



Final Program

Quality of Life: Advancing Measurement Science
and Transforming Healthcare

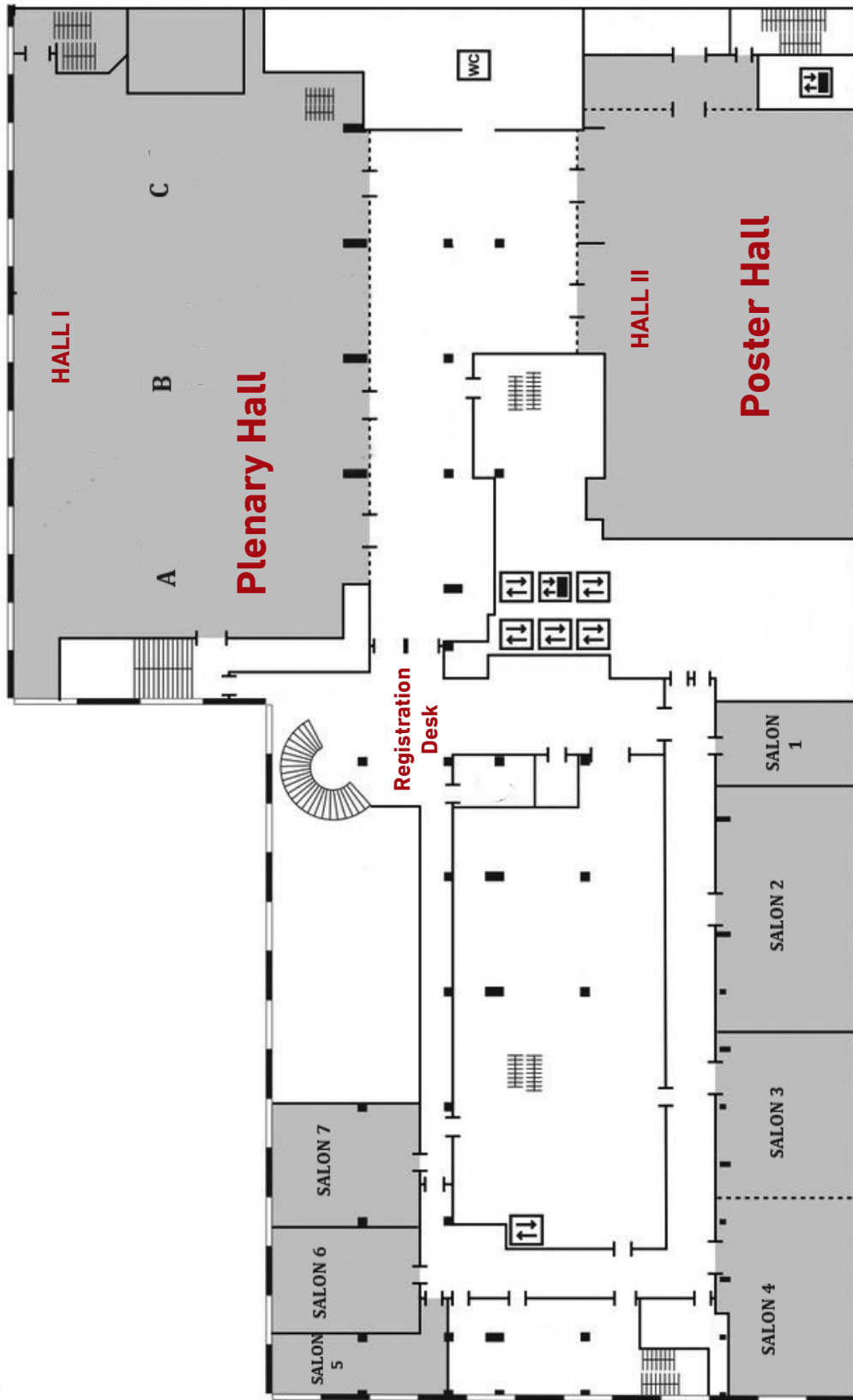
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ISOQOL
21ST ANNUAL CONFERENCE

15-18 October, 2014  Berlin, Germany

HOTEL FLOOR PLAN



Quality of Life: Advancing Measurement Science and Transforming Healthcare

Welcome to the 21st Annual Conference of the International Society for Quality of Life Research, 15-18 October 2014



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WELCOME FROM THE PROGRAM CHAIRS

Willkommen to Berlin!

On behalf of the 38 members of the Scientific Program Committee, it is our pleasure to invite you to the ISOQOL 21st Annual Conference, **Quality of Life: Advancing Measurement Science and Transforming Healthcare**. This year's conference highlights outstanding work in three areas: the integration of patients and other users in measurement development and use; the impact of QOL/PRO measurement; and the emerging importance of mental health in QOL assessments.

Increasing the Reach of ISOQOL Members' Work

To increase awareness of ISOQOL as the leading scientific meeting on QOL/PRO research, we've reached out to invite researchers, clinicians and health services professionals throughout Germany, Europe, and the international community. ISOQOL is also sponsoring attendance by patient representatives Anne Lyddiatt (Canada) and Samantha Brace-McDonnell (UK) to help champion patient engagement within ISOQOL. Also, a full day workshop in German entitled *Basics You Need to Know about QOL Methods and Research* will be hosted by Profs. Matthias Rose, Sandra Nolte and Felix Fisher.

2014 Plenary Sessions

Do not miss the international group of thought leaders from outside and inside ISOQOL who will share their expertise and innovative research in Plenaries including:

- *PROS: Contributing to Better Services & Better Societies* (Thursday)
Nick Black, MD; Laurie Burke, MPH; Christopher B. Forrest, MD PhD
- *Cutting Edge Research* (Thursday)
Thomas Willgoss, PhD; Jakob Bjorner, MD PhD; Claire Snyder, PhD
- *Integrating Patients into PRO Development and Research* (Friday)
John Kirwan, BSc MD FRCP; Maarten de Wit, PhD; Lori Frank, PhD
- *Well-Being and Mental Health Measurement Opportunities* (Saturday)
Carol Ryff, PhD; David Cella, PhD; John Brazier PhD

New Events Added This Year

- *Building on the Legacy of German QOL Research* (Wednesday Welcome Reception)
- *Expert Panel Discussion: Patient-Centered Outcome Measurement: Routes, Roadblocks and Roadmaps* (Thursday at lunch)

Mitte Berlin. Enjoy the warm hospitality of one of Europe's most vibrant and beautiful cities. As time permits, you can explore Museum Island, Brandenburg Gate, Reichstag, Unter den Linden, Alexanderplatz, or Hackenscher Markt—all just a short walk away. Our closing dinner at **Spiegelsaal (Mirror Hall)** in the Clärchens Ballhaus is one of few remaining, original dancehalls to survive World War II and still operate today.

We welcome all attendees, from familiar faces over two decades of ISOQOL to those joining us for the first time. We invite you to meet up with old friends, engage with new colleagues, discuss and debate tried and true methods and innovative approaches to shape the future of QOL research. Thank you for sharing your passion and commitment for QOL research and for helping us make this meeting a resounding success.

Ein Prosit!

Jordi Alonso MD PhD and Susan Bartlett PhD



SCHEDULE AT A GLANCE

WEDNESDAY, 15 OCTOBER		
9:00 am - 12:00 pm	Morning Workshops (Ticket Required)	
	WK01: An Introduction to Health-Related Quality of Life Assessment	Salon 2
	WK02: Discrete Choice Experiments: Enhancing PRO Beyond QALYs	Salon 6
	WK03: Best Practices for Qualitative Methods for Patient-Reported Outcomes Research	Salon 3
	WK04: Analyzing Longitudinal Quality of Life Outcome Data	Salon 4
	WK05: Standardized Evaluations of Patient-Reported Outcomes: The EMPRO Methodology	Salon 7
1: 00 pm - 4:00 pm	Afternoon Workshops (Ticket Required)	
	WK06: Introducing the Concept of Response Shift – An Overview of Theory & Methods	Salon 2
	WK07: Translation Methodology for Clinical Outcomes Assessments in Global Trials	Salon 3
	WK08: Improving the Design of Clinical Trials with PROs: Tips for Protocol Design and Review	Salon 4
	WK09: How to Integrate Patient-Led Research in Your Health-Related Quality of Life Studies	Salon 6
	WK10: Whose QOL Assessment Data Should You Use? A Bayesian Testlet IRT Model Perspective	Salon 7
9:00 am - 4:00 pm	Full Day Workshop -Presented in German (Ticket Required)	
	WK11: Basics You Need to Know About Methods Used in Quality of Life Research	Salon 1
4:30 pm - 6:00 pm	Industry Advisory Committee (IAC) Symposium <i>Advancing Measurement Science Beyond PROs: Patient-Centeredness and Validity Across All Clinical Outcome Assessments</i>	Salon 3&4
6:00 pm - 7:30 pm	Welcome Reception and <i>Building on the Legacy of German QOL Research</i>	Hall II

THURSDAY, 16 OCTOBER		
7:30 am - 8:25 am	Committee Meetings	
	CONSORT PRO Guidance Implementation Tools Team	Salon 2
	Industry Advisory Committee (IAC)	Salon 3
	Patient Scholarship Orientation	Salon 4
8:30 am - 10:15 am	Welcome and Plenary PROs: Contributing to Better Services, Better Societies	Hall I - AB
10:25 am - 10:45 am	Thursday Poster Session 1 - Odd Numbered Posters (1003-1109)	Hall II
11:00 am - 12:15 pm	Plenary - Cutting Edge Research	Hall I - AB
12:15 pm - 1:15 pm	Lunch Buffet	Hall II
12:30 pm - 1:45 pm	Expert Panel Session - Patient-Centered Outcome Measurement: Routes, Roadblocks, and Roadmaps	Hall I - C
12:30 pm - 1:30 pm	Committee Meeting - Companion to User's Guide	Salon 3
2:00 pm - 3:15 pm	Concurrent Oral Sessions	
	101: <i>Advancing Quality of Life Measurement in Neurology</i>	Hall I - A
	102: <i>The Importance of Context: Response Shift and Differential Item Functioning</i>	Hall I - B
	103: <i>Transforming Care: Quality of Life, Policy & Decision Making</i>	Salon 2
	104: <i>Advancing Quality of Life Measurement in Older Adults</i>	Salon 4
	105: <i>New Approaches to Evaluating Cancer Treatments</i>	Hall I - C
3:25 pm - 3:45 pm	Thursday Poster Session 2 - Even Numbered Posters (1002 - 1110)	Hall II



SCHEDULE AT A GLANCE

THURSDAY, 16 OCTOBER CONTINUED		
4:00 pm - 5:30 pm	Concurrent Oral Sessions	
	106: <i>New Measures and Methods I: Development & Evaluation</i>	Salon 2
	107: <i>Transforming Clinical Practice</i>	Hall I - A
	108: <i>Advancing Utility Assessments</i>	Hall I - B
	109: <i>New Measures and Methods II: Interpretation & Implementation</i>	Salon 4
6:00 pm - 7:30 pm	Mentor/Mentee Reception (Pre-registration Required) <i>Featuring the New Investigator SIG Tricks of the Trade</i>	Hall I - C

FRIDAY, 17 OCTOBER		
7:30 am - 8:45 am	Committee & Special Interest Group (SIG) Meetings	
	Protocol Checklist Development Team	Salon 3
	Health Preference Research SIG	Salon 2
	Patient Engagement SIG	Hall I - C
	Response Shift SIG	Salon 4
9:00 am - 10:30 am	Plenary - Integrating Patients into PRO Development and Research	Hall I - AB
10:45 am - 11:05 am	Friday Poster Session 1 - Odd Numbered Posters (2001-2109)	Hall II
11:15 am - 12:45 pm	Concurrent Symposium Sessions	
	1: <i>Patient and Public Engagement Café (PPI) II: Towards a Model of Patient Engagement for ISOQOL</i>	Hall I - C
	2: <i>Doc, How Bad Is It? Setting Standards for Severity of Patient-Reported Outcomes Data Using Item Banks from PROMIS® and Neuro-QOL</i>	Salon 2
	3: <i>Applying Computer Adaptive Testing in Child-Reported Outcome Measurement - A New Era of Assessment?</i>	Salon 4
12:45 pm - 1:45 pm	Lunch Buffet	Hall II
1:00 pm - 2:00 pm	Committee Meeting - QOLR Journal Associate Editors	Salon 3
2:00 pm - 3:15 pm	Concurrent Oral Sessions	
	201: <i>Transforming Practice: Rehabilitation</i>	Salon 2
	202: <i>Advancing Quality of Life Measurement in eHealth</i>	Hall I - B
	203: <i>Transforming the Quality of Care</i>	Hall I - A
	204: <i>PRO Development: From Conception through Revision</i>	Salon 4
	205: <i>Expanding Cancer Assessments: New Measures & Methods</i>	Hall I - C
3:25 pm - 3:45 pm	Friday Poster Session 2 - Even Numbered Posters (2002-2110)	Hall II
4:00 pm - 5:30 pm	Concurrent Oral Sessions	
	206: <i>PROMIS®: New Measures, New Populations</i>	Hall I - C
	207: <i>Advancing Mental Health Assessment</i>	Hall I - A
	208: <i>Advancing Preference-Based Measurement Science</i>	Salon 2
	209: <i>Adapting Measures Across Languages and Cultures</i>	Salon 4
	210: <i>Advancing PROs: Patient-Centered Outcomes Research</i>	Hall I - B
5:45 pm - 6:30 pm	Special Interest Group (SIG) Meetings	
	Ibero America SIG	Salon 4
	New Investigator SIG	Salon 2
	Psychometrics SIG	Hall 1-C

SCHEDULE AT A GLANCE

SATURDAY, 18 OCTOBER		
7:30 am - 8:45 am	Special Interest Group (SIG) Meetings	
	Child Health SIG	Salon 2
	QOL in Clinical Practice SIG	Hall I - C
	Translation & Cultural Adaptation (TCA) SIG	Salon 4
9:00 am - 10:15 am	ISOQOL Member Business Meeting and Awards Presentation	Hall I - AB
10:25 am - 10:45 am	Saturday Poster Session 1 - Odd Numbered Posters (3001-3107)	Hall II
11:00 am - 12:30 pm	Plenary - Well-Being and Mental Health Measurement Opportunities	Hall I - AB
12:30 pm - 1:30 pm	Lunch Buffet	Hall II
12:30 pm - 1:30 pm	Committee Meeting - SIG Leader Council	Salon 3
1:45 pm - 3:15 pm	Concurrent Symposium Sessions	
	4: <i>Quality of Life and Cancer Prevention</i>	Salon 2
	5: <i>Ambulatory Monitoring and Mobile Assessment of Quality of Life</i>	Salon 4
	6: <i>An International Consensus Process to Identify Priorities in Child-Reported Outcomes Research</i>	Hall I - A
	7: <i>2014 PROMIS® Update: News, Expanded Pediatric Item Banks, International, and Industry Developments</i>	Hall I - B
	8: <i>Monitoring Patient-Reported Outcome Alerts in Clinical Trials and Routine Practice: An Expert Panel Discussion of Current Knowledge and Priority Areas for Research</i>	Hall I - C
3:25 pm - 3:45 pm	Saturday Poster Session 2 - Even Numbered Posters (3004-3106)	Hall II
4:00 pm - 5:30 pm	Concurrent Oral Sessions	
	301: <i>Advancing Measurement in Cognitive and Neurological Disorders</i>	Hall I - A
	302: <i>Assessing Well-Being and Health Across Cultures</i>	Salon 4
	303: <i>Advancing Measurement of Physical and Mental Health in General Populations</i>	Salon 2
	304: <i>Advancing Measurement in Children</i>	Hall I - B
	305: <i>Evaluating Impact of Cancer on Quality of Life</i>	Hall I - C
7:00 pm - 10:00 pm	Closing Dinner (Ticket Required) <i>Spiegelsaal, Clärchens Ballhaus</i>	<i>Off-site</i>



GENERAL CONFERENCE INFORMATION

Conference Theme

Quality of Life: Advancing Measurement Science and Transforming Healthcare

Target Audience

The annual conference of the International Society for Quality of Life Research provides a multidisciplinary forum for clinicians, outcomes researchers, surgeons, psychologists, psychometricians, nurses, new investigators, patient partners and other medical professionals focused on promotion of high quality research in the science of health-related quality of life (HRQOL) measurement and patient-reported outcomes (PRO) to identify effective interventions, enhance the quality of health care and promote the health of populations. ISOQOL provides the premiere opportunity for those in HRQOL and outcomes research to connect and network.

Session Types

The ISOQOL annual conference offers conference attendees educational opportunities in a variety of formats. The following descriptions can help attendees understand the features of each session type and select the type of instruction best suited to educational needs.

Plenary Sessions

Plenary Sessions are the premiere educational sessions of the Scientific Program. Invited speakers will present on topics of interest to the overall meeting audience in a didactic or panel debate format.

Symposium Sessions

Symposia are didactic or panel presentations that examine important issues from a variety of different perspectives. Presentations and debate among presenters will address alternative solutions, interpretations, or points-of-view on an identified body of knowledge within the advertised topic area or theme. Symposia are selected based on peer-reviewed abstract submissions.

Workshops

Workshops are held on Wednesday, the “Pre-Conference” day. These sessions typically last a half day and feature numerous speakers focused on a specific topic. Admission to courses is by paid ticket only and seating is limited. Workshops are selected based on peer-reviewed abstract submissions.

Expert Panel Discussion and Industry Advisory Committee Symposium

These sessions focus on specific topics with various viewpoints expressed by a panel of experts. These are invited sessions and have not been peer reviewed. Pre-registration is required for these sessions.

Oral Sessions

Oral Sessions are based on peer-reviewed abstracts clustered around common themes and presented via oral presentations. Each presentation is approximately 13 minutes in length—10 minute presentation followed by 3 minutes of questions and answers from the audience.

Poster Sessions

Poster Sessions featuring presentations of peer-reviewed abstracts in thematic groupings will take place on each day during the conference. Each session allows abstract authors to discuss their research with interested colleagues in an informal setting. Poster Sessions are a great way to see the latest research in the field while socializing with colleagues.

Presenters are responsible for setting up and removing posters during the assigned set up and removal times. Posters should be displayed for the full day in which they are assigned. A detailed schedule of set up and removal times is listed below.

	Thursday 16 October	Friday 17 October	Saturday 18 October
Poster Set Up <i>All posters</i>	7:00 - 10:00 am	7:00 - 10:00 am	7:00 - 10:00 am
Session 1 Presentations <i>Odd numbers</i>	10:25 - 10:45 am	10:45 - 11:05 am	10:25 - 10:45 am
Session 2 Presentations <i>Even numbers</i>	3:25 - 3:45 pm	3:25 - 3:45 pm	3:25 - 3:45 pm
Poster Removal <i>All posters</i>	5:30 - 7:00 pm	5:30 - 7:00 pm	5:30 - 7:00 pm

Posters that are not removed by the end of the scheduled removal time will be discarded.

Session Recording

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

GENERAL CONFERENCE INFORMATION

Registration Desk Hours

Wednesday, 15 October: 7:00 am – 6:00 pm
Thursday, 16 October: 7:00 am – 5:00 pm
Friday, 17 October: 7:00 am – 5:00 pm
Saturday, 18 October: 7:00 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, 17 October at 11:30 am.

ISOQOL accepts MasterCard, Visa, American Express, and Discover credit cards. Cash transactions may be made in US dollars or Euro. Payment by check is accepted so long as the check is in US dollars and drawn on a US bank account.

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.

Certificates of Attendance

Certificates of Attendance will be emailed to all attendees the week following the conclusion of the conference.

Certificates of Presentation

Certificates of Presentation have been created for presenters that have requested a certificate on the registration form. Oral presentation certificates will be distributed at the conclusion of each oral session by the session chair. Poster certificates can be picked up from the registration desk.

If you did not request a certificate in advance, you can request a certificate by sending an e-mail to the ISOQOL office at info@isoqol.org. Certificates requested during the conference will be distributed following the conclusion of the conference.

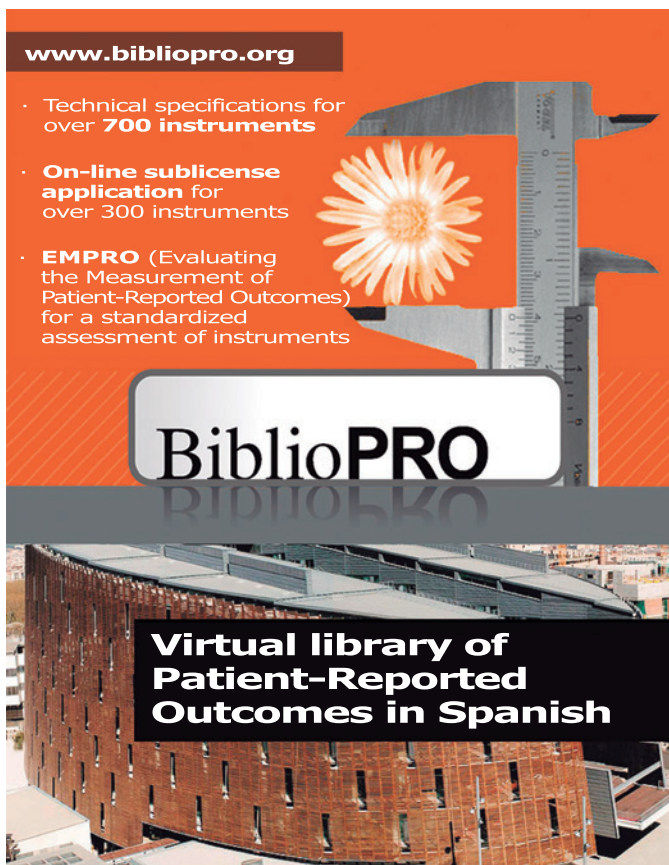
Evaluations

Please take time to complete the Annual Conference evaluation that will be distributed electronically immediately following the conclusion of the conference. Your input and comments are essential in planning future educational events.

