Gerigk, University Medical Center Hamburg; Franka Metzner, University Medical Center Hamburg; Michael Herdmann, IMIM University, Insight Consulting and Research; Margarita Hurtado, MPH Consulting; Graciella Castillo, American Institutes for Research; JeanHee Moon, Children's Hospital of Philadelphia; Christopher B. Forrest, MD, PhD, University of Pennsylvania, School of Medicine, United States; Ulrike Ravens-Sieberer, University Medical Center of Hamburg

(1032) **How do respondents perceive health state valuation tasks? A 'think aloud' study investigating Time Trade Off and Discrete Choice Experiments**

Brendan Mulhern, University of Sheffield, United Kingdom; Aki Tsuchiya, School of Health and Related Research, University of Sheffield; John E. Brazier, PhD, Univ of Sheffield, United Kingdom; Donna Rowen, PhD, University of Sheffield, United Kingdom

(1033) **Valuing a vision 'bolt-on' item for the EQ-5D**

Louise Longworth, Jr., Health Economics Research Group, Brunel University; Yaling Yang, PhD, Brunel University, United Kingdom; John E. Brazier, PhD, Univ of Sheffield, United Kingdom; Donna Rowen, PhD, University of Sheffield, United Kingdom; Aki Tsuchiya, School of Health and Related Research, University of Sheffield; Tracey A. Young, PhD MSc BSc CStat, University of Sheffield, United Kingdom

(1035) **Quantifying the top region of the QALY scale with multidimensional scaling**

A.M.M Arons, MSc, Radboud University Nijmegen Medical Centre, Netherlands; Paul F.M. Krabbe, PhD, University of Groningen, Dept. of Epidemiology, Netherlands

(1036) **New series of tools for comprehensive symptom profile assessment in patients with hematological malignancies**

Tatiana I. Ionova, Multinational Center for Quality of Life Research, Russian Federation; Denis A. Fedorenko, PhD, Nat'l Pirogov Med Surgical Ctr, Russia; Tatiana Nikitina, PhD, Multinational Ctr for QoL Research, Russia; Nikita Mochkin, MD, National Medical Surgical Center, Russia; Kira A. Kurbatova, Multinational Center for Quality of Life Research, Russian Federation; Gary I. Gorodokin, New Jersey Center for Quality of Life and Health Outcomes Research, NJ, USA; Andrei Novik, MD PhD, National Medical Surgical Center, Russia

(1037) **A Study of the QOL Criteria of Nursing College Students**

Keiko Saitou, Kwassui Women's University, Omura, Nagasaki, Japan; Michiko Kobayashi, MD PhD, Kwassui Women's College, Japan; Takashi Mandai, MD, Japanese Society of Quality of Life Research, Japan

(1038) **Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID): Evolution of Content, Structure, and Functionalities (2001-2012)**

Marie-Pierre Emery, MSc, MAPI Research Trust, France; Martine Caron, MAPI Research Trust, France; Laure-Lou Perrier, MAPI Research Trust; Katrin Conway, MA, MAPI Research Trust, France

(1039) **Quality of Life Dimensions in Elderly People and its Relation to Religiosity**

Neyde Cintra Santos, Faculdade Adventista da Bahia, Brazil; Gina A. Abdala, MPH, Brazil Adventist University, Brazil; Rafael BMO Vidal, PUC Minas Brazil, Brazil

(1040) **Tobacco and Quality of life in secondary students of Mexico**

Carlos Alejandro Hidalgo Rasmussen, PhD, University of Guadalajara, Mexico; Claudia C. Marti Criollo, University of Guadalajara, Mexico; Gerardo Jimenez Haro, University of Guadalajara

(1041) **Quality of Work Life of Academicians in Ankara, Turkey**

Selda Tasdemir Afsar, Nigde University, Turkey

(1042) **Etiological factors affected Quality of Life due to their association with Traditional Chinese Medicine Syndrome**

Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Wang Yang, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

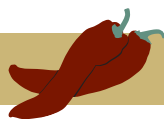
(1043) **Health-Related Quality of Life (HRQL) after Surgery for Esophageal Cancer: Data of a Systematic Review and Preliminary Meta-Analysis**

Marc Jacobs, MSc, Amsterdam Medical Center, Netherlands; Rhiannon C. Macefield, University of Bristol, United Kingdom; Jane Blazeby, MD, University of Bristol, United Kingdom; Ida Korfage, PhD, Erasmus MC, Netherlands; Mark I. Van Berge Henegouwen, Department of Surgery, Academic Medical Center, The Netherlands; Hanneke C.J.M. De Haes, Department of Medical Psychology, Academic Medical Center, The Netherlands; Ellen M. Smets, Department of Medical Psychology, Academic Medical Center, The Netherlands; Mirjam AG Sprangers, PhD, Academic Medical Center, Netherlands

(1044) **Daytime sleepiness and sleep quality are associated with health-related quality of life in Norwegian dialysis patients**

Fredrik B. Brekke, Student of medicine, University of Oslo, Norway; Amin Anro, Oslo University Hospital; Tone B. Østhus, Oslo University Hospital, Norway; Helga Gudmundsdottir, Oslo University Hospital; Bård Waldum, University of Oslo; Ingrid Os, University of Oslo, Norway

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Thursday, 25 October, 3:00 pm – 4:00 pm

**(1045) Effects of complementary health practices on perceived stress and quality of life in Japanese outpatients**

Tomoaki Kimura, PhD, MOA Health Science Foundation, Japan; Hiroshi Matsuo, Aiwakai Tatekawa Clinic, Japan; Naoharu Iida, Zuisenkai MOA Sapporo Clinic; Yoshiteru Maki, Korinkai Kagoshima Clinic, Japan; Kazuo Nitta, Gyokusenkai MOA Takanawa Clinic, Japan; Seiya Uchida, MOA Health Science Foundation; Yasutami Tsuda, MOA Health Science Foundation; Hiroyuki Sakaguchi, MOA Health Science Foundation; Kiyoshi Yamaoka, MOA Health Science Foundation; Kiyoshi Suzuki, Gyokusenkai MOA Takanawa Clinic

**(1046) Reliability and Validity of the Body Image Quality of Life Inventory: Version for Brazilian Burn Victims**

Flávia F. O. Assunção, Universidade de Ribeirão Preto; Natália Gonçalves, University of São Paulo; Jayme A. Farina-Junior, University of São Paulo; Rosana Spadoti Dantas, PhD, University of São Paulo, Brazil; Márcia A. Ciol, University of Washington; Lidia A. Rossi, PhD, University of Sao Paulo, Brazil

**(1047) Linguistic differences between translations of quality-of-life questionnaires: a comparative study of the English and Polish versions of EORTC QLQ-C30**

Dagmara Kulis, EORTC, Belgium; Maria Arnott, EORTC; Cheryl Whittaker, EORTC; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; Andrew Bottomley, PhD, EORTC Headquarters, Belgium; Michael Koller, PhD, Center for Clinical Studies, Germany

**(1049) Assessing the Measurement Invariance of the Functional Assessment of Cancer Therapy-Colorectal Quality of Life Instrument between Self- and Interviewer-administration**

Carlos King Ho Wong, Mphil, BSc, Department of Family Medicine and Primary Care, The University of Hong Kong, Hong Kong; Cindy L.K. Lam, MD, The University of Hong Kong, Peoples Republic of China; Brendan Mulhern, University of Sheffield, United Kingdom

**(1050) The Development and Content Validation of a Novel Generic Family Quality of Life Instrument: the Family Reported Outcome Measure**

Catherine J. Golics, MPharm, Cardiff University, United Kingdom; Mohammad K.A. Basra, MD, Cardiff University, United Kingdom; Sam Salek, BSc RPh PhD FFPM, Cardiff University, Redwood Bldg, United Kingdom; Andrew Finlay, FRCP, Univ. of Wales College of Medicine, United Kingdom

**(1051) Application methodology of the Focal Groups technique in deaf people who communicate in sign language.**

Soraya Bianca Reis Durate, Ms, Instituto Federal de Educação, Ciência e Tecnologia -IFG, Brazil; Adriana Ribeiro De Freitas, Pontifícia Universidade Católica de Goiás; Neuma Chaveiro, Federal University of Goiás, Brazil; Celmo Porto, Universidade Federal de Goiás; Maria Alves Barbosa, Universidade Federal de Goiás; Marcelo P. Fleck, PhD, Hospital de Clinicas de Porto Alegre, Brazil

**(1052) Calling Pain Pain: What Should We Ask MS Patients about Pain Severity?**

Shahnaz Shahrbanian, McGill University, Canada; Nancy E. Mayo, PhD, McGill University, Royal Victoria Hospital, Canada; Pierre Duquette, University of Montreal; Aysel Kuspinar, BSc(PT) MSc, McGill University, Canada; Shang Yuan Teng, MSc, McGill University, Canada

**(1053) Comparison of the Dermatology Life Quality Index (DLQI) and EuroQol-5D (EQ-5D) for their Use in Economic Studies of Dermatological Treatments**

Sam Salek, BSc RPh PhD FFPM, Cardiff University, Redwood Bldg, United Kingdom; Mohammad K.A. Basra, MD, Cardiff University, United Kingdom; Pedro Cruz, Cardiff University; Vicent Piquet, Cardiff University; Andrew Finlay, FRCP, Univ. of Wales College of Medicine, United Kingdom

**(1054) Evaluation of a newly developed questionnaire to measure satisfaction with health among people living with type 2 diabetes (T2DM): The Current Health Satisfaction Questionnaire (CHES-Q)**

Shana B. Traina, Janssen Global Services; Susan D. Mathias, MPH, Health Outcomes Solutions; Hilary H. Colwell, Health Outcomes Solutions; Ross Crosby, PhD, Neuropsychiatric Research Institute

**(1055) Assessment of healthcare needs among crime victims in Japan**

Kazuaki Hirai, Oita University, Japan; Takayuki Kageyama, Oita University of Nursing & Health Sciences; Namiko KAWAMURA, Oita University

**(1056) The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) and its psychometric properties**

Carlijn H. Van Der Zee, MSc, Rehabilitation Center De Hoogstraat, Netherlands; Marcel Post, PhD, Institute for Rehabilitation Research, Netherlands; Johanna MA Visser-Meily, University Medical Center Utrecht; Eline Lindeman, University Medical Center Utrecht, Netherlands

**(1057) Cost-effectiveness Analysis of Anti-viral Treatments in Patients with Chronic Hepatitis B Infection in Hong Kong**

T.P. Elegance Lam, PhD, The University of Hong Kong, Hong Kong; Cindy L.K. Lam, MD, The University of Hong Kong, Peoples Republic of China; C.L. Lai, The University of Hong Kong; M.F. Yuen, The University of Hong Kong, Hong Kong; Sarah McGhee, The University of Hong Kong, Hong Kong; Daniel Fong, PhD, The University of Hong Kong, Hong Kong; Gabriel Leung, The University of Hong Kong, Hong Kong

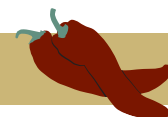
**(1058) Optimizing Satisfaction in Breast Reconstruction: The Importance of the Preoperative Information and Patient-Physician Communication**

Adelyn L. Ho, MD MPH, University of British Columbia, Canada; Anne Klassen, D Phil, McMaster University, Canada; Stefan Cano, BSc PhD, Peninsula College of Medicine & Dentistry, United Kingdom; Amie M. Scott, MPH, Memorial Sloan-Kettering Cancer Center; Andrea Pusic, MD MHS FRCSC, Memorial Sloan Kettering Cancer Ctr

**(1059) The use of Secondary Qualitative Analysis to establish domains of Patient-Centred Care in people with Long Term Conditions**

Monica Hadi, PhD, University of Oxford, United Kingdom; Louise Locock, University of Oxford, United Kingdom; Sara Ryan, University of Oxford; Raymond Fitzpatrick, PhD, Univ of Oxford, Dept of Public Hlth, United Kingdom; Elizabeth J. Gibbons, MSc, University of Oxford, United Kingdom

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Thursday, 25 October, 3:00 pm – 4:00 pm

**(1060) Does the Hospital Depression and Anxiety scale tick the boxes in rheumatology: a Rasch Measurement Theory analysis**

Sophie Cleanthous, MSc BSc, University College London, United Kingdom; Stanton P. Newman, City University, United Kingdom; Michael Shipley, University College London Hospital; David A. Isenberg, University College London; Stefan Cano, BSc PhD, Peninsula College of Medicine & Dentistry, United Kingdom

**(1061) Quality of life assessment in patients with idiopathic normal pressure hydrocephalus**

Hideki Origasa, PhD, Univ of Toyama at Sugitani School of Medicine, Japan; Masaaki Hashimoto, MD, Department of Neurosurgery, Noto General Hospital, Japan; Masakazu Miyajima, MD, Department of Neurosurgery, Juntendo University School of Medicine, Japan; Hajime Arai, MD, Department of Neurosurgery, Juntendo University School of Medicine, Japan

**(1062) Attitude of medical recipients (patients) and medical providers (nurses and doctors) toward life and death**

Yujiro Kuroda, the University of Tokyo Hospital, Japan; Keiichi Nakagawa, the University of Tokyo, Japan; Yumi Iwamitsu, Kitasato University; Midori Kotani, Dai-ichi Life research institute; Yutaka Kitazawa, Toyo Eiwa University; Yoichi Yamada, University of Tsukuba; Osamu Sakura, The University of Tokyo

**(1063) The Effect of Neurological Function on Dyssomnia of Patients with Post Stroke Depression (PSD)**

Hai Ying, Department of Neurology, Affiliated Hospital of Liaoning University of TCM, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Li, Department of Neurology, Affiliated Hospital of Liaoning University of TCM, Peoples Republic of China; Qi Wencheng, department of neurology, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yuan Dongchao, department of neurology, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

**(1064) An improvement of the established TCM-SAQ: Another Syndrome-specific Instruction to Assess quality of life for Angina Treated by Traditional Chinese Medicine. (QBS)**

Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Wang Yang, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

**(1065) Developing a core outcome set for oesophageal cancer surgery: the role of patient-reported outcomes**

Natalie Blencowe, University of Bristol; Rhiannon C. Macefield, University of Bristol, United Kingdom; Marc Jacobs, MSc, Amsterdam Medical Center, Netherlands; Sean Strong, Bmed MRCS MSC, University of Bristol, United Kingdom; Sara Brookes, University of Bristol; Mirjam AG Sprangers, PhD, Academic Medical Center, Netherlands; Jane Blazeby, MD, University of Bristol, United Kingdom

**(1066) Cross-cultural adaptation and validation of the Portuguese version of the Pregnancy Physical Activity Questionnaire (PPAQ)**

