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Welcome to the 20th Annual Conference of the International Society for Quality of Life Research

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

TABLE OF CONTENTS

Schedule at a Glance .................................................................................................................. 2
Welcome from the Program Chairs .......................................................................................... 5
ISOQOL Leadership .................................................................................................................. 6
Scientific Program Committee ................................................................................................. 7
General Information ................................................................................................................ 8
Highlighted Events ................................................................................................................... 10
ISOQOL Committees & Special Interest Groups (SIGs) ............................................................ 12
Workshops .................................................................................................................................. 14
Plenary Speakers ..................................................................................................................... 17
Concurrent Symposia Sessions ................................................................................................. 21
Concurrent Oral Sessions ........................................................................................................ 26
Poster Sessions ...................................................................................................................... 36
Sponsors and Exhibitors ........................................................................................................... 54
Notes .......................................................................................................................................... 56
Hotel Floor Plan ........................................................................................................................ 57

ISOQOL Executive Office, 555 E. Wells Street, Suite 1100, Milwaukee, WI 53202, USA
Telephone: +1(414) 918-9797 Fax: +1(414) 276-3349 E-mail: info@isoqol.org
Web: www.isoqol.org

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

## Wednesday, October 9

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00 am - 12:00 pm</td>
<td>Morning Workshops (WK01 - WK03)*</td>
<td>See Page 14</td>
</tr>
<tr>
<td>1:00 pm - 4:00 pm</td>
<td>Afternoon Workshops (WK04 - WK07)*</td>
<td>See Page 15</td>
</tr>
</tbody>
</table>
| 4:30 pm - 6:00 pm   | IAC Symposium  
*Innovations for Patient Engagement in Health Outcomes Development, Selection and Measurement: Opportunities and Limitations* | Escorial/Alhambra Room                  |
| 6:00 pm - 7:30 pm   | Welcome Reception                                                                         | Versailles Ballroom                     |

## Thursday, October 10

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
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<tbody>
<tr>
<td>7:30 am - 8:45 am</td>
<td>Child Health SIG Meeting</td>
<td>Balmoral Room</td>
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<tr>
<td>7:30 am - 8:45 am</td>
<td>Psychometrics SIG Meeting</td>
<td>Sandringham/Windsor Room</td>
</tr>
<tr>
<td>7:45 am - 8:45 am</td>
<td>Industry Advisory Committee (IAC) Meeting</td>
<td>Michelangelo Room</td>
</tr>
</tbody>
</table>
| 9:00 am - 10:30 am | Plenary  
*New Horizons in Quality of Life Research*  
*Cutting Edge Research in Quality of Life* | Versailles Ballroom                     |
| 10:30 am - 11:15 am | Poster Session 1                                                                          | Biscayene Ballroom                     |
| 10:30 am - 11:15 am | Exhibits Open                                                                             | Mezzanine East                          |
| 11:15 am - 12:45 pm | Plenary  
*Cutting Edge Research in Quality of Life*  
*Lunch on Your Own* | Versailles Ballroom                     |
| 12:45 pm - 1:45 pm | New Investigator Roundtable  
Career Topic: Networking and Interviews                                                     | Hibiscus Isle Room, Lobby Level        |
| 12:45 pm - 1:45 pm | Quality of Life Research Journal Associate Editor Meeting                                 | Raphael Room                            |
| 12:45 pm - 1:45 pm | SIG Leader Meeting                                                                        | Michelangelo Room                       |
| 2:00 pm - 3:30 pm  | Concurrent Oral Sessions                                                                  | Balmoral Room                           |
|                  | Oral Session 101: *Positive Psychology/Life Satisfaction*                                 | Sandringham Room                        |
|                  | Oral Session 102: *Response Shift*                                                        | Sandringham Room                        |
|                  | Oral Session 103: *Cancer Clinical Trials Issues*                                          | Escorial/Alhambra Room                  |
|                  | Oral Session 104: *Patient-Reported Outcomes Measure Development and Evaluation*          | Escorial/Alhambra Room                  |
| 3:30 pm - 4:00 pm  | Exhibits Open and Afternoon Break                                                          | Mezzanine East                          |
| 4:00 pm - 5:30 pm  | Concurrent Symposium Sessions                                                              | Mezzanine East                          |
|                  | Symposium 1: *The Application of PROMIS® in Real-World Settings: Advancing Patient-Centered Research and Care* | Sandringham/Windsor Room                |
|                  | Symposium 2: *Patient and Public Engagement in Health Research*                           | Raphael/Michelangelo Room               |
|                  | Symposium 3: *Genes, Cells and Symptom Clusters - What’s the Story?*                      | Escorial/Alhambra Room                  |
| 6:00 pm - 7:30 pm  | Mentor/Mentee Reception  
*Featuring the New Investigator SIG Tricks of the Trade* | Versailles Ballroom                     |

* Ticket Required

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

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

**Friday, October 11**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 am - 8:45 am</td>
<td>2014 Annual Conference Planning Meeting</td>
<td>Escorial/Alhambra Room</td>
</tr>
<tr>
<td>7:30 am - 8:45 am</td>
<td>New Investigator SIG Meeting</td>
<td>Balmoral Room</td>
</tr>
<tr>
<td>7:30 am - 8:45 am</td>
<td>QOL in Clinical Practice SIG Meeting</td>
<td>Sandringham/Windsor Room</td>
</tr>
<tr>
<td>9:00 am - 10:30 am</td>
<td><strong>Plenary</strong>&lt;br&gt;Accentuate the Positive: The Sunny Side of Quality of Life Research</td>
<td>Versailles Ballroom</td>
</tr>
<tr>
<td>10:30 am - 11:15 am</td>
<td><strong>Poster Session 2</strong></td>
<td>Biscayne Ballroom</td>
</tr>
<tr>
<td>10:30 am - 11:15 am</td>
<td>Exhibits Open</td>
<td>Mezzanine East</td>
</tr>
<tr>
<td>11:15 am - 12:45 pm</td>
<td><strong>Concurrent Symposium Sessions</strong></td>
<td></td>
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<tr>
<td>12:45 pm - 1:45 pm</td>
<td>Lunch on Your Own</td>
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<tr>
<td>2:00 pm - 3:30 pm</td>
<td><strong>Concurrent Oral Sessions</strong></td>
<td></td>
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<tr>
<td>4:00 pm - 5:30 pm</td>
<td><strong>Concurrent Oral Sessions</strong></td>
<td></td>
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<tr>
<td>5:45 pm - 6:30 pm</td>
<td>Ibero America SIG Meeting</td>
<td>Balmoral Room</td>
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<tr>
<td>5:45 pm - 6:30 pm</td>
<td>Response Shift SIG Meeting</td>
<td>Sandringham Room</td>
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<tr>
<td>5:45 pm - 6:30 pm</td>
<td>Patient Engagement SIG Meeting</td>
<td>Windsor Room</td>
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</tbody>
</table>
## Schedule At A Glance

### Saturday, October 12

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

* Ticket Required

### Registration Desk Hours

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

### Poster Hall Hours

All Poster presentations will take place in the **Biscayne Ballroom**. The Biscayne Ballroom will be open daily from **7:00 am – 7:00 pm** from Thursday, October 10 – Saturday, October 12.
Buenos Días and Welcome to Beautiful Miami, Florida!

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

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

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

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

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

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

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

David Eton, PhD
Co-chair,
Scientific Program Committee

Simon Pickard, PhD
Co-chair,
Scientific Program Committee
ISOQOL LEADERSHIP

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Co-Chair: Simon Pickard, PhD, United States

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

Mentor/Mentee Reception
Chair: Elena Andresen, PhD, United States

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

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Marc Jacobs, MSc, The Netherlands
Puja Joshi, MSc, United Kingdom
Ana A. Popielnicki, BA, United States
Ana Maria Rodriguez, PhD MSc BSc PT, Canada
Rick Sawatzky, PhD RN, Canada
Carolyn E. Schwartz, ScD, United States

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Gloria Juarez, PhD RN MSN, United States
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Cindy L.K. Lam, MD, Hong Kong, SAR China
Muirne CS Paap, The Netherlands
Ana A. Popielnicki, BA, United States
Ana Maria Rodriguez, PhD MSc BSc PT, Canada
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Carlos King Ho Wong, PhD MPhil BSc, Hong Kong, SAR China
Tracey Young, PhD MSc BSc CStat, United Kingdom

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Gloria Juarez, PhD RN MSN, United States
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Youngmee Kim, PhD, United States
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Nalin Payakachat, BPharm MS PhD, United States
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Andrea Pusic, MD MHS FRCSC, United States
Maria-Jose Santana, PhD, Canada
Silke Schmidt, PhD, Germany
Carolyn E. Schwartz, ScD, United States
Elizabeth J. Unni, PhD, United States
Galina Velikova, MD, United Kingdom
Mathilde Verdam, The Netherlands
Valerie Williams, PhD, United States
Vasoontara Yengprugsawan, Thailand/Australia
Huiyong Zhang, MD, Peoples Republic of China
GENERAL INFORMATION

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

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

InterContinental Miami Hotel
100 Chopin Plaza, Miami, Florida, 33131
Telephone: +1(305) 577-1000
www.icmiamihotel.com
A full service Fed Ex Office is located inside the InterContinental Miami. The Fed Ex Office is located on the Lobby Level near Starbucks.

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

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

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

Cancellation Policy
ISOQOL reserves the right to cancel any event due to lack of enrollment or other factors. In the event of a cancellation, registered participants will be notified by e-mail and will have the option to exchange their ticket for an available alternative, or to receive a complete refund.
All registration cancellations by participants must be received in writing and all refunds will be paid after the conference. Cancellations received after September 16 will not be eligible for a refund.

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

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

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

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

VISIT: http://jobs.isoqol.org
BrightOutcome is pleased to announce the launch of:

**PROmeasure™**

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

- Affordable and turn-key HIPAA-compliant SaaS ePRO solution
- Featuring the industry’s leading database of validated electronic PRO instruments, including:
  - PROMIS® Short Forms, Item Banks, and Profiles
  - DSM-5 Section III Online Assessment Measures
  - FACIT® Measurement System
  - RAND® Health Surveys
  - And many more!
- Ideal for small to medium-sized PRO studies and practices

Stop by the BrightOutcome booth at ISOQOL 2013, or visit [www.brightoutcome.com](http://www.brightoutcome.com) to schedule a demo!

ISOQOL members receive discounted pricing on PROmeasure™ before January 1st!
Welcome Reception
Wednesday, October 9, 6:00 pm – 7:30 pm
Versailles Ballroom

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

Mentor/Mentee Reception
Thursday, October 10, 6:00 pm – 7:30 pm
Versailles Ballroom

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

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

TRicks of the Trade: Advice for New Investigators in Quality of Life Research

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

Panelists:
Donald Patrick, PhD MSPH, University of Washington, Seattle, WA, United States
Karen Sousa, PhD, University of Colorado, Denver, CO, United States
Melanie Calvert, PhD, The University of Birmingham, United Kingdom

Industry Advisory Committee Symposium

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

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

Panelists:
Alicyn Campbell, PhD, Genentech, United States
Dennis Revicki, PhD, Evidera, United States
Doug Rivers, PhD, YouGov, United States
Tom Simon, Director, I CARE, Inc., United States
Moderator:
Heather Gelhorn, PhD, Evidera, United States

New Investigator SIG Roundtable Discussion

CAREER TOPIC: NETWORKING AND INTERVIEWS
Thursday, October 10, 12:45 pm – 1:45 pm
Hibiscus Isle Room, Lobby Level

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

The roundtable is open to all new investigators, with a maximum of 20 participants. Lunch will not be provided.
ISOQOL Business Meeting and Award Presentation

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

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

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

2013 PRESIDENT’S AWARD
The President’s Award is awarded to an individual who has advanced HRQOL research and has made outstanding contributions to the Society in one or more of the following areas: education of professionals, patients or lay individuals about HRQOL’s value; promotion or execution of HRQOL or other scholarly activities; and facilitating or furthering policy initiatives that have an impact on HRQOL. The awardee is selected by the Executive Committee and endorsed by the Board of Directors.

EMERGING LEADER AWARD – IN HONOR OF DONNA LAMPING
The Emerging Leader Award was established in 2011 to honor and commemorate Past-President Donna Lamping’s contribution to the leadership of the Society. It will be awarded to an ISOQOL member who has shown exceptional leadership skills and potential.