Workshops attendees will receive paper evaluations at the workshops. Workshop evaluations can be returned to the instructor at the conclusion of the workshop, or returned to the Registration Desk. Workshop evaluations should be completed and returned on Wednesday, 15 October.

Final Program

The 21st Annual Conference program will be archived online at <http://www.isoqol.org/annual-conference/past-conferences>.



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ABOUT ISOQOL

Dedicated to the promotion of excellence in the science of health-related quality of life.

International Society for Quality of Life Research (ISOQOL) established in 1993, is a non-profit society 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. ISOQOL provides the premiere opportunity for those in the quality of life research field to connect and network.

Quality of life has become a prominent subject in philosophy, social science, clinical medicine, health services, and outcomes research. With over 600 members representing 43 countries, ISOQOL is an international society with activities focused on promotion of high quality research in the science of health-related quality of life (HRQOL) measurement and patient-reported outcomes (PRO).

Programs and Projects

Education Programs

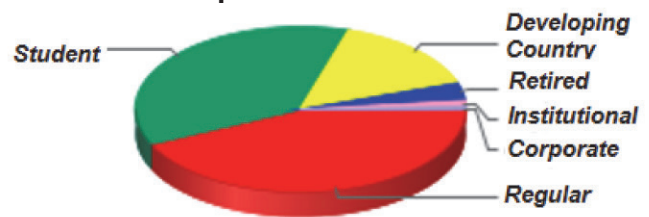
- Special Interest Group's Webinar Series
- 22nd Annual Conference
- Mentor/Mentee Program

Publications

- *Quality of Life Research* Journal
- ISOQOL Recommends Minimum Standards for Patient-Reported Outcome Measures Used in Patient-Centered Outcomes and Comparative Effectiveness Research (2013)
- Patient-Reported Outcomes in Randomized Clinical Trials (2012/2013)
- Using Patient-Reported Outcome Measures to Improve Clinical Practice (2012)
- User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice (2011)
- Quality of Life: The Assessment, Analysis and Interpretation of Patient-reported Advancing Health Outcomes Research Methods and Clinical Applications Outcomes
- Assessing Quality of Life in Clinical Trials, 2nd Edition
- Measuring and Valuing Health Benefits for Economic Evaluation

ISOQOL Membership

2014 Membership



Benefits of Membership

News & Publications

- Complimentary online subscription to *Quality of Life Research*
- Discounted print subscription to *Quality of Life Research*
- ISOQOL's newsletter - Quality of Life Quarterly
- Discounted access to Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID)

Educational Programs

- Online Education with reduced rates
- Discounted Annual Conference registration
- Waived Annual Conference abstract submission fee

Leadership Opportunities

- ISOQOL Special Interest Groups
- ISOQOL committees and initiatives

Networking & Public Awareness

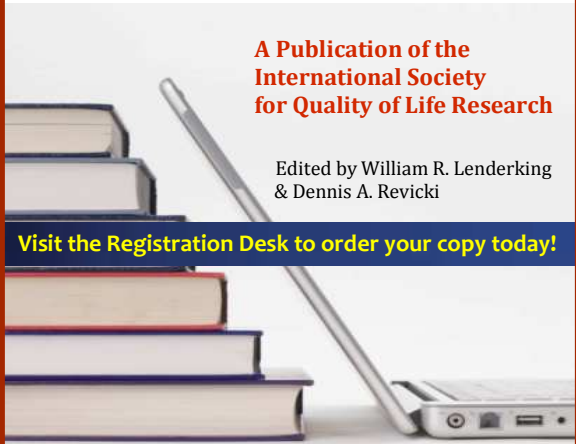
- Access to ISOQOL Membership Directory and listserv

**Advancing Health Outcomes
Research Methods and Clinical Applications**

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

Edited by William R. Lenderking
& Dennis A. Revicki

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Donald L. Patrick, PhD MSPH, United States – Co-Chair

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2006-2007 Madeleine T. King, PhD, Australia
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2004-2005 David Feeny, PhD, Canada
2003-2004 Albert W. Wu, MD MPH, United States
2002-2003 Mirjam AG Sprangers, PhD, Netherlands
2001-2002 David Osoba, MD, Canada
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Melanie Calvert, PhD, United Kingdom

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Kathy W. Wyrwich, PhD, United States

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Roxanne E. Jensen, PhD, United States – Student/New
Investigator Awards
Cynthia Gross, PhD, United States – Mentor/Mentee Program

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Jose M. Valderas, MD MPH PhD, United Kingdom
Doris M. Mwesigire, MD, Uganda

21st Annual Conference Scientific Program Committee

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Sara Ahmed, PhD, Canada
Skye Barbic, PhD, Canada
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Maria-Jose Santana, PhD, Canada
Silke Schmidt, PhD, Germany
Caroline Terwee, PhD, Netherlands
Jose “Chema” Valderas, MD PhD, United Kingdom
Galina Velikova, MD, United Kingdom
Annika Waldmann, PhD, Germany
Hwee-Lin Wee, PhD, Singapore

SCHOLARSHIPS AND AWARDS

Special Interest Groups (SIGs)

Child Health

Katherine Bevans, PhD, United States – Chair

Health Preference Research

Benjamin M. Craig, PhD, United States
Axel C. Muehlbacher, Germany

Ibero America

Pedro L. Ferriera, PhD, Portugal
Monica Avila, BPharm, MPH, Spain

New Investigators

Katerina Papageorgiou, MSc, Netherlands
Marc Jacobs, PhD Candidate, Netherlands

Patient Engagement

Sam Salek, BSc RPh PhD FFPM, United Kingdom

Psychometrics

Lori D. McLeod, PhD, United States
Stefan J. Cano, PhD CPsychol AFBPsS, United Kingdom

QOL Clinical Practice

Kirstie L. Haywood, DPHiL BSc, United Kingdom
Colleen M. Norris, PhD, United States

Response Shift

Leah M. McClimans, PhD, United States
Ruth Barclay, PhD MHSc BMR (PT), Canada

Translation & Cultural Adaptation

Sonya Eremenco, MA, United States
Mona L. Martin, RN MPA, United States

Awards & Scholarships

President's Award

The President's Award is presented to an individual who has advanced HRQOL research and 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.

2014 President's Award Recipient – *Mirjam AG Sprangers, PhD, Netherlands* presented by *Galina Velikova, MD PhD FRCP*

Previous Recipients

2013 Peter Fayers, PhD *presented by Bryce B. Reeve, PhD*
2012 Diane Fairclough, DrPH *presented by Bryce B. Reeve, PhD*
2011 Carolyn C. Gotay, PhD *presented by Carol M. Moinpour, PhD*
2010 David Feeny, PhD *presented by Diane Fairclough DrPH*
2009 Ronald D. Hays, PhD *presented by Neil Aaronson, PhD*
2008 David Cella, PhD *presented by Donna Lamping, PhD*
2007 Dennis Revicki, PhD *presented by Madeleine T. King, PhD*
2006 David Osoba, MD *presented by Peter Fayers, PhD*
2005 Neil Aaronson, PhD *presented by David Feeny, PhD*
2004 Robert Kaplan, PhD *presented by Albert Wu, MD MPH*
2003 John E. Ware, PhD *presented by Mirjam AG Sprangers, PhD*
2002 George Torrance, PhD *presented by David Osoba, MD*
2001 Donald Patrick, PhD MSPH *presented by Ivan Barofsky, PhD*

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.

2014 Emerging Leader Award Recipient – *Antonia V. Bennett, PhD, United States*

Previous Recipients

2013 Roxanne Jensen, PhD
2012 Melanie Calvert, PhD



Awards & Scholarships

Outstanding Article of the Year

This award recognizes the single best article dedicated to HRQOL research published in *Quality of Life Research* journal during the previous calendar year. The 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 Article of the Year (2013 Journal)

Bentley JP, Brown CJ, McGwin G, Sawyer P, Allman RM, Roth DL. **Functional status, life-space mobility, and quality of life: a longitudinal mediation analysis.** *Qual Life Res* 2013;22: 1621-1632.

2013 Finalists

Ferreira MLP, Almeida RMVR, Luiz RR. **A new indicator for the measurement of change with ordinal scores.** *Quality of Life Research* 2013; 22:1999-2003.

Boyce MB, Browne JP. **Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review.** *Quality of Life Research* 2013; 22: 2265-2278.

Previous Recipients

- 2012 Gershon R, et al. Neuro-QOL: quality of life item banks for adults with neurological disorders: item development and calibrations based upon clinical and general population testing. *Quality of Life Research* April 2012, Volume 21, Issue 3, pp 475-486
- 2011 Brundage M, Bass B, Davidson J, Queenan J, Bezjak A, Ringash J, Wilkinson A, Feldman-Stewart D. Patterns of reporting health-related quality of life outcomes in randomized clinical trials: implications for clinicians and quality of life researchers. *Qual Life Res* (2011) 20:653–664. DOI 10.1007/s11136-010-9793-3
- 2010 Post, W.J., Buijs, C., Stolk, R.P., deVries, E.G.E., and le Cessie, S. The analysis of longitudinal quality of life measures with informative drop-out: A pattern mixture approach. *QLR* 2010; 137-148.
- 2009 Barclay-Goddard, R, Epstein, J.D., and Mayo, N. *QLR* 2009 18(4): 335-346, Response shift: a brief overview and proposed research priorities
- 2008 Westerman, M. J., Hak, T., Sprangers, M. A. G., Groen, H. J. M., van der Wal, G., and The, A. M. 2008 Listen to their answers! Response behaviour in the measurement of physical and role functioning. *Qual Life Res* (2008) 17:549–558.
- 2007 Hahn, E. A., et al. 2007 The impact of literacy on health-related quality of life measurement and outcomes in cancer outpatients. *Qual Life Res.* 16(3):495-507.
- 2006 Osoba D, Hsu M-A, Copley-Merriman C, Coombs J, Johnson FR, Hauber, B, Manjunath R, Pyles A. Stated preferences of patients with cancer for health-related quality-of-life (HRQOL) domains during treatment. *Qual Life Res.* March 2006; 15 (2): 273-283.
- 2005 M. Brundage, D. Feldman-Stewart, A. Leis, A. Bezjak, L. Degner, K. Velji, L. Zetes-Zanatta, D. Tu, P. Ritvo, and J. Pater., Communicating Quality of Life Information to Cancer Patients: A Study of Six Presentation Formats., *Journal of Clinical Oncology*, Volume 23, Number 28, October 1, 2005
- 2004 Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, Selby PJ. Measuring quality of life in routine oncology practice improves Communication and patient well-being: a randomized controlled trial. *J Clin Oncol.* 2004 Feb 15;22(4):714-24.
- 2003 Ware JE, Kosinski M, Bjorner JB et al. "Applications of computerized adaptive testing (CAT) to the assessment of headache impact." *Qual Life Res* 2003; 12: 935-52
- 2002 Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *Journal of Health Economics.* 2002 Mar; 21(2):271-92.

SCHOLARSHIPS AND AWARDS

Awards & Scholarships

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 received during the abstract review process.

Congratulations to the 2014 Finalists

New Investigator Oral Presentation

Skye Barbic, PhD OT, Univ. of British Columbia, Vancouver, Canada

207.1: What Can Modern Measurement Methods tell Clinicians about Adaptive Responses of Depression?

Andréa L. Monteiro, MSc, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil

108.4: States Selection on the Valuation of EQ-5D-3L. Brazilian Study

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

107.1: AmbuFlex – Experiences of PRO Based Decisions in Clinical Practice

New Investigator Poster Presentation

Simone Freitag, PhD, University of Greifswald, Germany

(1067) The Effects of Autobiographical Disclosure on Quality of Life in Older Adults – A Preventive Approach

Brittney Major, Mayo Clinic, United States

(2025) Racial Differences in Quality of life in Patients with Gout

Claudia Rutherford, PhD, Univ. of Sydney, Australia

(2082) Mode of Administration of Patient-Reported Outcomes (PROs): A Systematic Review

Student Oral Presentation

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

206.6: The Impact of Dutch- Versus English-Language Calibrations on Theta Estimates of the Dutch-Flemish PROMIS® Pain Behavior and Pain Interference Item Banks

Pierre Michel, Aix Marseille Université, Marseille, France

207.2: How to Interpret Multidimensional Quality of Life Questionnaire in Schizophrenia?

Gemma Vilagut, MSc, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain

206.4: Psychometric Properties of the Spanish Version of the Patient-Reported Outcomes Measurement Information System (PROMIS®) Depression Item Bank in a Clinical Sample

Student Poster Presentation

Haikel A. Lim, BSocSci(Hons), National University of Singapore

(1036) Quality of Life in Patients on Different Peritoneal Dialysis Modalities: A Longitudinal Study in Singapore


Alaa M. Arafah, MSc, McGill University, Montreal, Canada

(1043) What Matters to Women Living with MS in Saudi Arabia

Anais Jouin, Centre Oscar Lambret, Lille, France

(1087) Quality Adjusted Survival in Oncology: A Review of the Q-TWiST Method used theseTwenty Past Years

Outstanding Poster Abstract Awards

The top posters that scored the highest during the abstract review process will be recognized with a ribbon posted on their poster board. Each Outstanding Poster Abstract Award recipients will be designated in the Final Program with a  in front of their poster number.



SCHOLARSHIPS AND AWARDS

Scholarships

Developing Country Scholarship

Danielle Maria S S dos Santos, PhD, Univ. of Rio de Janeiro, Brazil

Doris M. Mwesigire, MD, Makerere University, Uganda

Khaled Hassine, ANCSEP / Ministry of Health, Tunisia

Raluca I. Antonie, Babes-Bolyai University, Romania

New Investigator and Student Scholarship

Monica Avila, BPharm, MPH, IMIM -Hospital Del Mar Medical Research Institute, Spain

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

Siyan Baxter, University of Tasmania, Australia

Patient Engagement Scholarship

Samantha Brace-McDonnell, United Kingdom

Anne Lyddiatt, Canada

Thank you to Ferrer International and Health Utilities, Inc. for supporting the ISOQOL Scholarship Fund.

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SCHOLARSHIPS AND AWARDS

Thank you to the 2014 Abstract Reviewers

Sarah Acaster, MSc, United Kingdom
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Sara Ahmed, PhD, Canada
Jordi Alonso, MD PhD, Spain
Dagmar Amtmann, PhD, United States
Juan Ignacio Arraras, PhD, Spain
Vanitha Arumugam, PT, MPT, Canada
Skye P. Barbic, PhD OT, Canada
Jill Bell, United States
Antonia V. Bennett, PhD, United States
Christine Blome, PhD, Germany
Steven I. Blum, MBA MA, United States
Virginia V. Brasil, PhD, Brazil
Carla Carneiro, Portugal
David Cella, PhD, United States
Monica A C T Cintra, MD PhD, Brazil
Benjamin M. Craig, PhD, United States
Martin Nikolaus Dichter, MScN, Germany
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Thomas E. Elliott, MD, United States
Antonio Escobar, PhD MD, Spain
Diane L. Fairclough, DrPH, United States
David Feeny, PhD, Canada
Pedro L. Ferreira, PhD, Portugal
Montserrat Ferrer, MD PhD MPU, Spain
Felix Fischer, PhD, Germany
Marcelo P. Fleck, MD PhD, Brazil
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Elizabeth J. Gibbons, MSc, United Kingdom
Catherine J. Golics, MPharm PhD, United Kingdom
Sandra D. Griffith, PhD, United States
Cynthia Gross, PhD, United States
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Roxanne E. Jensen, PhD, United States
Gloria Juarez, PhD RN MSN, United States
Cicely Kerr, MSc PhD, United Kingdom
Shulamith Kreitler, Israel
Ayse Kuspinar, BSc(PT) MSc, United States
Cindy L.K. Lam, MD, Hong Kong
Kathryn E. Lasch, PhD, United States
William Lenderking, PhD, United States
Lauren Lent, DHA MS, United States
Zhao-hui Liang, Peoples Republic of China
Mona L. Martin, RN MPA, United States
Susan D. Mathias, MPH, United States
Nancy E. Mayo, PhD, Canada
Deborah M. Miller, PhD, United States
Sandra A. Mitchell, PhD CRNP AOCN, United States
Tha'er G. Momani, PhD(c) RN, United States
Andréa L. Monteiro, MSc, Brazil
Sami P. Moubayed, Canada
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Hongmei Yu, PhD, Peoples Republic of China
Huiyong Zhang, MD, Peoples Republic of China
Efsthios Zikos, MS MA, Belgium



PLENARY SPEAKERS

Jakob Bue Bjorner, MD PhD

Chief Science Officer, QualityMetric - a part of Optum, United States; Prof. of Epidemiology, Danish National Research Centre for the Working Environment; Honorary Professor, Univ. of Copenhagen, Denmark and Univ. of Sheffield, United Kingdom



Dr. Bjorner specializes in applying modern psychometric theory to the measurement of health outcomes. Together with John E. Ware, Jr, PhD, Dr. Bjorner developed the Dynamic Health Assessment (DYNHA®) system and numerous computerized adaptive health assessments of generic and disease-specific health outcomes. An MD by training, Dr Bjorner has a PhD in medical sociology from the University of Copenhagen, where he received an award for his qualitative research on stigma and coping in HIV infection. In addition to his psychometric work, Dr. Bjorner is interested in factors affecting questionnaire response and the application of health outcomes research across healthcare.

Nick Black, MD

Chair, NHS England National Advisory Group for Clinical Audit & Enquiries
Professor, Health Services Research
London School of Hygiene and Tropical Medicine
London, United Kingdom



Dr. Black's main interests are the use of clinical databases for evaluation and audit of health services, patient-reported outcome measures (PROMs), the relationship between research and policy, and the history of health services. He co-edits the *Journal of Health Services Research & Policy*, was founding Chair of the UK Health Services Research Network. Since 2007 he has advised NHS England and the Care Quality Commission on quality assessment including avoidable hospital deaths, PROMs and national clinical audits and enquiries. In 2013 he was the first recipient of a new international Career Achievement Award for work on PROMs by the Medical Outcomes Trust, United States.

John Brazier, PhD

Professor, Health Economics
School of Health and Related Research (ScHARR)
University of Sheffield, United Kingdom



Dr. Brazier is Professor of Health Economics in the School of Health and Related Research at the University of Sheffield with more than 20 years' experience of conducting economic evaluations of health care interventions for policy makers. He is Director of the Economic Evaluation Policy Research Unit (EEPRU) funded by the Department of Health in England. He was a member of the National Institute for Clinical Excellence (NICE) Technology Appraisal Committee and is a scientific adviser to NICE. He has a long standing interest in the development, testing and use of measures of health and well-being in economic evaluation.

Laurie Burke, MPH

Founder, LORA Group, LLC
Royal Oak, MD, United States



Ms. Burke, an expert in medical product outcomes research, global regulatory strategy, drug labeling, and advertising, currently advises global organizations in achieving development goals through application of state-of-the-science methodologies in measurement and design. She was a career Public Health Service officer with the US Food and Drug Administration, Center for Drug Evaluation and Research, in positions related to epidemiologic research in drug safety, evidence review for promotion and advertising claims, and regulatory policy related to labeling, outcomes measurement in clinical trials and economic information dissemination. Her experience includes extensive collaboration with the European Medicines Agency, the National Institutes of Health, and the World Health Organization.

PLENARY SPEAKERS

David Cella, PhD

Professor and Chair, Dept. of Medical Social Sciences
Feinberg School of Medicine, Northwestern University
Chicago, IL, United States



Dr. Cella is Professor and Chair of the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine. His research focuses in basic measurement, descriptive studies of quality of life (QoL) and cancer survival, analysis and interpretation of patient-reported

outcomes data in clinical trials, and QoL intervention research. He has developed and validated several dozen questionnaires, known collectively as the Functional Assessment of Chronic Illness Therapy Measurement System (FACIT). Dr. Cella has led the NIH Common Fund Patient reported Outcomes Measurement Information System (PROMIS®) as chair of its Steering Committee and PI of its Statistical Center. His project PROsetta Stone® links common QoL measures across important life domains.

Maarten de Wit, PhD

VU University
Amsterdam, Netherlands



Dr. de Wit has been active in patient organizations at the local, national and international level for 15 years. From 2005-2009, he was the European League Against Rheumatism (EULAR) vice president representing People with Arthritis/Rheumatism in Europe (PARE). Since 2002,

Dr. de Wit has been a patient research partner with OMERACT, organizing patient involvement to develop and validate new QOL instruments for rheumatoid arthritis (RAID) and psoriatic arthritis (PsAID). In January 2014, he defended his doctoral thesis which evaluated the process and outcomes of a decade of patient involvement in OMERACT. He has been a member of the OMERACT executive committee since October 2013.

Christopher B. Forrest, MD PhD

Professor, Pediatrics and Health Care Management
The Children's Hospital of Philadelphia
University of Pennsylvania
Philadelphia, PA, United States



Dr. Forrest is the Director of the Center for Child and Family-Centered Research at the Children's Hospital of Philadelphia, which is devoted to advancing person-focused outcomes research for children, youth, and families. Forrest also directs PEDSnet, which is a national consortium of children's

hospitals and research networks that conduct comparative effectiveness research and quality improvement within the context of a rapid learning health system. He chairs the National Institute of Health'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 Health Services and Outcomes Research at Johns Hopkins School of Public Health.