Rui Soles Goncalves, PhD, Centre for Health Studies and Research of the University of Coimbra, Portugal; Filipa Pombo, Alcoitão Health College; Ana Cristina Silva, Alcoitão Health College; António Fernandes Lopes, Alcoitão Health College; Luis Manuel Cavalheiro, PhD, University of Coimbra, Portugal; Joao Antonio Gil, PT PhD, University of Coimbra, Portugal; Pedro L. Ferreira, PhD, University of Coimbra, Portugal

**(1067) Reliability and validity of a new measure to evaluate mobility in the elderly (Functional Mobility Scale - Elderly and Very Elderly) in the Portuguese population**

Irene Higgs, Alcoitão health college; Luis Manuel Cavalheiro, PhD, University of Coimbra, Portugal; José Millán Calenti, University of A Coruña; Rui Soles Goncalves, PhD, Centre for Health Studies and Research of the University of Coimbra, Portugal; Pedro L. Ferreira, PhD, University of Coimbra, Portugal; Joao Antonio Gil, PT PhD, University of Coimbra, Portugal

**(1068) Psychometric Validation of Patient-Reported Outcome Measures for Assessing Chronic Constipation Symptom Severity: Results from Phase 2b and Phase 3 Trials of Linaclotide**

Mollie J. Baird, MPH, Ironwood Pharmaceuticals; Robyn Carson, MPH, Forest Research Institute; Cheryl D. Coon, PhD, RTI Health Solutions; Sheri Fehnel, PhD, RTI Health Solutions; James MacDougall, Ironwood Pharmaceuticals; Lauren Nelson, RTI Health Solutions; Stavros Tourkodimitris, Forest Research Institute; Valerie Williams, PhD, RTI Health Solutions; Jeffrey M. Johnston, Ironwood Pharmaceuticals

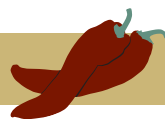
**(1069) Psychometric Evaluation of Patient-Reported Outcome Measures Assessing IBS-C Symptom Severity and Change: Results from Two Randomized, Double-Blind, Placebo-Controlled Phase 3 Trials of Linaclotide**

Robyn Carson, MPH, Forest Research Institute; Mollie J. Baird, MPH, Ironwood Pharmaceuticals; Cheryl D. Coon, PhD, RTI Health Solutions; Sheri Fehnel, PhD, RTI Health Solutions; James MacDougall, Ironwood Pharmaceuticals; Lauren Nelson, RTI Health Solutions; Stavros Tourkodimitris, Forest Research Institute; Valerie Williams, PhD, RTI Health Solutions; Jeffrey M. Johnston, Ironwood Pharmaceuticals

**(1070) Self-efficacy impacts quality of life: a methodological study in subject with multiple sclerosis**

Rosalba Rosato, PhD, University of Turin, Italy; Giorgia Molinengo, University of Turin, Italy; Silvia Testa, University of Turin; Alessandra Oggero, Referral Regional Multiple Sclerosis Center, Italy; Antonio Bertolotto, Referral Regional Multiple Sclerosis Center, AOU San Luigi, Orbassano, Turin

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Thursday, 25 October, 3:00 pm – 4:00 pm

## (1071) Stories of Life with Life-threatening Illness

Kara L. Schick Makaroff, PhD RN, University of Alberta, Canada; Anita Molzahn, PhD RN, University of Alberta, Canada; Laurene Shields, University of Victoria; Anne Bruce, University of Victoria; Kelli Stajduhar, University of Victoria; Rosanne Beuthin, Vancouver Island Health Authority; Sheryl Shermak, University of Victoria

## (1072) Streamlining Aged Care Assessment

Janet E. Sansoni, MSc, University of Wollongong, Australia; Peter Samsa, University of Wollongong; Alan Owen, University of Wollongong; Kathy Eagar, University of Wollongong

## (1073) Threats to the Internal Validity of Spinal Surgery Outcome Assessment: Recalibration Response Shift or Implicit Theories of Change?

Joel A. Finkelstein, MSc MD FRCS(C), Sunnybrook Health Sciences Center, Sunnybrook Center for Spinal Trauma, University of Toronto, Toronto, Canada; Brian R. Quaranta, BS, DeltaQuest Foundation, Inc., Concord, MA, USA; Gary Naglie, MD FRCP(C) FGSA, Department of Medicine and Kunin-Lunenfeld Applied Research Unit, Baycrest Geriatric Health Care System; Research Departments, Toronto Rehabilitation Institute and Toronto General Research Institute; University of Toronto, Toronto, Canada. Geriatric Medicine Research; Departments of Medicine and Health Policy, Management and Evaluation, University of Toronto, Toronto, Canada; Alex Kiss, PhD, Department of Research Design and Biostatistics; Clinical Epidemiology, Sunnybrook Health Sciences Centre, University of Toronto, Toronto, Canada; Aileen M. Davis, PhD, Division of Health Care and Outcomes Research, Arthritis and Community Research and Evaluation Unit, Toronto Western Research Institute, University of Toronto, Toronto, Canada; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, MA; Departments of Medicine and Orthopaedic Surgery, Tufts University Medical School, Boston, MA, USA

## 🏆 (1074) Computer-based quality of life monitoring with the EORTC QLQ-C30 in daily oncological routine - much information in little time

Monika J. Sztankay, Innsbruck Medical University, Austria; Lisa M. Wintner, Department of Psychiatry and Psychotherapy, Innsbruck Medical University, Austria; Johannes M. Giesinger, PhD, Innsbruck Medical University, Austria; August Zabernigg, Department of Internal Medicine, Kufstein County Hospital, Kufstein, Austria, Austria; Georg Kenmmler, PhD, Innsbruck Medical University, Austria; Eva-Maria Gamper, Department of Psychiatry and Psychotherapy, Innsbruck Medical University; Anne S. Oberguggenberger, Innsbruck Medical University, Austria; Bernhard Holzner, PhD BE, Univ. Hospital, Innsbruck, Austria

## 🏆 (1075) Assessment of the influence of explanatory and confounding variables on health-related quality of life – does response shift bias the results?

Pranav Gandhi, PhD, South College, United States; L. Douglas Ried, University of South Florida; I-Chan Huang, PhD, University of Florida; Teresa Kauf, University of Florida; Carole Kimberlin, University of Florida

## (1076) Assessment of effects of response shift in palliative care patients using the structural equation modeling approach

Yoshimi Suzukamo, PhD, Tohoku Univ, Dept of Physical Med & Rehab, Japan; Kikuko Miyazaki, PhD, Schl of Pblc Hlth - Kyoto University, Japan; Kojiro Shimozuma, Dept. of Biomedical Sciences, College of Life Sciences, Ritsumeikan University, Japan; Takeo Nakayama, MD PhD, Kyoto University School of Public Health, Japan

## (1077) The responsiveness of disability in multiple sclerosis patients: comparison of a disease-specific (MusiQoL) and a generic (SF36) instruments

Mohamed Boucekine, Self-perceived Health Assessment Research Unit, France; Karine Baumstarck, France; Julie Berbis, Department of Public Health, Medicine University, France; Oscar Fernández, Institute of Clinical Neurosciences, Málaga, Spain; Peter Flachenecker, Neurological Rehabilitation Center Quellenhof, Bad Wildbad, Germany; Helmut Butzkueven, MS Unit, Melbourne, Victoria, Australia; Jean Pelletier, Neurology, Timone University Hospital, Marseille, France; Sergio Stecchi, Multiple Sclerosis Unit, Department of Neuroscience AUSL, Bologna, Italy; Egemen Idiman, Department of Neurology, Dokuz Eylul University, Izmir, Turkey; Pascal Auquier, PhD, Laboratoire de Sante Publique, France

## (1078) Patient Recovery after Surgery for Bladder Cancer: A Comparison of Open versus Robotic Approaches

John M. Hollingsworth, University of Michigan, Department of Urology, United States; Jeffrey S. Montgomery, University of Michigan; Scott Gilbert, University of Florida, Department of Urology; John T. Wei, MD, University of Michigan, United States; Rodney Dunn, MS, University of Michigan Dept of Urology; Brent Hollenbeck, MD, MS, University of Michigan

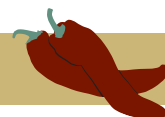
## 🏆 (1079) Does change in health-related quality of life (HRQoL) score predict survival? Sensitivity analysis of a lung cancer RCT

Divine Ewane Ediebah, MSc, EORTC HQ, Belgium; Corneel Coens, MSc, EORTC HQ, Belgium; Efsthios Zikos, MSc, MA, EORTC HQ, Belgium; Chantal Quinten, MSc, EORTC, Belgium; Jolie Ringash, MD, The Princess Margaret Hospital, Canada; Carolyn C. Gotay, PhD, UBC School Pop & Pub Health, Canada; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; David Osoba, FRCPC, QOL Consulting, Canada; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; Henning H. Flechtner, PhD, Otto-von-Guericke University (KKJP), Germany; Martin Taphoorn, PhD, Medical Centre Haaglanden, Neurology, The Hague, The Netherlands; J. Schmucker von Koch, PhD, University of Regensburg, Medical Ethics, Regensburg, Germany; Joachim Weis, PhD, University of Freiburg, Psychooncology, Freiburg, Germany; Charles S. Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, Unites States; E.F. Smit, PhD, Free University Hospital, Dept. of Pulmonology, Amsterdam, the Netherlands; Andrew Bottomley, PhD, EORTC, Quality of Life, Brussels, Belgium on behalf of the Lung Cancer Cooperative Group, Quality of Life Department and Patient Reported Outcome and Behavioral Evidence (PROBE)

## (1080) The new instrument for comprehensive symptom assessment in patients with chronic myeloid leukemia

Tatiana Nikitina, PhD, Multinational Ctr for QoL Research, Russia; Denis A. Fedorenko, PhD, Nat'l Pirogov Med Surgical Ctr, Russia; Kira A. Kurbatova, Multinational Center for Quality of Life Research, Russian Federation; Elena I. Usacheva, Hematological Center ?I, Saint-Petersburg, Russia; Tatiana I. Ionova, Multinational Center for Quality of Life Research, Russian Federation; Gary I. Gorodokin, New Jersey Center for Quality of Life and Health Outcomes Research, NJ, USA; Andrey A. Novik, National Pirogov Medical Surgical Center, Moscow, Russia

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# Poster Sessions

Thursday, 25 October, 3:00 pm – 4:00 pm

## (1081) Understanding the Relationships Between Health-Related Quality of Life Domains During Recovery from Joint Replacement

Aileen M. Davis, PhD, Toronto Western Research Institute and University of Toronto, Toronto, Canada, Canada; Selahadin Ibrahim, Institute for Work and Health; Sheilah Hogg-Johnson, Institute for Work and Health and University of Toronto, Toronto, Canada; Anthony V. Perruccio, University Health Network and University of Toronto, Toronto, Canada; Rose Wong, Toronto Western Research Institute, Canada; Dorcas Beaton, PhD, St. Michael's Hospital, Canada; Monique A. Gignac, Toronto Western Research Institute and University of Toronto, Toronto, Canada; Elizabeth M. Badley, Toronto Western Research Institute, Canada

## (1082) The importance of the domain in self-reported quality of life of elderly Chileans

Alfonso Urzua, PhD, Escuela de Psicología-Universidad Católica del Norte, Chile

## (1083) Practices in PRO psychometric validation studies: a systematic literature review

Emmanuelle Anthoine, University of Nantes, France; Leila Moret, University Hospital of Nantes; Véronique Sébille, University of Nantes, France; Jean-Benoît Hardouin, PhD, University of Nantes - EA4275, France

## (1084) Patient-specific measures for goal setting. Research plan and first results

Anita Stevens, Zuyd University of applied science; Anna Beurskens, PhD, Zuyd University of applied sciences, Netherlands; Albère Köke, Adelante Centre of Expertise in Rehabilitation; Trudy Van Der Weijden, Maastricht University

## (1085) Development and Validation of the System of Quality of Life Instruments for Cancer Patients (QLICP) in China

Chonghua Wan, PhD, Guangdong Medical College, Peoples Republic of China; Zheng Yang, Guangdong Medical College, Peoples Republic of China; Jiahong Luo, Kunming Medical University; Qiong Meng, Kunming Medical University; Xiaoqing Zhang, Kunming Medical University; Xueliang Tang, Yunnan Tumor Hospital; Gaofeng Li, Yunnan Tumor Hospital; Yingli Cun, Yunnan Tumor Hospital

## (1086) Health-related quality of life, marital satisfaction, and social support with a special focus on gender differences in medical staff in Tehran- Iran

Arian Rostami, Umeå University; Mehdi Ghazinour, Umea University-Department of social work; Lennart Nygren, Umeå University-Department of Social Work, Sweden; Jörg Richter, Centre for Child and Adolescent Mental Health, Oslo, Norway

## (1087) The association between oral health-related quality of life and self-rated presenteeism

Hiroya Takiuchi; Aya Kimura-Ono, Okayama Univ. Grad. Sch. Med., Dent. and Pharmaceu. Sci., Okayama, Japan.; Hikaru Arakawa, Okayama Univ. Grad. Sch. Med., Dent. and Pharmaceu. Sci., Okayama, Japan., Japan; Takuya Mino, Okayama Univ. Grad. Sch. Med., Dent. and Pharmaceu. Sci., Okayama, Japan.; Asuka Masaki, Okayama University, Japan; Emilio Satoshi Hara, Okayama Univ. Grad. Sch. Med., Dent. and Pharmaceu. Sci., Okayama, Japan.; Manabu Kanyama, Okayama Univ. Grad. Sch. Med., Dent. and Pharmaceu. Sci., Okayama, Japan.; Yoshizo Matsuka, Okayama University, Japan; Takuo Kuboki, Okayama Univ. Grad. Sch. Med., Dent. and Pharmaceu. Sci., Okayama, Japan

## (1089) QOL and the disability among the elderly in Japan

Miyako Tazaki, PhD, Toho University, Japan; Tetsuo Yamaguchi, Toho University; Mitsutoshi Yatsunami, Tokyo University of Science, Japan; Yoshihumi Nakane, Nagasaki University

## (1090) Necessary and Sufficient Contributors to Participation Post Stroke

Nancy E. Mayo, PhD, McGill University, Royal Victoria Hospital, Canada; Lois Finch, MSc, Canada; Susan C. Scott, MSc, McGill University, Canada; Sydney Miller, Concordia University

## (1092) QOL and Pessimism in Alcohol Complicated and Alcohol Free Couples

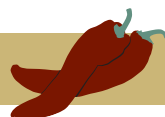
Selwyn Stanley, PhD, University of Plymouth, United Kingdom

## 🏆 (1093) Psychometric studies of the European Portuguese version of the quality of life index EUROHIS-QOL-8 in HIV-infected patients

Marco Pereira, Universidade de Coimbra, Portugal; Maria Cristina Canavarro, Universidade de Coimbra, Portugal