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

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

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

Closing Dinner

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

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

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

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

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

DEVELOPING COUNTRY SCHOLARSHIPS

Congratulations to the 2013 Developing Country Scholarship Recipients:

Yu Changhe, MSc, Student, Liaoning University of Traditional Chinese Medicine, China
Divine Ewane Ediebah, MSc, Research Fellow in Biostatistics, EORTC HQ, Belgium
Yash Jalundhwala, MSc, Doctoral Candidate and Research Assistant, University of Illinois at Chicago, United States
Vasoontara Yiengprugsawan, PhD, Postdoctoral Research Fellow, Thai Health Risk Transition Project; Thailand/Australia
ISOQOL COMMITTEES & SPECIAL INTEREST GROUPS (SIGS)

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

INDUSTRY ADVISORY COMMITTEE (IAC)
Chair: Josephine Norquist, MS, United States

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

Industry Advisory Committee Meeting
Thursday, October 10, 7:45 am – 8:45 am
Michelangelo Room

Don’t miss the IAC Symposium on Wednesday!

2014 ANNUAL CONFERENCE PLANNING COMMITTEE
2014 Co-Chairs: Jordi Alonso, MD PhD, Spain
               Susan Bartlett, PhD, Canada

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

2014 Planning Committee Meeting
Friday, October 11, 7:30 am – 8:45 am
Escorial/Alhambra Room

BEST PRACTICES FOR PROS IN RANDOMIZED CLINICAL TRIALS TASK FORCE
Oversight Executive: Jane Blazeby, MD, United Kingdom
                     Michael Brundage, MD, Canada
                     Melanie Calvert, PhD, United Kingdom
                     Dennis Revicki, PhD, United States

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

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

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

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

CHILD HEALTH
Chair: Katherine Bevans, PhD, United States

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

Child Health SIG Meeting
Thursday, October 10, 7:30 am – 8:45 am
Balmoral Room

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

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

Ibero America SIG Meeting
Friday, October 11, 5:45 pm – 6:30 pm
Balmoral Room
ISOQOL COMMITTEES & SPECIAL INTEREST GROUPS (SIGS)

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

*The New Investigators SIG is targeted at people new to QOL research. We welcome students, post docs, and anyone who has been working in QOL research for five years or less. We aim to:*
- Create a network for investigators new to the field of QOL  
- Facilitate discussions, both theoretical and practical  
- Help solve common problems at early stages of one’s career

**New Investigator SIG Meeting**
Friday, October 11, 7:30 am - 8:45 am  
Balmoral Room

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

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

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

**Patient Engagement SIG Meeting**
Friday, October 11, 5:45 pm - 6:30 pm  
Windsor Room

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

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

**Psychometrics SIG Meeting**
Thursday, October 10, 7:30 am – 8:45 am  
Sandringham/Windsor Room

**QUALITY OF LIFE IN CLINICAL PRACTICE**
Chairs: Kirstie Haywood, DrPhil BSc, United Kingdom; Colleen Norris, PhD, Canada

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

**QOL in Clinical Practice SIG Meeting**
Friday, October 11, 7:30 am – 8:45 am  
Sandringham/Windsor Room

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

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

**Response Shift SIG Meeting**
Friday, October 11, 5:45 pm – 6:30 pm  
Sandringham Room

**TRANSLATION & CULTURAL ADAPTATION (TCA)**
Chairs: Sonya Eremenco, MA, United States  
Mona Martin, RN MPA, United States

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

**TCA SIG Meeting**
Friday, October 11, 5:45 pm – 6:30 pm  
Escorial/Alhambra Room

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

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

### Morning Workshops

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

(WK01) **An Introduction to Health-Related Quality of Life Assessment**  
Sandringham Room  
*Heather Gelhorn, PhD and Kathy Wyrwich, PhD, Evidera, United States*

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

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

(WK02) **Everything You Wanted to Know About Rasch Measurement Theory But Were Too Afraid to Ask - Part 1**  
Windsor Room  
*Stefan Cano, PhD CPsychol AFBPsS and Jeremy C. Hobart, PhD, Peninsula Schools of Medicine and Dentistry, United Kingdom*

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

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

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

(WK03) **Discrete Choice Experiments: Enhancing PRO Beyond QALYs**  
Balmoral Room  
*Benjamin M. Craig, PhD, Moffitt Cancer Center, United States*

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

This workshop will cover DCEs for health valuation, including paired comparison and partial rank tasks, such as best-worst scaling. The workshop will further discuss differences between DCE and traditional valuation approaches for standardized instruments (e.g., time trade-off EQ-5D, standard gambles of SF-6D) and conclude with an econometric overview of QALYs, such as its constant proportionality assumptions. As a hands-on exercise, attendees will be arranged in groups and asked to design a DCE of a PRO instrument demonstrating a key advantage that sets DCE apart from more complex institutional approaches: anyone can design and run a proper DCE. Level: Advanced
(WK04) The Development and Validation of Clinician-Reported Outcome Instruments: The Application of Methods from Patient-Reported Outcomes
Sandringham Room
Sophi Tatlock, MA, Adelphi Values, United Kingdom; Helen Kitchen, MSc, The University of Manchester, United Kingdom; Rob Arbuckle, MSc, Adelphi Values, United Kingdom
This workshop will give attendees a sound understanding of the application of Patient-Reported Outcome (PRO) development and validation methods to the development and validation of Clinician-Reported Outcomes (ClinRO) to regulatory standards. Specifically, aspects of PRO methods that can be applied without change, those that may be adapted, and methods specific to or of increased importance for ClinROs will be outlined. Drawing on examples and including several interactive exercises, all stages of instrument development and validation will be discussed. Specifically, attendees will code clinician interview transcripts and group example clinician and patient quotes by domain. The group will then generate items based on those quotes, highlighting differences in item wording for clinicians and patients. Cognitive debriefing with clinicians and patients will be discussed, with similarities and differences compared. The value of observing or recording clinician-patient interactions and associated ethical issues will be discussed. Specific considerations for psychometric validation of ClinROs, including inter-rater reliability and developing cut-points through Receiver Operating Characteristic (ROC) analysis will be explored. Finally, specific considerations for implementing ClinROs in clinical trials and other large scale studies will be discussed alongside the challenges of using measures developed for use in clinical practice as trial endpoints, and vice versa. Level: Basic

(WK05) Everything You Wanted to Know About Rasch Measurement Theory But Were Too Afraid to Ask - Part 2
Windsor Room
Stefan Cano, PhD CPsychol AFBPsS and Jeremy C. Hobart, PhD, Peninsula Schools of Medicine and Dentistry, United Kingdom
Please see the description of WK02 for more information. Enrollment in (WK02) Everything You Wanted to Know About Rasch Measurement Theory But Were Too Afraid to Ask - Part 1 is not required, but it is recommended. Level: Advanced

(WK06) Making QALY Instruments From PROs: Methods for Developing Preference Based Measures of Health from Existing Measures
Balmoral Room
Brendan Mulhern, Mres; John E. Brazier, PhD; Tracey Young, PhD and Simon Palfreyman, PhD, University of Sheffield, United Kingdom
Recent years have seen increasing reliance on a few generic preference-based measures of health (e.g. EQ-5D, HUI3, or SF-6D) for calculating Quality Adjusted Life Years (QALYs) for economic evaluation. However, generic measures may not be used in key clinical studies. This may be due to a desire to reduce patient burden or a view that generic instruments are not valid for the condition or responsive to the effects of treatment. For these reasons there is interest in developing new preference-based measures of health. This workshop focuses on the estimation of the preference-based indices from existing generic and condition specific measures of health related quality of life. We will cover in detail the derivation of health states from existing measures using psychometric methods. We will also describe in detail both new and existing methods of health state valuation that can be used to derive the preference-based index that is used in the calculation of QALYs. New valuation methods covered include Discrete Choice Experiments incorporating duration and a hybrid Time Trade Off method used to value EQ-5D-5L. This workshop offers a practical introduction to the use of psychometric methods in the development and refinement of health state classifications, and the use of a range of valuation methods. It will also examine the policy implications of using different descriptive systems to derive preference-based measures. It assumes a basic knowledge of HRQOL measurement and QALYs. Level: Advanced
Using Patient-Reported Outcome Measures to Improve Care in Chronically Ill Patients
Presented in Spanish

Michelangelo Room

Maria-Jose Santana, PhD, University of Calgary, Canada; Juan J. Dapueto, MD PhD, Universidad de la República, Montevideo, Uruguay; and Jose (Chema) Maria Valderas, MD PhD MPH, University of Oxford, United Kingdom

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

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

Afternoon Workshops

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

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

Congratulations to the Presentation Award Finalists

Student Oral Presentation Finalists

Jo Brett, United Kingdom,
Oral Session 205: Quality of Care Experience
Sophie Cleanthous, MSc, BSc, United Kingdom,
Oral Session 104: Patient-Reported Outcomes Measure Development and Evaluation
Kim Nicolaije, The Netherlands,
Oral Session 204: Personalized Medicine

New Investigator Oral Presentation Finalists

Zeeshan Butt, PhD, United States,
Oral Session 207: Patient-Reported Outcomes Measure Development and Evaluation
Brendan Mulhern, United Kingdom
Oral Session 206: Health Utilities
Ester Villalonga, PhD, United States,
Oral Session 201: Quality of Life in Children

Student Poster Presentation Finalists

Amin Abdul-Galeel Amro, RN, MSN, Norway,
Poster Session 1, Number 1072
Amélie Anota, France,
Poster Session 2, Number 2013
Aaron C. Roberts, United States,
Poster Session 1, Number 1001

New Investigator Poster Presentation Finalists

Hyewon Chung, Korea,
Poster Session 1, Number 1056
Eva-Maria Gamper, Austria,
Poster Session 1, Number 1025
Jiseon Kim, United States,
Poster Session 1, Number 1029

Winners will be announced at the ISOQOL Business Meeting and Awards Presentation on Saturday, October 12.
Christopher B. Forrest, MD PhD
The Children's Hospital of Philadelphia
University of Pennsylvania
Philadelphia, PA, United States

Christopher B. Forrest, MD PhD is a Professor of Pediatrics and Health Care Management at the University of Pennsylvania and Children's Hospital of Philadelphia. His research unit focuses on the theory and measurement of health across the life course, value in pediatric healthcare, and delivery system transformation. He leads a federally funded Pediatric Quality Measures Program Center of Excellence and a national program in pediatric learning health systems (which are dedicated to advancing the health of children through research, quality improvement, and informatics). He chairs the NIH’s Patient-Reported Outcome Measurement Information System’s (PROMIS)® Executive Committee and serves on the Steering Committee for the National Children Study’s Health Measurement Network. Dr. Forrest received his BA and MD degrees at Boston University as part of a dual-degree program, and completed a PhD in Outcomes Research at Johns Hopkins School of Public Health.

Carolyn E. Schwartz, ScD
DeltaQuest Foundation, Inc
Tufts University School of Medicine
Concord, MA, United States

Carolyn E. Schwartz, ScD is President and Chief Scientist at DeltaQuest Foundation in Concord, MA, USA, and Adjunct Research Professor of Medicine and Orthopaedics at the Tufts University School of Medicine. A specialist in outcomes research and measurement development, her interdisciplinary and methodological research focuses on understanding what patients can do to have an impact on the course of their disease and their well-being. Her work has spanned a number of medical conditions, patient-reported outcome tools development, and the theoretical and methodological foundations of response shift phenomena in longitudinal quality-of-life research. A long-standing member of ISOQOL, she has served as Co-Editor-in-Chief of Quality of Life Research since 2009.

Kirsí Tirri, PhD MTh
Department of Teacher Education
University of Helsinki
Helsinki, Finland

Kirsí Tirri, PhD MTh is a Professor of Education and Research Director at the Department of Teacher Education at the University of Helsinki, Finland. She is also a visiting scholar with the Stanford Center on Adolescence, USA. Dr. Tirri has been the President of ECHA (European Council for High Ability) for the years 2008-2012. She is the President of the SIG International Studies at AERA (American Educational Research Association). Her research interests include moral and religious education, gifted education, teacher education and cross-cultural studies. She has published 12 monographs and numerous journal articles related to these fields. She has led the Finnish team in many national and international research projects.

Session chaired by Katherine Bevans, PhD, Children’s Hospital of Philadelphia, PA, United States and Simon Pickard, PhD, University of Illinois at Chicago, IL, United States
INTERNET-BASED FOCUS GROUP DISCUSSIONS ARE FEASIBLE FOR INVESTIGATION OF SENSITIVE ISSUES AMONG YOUNG CANCER SURVIVORS

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

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

To test the property of “measurement equivalence” in outcome measures, studies often evaluate whether persons who possess a same trait level but come from different demographic and clinical subgroups answer items differently (i.e., differential item function or DIF). However, when standard criteria identify DIF items, the overall impact of DIF on scores may be trivial. DIF studies should consider not just the statistical identification of DIF but also its practical impact on obtained scores.
Jordi Alonso, MD MPH
Director, Epidemiology & Public Health Program
IMIM-Hospital del Mar Medical Research Institute
Barcelona, Spain

Jordi Alonso, doctor of medicine, specialist in family and community medicine, preventive medicine and public health, is director of the program of Epidemiology and Public Health at the IMIM-Mar Hospital Medical Research Institute. He is a professor of public health at the Pompeu Fabra University (Barcelona), and an associate professor at the Johns Hopkins University. His research focuses on the measurement of perceived health and evaluation of the need for and effectiveness of health services, especially in the area of mental health. He is a regional coordinator of the WHO World Mental Health (WMH) Surveys Initiative, and editor of the book “Burdens of Mental Disorders” based on that large international study. Dr. Alonso has served on several steering committees including those of the Spanish Society of Epidemiology (SEE) and the International Society for Quality of Life Research (ISOQOL). In 2005, he received the Professional Excellence award by the Council of Medicine Colleges of Catalonia.