Lori Frank, PhD

Program Director of Research Integration and Evaluation
PCORI - Patient-Centered Outcomes Research Institute
Washington, DC, United States



As Program Director of the Research Integration and Evaluation program at PCORI, Dr. Frank focuses on methods to bring the patient perspective to comparative effectiveness research to improve decision-making by healthcare consumers and providers. She served as

Principal Investigator of the Cognition Initiative, a multi-sponsor PRO development consortium (now part of the Critical Path Institute PRO Consortium). Other work addresses psychological, ethical, and legal aspects of memory screening and medical decision making by older adult patients. Dr. Frank serves on the Memory Screening Advisory Board of the Alzheimer's Foundation of America, bringing the patient perspective to maximize patient autonomy and optimize patient and caregiver care decision making.



PLENARY SPEAKERS

John Kirwan, BSc MD FRCP

Professor, Rheumatic Diseases, University of Bristol
Consultant Rheumatologist, University Hospitals
Bristol NHS Foundation Trust
Bristol, United Kingdom



For 30 years, Professor Kirwan's research has centered on rheumatic diseases. His research team first established that the progressive joint destruction of rheumatoid arthritis can be stopped. Over the past 15 years, he has led efforts to collaborate with patients as partners in the development, conduct, assessment and dissemination of research. Professor Kirwan was responsible for guiding and implementing the integration of patients into Outcome Measures in Rheumatology (OMERACT), and the emergence of current policy which says outcome measures can only be adopted for international consensus if patients have participated in their development. He has conducted research and published recommendations on the best way to involve patients locally, nationally and internationally.

Carol D. Ryff, PhD

Director, Institute on Aging
Marie Jahoda Professor of Psychology
University of Wisconsin-Madison
Madison, WI, United States



Dr. Ryff's research centers on the study of psychological well-being and has developed multidimensional assessment scales used internationally in diverse scientific fields. Her investigations have addressed how psychological well-being varies by age, gender, socioeconomic status, ethnic/minority status, and cultural context as well as by the experiences, challenges, and transitions individuals confront as they age. A guiding theme in much of this inquiry is human resilience in the face of significant life challenge and what neurobiology underlies this capacity. Dr. Ryff currently directs the MIDUS (Midlife in the U.S.) and is Principal Investigator of MIDJA (Midlife in Japan), for which she received an NIH Merit Award.

Claire Snyder, PhD

Associate Professor of Medicine, Oncology, and Health
Policy Management
Johns Hopkins Schools of Medicine and Public Health
Baltimore, MD, United States



Dr. Snyder's research focuses on the quality of cancer care, with particular emphasis on using patient-reported outcomes (PROs) in clinical practice. Dr. Snyder and colleagues developed the PatientViewpoint webtool for collecting PRO data and incorporating them in patient visits, and they are currently examining best practices for presenting PRO data to promote understanding and use. Previously, Dr. Snyder worked at the National Cancer Institute where she co-edited *Outcomes Assessment in Cancer: Measures, Methods, and Applications*. She began her career at Covance Health Economics and Outcomes Services.

Thomas Willgoss, PhD

Project Lead, Clinical Outcomes Assessment
Abacus International
Visiting Lecturer, Manchester Metropolitan University
Manchester, United Kingdom

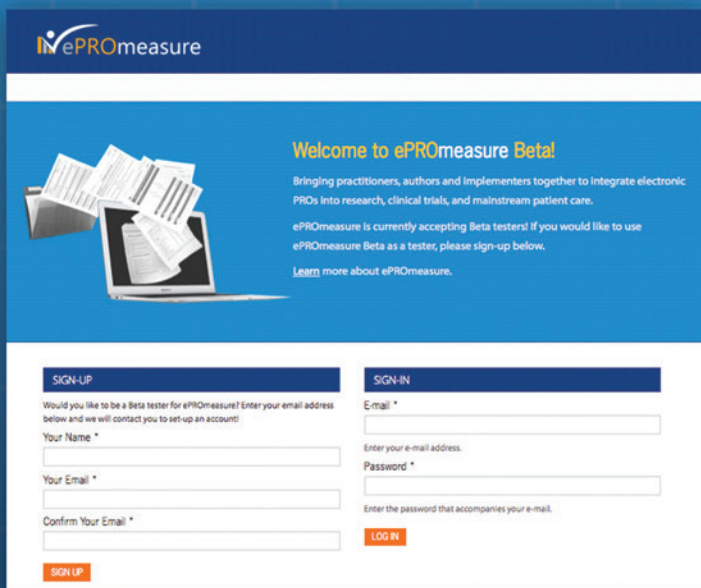


Having undertaken clinical training as a physiotherapist, Dr. Willgoss has been involved in patient-reported outcome (PRO) research since 2008 and has particular expertise in the development and evaluation of PROs in respiratory and mental health conditions. His research focus is on utilizing mixed methods approaches for PRO selection and development, with an emphasis on maximizing patient involvement through a 'patient as researcher' philosophy. Dr. Willgoss' research seeks to develop pragmatic and innovative solutions to current research challenges by applying and evolving established mixed methods approaches from social sciences.



ePROmeasure

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



The screenshot shows the ePROmeasure Beta sign-up page. At the top left is the ePROmeasure logo. Below it is a blue banner with the text "Welcome to ePROmeasure Beta!" and a sub-header "Bringing practitioners, authors and implementers together to integrate electronic PROs into research, clinical trials, and mainstream patient care." Below this is a paragraph: "ePROmeasure is currently accepting Beta testers! If you would like to use ePROmeasure Beta as a tester, please sign-up below." and a link "Learn more about ePROmeasure." To the left of the text is an image of a laptop displaying a survey form. Below the banner are two columns: "SIGN-UP" and "SIGN-IN". The "SIGN-UP" column has a heading "Would you like to be a Beta tester for ePROmeasure? Enter your email address below and we will contact you to set-up an account!" and fields for "Your Name *", "Your Email *", and "Confirm Your Email *", with a "SIGN UP" button at the bottom. The "SIGN-IN" column has fields for "Email *", "Enter your e-mail address.", "Password *", "Enter the password that accompanies your e-mail.", and a "LOG IN" button.

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SCIENTIFIC PROGRAM

Wednesday, 15 October

7:00 am – 6:00 pm Registration Desk Open

9:00 am – 4:00 pm Full Day Workshop – Presented in German SALON 1

(WK11) Basics You Need to Know About Methods Used in Quality of Life Research (Presented in German)

Matthias Rose, MD PhD; Sandra Nolte, PhD; and Felix Fischer, PhD, Charité - University Medicine Berlin, Germany

The workshop is presented in German and is aimed at clinicians and researchers who are new to ISOQOL and interested in beginning to use PROs in clinical practice and research.

9:00 am – 12:00 pm Morning Workshops

(WK01) An Introduction to Health-Related Quality of Life Assessment SALON 2

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

(WK02) Discrete Choice Experiments: Enhancing Patient-Reported Outcomes Beyond QALYS SALON 6

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

(WK03) Best Practices for Qualitative Methods for Patient-Reported Outcomes Research SALON 3

Cicely Kerr, MSc PhD; Claire Friedemann; and Catherine Golics, MPharm PhD, ICON Patient Reported Outcomes, Oxford, United Kingdom; Elizabeth Gibbons, MSc, University of Oxford, Dept. of Public Health, Oxford, United Kingdom

(WK04) Analyzing Longitudinal Quality of Life Outcome Data SALON 4

Stephen J. Walters, PhD, School of Health and Related Research, Univ. of Sheffield, United Kingdom

(WK05) Standardized Evaluations of Patient-Reported Outcomes: The EMPRO Methodology SALON 7

Jose M. (Chema) Valderas, MD MPH PhD, PenCLAHRC, Institute of Health Services Research Univ. of Exeter Medical School, Exeter, United Kingdom; Montse Ferrer, MD MPH PhD and Gemma Vilagut, MSc, Health Services Research Group, IMIM -Institut Hospital del Mar d'Investigacions Mèdiques, Barcelona, Spain

1:00 pm – 4:00 pm Afternoon Workshops

(WK06) Introducing the Concept of Response Shift - An Overview of Theory & Methods SALON 2

Ruth Barclay, PhD MHSc BMR (PT), Univ. of Manitoba, Canada; Bellinda King-Kallimanis, PhD, Pharmerit International

Thank you to Sandra Nolte, PhD; Leah McClimans, PhD; and also the Co-Chairs of the New Investigator SIG, Marc Jacobs, PhD and Katerina Papageorgiou, MSc for their contributions in developing this workshop.

(WK07) Translation Methodology for Clinical Outcome Assessments in Global Trials SALON 3

Catherine Acquadro; and Katrin Conway, BA, Mapi Research Trust, France; Sonya Eremenco, MA, Evidera, United States; Valeska Kantzer; and Mona Martin, RN MPA, Health Research Associates, Inc., United States; Donald Patrick, PhD MSPH, Seattle Quality of Life Group, United States

Workshop conducted by the Translation and Cultural Adaptation (TCA) SIG.

(WK08) Improving the Design of Clinical Trials with Patient-Reported Outcomes: Tips for Protocol Design and Review SALON 4

Melanie Calvert, PhD; and Derek Kyte, MSc, Univ. of Birmingham, United Kingdom; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG), Univ. of Sydney, Australia

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(WK09) How to Integrate Patient-Led Research in Your Health-Related Quality of Life Studies **SALON 6**
Nancy Marlett and Svetlana Shklarov, PACER, University of Calgary, Canada; Maria-Jose Santana, PhD, Senior Researcher, University of Calgary, Canada; Colin Penman and Sandra Zelinsky, Patient and Community Engagement Researcher, Calgary, Canada

(WK10) Whose Quality of Life Assessment Data Should You Use? A Bayesian Testlet IRT Model Perspective **SALON 7**
Yuelin Li, PhD and Thomas Atkinson, PhD, Memorial Sloan-Kettering Cancer Center, United States

4:30 pm – 6:00 pm Industry Advisory Committee (IAC) Symposium SALON 3+4

Advancing Measurement Science Beyond Patient-Reported Outcomes: Patient-Centeredness and Validity Across All Clinical Outcome Assessments

The Industry Advisory Committee (IAC) Symposium will address some of the key questions around the evaluation of clinical outcome assessments beyond PROs. The symposium will use case studies in certain therapeutic areas (e.g., multiple sclerosis), in which clinician-reported outcomes (ClinROs), observer-reported outcomes (ObsROs) and performance outcomes (PerfOs) are particularly relevant, in order to highlight some of the challenges of establishing the validity of these assessments and discuss possible solutions to help advance the measurement of these outcomes.

Presenters

David Cella, PhD, Professor and Chair, Dept. of Medical Social Sciences, Feinberg School of Medicine, Northwestern Univ. United States
Jeremy C. Hobart, PhD FRCP, Clinical Neurology Research, Plymouth Univ. Peninsula Schools of Medicine and Dentistry, United Kingdom
Diana Rofail, MSc CPsychol, Global Head of Patient Reported Outcomes, CNS & Metabolism, Roche Products Limited, United Kingdom

Panelists

Laurie Burke, MPH, LORA Group, LLC, United States
Samantha Brace-McDonnell, Patient Researcher, United Kingdom
Anne Lyddiatt, Patient Researcher, Canada

Moderators:

William Lenderking, PhD, Senior Research Leader, Evidera, United States
Josephine Norquist, MSc, Patient Reported Outcomes Specialist, Merck Sharp & Dohme Corp., United States

Admission to the IAC Symposium is included with the conference registration fee, but registration is required as space is limited.

6:00 pm – 7:30 pm Welcome Reception HALL II

Begin your time at the conference by visiting with old friends and networking with new friends and colleagues.

A cash bar (Euro only) will be available. Credit cards will be accepted at the welcome reception bars.



 Outstanding Poster Abstract Award





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Evidera presenters and authors include:

Workshops

- **An Introduction to Health-Related Quality of Life Assessment**
Gelhorn H, Wyrwich K
- **Translation Methodology for Clinical Outcome Assessments in Global Trials**
Martin M, Kantzer V, Eremenco S, Conway K, Patrick D

Oral Presentations

- **Developing a Conceptual Model of Patients' Experience of Migraine**
Skalicky AM, Mannix S, Oko-Osi H, Widnell KL, Hareendran A, Corey-Lisle PK
- **Exploratory and Confirmatory Factor Analysis of PROMIS Pain Quality Version-2 Items**
Revicki D, Chen WH, Morgan-DeWitt E, Nowinski C, Michaud K, Wolfe F, Cella D

Poster Presentations

- **Engaging Patients in Developing Outcome Measures - Does Context of Use Drive Methodological Decisions?**
Skalicky A, Magasi S, Hareendran A
- **Experience of Pain in Patients with Moderate to Severe Plaque Psoriasis**
Revicki D, Wilson H, Pinto L, Viswanathan HN
- **Gastroparesis Symptom Severity between Patients with Idiopathic and Diabetic Gastroparesis: Evidence for a Unidimensional Symptom Scale for Gastroparesis**
Revicki DA, Camilleri M, Parkman HP

SCIENTIFIC PROGRAM

Thursday, 16 October

7:00 am – 5:00 pm Registration Desk Open

7:30 am – 8:25 am Committee Meetings

CONSORT PRO Guidance Implementation Tools Team Meeting SALON 2

Industry Advisory Committee (IAC) Meeting SALON 3

Patient Scholarship Orientation SALON 4

8:30 am – 8:45 am Welcome and Opening Remarks HALL I – AB

Official welcome and opening remarks.

Staatssekretärin Demirbükten-Wegner, Secretary of State of the Berlin Senate Department for Health and Social Services

Galina Velikova, MD PhD FRCP, ISOQOL President

Jordi Alonso, MD PhD and Susan Bartlett, PhD Scientific Program Chairs

8:45 am – 10:15 am PROS: Contributing to Better Services, Better Societies HALL I – AB

Plenary session sponsored by Evidera.

The role of PROs in research and the evaluation of the effectiveness of health care interventions is well established, but there is an increasing need for translating this expertise to other relevant areas in the organization and evaluation of health and health care systems.

This plenary session will provide an in-depth, lively review of the evidences and the challenges about the role for PROs in improving services provision, evaluation, and regulation, and monitoring of the health of the society at large. Speakers will provide a range of perspectives, including clinical practice, regulatory agencies, and population monitoring, with a focus on the critical evaluation of current and past experiences and vision of challenges and goals.

Speakers

Nick Black, MD, Chair, NHS England National Advisory Group for Clinical Audit & Enquiries; Professor, Health Services Research, London School of Hygiene and Tropical Medicine, London, United Kingdom

Laurie Burke, MPH, Founder, LORA Group, LLC, Royal Oak, MD, United States

Christopher B. Forrest, MD PhD, Children's Hospital of Philadelphia, Univ. Of Pennsylvania, United States

Plenary chaired by Sara Ahmed, PhD, McGill University, Montreal, Canada and Jose M. "Chema" Valderas, MD MPH PhD, University of Exeter, United Kingdom

10:00 am – 5:00 pm Poster Hall Open Hall II

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

Thursday, 16 October

 Outstanding Poster Abstract Award

FINAL
PROGRAM



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Cancer

(1003) Comparison of Different Generic and Lung Cancer Specific Quality of Life Instruments for Their Predictive Ability of Survival in Patients with Advanced Lung Cancer

Sultan Eser, Hacettepe Univ.; Tuncay Göksel, Ege Univ.; Ahmet Emin Erbaycu, Dr Suat Seren Chest Diseases and Thoracic SER Hospital; Erhan Eser, MD, Celal Bayar Univ., Manisa, Turkey; Burcu Basarik, Ege Univ.; Aysen Öz, Celal Bayar Univ.; Kader Kiyar Gürsul Dr Suat Seren Chest Diseases and Thoracic SER Hospital; Pinar Çelik, Celal Bayar Univ.; Ebru Çakir Ediz, Trakya Univ.; Osman Hatipoglu, Trakya Univ.; Bedriye Atay Yayla, Pamukkale Univ.; Sevin Başer, Pamukkale Univ.; Hakan Baydur, Celal Bayar

(1005) Patient-Centered Evaluation of Treatment Outcomes in CML Patients after 12 months of Second-Line Treatment: Quality of Life and Symptom Burden

Tatiana I. Ionova, Multinational Center for Quality of Life Research, St. Petersburg, Russian Federation; Denis A. Fedorenko, PhD, National Medical Surgical Center; Tatiana Nikitina, PhD; and Kira Kurbatova, Multinational Center for Quality of Life Research

(1007) Symptoms and Biomedical Factors Show who is at Risk of Poor Quality of Life and High Cost in Multiple Myeloma – A Systematic Review and Meta-Analysis

Christina Ramsenthaler, King's College London, United Kingdom; Pauline M. Kane, King's College London; Richard J. Siegert, Auckland Univ. of Technology; Wei Gao, King's College London; Polly Edmonds; and Steve Schey, King's College Hospital; Irene J. Higginson, King's College London

(1011) Patient-reported Outcomes in a Randomized Trial of Bevacizumab in the treatment of Advanced Cervical Cancer: A Gynecologic Oncology Group Study

Richard T. Penson, Massachusetts General Hospital; Helen Q. Huang, MS, GOG Statistical & Data Center; Lari Wenzel, PhD, Univ. of California, Irvine, CA, United States; Krishnansu Tewari, Univ. of California, Irvine; Bradley J. Monk, St. Joseph's Hospital; Michael Sill, GOG Statistical & Data Center; Sharon Stockman, Univ. of Iowa; Lois Ramondetta, Univ. of Texas, MD Anderson Cancer Center; Lisa Landrum, Oklahoma Univ. Health Science Center; Ana Oaknin, GEICO Barcelona; Thomas Reid, Kettering Med Center; Mario Leitao, MSKCC

(1013) Comparison of Three Longitudinal Analysis Models for the Health-Related Quality of Life in Oncology: A Simulation Study

Amélie Anota, Quality of Life in Oncology Platform, France; Antoine Barbieri, ICM - Val d'Aurelle; Marion Savina, Institut Bergonié; Alhousseiny Pam, Univ. Hospital of Besançon; Sophie Gourgou-Bourgade, CRLC Val d'Aurelle; Franck Bonnetain, PhD, Univ. Hospital of Besançon; Caroline Bascoul-Molleli, ICM - Val d'Aurelle

(1015) Symptom Burden and Health-related Quality of Life in Patients with Unresectable or Metastatic Melanoma: results from the IMAGE Study

Susan D. Mathias, MPH, Health Outcomes Solutions, United States; Srividya Kotapati; and T Kim Le, Bristol-Myers Squibb; Amy P. Abernethy, Duke Comprehensive Cancer Center

Cardiovascular

(1017) The Most Frequently Reported Symptoms of Heart Failure, their Impacts on Daily Life, and Why these Matter with Respect to Clinical Outcomes

Renee F. Pierson, MBA; and Shana Traina, PhD, Janssen Research & Development, LLC; Lauren Braam, MIH; Donald M. Bushnell, III, MA; Kelly P. McCarrier, PhD MPH; and Mona L. Martin, RN MPA, Health Research Associates, Inc.