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# Poster Sessions

Friday, 26 October, 1:15 pm – 2:15 pm

## ERZSÉBET BALLROOM

### (2001) Agreement between mothers and children aged 5-6 years in rating child oral health-related quality of life

Jenny Abanto, Department of Pediatric Dentistry, University of São Paulo, Brazil; Georgios Tsakos, PhD, University of College London, United Kingdom; Saul Martins Paiva, Federal University of Minas Gerais; Daniela Prócida Raggio, University of São Paulo; Marcelo Bönecker, Department of Pediatric Dentistry, University of São Paulo

### (2002) The importance of domain in the evaluation of quality of life in childrens

Alfonso Urzua, PhD, Escuela de Psicología-Universidad Católica del Norte, Chile

### (2003) Impairment of quality of life in parents of children with autism spectrum disorder

Virginie Villes, Public Health Laboratory, Marseilles, France; Anne-Marie Bartolini, Resource autism center, marseilles; Clarisse Chatel, Resource autism center, marseilles; François Poinso, Resource autism center, marseilles

### (2004) Structural relations between socio-demographic factors, parenting stress, parental perceived quality of life and young children's weight outcomes in Hong Kong

Christine MS Chan, PhD, Institute of Education, HK, Hong Kong; John H.M. Lam, The Hong Kong Institute of Education

### (2005) Relationship between protective health behaviors and health-related quality of life in German preschool children

Angela Gosch, Dr. Phil, Munich University of Applied Sciences, Germany; Rainer Pankau, Finkelstein Pediatric Hospital, Heidekreis, Germany

### (2006) Dimensions of Quality of Life of Brazilian Children and Adolescents in Hemodialysis

Isabella S. Abreu, Universidade de São Paulo, Brazil; Danielle Maria S S dos Santos, MD, University of Sao Paulo, Brazil; Keila C. Deon, MD, University of São Paulo, Brazil; Regina Aparecida Garcia de Lima, University of São Paulo, Brazil; Maria Fernanda Cabral Kourrouski, University of São Paulo, Brazil; Lucila Castanheira Nascimento, University of São Paulo, Brazil; Roberta A. Reis, PhD, Universidade Federal do Rio Grande do Sul, Brazil; Claudia Benedicta dos Santos, MISP-EERP-USP, Germany

### (2007) Patient Reported Outcomes in Pediatric Clinical Trials: A Systematic Literature Review

Rachel E. Teneralli, MS, RD, Children's Hospital of Philadelphia, United States; Katherine Bevans, PhD, Children's Hospital of Philadelphia; Christopher B. Forrest, MD, PhD, University of Pennsylvania, School of Medicine, United States

### (2008) Does the severity of childhood asthma affect caregiver's quality of life?

Karen H. Sousa, RN PhD, University of Colorado Denver; College of Nursing; Judy A. Harris, Phoenix Children's Hospital; Susanne W. Cook, Retired

### (2009) Instruments for measure of the Quality of Life of children and adolescents with Atopic Dermatitis: A Literature Review

Keila C. Deon, MD, University of São Paulo, Brazil; Danielle Maria S S dos Santos, MD, University of Sao Paulo, Brazil; Isabella S. Abreu, Universidade de São Paulo, Brazil; Monika Bullinger, PhD, Inst for Medical Psychology, Hamburg Univ, Germany; Claudia Benedicta dos Santos, MISP-EERP-USP, Germany

### (2010) Factors related to the Quality of Life of Carers of People with Parkinson's Disease

Michele Peters, PhD, University of Oxford, United Kingdom; David Morley, University of Oxford; Sarah Dummett, University of Oxford; Laura Kelly, University of Oxford; Jill Dawson, University of Oxford; Raymond Fitzpatrick, PhD, Univ of Oxford, Dept of Public Hlth, United Kingdom; Crispin Jenkinson, Health Services Research Unit, United Kingdom

### (2011) The association between a parents' emotional distress and the health-related quality of life of youths with type 1 diabetes: Is the parents' perception of the social and familial impact of the illness a relevant mediator?

Helena Moreira, Faculty of Psychology and Education Sciences, University of Coimbra, Portugal; Maria Cristina Canavarró, Universidade de Coimbra, Portugal; Monika Bullinger, PhD, Inst for Medical Psychology, Hamburg Univ, Germany

### (2012) Quality of Life Interaction Between Caregivers and Their Family Patients With Hemodialysis

Hironasa Hirai, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Takashi Nakano, Japanese Society of Quality of Life Research, Japan; Satio Kawanishi, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Kunio Nakayama, Japanese Society of Quality of Life Research, Japan; Yuri Kitamura, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Rika Hayashida, MS, Siebold Univ of Nagasaki, Japan; Michiko Kobayashi, MD PhD, Kwassui Women's College, Japan; Haruyasu Fujita, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Kozaburo Adachi, PhD, Agape-Kabutoyama Hospital, Japan; Takashi Mandai, MD, Japanese Society of Quality of Life Research, Japan

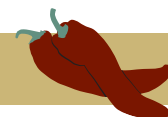
### (2013) Anxiety and Depression in Fathers and Mothers of Children with a Chronic Disease

Hedy Van Oers, Emma Children's Hospital/Academic Medical Center; Lotte Haverman, MSc, Emma Children's Hospital - Academic Medical Centre, Netherlands; Perrine Limperg, Emma Children's Hospital/Academic Medical Center, Netherlands; Alice Van Dijk-Lokkart, VU medical centre; Heleen Maurice-Stam, MSc, Emma's Children's Hosp, Academic Medical Ctr, Netherlands; Martha Grootenhuis, PhD, Academic Medical Center, Netherlands

### (2014) A Clinic-Based Assessment of the Relation of Depression and Other Clinical Parameters to Clinically Significant Worsening in Walking Time in Persons with Multiple Sclerosis

Deborah Miller, PhD, The Cleveland Clinic Foundation; Nicolas Thompson, Cleveland Clinic; Jeffrey Cohen, Cleveland Clinic; Robert Fox, Cleveland Clinic; Jennifer Hartman, Cleveland Clinic; Kathleen Schwetz, Cleveland Clinic; Richard Rudick, Cleveland Clinic

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Friday, 26 October, 1:15 pm – 2:15 pm

**(2015) Can psychosomatic symptoms explain gender and age differences in health related quality of life among Swedish schoolchildren?**

*Eva Boman, PhD, University of Gävle, Sweden; Pia Svedberg, PhD, Karolinska Institutet, Sweden*

**(2016) Health-related quality of life, depression, and sense of coherence in hospitalized patients with chronic heart failure**

*Viviane M. Pelegrino, University of São Paulo; Rosana Spadoti Dantas, PhD, University of São Paulo, Brazil; Márcia A. Ciol, University of Washington; Lidia A. Rossi, PhD, University of Sao Paulo, Brazil; Suemara P. Silva, University of São Paulo; Carina M. Dessotte, University of São Paulo; Fabiana Bolela, University of São Paulo*

**(2017) Biological Signal for Human Flourishing: The necessity of adjusting cognitive misjudgement in the Capability Approach**

*Tadashi Hirai, PhD, The University of Tokyo, Japan; Yukio Ikemoto, The University of Tokyo*

**(2018) Measuring 'instrumental activities in daily living' in dementia: the diagnostic usefulness of the Amsterdam IADL Questionnaire ®.**

*Sietske Sikkes, PhD, VU University Medical Center, Netherlands; Yolande Pijnenburg, VU University Medical Center; Elly De Lange-de Klerk, VU University Medical Center; Philip Scheltens, VU University Medical Center; Bernard Uitdehaag, VU University Medical Center*

**(2019) Basic Genetics: What the QOL Researcher Needs to Know**

*Jeff Sloan, PhD, Mayo Clinic, United States; Mirjam AG Sprangers, PhD, Academic Medical Center, Netherlands*

**(2020) Emotional well-being and lifestyle factors among community-dwelling older adults**

*Yuko Yoshida, Japan; Hajime Iwasa, Tokyo Metropolitan Institute of Gerontology; Shu Kumagai, University of Human Arts and Sciences; Takao Suzuki, National Center for Geriatrics and Gerontology; Yuko Yoshida, Japan; Yuko Yoshida, Japan; Hideyo Yoshida, Tokyo Metropolitan Institute of Gerontology, Japan*

**(2021) Busting the Top Myths About Quality of Life Assessment in Clinical Practice**

*Carolyn C. Gotay, PhD, UBC School Pop & Pub Health, Canada*

**(2022) Symptoms and Quality of Life Indicators of Persons with Lower Limb Loss**

*Dagmar Amtmann, PhD, University of Washington; Daniel C. Abrahamson, University of Washington; Sara Morgan, University of Washington; Rana Salem, University of Washington; Robert L. Askew, BA, UT - M.D. Anderson Cancer Center; Brian Hafner, University of Washington*

**(2023) Translation and Linguistic Validation of Two COPD Symptom Diaries for Use in Global Clinical Trials**

*Sonya Eremenco, MA, United BioSource Corporation; Michelle MocarSKI, MPH, Forest Laboratories; Benjamin J. Arnold, MA, FACITtrans, Brazil; Andrew Palsgrove, United BioSource Corporation; Asha Hareendran, PhD, United BioSource Corporation, United Kingdom*

**(2024) Implementation of Quality of Life Evaluation in Oncology daily practice: breast cancer in focus**

*Ariana Santos, Portuguese Oncology Institute, Porto, Portugal; Augusta Silveira, University Fernando Pessoa, Portugal; Joaquim Gonçalves, Polytechnic Institute of Cávado & Ave, Portugal; Cláudia C. Ribeiro, Universidade Católica Portuguesa, Portugal; Joana Teixeira, Nurse, Portuguese Oncology Institute, Porto, Portugal, Portugal; Joaquim Abreu Sousa, Portuguese Oncology Institute, Porto, Portugal; Teresa Sequeira, Portugal*

**(2025) Unidimensionality, Validity and Responsiveness of the ANMS Gastroparesis Cardinal Symptom Index-Daily Diary**

*Dennis Revicki, PhD, United BioSource Corporation; Wen-Hung Chen, PhD, United BioSource Corporation; Michael Camilleri, Mayo Clinic; Henry Parkman, Temple University*

 **(2026) Long-term quality of life monitoring in patients with neuroendocrine tumors**

*Lisa M. Wintner, Department of Psychiatry and Psychotherapy, Innsbruck Medical University, Austria; Eva-Maria Gamper, Department of Psychiatry and Psychotherapy, Innsbruck Medical University; Johannes M. Giesinger, PhD, Innsbruck Medical University, Austria; Anne S. Oberguggenberger, Innsbruck Medical University, Austria; Sabine Buxbaum, University Clinic for Nuclear Medicine, Innsbruck Medical University; Dietmar Waitz, University Clinic for Nuclear Medicine, Innsbruck Medical University; Daniel Putzer, University Clinic for Nuclear Medicine, Innsbruck Medical University; Bernhard Nilica, Innsbruck Medical University, Austria; Irene Virgolini, University Clinic for Nuclear Medicine, Innsbruck Medical University; Bernhard Holzner, PhD BE, Univ. Hospital, Innsbruck, Austria*

**(2027) The effects of Pilates exercises in articular movement and HRQL of JIA patients**

*Tania Maria S. Mendonca, Sr., Universidade Federal de Sao Paulo, Brazil; Claudio A. Len, Sr., UNIFESP-EPM; Maria Teresa RA Terreri, Sr., UNIFESP-EPM; Maria Odete E. Hilario, Sr., UNIFESP-EPM; Carlos Henrique Martins da Silva, MD, Brazil; Rogério M C Pinto, Federal University of Uberlandia*

**(2028) Sense of coherence among people with psoriasis**

*Eva Langeland, Bergen University College, Norway; Hilde S. Robinson, University of Oslo; Marie H. Larsen, University of Oslo, Norway; Anne-Lene Krogstad, Oslo University Hospital; Torbjørn Moum, University of Oslo, Norway; Astrid Wahl, PhD, University of Oslo, Norway*

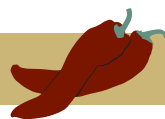
**(2029) Qualitative Interviews with Psoriasis Patients Evaluating Paper to Electronic Migration of the Psoriasis Symptom Inventory (PSI)**

*Mona L. Martin, RN MPA, Health Research Associates, Inc.; TeChieh Chen, Health Research Associates; Dina Chau, Amgen Inc; Hema Viswanathan, Amgen, Inc.*

**(2030) Feasibility and acceptability of patient-reported outcomes data collection for clinical care following breast reconstruction**

*Andrea Pusic, MD MHS FRCSC, Memorial Sloan Kettering Cancer Ctr; Stefan Cano, BSc PhD, Peninsula College of Medicine & Dentistry, United Kingdom; Anne Klassen, D Phil, McMaster University, Canada; Amie M. Scott, MPH, Memorial Sloan-Kettering Cancer Center; Marwan Shouery, Memorial Sloan-Kettering Cancer Center; Ethan Basch, MD MSc, Memorial Sloan-Kettering Cancer Center; Peter Cordeiro, Memorial Sloan Kettering Cancer Center*

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# Poster Sessions

Friday, 26 October, 1:15 pm – 2:15 pm

## (2032) Effectiveness of social supports on quality of life in breast cancer patients: a meta-analysis of randomized controlled trials

Ayako Matsuda, National Cancer Center, Japan; Kazue Yamaoka, PhD, Teikyo University, Graduate School of Public Health, Japan; Toshiro Tango, Center for Medical Statistics, Japan; Tomohiro Matsuda, National Cancer Center, Japan; Hiroshi Nishimoto, National Cancer Center, Japan

## (2033) Patient-reported outcome is important in psychosocial intervention for dementia: A secondary analysis on RCT of group reminiscence approach data

Kenichi Meguro, Dpt Geriatr Behav Neurol, Tohoku Univ Grad Sch Med, Japan; Kyoko Akanuma, Dpt Geriatr Behav Neurol, Tohoku Univ Grad Sch Med

## (2034) CONSORT PRO 2012: Translating guidance to practice

Melanie Calvert, PhD, The University of Birmingham, United Kingdom; Jane Blazeby, MD, University of Bristol, United Kingdom; Doug G. Altman, University of Oxford, United Kingdom; Dennis Revicki, PhD, United BioSource Corporation; Brenda Bass, Queen's University, Canada; Helen Duffy, BA, University of Birmingham, United Kingdom; David Moher, Ottawa Hospital Research Institute; Michael Brundage, MD, Queen's University, Canada

## (2035) Developing 5 Item Banks to Measure Patient-reported Physical Functioning as part of the Spinal Cord Injury Functional Index (SCI-FI) Measurement System.