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

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

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

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

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

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

Mihaly Csikszentmihalyi, PhD is the C.S. and D.J. Davidson Professor of Psychology at the School of Behavioral and Organizational Sciences, and the Peter F. Drucker Graduate School of Management, at Claremont Graduate University; and co-Director of the Quality of Life Research Center. He is a Fellow of several scientific societies, The National Academy of Education, and a member of the Hungarian Academy of Sciences.

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

**Crystal L. Park, PhD**  
Professor of Psychology  
Director, Health Psychology Graduate Certificate Program  
University of Connecticut, Storrs, CT, United States

Crystal Park, PhD is a Professor of Psychology and Director of the Health Psychology graduate certificate program at the University of Connecticut, Storrs. Dr. Park has an extensive record of research in the area of post-traumatic growth and psychological adjustment after cancer, including investigation of the religious and non-religious pathways to growth and meaning making in cancer survivors. She also has experience in measure development and currently has an NCCAM-funded R01 to develop a questionnaire to measure the key dimensions of an effective yoga intervention.

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

**Twenty Years of ISOQOL – A Celebration**

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

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

**ISOQOL PAST PRESIDENTS**

Donald L. Patrick, PhD MSPH, United States, 1993-1994
Robert Kaplan, PhD, United States, 1994-1996
Monika Bullinger, PhD, Germany, 1996-1998
Sharon Wood-Dauphinee, PhD, Canada, 1998-2000
Ivan Barofsky, PhD, United States, 2000-2001*
David Osoba, MD, Canada, 2001-2002*
Mirjam AG Sprangers, PhD, The Netherlands, 2002-2003*
Albert W. Wu, MD MPH, United States, 2003-2004*
David Feeny, PhD, United States, 2004-2005*
Peter Fayers, PhD, United Kingdom, 2005-2006*
Madeleine T. King, PhD, Australia, 2006-2007*
Donna L. Lamping, PhD, United Kingdom, 2007-2008
Neil K. Aaronson, PhD, The Netherlands, 2008-2009
Diane L. Fairclough, DrPH, United States, 2009-2010*
Carol M. Moinpour, PhD, United States, 2010-2011*
Bryce B. Reeve, PhD, United States, 2011-2013*

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

*Attending the Plenary Session*
CONCURRENT SYMPOSIA SESSIONS

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

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

Sandringham/Windsor Room

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

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

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

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

INDIVIDUAL PRESENTATIONS

PROMIS® Instruments: Ready for the Big Time
Carole A. Tucker PhD, Temple University, Philadelphia, PA, United States

Developing Methods to Identify Child Health Outcome Priorities
Katherine B. Bevans, PhD, Children’s Hospital of Philadelphia and the University of Pennsylvania School of Medicine, Philadelphia, PA, United States

Symposium 2: Patient and Public Engagement in Health Research

Raphael/Michelangelo Room

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

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

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

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

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

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

**PANEL DISCUSSANTS AND PRESENTERS**

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

**Symposium 3: Genes, Cells and Symptom Clusters -What’s the Story?**

Escorial/Alhambra Room

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

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

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

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

**INDIVIDUAL PRESENTATIONS**

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

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

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

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

**Pre-Clinical Biological Basis**

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

**Studying the Biological Underpinnings of Quality of Life: Update on the Geneqol Consortium Activities**

Mirjam AG Sprangers, PhD, Academic Medical Center, University of Amsterdam, The Netherlands
Symposium 4: Tools for Assessing Religiousness and Spirituality in Health Research

Sandringham/Windsor Room

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

Religiousness and spirituality are increasingly shown to be related to myriad aspects of health and well-being. There has been growing interest in the links among religion, spirituality and health outcomes which has catalyzed research in the field and stimulated a deeper exploration of religion and spirituality. As researchers increasingly include these variables, they face a bewildering array of methods and measures. The proliferation has led to a number of surveys which vary widely in psychometric quality and conceptual validity.

During this panel, researchers will identify important considerations in the measurement of religion and spirituality, as well as considerations when designing a study to measure religion and spirituality. The panel will use specific health issues as exemplars of how to identify quality assessment tools. We will discuss specific assessment tools and provide specific criteria for evaluating their appropriateness in particular studies. By using empirically validated information, the panel will discuss the religion and spirituality variables that are particularly pertinent to the health issue.

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

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

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

The RS detection methods investigated include: (1) Relative importance analysis based on discriminate function and logistic regression analysis to detect reprioritization RS; (2) Item-response theory-based (IRT) to detect recalibration, reprioritization, and reconceptualization RS; and (3) Oort’s structural equation modeling (SEM) to detect recalibration, reprioritization, and reconceptualization RS. Four longitudinal health-related QOL datasets: (a) stroke caregivers; (b) multiple sclerosis; (c) cancer; (d) chronic disease. Tested missing-data techniques included case-wise deletion, available-case analysis, single imputation, and multiple imputation methods.

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

Results suggest that missing data imputation techniques generate similar findings across relative importance methods, and that IRT- and SEM-based analyses are robust to missing data. This symposium will provide a rich forum for discussing future directions for this untapped research area.
**Symposium 6: New Developments in Valuing Health: Directions for the EQ-5D**

Raphael/Michelangelo Room  
**Moderator: Paul Kind, MS, University of Leeds, Leeds, United Kingdom**

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

**INDIVIDUAL PRESENTATIONS**

**Overview of the EQ-5D-3L and New Directions for Valuation**  
Paul Kind, MS, University of Leeds, Leeds, United Kingdom

**Recent Developments in EQ-5D Measures and Valuation**  
Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States

**The EQ-5D-5L International Protocol and the Canadian Experience**  
Feng Xie, BSc(Pharm) MSc PhD, McMaster University, Hamilton, ON, Canada
**CONCURRENT ORAL SESSIONS**

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

**Oral Session 101: Positive Psychology/Life Satisfaction**

*Session Chair: David Eton, PhD, United States*

Balmoral Room

(101.1) A Pilot Study of Salutogenic Cafe Which Improves Sense of Coherence in a Work Place

Shin-ichiro Sasahara, University of Tsukuba, Tsukuba-City, Japan

(101.2) Positive Mental Health Among People with Psoriasis

Eva Langeland, Bergen University College, Bergen, Norway

(101.3) Cognitive Judgment Towards Eudaimonia Through Basic Needs Satisfaction

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

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

Ragnhild Sollesnes, Bergen University College, Bergen, Norway

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

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

**Oral Session 102: Response Shift**

*Session Chair: Leah McClimans, PhD, United States*

Windsor Room

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

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

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

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

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

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

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

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

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

*Session Chair: Melanie Calvert, PhD, United Kingdom*

Sandringham Room

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

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

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

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

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

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

(103.4) Concordance Between Clinician-Rated Adverse Symptom Events and Patient Grading Using the Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE): Application of a Bayesian Graded Item Response Model

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

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

Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Sydney, Australia
Oral Session 104: Patient-Reported Outcomes Measure Development and Evaluation

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

(104.1) Assessing the Translatability of a New Patient-Reported Outcome Measure for Major Depressive Disorder
Mona L. Martin, RN MPA, Health Research Associates, Inc., Mountlake Terrace, WA, United States

(104.2) Development of a Clinical Outcome Assessment for Autism Spectrum Disorder
Linda S. Deal, MS, Shire, Wayne, PA, United States

(104.3) Development and Validation of a New Patient-Reported Instrument of Uncertainty in Systematic Lupus Erythematosus (SLE) and Rheumatoid Arthritis (RA)
Sophie Cleanthous, MSc BSc, University College London, London, United Kingdom
STUDENT PRESENTATION AWARD FINALIST

(104.4) Development of a Composite Thyroid-Specific Quality of Life Scale for a Randomized Clinical Trial Among Hypothyroid Patients with Chronic Autoimmune Thyroiditis, Based on the ThyPRO Questionnaire
Kristian Winther, MD, Odense University Hospital, Odense, Denmark

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

Friday, October 11, 2:00 pm – 3:30 pm

Oral Session 201: Quality of Life in Children
Session Chair: Anne Riley, PhD, United States
Balmoral Room

(201.1) Health-Related Quality of Life and HIV Stigma in Children Living with HIV in Sweden
Lise-Lott Rydström, PhD-candidate, Karolinska Institutet, Sweden, Huddinge, Sweden

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

(201.3) Health-Related Quality of Life of Children with Immigrant Backgrounds: Towards a New Pattern in Europe?
Ester Villalonga, PhD, Harvard School of Public Health, Boston, MA, United States

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

(201.4) Factors Influencing Quality of Life in Children with Epilepsy: A Structural Equation Modeling Approach
Nora Fayed, University Health Network, Hamilton, Canada

(201.5) Developing a Disease Specific Quality of Life Measure for Children with Osteogenesis Imperfecta
Wendy O. Baird, PhD, University of Sheffield, Sheffield, United Kingdom

Oral Session 202: Concepts and Frameworks
Session Chair: Cindy Gross, PhD, United States
Escorial/Alhambra Room

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

(202.2) On the Conceptual Structure of the Chemotherapy-Induced Peripheral Neuropathy Scale of the EORTC Quality of Life Questionnaire (QLQ-CIPN20)
Jacobien Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

(202.3) Finalizing a Measurement Framework of Burden of Treatment in Complex Patients with Chronic Conditions
David T. Eton, PhD, Mayo Clinic, Rochester, MN, United States

(202.4) What’s Important to Patients Following Fragility Hip Fracture? A Qualitative Exploration of Outcomes
Kirstie L. Haywood, DPHIL BSc, Warwick Medical School, Coventry, United Kingdom

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

Oral Session 203: Statistical Methods
Session Chair: Diane Fairclough, DrPH, United States
Raphael/Michelangelo Room

(203.1) Development of a Crosswalk Between Measures of Work Role Limitations
Milena D. Anatchkova, PhD, University of Massachusetts Medical School, Worcester, MA, United States

(203.2) Mortality Bias in Quality of Life Scores Between Cancer Patients With and Without Follow-up Surveys
Ryan M. McCabe, Cancer Treatment Centers of America, United States

(203.3) Sample Size Determination Using Type I Error and Power When Conducting a Confirmatory Factor Analysis (CFA): A Simulation Study
Emmanuelle Anthoine, University of Nantes, Nantes, France

(203.4) Auxiliary Item Score Information to Deal with Missing Data in Longitudinal Patient-Reported Outcomes
Iris Eekhout, VU University Medical Center, Amsterdam, The Netherlands

Continued on next page...
CONCURRENT ORAL SESSIONS

Friday, October 11, 2:00 pm – 3:30 pm

(203.5) Power and Sample Size Determination for the Group Comparison of PROs in IRT: Impact of a Misspecification of the Parameters
Myriam Blanchin, University of Nantes, France

Oral Session 204: Personalized Medicine
Session Chair: Mirjam AG Sprangers, PhD, The Netherlands Sandringham Room

(204.1) Profiling Chronic Myeloid Leukemia Patients Reporting Intentional and Unintentional Non-Adherence to Lifelong Therapy with Tyrosine Kinase Inhibitors
Francesco Cottone, PhD, GIMEMA (Italian Group for Adult Hematologic Diseases), Rome, Italy

(204.2) The Impact of an Automatically Generated Survivorship Care Plan on Patient-Reported Outcomes: Results of a Pragmatic Cluster Randomized Controlled Trial (ROGY Care) Among Endometrial Cancer Patients
Kim Nicolaije, Tilburg University, Tilburg, The Netherlands
STUDENT PRESENTATION AWARD FINALIST

(204.3) Using Cluster Analysis to Generate Outcome Variables for Gene-Symptom Association Study in Cancer Patients
Qiuling Shi, PhD, University of Texas M.D. Anderson Cancer Center, Houston, TX, United States

(204.4) A Randomized Trial of the Psychosocial Aspects of Hereditary Cancer (PAHC) Questionnaire in Cancer Genetic Counseling: Effect on Counselees’ Levels of Psychosocial Distress
Willem Eijzenga, MSc, The Netherlands Cancer Institute, Amsterdam, The Netherlands