(1019) An Educational Program to Improve Health-Related Quality of Life in Patients Initiating Oral Anticoagulant Therapy: A Randomized Controlled Trial

Flávia M. Pelegriño; Fabiana Boleta; and Rejane K. Furuya, Univ. of São Paulo; Márcia A. Ciol; and Jeanne M. Hoffman, Univ. of Washington; André Schmidt; Lidia A. Rossi, PhD; and Rosana Spadoti Dantas, PhD, Univ. of São Paulo, Brazil

(1021) The Effect of Hypertension Diagnosis on Change in Quality of Life: The Role of Personality, Social Support and Initial Chronic Disease Status

Eithne Sexton, Royal College of Surgeons in Ireland, Dublin, Ireland; Bellinda L. King-Kallimanis, PhD, Trinity College Dublin; Richard Layte, Economic and Social Research Inst.; Anne Hickey, Royal College of Surgeons in Ireland

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(1023) Minimal Clinically Important Differences in Health-Related Quality of Life at 1-Year Post Discharge in Patients with Heart Failure

Antonio Escobar, PhD MD, Hospital Univ. Basurto, Spain; Amaia Bilbao; Marta Gonzalez-Saenz de Tejada; and Ziortza Trancho, Hospital Univ. Basurto; Raul Quiros, Hospital Costa del Sol; Lidia Garcia-Perez, Servicio Canario de la Salud; Gema Navarro, Hospital Parc Taulí. Sabadell; Iratxe Lafuente, Hospital Galdakao-Usansolo

(1025) Responsiveness of EQ-5D-5L in Patients with Stroke

Dominik Golicki, MD PhD, National Inst. of Public Health, Warsaw, Poland; Maciej Niewada, Medical Univ. of Warsaw; Anna Karlinska; Julia Buczek; and Adam Kobayashi, Inst. of Psychiatry and Neurology; M.F. Janssen, Erasmus MC; Simon Pickard, PhD, Univ. of Illinois at Chicago, United States

Nephrology/Urology

(1027) Changes in Depression from Dialysis to Transplantation: A Longitudinal Follow-Up Study

Nanna Von Der Lippe, Univ. of Oslo, Norway; Bård Waldum, Univ. of Oslo; Amin Amro, RN, MSN, Oslo Univ. Hospital; Fredrik B. Brekke, Univ. of Oslo; Ingrid Os, MD PhD, Univ. of Oslo Medical School

(1029) Symptom Perception from Dialysis to Renal Transplantation: A Longitudinal Study

Amin Amro, RN, MSN, Oslo Univ. Hospital, Oslo, Norway; Bård Waldum, Univ. of Oslo; Nanna Von Der Lippe, Univ. of Oslo; Fredrik B. Brekke, Univ. of Oslo; Ingrid Os, MD PhD, Univ. of Oslo Medical School

(1031) Knowledge of Chronic Kidney Disease among Pre Dialysis Patients

Virginia V. Brasil, PhD, Federal Univ. of Goias, Brazil; Katarinne L. Moraes; Jacqueline Andréia B L Cordeiro; and Gabriela Ferreira De Oliveira, Federal Univ. of Goias; Antonio Márcio Teodoro Cordeiro, Pontifical Catholic Univ. of Goias; Luiz Antonio Brasil; Maria Alves Barbosa, PhD; Isabela C F Fernandes; Carla P. Bernardes; and Ruth Minamisava, Federal Univ. of Goias

(1033) Comparison of Quality of Life in Hemodialysis Patients Receiving either Acetate-Based or Acetate-Free Citrate Dialysate

Hideaki Ishikawa, Tokai Central Hospital of Japan Mutual Aid Association, Japan; Saori Tukushi; and Junichi Sakamoto, Tokai Central Hospital of Japan Mutual Aid Association

(1035) Health-Related Quality of Life of Adults and Seniors with Chronic Renal Insufficiency on Hemodialysis: Associated Factors

Jéssica Maria Lopes; Raiana Fukushima; and Ana Carolina Ottaviani, Univ. Federal de São Carlos, Brazil; Fabiana Souza Orlandi, PhD, Univ. Federal de São Carlos

(1037) Renal Transplantation in Spain - Utility and Health-Related Quality of Life of Five (5) Profiles of Transplantation

Angeles Crespo, LASER Analytica; Carmen Díaz-Corte, Hospital Universitario Central de Asturias; Jesús Cuervo; and Pablo Rebollo, PhD, LASER ANALYTICA, Spain; Erika De-Sousa, Hospital la Paz de Madrid; Ramón Romero, Hospital Germans Trias i Pujol de Badalona; M^{re} Carmen Cantarell, Hospital Vall d'Hebron de Barcelona; Frederic Cofan, Hospital Clinic de Barcelona; Laura Fernández, Hospital Universitario Central de Asturias; Estefania Pérez, Hospital Universitario de Tenerife; Julia Kanter, Hospital Doctor Peset de Valencia; Red Temática de Investigación Renal (REDinREN), RD 06/0016/1009, Instituto de Salud Carlos III

Neurology

(1039) Development of a Questionnaire Assessing the Cognitive Dimension of HRQOL - the COGQOL (Cognitive Quality Of Life)

Nicole Von Steinbuchel-Rheinwall, Univ. of Goettingen, Germany; Martin L. Werkmeister; and Joy C. Backhaus, Inst. for Medical Psychology and Sociology

(1041) Development of Computerized Adaptive Test (CAT) Item Bank for Assessing Quality of Life in Multiple Sclerosis: Preliminary Results from a European Multi-Center Study

Pierre Michel, Aix Marseille Université, Marseille, France; Karine Baumstarck, Aix Marseille Univ.; Mohamed Boucekine, Self-perceived Health Assessment Research Unit; Laurent Boyer, PhD, Aix Marseille Univ.; Anderson Loundou, Self-perceived Health Assessment Research Unit; Jean Pelletier, Timone Univ. Hospital; Badih Ghattas, Faculté Des Sciences de Luminy; Pascal Auquier, Univ. Hospital of Marseille

 Outstanding Poster Abstract Award

Thursday, 16 October



SCIENTIFIC PROGRAM

(1043) What Matters to Women Living with MS in Saudi Arabia

Alaa M. Arafah, MSc, McGill Univ., Montreal, Canada; Mona M. Alkhwajah, King Faisal Specialist Hospital and Research Center; Shahnaz Shahrbanian, McGill Univ.; Asma Alkusayer, King Saud Bin Abdulaziz Univ. for Health Sciences; Nancy E. Mayo, PhD, McGill Univ. Health Centre

STUDENT PRESENTATION AWARD FINALIST

(1045) Reliability of the Original and Short Versions of the Falls Efficacy Scale-International (FES-I) in People with Parkinson's Disease

Stina B. Jonasson, RPT MSc, Lund Univ., Sweden; Maria H. Nilsson, MSc; and Jan Lexell, Lund Univ.

(1049) Patient-Reported Outcomes in Randomized Controlled Trials of Primary Brain Tumour Patients: Methodological Quality and Impact on Clinical Decision-Making

*Linda Dirven, PhD, VU Univ. Medical Center; Martin Taphoorn, MD PhD, Medical Center Haaglanden; Jaap C. Reijneveld, VU Univ. Medical Center; Jane Blazeby, MD, Univ. of Bristol; Marc Jacobs, Academic Medical Center, Amsterdam; Andrea Pusic, MD MHS FRCSC, MSKCC; Edoardo La Sala, GIMEMA; Peter Fayers, PhD, Univ. of Aberdeen; **Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy, on behalf of the EORTC Quality of Life Group (Patient-Reported Outcome Measurements Over Time In Oncology-PROMOTION Registry)***

(1051) Factors Associated with Quality of Life in the 18 Months Following Stroke - A Longitudinal Study using a Specific Questionnaire

Sylvia Cael, Univ. of Dijon, France; Hervé Devilliers; and Abderrahmane Bourredjem, Univ. Hospital, Inserm; Odile Troisgros; and Maurice Giroud, Univ. Hospital, Dijon; Christine Binquet, Univ. Hospital, Inserm; Mariette Mercier, Univ. Hospital of Besancon

Children

(1053) Health-Related Quality of Life in Children and Adolescents in Germany

Ute Ellert, Robert Koch Institute, Berlin, Germany; Anna K. Brettschneider, Robert Koch Institute; Ulrike Ravens-Sieberer, MPH, Univ. Medical Center Hamburg-Eppendorf

(1057) Reliability and Validity of the Colombian version of Kidscreen-52 for the Child and Adolescent Student Population of Bucaramanga (Colombia)

Diana M. Camargo Lemos, MSc, Univ. Industrial de Santander, Colombia; Martha J. Rodriguez; and Luis Carlos LC Orozco, Universidad Industrial de Santander

(1059) Validation for Brazil of DISABKIDS®- Cystic Fibrosis Module, Proxy Version, for Parents or Caregivers of Children and Adolescents with Cystic Fibrosis

Danielle Maria S S dos Santos, PhD, Univ. of Rio de Janeiro, Brazil; Keila C. Deon, PhD, Federal Univ. of Rio Grande do Sul; Maria Fernanda Cabral Kourrouski, Univ. of São Paulo; Monika Bullinger, PhD, Hamburg Univ.; Claudia Benedita dos Santos, PhD, MISP-EERP-USP

Elderly

(1061) Challenges of Measuring Physical Function for Randomized Control Trials of Seniors: To PRO or Not?

Sabrina M. Figueiredo, McGill Univ., Montreal, Canada; Nancy E. Mayo, PhD, McGill Univ. Health Centre

(1063) Is the WHOQOL-OLD a Good Add-On Module to the WHOQOL-BREF? A Study from the Elderly People of Taiwan

Grace Yao, PhD, National Taiwan Univ., Taipai, Taiwan; Cheng Chun Chien, National Taiwan Univ.

(1065) Surgical Elderly Patients' QOL after ICU Treatment

Carla Carneiro, Hospital Prof. Dr. Fernando Fonseca, Lisbon, Portugal; Dulce Oliveira; Sabrina Tavares; Ricardo Rocha; Rui Marinho; Antonio Gomes; Marta Sousa; Teresa Brandão; Isabel Braga; and Vitor Nunes, Hospital Prof. Dr. Fernando Fonseca

(1067) The Effects of Autobiographical Disclosure on Quality of Life in Older Adults – A Preventive Approach

Simone Freitag, PhD, Univ. of Greifswald, Germany; Carolin Wendt; Katrin Stegemann; and Silke Schmidt, PhD, Univ. of Greifswald

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

Health Policy

(1071) The Ugandan Patient Perception of Quality of Life and Living with HIV: Qualitative Study

Doris M. Mwesigire, MD, Makerere Univ., Kampala, Uganda; Janet Seeley, Medical Research Council; Faith Martin, MA, Univ. of Bath; Achilles Katamba, Makerere Univ.

(1073) The Impact of Extreme Weather Events on the Quality of Life: Levels of Perception

Raluca I. Antonie, Babes-Bolyai Univ., Romania; Adina E. Croitoru, Babes-Bolyai Univ.

Patient-Centered Research

(1075) Using PROs and PROMs for Different Purposes: A Discussion of the Dilemmas

Anna Beurskens, PhD, Zuyd Univ. of Applied Sciences; Caroline B. Terwee, PhD, VU Univ. Medical Center, Amsterdam, Netherlands; Lotte Haverman, PhD, Emma Children's Hospital - Academic Medical Centre; Jolanda De Vries, Tilburg Univ.; Raymond Swinkels, Zuyd Univ. of Applied Sciences; Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center

(1079) Development of the Revised McGill Quality of Life Questionnaire for People with Life-Threatening Illnesses

Richard Sawatzky, PhD RN, Trinity Western Univ., Canada; S. Robin Cohen, PhD, McGill Univ. and Jewish General Hospital; Javad Shahidi, Bayer HealthCare Canada; Andrew Day; and Xuran Jiang, Kingston General Hospital

Statistical Analysis of Patient-Reported Outcomes

(1083) Evaluating the Invariance of the Hyperhidrosis Quality of Life Index (HidroQOL ©): A Comparison of Two Paradigms, Confirmatory Factor Analysis vs. Rasch Analysis

Paul Kamudoni, Cardiff Univ., United Kingdom; Berno Müller, Riemser Pharma GmbH; Sam Salek, BSc RPh PhD FFPM, Cardiff Univ.

🦁 (1085) Testing the Applicability of a Conceptual Model of Oral Health-Related Quality of Life in Older Adults

Camila M. Dos Santos, Federal Univ. of Rio Grande do Sul, Brazil; Roger K. Celeste; Juliana B. Hilgert; and Fernando N. Hugo, Federal Univ. of Rio Grande do Sul

(1087) Quality Adjusted Survival in Oncology: A Review of the Q-TWiST Method used these Twenty Past Years

Anais Jouin, Centre Oscar Lambret, Lille, France; Bastien Cabarrou; and Thomas Filleron, Institut Claudius Regaud; H el ene Behal; and Alain Duhamel, Universit e de Lille; Andrew Kramar, PhD, CRLC Val d'Aurelle

STUDENT PRESENTATION AWARD FINALIST

(1089) A Guttman's Errors Based Method for Response-Shift detection at the Individual Level: Algorithm and Comparison with the Ahmed's Procedure

Jean-Benoit Hardouin, PhD ScD; Myriam Blanchin; and Veronique Sebill e, ScD, Univ. of Nantes, France.

(1091) Confirmation of the Factor Structure of the PROQOL-HIV Questionnaire in Han and Uygur HIV+ Patients

Christophe Lalanne, DRCD Hospital Saint-Louis; Rena Maimaiti, Xinjiang Medical Univ.; Rune Andersson, Univ. of Gothenburg; Olivier Chassany, MD PhD, Direction de la Politique Medicale; Martin Duracinsky, MD PhD, Hospital Bicetre, Paris, France

(1093) Validscale: A Free Module to Validate a Uni- or Multi-Dimensional PRO-Based Questionnaire

Bastien Perrot, Univ. of Nantes, France; Emmanuelle Anthoine; and Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes

Measure Development

(1095) Generating Items for the Oxford Participation and Activities Questionnaire (Ox-PAQ)

Laura Kelly, Univ. of Oxford, United Kingdom; Sarah Dummett; Jill Dawson; and Raymond Fitzpatrick, PhD, Univ. of Oxford; Crispin Jenkinson, Health Services Research Unit; David Morley, Univ. of Oxford

(1097) Development of an Item Bank to Measure Economic Quality of Life (ECQ) for Individuals with Disabilities

David Tulskey, PhD, Kessler Foundation, New York, NY, United States; Allen W. Heinemann; and Jin-Shei Lai, PhD, Northwestern Univ.; Noelle Carozzi; and Pamela A. Kisala, Univ. of Michigan; Patrick Semick, Rehabilitation Institute of Chicago

 Outstanding Poster Abstract Award

Thursday, 16 October



SCIENTIFIC PROGRAM

(1099) From Apathy to Motivation: An Exploration of a Construct

Christiane B. Lourenco, PhD, McGill Univ., Montreal, Canada; Lesley Fellows, McGill Univ.; Nancy E. Mayo, PhD, McGill Univ. Health Centre

(1101) Patient Benefit Measurement in Dermatology: Using Qualitative Interviews to Explore the Content of Treatment Goal Items

Christine Blome, PhD, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Kathrin Von Usslar; and Matthias Augustin, MD, Univ. Medical Center Hamburg

(1103) Improving the Individual Work Performance Questionnaire using Rasch analysis

Linda Koopmans; Claire Bernaards; Vincent H. Hildebrandt; and Stef Van Buuren, Netherlands Organisation of Applied Research TNO; Allard J. Van Der Beek, VU Univ. Medical Center; Henrica C.W. de Vet, Sr., PhD, EMGO Institute VU Medical Center, Amsterdam, Netherlands

(1105) Rasch Analysis of the Spanish Version of the Oral Health Impact Profile (OHIP) in Periodontal Patients

Karina J. Espinoza, MSc, Distrito Federal, Mexico; Luz Dary LD Upegui, MSc, Univ. Industrial de Santander; Ingris Pelaez; and Gloria A. Moreno, Univ. Nacional Autónoma de México

(1107) Interview administered versus self-administered PROQOL-HIV scale in India

Rewa Malhotra Kohli, National AIDS Research Inst.; Christophe Lalanne, DRCD Hospital Saint-Louis; Ramesh S. Paranjape; Amit Nirmalkar; and Manisha Ghate, National AIDS Research Inst.; Susan Herrmann, Murdoch Univ.; Olivier Chassany, MD PhD, Direction de la Politique Medicale; Martin Duracinsky, MD PhD, Hospital Bicetre, Paris, France

(1109) Quality of Life Assessment in Menstrual Problems

Pamela Warner, Univ. of Edinburgh, Teviot Place, United Kingdom

11:00 am – 12:15 pm

Cutting Edge Research

HALL I – AB

Plenary session sponsored by Genentech.

This session will highlight some of the high quality research of members of the ISOQOL community. Three top rated abstracts submitted during ISOQOL's call for oral and poster abstracts have been selected to be featured at this plenary session.

Thomas Willgoss, PhD, Project Lead, Abacus International and Manchester Metropolitan University, Manchester, United Kingdom
Group Concept Mapping: A Novel, Patient-Centered, Mixed Methods Approach to Identifying Relevant Concepts for Patient-Reported Outcome Measures and Facilitating Participant Engagement

Jakob Bue Bjorner, MD PhD, Chief Science Officer, QualityMetric - a part of Optum, United States; Prof. of Epidemiology, Danish National Research Centre for the Working Environment; Honorary Professor, Univ. of Copenhagen, Denmark and Univ. of Sheffield, United Kingdom
Do Different Health Attributions Make a Difference in Questions about Work and Other Role Activities?

Claire Snyder, PhD, Johns Hopkins Schools of Medicine and Public Health, Baltimore, MD, United States
What's "Up": Patients' and Clinicians' Intuitive Interpretation of PRO Scores

Plenary chaired by **Nancy Mayo, PhD**, McGill University Health Centre, Montreal, Canada and Bryce Reeve, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

12:15 pm – 1:15 pm

Lunch Buffet

Served in Poster Hall

12:30 pm - 1:30 pm

Committee Meeting

Salon 3

Companion to User's Guide

 Outstanding Poster Abstract Award

Thursday, 16 October

SCIENTIFIC PROGRAM

12:30 pm – 1:45 pm

Expert Panel Discussion: Patient-Centered Outcome Measurement: Routes, Roadblocks, and Roadmaps

HALL I - C

Plenary session sponsored by Bayer.

The Expert Panel Discussion will focus on the current state of play of patient-centered outcome measurement from the perspective of the three speakers. We will first describe the significant progress that has been made during our working careers, and will then flag some concerning problems in the field, in particular, the ‘routes’ (i.e. competing methodologies) and ‘roadblocks’ (i.e., barriers preventing widespread take up of state of the art techniques). As exemplars we will introduce five key challenges: 1) which measurement paradigm to guide instrument development and evaluation; 2) how to recognize the limitations of psychometric “statistics”; 3) how best to measure change over time; 4) what sample sizes for scale development and evaluation studies; and 5) how to overcome the legacy of ‘legacy’ instruments? We will then go onto describe how the current best practice recommendations from the US Food and Drug Administration (the ‘Roadmap’) enables the development of clinically meaningful patient focused outcome measures.

Presenters:

Laurie Burke, MPH, LORA Group, LLC, United States

Jeremy C. Hobart, PhD FRCP, Clinical Neurology Research, Plymouth Univ. Peninsula Schools of Medicine and Dentistry, United Kingdom

Stefan J Cano, PhD, Modus Outcomes, Newton, MA, United States

Admission to the Expert Panel Discussion is included in the registration fees, but preregistration is required as space is limited.

2:00 pm – 3:15 pm

Concurrent Oral Sessions

Oral Session 101: Advancing Quality of Life Measurement in Neurology

HALL I - A

Session Chair: Deborah Miller, PhD, United States

2:05 – 2:18 pm (101.1) Developing a Conceptual Model of Patients’ Experience of Migraine

Anne Skalicky, MPH; Sally Mannix, BA; and Hafiz Oko-Osi, Evidera; Katherine L. Widnell, MD, Amgen; Asha Hareendran, PhD, Evidera; Patricia K. Corey-Lisle, PhD; and Sandhya J. Sapra, PhD, Amgen

2:19 – 2:32 pm (101.2) Quality of Life and Patient Preferences: Identification of Sub-Groups of Multiple Sclerosis Patients

Rosalba Rosato, PhD, Univ. of Turin, Italy; Silvia Testa; and Giorgia Molinengo, Univ. of Turin

2:33 – 2:46 pm (101.3) Development of a New Measurement System to Assess HRQOL in Individuals with Spinal Cord Injury

David Tulskey, PhD, Kessler Foundation, New York, NY, United States; Pamela A. Kisala, Univ. of Michigan; Denise G. Tate, PhD, Univ. of Michigan; Allen W. Heinemann, Northwestern Univ.; David Victorson, PhD, Northwestern Univ.; Susan Charlifue, PhD, Craig Hospital; Seung W. Choi, PhD; and David Cella, PhD, Northwestern Univ.

2:47 – 3:00 pm (101.4) Improving the Measurement of QALYs in Multiple Sclerosis: Estimating a Preference-Based Index for use in Deriving Quality-Adjusted Life-Years (QALYs) for Multiple Sclerosis

Elizabeth Goodwin, Univ. of Exeter Medical School, United Kingdom; Colin Green, PhD, Univ. of Exeter

3:01 – 3:14 pm (101.5) Patients and Health Economists: Working Together to Build a Better Research Base for Making Decisions about the Funding of Treatments for MS

Annie Hawton, Univ. of Exeter Medical School, United Kingdom; Elizabeth Goodwin, Univ. of Exeter Medical School

Thursday, 16 October

 Outstanding Poster Abstract Award

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PROGRAM



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SCIENTIFIC PROGRAM

Oral Session 102: The Importance of Context: Response Shift and Differential Item Functioning

HALL I - B

Session Chair: Sandra Nolte, PhD, Germany

2:05 – 2:18 pm (102.1) Latent Variable Mixture Models for Differential Item Functioning: Application to the SF-36 Physical Functioning and Mental Health Sub-Scales

Xiuyun Wu, Univ. of Manitoba, Winnipeg, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ.; Wilma Hopman, Kingston General Hospital; Nancy E. Mayo, PhD, McGill Univ. Health Centre; Tolulope T. Sajobi, PhD, Univ. of Calgary; Juxin Liu, Univ. of Saskatchewan; Lisa M. Lix, Univ. of Manitoba

2:19 – 2:32 pm (102.2) Structural Equation Modeling to Characterize the Occurrence of Response Shift Effect in a Longitudinal Quality of Life Study using EORTC Questionnaires

Amélie Anota, Quality of Life in Oncology Platform, France; Caroline Bascoul-Mollevi, ICM | Val d'Aurelle; Thierry Conroy, Centre Alexis Vautrin; Francis Guillemain, MD PhD, Lorraine Univ.; Michel Velten, College of Medicine, Strasbourg; Damien Jolly, Univ. Hospital of Reims; Zeinab Hamidou, Aix-Marseille Univ.; Franck Bonnetain, PhD, Univ. Hospital of Besançon

2:33 – 2:46 pm (102.3) Comparison of Item Response Theory and Structural Equation Models for Response Shift Detection at the Item Level

Myriam Blanchin, Univ. of Nantes, France; Alice Guilleux, Univ. of Nantes; Antoine Vanier, MD, Univ. Pierre Et Marie Curie; Jean-Benoit Hardouin, PhD ScD; and Veronique Sebillé, ScD, Univ. of Nantes

2:47 – 3:00 pm (102.4) Estimating Quality of Life when Differential Item Functioning is Present

Jean-Francois Hamel, Univ. Hospital of Angers, France; Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes; Yves Roquelaure, Univ. of Angers; Veronique Sebillé, ScD, Univ. of Nantes

3:01 – 3:14 pm (102.5) Can Appraisal as a Person Factor be Used for Detecting Response Shift?