David Tulskey, PhD, University of Michigan; Pamela A. Kisala, University of Michigan; Alan Jette, PhD, Boston University; Mary D. Slavin, Boston University; Pengsheng Ni, Boston University

## (2036) Health States Utilities in Chronic Immune Diseases

Cláudia C. Ribeiro, Universidade Católica Portuguesa, Portugal; Augusta Silveira, University Fernando Pessoa, Portugal; Teresa Sequeira, Portugal; Isabel Santos, Hospital Santa Maria da Feira; Augusta Marques, Universidade Santiago de Compostela; Carlos Vasconcelos, Hospital Santo Antonio Centro Hospitalar do Porto

## (2037) Predicting SF-6D Preference-based Score Based on the European Organization for Treatment and Research of Cancer Quality of Life Questionnaire in Colorectal Cancer

Carlos King Ho Wong, Mphil, BSc, Department of Family Medicine and Primary Care, The University of Hong Kong, Hong Kong; Cindy L.K. Lam, MD, The University of Hong Kong, Peoples Republic of China; Donna Rowen, PhD, University of Sheffield, United Kingdom; Eric Yuk Fai Wan, The University of Hong Kong

## (2038) Adding categories to EuroQol-5D instrument to remove the ceiling effect

Jorge S. Cortes, Sr., Universidad de la Frontera, Chile; Juan F. Blanco, Sr., Trauma Unit, Facultad de Medicina, Universidad de Salamanca, España; Claudio R. Castro, Sr., Facultad de Estadística e Informática, Universidad Veracruzana, México; Rosa A. Sepúlveda, Departamento de Estadística, Universidad de Salamanca, España; Sergio R. Muñoz, Sr., Departamento de Salud Pública, Universidad de la Frontera, Chile; Norman Moreno-García, Sr., Universidad Católica de Temuco, Chile

## (2039) Quality of life and violence against women

Rosa Aurea Q. Fernandes, PhD, Universidade Guarulhos, Brazil; Mari Anna T. Lima, Guarulhos University, Brazil

## (2040) Attitudes of Portuguese nurses facing end-of-life decisions

Pedro L. Ferreira, PhD, University of Coimbra, Portugal; Cristina R. Nogueira, Coimbra University Hospital, Brazil

## (2041) Association of perceived health status and mental health in patients after percutaneous coronary intervention following hospital discharge

Rejane K. Furuya, University of Sao Paulo at Ribeirao Preto College of Nursing; Vitor C. Richter, University of São Paulo at Ribeirão Preto College of Nursing; Mariana Coelho, University of São Paulo at Ribeirão Preto College of Nursing; Eliana C.A. Costa, University of São Paulo at Ribeirão Preto College of Nursing; André Schmidt, School of Medicine of Ribeirão Preto, University of São Paulo; Rosana Spadoti Dantas, PhD, University of São Paulo, Brazil; Márcia A. Ciol, University of Washington; Lidia A. Rossi, PhD, University of Sao Paulo, Brazil

## (2042) The impact of self-stigmatization on functioning in bipolar disorder

Omer Aydemir, Celal Bayar University, Turkey; Burak Uykur, Celal Bayar Uni. Dept. of Psychiatry Manisa Turkey

## (2043) Psychosocial correlates in Visually Impaired People: A gender based analysis.

Selwyn Stanley, PhD, University of Plymouth, United Kingdom; Velliah Sethuramalingam, PhD MA, Bharathioasan University, India

## (2044) Completion time reflecting the quality of outcomes across multiple questionnaires

Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

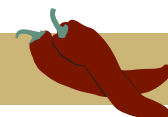
## (2045) Integrating disability with sickness leave days for return-to-work assessment in traumatic limb injuries

Wen-Hsuan Hou, E-Da Hospital & I-Shou University, Taiwan; Hung-Yi Chuang, Department of Public Health, Kaohsiung Medical University; Jing-Shiang Hwang, Institute of Statistical Science, Academia Sinica

## (2046) Cohen's kappa assesses reliability, not agreement

Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center, Netherlands; Caroline B. Terwee, PhD, VU University Medical Center, Department of Epidemiology and Biostatistics, Netherlands; Lidwine B. Mokkink, VU University Medical Center, Netherlands; Dirk L. Knol, Department of Epidemiology and Biostatistics, VU University Medical Center

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Friday, 26 October, 1:15 pm – 2:15 pm

**(2047) Changes in Health-Related Quality of Life in patients with Heart Failure**

Antonio Escobar, PhD MD, Hospital Universitario Basurto, Spain; Esther Rekalde, Hospital Mendaro; Maria L. Fernandez-Soto, Hospital Universitario Donostia; Marta Gonzalez-Saenz de Tejada, Hospital Universitario Basurto; Iratxe Lafuente, Hospital Galdakao-Usansolo

 **(2048) Development and Preliminary Validation of the System of Quality of Life Instruments for Chronic Diseases (QLICD) in China**

Chonghua Wan, PhD, Guangdong Medical College, Peoples Republic of China; Zheng Yang, Guangdong Medical College, Peoples Republic of China; Xiaomei Li, Kunming Medical University; Xiaoqing Zhang, Kunming Medical University; Chuanzhi Xu, Kunming Medical University; Zhihuan Zhao, The first affiliated hospital of Kunming Medical University; Wu Li, The first affiliated hospital of Kunming Medical University; Zhaoping Lu, The first affiliated hospital of Kunming Medical University

**(2049) Items Analysis on General Module of the System of Quality of Life Instruments for Chronic Diseases (QLICD-GM) by Item Response Theory and Classical Test Theory**

Zheng Yang, Guangdong Medical College, Peoples Republic of China; Chonghua Wan, PhD, Guangdong Medical College, Peoples Republic of China; Xiaomei Li, Kunming Medical University; Chuanzhi Xu, Kunming Medical University; Zhihuan Zhao, The first affiliated hospital of Kunming Medical University; Liping Duan, The first affiliated hospital of Kunming Medical University; Hong Li, The first affiliated hospital of Kunming Medical University

**(2050) Religiosity and Health Related Quality of Life in Elderly People**

Gina A. Abdala, MPH, Brazil Adventist University, Brazil; Miako Kimura, PhD, University of Sao Paulo, School of Nursing, Brazil; Yeda Aparecida De Oliveira Duarte, PhD, University of Sao Paulo-Brazil, Brazil; Maria Lúcia Lebrão, University of Sao Paulo, Brazil; Lucas P. Damiani, University of Sao Paulo

**(2051) Quality of Life is a Process Not an Outcome**

Leah M. McClimans, PhD, University of South Carolina, United States; John Browne, PhD, University College Cork, Ireland

**(2052) Pre-testing the EORTC QLQ-ELD15 in patients aged 70 years and above with a haematological malignancy**

Colin Johnson, MChir, Dept of Surgery, United Kingdom; Sally J. Wheelwright, University of Southampton, United Kingdom; Deborah Fitzsimmons, Swansea University, United Kingdom; Teresa Young, BSc, Mount Vernon Hospital, United Kingdom

**(2053) Pregnancy complications, resilience and quality of life**

Eva Mautner, Medical University Graz, Austria; Christina Stern, Medical University Graz; Maria Deutsch, Medical University Graz; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; Uwe Lang, Medical University Graz; Mila Cervar-Zivkovic, Medical University Graz

**(2054) Scale-specific Minimal Important Differences of the thyroid-specific patient-reported outcome ThyPRO**

Torquil Watt, MD PhD, Copenhagen University Hospital, Denmark; Jakob Bjorner, PhD, National Research Centre for the Working Environment, Denmark; Steen J. Bonnema, Odense University Hospital; Laszlo Hegedüs, Odense University Hospital; Åse K. Rasmussen, Copenhagen University Hospital Rigshospitalet, Denmark; Ulla Feldt-Rasmussen, Copenhagen University Hospital; Mogens Groenvold, MD, PhD, University of Copenhagen, Denmark

**(2055) Comprehensive symptom profile in patients with breast cancer: practicability and sensitivity of the new symptom assessment tool CSP-Br**

Tatiana I. Ionova, Multinational Center for Quality of Life Research, Russian Federation; Denis A. Fedorenko, PhD, Nat'l Pirogov Med Surgical Ctr, Russia; Ivan V. Rykov, Regional Clinical Hospital, Saint-Petersburg, Russia; Tatiana Nikitina, PhD, Multinational Ctr for QoL Research, Russia; Kira A. Kurbatova, Multinational Center for Quality of Life Research, Russian Federation; Gary I. Gorodokin, New Jersey Center for Quality of Life and Health Outcomes Research, NJ, USA; Andrei Novik, MD PhD, National Medical Surgical Center, Russia

**(2056) Diminished Quality of Life Among U.S. Student Pharmacists: How Self-perception Toward Pharmacy Study Plays Role?**

Nalin Payakachat, BPharm, MS, PhD, Univ of Arkansas for Med Sci; Sarah E. Norman, Univ of Arkansas for Medical Sciences, United States; Anne Pace, Univ of Arkansas for Medical Sciences College of Pharmacy; Schwanda K. Flowers, Univ of Arkansas for Medical Sciences College of Pharmacy; Denise Ragland, Univ of Arkansas for Medical Sciences College of Pharmacy; Paul O. Gubbins, Univ of Arkansas for Medical Sciences College of Pharmacy

**(2057) Construct validity of two commonly used functional medicine instruments: Five Facet Mindfulness Questionnaire (FFMQ) and Medical Symptoms/Toxicity Questionnaire (MSQ)**

Duska M. Franic, PharmD, PhD, Univ of Georgia, College of Pharmacy; Cathy Snapp, Tallahassee Memorial Healthcare Foundation; Ruth DeBusk, Tallahassee Memorial Healthcare Foundation; Narayanan Krishnamoorthy, Tallahassee Memorial Healthcare Foundation

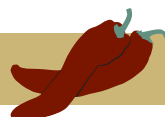
**(2058) Identifying symptom clusters in the endocrine scale of the Functional Assessment of Cancer Therapy Measurement System (The FACT-ES)**

Jacobien Kieffer, Ph.D, The Netherlands Cancer Institute, Department of Psychosocial Research, Netherlands; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Netherlands

**(2059) Who in the general population may experience poor health-related quality of life?**

Therese Djarv, MD PhD, Karolinska Institutet, Sweden; Anna Wikman, Karolinska Institutet, Sweden; Mohammed A. Johar, BSc(Hons), MSc, Karolinska Institutet, Sweden; Pernilla Lagergren, PhD RN, Karolinska Institute, Dept. of Molecular Med, Sweden

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Friday, 26 October, 1:15 pm – 2:15 pm

## (2060) Psychosocial Problems, Family Functioning and General Perception of Health

Juan J. Dapucto, MD, PhD, Facultad de Medicina, Universidad de la República, Uruguay; Laura De Souza, Institute of Clinical Psychology, Psychology, Universidad de la República; Nicolás Fiori, Faculty of Social Sciences; Claudia Antiga, University Health Division, Universidad de la República; Iris Dutra, Faculty of Nursing, Universidad de la República; Darío Padula, Faculty of Psychology, Universidad de la República; Raúl Ramírez, Faculty of Economics

## (2061) Evaluation of fatigue levels among workers affected by the East Japan Great Earthquake in order to determine health care needs and prevent disaster-related disease

Toshiko Yoshida, PhD, Miyagi Univ School of Nursing, Japan; Daisuke Sato, Miyagi University; Toshie Sawaguchi, Miyagi University; Yukie Yamada, Miyagi University, Japan; Makoto Shimoyama, Miyagi University; Masayasu Inoue, Miyagi University; Hirohiko Kuratsune, Kansai University of Welfare Sciences

## (2062) The DysDD: a new patient assessment for dysmenorrhea

Josephine M. Norquist, MS, Merck Sharp & Dohme Corp.; Louise Humphrey, Adelphi Values; Helen Kitchen, Adelphi Values, United Kingdom; Ellen Mommers, Merck Sharp & Dohme, Corp.; Tayyaba Rehman, Merck Sharp & Dohme, Corp.; Allison Martin, MHA, Merck & Co. Inc. Pharmaceuticals

## (2063) Cognition and functional recovery after hip fracture

Gian Jhangri, University of Alberta; Allyson Jones, PhD, University of Alberta, Dept. of Physical Therapy, Canada; David Feeny, PhD, University of Alberta, United States

## (2064) Inside the black box: Patients' attitudes to PRO assessment

Rebecca L. Mercieca-Bebber, The University of Sydney, Australia; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; Phyllis Butow, PhD, University of Sydney, School of Psychology, Australia

## (2065) Subjective well-being and six-year survival among very old people living in a Japanese community

Hajime Iwasa, PhD, Tokyo Metropolitan Institute of Gerontology, Japan; Yasuyuki Gondo, Osaka University; Yukie Masui, Tokyo Metropolitan Institute of Gerontology, Japan; Hiroki Inagaki, Tokyo Metropolitan Institute of Gerontology

## (2066) Equating scores on two dermatology-specific patient-reported outcome measures

James Twiss, BSc, Galen Research Ltd, United Kingdom; Stephen P. McKenna, PhD, Galen Research Ltd., United Kingdom

## (2067) Outcomes of a secondary preventive self-management program in occupational skin disease

Katja Spanier, M.A., Hannover Medical School, Coordination Centre for Applied Rehabilitation Research, Germany; Matthias Lukaszczik, University of Wuerzburg, Germany; Sandra Nolte, PhD, Deakin University, Australia, Germany; Ute Pohrt, (4) Inst. for Statutory Accident Insurance and Prevention; Michael Schuler, University of Wuerzburg; Monika Schwarze, Medical School Hannover, Germany

## (2068) Development and Evaluation of a Syndrome Diagnostic Instrument for Angina: Syndrome Differentiation Questionnaire of Qi Deficiency and Blood Stasis (SDQ-QDBS)

Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

## (2069) The application of the Health Education Impact Questionnaire (heiQ) in Japan – adaptation and validation of a measure to evaluate chronic disease self-management interventions

Sandra Nolte, PhD, Deakin University, Australia, Germany; Rie Morita, Division of Health Sciences, Osaka University; Mikako Arakida, International University of Health and Welfare; Hiroshi Mikami, Osaka University, Japan; Gerald R. Elsworth, Deakin University; Richard H. Osborne, Deakin University

## (2070) The Outcomes and Experiences Questionnaire: Development and Content Validation

Elizabeth J. Gibbons, MSc, University of Oxford, United Kingdom; Carolina Casanas I Comabella, PROM Group, University of Oxford; Monica Hadi, PhD, University of Oxford, United Kingdom; Anne Mackintosh, BA, PROM Group, Univ of Oxford, United Kingdom; Raymond Fitzpatrick, PhD, Univ of Oxford, Dept of Public Hlth, United Kingdom

## (2071) Effect of recall period on item responses to activity limitation items in multiple sclerosis

Peter Hagell, Kristianstad University, Sweden

## (2072) Which scales in the thyroid-specific patient-reported outcome ThyPRO are most responsive to treatment of Graves' disease?