(204.5) Impact of Rapid Genetic Counseling and Testing on Health-Related Quality of Life in Breast Cancer Patients: Findings from a RCT
Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

Oral Session 205: Quality of Care Experience
Session Chair: San Keller, PhD, United States Windsor Room

(205.1) Measuring Cancer Care Quality: The Impact of Patient and Stakeholder Input on Survey Design
Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States

(205.2) Patient-Reported Experience of Fracture of the Proximal Femur in Patients Over 65 Years
Jo Brett, University of Warwick, Oxfordshire, United Kingdom
STUDENT PRESENTATION AWARD FINALIST

(205.3) Measuring Cancer Care Quality: Psychometric Properties of an Instrument for Assessing Patient Experience with Cancer Care
Christian Evensen, MS, American Institutes for Research, Chapel Hill, NC, United States

(205.4) The Development of a Patient-Centered Experience/Outcomes of Care Questionnaire for People with Chronic Conditions
Monica Hadi, PhD candidate, University of Oxford, Oxford, United Kingdom

(205.5) A Multi-Centre Study of Patient Experiences with Acute and Post-Acute Injury Care
Niklas JH Bobrovitz, BHSc(h), University of Calgary, Calgary, Canada
Friday, October 11, 4:00 pm – 5:30 pm

**Oral Session 206: Health Utilities**

*Session Chair: Pedro Ferreira, PhD, Portugal*

**Balmoral Room**

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

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

*(206.2) Valuation of Health Outcomes Measured Using the PROMIS®-29*

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

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

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

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

Brendan Mulhern, University of Sheffield, Sheffield, United Kingdom

**NEW INVESTIGATOR PRESENTATION AWARD FINALIST**

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

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

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

*Session Chair: Susan Bartlett, PhD, Canada*

**Escorial/Alhambra Room**

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

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

**NEW INVESTIGATOR PRESENTATION AWARD FINALIST**

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

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

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

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

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

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

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

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

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

*Session Chair: Georg Kemmler, PhD, Austria*

**Raphael/Michelangelo Room**

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

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

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

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

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

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

Continued on next page...
Oral Session 209: Responsiveness of Quality of Life Measures

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

(209.1) Using the EORTC QLQ-C30: What Score Represents a Change in Patients’ Supportive Care Needs?
Claire Snyder, PhD, Johns Hopkins, Baltimore, MD, United States

(209.2) Minimal Important Difference Established for PROMIS® Pain Interference
Jiseon Kim, University of Washington, Seattle, WA, United States

(209.3) Responsiveness and Minimal Important Difference of the Rheumatoid Arthritis-Work Instability Scale (RA-WIS)
Arijit Ganguli, PhD MBA, AbbVie, Inc., North Waukegan, IL, United States

(209.4) Validation for Pediatric Patient-Reported Outcomes Measurement Information System (PROMIS)® in Asthmatic Children: A Responsiveness Study
I-Chan Huang, PhD, University of Florida, Gainesville, FL, United States

(209.5) Responsiveness to Change for the Brazilian Scale of Oral Health Outcomes for 5-Year-Old Children (SOHO-5)
Jenny Abanto, University of Sao Paulo, Sao Paulo, Brazil

Oral Session 210: Caregiver Health

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

(210.1) Dyadic Effects of Social Support and Loneliness on Quality of Life of Cancer Patients and Their Family Caregivers
Youngmee Kim, PhD, University of Miami, Coral Gables, FL, United States

(210.2) Bereaved Family Caregivers’ Unmet Needs Predict Grief Severity
Aurelie Lucette, University of Miami, Coral Gables, FL, United States

(210.3) Relationship Between Child Health-related Quality of Life and SF6D Scores for Children with Autism and Their Caregivers
Nalin Payakachat, BPharm MS PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

(210.4) Validation of the Final Version of the Family Reported Outcome Measure (FROM-16)©
Catherine J. Golics, MPharm, Cardiff University, Cardiff, United Kingdom

(210.5) A Longitudinal View of Caregiver Emotional Vitality
Skye P. Barbic, PhD candidate, OT, McGill University, Montreal, Canada
Concurrent Oral Sessions

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

Oral Session 301: Longitudinal Follow Up in Cancer

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

(301.1) Baseline Quality of Life as Prognostic Factor of Relative Survival in Elderly Patients with Colorectal Cancer: A Population-Based Study
Evelyne Fournier, MPH, Doubs and Belfort Cancer Registry, University Hospital of Besançon, Besançon, France

(301.2) Long-Term Quality of Life in Breast Cancer Patients According to Sentinel Lymph Node Biopsy or Axillary Lymph Node Dissection: A Multicenter Cohort Study with 6 Years Follow-Up
Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges François Leclerc, Dijon, Burgundy, France

(301.3) Relationship Between Survival Time and Quality of Life in Terminal Cancer Patients Receiving Palliative Care Intervention
Kikuko Miyazaki, PhD, Kyoto University, Kyoto, Japan

(301.4) Quality of Life (QoL) for Prostate Cancer after Prostatectomy, Brachytherapy and External Beam Radiotherapy with a Follow-up of 5 years
Monica Avila Pacheco, MPH, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

(301.5) Quality of Life in a Urinary Bladder Cancer Cohort with Patients from Seven Spanish Hospitals
Stefanie Schmidt, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

Oral Session 302: Quality of Life and Health Evaluation

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

(302.1) Health-Related Quality of Life in Kidney Donors from the Last Five Decades: Results from the RELIVE Study
Cynthia Gross, PhD, University of Minnesota, Minneapolis, MN, United States

(302.2) Health-Related Quality of Life Associated with Imbalanced Body Constitution
Cindy L.K. Lam, MD, The University of Hong Kong, Hong Kong SAR, Peoples Republic of China

(302.3) Firefighters’ Quality of Life and Emergency-Related Factors - Cross-National Data
Doris Kehl, University of Greifswald, Germany

(302.4) The Cognitive Basis of the Visual Analog Scale (VAS)
Ivan Barofsky, PhD, The Quality of Life Institute, East Sandwich, MA, United States

(302.5) Patient-Reported Outcomes in Medicare Beneficiaries with Less Common Cancers: Population-Based Surveillance Using the SEER-MHOS Data Linkage.
Steven B. Clauser, PhD, National Cancer Institute, Rockville, MD, United States

2013 ISOQOL President’s Award

Peter Fayers, PhD
Retired, University of Aberdeen, United Kingdom
Oral Session 303: Methods and Psychometric Approaches

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

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

(303.2) Assessment of the Relative Precision of the NEI VFQ-25 and a Modified, Rasch-Scored NEI VFQ in Clinical Trial Data for Patients with Diabetic Macular Edema (DME)
Stefan J. Cano, PhD CPsychol AFBPsS, Plymouth University Peninsula Schools of Medicine & Dentistry, Plymouth, United Kingdom

(303.3) A Simple Ratio-Based Approach for Power and Sample Size Determination in Rasch Family Models
Jean-Benoit Hardouin, PhD ScD, University of Nantes, Nantes, France

(303.4) Use of Latent Growth Modeling to Evaluate Construct Validity in Longitudinal Studies
Lauren Nelson, RTI Health Solutions, Research Triangle Park, NC, United States

(303.5) Self-Reported Cognitive Concerns and Abilities: Two Sides of One Coin?
Jin-Shei Lai, PhD, Northwestern University, Chicago, IL, United States

Oral Session 304: eHealth/ Health Technology

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

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

(304.2) Developing a Tool to Measure the Effects of Using Health-Related Websites (The e-Health Impact Questionnaire)
Laura Kelly, University of Oxford, Oxford, United Kingdom

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

(304.4) A Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care
Roxanne E. Jensen, PhD, Georgetown University, Washington, DC, United States

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

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

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

(305.1) Lifestyle Behaviors as Predictors of Bad Quality of Life in Thai Resident Physicians
Anawin Sanguankeo, Johns Hopkins University, Bangkok, Thailand

(305.2) Is There Any Difference on Quality of Life Between Hospital Doctor and Practitioner?
Sho Matsui, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, Japan

(305.3) Withdrawn

(305.4) Burnout and Quality of Life Among Health Sciences Research Faculty
Jeff Sloan, PhD, Mayo Clinic, Rochester, MN, United States

(305.5) Mexican Professors’ Quality of Life in Comparison with Other Occupations
Fernando Arias-Galicia, Sr., Morelos State University, Cuernavaca, Mexico
CONCURRENT ORAL SESSIONS

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

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

*Session Chair: Jin-Shei Lai, PhD, United States*

Balmoral Room

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

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

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

*Solveig Petersen, Umea University, Umea, Sweden*

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

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

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

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

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

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

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

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

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

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

(307.4) Using Baseline Patient Self-Rating of Health to Predict the Outcomes of Hip Replacement Surgery

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

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

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

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

*Session Chair: Jose (Chema) Valderas, MD PhD MPH, United Kingdom*

Escorial/Alhambra Room

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

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

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

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

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

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

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

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

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

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

Continued on next page...
CONCURRENT ORAL SESSIONS

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

(308.5) Component Causes of QOL Trajectories in People with Advanced Cancer
Ana Maria Rodriguez, PhD MSc BS PT, McGill University, Montreal, Canada

Oral Session 309: Body Image/Sexual Function
Session Chair: Peter Fayers, PhD, United Kingdom
Sandringham Room

(309.1) Do Existing Questionnaires for Sexual Dysfunction Measure Items Relevant to Patients with HIV and HCV?
Marcelo Watanabe, Medicine School of ABC, Sao Paolo, Brazil

(309.2) Conceptual Model for the PROMIS® Sexual Function and Satisfaction Measure
Kathryn E. Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States

(309.3) Assessing Quality of Life in Patients Awaiting Delayed Breast Reconstruction
Helen C. Miller, BS, Memorial Sloan-Kettering Cancer Center, Great Falls, MT, United States

(309.4) Reasons for Sexual Inactivity in a U.S. National Survey of Adults
Kevin P. Weinfurt, PhD, Duke Clinical Research Institute, Durham, NC, United States

(309.5) Quality of Life and the Impact of Altered Facial Appearance in Head and Neck Cancer Patient Populations: A Qualitative Study
Jessica L. Lawson, MSc, Yeshiva University, New York, NY, United States

Oral Session 310: Respiratory Diseases
Session Chair: Sara Ahmed, PhD, Canada
Windsor Room

(310.1) Psychometric Performance of the Asthma Symptom Diary (ASD) in Adult and Adolescent Subjects with Persistent Asthma
Gary Globe, Amgen Inc., United States

(310.2) Validation of the RAND Impact of Asthma on Quality of Life Item Bank Short-Forms
Cathy Sherbourne, The RAND Corporation, Santa Monica, CA, United States

(310.3) Selecting Relevant PROMIS® Item Banks for Patients with Chronic Obstructive Pulmonary Disease: An Interview Study
Muirne CS Paap, University of Twente, Enschede, The Netherlands

(310.4) The Psychometric Development of an Item Bank and Short Forms that Assess the Impact of Asthma on Quality of Life
Brian D. Stucky, RAND Corporation, Santa Monica, CA, United States

(310.5) Evaluating Predictors of Perceived Asthma Control to Maximize the Impact of Interventions in Primary Care
Owis J. Eilayyan, McGill University, Montreal, Canada
POSTER SESSIONS

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

**eHealth/ePROs**

(1001) **Behind the Scenes: A Review of Instruments Used in Electronic Patient-Reported Outcomes Systems**
Aaron C. Roberts, Georgetown University, Washington, DC, United States
STUDENT PRESENTATION AWARD FINALIST

(1002) **Update of the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID): Inclusion of e-PRO Information**
Katrin Conway, MA, Mapi Research Trust, Lyon, France

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

(1004) **Cheap PRO Collection on the Web with Low Response Rates vs Expensive Paper Forms with High Rates: Do We Have to Choose?**
Niels Henrik Hjollund, Aarhus University Hospital, Herning, Denmark

**Patient-Reported Outcomes in Clinical Practice**

(1006) **The Use of Individualized Measurement Instruments in the Process of Goal Setting: A Systematic Review**
Anna Beurskens, PhD, Zuyd University of Applied Sciences, Heerlen, The Netherlands

**Conceptual Issues/Frameworks**

(1009) **Empowerment: An Individual Characteristic of Health-Related Quality of Life?**
Jane Kass-Wolff, University of Colorado Anschutz Medical Campus, United States

(1010) **Improving Patient Safety: A Framework to Assess Patient-Reported Adverse Outcomes**
Barbara M. Okoniewska, University of Calgary, Canada

**Guidelines and Guidance**

(1014) **The Role of Measurement in Establishing Evidence-Based Medicine**
Leah M. McClimans, PhD, University of South Carolina, Columbia, SC, United States