Karl Bang Christensen, Univ. of Copenhagen, Denmark; Armon Ayandeh, DeltaQuest Foundation; Bruce D. Rapkin, PhD, Yeshiva Univ.; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc.

Oral Session 103: Transforming Care: Quality of Life, Policy & Decision Making

SALON 2

Session Chair: Lori McLeod, PhD, United States

2:05 – 2:18 pm (103.1) Quality of Life in the Early Assessment of Benefit in Germany: A Qualitative Study

Christine Blome, PhD, Univ. Medical Center Hamburg-Eppendorf, Germany; David Lohrberg; and Matthias Augustin, MD, Univ. Medical Center Hamburg

(103.2) WITHDRAWN

2:19 – 2:32 pm (103.3) Understanding Safe Surgery Checklist Experiences in Alberta

Sandra Zelinsky, Univ. of Calgary, Canada; Mary Sheridan; Nancy Marlett; and Svetlana Shklarov, Univ. of Calgary; Tracy Wasylak, Alberta Health Services

2:33 – 2:46 pm (103.4) Integration of Patient-Reported Outcomes (PRO) in Drug Development Strategy Decisions

Anders P. Ingelgård, PhD Docent, Covance, Sweden; Mika Nokela; Anna-Karin Berger, PhD; and Jason C. Cole, PhD, Covance Market Access Services

2:47 – 3:00 pm (103.5) Patients' Health-Related Quality of Life While Transitioning from Acute-Based to Community-Based Care

Maria-Jose Santana, PhD, Univ. of Calgary, Canada; Barbara Okoniewska, BSc; Katy Eso, MS CGC; Wrechelle Ocampo, RN MBT; Nancy Clayden, EMT-P; Jayna Holroyd-Leduc, MD FRCPC; Maeve O'Beirne, MD FCFP PhD; W. Flemons, MD FRCPC; and Deborah White, RN PhD, Univ. of Calgary; AJ Forster, MD FRCPC MSc, Univ. of Ottawa; William Ghali, MD FRCPC MPH, Univ. of Calgary

 Outstanding Poster Abstract Award

Thursday, 16 October

SCIENTIFIC PROGRAM

Oral Session 104: Advancing Quality of Life Measurement in Older Adults

SALON 4

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

2:05 – 2:18 pm (104.1) Bibliometric Analysis of PROMs and PREMs for Elderly Patients in Acute Care

Eric K. H. Chan, PhD, Trinity Western Univ., Canada; Richard Sawatzky, PhD RN; Duncan Dixon; and Doreen M. Wolfs, Trinity Western Univ.; Anne M. Gadermann, PhD, Univ. of British Columbia; PROM-PREM Knowledge Synthesis Team, Trinity Western Univ.

2:19 – 2:32 pm (104.2) Response Shift in Quality of Life in Older Men: The Manitoba Follow-up Study

Maryam A. Alshammari, Univ. of Manitoba, Winnipeg, Canada; Robert B. Tate; Donna Collins; and Ruth Barclay, PhD MHS BMR (PT), Univ. of Manitoba

2:33 – 2:46 pm (104.3) MIBBO: A Tool to Assess Meaningful Physical Activities for Nursing Home Residents

Melanie Kleynen; Susy Braun; Kim Van Vijven; Erik Van Rossum; and Anna Beurskens, PhD, Zuyd Univ. of Applied Sciences, Netherlands

(104.4) WITHDRAWN

2:47 – 3:00 pm (104.5) Community Aged Care Assessment: Results from a National Field Trial

Janet E. Sansoni, MSc, Univ. of Wollongong, Australia; Peter Samsa; Cathy Duncan; and Kathy Eagar, Univ. of Wollongong; Bruce Shadbolt, Australian National Univ.

Oral Session 105: New Approaches to Evaluating Cancer Treatments

HALL I - C

Session Chair: Ida J. Korfage, PhD, Netherlands

2:05 – 2:18 pm (105.1) Effect of Low Versus High Intensity Physical Exercise During Chemotherapy on Physical Fitness, Fatigue and Chemotherapy Completion Rates: Results of a Randomized, Controlled Trial

Hanna Van Waart; Martijn M. Stuiver; Gabe S. Sonke; Wim H. Van Harten; and Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands

2:19 – 2:32 pm (105.2) Quality of Life among Patients after Bilateral Prophylactic Mastectomy: A Systematic Review of Patient-Reported Outcomes.

Shantanu N. Razdan, MD MSPH, Memorial Sloan-Kettering Cancer Center (MSKCC), United States; Vishal Patel, BS, Weill Cornell Medical College; Colleen McCarthy, MD MS, MSKCC

2:33 – 2:46 pm (105.3) Quality of Life in Patients with Localized Prostate Cancer According to Treatment and Biochemical Relapse

Monica Avila, PharmD, MPH, IMIM -Hospital Del Mar Medical Research Institute, Barcelona, Spain; Angels Pont Acunda, Health Svcs Research Unit; Olatz Garin, MPH, PhD, IMIM-Hospital del Mar Medical Research Institute; Montserrat Ferrer, MD PhD MPU, IMIM-Hospital del Mar Medical Research Institute

2:47 – 3:00 pm (105.4) Health-Related Quality of Life in Patients with Unresectable or Metastatic Melanoma: Preliminary Results from IMAGE Study

Susan D. Mathias, MPH, Health Outcomes Solutions, United States; Srividya Kotapati; and T Kim Le, Bristol-Myers Squibb; Amy P. Abernethy, Duke Comprehensive Cancer Center

3:01 – 3:14 pm (105.5) Evolution of Trial Outcome Index (TOI) Scores at Different Time Periods for Esophageal Cancer Patients Treated with Neoadjuvant Chemoradiation and Surgery

Julie G. Trudel, PhD, Univ. Health Network, Toronto, Canada; Joanne Sulman, Qualitative Research and Group Work Consultant; Eschetu Atenafu, Princess Margaret Cancer Center; Jennifer Lister, Toronto General Hospital; Gail Darling, Toronto General Hospital

3:15 pm – 4:00 pm

Exhibits Open and Refreshment Break

Thursday, 16 October

 Outstanding Poster Abstract Award

FINAL
PROGRAM



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Cancer

(1002) Health-Related Quality of Life and Mental Health in Long Term Survivors with Brain Tumour, Hodgkin's or Non-Hodgkin's Lymphoma: A Registry Based Study in Schleswig-Holstein, Germany, Based on Adults

Annika Waldmann, University of Luebeck, Germany; Dorothea Bethge; and Eva M. Fick, Inst. of Social Medicine and Epidemiology; Judith Gebauer; and Georg Brabant, Experimental and Clinical Endocrinology

(1004) Working and Occupational Condition after Esophagectomy for Cancer

Eleonora Pinto, PsyD, Veneto Inst. of Oncology, Padova, Italy; Marco Scarpa; Francesco Cavallin; Rita Alfieri; Matteo Cagol; Luca M. Saadeh; Silvia Mantoan; and Carlo Castoro, Veneto Inst. of Oncology

(1006) Quality of Life Related to Health in Patients with Myeloproliferative Syndromes in Colombia

Martin Romero, MD PhD(c), Universidad Nacional de Colombia, Colombia; Ruben Marrugo, Fundacion Salutia

(1008) The Burden of Pain and Fatigue in Multiple Myeloma: Results of a Systematic Literature Review

Colleen A. McHorney, Covance Market Access, Inc., United States; Bhumi Trivedi; and Andrew Palsgrove, Covance; William B. Jones; and Peter Trask, Sanofi

(1010) Effect of Completion-Time Windows in the Analysis of Health-Related Quality of Life (HRQOL) Outcomes in Radiotherapy Clinical trial

*Divine Ewane Ediebah, PhD (c), EORTC Headquarters; Warren Grant, Cheltenham General Hospital; Corneel Coens, MSc, Belgium; Chantal Quinten, MSc, and Efsthios Zikos, MS MA, EORTC Headquarters; Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill; Carolyn C. Gotay, PhD, Univ. of British Columbia; Jolie Ringash, MD, The Princess Margaret Cancer Centre; Charles S. Cleeland, PhD, Univ. of Texas-MD Anderson Cancer Center; Henning H. Flechtner, PhD, Otto-von-Guericke Univ. (KKJP); Eva Greimel, PhD, Medical Univ. Graz; Galina Velikova, MD PhD FRCP, Univ. of Leeds; Joseph Schmucker-Von Koch, Univ. of Regensburg; Carla Van Herpen, Radboud Univ. Nijmegen Medical Centre; Jan B. Vermorcken, Emeritus Professor, Antwerp Univ. Hospital; Martin Taphoorn, MD PhD, VU Medical Center/Medical Center Haaglanden; Andrew Bottomley, PhD, EORTC Headquarters; **Dagmara Kulis, EORTC, Brussels, Belgium***

(1012) Combining Survival and Toxicity Effect Sizes from Clinical Trials into an Interpretable Quality-Adjusted Survival Effect Size Estimate Of Treatment Efficacy

Jeff Sloan, PhD, Mayo Clinic, United States; Brittany Major; Paul J. Novotny; Axel Grothey; Randolph Marks; Daniel Sargent; and Amylou C. Dueck, PhD, Mayo Clinic

(1014) Normative Data and Clinically Significant Effect Sizes for Single-Item Numerical Linear Analogue Self-Assessment (LASA) Scales.

*Jasvinder A. Singh, MD MPH, Univ. of Alabama at Birmingham; Daniel Satele; Suneetha Puttabasavaiah; Jan Buckner; and **Jeff Sloan, PhD, Mayo Clinic, United States***

Cardiovascular

(1016) Impact of a Symptom Management Program on Health-Related Quality of Life for Patients with Heart Failure

*Viviane P. Ferreira; Carina A.M. Dessotte; Rafaela O. Monzato; Luma N. Silva; and Rejane K. Furuya, Univ. of São Paulo; Márcia A. Ciol; and Jeanne M. Hoffman, Univ. of Washington; Lidia A. Rossi, PhD; and **Rosana Spadoti Dantas, PhD, Univ. of São Paulo, Brazil***

(1018) Factors Associated with Quality of Life and Anxiety among Brazilian Patients Undergoing Percutaneous Coronary Intervention

*Liege L S Vieira; Maria Alves Barbosa, PhD; Virginia V. Brasil, PhD; and **Lizete M A C Oliveira, PhD, Federal Univ. of Goias, Goiânia, Brazil**; Isabela C F Fernandes; Karina M. Siqueira; Alcides P S Neto; Katarinne L. Moraes; Carla P. Bernardes; and Jacqueline Andréia B L Cordeiro, Federal Univ. of Goias*

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(1020) A Quality Check of Patient-Reported Outcome Measures for Intermittent Claudication - Room For Improvement!

Anne P. Conijn, MD, Academic Medical Center Amsterdam, Netherlands; Sjoerd Jens, Academic Medical Center Amsterdam; Caroline B. Terwee, PhD, VU Univ. Medical Center; Mark JW Koelemay, Academic Medical Center Amsterdam

(1022) Concepts Most Relevant to Patients with Heart Failure to Inform Clinical Decision Making

Shana Traina, PhD; and Renee F. Pierson, MBA, Janssen Pharmaceutical; Lauren Braam, MIH; Donald M. Bushnell, III, MA, Health Research Associates, Inc.; Kelly P. McCarrier, PhD, MPH; and Mona L. Martin, RN MPA, Health Research Associates, Inc.

(1024) Collection of Health Utility Data in a Clinical Setting: Comparison to a nationally-representative sample

Janel Hanmer, MD PhD, Univ. of Pittsburgh, PA, United States; Rachel Hess, MD; Sarah Sullivan; Jeffrey Teuteberg; Suresh Mulukulta; and Dio Kavalieratos, PhD, Univ. of Pittsburgh

Nephrology/Urology

🏆 (1026) Understanding long-term outcomes in living kidney donors: The impact of health outcomes on Psychosocial Aspects of Kidney Donation

Kathe Meyer, RN MScN, Oslo Univ. Hospital, Oslo, Norway; Marit Helen Andersen, Oslo Univ. Hospital; Astrid K. Wahl, PhD, Univ. of Oslo; Anders Hartmann, Oslo Univ. Hospital; Armon Ayandeh; and Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc

(1028) Sleep Complaints in Dialysis and Kidney Transplanted Patients

Fredrik B. Brekke, Univ. of Oslo, Norway; Nanna Von Der Lippe, Univ. of Oslo; Amin Amro, RN MSN, Oslo Univ. Hospital; Bård Waldum, Univ. of Oslo; Ingrid Os, MD PhD, Univ. of Oslo Medical School

(1030) Health-Related Quality of Life and Clinical and Laboratory Data among Pre Dialysis Patients

Virginia V. Brasil, PhD; and Jacqueline Andréia B L Cordeiro, Federal Univ. of Goias; Antonio Márcio Teodoro Cordeiro, Pontifical Catholic Univ. of Goias; Katarinne L. Moraes; and Luiz Antonio Brasil; Lizete M A C Oliveira, PhD, Federal Univ. of Goias, Brazil; Maria Alves Barbosa, PhD; Isabela C F Fernandes; Rafaela Peres Boaventura; and Gabriela Ferreira De Oliveira, Federal Univ. of Goias

(1032) Usefulness of the Adaptive Measurement of Change in the Assessment of Individual Changes in HRQOL of Hemodialysis Patients

Nacho Castejón, LASER Analytica; Dolores Arenas, Hospital Perpetuo Socorro; Pablo Rebollo, PhD; and Jesús Cuervo, LASER Analytica

(1036) Quality of Life in Patients on Different Peritoneal Dialysis Modalities: A Longitudinal Study in Singapore

Haikel A. Lim, BSocSci(Hons), National Univ. of Singapore; Zhenli Yu, Khoo Teck Puat Hospital; Augustine W. C. Kang, National Univ. of Singapore; Marjorie W. Y. Foo, Singapore General Hospital; Konstadina Griva, National Univ. of Singapore

STUDENT PRESENTATION AWARD FINALIST

Neurology

(1038) Using Multi-Group Confirmatory Factor Analysis to Develop a Cognitive Health-Related Quality of Life Instrument Applicable across Diseases - The COGQOL -

Joy C. Backhaus, Inst. for Medical Psychology and Sociology in Göttingen, Germany; Martin L. Werkmeister, Inst. of Medical Psychology and Medical Sociology; Nicole Von Steinbuechel-Rheinwall, Univ. of Goettingen

(1040) Younger Onset Dementia: An Overview of Service and Research Issues

Janet E. Sansoni, MSc, Univ. of Wollongong, Australia; Cathy Duncan; Pam Grootemaat; Anita Westera; Jacquelin Capell; and Peter Samsa, Univ. of Wollongong

(1042) Generic Preference-Based Measures for use with People with Multiple Sclerosis: Are they Appropriate?

Annie Hawton, Univ. of Exeter Medical School, Exeter, United Kingdom; Colin Green, PhD, Univ. of Exeter Medical School

🏆 (1044) Coping and Quality of Life in a 2-Year Cohort of Patients with Multiple Sclerosis: A Structural Equation Modeling Approach

Mohamed Boucekine, Self-perceived Health Assessment Research Unit, Marseille, France; Anderson Loundou, Self-perceived Health Assessment Research Unit; Pierre Michel, Aix Marseille Université; Jean Pelletier, Timone Univ. Hospital; Patricia Minaya Flores, MA, Laboratoire de Sante Publique; Badih Ghattas, Faculté Des Sciences de Luminy; Laurent Boyer, PhD, Aix-Marseille Univ.; Pascal Auquier, Univ. Hospital of Marseille; Karine Baumstarck, Aix-Marseille Univ.

🏆 Outstanding Poster Abstract Award



SCIENTIFIC PROGRAM

(1046) Predictors of Therapeutic Benefit from Treatment of Parkinson's Disease with Rasagiline in the Real World Setting

Paul Kamudoni, Cardiff Univ., United Kingdom; Biju Muhamed; and Chris Thomas, Rookwood Hospital & Univ. Hospital Wales; Sandip Raha, Princess of Wales Hospital; Samuel Salek, BSc RPh PhD FPPM, Cardiff Univ.

(1050) Quality of Life in Patients with Glaucoma and its Relation with Binocular Visual Field

Olivia Pujol, Parc de Salut Mar, Barcelona, Spain; Clara Mora; Silvia Gudiña; Laia Pastor; Robert Maull; Zaida Vega; and Alfonso Anton, Parc de Salut Mar

(1052) Factors Associated with Self-Rated Health after Lacunar Stroke: Findings from the Secondary Prevention of Small Subcortical Strokes (SPS3) Trial

Carole L. White, PhD, Univ. of Texas Health Science Center at San Antonio, TX, United States; Leslie A. McClure, Univ. of Alabama at Birmingham; Helena Lau, Boston Medical Center; Mandip S. Dhamoon, Mount Sinai School of Medicine; Kamakshi Lakshminarayan, Univ. of Minnesota Medical Center; Donna J. Brauer, PhD, Minnesota State Univ.; Oscar R. Benavente, Univ. of British Columbia

Children

(1056) Unidimensional Colombian Version of Kidscreen-52: A 33-Item New Proposal Applying Rasch Model

Martha J. Rodriguez, Univ. Industrial de Santander, Colombia; Diana M. Camargo Lemos, MSc; and Luis Carlos LC Orozco, Univ. Industrial de Santander

(1058) Measuring Health-Related Quality of Life in Children: Reliability and Validity of the Portuguese Version of the Activities Scale for Kids (ASK)

Luis Manuel Cavalheiro, PhD, Centre for Health Studies and Research of the Univ. of Coimbra, Portugal; Daniela Paixão, Polytechnic Inst. of Coimbra; Rui Soles Goncalves, PhD, Centre for Health Studies and Research of the Univ. of Coimbra; Pedro L. Ferreira, PhD, Univ. of Coimbra

Elderly

(1062) Validation of the Modified Diet-Related Quality of Life Scale for Gerontological Research

Yoshimi Suzukamo, PhD, Tohoku Univ., Japan; Hajime Iwasa, Fukushima Medical Univ.; Yuko Yoshida, Tokyo Metropolitan Inst. of Gerontology

(1064) Interference in Life Quality and Functionality of Elderly with Chronic Pain in São Carlos City, Brazil

Marielli Terassi, Univ. Federal de São Carlos, Brazil; Fernanda Nascimento Costa; and Karina Gramani-Say, Univ. Federal de São Carlos

Health Policy

(1068) Quality of Life for Strategic Planning

Raluca I. Antonie, Babes-Bolyai Univ., Romania; Calin E. Hinte, Babes-Bolyai Univ.

(1070) Patient-Reported Outcome Measurement in Primary Care for People with Long-Term Conditions: Stakeholders Views

Elizabeth J. Gibbons, MSc, Univ. of Oxford, United Kingdom; Crispin Jenkinson, Health Services Research Unit; Raymond Fitzpatrick, PhD; and Michele Peters, PhD, Univ. of Oxford

(1072) The Effect of Tailored Sasang Constitution Healthcare Program for Vietnamese

Jonghyang Yoo, Korea Institute of Oriental Medicine, Daejeon, Korea; Jihye Kwon, Korea Institute of Oriental Medicine

Patient-Centered Research

(1074) PRO/QOL-Related Articles by Clinical Specialty

Kikuko Miyazaki, PhD, Kyoto Univ., Japan; Miwa Hinata; Toshimitsu Ikeuchi; and Takeo Nakayama, MD PhD,

(1076) Is the Vignette Method used to Assess Quality of Life in Practice?

Monika Szkultecka-Debek, Military Inst. of Medicine; Mariola Drozd, Medical Univ. of Lublin, Poland; Marta Bem, Warsaw Univ. of Life Sciences

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(1078) Patient-Reported Outcome (PRO) Assessment in Clinical Trials: A Systematic Review of Guidance for Trial Protocol Writers

Melanie Calvert, PhD, Univ. of Birmingham, United Kingdom; Derek Kyte, MSc; Helen Duffy; and Adrian Gheorghe, Univ. of Birmingham; Rebecca L. Mercieca-Bebber, Univ. of Sydney; Jonathan CS Ives, PhD; and Heather Draper, Univ. of Birmingham; Michael Brundage, MD, Queen's Univ.; Jane Blazeby, MD, Univ. of Bristol; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG)

(1080) Feasibility of Patient Reporting of Symptomatic Adverse Events via the PRO-CTCAE in a Radiation Therapy Oncology Group (RTOG) Cooperative Group Clinical Trial

Ethan Basch, MD, Univ. of North Carolina at Chapel Hill; Stephanie L. Pugh, NRG Oncology Statistics and Data Management Center; Amylou C. Dueck, PhD, Mayo Clinic; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Lawrence Berk, MD PhD, Univ. of South Florida; Lauren Rogak, MA, MSKCC; Marcha Gatewood, Emory Univ.; Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill; Tito R. Mendoza, PhD, Univ. of Texas MD Anderson Cancer Ctr.; Ann O'Mara, PhD; Andrea Denicoff, RN MS; and Lori Minasian, MD, National Cancer Institute; Shannon Fogh, MD, Univ. of California San Francisco; Kevin Roof, MD, Southeast Cancer Control Consortium, Inc. CCOP; Joan K Moore, RN, York Cancer Center; Thomas Gergel, MD, Geisinger Medical Center CCOP; Kevin Stephans, MD, Cleveland Clinic Foundation; Andreas Rimner, MD, MSKCC; Albert DeNittis, MD, Main Line CCOP; Deborah W. Bruner, RN, PhD, FAAN, Emory Univ.