Per Cramon, Copenhagen University Hospital, Denmark; Jakob Bjorner, PhD, National Research Centre for the Working Environment, Denmark; Steen J. Bonnema, Odense University Hospital; Laszlo Hegedüs, Odense University Hospital; Ulla Feldt-Rasmussen, Copenhagen University Hospital; Åse K. Rasmussen, Copenhagen University Hospital Rigshospitalet, Denmark; Mogens Groenvold, MD, PhD, University of Copenhagen, Denmark; Torquil Watt, MD PhD, Copenhagen University Hospital, Denmark

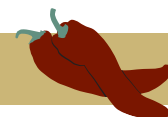
## (2073) Using the Personal Wellbeing Index (PWI) in a population living with HIV

Vicki E. Hutton, Monash University; Roseanne Misajon, Monash University, Australia

## (2074) Improving PRO content analysis using World Health Organization definitions and the ICF

Nora Fayed, University Health Network, Canada; Alarcos Cieza, Ludwig-Maximilians-Universität, Munich, Germany

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Friday, 26 October, 1:15 pm – 2:15 pm

**(2076) Adherence to long term quality of life questionnaires in localised high risk prostate cancer and causes of non compliance**

Abdenour Nabid, MD, FRCP(C), Centre hospitalier Universitaire de Sherbrooke, Canada; Nathalie Carrier, Centre hospitalier Universitaire de Sherbrooke; André-Guy Martin, Hôtel-Dieu de Québec, Canada; Jean-Paul Bahary, MD, FRCP, Centre Hospitalier de L'Université de Montréal, Canada; Marie Duclos, Centre Universitaire de Santé McGill; Francois Vincent, Centre hospitalier régional de Trois-Rivières; Sylvie Vass, CSSS de Chicoutimi; Boris Bahoric, Hôpital général juif; Robert Archambault, Hôpital de Gatineau; Céline Lemaire, Hôpital Maisonneuve-Rosemont, Canada

**(2077) Assessing Quality of Care in Lung Transplant Patients**

Maria-Jose Santana, PhD, University of Calgary, Canada; David Feeny, PhD, University of Alberta, United States; Sunita Ghosh, University of Alberta; Dale C. Lien, University of Alberta, Canada

**(2078) Comparing two methods for longitudinal analysis on questionnaire data: multilevel analysis versus multilevel IRT analysis.**

Rosalie Gorter, VU University Medical Centre, Netherlands; Michiel R. De Boer, VU University, Amsterdam, The Netherlands; Martijn W. Heijmans, VU University Medical Centre, Amsterdam, The Netherlands; Jos WR Twisk, VU University Medical Centre, Amsterdam, The Netherlands

**(2079) Measuring the Quality of Care Delivered to Patients Suffering from a Rare Disease**

San Keller, PhD, American Institutes for Research; Christian Evensen, American Institutes for Research; Roger Levine, American Institutes for Research; Marsha Treadwell, Children's Hospital and Research Center at Oakland

**(2080) Towards a Meaningful Patient Report Outcomes Measures (PROMs) for Patients with MPSIII**

Vanessa M. Ferreira, Lysogene, France

**(2081) Identifying Cancer Patients with High Levels of Treatment-related Neuropathy and Other Symptoms in Response to Oxaliplatin-based Chemotherapy**

Xin Shelley Wang, MD MPH, UT MD Anderson Cancer Center; Charles S. Cleeland, PhD, UT-MD Anderson Cancer Center; Mary Sailors, MDACC; Raza Bokhari, MDACC; Cathy Eng, MDACC

**(2082) Thanks for the Score Report -- But What Does It Mean? Helping Clinicians Interpret Patient-Reported Outcome (PRO) Scores by Identifying Cut-offs Representing Unmet Needs**

Claire Snyder, PhD, Johns Hopkins; Amanda Blackford, Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins; Toru Okuyama, Nagoya City University Graduate School of Medical Sciences; Tatsuo Akechi, Nagoya City University Graduate School of Medical Sciences, Japan; Hiroko Yamashita, Hokkaido University Hospital; Tatsuya Toyama, Nagoya City University Graduate School of Medical Sciences; Michael Carducci, Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins; Albert W. Wu, MD MPH, Johns Hopkins Bloomberg School of Public Health

**(2083) Oral health-related quality of life and self-rated health in middle and older aged Thai adults**

Tewarit Somkotra, Chulalongkorn University; Vasoontara Yiengprugsawan, The Australian National University, Australia; Samang Seubsman, Sukhothai Thammathirat Open University; Adrian Sleigh, The Australian National University

**(2084) Improving the Linguistic Validation Process of Patient Reported Outcomes Instruments into South African Languages**

Mary C. Gawlicki, MBA, Corporate Translations, Inc., United States; Shawn McKown, MA, Corporate Translations, Inc.; Matthew Talbert, Corporate Translations; Barbara A. Brandt, MA, Corporate Translations, Inc., United States

**(2085) Limitations of the social relationships domain of WHOQOL-Bref**

Brigida F. Patricio, MSc, Escola Superior de Tecnologia da Saude do Porto, Instituto Politecnico do Porto, Portugal; Luis M.T. Jesus, Universidade de Aveiro; Madeline Cruice, PhD, Dept of Language & Communication Science, United Kingdom; Andreia Hall, Universidade de Aveiro

**(2086) Older Adults' Quality of Life and Adjustment to Aging: Findings from SF-6D and ATAS-33**

Sofia Von Humboldt, MSc, Research Unit in Psychology and Health; ISPA – Instituto Universitário, Portugal; Isabel Leal, PhD, UIPES-Health & Psychology Investigation Unit, Portugal

**(2087) How does Spinal Stenosis affect health-related Quality of Life of Chinese Older People?**

Chi Yan Yeung, The Open University of Hong Kong, Hong Kong; Doris S.F. Yu, The Chinese University of Hong Kong, Hong Kong

**(2088) Association between smoking status and oral health-related quality of life among Japanese adults: LEMONADE study**

Mariko Naito, DDS PhD, Nagoya University Graduate School of Medicine, Japan; Kenji Wakai, Nagoya University Graduate School of Medicine; Toru Naito, Fukuoka Dental College, Japan; Haruo Nakagaki, Aichi-Gakuin University; Nobuhiro Hanada, Tsurumi University; Takashi Kawamura, Kyoto University Health Service

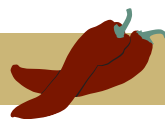
**(2090) Developing and Pilot-Testing a self-report version of the child health care questionnaire on satisfaction, utilization and needs (CHC-SUN) for children and adolescents with chronic health conditions**

Silke Schmidt, PhD, University of Greifswald, Germany; Carsten Herrmann, Ernst-Moritz-Arndt-University; Holger Muehlan, Ernst-Moritz-Arndt University Greifswald, Germany, Germany; Franziska Bomba, University of Luebeck; Ute Thyen, MD, Universitaetsklinikum Schleswig-Holstein, Germany

**(2091) Crohn's Disease: Symptoms, functional limitations and quality of life**

Stephen P. McKenna, PhD, Galen Research Ltd., United Kingdom; Jeanette Wilburn, Galen Research Ltd; James Twiss, BSc, Galen Research Ltd, United Kingdom; Mitra Ben-Lamri, BSc, MPhil, Galen Research Ltd, United Kingdom; Karen Kemp, Dept of Gastroenterology, Manchester Royal Infirmary, UK; Simon Campbell, Dept of Gastroenterology, Manchester Royal Infirmary, UK

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# Poster Sessions

Friday, 26 October, 1:15 pm – 2:15 pm

## (2092) Discrepancies in the Onset of Disease as Shown by Quality of Life (QOL) Among Patients with Angina

Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Wang Yang, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

## (2093) Comparisons of Psychometric Properties of the WHOQOL-BREF Between Mainland China and Taiwan in Early Adolescence

Grace Yao, PhD, Dept of Psychology, Nat'l Taiwan Univ, Taiwan; Zhaoming Guo, College of Educational Science, Yangzhou University, Mainland China

## (2094) Health-related quality of life in persons with COPD attending self-management courses and pulmonary rehabilitation compared with the general population

Randi Andenas, PhD, Oslo and Akershus University College, Norway; Kari Hvinden, Glittrelinikken; May Solveig Fagermoen, Oslo University Hospital, Department of Gastroenterology; Anners Lerdal, Lovisenberg Deaconale University College

(2095) Development of a checklist to comply with the FDA review requirements for the translation of PRO instruments  
Isabelle Mear, Mapi Research Institute, France; Caroline Anfray, MAPI Institute, France; Katrin Conway, MA, MAPI Research Trust, France

## 🏆 (2096) Patient reported outcome measures: a revised model-based classification system for research and clinical practice

Jose M. Valderas, MD PhD MPH, University of Oxford, United Kingdom; Daniela C. Gonçalves, University of Oxford, United Kingdom; Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Spain

## (2097) A Comprehensive Review of the Validation and Clinical Application of the Infant Dermatitis Quality of Life (IDQoL) Index

Sam Salek, BSc RPh PhD FFPM, Cardiff University, Redwood Bldg, United Kingdom; Vrutti Gada, Cardiff University; Mohammad K.A. Basra, MD, Cardiff University, United Kingdom; Andrew Finlay, FRCP, Univ. of Wales College of Medicine, United Kingdom

## (2098) The Dermatitis Family Impact Instrument: An Evaluation of its Psychometric Properties and Clinical Application

Sam Salek, BSc RPh PhD FFPM, Cardiff University, Redwood Bldg, United Kingdom; Sean Dodington, Cardiff University; Mohammad K.A. Basra, MD, Cardiff University, United Kingdom; Andrew Finlay, FRCP, Univ. of Wales College of Medicine, United Kingdom

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- self-complete and interview formats

### HUI has ...

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- utility scoring formulas based on preferences of various communities

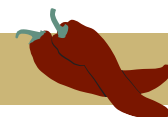
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Saturday, 27 October, 3:15 pm – 4:15 pm

## ERZSÉBET BALLROOM

### (3001) Psychometric properties of the KIDSCREEN-27 in Brazilian children and adolescents

Silvia M S Rodrigues, MD MSc, Universidade Federal do Pará, Brazil; Janari S. Pedrosa, Universidade Federal do Pará; Fernando Augusto R. Pontes, Universidade Federal do Pará; Christoph O. Kappeler, Technische Universität Dortmund; Celina Maria C. Magalhães, Universidade Federal do Pará, Brazil

### (3002) Applicability of the WHOQOL-BREF on Early Adolescence in China

Zhaoming Guo, College of Educational Science, Yangzhou University, Mainland China; Grace Yao, PhD, Dept of Psychology, Nat'l Taiwan Univ, Taiwan

### (3003) Evaluation of the measurement properties of the Children's Dermatology Life Quality Index (CDLQI)

Sam Salek, BSc RPh PhD FFPM, Cardiff University, Redwood Bldg, United Kingdom; Soora Jung, Cardiff University; Mohammad K.A. Basra, MD, Cardiff University, United Kingdom; Andrew Finlay, FRCP, Univ. of Wales College of Medicine, United Kingdom

### (3004) Brazilian children and adolescents infected with HIV: the initial stage of development an instrument of health-related Quality of Life - DISABKIDS Group

Maria Fernanda Cabral Kourrouski, University of São Paulo, Brazil; Isabella S. Abreu, Universidade de São Paulo, Brazil; Ana Carolina Gomes Martins Oliveira, University of São Paulo, Brazil; Danielle Maria S S dos Santos, MD, University of São Paulo, Brazil; Keila C. Deon, MD, University of São Paulo, Brazil; Maria Célia Cervi, University of São Paulo; Roberta A. Reis, PhD, Universidade Federal do Rio Grande do Sul, Brazil; Lucila Castanheira Nascimento, University of São Paulo, Brazil; Claudia Benedicta dos Santos, MISP-EERP-USP, Germany; Regina Aparecida Garcia de Lima, University of São Paulo, Brazil

### (3005) Effect of resistance exercise on quality of life of mothers of children and adolescents with cerebral palsy

Nivea Morales, MD; MSc; PhD, Federal University of Uberlândia, Brazil; Moisés Rosa Batista, Sr., Professor, Universidade Federal de Uberlândia, Brazil; Jaqueline Pontes Batista, Federal University of Uberlândia; Jussara Caetano Furtado, Federal University of Uberlândia; Jorge Guto Mendes, Federal University of Uberlândia; Hygor Nunes Araujo, Federal University of Uberlândia; Eduardo Henrique Tavares, Federal University of Uberlândia; Luiz Duarte Rocha, Jr., Federal University of Uberlândia; Rogério M C Pinto, Federal University of Uberlândia; Carlos Henrique M. Silva, Federal University of Uberlândia

### (3006) Young Adults with Disability Benefits

Eefje Verhoof, Emma Childrens Hospital; Heleen Maurice-Stam, MSc, Emma's Children's Hosp, Academic Medical Ctr, Netherlands; Hugo Heymans, Emma Childrens Hospital; Martha Grootenhuis, PhD, Academic Medical Center, Netherlands

### (3007) Family burden and quality of life of parents of children with a diagnosis of congenital anomaly: The mediating role of parenting stress

Marco Pereira, Universidade de Coimbra, Portugal; Sara Albuquerque, University of Coimbra; Ana Fonseca, University of Coimbra; Maria Cristina Canavarró, Universidade de Coimbra, Portugal

### (3008) Self and Proxy Evaluation of HRQOL in Turkish Epileptic Children by Using KINDL

Dilek Ergin, celal bayar university, Turkey; Erhan Eser, MD, Celal Bayar University, School of Medicine, Dept. Public Health, Turkey; Muzaffer Polat, Celal Bayar University; Pinar Yazici, Celal Bayar University

### (3010) Psychometric Properties of KIDSCREEN-27 among Childhood Cancer Survivors and Age Matched Peers - A Rasch Analysis

Anna Jervaeus, Karolinska Institutet, Sweden; Anders Kottorp, Karolinska Institutet; Lena Wettergren, PhD, Karolinska Institute, Sweden

### (3011) Quality of Life in Caregivers Who Take Care of Family Patients with Hemodialysis

Takashi Mandai, MD, Japanese Society of Quality of Life Research, Japan; Hiromasa Hirai, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Takashi Nakano, Japanese Society of Quality of Life Research, Japan; Satio Kawanishi, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Kunio Nakayama, Japanese Society of Quality of Life Research, Japan; Yuri Kitamura, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Rika Hayashida, MS, Siebold Univ of Nagasaki, Japan; Michiko Kobayashi, MD PhD, Kwassui Women's College, Japan; Atsuhiko Fukuoka, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN; Kozaburo Adachi, PhD, Agape-Kabutoyama Hospital, Japan

### (3012) Differences in mothers' and fathers' quality of life (QoL) of children treated for acute leukemia (AL)

Patricia Minaya Flores, MA, Laboratoire de Sante Publique EA3279, France; Gérard Michel, Pediatric Haematology Departments, University Hospital of Marseille, France; Julie Berbis, Department of Public Health, Medicine University, France; Pascal Auquier, PhD, Laboratoire de Sante Publique, France

### (3013) The QOL of Dementia Caregivers

Michiko Kobayashi, MD PhD, Kwassui Women's College, Japan; Yuzaburo Hirata, Matsuura City Office, Matsuura, Nagasaki, Japan; Takashi Mandai, MD, Japanese Society of Quality of Life Research, Japan

### (3014) The Practice of Mindful Yoga and Breath Awareness Meditation in Promoting Health

Fusako Nakamachi, MS, Tokyo Kasei-gakuin University, Japan; Ikuko Yamaguchi, Japanese Society for Mindful Living; Yoshiro Konishi, Japanese Society for Mindful Living; Yutaka Haruki, Japanese Society for Mindful Living; Hidehumi Oga, Japanese Society for Mindful Living, Japan

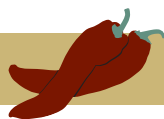
### (3015) Psychological Effects of Hill Walking at Kaminoyama Japan - Relations among Mood Alteration, Weathers and Trail Characteristics

Kayoko Machida, Sapporo City University, Japan; Hirofumi Ueda, Sapporo City University; Namiko KAWAMURA, Oita university; Nobuyuki KOSEKI, Kurort Lab.