(1015) **PRO Trial Protocols: The Current State of Play**
Melanie Calvert, PhD, The University of Birmingham, Birmingham, United Kingdom

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

(1017) **CLEFT-Q: Cross-Cultural and Age-Related Similarities in Developing a Patient-Reported Outcome Instrument for Children with a Cleft Lip and/or Palate**
Karen W.Y. Wong, MD MSc FRCSC, Hospital for Sick Children, Toronto, Canada

(1011) **Understanding Health Care Needs of People With Chronic Conditions: Patient Experiences, Outcomes and Quality of Life**
Monica Hadi, PhD candidate, University of Oxford, Oxford, United Kingdom

(1012) **Differences in the Perception of Quality of Life Domains Between Hospital and Community Patients with Pressure Ulcers**
Simon J. Palfreyman, PhD, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom

(1013) **Framework to Assess the Effects of Using Patient-Reported Measures in Chronic-Care Management**
Maria-Jose Santana, PhD, University of Calgary, Calgary, Canada

Outstanding Poster Abstract Award
Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

**Translation and Cultural Adaptation**

(1018) Transformation of Retrospectively Worded Questionnaire Items into Momentary Wording Using Cognitive Interviewing
Stine Birk Nissen, University of Copenhagen, København, Denmark

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

(1020) Translation of Oswestry Disability Index in to Tamil with Cross Cultural Adaptation and Evaluation of Reliability and Validity
Joshua I. Vincent, PT MPT, The University of Western Ontario, London, Canada

(1021) New Concepts for Back Translation Review: The EORTC’s Perspective
Dagmara Kulis, EORTC, Brussels, Belgium

(1022) Trans Cultural Adaptation of PROMIS® Social Function Item Banks to Portuguese
Carlos Henrique Martins Silva, Sr., Universidade Federal de Uberlândia - FAMED, Brazil

(1023) Measuring Physical Functioning in the Elderly Population: Adaptation and Validation of the Late-Life Function and Disability Instrument (LLFDI) to the Portuguese Culture
Luis Manuel Cavalheiro, PhD, Centre for Health Studies and Research of the University of Coimbra, Coimbra, Portugal

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

(1024) Validation of the Dutch-Flemish PROMIS® Physical Functioning Item Bank in Patients with Chronic Pain
Martine H.P. Crins, Reade | Amsterdam Rehabilitation Research Center, Amsterdam, The Netherlands

(1025) Development and Calibration of an Item Bank for the EORTC Role Functioning Computer Adaptive Test (EORTC RF-CAT)
Eva-Maria Gamper, Innsbruck Medical University, Innsbruck, Austria

**Non-IRT Measures**

(1026) Applying Partial Least Square Regression to Further Explore Concept Structure and Interviewee Profiles in Qualitative Research
Fatoumata Fofana, Mapi and University of Nantes, Lyon, France

(1027) Propensity Score Matching and Age-Gender Adjustment Methods for Quality of Life Comparisons Between Non-Randomized Groups: The Influence of Sample Size on Bias Reduction
Francesco Cottone, PhD, GIMEMA (Italian Group for Adult Hematologic Diseases), Rome, Italy

**Psychometrics**

(1028) Applying Multilevel IRT Modeling for Analyzing Longitudinal Data
Rosalie Gorter, VU University Medical Centre, Amsterdam, The Netherlands

(1029) Validation of CESD-20 and PHQ-9 Crosswalks to PROMIS® Depression in Multiple Sclerosis
Jiseon Kim, University of Washington, Seattle, United States

(1031) Testing for Unidimensionality Using the Principal Component Analysis (PCA)/T-Test Protocol in Rasch Analysis: A Cautionary Note
Peter Hagell, Kristianstad University, Kristianstad, Sweden

(1033) Quality of Life after Brain Injury and the QOLIBRI Overall Scale: A Brief Index
Nicole Von Steinbuchel, PhD, University of Goettingen, Goettingen, Germany

Outstanding Poster Abstract Award

New Investigator Presentation Award Finalist

NEW INVESTIGATOR PRESENTATION AWARD FINALIST
### POSTER SESSIONS

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

#### Utilities

(1034) Valuation of Child Health-Related Quality of Life in the United States  
*Benjamin M. Craig, PhD, Moffitt Cancer Center, Tampa, FL, United States*

(1035) Predicting Health Utilities for Children with Autism Spectrum Disorders  
*Nalin Payakachat, BPharm MS PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States*

(1036) Assessing the Burden of Illness from Cervical Dystonia Using TWSTRS Scores and Health Utilities: Meta-Analysis of Baseline Patient-Level Clinical Trial Data  
*Jerome Dinet, PhD, Ipsen, France*

#### Caregivers

(1042) Addressing the Needs of Cancer Patients and Caregivers through Multi-Disciplinary Psychosocial Interventions  
*Pamela J. Atherton, MS, Mayo Clinic, Rochester, MN, United States*

(1044) The Influence of Culture on Quality of Life of Hispanic Family Caregivers of Patients with Advanced Cancer  
*Gloria Juarez, PhD RN MSN, City of Hope, Duarte, CA, United States*

(1045) Caregiver Burden, Self Efficacy, and Quality of Life Among Hispanic Working Caregivers  
*Joan J. Branin, PhD, University of La Verne, Pasadena, CA, United States*

#### Patient Populations

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

(1038) The ‘Wound-QoL’ – Development of a Short Quality of Life Questionnaire on the Basis of Three Established Wound-Specific Instruments  
*Christine Blome, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany*

(1039) Developing the Eating Behavior Scale for Diabetes (EBSD): A Brief Screening Instrument for Disordered Eating in Diabetes  
*Brendan Mulhern, University of Sheffield, Sheffield, United Kingdom*

(1040) Health-Related Quality of Life of People Living with Methicillin-Resistant Staphylococcus Aureus  
*Lars E. Eriksson, PhD, Karolinska Institute, Huddinge, Sweden*

(1041) What Matters to Children with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME)? A Qualitative Exploration of Important Outcomes  
*Kirstie L. Haywood, DPHIL BSc, Warwick Medical School, Coventry, United Kingdom*

#### Children

(1046) Quality Of Life (QOL) Questionnaire for Children and Mothers  
*Rika Hayashida, MS, University of Nagasaki, Siebold, Japan*

(1047) Health-Related Quality of Life in Children with Urea Cycle Disorders  
*Natalie M. Gallant, UCLA, Los Angeles, CA, United States*

(1049) Parent Prognostic Outlook throughout the Pediatric Hematopoietic Stem Cell Transplant (HSCT) Course  
*Christina K. Ullrich, MD MPH, Dana-Farber Cancer Institute, Boston, MA, United States*

(1050) Health-Related Quality of Life in Children Under Active Treatment for Cancer: State of the Science  
*Tha’er G. Momani, PhD(c) RN, St. Jude Children’s Research Hospital, Memphis, TN, United States*

(1051) Super Marrow: A Psychotherapeutic Resource to Prepare Oneself for the Illness Process  
*Maribel P. Doro, PhD, Clinical Hospital, Curitiba, Brazil*
Poster Session 1: Thursday, October 10, 10:30 am – 11:15 am

**Aging/Dementia**

(1052) The Association of Poor Medication Adherence and Drug-Related Problems with Health Status of Community-Dwelling Asian Elderly: An Interim Analysis  
McVin Hua Heng Cheen, Singapore General Hospital, Singapore, Singapore

(1053) The Relationships Among Health Status, Service Coordination, and Patient-Reported Outcomes in Medicaid Long Term Care Program  
Zheng Li, MPH, University of Florida, Gainesville, FL, United States

(1054) Apolipoprotein E and Quality of Life in the Arizona ApoE Cohort  
Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States

(1055) Better Response Rate to EQSD Questionnaire Using Script for Telephone Interview, in Low Income Older People in Brazil  
Monica A C T Cintra, MD, National Institute of Cardiology Brazil, Rio de Janeiro, Brazil

**Mental Health**

(1056) Assessing Measurement Invariance of Three Depression Measures Between Neurologic and Community Samples  
Hyewon Chung, Chungnam National University, Daejeon, Korea

(1057) Quality of Life in Mood Disorders: A WHOQOL – BREF Comparison with the Brazilian Normative Values  
Ana Flavia da Silva Lima, PhD, UFRGS, Porto Alegre, Brazil

(1058) Valuations of Depression: Discrepancies Between Individuals With and Without Depression.  
Katerina Papageorgiou, MSc, University Medical Center Groningen, Groningen, The Netherlands

(1059) The Impact of Hazardous Jobs on Mental Health and Well Being Among Working Thai Adults  
Vasoontara Yiengprugsawan, The Australian National University, Acton, Canberra ACT, Australia

(1060) Psychotic and Non-Psychotic Depression: Are There Differences in Symptom Intensity and Quality of Life Among Hospitalized Patients?  
Neusa Sica da Rocha, MD, Federal University of Rio Grande Du Sul, Porto Alegre, Brazil

(1061) Myth or Reality: Are Head and Neck Cancer Patients At Increased Risk for Suicidal Thoughts and Gestures? – Preliminary Results  
Melissa Henry, McGill University, Montreal, Canada

(1062) QOL Measures in Mood Disorders: A Brazilian Sample Assessment and Comparison Between Models.  
Sandro R P S Miguel, MD, Institute for Health Technology Assessment, Porto Alegre - Rio Grande Do Sul, Brazil

(1063) Quality of Life Among Non-Depressed and Depressed Older Adults  
Liv Halvorsrud, Oslo and Akershus University College of Applied Science, Oslo, Norway

**Respiratory Disease**

(1064) Predictors of Mental and Physical Quality of Life in Patients with COPD  
Randi Andenas, PhD, Oslo and Akershus University College, Oslo, Norway

(1065) Illness Perception Among People with COPD  
Christine R. Borge, Institute of Health and Society, Sofiemyr, Norway
**Poster Sessions**

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

**Cardiovascular/Stroke**

(1067) Overlap Between TCM-SAQ and SAQ on Patients with Stable Angina Pectoris and Phlegm and Blood-Stasis Syndrome  
Jin Wu, Liaoning University of Traditional Chinese Medicine, Shenyang, People's Republic of China

(1068) The Further Validation of a Syndrome-Specific Instruction to Assess QoL for Angina Treated by Traditional Chinese Medicine (TCM-SAQ): The Ability to Detect Change  
Huiyong Zhang, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Shenyang, People’s Republic of China

(1069) The Effect of Disease Severity on Quality of Life for Patients with Angina  
Lv Meijun, Liaoning University of Traditional Chinese Medicine, Shenyang, People’s Republic of China

**Kidney/Liver/Gastrointestinal**

(1072) Symptom Clusters Predict Mortality Among Dialysis Patients in Norway  
Amin Amro, RN MSN, Oslo University Hospital, Oslo, Norway

**Outstanding Poster Abstract Award**

(1073) Cost-Effectiveness of Three Types of Dialysis Modalities in Mexicans with End-Stage Renal Disease  
Luxana Reynaga-Ornelas, Universidad de Guanajuato, Guanajuato, Mexico

(1074) Digestive Functions May Differently Affect Quality of Life According to Each Sasang Constitution in Korea  
Eunsu Jang, Korea Institute of Oriental Medicine, Daejeon, Korea

**Musculoskeletal**

(1075) Emotional Support Contributes to Outcomes Following Distal Radius Fractures  
Joy MacDermid, PhD, McMaster University, Hamilton, ON, Canada

(1077) Psychometric Properties of the Dutch Short Musculoskeletal Function Assessment Questionnaire (SMFA) in Patients with a Fracture of the Upper or Lower Extremity  
Marleen Van Son, MSc, Tilburg University, Tilburg, The Netherlands

(1078) Patients with a Single Fracture of the Upper or Lower Extremity Have Worse Health Status and Quality of Life Six Months Post-Injury Compared to Their Pre-Injury Status  
Marleen Van Son, MSc, Tilburg University, Tilburg, The Netherlands

(1079) Baseline Predictors of Work Instability in Patients with Work-Related Upper Extremity Disorders (WRUED)  
Vanitha Arumugam, PT MPT, University of Western Ontario, London, Canada

(1080) Can Expectancy, Credibility, Hope, Optimism and Pessimism be Distinguished in Total Hip and Total Knee Arthroplasty Patients in a Meaningful Way?  
Tsjitske M. Haanstra, MSc, VU University Medical Centre, Amsterdam, The Netherlands
POSTER SESSIONS

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

Cancer Symptoms and Quality of Life

(1081) Using Structural Equation Modeling to Detect Response Shift and True Change in Quality of Life Score of Palliative Care Patients
Yoshimi Suzukamo, PhD, Tohoku University, Sendai, Japan

(1082) Incorporating Quality of Life Data into Surgical Decision-Making and Treatment Strategies: A Literature Review and Recommendations
Juliane Bingener, Mayo Clinic, Rochester, MN, United States