🦋 (1082) Patient-Reported Outcome (PRO) Assessment in Multiple Myeloma (MM): A Review of Cancer-Specific PROs According to Food and Drug Administration (FDA) PRO Guidance Criteria

Colleen A. McHorney, Covance Market Access, Inc., United States; Andrew Palsgrove; and Bhumi Trivedi, Covance; William B. Jones; and Peter Trask, Sanofi

Statistical Analysis of PROs

(1084) Assessing Oral Health-related Quality of life and Missing Data using OHIP-14

Manoharan Andiappan, King's College London, United Kingdom; Stephen Dunne; and Nora Donaldson, King's College London

(1086) The Functional Assessment of Cancer Therapy – Prostate (FACT-P) & Trial Outcomes Index (TOI): A Rasch analysis

Adam B. Smith, York Health Economics Consortium, Univ. of York, United Kingdom; Kim Cocks, Univ. of York; David Parry, AstraZeneca Pharmaceuticals Ltd; Matthew Taylor, York Health Economics Consortium

🦋 (1088) Differential Item Functioning in the SF-36 Physical Functioning and Mental Health Sub-Scales: A Population-Based Analysis from Canada

Lisa M. Lix, Univ. of Manitoba, Winnipeg, Canada; Xiuyun Wu, Univ. of Manitoba; Wilma Hopman, Kingston General Hospital; Nancy E. Mayo, PhD, McGill Univ. Health Centre; Tolulope T. Sajobi, PhD, Univ. of Calgary; Juxin Liu, Univ. of Saskatchewan; Richard Sawatzky, PhD RN, Trinity Western Univ.

(1090) Power and Type-I-Error of Global Assessment of Response Shift Occurrence using Likelihood-Ratio Test or Information Criteria in Oort's Procedure: A Simulation Study

Antoine Vanier, MD, Univ. Pierre Et Marie Curie, Paris, France; Veronique Sebille, ScD; Myriam Blanchin; Alice Guilleux; and Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes

Measure Development

(1092) Development of Patient-Reported Outcomes Measure of Pharmaceutical Therapy for Quality of Life (PROMPT-QoL)

Phantipa Sakthong, PhD, Chulalongkorn Univ., Bangkok, Thailand; Phattrapa Suksanga; and Rungpetch Sakulbumrungsil, Chulalongkorn Univ.; Win Winit-Watjana, Univ. of Dammam

(1094) The Validity Study for the Development of Health-Related Questionnaire - Korea

Eunsu Jang, Korea Institution of Oriental Medicine, Daejeon, Korea; Siwoo Lee; Younghwa Baek; and Kihyun Park, Korea Institute of Oriental Medicine



SCIENTIFIC PROGRAM

(1096) Core Outcome Measures in Effectiveness Trials (COMET) Initiative: An International Delphi Study to Achieve Consensus on How to Select Outcome Measurement Instruments for Outcomes Included in a 'Core Outcome Set'

Cecilia AC Prinsen, VU Univ. Medical Center, Amsterdam, Netherlands; Sunita Vohra, Univ. of Alberta; Michael R. Rose, King's College Hospital, London; Caroline B. Terwee, PhD, VU Univ. Medical Center

(1098) Cognitive Debriefing of Clinical Outcomes Assessment Questionnaires with Subjects Aged 65 and Older

Matthew Talbert; Barbara A. Brandt, MA; and Shawn McKown, MA, Corporate Translations, Inc., United States; Mary C. Gawlicki, MBA, Corporate Translations, Inc.,

(1100) Development and Validation of a Single Item Screener for Self-Reported Sexual Problems

Kathryn E. Flynn, PhD, Medical College of Wisconsin, United States; Stacy T. Lindau, Univ. of Chicago; Li Lin, Duke Clinical Research Inst.; Jeanne Carter, MSKCC; Diana Jeffery, Department of Defense; Jennifer B. Reese, Johns Hopkins Univ. School of Medicine; Emily M. Abramsohn, Univ. of Chicago; Kevin P. Weinfurt, PhD, Duke Clinical Research Inst.

(1102) Experience of Pain in Patients with Moderate to Severe Plaque Psoriasis

Dennis Revicki, PhD, Evidera, United States; Hilary D. Wilson, Evidera; Lionel A. Pinto; and Hema Viswanathan, Amgen, Inc.

(1106) Establishing the Conditions for the Development of a PROM for Children and Adolescents Born with Esophageal Atresia.

Michaela Dellenmark Blom, PhD-student, Queen Silvia Children's Hospital, Sweden; Kate Abrahamsson, MD; and John E. Chaplin, PhD AFBPs C.Psychol, Sahlgrenska Academy at the Univ. of Gothenburg

(1108) Validation of a New Disease-Specific ePRO Measure to Support Dysmenorrhea Clinical Trials: The Dysmenorrhea Daily Diary (DysDD)

Josephine M. Norquist, MS, Merck Sharp & Dohme Corp., PA, United States; Tjeerd Korver; and Fang Chen, Merck & Co., Inc.; Rob Arbuckle; and Alice Turnbull, Adelphi Values; Allison M. Nguyen, Merck & Co., Inc.

(1110) Assessing Patient-Reported Impact of Endometriosis Pain using a 7-day versus Daily Recall Period

Adam Gater, Adelphi Values Ltd; Kamonthip Wichmann, Bayer Pharma AG; Christian Seitz, Bayer Healthcare; Christopher Gerlinger, Bayer Pharma AG; Wen-Hung Chen, RTI; Anna Filonenko, Bayer Pharma AG

4:00 pm – 5:30 pm

Concurrent Oral Sessions

Oral Session 106: New Measures and Methods I: Development & Evaluation

SALON 2

Session Chair: Leo Morales, MD PhD, United States

4:05 – 4:18 pm (106.1) Preliminary Validity Evidence for the PROMIS® Smoking Assessment System

Maria O. Edelen, PhD; and Brian D. Stucky, PhD, RAND Corporation, United States; and Joan S. Tucker, RAND Corporation; Mark Hansen, UCLA-CRESST; William Shadel, RAND Corporation

4:19 – 4:32 pm (106.2) Replication and Relative Validity of the Mental and Physical Higher Order Model of the EORTC QLQ-C30

Jacobien M. Kieffer, PhD, The Netherlands Cancer Institute; Johannes M. Giesinger, PhD, Innsbruck Medical Univ., Austria; Peter Fayers, PhD, Univ. of Aberdeen; Mogens Groenvold, MD PhD, Univ. of Copenhagen; Morten Aa Petersen, MScI, Bispedjerg Hospital; Neil W. Scott, MA MSc PhD, Univ. of Aberdeen; Mirjam AG Sprangers, PhD, Academic Medical Center; Galina Velikova, MD PhD FRCP, Univ. of Leeds; Neil K. Aaronson, PhD, The Netherlands Cancer Institute

4:33 – 4:46 pm (106.3) The Minimally Important Difference for Better Interpretation of Patient-Reported Outcome Measures in Patients with Intermittent Claudication

Anne P. Conijn, MD, Academic Medical Center Amsterdam, Netherlands; Wilma Jonkers, Achmea Insurances.; Ellen V. Rouwet, Erasmus Medical Center Rotterdam; Anco Vahl, OLVG Amsterdam; Mark JW Koelemay, Academic Medical Center Amsterdam

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4:47 – 5:00 pm (106.4) Minimal Clinically Important Difference (MCID) Calculated Using the Standard Error of the Measurement (SEM) May Vary as a Function of the Patient Population

Arlene S. Swern, PhD, Celgene Corporation, United States; Mikkael A. Sekeres, Cleveland Clinic Taussig Cancer Institute; Chengqing Wu; and Mary M. Sugrue, Celgene Corporation

5:01 – 5:14 pm (106.5) Normative Data and Clinically Significant Effect Sizes for Single-Item Numerical Linear Analogue Self-Assessment (LASA) Scales

Jasvinder A. Singh, MD MPH, Univ. of Alabama at Birmingham; Dona EC Locke; Daniel Satele; Suneetha Puttabasavaiah; Jan Buckner; Jeff Sloan, PhD; and Brittny Major, Mayo Clinic, United States

5:15 – 5:28 pm (106.6) Multiple Imputation of Missing Values in Studies with Many Multi-Questionnaire Outcomes

Iris Eekhout, VU Univ. Medical Center, Amsterdam, Netherlands; Henrica C.W. de Vet, Sr., PhD; Michiel R. De Boer; Jos WR Twisk; and Martijn W. Heymans, VU Univ. Medical Center

Oral Session 107: Transforming Clinical Practice

HALL I - A

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

4:05 – 4:18 pm (107.1) AmbuFlex – Experiences of PRO Based Decisions in Clinical Practice

Liv Marit Valen Schougaard, VestKronik, Regional Hospital West Jutland, Denmark; Louise Pape Larsen, WestChronic; Anne Jessen, WestChronic; Niels Henrik Hjollund, Aarhus Univ. Hospital

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

4:19 – 4:32 pm (107.2) Using Patient-reported Outcomes (PROs) to Inform Interdisciplinary Team Clinical Decision-Making: Clinicians' Perceived Benefits and Challenges

Sara Ahmed, PhD, McGill Univ., Montreal, Canada; Owis J. Eilayyan; Patrick Ware; and Amede Gogovor, McGill Univ.; Roderick Finlayson; and Regina Visca, McGill Univ. Health Center

4:33 – 4:46 pm (107.3) Using a Patient-Reported Outcome Measure in Chemotherapy Review Consultations: The Impact of an Interactive Doctor Training Session

Kate Absolom, PhD, Univ. of Leeds, United Kingdom; Elena Takeuchi; Lorraine Warrington; Patricia Holch, PhD; Ceri Hector; and Emma Ingleson, Univ. of Leeds; Lucy Kenyon, Leeds Teaching Hospitals NHS Trust; Galina Velikova, MD PhD FRCP, Univ. of Leeds

4:47 – 5:00 pm (107.4) What Can Content Analysis of the Medical Record tell us about Physician-Patient Communication?

Joel Finkelstein, MD, Sunnybrook Health Sciences Ctr, Toronto, Canada; Armon Ayandeh, DeltaQuest Foundation; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc.,

5:01 – 5:14 pm (107.5) Development and Pre-testing of a Communication-Specific EORTC Questionnaire

Juan Ignacio Arraras, PhD, Servicio Navarro de Salud, Spain; Anne Bredart, PhD, Institut Curie; Anna Costantini, Sant'Andrea Hospital, Sapienza Univ. of Rome; Dirk Hofmeister, Univ. of Leipzig; Meropi Kontogianni, Harokopio Univ., Athens; Monika J. Sztankay, Innsbruck Medical Univ.; Krzysztof Tomaszewski, Jagiellonian Univ. Medical College; Iwona M Tomaszewska, Jagiellonian Univ. Medical College; Lisa M. Wintner, Innsbruck Medical Univ.; Wei-Chu Chie, PhD, Nat'l Taiwan Univ.; Eva Greimel, PhD, Medical Univ. Graz; Michael Koller, PhD, Univ. Hospital Regensburg; Karin Kuljanic, Univ. Hospital Center; Dagmara Kulis, EORTC QoL Unit.; Astrid Helene Liavaag, Sørlandets Sykehus; Andrea Talacchi, Univ. of Verona, Italy; Teresa Young, BSc, Mount Vernon Hospital, London

5:15 – 5:28 pm (107.6) An Educational Program to Improve Self-Care in Brazilian Patients who Underwent Percutaneous Coronary Intervention: A Randomized Controlled Trial

Rejane K. Furuya, Univ. of São Paulo, Brazil; Eliana C. Arantes; and Carina A.M. Dessotte, Univ. of São Paulo; Márcia A. Ciol; and Jeanne M. Hoffman, Univ. of Washington; André Schmidt; Rosana Spadoti Dantas, PhD; and Lidia A. Rossi, PhD, Univ. of São Paulo

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 Outstanding Poster Abstract Award

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Oral Session 108: Advancing Utility Assessments

HALL I - B

Session Chair: Pedro L. Ferreira, PhD, Portugal

4:05 – 4:18 pm (108.1) The Development of Cancer-Specific Multi-Attribute Utility Instruments from the EORTC QLQ-C30 and FACT-G

Daniel S. J. Costa, PhD, Psycho-oncology Co-operative Research Group (PoCoG), Sydney, Australia; Madeleine T. King, PhD, PoCoG; Neil K. Aaronson, PhD, The Netherlands Cancer Institute; John E. Brazier, PhD, Univ. of Sheffield; David Cella, PhD, Northwestern Univ.; Peter Grimison, Chris O'Brien Lifehouse and Univ. of Sydney; Monika Janda, PhD, Brisbane, Australia; Helen McTaggart-Cowan, PhD, Canadian Centre for Applied Research in Cancer Control; A Simon Pickard, Univ. of Illinois at Chicago; Rob Arbuckle, Adelphi Values

4:19 – 4:32 pm (108.2) Valuing a utility instrument derived from the EORTC QLQ-C30 (QLU-C10D): Feasibility and Respondent Preference for Presentation of 10 Domains in a Discrete Choice Experiment (DCE)

Richard Norman, PhD; and Rosalie Viney, PhD, Univ. of Technology Sydney; Daniel Costa, PhD, PoCoG, Univ. of Sydney; Neil Aaronson, PhD, The Netherlands Cancer Institute; David Cella, PhD, Northwestern Univ.; Peter Fayers, PhD, Univ. of Aberdeen, and Norwegian Univ. of Science and Technology; Georg Kemmler, PhD, Innsbruck Medical Univ.; A. Simon Pickard, PhD, Univ. of Illinois at Chicago; Deborah Street, Univ. of Technology Sydney; Galina Velikova, MD PhD FRCP, Univ. of Leeds; Tracey Young, PhD MSc BSc CStat, Univ. of Sheffield; Madeleine T King, PhD, Psycho-oncology Co-operative Research Group (PoCoG), Univ. of Sydney, Australia on behalf of the MAUCA Consortium

4:33 – 4:46 pm (108.3) Retrospective Calculation of Disease-Specific Utilities for Cancer Patients – A Demonstration of its use Based on the EORTC QLQ-C30

Georg Kemmler, PhD, Innsbruck Medical Univ., Austria; Eva-Maria Gamper, Innsbruck Medical Univ.; Johannes Giesinger, Netherlands Cancer Institute; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG); Bernhard Holzner, PhD BE, Univ. Hospital Innsbruck,

4:47 – 5:00 pm (108.4) States Selection on the Valuation of EQ-5D-3L. Brazilian study

Andréa L. Monteiro, MSc, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil; Monica A C T Cintra, MD PhD; Bernardo R. Tura; and Bráulio Santos, National Institute of Cardiology; Monica V. Andrade; and Kenya Noronha, Universidade Federal de Minas Gerais; Luciane N. Cruz, MD PhD; and Suzy A. Camey, Federal Univ. of Rio Grande do Sul; Marisa Santos, MD, Instituto Nacional de Cardiologia

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

(108.5) WITHDRAWN

5:01 – 5:14 pm (108.6) Comparing and Assessing the Performance of the EQ-5D-3L and the EQ-5D-5L in Young Adults

Pedro L. Ferreira, PhD, Univ. of Coimbra, Portugal; Lara N. Ferreira, PhD, CEISUC-Centre for Health Studies & Research, Univ. of Coimbra, Portugal; Luis N. Pereira, Univ. of the Algarve-ESGHT; CIEO; Filipa Perdigão, CSSL/ESGHT

Oral Session 109: New Measures and Methods II: Interpretation & Implementation

SALON 4

Session Chair: Maria-Jose Santana, MPharm, PhD, Canada

4:05 – 4:18 pm (109.1) Conducting Meaningful Cognitive Debriefing Interviews for Patient-Reported Outcome Assessment: Theory and Practice

Bhumi Trivedi; Andrew Palsgrove; Rebecca Cheng; Colleen A. McHorney; and Jason C. Cole, PhD, Covance Market Access Services

4:19 – 4:32 pm (109.2) From Conceptual Framework to Questionnaire: Cognitive Testing a New Measure of Patient Treatment Burden

David T. Eton, PhD, Mayo Clinic, United States; Kathleen J. Yost, PhD; Jennifer L. Ridgeway; and Jason S. Egginton, Mayo Clinic; Mark Linzer; and Deborah Boehm, Hennepin County Medical Center; Sara Poplau, Minneapolis Medical Research Foundation; Laura Odell, Mayo Clinic; Roger Anderson, PhD, Penn State Hershey

4:33 – 4:46 pm (109.3) Measuring Physical Abilities by Self-Report: An Approach Based on the Activity Space Model

Jacek Kopec, PhD, Univ. of British Columbia, Canada; Lara Russell, Providence Health Care Research Institute; Eric C. Sayre, PhD; and M. Mushfiqur Rahman, Arthritis Research Centre of Canada

 Outstanding Poster Abstract Award

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4:47 – 5:00 pm (109.4) A New Perspective on Proxy Report: Implicit Processes of Understanding and Neurological Reserve

Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., United States; Armon Ayandeh, DeltaQuest Foundation; Jonathan D. Rodgers, Univ. of Buffalo; Paul Duberstein, Univ. of Rochester Medical Center; Bianca Weinstock-Guttman; and Ralph HB Benedict, Univ. of Buffalo

5:01 – 5:14 pm (109.5) Update of the COSMIN Checklist for Evaluating the Methodological Quality of Studies on Measurement Properties

Caroline B. Terwee, PhD, VU Univ. Medical Center, Amsterdam, Netherlands; Cecilia AC Prinsen; Henrica C.W. de Vet, Sr., PhD; and Lidwine B. Mokkink, VU Univ. Medical Center

5:15 – 5:28 pm (109.6) An Updated Guideline for Systematic Reviews of Measurement Instruments

Cecilia AC Prinsen, VU Univ. Medical Center, Amsterdam, Netherlands; Lidwine B. Mokkink; Henrica C.W. de Vet, Sr., PhD; and Caroline B. Terwee, PhD, VU Univ. Medical Center

6:00 pm – 7:30 pm

Mentor/Mentee Reception and Tricks of the Trade

HALL I – C

6:00 pm – 6:25 pm Tricks of the Trade –Advice for New Investigators in Quality of Life Research

Join the invited panelists, as they share their career development stories; offer advice to New Investigators and answer questions on how to develop a career in QoL research. Panelists will also discuss their predictions on future directions on QoL research. The session will start with individual presentations, and will be followed by lively discussion between the panelists and the audience.

Panelists:

*Carolyn Schwartz, ScD, DeltaQuest Foundation, Inc.; and Medicine and Orthopaedic Surgery, Tufts Univ. Medical School, United States
Galina Velikova, MD PhD FRCP, St James's Institute of Oncology, St James's Hospital, United Kingdom*

The “Tricks of the Trade” is intended for New Investigators, but all conference attendees are welcome to attend and to contribute to the discussions. There will be a brief intermission immediately following the Tricks of the Trade panel in order to segue into the Mentor/Mentee Reception.

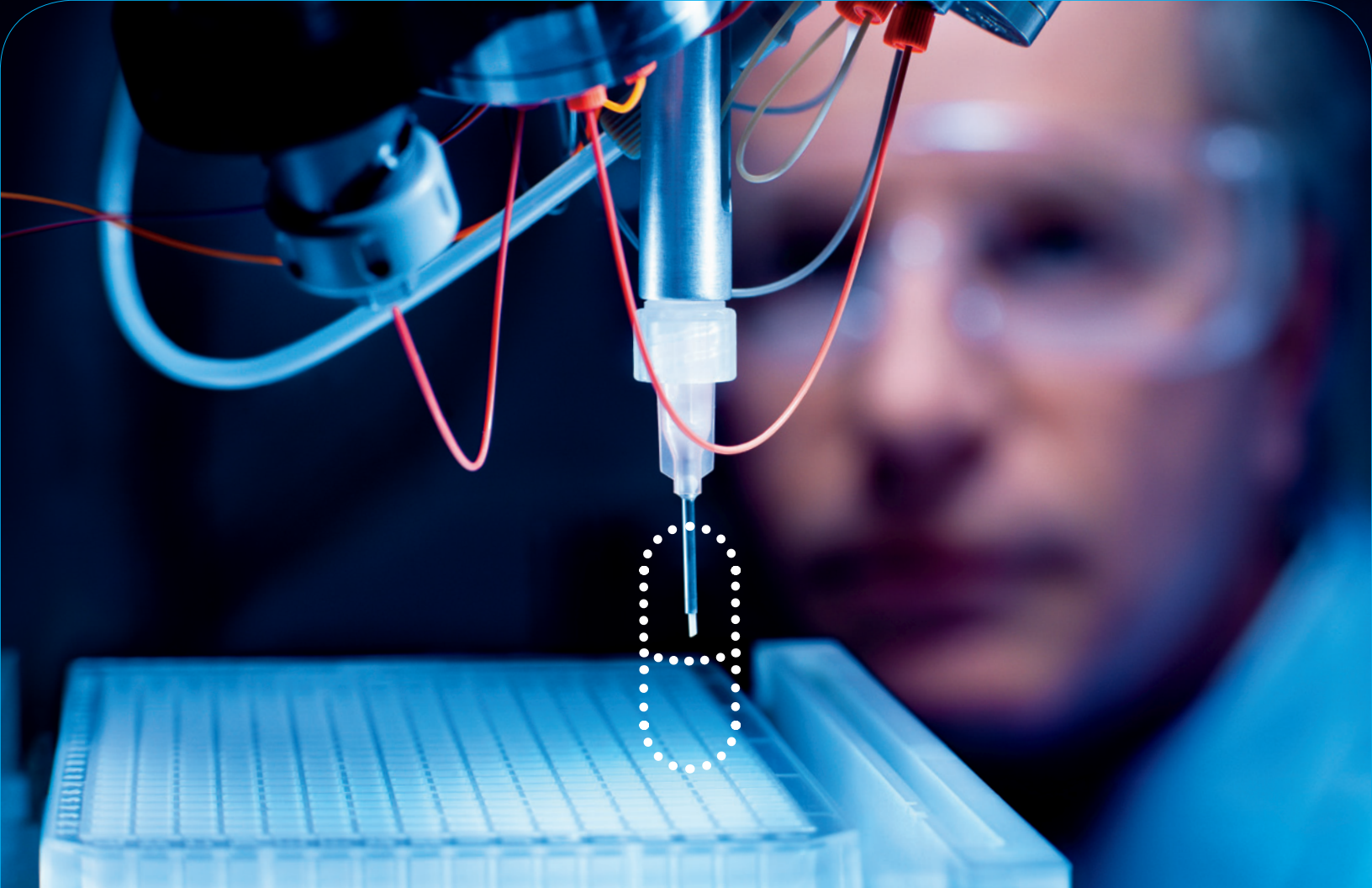
6:30 pm – 7:30 pm Mentor/Mentee Reception

Pre-registration is required for the Mentor/Mentee Reception.