### (3016) Review of methods used to translate neurocognitive assessments

Christelle Giroudet, MAPI Institute; Caroline Anfray, MAPI Institute, France

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**Saturday, 27 October, 3:15 pm – 4:15 pm**

**(3017) Relationship between outcome of hospitalization for the first episode of acute coronary syndrome and baseline health-related quality of life and depression**

Carina M. Dessotte, University of São Paulo; Gislaine P. Gil, University of São Paulo; Márcia A. Ciol, University of Washington; Lidia A. Rossi, PhD, University of São Paulo, Brazil; Fernanda S. Silva, University of São Paulo; André Schmidt, School of Medicine of Ribeirão Preto, University of São Paulo; Rosana Spadoti Dantas, PhD, University of São Paulo, Brazil

**(3018) Evaluation of the impact of the psychiatric hospitalization on quality of life**

Gabriela L. Nuernberg, Universidade Federal do Rio Grande do Sul, Brazil; Eduardo Trachtenberg, Universidade Federal do Rio Grande do Sul; Fernanda Baeza, Universidade Federal do Rio Grande do Sul; Thiago V. Freire, Hospital de Clínicas de Porto Alegre; Martina Kopittke, Hospital de Clínicas de Porto Alegre; Bruno P. Mosqueiro, Hospital de Clínicas de Porto Alegre, Brazil; Felipe B.P. Costa, Hospital de Clínicas de Porto Alegre; Tatiana K. Sansonowicz, Universidade Federal do Rio Grande do Sul; Marcelo P. Fleck, PhD, Hospital de Clínicas de Porto Alegre, Brazil; Neusa Rocha, MD, Universidade Federal do Rio Grande do Sul, Brazil

**(3020) Are patients in the United Kingdom receiving written information about health related quality of life following oesophageal cancer surgery?**

Sean Strong, Bmed, MRCS, MSC, University of Bristol, United Kingdom; Natalie Blencowe, University of Bristol; Rhiannon C. Macefield, University of Bristol, United Kingdom; Sara Brookes, University of Bristol; Joanne Nicklin, University Hospital Bristol NHS Foundation Trust; Kerry Avery, PhD, Dept of Social Med, Univ of Bristol, United Kingdom; Jane Blazehy, MD, University of Bristol, United Kingdom

**(3022) Oncologists' perceptions of psychosocial communication during outpatient visits – Barriers and orientation**

Hanna Fagerlind, Uppsala University, Sweden; Åsa Kettis, Uppsala university; Bengt Glimelius, Uppsala university; Lena Ring, PhD, Medical Products Agency (MPA) and Uppsala University, Sweden

**(3023) Framework and criteria to sort, select and reduce measurement instruments for daily practice in physical therapy**

Anna Beurskens, PhD, Zuyd University of applied sciences, Netherlands; Guus Meerhoff, Royal Dutch Society of Physical Therapy, Netherlands; Victorine De Graaf-Peters, Royal Dutch Society of Physical Therapy; Raymond Swinkels, Zuyd University of applied sciences

**(3024) Surgical decision in breast cancer: impact on Health Related Quality of Life**

Teresa Sequeira, Portugal; Ariana Santos, Portuguese Oncology Institute, Porto, Portugal; Joaquim Gonçalves, Polytechnic Institute of Cávado & Ave, Portugal; Cláudia C. Ribeiro, Universidade Católica Portuguesa, Portugal; Joana Teixeira, Nurse, Portuguese Oncology Institute, Porto, Portugal; Joaquim Abreu Sousa, Portuguese Oncology Institute, Porto, Portugal; Augusta Silveira, University Fernando Pessoa, Portugal

**(3025) Does thyroid disease affect work function? Results from a qualitative study**

Mette A. Nexø, PhD Student, The National Research Centre for the Working Environment, Denmark; Torquil Watt, MD PhD, Copenhagen University Hospital, Denmark; Ulla Feldt-Rasmussen, Copenhagen University Hospital; Åse K. Rasmussen, Copenhagen University Hospital Rigshospitalet, Denmark; Steen J. Bonnema, Odense University Hospital; Laszlo Hegedüs, Odense University Hospital; Mogens Groenvold, MD PhD, University of Copenhagen, Denmark; Jakob Bjorner, PhD, National Research Centre for the Working Environment, Denmark

 **(3026) Reliability and Validity of the Psoriasis Symptom Inventory in Patients with Moderate to Severe Psoriasis**

Dennis Revicki, PhD, United BioSource Corporation; Ying Jin, United BioSource Corporation; Dina Chau, Amgen Inc; Hema Viswanathan, Amgen, Inc.

**(3028) Developing and pre-testing an item pool relating to the effects of exposure to health websites.**

Laura Kelly, PhD, United Kingdom; Sue Ziebland, University of Oxford, United Kingdom; Crispin Jenkinson, Health Services Research Unit, United Kingdom

**(3029) Identification and classification of individualized patient-reported outcome measures**

Daniela C. Gonçalves, University of Oxford, United Kingdom; Ignacio Ricci-Cabello, University of Oxford; Jose M. Valderas, MD, PhD, MPH, University of Oxford, United Kingdom

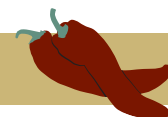
**(3030) Patient-Reported Quality of Life Outcomes After Cystectomy for Bladder Cancer: A Comparison of Open and Robotic-Assisted Laparoscopic Techniques**

Jeffrey S. Montgomery, University of Michigan; John M. Hollingsworth, University of Michigan, Department of Urology, United States; Change He, University of Michigan; Scott Gilbert, University of Florida, Department of Urology; John T. Wei, MD, University of Michigan, United States; Rodney Dunn, MS, University of Michigan Dept of Urology; Brent Hollenbeck, MD, MS, University of Michigan; Alon Z. Weizer, University of Michigan

**(3033) Analysis for DIF in the Spanish PROMIS Pain Interference Item Bank**

Leo Morales, MD, Group Hlth Research Institute; Sylvia H. Paz, PhD, UCLA; Karen L. Spritzer, UCLA; Ronald D. Hays, PhD, UCLA David Geffen

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**Saturday, 27 October, 3:15 pm – 4:15 pm**

**(3034) Dutch-Flemish translation of the PROMIS item banks**

Caroline B. Terwee, PhD, VU University Medical Center, Department of Epidemiology and Biostatistics, Netherlands; Leonard Roorda, MD PhD, Netherlands; Maarten Boers, VU University Medical Center, Department of Epidemiology and Biostatistics; Joost Dekker, VU University Medical Center, Department of Rehabilitation Medicine, Amsterdam, the Netherlands; Rene Westhovens, University Leuven, Belgium, Belgium; Jaap van Leeuwen, CEO Leones Group BV, the Netherlands; Martha Grootenhuis, PhD, Academic Medical Center, Netherlands; Lotte Havermann, Emma Children's Hospital/AMC, Psychosocial Department, Amsterdam, the Netherlands; Hein Raat, Erasmus MC, University Medical Center, Department of Public Health, Rotterdam, the Netherlands; Eline van Dulmen-den Broeder, VU University Medical Center, Department of Pediatrics, Amsterdam, the Netherlands; Marion AJ van Rossum, Amsterdam Rehabilitation Research Center, and Emma Children's Hospital/AMC, Psychosocial Department, Amsterdam, the Netherlands; Karel Hoppenbrouwers, Centre of Youth Health Care, KU Leuven, Belgium; Helena Correia, Northwestern University, United States; Benjamin J. Arnold, MA, FACITtrans, Brazil; David Cella, PhD, Northwestern University; Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center, Netherlands

**(3035) The Use of EuroQoL-5D in Pharmacoeconomic Studies of Dermatological Treatments: Is it Relevant?**

Sam Salek, BSc RPh PhD FPPM, Cardiff University, Redwood Bldg, United Kingdom; Mohammad K.A. Basra, MD, Cardiff University, United Kingdom; Flavia Pereira, Cardiff University; Vicent Piquet, Cardiff University; Andrew Finlay, FRCP, Univ. of Wales College of Medicine, United Kingdom

**(3036) Language and Age Equivalence in the Patient-Reported Outcomes Information System (PROMIS®) Physical Functioning Items**

Sylvia H. Paz, PhD, UCLA; Karen L. Spritzer, UCLA; Leo Morales, MD, Group Hlth Research Institute; Ronald D. Hays, PhD, UCLA David Geffen

**(3037) Using the PROMs Data to Understand and Interpret Changes in EQ-5D Scores**

Fang-Ju Lin, University of Illinois at Chicago, United States; Jennifer C. Samp, University of Illinois at Chicago; Alexis R. Munoz, University of Illinois at Chicago; Pei Shieen Wong, University of Illinois at Chicago; Simon Pickard, PhD, University of Illinois at Chicago, College of Pharmacy, United States

**(3039) Quality of life predictors for Portuguese general population**

Brigida F. Patricio, MSc, Escola Superior de Tecnologia da Saude do Porto, Instituto Politecnico do Porto, Portugal; Luis M.T. Jesus, Universidade de Aveiro; Madeline Cruice, PhD, Dept of Language & Communication Science, United Kingdom; Andreia Hall, Universidade de Aveiro

**(3040) Quality of Life and Subjective Age in Southern European Older Adults: A Comparative Multiple Correspondence Analysis for Latent Constructs**

Sofia Von Humboldt, MSc, Research Unit in Psychology and Health; ISPA – Instituto Universitário, Portugal; Isabel Leal, PhD, UIPEs-Health & Psychology Investigation Unit, Portugal

**(3042) Dyspnea and quality of life (QOL) in patients with COPD**

Ljiljana M. Danojevic, MD, Health Care Centre Grocka, Serbia; Srdjan R. Dimitrijevic, no; Zeljka D. Bozalo, Spomenak

**(3043) An extended study of the psychometric properties TCM-SAQ-QBS: Traditional Chinese Medicine Syndrome of Angina Questionnaire-Phlegm and Blood Stasis syndrome pattern**

Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Lv Meijun, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Wang Yang, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

**(3044) Instrument and Translation Errors That Can Be Caused By Use of Upgraded Indian Fonts**

Kimberley Ahchak, Health Research Asia; Beng Li Ting, Health Research Asia, Singapore; Mona L. Martin, RN MPA, Health Research Associates, Inc.

**(3045) Return to work and quality-of-life in workers with traumatic limb injuries: A 2-year repeated measurements study**

Wen-Hsuan Hou, E-Da Hospital & I-Shou University, Taiwan; Chung-Yi Li, Taiwan; Huey-Wen Liang, National Taiwan University Hospital, Taiwan

**(3046) Health related quality of life as an independent predictor of long-term disability for patients with relapsing remitting multiple sclerosis**

Karine Baumstarck, France; Jean Pelletier, Neurology, Timone University Hospital, Marseille, France; Helmut Butzkueven, MS Unit, Melbourne, Victoria, Australia; Oscar Fernández, Institute of Clinical Neurosciences, Málaga, Spain; Peter Flachenecker, Neurological Rehabilitation Center Quellenhof, Bad Wildbad, Germany; Egemen Idiman, Department of Neurology, Dokuz Eylul University, Izmir, Turkey; Sergio Stecchi, Multiple Sclerosis Unit, Department of Neuroscience AUSL, Bologna, Italy; Pascal Auquier, PhD, Laboratoire de Sante Publique, France

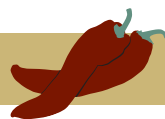
**(3047) Measuring subjective symptoms in COPD and their impact on quality of life**

Muirne CS Paap, University of Twente, Netherlands; Cees AW Glas, University of Twente; Benjamin Forstreuter, University of Twente; Job Van Der Palen, Medisch Spectrum Twente

**🏆 (3048) A review of the existing EORTC quality of life measures in Spanish: response scales evaluation**

Maria Arnott, EORTC; Michael Koller, PhD, Center for Clinical Studies, Germany; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; Andrew Bottomley, PhD, EORTC Headquarters, Belgium; Cheryl Whittaker, EORTC; Dagmara Kulis, EORTC, Belgium

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# Poster Sessions

Saturday, 27 October, 3:15 pm – 4:15 pm

## (3049) Has the quality of systematic reviews of measurement properties improved over time?

Caroline B. Terwee, PhD, VU University Medical Center, Department of Epidemiology and Biostatistics, Netherlands; Lidwine B. Mokkink, VU University Medical Center, Netherlands; Arnela Haagmans-Suman, VU University Medical Center, Department of Epidemiology and Biostatistics; Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center, Netherlands

## 🏆 (3050) Assessing quality of life in new regions of the World: Further development of the PsAQoL

Mitra Ben-Lamri, BSc, MPhil, Galen Research Ltd, United Kingdom; Stephen P. McKenna, PhD, Galen Research Ltd., United Kingdom; Jeanette Wilburn, Galen Research Ltd; James Twiss, BSc, Galen Research Ltd, United Kingdom

## (3051) The Added Clinical Value of Health-Related Quality of Life Research: Major Outcomes of the Pooled Analysis of Phase III Randomised Clinical Trials

Efstathios Zikos, MSc, MA, EORTC HQ, Belgium; Divine Ewane Ediebah, MSc., EORTC HQ, Belgium; Corneel Coens, MSc, EORTC HQ, Belgium; Chantal Quinten, MSc, EORTC, Belgium; Jolie Ringash, MD, The Princess Margaret Hospital, Canada; Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, United States; Charles S. Cleeland, PhD, UT-MD Anderson Cancer Center; Henning H. Flechtner, PhD, Otto-von-Guericke University (KKJP), Germany; Carolyn C. Gotay, PhD, UBC School Pop & Pub Health, Canada; Eva Elfriede Greimel, PhD, Medical University Graz, Austria; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Australia; David Osoba, FRCPC, QOL Consulting, Canada; Joseph Schmucker von Koch, PhD, University of Regensburg, Medical Ethics, Regensburg, Germany; Martin Taphoorn, Department of Neurology, MC Haaglanden, The Hague, The Netherlands; Joachim Weis, PhD, University of Freiburg, Psychooncology, Freiburg, Germany; Andrew Bottonley, PhD, EORTC, Quality of Life Department, Brussels, Belgium, on behalf of the European Organisation for Research and Treatment of Cancer (EORTC) and the Patient-Reported Outcome and Behavioural Evidence (PROBE)