(1083) Prediction of Survival by Preoperative Health-Related Quality of Life Scores in a Prospective Cohort of Elderly Oncosurgical Patients
Maren Schmidt, Charité Universitätsmedizin Berlin, Berlin, Germany

(1084) Are Health-Related Quality of Life Decrements After Breast Cancer Diagnosis Time-Limited for Women Ages 65 and Older? - A Matched Comparative Study of Medicare Beneficiaries
Angela M. Stover, University of North Carolina at Chapel Hill, Durham, NC, United States

(1085) Impact of Response Shift on the Assessment of Health-Related Quality of Life in Breast Cancer Patients After Surgery
Kazuhiro Nakamura, Ritsumeikan University, Japan

(1086) Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) in NCCTG (Alliance) N1031 (Randomized Phase II Study of Two Doses of Pixantrone in Patients with Metastatic Breast Cancer)
Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States

(1087) Concordance Between Symptomatic Adverse Event Ratings by Clinicians and Patients: A Systematic Review
Thomas M. Atkinson, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY, United States

(1088) Incorporating Patient-Reported Outcomes in a Phase I Clinical Trial
Jeff Sloan, PhD, Mayo Clinic, Rochester, MN, United States

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

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

(1091) Initial Quality of life Deficit in Patient-Reported Outcome is Related to Cancer Stage: A Mayo Clinic Esophageal Adenocarcinoma and Barrett’s Esophagus Registry Consortium Study
Terence T. Sio, MD MS, Mayo Clinic, Rochester, MN, United States

(1092) A Prospective Assessment of Aspects of Emotional Functioning Following Oesophageal Cancer Surgery
Ylva V. Hellstadius, PhD student, Molecular Medicine and Surgery, Stockholm, Sweden

(1093) Patient-Proxy Agreement of Health-Related Quality of Life (HRQOL) Measurements in Low-Grade Glioma Patients
Divine Ewane Ediebah, MSc, EORTC HQ, Brussels, Belgium

Outstanding Poster Abstract Award
**Poster Session 2: Friday, October 11, 10:30 am – 11:15 am**

### eHealth/ePROs

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

**(2002)** Implementing New Clinical Outcome Assessment Instruments on Alternative Data Collection Modes: The Electronic Implementation Assessment and Migration Process  
*Sonya Eremenco, MA, Evidera, Bethesda, MD, United States*

**(2003)** AmbuFlex/Epilepsy – Implementation of Patient-Reported Outcomes in Epilepsy Clinics  
*Liv Marit Valen Schougaard, VestKronik, Regional Hospital West Jutland, Herning, Denmark*

**(2004)** Short-Term Findings from The Norwegian (RCT) Study of Renewing Health: A Low-Intensity and Low-Cost Mobile Health Intervention with Health Counseling  
*Astrid CV Torbjørnsen, Oslo and Akershus University College of Applied Sciences, Oslo, Norway*

**(2005)** Increasing Symptom Management Self Efficacy Using a Novel eHealth Tool for Men with Clinically Localized Prostate Cancer  
*David Victorson, PhD, Northwestern University Feinberg School of Medicine, Evanston, IL, United States*

### Patient-Reported Outcomes in Clinical Practice

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

**(2007)** Oncologists’ Preferences for Presentation of PRO Data in Randomized Clinical Trial (RCT) Publications: A Quantitative Assessment  
*Michael Brundage, MD, Queen’s University, Kingston, Canada*

**(2008)** Development and Feasibility of a Web-Based Question Prompt Sheet Aimed to Increase the Discussion of Health Related Quality of Life Topics in the Initial Follow-up Consultation after Esophageal Cancer Surgery  
*Marc Jacobs, Academic Medical Center, Amsterdam, The Netherlands*

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

### Conceptual Issues/Frameworks

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

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

### Minimally Important Differences/Clinical Significance

**(2013)** QoLR: An R package for the Longitudinal Analysis of Health-Related Quality of Life in Oncology  
*Amélie Anota, Quality of Life in Oncology Platform, France, Besançon, France*

**(2014)** Clinical Significance in Self-Rated HRQoL Among Survivors after Childhood Cancer  
*Anna Jervaeus, Karolinska Institutet, Huddinge, Sweden*

**(2015)** Ferrans & Powers Quality of Life Index – Wound Version: A Study about Responsiveness  
*Alciclea dos Santos Oliveira, MS, Beneficencia Portuguesa Hospital/ Sao Paulo, Sao Paulo, Brazil*

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*Outstanding Poster Abstract Award*
Poster Session 2: Friday, October 11, 10:30 am – 11:15 am

Guidelines and Guidance

(2016) Stakeholder Perspectives on the PRO Guidance
Ari Gnanasakthy, MSc MBA, Novartis Pharmaceuticals, East Hanover, NJ, United States

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

Translation and Cultural Adaptation

(2018) Translation and Psychometric Testing of the Chinese Version of Measure Yourself Medical Outcome Profile (MYMOP)
Fan Zhang, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

(2019) Face Validation and Translatability Assessment of Patient Questionnaires
Matthew Talbert, Corporate Translations, Chicago, IL, United States

(2021) Portuguese Translation and Cross-Cultural Adaptation of the PROMIS® Anxiety and Depression Items Bank
Carlos Henrique Martins Silva, Sr., Universidade Federal de Uberlândia - FAMED, Brazil

(2022) Cross-Cultural Adaptation and Validation of the Portuguese Version of the Dougados Functional Index (DFI)
Rui Soles Goncalves, PhD, Centre for Health Studies and Research of the University of Coimbra, Coimbra, Portugal

Non-IRT Measures

(2023) A Mixed Method Approach to Saturation: Applying Partial Least Square Regression to Qualitative Data
Fatoumata Fofana, Mapi and University of Nantes, Lyon, France

(2024) Longitudinal Quality of Life Assessment in Cancer Trials: Should Data Be Treated as Continuous or Ordinal?
Dagmara Kulis, EORTC, Brussels, Belgium

Psychometrics

(2025) Precision Where You Need It? - Comparing Different Computerized Adaptive Tests for Depression Screening
Matthias Rose, MD PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany

(2028) Validity of the Singapore Short Form 12 Version 2
Maudrene LS Tan, MSc, National University of Singapore, Singapore

(2029) Online Analyses of PRO Using CTT and IRT Methods for Validating, Analyzing Scales or for Planning Studies
Jean-Benoit Hardouin, PhD ScD, University of Nantes, Nantes, France

(2031) The Vulvar Discomfort Domain of the PROMIS® Sexual Function and Satisfaction Measure
Kathryn E. Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States

(2032) Psychometric Evaluation of the Swedish MRSA Stigma Scale
Maria H. Lindberg, Karolinska Institutet, Huddinge, Sweden

Outstanding Poster Abstract Award
### Poster Sessions

**Poster Session 2: Friday, October 11, 10:30 am – 11:15 am**

<table>
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<th>Utilities</th>
<th>Caregivers</th>
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<tbody>
<tr>
<td>(2033) Metric Properties of the Spanish Version of the Patient-Oriented Prostate Utility Scale (PORPUS)</td>
<td>(2042) Dementia with Lewy Bodies: The Caregivers’ Quality of Life</td>
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<tr>
<td>Monica Avila Pacheco, MPH, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain</td>
<td>Maria Alves Barbosa, Nursing Faculty of Federal University of Goiás, Goiânia, Brazil</td>
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<tr>
<td>(2034) Comparison of Three Utility Measures Using Item Response Theory in Stroke Patients</td>
<td>(2044) A Novel Approach for Measuring Outcomes in Infants and Young Children—Using the Eyes and Ears of Caregivers</td>
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<tr>
<td>Ryota Izumi, MS, Niigata University of Health and Welfare, Niigata-Shi, Japan</td>
<td>Todd C. Edwards, PhD, University of Washington, Seattle, WA, United States</td>
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<tr>
<td>(2035) Preferences for EQ-5D Health States Among Patients Undergoing Knee Replacement Surgery</td>
<td>(2045) The Effects of an Early Intervention on Maternal Confidence in Mothers of Moderately and Late Preterm Infants - A Randomized Controlled Trial</td>
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<tr>
<td>Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States</td>
<td>Ingrid Helen Ravn, Pub.H.RN. MSN PhD, Oslo and Akershus University College, Oslo, Norway</td>
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<td>(2036) How Better is EQ-5D-5L Compared to EQ-5D-3L?</td>
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<td>Pedro L. Ferreira, PhD, University of Coimbra, Coimbra, Portugal</td>
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<th>Patient Populations</th>
<th>Children</th>
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<tr>
<td>(2037) A Review of the Impact of Long-Term Armed Conflict on Health-Related Quality of Life</td>
<td>(2046) The HIV Stigma Scale for Children – Validity and Reliability of the Swedish Version</td>
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<td>Yara M. Asi, University of Central Florida, Oviedo, FL, United States</td>
<td>Maria Wiklander, PhD, Karolinska Institutet, Huddinge, Sweden</td>
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<tr>
<td>(2038) Assessment of the Quality of Life in Chinese Myasthenia Gravis Patients with Ocular, Mild and Moderate Groups</td>
<td>(2048) Measurement Properties of the Adolescent Quality of Life Mental Health Scale (AQOL-MHS)</td>
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<td>Huiyong Zhang, MD, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China</td>
<td>Ljigia M. Chavez, PhD, University of Puerto Rico, San Juan, Puerto Rico</td>
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<tr>
<td>(2039) Perceptions of Treatment Benefit and Quality of Life in Adults with Growth Hormone (GH) Deficiency Replaced with GH: An International Surveillance Study from the KIMS Database</td>
<td>(2049) Quality of Life and Anxiety Evaluation in Normal-Weight, Overweight and Obese Children</td>
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<td>Andreas Pleil, PhD, Pfizer, Inc., San Diego, CA, United States</td>
<td>Paula M. Castelo, Professor, UNIFESP, Diadema, Brazil</td>
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<td>(2040) Factors Associated with Quality of Life Among HIV Patients Attending an Urban Clinic in a Resource Limited Setting-Uganda</td>
<td>(2050) Mental Health of Indigenous School Children in Northern Chile</td>
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<td>Doris M. Mwesigire, MD, Makerere University, Kampala, Uganda</td>
<td>Alejandra Caqueo-Urízar, PhD, Universidad de Tarapacá, Arica-Chile, Arica, Chile</td>
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<td>(2041) Gender Differences on Perceived Health in Multiple Sclerosis Detected Using Regression Shrinkage, Not Using Conventional Methods</td>
<td>(2051) I Feel I Mean Something for Someone</td>
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<tr>
<td>Nancy E. Mayo, PhD, McGill University Health Centre, Montreal, Canada</td>
<td>Lisbeth G. Kvarme, PhD, Oslo and Akershus University College, Oslo, Norway</td>
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</table>

**Outstanding Poster Abstract Award**
**Poster Session 2: Friday, October 11, 10:30 am – 11:15 am**

**Aging/Dementia**

(2052) Health Status Profiles of Community-Dwelling Elderly Using Self-Reported Health Indicators: A Latent Class Analysis  
Charis Wei Ling Ng, BA MPH, Health Services & Outcomes Research (HSOR), NHG, Singapore

(2053) Physical Component of SF-12 Predicts Mortality in Seniors. Evidences from the SABE Study  
Sao Paulo – Brazil  
Jair Licio Ferreira Santos, PhD, University of Sao Paulo, Ribeirao Preto, Brazil

(2054) Health Related of Quality of Life (HRQOL) of the Elderly: SABE Study – Brazil  
Keila C. Trindade Da Cruz, Brasília University, Lago Sul – Brasília, DF, Brazil

(2055) Determinants of Health Related Quality of Life Among Community Dwelling Elderly in Singapore  
Pradeep Paul George, Health Services & Outcomes Research (HSOR), NHG Singapore

**Cardiovascular/Stroke**

(2063) Patient-Reported Outcomes in Long-Term Conditions: A Cohort Survey in England  
Michele Peters, PhD, University of Oxford, Oxford, United Kingdom

(2064) Do One Comprehensive Question Equal to a Corresponding Dimension with Several Items? A Study of Seattle Angina Questionnaire (SAQ)  
Changhe Yu, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

(2065) Influence of Resting Heart Rate on the Angina Patients’ Quality of Life  
Yang Mingqian, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

(2066) The Influence of Disease-Related Risk Factors on Angina Patients as Shown in Seattle Angina Questionnaire (SAQ)  
Chen Zhihui, MD, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

(2067) Health-Related Quality of Life (HRQoL) in Abdominal Aortic Aneurysm (AAA) Patients  
Yaping Ai, Hong Kong