The ISOQOL mentoring program promotes career development and provides networking opportunities for students and new investigators within the society. Individuals interested in serving as a Mentor will be paired up with students and new investigators that have signed up for the program as Mentees. This reception provides a forum for the exchange of knowledge in a relaxed atmosphere. Refreshments will be provided.

Thursday, 16 October





Inspiration

Breakthrough cancer treatments often begin with a spark of insight, but your patients are the true inspiration for what we do. We're focused on translating potential into promise for those who need it most.

Focused on what truly matters.



SCIENTIFIC PROGRAM

Friday, 17 October

7:00 am – 5:00 pm Registration Desk Open

7:30 am – 8:45 am Committee & Special Interest Group (SIG) Meetings

Protocol Checklist Development Team Meeting SALON 3

Health Preference Research SIG Meeting SALON 2

Patient Engagement SIG Meeting HALL I - C

Response Shift SIG Meeting SALON 4

9:00 am – 10:30 am Integrating Patients into PRO Development and Research HALL I - AB

Plenary session sponsored by EORTC.

PROs provide unique information from the patients' perspective on symptoms experienced, the impact on social, emotional and physical function, as well as how an illness and its treatment affects quality of life. Involving patients in the conceptualization, development and testing of new PROs is critical to ensuring they capture the core aspects that matter most to patients living with health conditions.

This plenary session will offer perspectives from researchers, patients and other stakeholders on how to integrate patients into all aspects of PRO development and research from inception through implementation in trials and care settings. Speakers are recognized leaders who will offer lessons learned from their own work and that of others on optimal strategies for collaborating with patients as research partners and creating policy that supports patient-centered health outcomes measurement.

Speakers

John Kirwan, BSc MD FRCP, Univ. of Bristol; Consultant Rheumatologist, Univ. Hospitals; Bristol NHS Foundation Trust, United Kingdom

Maarten de Wit, PhD, VU University, Amsterdam, Netherlands

Lori Frank, PhD, PCORI - Patient-Centered Outcomes Research Institute, Washington, DC, United States

Plenary chaired by **Susan Bartlett, PhD**, McGill University, Montreal, Canada **and Francis Guillemin, MD PhD**, Ecole de Sante Publique - Lorraine University, Nancy, France

10:00 am – 5:00 pm Poster Hall Open Hall II

10:30 am – 11:15 am Exhibits Open and Refreshment Break

10:45 am – 11:05 am Friday Poster Session 1 Hall II

Cancer

(2001) The Impact of Demographic, Medical and Nutritional Factors on Quality of Life in Advanced Cancer Patients

Shulamith Kreitler, Tel-Aviv Univ., Israel; Frida Barak, Barzilai Medical Center; Nava Danieli-Siegelman, Maccabi Health Service; Arie Ostrowsky, Leumit Health Service; Yasmin Alkalay, Tel-Aviv Univ.

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(2003) Distress, Problems, and Wish for Referral in Esophageal Cancer Patients Prior to Treatment

Marc Jacobs, Academic Medical Center, Amsterdam, Netherlands; Maarten C.J. Andereg; Annuska Schoorlemmer; Estelle M. Altena; Ellen M. Smets; Mirjam AG Sprangers, PhD; Mark I. Van Berge Henegouwen; Hanneke C.J.M. De Haes; and Jean H.G. Klinkenbijn, Academic Medical Center

(2005) QOL Assessments in Clinical Practice: Usefulness of ERORTC-QLQC-30 and the SEIQOL

Lena Ring, PhD, Medical Products Agency (MPA) and Uppsala Univ., Sweden; Lena Wettergren, PhD, Karolinska Institutet; Hanna Fagerlind, The Swedish Agency for Health and Care Services Analysis; Bengt Glimelius, Mathilde Hedlund Lindberg; and Åsa Kettis, Uppsala Univ.

(2007) Enhancing Standards and Ensuring Good Long-Term Use of Data in Quality of Life

Research: An Update on the EORTC QLG Data Repository Project

Francesca Martinelli, MSc, EORTC, Brussels, Belgium; Deborah Fitzsimmons, Swansea Univ.; Colin Johnson, MChir, Dept of Surgery, Southampton; Galina Velikova, MD PhD FRCP, Univ. of Leeds; Mogens Groenvold, MD PhD, Univ. of Copenhagen; Andrew Bottomley, PhD, EORTC Headquarters

(2009) EORTC QLQ-C30 Transversal and Longitudinal Analyses with STATA Procedures

Caroline Bascoul-Mollevi, ICM | Val d'Aurelle, Montpellier, France; Antoine Barbieri, ICM - Val d'Aurelle; Amélie Anota, Quality of Life in Oncology Platform, France; Marion Savina, Institut Bergonié; David Azria, ICM | Val d'Aurelle; Franck Bonnetain, PhD, Univ. Hospital of Besançon; Sophie Gourguou-Bourgade, CRLC Val d'Aurelle

(2013) Development of an Adherence to Iron-Chelation Therapy Measure Through a Qualitative Study: Patient and Caregiver Perspectives in Transfusion-Dependent Anemias and Myelodysplastic Syndrome

Kathryn E. Lasch, PhD, Pharmerit International, United States; Erica G. Horodniceanu, Pharmerit International; Vasudha Bal; Isabelle Cote; Amy Dorgan; and Isabelle Malet, Novartis Pharmaceuticals Corporation

Musculoskeletal/Rheumatology

(2015) Humanistic Burden of Disease in Rheumatoid and Psoriatic Arthritis: A Qualitative Synthesis

Stacie Hudgens, MA (AbD), Clinical Outcomes Solutions; Aki Shiozawa, Takeda Pharmaceuticals International, Inc, United States; Michael Hagan, Takeda Pharmaceuticals International

(2017) A Spanish Validation of the ASES-p Questionnaire for Shoulder Pathologies

Kalliopi Vrotsou, MSc, Osakidetza, Donostia-San Sebastian, Spain; Antonio Escobar, PhD MD, Hospital Universitario Basurto; Ricardo Cuellar, Donostia Univ. Hospital; Miguel Angel Rodriguez, Cruces Univ. Hospital; Gorka Busto, Mendaro Hospital; Daniel Garay, Galdakao Hospital; Felix Silio, Basurto Univ. Hospital; Ziortza Trancho, Hospital Universitario Basurto

(2019) Quality of Life is Not a Predictor of Long-Term Mortality in Patients with Low-Energy Hip Fractures!

Gudrun Rohde, PhD, Univ. of Agder, Kristiansand, Norway; Andreas P. Diamantopoulos; and Glenn Haugeberg, Sorlandet Hospital

(2021) Gender Based Differences in Experiences of Patients Receiving Pain Medications in Carpal Tunnel Release

Vanitha Arumugam, PT, MPT, Univ. of Western Ontario, Canada; Joy MacDermid, PhD; Margaret Lomotam; and Kathryn Corbett, McMaster Univ.

(2025) Racial Differences in Quality of Life in Patients with Gout

Jasvinder A. Singh, MD MPH, Univ. of Alabama at Birmingham; Puja Khanna, Univ. of Michigan; Cleopatra Aquino-Beaton; and Jay E. Persselin, VA Greater Los Angeles Healthcare System; Erin Duffy; and David Elashoff, Univ. of California Los Angeles; Dinesh Khanna, MD MS, Univ. of Cincinnati; Brittny Major, Mayo Clinic, United States

Nephrology/Urology

(2027) A Systematic Review of Health-Related Quality of Life and Patient Preferences in Patients with Urinary Stone Disease

Zara Hekmati, Welsh School of Pharmacy; Aditya Raja, Univ. Hospital of Wales; Hrishi Joshi; and Sam Salek, BSc RPh PhD FFPM, Cardiff Univ., United Kingdom

 Outstanding Poster Abstract Award

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(2029) Influence of Smoking in the Bacterial Resistance and the Quality of Life of Women Treated because of Recurrent Urinary Infections

Bárbara Padilla-Fernández, Univ. Hospital of the Canary Islands (Tenerife), Spain; Álvaro Julio Virseda-Rodríguez; María Tatiana Santos-Antunes; María Begoña García-Cenador; José Antonio Mirón-Canelo; and María Fernanda Lorenzo-Gómez, Univ. of Salamanca; Bárbara Padilla-Fernández, Univ. Hospital of the Canary Islands (Tenerife)

Rehabilitation

(2033) Measuring Patient-Specific Complaints in Physiotherapy Goal Setting. What are the Patients' Experiences?

Anita Stevens; and Anna Beurskens, PhD, Zuyd Univ. of Applied Science, Netherlands; Albere Köke; and Albine Moser, Zuyd Univ. of Applied Sciences; Trudy Van Der Weijden, Maastricht Univ.,

(2037) Randomized Controlled Clinical Trial on Telephone Follow-Up in Rehabilitation of Burn Patients: Impact on Health Status

Natália Gonçalves; and Rosana Spadoti Dantas, PhD, Univ. of São Paulo; Márcia A. Ciol, Univ. of Washington; Jayme A. Farina-Junior; Noelle O. Freitas; Marina Caltran; and Lidia A. Rossi, PhD, Univ. of São Paulo, Brazil

Quality of Care/Patient Satisfaction

(2041) Validating the Spanish Version of the Nursing Homes Survey on Patient Safety

Kalliopi Vrotsou, MSc, Osakidetza, Donostia-San Sebastian, Spain; Mónica Machón; and Carmen Silvestre, Osakidetza; Pastora Pérez, Sanitary Quality Agency of Andalucía; Gorra Alias, Matia Fundazioa - Matia Gerontologic Institute; Enrique Peiro, Osakidetza; Lena Ferrús, Consorci Sanitary Integral; Naroa Amiama; and Inés Gamio, Matia Fundazioa - Matia Gerontologic Institute; Itziar Vergara, Osakidetza

(2043) Development and Psychometric Testing of a Barriers to HIV Testing Scale in a Swedish context

Lars E. Eriksson, PhD, Karolinska Institutet, Sweden; Maria Wiklander, PhD; Johanna Brännström; and Veronica Svedhem-Johansson, Karolinska Institutet

(2045) Self-Reporting Hand-Foot Syndrome (HFS) is Practical in Cancer Patients with Chemotherapy-Induced Dermatological Toxicity

Tatiana I. Ionova, Multinational Center for Quality of Life Research, St. Petersburg, Russian Federation; Denis A. Fedorenko, PhD, National Medical Surgical Center, Moscow; Tatiana Nikitina, PhD; and Kira Kurbatova, Multinational Center for Quality of Life Research, Saint-Petersburg

Caregivers

(2049) Quality of Life among Parents of Adult Patients with Congenital Heart Disease

Misa Takegami, RN PhD, MPH, National Cerebral and Cardiovascular Center, Japan; Kenji Yasuda, Shimane Univ.; Hideo Ohuchi; Jun Negishi; Kanae Noritake; Aya Miyazaki; Osamu Yamada; Yoshihiro Miyamoto; and Isao Shiraishi, National Cerebral and Cardiovascular Center

(2051) Validation of the TranQoL Parental Burden Measure: a New Tool for Parents of Children with Thalassemia Major

Robert Klaassen, MD, Children's Hospital of Eastern Ontario, Canada; Nicholas Barrowman, Children's Hospital of Eastern Ontario Research Institute; Manuela Merelles-Pulcini, Hospital for Sick Children; Elliott P. Vichinsky, Children's Hospital Oakland Research Institute; Melanie Kirby-Allen, Hospital for Sick Children; Ellis Neufeld, Boston Children's Hospital; Janet Kwiatkowski, Children's Hospital of Philadelphia; John Wu, British Columbia Children's Hospital; Victor Blanchette, Hospital for Sick Children; Nancy L. Young, PhD, Laurentian Univ.

(2053) The Quality of Life of Family Caregivers of Cancer Patients: A Comparison between Caregivers of Patients in Ambulatory and Home Hospice Care Settings in Singapore

Haikel A. Lim, BSocSci(Hons), National Univ. of Singapore; Konstadina Griva; Mabel Q. H. Leow; Moon Fai Chan; Sally W. C. Chan; and Rathi Mahendran, National Univ. of Singapore

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(2055) The Cultural Dimension of Quality of Life and Religious Experiences of Hispanic Family Caregivers of Patients with Advanced Cancer

Gloria Juarez, PhD RN MSN, City of Hope; Joan J. Branin, PhD, Univ. of La Verne, CA, United States

(2057) Quality of Life of Informal Caregivers of Patients in the Terminal Stage of Cancer at Home in Brazil

Maria Alves Barbosa, PhD, Federal Univ. of Goiás, Goiânia, Brazil; Antônio Gomes Teles; Marinésia Aparecida Prado; Isabela C F Fernandes; Neuma Chaveiro; Cláudia Zanini; Virginia V. Brasil, PhD; and Lizete M A C Oliveira, PhD, Federal Univ. of Goiás

Children

(2059) Quality of Life in Chronically Ill Children: First Results from Clinical Application of the Computer Adaptive Test Kids-CAT.

Marcus O. Klein, Univ. Hospital Schleswig-Holstein, Kiel, Germany; Ute Thyen, MD, Universitaetsklinikum Schleswig-Holstein; Dana Barthel; Christiane Otto; Kirsten Gulau; Sigrid Reisinger; and Michaela Dabs, Univ. Medical Center Hamburg-Eppendorf; Matthias Rose, MD PhD, Charité; Sandra Nolte, PhD, Charité; Ulrike Ravens-Sieberer, MPH, Univ. Medical Center Hamburg-Eppendorf

(2061) A Validity Driven Approach to the comprehension of the Impact of Low Vision on the Lives of Children and Adolescents: The Development of the Participation and Activity Inventory for Children and Youth

Linda Rainey, VU Univ. Medical Center, Amsterdam, Netherlands; Ruth Van Nispen, PhD; Lisette M. Van Leeuwen, MSc; and Ger Van Rens, VU Univ. Medical Center

(2063) Improving Health-Related Quality of Life in Children, Adolescents and Young Adults with Achondroplasia

Julia Hannah Quitmann, Univ. Medical Center Hamburg-Eppendorf, Germany; Anja Rohenkohl; and Rachel Sommer, Univ. Medical Center Hamburg-Eppendorf; Sabine Kahrs; Karl-Heinz Klingebiel; and Ruzena Klingebiel, German Association for People of Short Stature and their Families; Monika Bullinger, PhD, Hamburg Univ.

(2067) Is There Any Possibility to Improve the Quality of Life in Children with Atopic Dermatitis besides Medical Treatment?

Yusuke Tanaka, Japanese Society of Quality of Life Research, Japan; Sho Matsui; Ryo Yoshioka; Kazunori Tanaka, PhD; Yuto Hayashi; Youko Kataoka, MD PhD; Haruyasu Fujita, MD PhD; and Michiko Kobayashi, MD, Japanese Society of QOL Research; Tomotaka Sobue, MD PhD, Osaka Univ.; Takashi Mandai, MD PhD, Japanese Society of QOL Research

Cross-Cultural Adaptation

(2069) A Study of Health-Related Quality of Work Life and Work-Related Anxiety among Industrial Workers with High Levels of Anxiety in Northeast Thailand

Anotnara Talkul Kuster, PhD, Khon Kaen Univ., Muang District, Thailand; Jiamjit Saengsuwan; Rattaphol Kraiklang; Kessarawan Nilvarangkul; and Anthony Charles Kuster, Khon Kaen Univ.

(2071) Reconciliation of Forward Translations as Part of the Linguistic Validation Process

Diane J. Wild, MSc, Icon plc, Oxford, United Kingdom; Helen Anderson, DPhil; Laura Towns; and Sujyotee Newoor, Icon plc

(2073) Translation as a Team-Building Effort: A Cost-Effective Method for Mass Translation of Quality-of-Life Tools

Randi Andenæs, RN PhD, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway; Borghild Løyland, RN PhD; Liv Halvorsrud, RN PhD; Ingrid H. Ravn, RN PhD; Sølvi Helseth, RN PhD; Lisbeth Kvarme, RN PhD; Astrid K. Wahl, RN; Lis Ribu, RN PhD; Berit Valeberg, RN PhD; Inger Utne, RN PhD; Marit Leegaard, RN PhD; and Nina Misvær, RN, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway; Carolyn E. Schwartz, ScD, DeltaQuest Foundation; Tufts Univ. School of Medicine; and Oslo and Akershus Univ. College of Applied Sciences

(2075) Project WHOQOL/Libras - Analysis for Focus Group of WHOQOL/BREF Translated into Brazilian Sign Language

Soraya Bianca Reis Duarte, Ms, Instituto Federal de Educação, Ciência e Tecnologia -IFG, Goiânia, Brazil; Neuma Chaveiro, Federal Univ. of Goiás; Adriana Ribeiro Freitas, Pontifícia Univ. Católica de Goiás; Celso Porto Celmo, PhD; and Maria Alves Barbosa, PhD, Federal Univ. of Goiás; Marcelo P. Fleck, MD PhD, Hospital de Clinicas de Porto Alegre

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(2077) Translation and Cross-Cultural Adaptation of the Portuguese Version of the Patient-Reported Outcomes Measurement Information System - PROMIS® - Physical Function

Diana A.C. Braga; Rogério M C Pinto; Tania Maria Silva Mendonca; Helena Paro, MD; Nivea da Macedo Oliveira Morales, MD; and Carlos Henrique Martins Silva, Sr., Univ. Federal de Uberlândia, Brazil

eHealth

(2079) Variation in Health States between Users of Paper and Electronic PRO Administration

Scott M. Gilbert, MD, H Lee Moffitt Cancer Center, Tampa, FL, United States; Carl Henriksen, Univ. of Florida; Jeffrey S. Montgomery; John M. Hollingsworth; and Brent Hollenbeck, MD MS, Univ. of Michigan; Michael Poch; Wade Sexton; and Paul B. Jacobsen, Moffitt Cancer Center & Research Inst.

(2081) PRO-Online: A Free Online Software to Analyze Patient-reported Outcomes using Various Paradigms of Data Analysis

Bastien Perrot, Univ. of Nantes, France; Tanguy Le Néel, Univ. of Nantes; Jean-Francois Hamel, Univ. Hospital of Angers; Myriam Blanchin; Veronique Sebillé, ScD; and Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes

(2083) Conducting Meaningful User Acceptance Testing for Electronic Patient-Reported Outcomes (ePROs): Best Practices

Bhumi Trivedi, Covance; Catherine Sage; and Jill Platko, Covance Market Access Services, Inc.

(2087) Home-Based Cancer Symptom Self-Management: Preliminary Results

DerShung Yang, PhD, BrightOutcome Inc.; Niina M. Haas, BrightOutcome, United States; Ana Maria Lopez, Univ. of Arizona; Michael A. Kallen, PhD MPH, Northwestern Univ.