## (3052) Impact of Socioeconomic factors and co-morbidity on Health-Related Quality of life in a Multi-ethnic HIV Cohort

Sherly George, PhD Student, University College Dublin, Ireland, Ireland; Michael Gibney, Institute of Food and Nutrition, University College Dublin; Fiona Mulcahy, St James's Hospital, Dublin, Ireland; Mary Codd, University College Dublin

## (3053) Quality of Life (QoL) in older adults: Survey data based on self-assessment versus face-to-face interview

Liv Halvorsrud, Diakonova University College, Norway, Norway; Mary Kalfoss, DrPH, Diakonova University College, Norway

## 🏆 (3054) Development of Asthma-Specific Quality of Life Items for Item Banking

Cathy Sherbourne, PhD, The RAND Corporation; Nicole K. Eberhart, RAND Corporation; Maria Orlando Edelen, PhD, RAND Corp.; Brian D. Stucky, RAND Corporation, United States; Marielena Lara-Greenberg, RAND Corporation; Nancy Sin, UC Riverside

## (3055) Satisfaction with the Drug Therapy Among Patients with Coronary Heart Disease: Psychometric Performance of the Brazilian Version of the Treatment Satisfaction Questionnaire for Medication - TSQM (Version 1.4)

Ana Carolina S. Liberato, Master's Student, University of Campinas, Brazil; Roberta CM Rodrigues, University of Campinas; Thais M. Spana, University of Campinas; Fernanda F. Januzzi, University of Campinas; Maria Cecília BJ Gallani, Université Laval

## 🏆 (3057) Development of a computer-adaptive version of the Forgotten Joint Score for outcome assessment after total knee arthroplasty

Johannes M. Giesinger, PhD, Innsbruck Medical University, Austria; Markus S. Kuster, Department of Orthopaedic Surgery, Royal Perth Hospital; Bernhard Holzner, PhD BE, Univ. Hospital, Innsbruck, Austria; Karlmeirad Giesinger, Department of Orthopaedic Surgery, Kantonsspital St. Gallen

## (3058) Clinician and Patient Ratings of Severity Compared with Short Assessment Tools for Urinary Incontinence

Janet E. Sansoni, MSc, University of Wollongong, Australia; Glenn Fleming, University of Wollongong; Graeme Hawthorne, PhD, Univ of Melbourne, Australia; Nicholas Marroszky, University of New South Wales Global, Australia

## (3059) Linking of at-work disability scales to the ICF

Vanitha Arumugam, PT, MPT, University of Western Ontario, Canada; Joy MacDermid, PhD, McMaster University, Canada; Ruby Grewal, University of Westren Ontario

## (3060) Quality of life in people living with HIV in a resource limited setting-Uganda

Doris M. Mwesigire, MD, Makerere University, Uganda

## (3061) What do we assess about health when we assess self-reported general health?

Cristina N. Bostan, University of Lucerne, University of Lucerne, Lucerne, Switzerland, Switzerland; Cornelia Oberhauser, Ludwig-Maximilians-Universität, Germany; Alarcos Cieza, Ludwig-Maximilians-Universität, Munich, Germany

## (3062) Surgical Decision-Making in Women with Hereditary Breast Cancer Risk Who Develop Breast Cancer

Marlene H. Frost, PhD, Mayo Clinic; Tanya L. Hoskin, Mayo Clinic; Constance I. Williams, Mayo Clinic; Teresa M. Allers, Mayo Clinic; Amy C. Degnim, Mayo Clinic; Lynn C. Hartmann, Mayo Clinic; Judy C. Boughey, Mayo Clinic

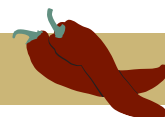
## (3063) Sarcoma patient's Quality of Life: understanding clinical and social-demographical aspects

Ana Maria Almeida, Instituto Português de Oncologia, Portugal; Teresa Sequeira, Portugal; Joaquim Gonçalves, Polytechnic Institute of Cávado & Ave, Portugal; Cláudia C. Ribeiro, Universidade Católica Portuguesa, Portugal; Matilde Ribeiro, Portuguese Oncology Institute, Porto, Portugal; Augusta Silveira, University Fernando Pessoa, Portugal

## (3064) Sense of belonging to the community of care and quality of life in chronic illness

Chiara Guglielmetti, Università degli Studi di Milano, Italy; Silvia Gilardi, Università degli Studi di Milano, Italy; Marco Lauriola, Università degli Studi di Roma Italy

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Saturday, 27 October, 3:15 pm – 4:15 pm

## **(3065) Likert or Number Rate Scale? A Comparison Study on Seattle Angina Questionnaire**

Yu Changhe, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Yang Guanlin, MD, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Chen Zhihui, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Zhang Huiyong, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; LV Meijuan, Liaoning university of Traditional Chinese medicine, Peoples Republic of China; Zhang Zhe, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Peoples Republic of China; Ma Yuan, Liaoning University of Traditional Chinese Medicine, Peoples Republic of China

## **(3066) Values Of Health In Patients With Systemic Lupus Erythematosus**

Cláudia C. Ribeiro, Universidade Católica Portuguesa, Portugal; Augusta Silveira, University Fernando Pessoa, Portugal; Teresa Sequeira, Portugal; Isabel Santos, Hospital Santa Maria da Feira; Catarina Ribeiro, Universidade Fernando Pessoa; Carlos Vasconcelos, Hospital Santo Antonio Centro Hospitalar do Porto

## **(3067) Translation and psychometric testing of the German version of the Health Education Impact Questionnaire (heiQ)**

Michael Schuler, University of Wuerzburg; Sandra Nolte, PhD, Deakin University, Australia, Germany; Katja Spanier, MA, Hannover Medical School, Coordination Centre for Applied Rehabilitation Research, Germany; Gunda Musekamp, University of Wuerzburg, Germany; Inge Ehlebracht-Koenig, Rehazentrum Bad Eilsen der Deutschen Rentenversicherung Braunschweig-Hannover; Christoph Gutenbrunner, Hanover Medical School; Hermann Faller, University of Wuerzburg; Richard H. Osborne, Deakin University; Monika Schwarze, Medical School Hannover, Germany

## **(3069) Revision of an Instrument for Measuring Patient Experiences with Injury Care**

Niklas JH Bobrovitz, BHSc(h), University of Calgary, Canada; Maria-Jose Santana, PhD, University of Calgary, Canada; Henry T. Stelfox, University of Calgary

## **📌 (3070) Analysis of Symptom Grading Thresholds for Patients and Clinicians using the Common Terminology Criteria for Adverse Events (CTCAE)**

Thomas Atkinson, Memorial Sloan-Kettering Cancer Center, United States; Yuelin Li, PhD, Memorial Sloan-Kettering Cancer Ctr., United States; Lauren Rogak, Memorial Sloan-Kettering Cancer Center; Natalie Barragan, Memorial Sloan-Kettering Cancer Center; Mary Shaw, Memorial Sloan-Kettering Cancer Center; Liora Pollick, Memorial Sloan-Kettering Cancer Center; Sean Ryan, Memorial Sloan-Kettering Cancer Center; Narre Heon, Memorial Sloan-Kettering Cancer Center; Antonia V. Bennett, PhD, Memorial Sloan-Kettering Cancer Center; Ethan Basch, MD MSc, Memorial Sloan-Kettering Cancer Center

## **(3071) Patient-reported satisfaction with psychosocial and sexual well-being and the nipple areola complex: Comparison of preservation and reconstruction.**

Alison N. Price, Memorial Sloan Kettering Cancer Center, United States; Amie M. Scott, MPH, Memorial Sloan-Kettering Cancer Center; Anne Klassen, D Phil, McMaster University, Canada; Stefan Cano, BSc PhD, Peninsula College of Medicine & Dentistry, United Kingdom; Babak J. Mehrara, Memorial Sloan Kettering Cancer Center; Joseph J. Disa, Memorial Sloan-Kettering Cancer Center; Colleen McCarthy, MD MS, Memorial Sloan Kettering Cancer Center; Evan Matros, MD, Plastic Surgery Department, Memorial Sloan Kettering Cancer Center, United States; Peter Cordeiro, Memorial Sloan Kettering Cancer Center; Virgilio Sacchini, MD, Memorial Sloan Kettering Cancer Center; Andrea Pusic, MD MHS FRCSC, Memorial Sloan Kettering Cancer Center, United States

## **(3072) Handling Missing Item Data On a Multi-item Instrument**

Iris Eekhout, VU University Medical Center, Netherlands; Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center, Netherlands; Michiel R. De Boer, VU University, Amsterdam, The Netherlands; Jos WR Twisk, VU University Medical Centre, Amsterdam, The Netherlands; Martijn W. Heymans, VU University Medical Center

## **📌 (3073) Attitudes to ageing: Do gender and culture make a difference in older age?**

Gail Low, PhD, Univ of Alberta, Faculty of Nursing, Canada; Anita Molzahn, PhD RN, University of Alberta, Canada; Mary Kalfoss, DrPH, Diakonova University College, Norway

## **(3074) A longitudinal analysis of satisfaction with care of patients treated in ambulatory oncology: the influence of health related quality of life**

Thanh Vân Nguyen, Clinical Research Department EA3181, France; Anne Bredart, PhD, Institut Curie, France; Jean-François Bosset, Radiotherapy Department, Besançon University Hospital, 25030 Besançon, France; Alain Monnier, Radiotherapy Department, Montbéliard Hospital, 25200 Montbéliard, France; Mariette Mercier, Cellular and molecular biology laboratory, University Hospital of Besançon

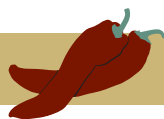
## **(3075) An international prospective study establishing minimal clinically important differences in the EORTC QLQ-BM22 and QLQ-C30 in cancer patients with bone metastases**

Liang Zeng, Canada; Edward Chow, University of Toronto; Liying Zhang, University of Toronto, Canada; Ling-Ming Tseng, National Yang-Ming University; Ming-Feng Hou, Kaohsiung Medical University Hospital; Alysa Fairchild, BSc MD FRCPC, Cross Cancer Institute, Canada; Vassilios Vassiliou, Bank of Cyprus Oncology Centre; Reynaldo Jesus-Garcia, Federal University of Sao Paulo; Mohamed A. Alm El-Din, Tanta University Hospital; Aswin Kumar, Regional Cancer Center, Trivandrum

## **(3076) The impact of psychotherapeutic support on quality of life in patients with gastrointestinal cancer**

Beate Bestmann, PhD, WINEG, Scientific Institute of TK for Benefit and Efficiency in Health Care, Germany; Thomas Kuechler, PhD, Referenzzentrum Lebensqualität, Germany; Doris Henne-Bruns, Department of Visceral and Transplantation Surgery, University Hospital of Ulm; Frank Verheyen, WINEG, Scientific Institute of TK for Benefit and Efficiency in Health Care; Sharon Wood-Dauphinee, PhD, McGill Univ.-School of Physical Therapy, Canada

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# Poster Sessions

Saturday, 27 October, 3:15 pm – 4:15 pm

**(3077) Two-part joint regression modeling to analyze longitudinal left censored patient reported outcomes**  
*Alette Spriensma, VU University Medical Center, Amsterdam, the Netherlands, Netherlands; Jos WR Twisk, VU University Medical Centre, Amsterdam, The Netherlands*

**(3078) Evaluating the response category translations of the EORTC QLQ-C30 questionnaire**  
*Neil W. Scott, MA MSc PhD, University of Aberdeen, United Kingdom; Josephine A. Etta, University of Aberdeen, United Kingdom; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Netherlands; Andrew Bottomley, PhD, EORTC Headquarters, Belgium; Peter Fayers, PhD, Aberdeen Medical School, United Kingdom; Mogens Groenvold, MD, PhD, University of Copenhagen, Denmark; Michael Koller, PhD, Center for Clinical Studies, Germany; Dagmara Kulis, EORTC, Belgium; Debbi Marais, University of Aberdeen; Morten Aa Petersen, MSc, Bispedjerg Hospital, Dept of Palliative Medicine, Denmark; Mirjam AG Sprangers, University of Amsterdam, Netherlands*



**(3079) Physical Activity Matters: The Associations Between Body Mass Index, Physical Activity and Health-Related Quality of Life Trajectories over 10 Years**  
*David Feeny, PhD, University of Alberta, United States; Rochelle Garner, Statistics Canada; Julie Bernier, MSc, Statistics Canada, Canada; Amanda Thompson, Statistics Canada; Bentson H. McFarland, Oregon Health & Science University; Nathalie Huguet, Portland State University; Mark S. Kaplan, Portland State University; Nancy A. Ross, McGill University; Chris Blanchard, Dalhousie University*

**(3081) Self-report quality of life measure is reliable and valid in patients suffering from schizophrenia with executive impairment**  
*Laurent Boyer, PhD, Aix-Marseille University, France; Karine Baumstarck, France; Romain Padovani, EA 3279; Julie Berbis, Department of Public Health, Medicine University, France; Julien Blanc, Aix-Marseille University, France; Christophe Lancon, MD, Laboratoire de Santé Publique, Faculté de Médecine, France; Pascal Auquier, PhD, Laboratoire de Santé Publique, France*

**(3083) Validating a measurement model for the CASP-19 quality of life scale in an older Irish cohort**  
*Eithne Sexton, Royal College of Surgeons in Ireland, Ireland; Bellinda L. King-Kallimanis, PhD, TILDA, Trinity College Dublin, Ireland; Anne Hickey, Royal College of Surgeons in Ireland*

**(3084) What characterizes middle aged and elderly individuals who do not answer questions on sexuality? Results from a quality of life study.**  
*Gudrun Rohde, PhD, University of Agder, Norway; Kari Hansen Berg, Sorlandet Hospital, Kristiansand, Department of Rheumatology; Glenn Haugeberg, Sorlandet Hospital, Kristiansand, Department of Rheumatology*

**(3085) Quality of Life and Psychological Factors in Manufacturing Workers in Mexico**  
*Jose Guadalupe Salazar Estrada, Sr., Psic, PhD, Universidad de Guadalajara, Mexico; Norma Alicia Ruvalcaba Romero, MA, Mexico; Norma S. Figueroa Villaseñor, Universidad de Guadalajara*



## EORTC Quality of Life Group

The EORTC Quality of Life Group develops measures for quality of life and patient-reported outcomes and supports their use in cancer clinical trials.