(2068) Looking at the Quality of Life of Artificial Cardiac Pacemaker Patients in Goiânia, Brazil  
Virginia V. Brasil, PhD, Nursing Faculty of the Federal University of Goias, Goiânia, Brazil

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**Mental Health**

(2056) The Effects of a Biography-Based Intervention on Quality of Life and Depression in Late Life  
Daniela Knuth, PhD, University of Greifswald, Greifswald, Germany

(2057) Predictors of Quality of Life and Perceived Stress Among People with Chronic Illness  
Hideaki Tanaka, Florida International University School of Public Health, Miami, FL, United States

(2059) The Association of Middle-Of-The-Night Awakening (MOTN) with Quality of Life and Work Productivity Among Patients With/Without Psychiatric Disorders  
Jill Bell, Oxford Outcomes, Purdue Pharma LP, United States

(2060) Multiple Psychiatric Readmissions and Quality of Life of Patients with Severe Mental Illness  
Lucas P. Alves, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil

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(2061) Are There Differences in Quality of Life Using the EUROHIS-QOL 8-Item in Psychiatric Inpatients Comparing Those with Readmissions with Those With No Readmissions on 12 Months Follow-Up?  
Fernanda LC Baeza, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil

(2062) Electroconvulsive Therapy Increases Quality of Life as Much as Standard Therapy in Severely Depressive Inpatients  
Lucas P. Alves, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil

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Outstanding Poster Abstract Award
POSTER SESSIONS

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

**Diabetes**

(2070) Sense of Coherence is a Predictor of Lifestyle Change in Subjects at Risk for Type 2 Diabetes
Vegard Nilsen, MD, Sorlandet Hospital and University of Bergen, Kristiansand, Norway

(2071) Motivation for Diet Change Among Persons with Type 2 Diabetes
Heidi Holmen, Oslo and Akershus University College of Applied Science, Oslo, Norway

(2073) Sample Size Requirements of Three Psychosocial Distress Measures in Patients with Type 2 Diabetes Mellitus
Hwee-Lin Wee, PhD, National University of Singapore, Singapore

**Musculoskeletal**

(2077) Patient-Reported Outcome Measures (PROMs) and Fragility Hip Fracture: A Systematic Review of Quality and Acceptability
Jo Brett, University of Warwick, Oxfordshire, United Kingdom

(2079) Evaluating the Longitudinal Construct Validity of the Health Utilities Indices Mark 2 and Mark 3 Over Recovery from Hip Fracture
David Feeny, PhD, University of Alberta, Portland, OR, United States

**Kidney/Liver/Gastrointestinal**

(2074) Quality of Life in Coeliac Disease: The Qualitative Development of a New Patient-Reported Outcome Measure
Helen Crocker, University of Oxford, Headington, Oxford, United Kingdom

(2075) Monitoring the National Specific Plan “Improving Quality of Life in Chronic Disease Patients”: The Example of End-Stage Renal Disease
Serge Briançon, MD, Nancy University, Vandoeuvre Les Nancy, France

(2076) Development and Content Validation of a New Patient Questionnaire for Studies in Patients with Chronic Hepatitis C Virus (HCV): The HCV Symptom and Impact Questionnaire (HCV-SIQv3)
Louise Humphrey, Adelphi Values, Bicester, United Kingdom

**Pain**

(2080) Health-Related Quality of Life in Patients Treated with Chronic Pain in Bogata
Martin Romero, MD PhD(c), Fundacion Salutia, Bogota, Colombia

(2081) How Do Patients with Different Conditions Describe Their Pain?
Donald M. Bushnell, III, MA, Health Research Associates, Inc., Mountlake Terrace, WA, United States

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ISOQOL 20TH ANNUAL CONFERENCE • October 9–12, 2013
Cancer Symptoms and Quality of Life

(2082) Feasibility and Value of Daily Symptom Reporting in Patients Undergoing Hematopoietic Cell Transplantation
William A. Wood, MD MPH, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

(2083) Exploratory Study of Health-Related Quality of Life in a Phase I Trial Studying Idarubicin-Loaded Beads for Chemoembolization of Hepatocellular Carcinoma
Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges Francois Leclerc, Dijon, Burgundy, France

(2084) Number of HRQOL Symptoms for Cancer Patients Impacts Functioning and Global Health Levels
Swetha B. Nutakki, MS, Cancer Treatment Centers of America, Zion, IL, United States

(2085) Quality of Life in a Prostate Cancer Cohort with Patients from Seven Spanish Hospitals
Stefanie Schmidt, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

(2086) Health-Related Quality of Life (HRQoL) Following Surgical Treatment for Penile Cancer
Jacobien Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

(2087) Social Support and Coping Among Hispanic and Non-Hispanic Women Participating in a Randomized Counseling Trial for Cervical Cancer Survivors
Lari Wenzel, PhD, University of California, Irvine, CA, United States

(2089) Evolution of Quality of Life of Elderly Patients With Colorectal Cancer: A Cohort Population-based Study
Evelyne Fournier, MPH, Doubs and Belfort Territory Cancer Registry, France

(2090) Head and Neck Cancer in Elderly Population: Quality of Life Evaluation
Pedro L. Ferreira, PhD, University of Coimbra, Coimbra, Portugal

(2091) Does Quality of Life Predict Malnutrition in Head and Neck Cancer Patients?
Ewa Silander, MD RD, Sahlgrenska University Hospital, Goteborg, Sweden

(2092) The Relationships of Reduction in Pain with Other Symptoms for Cancer Patients Treated with Stereotactic Body Radiation Therapy
Tito R. Mendoza, PhD, University of Texas M.D. Anderson Cancer Center, Houston, TX, United States

(2093) Patient-Reported Outcome Measures for People with Skin Cancer: A Structured Review
Elizabeth J. Gibbons, MSc, University of Oxford, Oxford, United Kingdom

Outstanding Poster Abstract Award

(2082) Feasibility and Value of Daily Symptom Reporting in Patients Undergoing Hematopoietic Cell Transplantation
William A. Wood, MD MPH, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States
**POSTER SESSIONS**

**Poster Session 3: Saturday, October 12, 10:00 am – 10:45 am**

**eHealth/ePROs**

(3001) Web-Based QOL Monitoring of Cancer Patients Undergoing Chemotherapy
Georg Kemmler, PhD, Innsbruck Medical University, Innsbruck, Austria

(3002) A Qualitative Study of Cancer Patients’ Views of the Usability of Computerized Versions of the EORTC-QLQ-C30 and the SEIQOL-DW
Lena Ring, PhD, Medical Products Agency (MPA) and Uppsala University, Uppsala, Sweden

(3003) Electronic Assessment of Health-Related Quality of Life Specific to HIV /AIDS: Reliability Study of PROQOL-HIV Questionnaire
Marcelo Watanabe, Medicine School of ABC, Sao Paolo, Brazil

(3004) Using iPads to Assess Health-Related Quality of Life in Clinical Kidney Nursing Practice
Kara L. Schick Makaroff, PhD RN, University of Alberta, Victoria, Canada

**Conceptual Issues/Frameworks**

(3010) Patient-Reported Pain in Autosomal Dominant Polycystic Kidney Disease (ADPKD): Concept Stability Between Europe and United States (US) Focus Groups
Jason C. Cole, PhD, Covance Market Access Services, Inc., United States

(3012) Concept Relevance and Respondent Comprehension of the Component Scales of the ENSEMBLE MDS 2.0 Questionnaire Battery
Donald M. Bushnell, III, MA, Health Research Associates, Inc., Mountlake Terrace, WA, United States

**Minimally Important Differences/Clinical Significance**

(3013) But What does this Score Mean? A Clinical Standard Setting Method Applied to Outcomes in a Sample of Persons with MS
Karon Cook, PhD, Northwestern University, Chicago, IL, United States

(3014) Single-Item Assessment of Perceived Health in Neurological Disorders: Verbal Response Categories vs Visual Analog Scale
Peter Hagell, Kristianstad University, Kristianstad, Sweden

**Patient-Reported Outcomes in Clinical Practice**

(3006) Inconsistencies in Quality of Life Data Collection in Clinical Trials: A Potential Source of Bias? Interviews with Research Nurses and Trialists
Derek Kyte, MSc, University of Birmingham, Birmingham, United Kingdom

(3008) Which Health-Related Quality of Life Outcomes Should be Discussed During the Initial Follow-up Consultation After Surgery for Esophageal Cancer? Preliminary Findings of a Delphi Survey
Marc Jacobs, Academic Medical Center, Amsterdam, The Netherlands

**Guidelines and Guidance**

(3016) Movers and Shakers: Who is Doing What with PRO-Related Topics as Online Keyword Search Queries
Adam Wilbur, BrightOutcome, Inc., Chicago, IL, United States

(3017) Implementing the CONSORT Patient-Reported Outcome Extension in RCTs in Oncology: Understanding the Items that Influence Clinical Decision-making
Rhiannon C. Macefield, University of Bristol, Bristol, United Kingdom

(3018) Evaluation of the CONSORT Extension Recommendations for PRO Reporting in Clinical Trials: An International Survey of Oncologists
Julie Rouette, Queen’s University, Trois-Rivieres, Canada

Outstanding Poster Abstract Award
## Poster Sessions

**Poster Session 3: Saturday, October 12, 10:00 am – 10:45 am**

### Translation and Cultural Adaptation

<table>
<thead>
<tr>
<th>Abstract ID</th>
<th>Title</th>
<th>Authors</th>
<th>Institution(s)</th>
</tr>
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<tbody>
<tr>
<td>(3019)</td>
<td>Translatability of Response Sets Used in Patient Reported Outcomes and Best Practices for Development</td>
<td>Shawn McKown, MA, Corporate Translations, Inc., Chicago, IL, United States</td>
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</tr>
<tr>
<td>(3020)</td>
<td>Obstacles to the Development of Universal Spanish Translations of PRO Instruments</td>
<td>Caroline Anfray, Mapi, Lyon, France</td>
<td></td>
</tr>
<tr>
<td>(3022)</td>
<td>RIMAS: A Repository of Portuguese Validated PRO measures</td>
<td>Luis Manuel Cavalheiro, PhD, Centre for Health Studies and Research of the University of Coimbra, Coimbra, Portugal</td>
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### Item Bank/Computer Adaptive Testing (CAT)

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<thead>
<tr>
<th>Abstract ID</th>
<th>Title</th>
<th>Authors</th>
<th>Institution(s)</th>
</tr>
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<tbody>
<tr>
<td>(3024)</td>
<td>Validity of PROMIS® CATs, Short Forms and Global Health Items in Rheumatoid Arthritis</td>
<td>Susan J. Bartlett, PhD, McGill University, Montreal, Canada</td>
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<tr>
<td>(3025)</td>
<td>Dimensionality of the PROMIS® Fatigue Item Bank in Patients with Fibromyalgia</td>
<td>Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States</td>
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### Psychometrics

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<th>Abstract ID</th>
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<th>Authors</th>
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<tr>
<td>(3027)</td>
<td>Development &amp; Validation of the Oxford Participation &amp; Activities Questionnaire: Exploring the Views of Relevant Stakeholders</td>
<td>Laura Kelly, University of Oxford, Oxford, United Kingdom</td>
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<tr>
<td>(3028)</td>
<td>A Literature Review of the Variance in ‘Interval Length’ Between Administrations for Assessment of Test-Retest Reliability and Equivalence of PRO Measures</td>
<td>Diane J. Wild, MSc, ICON plc, Oxford, United Kingdom</td>
<td></td>
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<tr>
<td>(3030)</td>
<td>Psychometric Properties of the PedsQL Multidimensional Fatigue Scale in Dutch Young Adults</td>
<td>Lotte Haverman, PhD, Emma Children’s Hospital - Academic Medical Centre, Amsterdam, The Netherlands</td>
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<td>(3031)</td>
<td>See Patient Populations</td>
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### Utilities

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<th>Title</th>
<th>Authors</th>
<th>Institution(s)</th>
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</thead>
<tbody>
<tr>
<td>(3033)</td>
<td>Health State (QALY) Values for Multiple Sclerosis: Improving the Quality of Information Used in Cost-Effectiveness Analyses of Treatments for MS</td>
<td>Annie J. Hawton, MSc, University of Exeter Medical School, Exeter, United Kingdom</td>
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<tr>
<td>(3035)</td>
<td>Health-Related Quality of Life in Patients with Multiple Sclerosis in Colombia</td>
<td>Martin Romero, MD PhD(c), Fundacion Salutia, Bogota, Colombia</td>
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### Patient Populations