Our core cancer questionnaire EORTC QLQ-C30 has many supplementary modules for different cancer sites. We were amongst the first to produce formal guidelines for development of questionnaires. We have an active research programme including methodology and clinical applications, and are constantly developing and validating new modules. The questionnaires are translated into over 70 languages through rigorous translation procedures and quality assurance, and we have a strong research interest in cross cultural issues. We are currently developing a CAT version of the EORTC QLQ-C30.

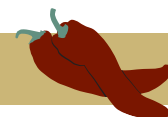
We are a multi-disciplinary group of clinicians and researchers, coming from over 15 European countries plus Canada, Australia, USA, Taiwan, Japan, and Brazil. We organise workshops and plenary sessions twice a year and those interested in collaborating in our research are welcome to join us.

Chairman:	Mogens Groenvold	<a href="mailto:mold@sund.ku.dk">mold@sund.ku.dk</a>
Membership issues:	Susanne Singer	<a href="mailto:Susanne.Singer@medizin.uni-leipzig.de">Susanne.Singer@medizin.uni-leipzig.de</a>
Meetings organisation:	Fabio Efficace	<a href="mailto:f.efficace@gimema.it">f.efficace@gimema.it</a>

For more information on the EORTC Quality of Life Group and its activities, please visit our website:  
<http://groups.eortc.be/qol>

Academic users can download the questionnaires and the user's agreement directly from:  
[http://groups.eortc.be/qol/questionnaires\\_downloads.htm](http://groups.eortc.be/qol/questionnaires_downloads.htm)

 = Top Scoring Abstract Poster Award



# Poster Sessions

Saturday, 27 October, 3:15 pm – 4:15 pm

## (3086) Patient-reported outcome measures in studies of colorectal cancer surgery: a systematic review

Robert N. Whistance, MB ChB BSc MRCS, University of Bristol, United Kingdom; Rachael O. Forsythe, University Hospitals Bristol NHS Foundation Trust; Angus McNair, MRCS, University of Bristol, United Kingdom; Sara Brookes, University of Bristol; Kerry Avery, PhD, Dept of Social Med, Univ of Bristol, United Kingdom; Anne M. Pullyblank, North Bristol NHS Trust; Jane Blazeby, MD, University of Bristol, United Kingdom

## (3087) Endorsing high quality standards in developing measures to assess QoL in cancer patients: the Data Repository initiative on behalf of the EORTC QLQ

Francesca Martinelli, MSc, EORTC, Belgium; Galina Velikova, MD, University of Leeds, United Kingdom; Colin Johnson, Mchir, Dept of Surgery, United Kingdom; Mogens Groenvold, MD PhD, University of Copenhagen, Denmark; Corneel Coens, MSc, EORTC HQ, Belgium; Andrew Bottomley, PhD, EORTC Headquarters, Belgium

## (3088) Health-Related Quality of Life in Patients with Alopecia Areata- A Report from the National Alopecia Areata Registry

Qiuling Shi, PhD, Univ. of Texas MD Anderson Cancer Center; Joyce S. Osei, Univ. of Texas MD Anderson Cancer Center; Tito R. Mendoza, PhD, Univ. of Texas MD Anderson Cancer Center; Madeleine Duvic, Univ. of Texas MD Anderson Cancer Center, United States

## (3089) Qualitative development and content validation of a new patient reported outcome measure in hyperhidrosis, the Hyperhidrosis Quality of Life Index (Hidroqol)

Paul Kamudoni, WSP Centre for Socioeconomic Research, Cardiff University, Germany; Berno Müller, Riemser Arzneimittel AG, Medical Science and Operations, Germany; Christian Müller, 2Riemser Arzneimittel AG, Medical Science and Operations, Germany; Sam Salek, BSc RPh PhD FFPM, Cardiff University, Redwood Bldg, United Kingdom

## (3090) Evaluation of severity and frequency levels that optimally differentiate between levels of interference for symptoms in the National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Tito R. Mendoza, PhD; University of Texas M. D. Anderson Cancer Center, Houston, TX, USA; Amylou C. Dueck, PhD; Mayo Clinic, Scottsdale, AZ, USA; Lauren J. Rogak; Memorial Sloan-Kettering Cancer Center, New York, NY, USA; Laura Sit; George Mason University, Fairfax, VA, USA; Yuelin Li, PhD; Memorial Sloan-Kettering Cancer Center, New York, NY, USA; Antonia Bennett, PhD; Memorial Sloan-Kettering Cancer Center, New York, NY, USA; Thomas Atkinson, PhD; Memorial Sloan-Kettering Cancer Center, New York, NY, USA; Steven B. Clauser, PhD; Outcomes Research Branch, NCI, Bethesda, MD, USA; Sandra A. Mitchell, PhD, CRNP; Outcomes Research Branch, NCI, Bethesda, MD, USA; Ethan Basch, MD; Memorial Sloan-Kettering Cancer Center, New York, NY, USA



## Associate Director – Patient Reported Outcomes (PRO)

Imagine being involved in cutting edge projects that change the course of our industry on a daily basis. At Covance, one of the world's largest and most comprehensive drug development service companies, you will have an opportunity to build an exciting career while you make a direct impact on the lives of millions.

We currently have an opening for an **Associate Director – Patient Reported Outcomes (PRO)**. The Associate Director manages or directs PRO, outcomes research, or other consulting projects ensuring client needs, agreed timelines and budgets are met. The Associate Director may assume line management responsibilities, including assisting with staff recruitment. The Associate Director takes an active role in ensuring the department's financial objectives are met, including developing new and repeat business opportunities for Covance.

As a Associate Director some of your daily job duties would include the following:

- Market and Sell Services: Work with Sales and Marketing and other CMA colleagues to prepare and present capabilities presentations.
- Understand Client Requirements: Works with clients to define how the assignment will be performed and determine deliverables that will be presented by the Firm.
- Prepare Proposal: Prepares and reviews proposals for consulting services following standard formats used for previous engagements.
- Manage and Direct Data Collection and Analysis: Identifies sources and manages or directs the day to day collection of information through primary and secondary research. Seeks consults from colleagues, as appropriate, to ensure that appropriate quantitative and qualitative analytical techniques are performed allowing inferences and conclusions to be drawn.

The Typical **Education** for the Associate Director position includes:

- A graduate degree in business administration, public health, public policy, management, statistics, clinical science, health services research, health economics, or other relevant discipline from and outstanding program at a distinguished university.
- Professional designations/certifications/licenses required

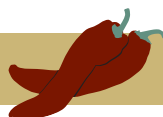
Required **Experience/Skills** for the Associate Director position includes:

- Well-documented history of experience with PROs and health outcomes' research, including publications, integration of PROs in larger medical studies, publications with PROs, and team management on PRO (especially psychometric) projects.
- Strong written and oral communication, problem solving, and organization skills.
- Understanding of the fundamental principles of statistics, analysis, and review.
- Able to work independently in a fast-paced environment, handling multiple activities at one time and meeting short deadlines with little notice.
- Works effectively in a team environment and is able to communicate with people at all levels of the organization.

To learn more about this position or to apply on-line please visit the Covance Career site- [www.covancecareers.com](http://www.covancecareers.com) and enter req # **35808**.

**\*Position can be located in our Gaithersburg, MD, San Diego, CA Office or Remotely\***

Covance is committed to diversity in the workplace and is an equal opportunity employer. (M/F/D/V). Your confidentiality and privacy are important to us.



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## Congratulations 2012 New Investigator & Student Award Finalists

### New Investigator Oral Presentation Finalists

Etienne Audureau, *Assistance Publique-Hôpitaux de Paris, France (Oral 101.1)*

Patricia Holch, PhD, *University Of Leeds, United Kingdom (Oral 109.2)*

Paulos Teckle, PhD, *Canadian Centre for Applied Research in Cancer, UBC, Canada (Oral 103.3)*

### Student Oral Presentation Finalists

Lotte Haverman, MSc, *Emma Children's Hospital - Academic Medical Centre, The Netherlands (Oral 109.5)*

Ana Maria Rodriguez, MSc, BSc, PT, *McGill University, Canada (Oral 107.4)*

Anna Wikman, *Karolinska Institutet, Sweden (Oral 105.1)*

### New Investigator Poster Presentation Finalists

Divine Ewane Ediebah, MSc, *EORTC HQ, Belgium (Poster 1079)*

Pranav Gandhi, PhD, *South College, Knoxville, TN, United States (Poster 1030)*

Marco Pereira, *Universidade de Coimbra, Brazil (Poster 1093)*

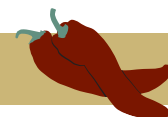
### Student Poster Presentation Finalists

Ly Meijun, *Liaoning University of Traditional Chinese Medicine, Peoples Republic of China (Poster 1063)*

Monika J. Sztankay, *Innsbruck Medical University, Austria (Poster 1074)*

Carlos King Ho Wong, Mphil, BSc, *The University of Hong Kong (Poster 1049)*

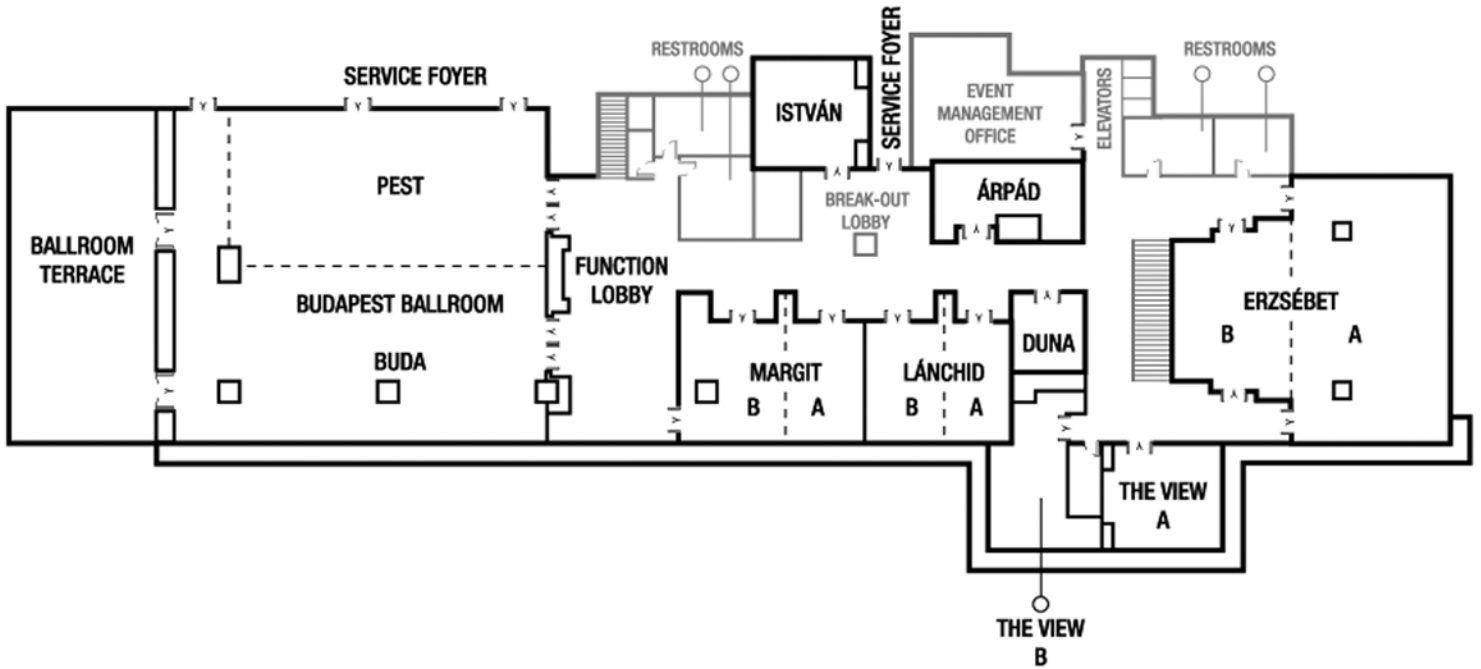
Award winners will be announced at the ISOQOL Business Meeting and Award Presentation on Friday, 26 October from 9:00 am – 10:30 am.



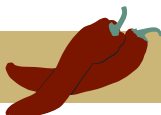
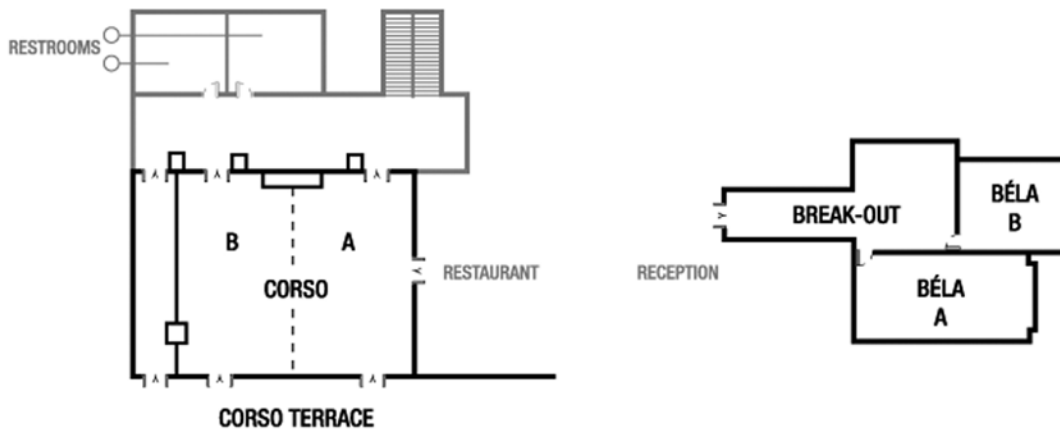


# Hotel Floor Plan

## MEZZANINE LEVEL



## GROUND FLOOR



# ISOQOL 20<sup>TH</sup> ANNUAL CONFERENCE



October 9–13, 2013 MIAMI, FLORIDA, USA



# MIAMI

FLORIDA USA

## Abstract Deadlines

Workshop and Symposium Abstract Submission  
Deadline: **Friday, February 1, 2013**

Oral and Poster Presentation Abstract Submission  
Deadline: **Friday, April 12, 2013**

[isoqol.org](http://isoqol.org)



# Delivering Excellence from Concept to Conclusion

## Patient Reported Outcomes

- Regulatory approval strategy
- Patient utility and preference studies
- Conceptual model development
- Instrument identification
- Instrument development and modification
- Statistical services including psychometric validation

## eCOA

- Vendor evaluation, selection and management
- eCOA process implementation support
- Migratability assessments
- Cognitive interviews and usability assessments
- Equivalence studies
- eCOA instrument management

## Translation services

- Linguistic validation of COAs
- Cognitive debriefing interviews
- Translation of clinical trial documentation
- Review of eCOA screenshots
- IVRS prompt recording and system testing
- Translatability assurance and linguistic consulting

Contact: Diane Wild, [diane.wild@oxfordoutcomes.com](mailto:diane.wild@oxfordoutcomes.com) +44 (0) 1865 324930