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<tr>
<td>(3031)</td>
<td>Job Satisfaction of Public University Professors: Reflections in their Quality of Life</td>
<td>Virginia V. Brasil, PhD, Nursing Faculty of the Federal University of Goiás, Goiânia, Brazil</td>
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<td>(3036)</td>
<td>Content Validation of the QoLissy Questionnaire (Quality of Life in Short Statured Youth) in American Children and Adolescents Based on the European Version</td>
<td>Andreas Pleil, PhD, Pfizer, Inc., San Diego, CA, United States</td>
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<tr>
<td>(3038)</td>
<td>Relationship Between Oral Health and Quality of Life of University Students</td>
<td>Ana G. Magallanes, PhD, Universidad Autónoma de Baja California, Tijuana, Mexico</td>
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<tr>
<td>(3039)</td>
<td>Longitudinal Associations Between Oral Health Status and Quality of Life Among a National Cohort of Thai Adults</td>
<td>Vasoontara Yiangprugsawan, The Australian National University, Acton, Canberra ACT, Australia</td>
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<tr>
<td>(3040)</td>
<td>The Associations of Oral Health-Related Quality of Life with Educational Level in Japanese Men and Women</td>
<td>Mariko Naito, DDS, PhD, Nagoya University Graduate School of Medicine, Nagoya, Japan</td>
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</tbody>
</table>

**Outstanding Poster Abstract Award**
**POSTER SESSIONS**

**Poster Session 3: Saturday, October 12, 10:00 am – 10:45 am**

### Caregivers

(3041) A Prototype Emotional Vitality Measure for Caregivers  
Skye P. Barbic, PhD candidate, OT, McGill University, Montreal, Canada

(3042) Validity and Reliability of the Family Reported Outcome Measure (FROM-16©) in Urology  
Sam Salek, BSc RPh PhD FFPM, Cardiff University, Cardiff, United Kingdom

(3043) The Early-Onset Scoliosis 24 Item Questionnaire (EOSQ-24) Reflects Changes in Quality of Life and Parental Burden After Growing Rod Surgery  
Hiroko Matsumoto, MA, Columbia University, New York, NY, United States

### Children

(3045) Quality of Life in Children: Development and Application of Computer-Adaptive Testing in Routine Pediatric Care (KIDS-CAT)  
Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany

(3046) Health-Related Quality of Life in Dutch Young Adults: Psychometric Properties of the PedsQL Generic Core Scales Young Adult Version  
Lotte Haverman, PhD, Emma Children’s Hospital - Academic Medical Centre, Amsterdam, The Netherlands

(3048) HRQOL and Pain Problems in Children  
Kristin Haraldstad, PhD, University of Agder, Kristiansand, Norway

(3049) Adolescents with High Frequency Use of OTC Analgesics May Have Reduced Quality of Life  
Siv Skarstein, RN MPA, Oslo and Akershus University College, Oslo, Norway

(3051) Effect of Wearing an Orthodontic Appliance on Quality of Life Among Adolescents: Case-Control Study  
Andréa Antônia Costa, Federal University of Minas Gerais, Brumadinho, Brazil

### Aging/Dementia

(3052) Quality of Life of Elderly Participants of Health Promotion Group Activities  
Lizete M A C Oliveira, PhD, Federal University of Goiás, Goiânia, Brazil

(3053) Health Related Quality of Life in Elderly Men Participating in a Systematic 12 Week Strength Training Program  
Gudrun Rohde, PhD, University of Agder, Kristiansand, Norway

(3054) How Does Chronic Disease Affect Quality of Life at Older Ages? A Systematic Review of the Evidence Based on Representative Population Samples  
Eithne Sexton, Royal College of Surgeons in Ireland, Dublin, Ireland

(3055) A Scoping Review: Transitioning into Retirement with Chronic Health Disorders  
Catherine P. Gelinas, University of Western Ontario, London, Canada

### Mental Health

(3056) Validity and Reliability of the Japanese Mental Health Continuum-Short Form (MHC–SF)  
Junko Sakano, Okayama Prefectual University, Soja, Okayama, Japan

(3057) Negative Life Events and Related Life Satisfaction or Psychological Distress  
Jocelyne M.R. Clench-Aas, PhD, Norwegian Institute of Public Health, Oslo, Norway

(3059) Addressing Challenges for Eliciting Concepts Among Adolescents with Attention Deficit Hyperactivity Disorder (ADHD) for Developing Patient-Reported Outcome (PRO) Tools  
Juliana Setyawan, Shire Development LLC, United States

(3060) Asenapine Effect on Quality of Life in Patients Suffering from Bipolar I Disorder with Mixed Episodes  
Christophe Sapin, Lundbeck SAS - Global Outcomes Research, Issy Les Moulineaux, France

**Outstanding Poster Abstract Award**
### Poster Session 3: Saturday, October 12, 10:00 am – 10:45 am

#### Respiratory Diseases

- **(3061)** Difficulties in Emotional Regulation and Quality of Life  
  Alfonso Urzua, PhD, Universidad Catolica del Norte, Antofagasta, Chile

- **(3062)** Quality of Work Life Perception and Mental Health in Primary Care Physicians  
  Raquel Gonzalez-Baltazar, PhD, University of Guadalajara, Guadalajara, Jalisco, Mexico

- **(3063)** Content Validity of the Asthma Symptom Diary (ASD) for Use in Adult and Adolescent Subjects with Persistent Asthma  
  Gary Globe, Amgen Inc., United States

- **(3064)** Usability of the Asthma Symptom Diary (ASD) on the AM3® Device for Use in Adult and Adolescent Subjects with Persistent Asthma  
  Sonya Eremenco, MA, Evidera, Bethesda, MD, United States

- **(3065)** Impact of Roflumilast on Dyspnea and Lung Function in Patients with Chronic Obstructive Pulmonary Disease: A Pooled Analysis of Four Clinical Trials  
  Shawn X. Sun, Forest Research Institute, United States

#### Diabetes

- **(3070)** Audit of Diabetes Dependent Quality of Life is a More Sensitive Measure of Health-Related Quality of Life Than the Diabetes Health Profile in Singapore  
  Maudrene LS Tan, MSc, National University of Singapore, Singapore

#### Kidney/Liver/Gastrointestinal

- **(3073)** Quality of Life of the Living Kidney Donors in France Before and After Surgery: A Surprisingly High Quality of Life  
  Serge Briançon, MD, Nancy University, Vandoeuvre Les Nancy, France

- **(3074)** Using Internal Cross-Validation to Identify Response Shift Potential in People with Inflammatory Bowel Disease (IBD)  
  Nancy E. Mayo, PhD, McGill University Health Centre, Montreal, Canada

- **(3075)** An Explanatory Model for Response Shift in the SF-36 in an Inflammatory Bowel Disease Cohort  
  Richard Sawatzky, PhD RN, Trinity Western University, Langley, Canada

#### Cardiovascular/Stroke

- **(3067)** The Feasibility of Blood Circulation by Removing Blood Stasis Method of Traditional Chinese Medicine Treatment of Stable Angina and the Evaluation of the Patient’s Quality of Life  
  Chen Lijuan, MD, Liaoning University of Traditional Chinese Medicine, Shenyang, Peoples Republic of China

- **(3068)** Benefits of a New Cardiac Rehabilitation Program Using Information and Communication Technologies for Patients with Cardiovascular Disease  
  Toshiko Yoshida, RN PHN PhD, Miyagi University School of Nursing, Kurokawa-gun, Miyagi, Japan

- **(3069)** Self-Reported Health After Stroke – A Follow-Up Study with Multiple Measurements Over a 2-Year Period  
  Louise Pape, MHSc, University of Aarhus, Herning, Denmark

#### Musculoskeletal

- **(3078)** The Level of Agreement Between Child Self-Reports and Parent Proxy-Reports of Health-Related Quality of Life for Boys with Duchenne Muscular Dystrophy  
  Yoonjeong Lim, University of Florida, Gainesville, FL, United States

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**Outstanding Poster Abstract Award**
**POSTER SESSIONS**

**Poster Session 3: Saturday, October 12, 10:00 am – 10:45 am**

### Pain

(3079) Validation of the Dutch-Flemish PROMIS® Pain Behavior and Pain Interference Item Banks in Patients with Chronic Pain
Martine H.P. Crins, Reade | Amsterdam Rehabilitation Research Center, Amsterdam, The Netherlands

(3080) Pain Assessment Screening Tool and Outcomes Registry: A Department of Defense and PROMIS® Partnership to Improve Pain Management
Karon Cook, PhD, Northwestern University, Chicago, IL, United States

(3081) Exploratory and Confirmatory Factor Analysis of PROMIS® Pain Quality Version -2 Affective Items
Dennis Revicki, PhD, Evidera, Bethesda, MD, United States

### Cancer Symptoms and Quality of Life

(3082) HRQOL Functioning in Cancer Patients: Symptom Pathways Dominate Disease Progression
Ryan M. McCabe, Cancer Treatment Centers of America, United States

(3083) Time to Health-Related Quality of Life Score Deterioration as a Modality of Longitudinal Analysis using Propensity Score Method to Deal with Missing Data: A Phase II Trial in Patients with Metastatic Non Pre-Treated Pancreatic Adenocarcinoma
Amélie Anota, Quality of Life in Oncology Platform, Besançon, France

(3084) Methods and Measures for Assessing the HRQoL of Long-Term Survivors of Testicular and Prostate Cancer Previously Participating in EORTC Phase III Clinical Trials
Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands

(3085) Normative Data of the EORTC QLQ-C30 in Germany: A Population-Based Survey
Annika Waldmann, University of Luebeck, Luebeck, Germany

(3086) Normative Data for the EORTC QLQ-HN35 in the General Swedish Population
Eva Hammerlid, MD PhD, Dept EMT-Head & Neck Surgery, Goteborg, Sweden

(3088) Young Cancer Survivors’ Experiences and Thoughts on Intimate Relationships and Having Children
Jenny Nilsson, Karolinska Institutet, Huddinge, Sweden

(3089) Heterogeneity in Posttraumatic Stress and Posttraumatic Growth Among Hematopoietic Stem Cell Transplant Survivors
Kelly Kenzik, PhD, University of Florida College of Medicine, Gainesville, FL, United States

(3091) Quality of Life in Long-Term Adult Survivors of Allogeneic Bone Marrow Transplantation and Comparison with a Control Group
Maribel P. Doro, PhD, Clinical of Hospital, Curitiba, Brazil

(3092) Quality of Life (QoL) and Symptoms in Transfusion-Dependent Patients with Myelodysplastic Syndromes (MDS) Undergoing Oral Chelation Therapy
Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy

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Evidera presenters and authors include:

**Plenary Session**
- **Twenty Years of ISOQOL — A Celebration**  
  *Session Co-Chair: Dennis Revicki, PhD*

**Workshop**
- **An Introduction to Health-Related Quality of Life Assessment**  
  *Heather Gelhorn, PhD and Kathleen Wyrwich, PhD*

**Symposium**
- **Innovative Methods for Incorporating the Patient Perspective into Health Outcomes Development and Measurement: Opportunities and Limitations**  
  *Heather Gelhorn, PhD and Dennis Revicki, PhD*

**Oral Sessions**
- **Psychometric Performance of the Asthma Symptom Diary (ASD) in Adult and Adolescent Subjects with Persistent Asthma**  
  *Mattera MS, Wiklund I, Chen WH*
- **Responsiveness and Minimal Important Difference of the Rheumatoid Arthritis-Work Instability Scale (RA-WIS)**  
  *Revicki D, Safikhani S*

**Posters**
- **Addressing Challenges for Eliciting Concepts among Adolescents with Attention Deficit Hyperactivity Disorder (ADHD) for Developing Patient Reported Outcome Tools**  
  *Steenrod A, Hareendran A, Pokrzywinski R*
- **Content Validity of the Asthma Symptom Diary (ASD) for Use in Adult and Adolescent Subjects with Persistent Asthma**  
  *Wiklund I, Mattera M, von Maltzahn R*
- **Implementing New Clinical Outcome Assessment Instruments on Alternative Data Collection Modes: The Electronic Implementation Assessment and Migration Process**  
  *Eremenco S*
- **Usability of the Asthma Symptom Diary (ASD) on the AM3® Device for Use in Adult and Adolescent Subjects with Persistent Asthma**  
  *Eremenco S, Devine M, Wiklund I*
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BrightOutcome is pleased to announce the launch of PROmeasure™, their next-generation ePRO solution for health care providers and research professionals at ISOQOL 2013.

Corporate Translations was founded in 1990 to specifically fulfill the life science industry’s demand for high quality translation and linguistic validation solutions. Their specialized approach and methodical operating procedures have allowed us to achieve an uncommonly high level of quality and preferred supplier status at many of the largest and most innovative biopharmaceutical companies in the world.

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The Mapi Group is a service provider to the global healthcare industry. The Mapi Group helps people who are shaping tomorrow’s health outcomes by offering strategic, insightful solutions for successful market access in our ever-changing healthcare environment.

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ISOQOL 21st Annual Conference

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Workshop Abstracts
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