PROMIS®

(2091) The use of PROMIS® in Pregnant Patients Presenting for Care in a Chiropractic Practice-Base Research Network

Joel Alcantara, International Chiropractic Pediatric Association (ICPA), United States; Jeanne Ohm, ICPA; Junjoe Alcantara, Alcantara Chiropractic

(2093) Validation of the PROMIS® Physical Function Domain in a Large Diverse Cancer Cohort

Roxanne E. Jensen, PhD, Georgetown Univ., Washington, DC, United States; Arnold L. Potosky, PhD; and Aaron C. Roberts, Georgetown Univ.; Carol M. Moinpour, PhD, Fred Hutchinson Cancer Research Center

🦁 (2095) Psychometric Assessment of the PROMIS® Global Health Scale in a Spanish-speaking sample of workers in Uruguay

Darío Padula, Univ. de la República; Juan J. Dapuzo, MD, PhD, Univ. de la República, Montevideo, Uruguay; Mario Luzardo; and Nicolás Fiori, Univ. de la República; David Cella, PhD, Northwestern Univ.; Ronald D. Hays, PhD, RAND Corporation

(2097) Portuguese Translation and Cross-Cultural Adaptation of the Patient-Reported Outcomes Measurement Information System (PROMIS®) Global Health Items Bank

Carlos Henrique Martins Silva, Sr., Univ. Federal de Uberlândia, Brazil; Camila E. Zumpano; Rogério M C Pinto; Tania Maria Silva Mendonca; Helena Paro, MD; and Nivea M. O. Morales, MD MSc PhD, Federal Univ. of Uberlândia

(2099) Fatigue and Social Function in Persons with Disability: A Short-Term Longitudinal Analysis

Ivan Molton, PhD, Univ. of Washington, Seattle, WA, United States; Mark Jensen; and Amanda E. Smith, Univ. of Washington

Measure Development

(2101) Enabling and Supporting People to Live with Long-term Conditions: Qualitative and Conceptual Development of a Patient-Reported Outcome Measure (PRO)

Cheryl Hunter, PhD, Univ. of Oxford, United Kingdom; Raymond Fitzpatrick, PhD, Univ. of Oxford; Anne-Sophie Darlington, PhD, Univ. of Southampton School of Medicine; Julien Forder, Univ. of Kent; Angela Coulter, Univ. of Oxford; Crispin Jenkinson, Health Services Research Unit; Michele Peters, PhD, Univ. of Oxford

🦁 Outstanding Poster Abstract Award



SCIENTIFIC PROGRAM

(2105) Do Cancer Patients Distinguish between the Importance and severity of their Quality of Life Concerns?

Daniel S. J. Costa, PhD, Psycho-oncology Co-operative Research Group (PoCoG), Sydney, Australia; Madeleine T. King, PhD, PoCoG; Neil K. Aaronson, PhD, Netherlands Cancer Institute; John E. Brazier, PhD, Univ of Sheffield; David Cella, PhD, Northwestern Univ; Peter Grimison, Chris O'Brien Lifecare and Univ. of Sydney; Monika Janda, PhD, Brisbane, Australia; Helen McTaggart-Cowan, PhD, Canadian Centre for Applied Research in Cancer Control; A. Simon Pickard, PhD, Univ. of Illinois at Chicago; Rob Arbuckle, Adelphi Values; Donna Rowen, Univ. of Sheffield; Tracey Di Sipio, Queensland Univ. of Technology on behalf of the MAUCA Consortium

(2107) Phase 1 & 2 Development of an EORTC QLG Health-Related Quality of Life Questionnaire for Patients with Cancer Cachexia

Sally J. Wheelwright, Univ. of Southampton, United Kingdom; Anne-Sophie Darlington, PhD, Univ. of Southampton School of Medicine; Deborah Fitzsimmons, Swansea Univ.; Jane B. Hopkinson, Univ. of Cardiff; Stein Kaasa, St Olavs Univ. Hospital; Monica Pinto, Istituto Nazionale Tumori "Fondazione G. Pascale"- IRCCS; Florian Strasser, Cantonal Hospital St Gallen; Colin Johnson, Mchir, Dept of Surgery, Southampton

(2109) Gastroparesis Symptom Severity between Patients with Idiopathic and Diabetic Gastroparesis: Are there Differences?

Dennis Revicki, PhD, Evidera; Michael Camilleri, Mayo Clinic; **Henry Parkman, Temple Univ., Philadelphia, PA, United States**

11:15 am – 12:45 pm Concurrent Symposium Session

Concurrent Symposium Session sponsored by Abacus International

Symposium #1: Patient and Public Engagement (PPI) Café II: Towards a model of Patient Engagement (PE) for ISOQOL

HALL I - C

Kirstie Haywood, DPHiL BSc, Royal College of Nursing Research Institute, United Kingdom

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

John Kirwan, BSc MD FRCP, University of Bristol, United Kingdom

Maarten de Wit, PhD, VU University, Amsterdam, Netherlands

During this World Café formatted symposium, organizers will explore with patient partners and other stakeholders, including health professionals, researchers, and members of ISOQOL, the 'best' solution for Patient Engagement in health-related quality of life, patient-centered outcomes, and PRO-related research and the involvement of patient partners within the ISOQOL community.

Symposium #2: Doc, how bad is it? Setting standards for severity of patient-reported outcomes data using item banks from PROMIS® and Neuro-QOL

SALON 2

Moderator: David Cella, PhD, Feinberg School of Medicine, Northwestern University, United States

Panelists:

Karon Cook, PhD, Feinberg School of Medicine, Northwestern University, United States

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

Deborah M. Miller, PhD, The Cleveland Clinic Foundation, United States

The members of this panel will provide a general introduction to the Bookmarking Method (BMM) methodology and share how they have adapted and applied BMM and cut score validation methodologies for setting clinically meaningful interpretation guidelines for IRT-developed PROs for persons with a range of cancers and MS.

A conceptual introduction from the Moderator, will be followed by key discussion questions to panelists, such as disease specific considerations when selecting standard setting participants, the pros and cons of using expert and/or patient panels, different score validation approaches (e.g., in-clinic vs. panel-testing organization) and differences in actual cut scores of the same measure across patient groups.

 Outstanding Poster Abstract Award

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SCIENTIFIC PROGRAM

Symposium #3: Applying Computer Adaptive Testing in Child Reported Outcome Measurement – a New Era of Assessment?

SALON 4

Moderators/Discussants:

Monika Bullinger, PhD, University Medical Center Hamburg-Eppendorf, Germany

Christopher B. Forrest MD PhD, Children's Hospital of Philadelphia, United States

This symposium will provide an overview about Computerized Adaptive Testing (CAT) applications and identify solutions for the barriers to adoption of pediatric CATs by evaluating several international case studies of CAT administration in a variety of clinical and research settings.

This symposium is presented as part of the ISOQOL Child Health Special Interest Group in recognition of the need to develop and disseminate new methods that address the challenges associated using new technologies when assessing Quality of Life (QOL) in pediatric populations.

INDIVIDUAL PRESENTATIONS

The Kids-CAT: Development and Application of a Computerized-Adaptive Test to Assess Generic Quality of Life in Children and Adolescents in Routine Pediatric Care

Dana Barthel, Dipl.-Psych., University Medical Center Hamburg-Eppendorf, Germany

Assessing Disease-Related Quality of Life in Children and Adolescents with Chronic Conditions: Development and Application of a Chronic-Generic CAT Derived from the DISABKIDS Framework

Holger Mühlan, Ernst-Moritz-Arndt-University, Greifswald, Germany

CATs in Pediatric Rehabilitation Medicine

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

Validation of a Computerized Adaptive Test for the Identification of Children with Psycho-Social Problems

Symone B. Detmar PhD, TNO Child Health, Leiden, Netherlands

Integrating Computerized Adaptive Tests into Electronic Health Records and Clinical Care

Christopher B. Forrest, MD PhD, Children's Hospital of Philadelphia, Univ. of Pennsylvania, United States

The Application of CATs in Young Adults – 10 Years of Experience with Depression, Anxiety and Stress CATs in a Psychosomatic Setting

Felix Fischer, PhD, Charité – University Medicine Berlin, Germany

12:45 pm – 1:45 pm

Lunch Buffet

Served in Poster Hall

1:00 pm – 2:00 pm

Committee Meeting

SALON 3

Quality of Life Research Journal Associate Editors Meeting

Friday, 17 October

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SCIENTIFIC PROGRAM

2:00 pm – 3:15 pm

Concurrent Oral Sessions

201: Transforming Practice: Rehabilitation

SALON 2

Session Chair: Nancy E. Mayo, PhD, Canada

(201.1) WITHDRAWN

2:05 – 2:18 pm (201.2) Using the ICF's Environmental Factors Framework to Develop an Item Bank Measuring Built and Natural Environmental Features Affecting Persons with Disabilities

Allen W. Heinemann, Northwestern Univ., Chicago, IL, United States; Jin-Shei Lai, PhD, Northwestern Univ.; David Gray, Washington Univ.; Susan Magasi, and Joy Hammel, Univ. of Illinois; David Tulsky, PhD, Kessler Foundation; Elizabeth Hahn, MA; and Sofia Garcia, PhD, Northwestern Univ.; Sara Jerousek; and Alex Wong, PhD, Rehabilitation Institute of Chicago

2:19 – 2:32 pm (201.3) Using the ICF's Environmental Factors Framework to Develop an Item Bank Measuring Services, Systems, and Policy Affecting Persons with Disabilities

Jin-Shei Lai, PhD, Northwestern Univ., Chicago, IL, United States; Joy Hammel, Univ. of Illinois; Allen W. Heinemann, Northwestern Univ.; David Gray, Washington Univ.; Susan Magasi, Univ. of Illinois; David Tulsky, PhD, Kessler Foundation; Elizabeth Hahn, MA; and Sofia Garcia, PhD, Northwestern Univ.; Sara Jerousek; and Alex Wong, PhD, Rehabilitation Institute of Chicago

2:33 – 2:46 pm (201.4) Validity and Utility of the Brandtstädter Tenacious Goal Pursuit/Flexible Goal Adjustment Measure in Adults Aging with Long-Term Physical Disabilities

Alexandra L. Terrill, Univ. of Washington; Ivan Molton, PhD, Univ. of Washington, Seattle, WA, United States; Amanda E. Smith; and Mark Jensen, Univ. of Washington

2:47 – 3:00 pm (201.5) Predictors of Self-Efficacy in Individuals Aging with a Disability

Dagmar Amtmann, PhD; Alyssa M. Bamer, MPH; Kathy Yorkston; and Amanda E. Smith, Univ. of Washington, Seattle, WA, United States

Oral Session 202: Advancing Quality of Life Measurement in eHealth

HALL I - B

Session Chair: Montserrat Ferrer, MD PhD MPU, Spain

2:05 – 2:18 pm (202.1) Development of the Spanish and Catalan Digital Versions of the KIDSCREEN-52 and Comparison with the Paper Version

Luis Rajmil, PhD, Catalan Agency for Health Quality and Assessment (AQuAS), Barcelona, Spain; Noemí Robles-Muñoz, AQuAS; Dolors Rodríguez-Arjona, AQuAS; Francisco Codina, Corporació de Salut del Maresme i la Selva; Marta Azuara, Corporació de Salut del Maresme i la Selva; Hein Raat, MD, PhD, MBA, Erasmus Univ Medical Ctr Rotterdam; Ulrike Ravens-Sieberer, MPH, Univ. Medical Center Hamburg-Eppendorf

2:19 – 2:32 pm (202.2) Long-Term Findings from Three Scandinavian RCT Studies in the European Telemedicine Project Renewing Health: Self-Management Telehealth Interventions with Health Counseling.

Astrid CV Torbjørnsen, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway; Anne Karen Jennum, Univ. of Oslo; Eirik Arsand, Norwegian Centre for Integrated Care and Telemedicine; Milada C. Smaastuen, Oslo and Akershus Univ.; Inger Lindberg, Luleå Univ. of Technology, Sweden; Tuula Karhula, Univ. of Helsinki, Finland; Lis Ribu, PhD, Oslo and Akershus Univ. College

2:33 – 2:46 pm (202.3) Lessons Learned from the Open Research Exchange

Paul Wicks, PhD, PatientsLikeMe, United Kingdom; Magdalena Harrington; Shimon Rura; Benjamin Heywood; and James A. Heywood, PatientsLikeMe

2:47 – 3:00 pm (202.4) Equivalence of Electronic and Paper Administration of Patient-Reported Outcome Measures: A Systematic Review and Meta-Analysis

Diane J. Wild, MSc, Icon plc; Helen Doll, DSc, MSc, Oxford Outcomes, United Kingdom; Paul O'Donohoe, CRF Health; Willie Muehlhausen, Oxford Outcomes

3:01 – 3:14 pm (202.5) An Interactive Web-Based Application for Displaying Population-Specific Comparisons using PROMIS® Scores

Sandra D. Griffith, PhD, Cleveland Clinic, Cleveland, OH, United States; Irene Katzan, Cleveland Clinic

 Outstanding Poster Abstract Award

Friday, 17 October

Oral Session 203: Transforming the Quality of Care

HALL I - A

Session Chair: Silke Schmidt, PhD, Germany

2:05 – 2:18 pm (203.1) Responsiveness of Items from the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events

Amylou C. Dueck, PhD, Mayo Clinic, United States; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Tito R. Mendoza, PhD, Univ. of Texas M.D. Anderson Cancer Center; Antonia V. Bennett, PhD, Univ. of North Carolina at Chapel Hill; Lauren Rogak; Thomas M. Atkinson, PhD; and Yuelin Li, PhD, MSKCC; Bryce B. Reeve, PhD; and Ethan Basch, MD MSc, Univ. of North Carolina - Chapel Hill, on behalf of the National Cancer Institute PRO-CTCAE Research Group

2:19 – 2:32 pm (203.2) The Outcomes and Experience Questionnaire: Development and Evaluation

Elizabeth J. Gibbons, MSc, Univ. of Oxford, United Kingdom; Paul Hewitson, Univ. of Oxford; David Morley, Univ. of Oxford; Crispin Jenkinson, Health Services Research Unit, Oxford; Raymond Fitzpatrick, PhD, Univ. of Oxford

2:33 – 2:46 pm (203.3) Development of a Measure of Patient-Reported Experiences and Outcomes of Patient Safety in Primary Care: The PREOS-PC Instrument

Jose M. Valderas, MD MPH PhD, Univ. of Exeter, United Kingdom; Anthony Avery, Univ. of Nottingham; Ignacio Ricci-Cabello, Univ. of Oxford

2:47 – 3:00 pm (203.4) Item Analysis of a Measure to Understand Over-the-Counter Medicine Safety among 6th Grade Students

Kristin Recchiuti, McNeil Consumer Healthcare; Stacie Hudgens, MA (ABD), Clinical Outcomes Solutions, Tucson, AZ, United States; Mary Kathryn Malone, Apple Seed; Brenda Zimmerman, McNeil Consumer Healthcare; Ed Kuffner, McNeil Consumer Healthcare

3:01 – 3:14 pm (203.5) Burnout among Surgeons – The Problem and Evolving Solutions

Juliane Bingener, Mayo Clinic, United States; Tait Shanafelt; Susan Hallbeck; and Jeff Sloan, PhD, Mayo Clinic

Oral Session 204: PRO Development: From Conception through Revision

SALON 4

Session Chair: Stefan Cano, PhD CPsychol AFBPsS, United Kingdom

2:05 – 2:18 pm (204.1) Development and Validation of the Myeloma Patient Outcome Scale (MyPOS): A Quality of Life Questionnaire for use in the Clinical Care of People with Multiple Myeloma

Thomas Osborne, MA MBBS MRCP, King's College London; Christina Ramsenthaler, King's College London, United Kingdom; Susanne De Wolf-Linder, King's College London; Katy Pannell, King's College London; Richard J. Siegert, Auckland Univ. of Technology; Polly Edmonds, King's College Hospital; Steve Schey, King's College Hospital; Irene J. Higginson, King's College London

2:19 – 2:32 pm (204.2) The Plus-M: Item Bank Of Mobility For Prosthetic Limb Users

Dagmar Amtmann, PhD, Univ. of Washington, Seattle, WA, United States; Daniel C. Abrahamson; Sara Morgan; Rana Salem; and Robert L. Askew, Univ. of Washington; Robert Gailey, Univ. of Miami; Ignacio Gaunaurd, VA Miami; Andre Kajlich; and Brian Hafner, Univ. of Washington

2:33 – 2:46 pm (204.3) Development of the EORTC Emotional Functioning Item Bank for Computer Adaptive Testing (CAT)

Morten Aa Petersen, MScI, Bispedjerg Hospital, Copenhagen, Denmark; Eva-Maria Gamper, Innsbruck Medical Univ.; Anna Costantini, Sant'Andrea Hospita, Sapienza Univ. of Rome.; Johannes M. Giesinger, PhD, Innsbruck Medical Univ.; Bernhard Holzner, PhD BE, Univ. Hospital, Innsbruck; Colin Johnson, Mchir, , Southampton General Hospital; Monika J. Sztankay, Innsbruck Medical; Teresa E. Young, BSc, Mount Vernon Hospital; Mogens Groenvold, MD PhD, Univ. of Copenhagen

2:47 – 3:00 pm (204.4) The Thyroid-Related Quality of Life Measure ThyPRO has Good Responsiveness and Ability to Detect Relevant Treatment Effects.

Torquil Watt, MD PhD, Copenhagen Univ. Hospital, Denmark; Per Cramon, MD, Copenhagen Univ. Hospital; Laszlo Hegedüs, Odense Univ. Hospital; Jakob B. Bjorner, MD PhD, QualityMetric; Steen J. Bonnema, Odense Univ. Hospital; Åse K. Rasmussen, Copenhagen Univ. Hospital; Ulla Feldt-Rasmussen, Copenhagen Univ. Hospital; Mogens Groenvold, MD PhD, Univ. of Copenhagen



SCIENTIFIC PROGRAM

3:01 – 3:14 pm (204.5) Psychometric Properties of the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being, Expanded

Hayley S. Whitford, PhD, Cancer Council Australia, Sydney, Australia; Simeon B. W. Jones, BA (Hons), Univ. of South Australia, Adelaide; Ian N. Olver, MD PhD FRACP, Cancer Council Australia

Oral Session 205: Expanding Cancer Assessments: New Measures & Methods HALL I - C

Session Chair: Madeleine T. King, PhD, Australia

2:05 – 2:18 pm (205.1) Evaluation of Pedometry as a Patient-Centered Outcome in Patients Undergoing Hematopoietic Stem Cell Transplant (HSCT): A Comparison of Pedometry and Patient-Reports of Symptoms, Physical Activity, Health, and Quality of Life.

Antonia V. Bennett, PhD, Univ. of North Carolina at Chapel Hill, United States; Bryce B. Reeve, PhD; and Ethan Basch, MD MSc, Univ. of North Carolina - Chapel Hill; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Mathew Meeneghan; Claudio Battaglini; Abbie Smith-Ryan; Charlotte Shatten; Thomas C. Shea; and William A. Wood, MD, MPH, Univ. of North Carolina at Chapel Hill

2:19 – 2:32 pm (205.2) Mixed-Effects Regression Models for Longitudinal Analysis of Quality of Life in Oncology

Antoine Barbieri, Biometrics Unit, ICM - Val d'Aurelle, Montpellier, France; Christian Lavergne, Institut de Mathématiques et de Modélisation de Montpellier; Thierry Conroy, Centre Alexis Vautrin; Sophie Gourgou-Bourgade, CRLC Val d'Aurelle; Beata Juzyna, Unicancer R&D; Caroline Bascoul-Mollevi, ICM - Val d'Aurelle

2:33 – 2:46 pm (205.3) Sleeping Like a Baby? Exploring PROMIS® Sleep Disturbance DIF by Race/Ethnicity and Age

Roxanne E. Jensen, PhD, Georgetown Univ.; Bellinda L. King-Kallimanis, PhD, TILDA, Trinity College Dublin, Ireland; Jeanne A. Teresi, Columbia Univ. Stroud Center; Eithne Sexton, Royal College of Surgeons in Ireland; Arnold L. Potosky, PhD, Georgetown Univ.

2:47 – 3:00 pm (205.4) Is the CTCAE System Suitable to use in Trials in Surgery and Radiotherapy? A Content Analysis of the NCI-PRO-CTCAE and EORTC Systems

Elaine E. O'Connell Francischetto, BSc MSc, Univ. of Bristol, United Kingdom; Alexandra Gilbert, Univ. of Leeds; Galina Velikova, MD PhD FRCP, Univ. of Leeds; Jane Blazeby, MD, Univ. of Bristol

3:01 – 3:14 pm (205.5) Institutional Quality of Life Compliance in an Advanced Ovarian Cancer Surgery Phase III Study

Corneel Coens, MSc, EORTC; E. Greimel, Medical Univ. Graz; A. Casado, Hospital Universitario San Carlos, Madrid; G. B. Kristensen, The Norwegian Radium Hospital; N. S. Reed, Beatson West of Scotland Cancer Centre; G. Rustin, Mount Vernon Hospital; Andrew Bottomley, PhD, EORTC Headquarters; I. Vergote, Gasthuisberg Univ. Hospital; Efstathios Zikos, MS MA, EORTC, Brussels, Belgium

3:15 pm – 4:00 pm Exhibits Open and Refreshment Break

3:25 pm – 3:45 pm Friday Poster Session 2 HALL II

Cancer

(2002) Sex Does Not Appear to be Strongly Related to Problems among Childhood Cancer Survivors - Findings from Online Focus Groups

Lena Wettergren, PhD, Karolinska Institute, Sweden; Anna Jervaeus; Jenny Nilsson; Claudia Lampic; Catarina Widmark; and Lars E. Eriksson, PhD, Karolinska Institutet

(2004) Global Quality of Life in Cancer Patients is Less Impaired than Specific Components of Quality of Life

Andreas Hinz, Univ. of Leipzig, Germany; Anja Mehnert, Univ. of Leipzig; Daniel Reissmann, Univ. Med Ctr Hamburg Eppendorf; Csaba Dégi, Babes-Bolyai Univ.; Dörte Schotte, Univ. of Leipzig; Thomas Schulte, Rehabilitation Clinic Bad Oexen

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(2006) Patients' Understanding of and Preferences for graphical presentation formats for quality of Life Scores Obtained with the EORTC QLQ-C30

Wilma Kuijpers, Netherlands Cancer Institute; Johannes M. Giesinger, PhD, Innsbruck Medical Univ., Austria; Teresa E. Young, BSc, Mount Vernon Hospital; Krzysztof Tomaszewski, Jagiellonian Univ. Medical College; Neil K. Aaronson, PhD, Netherlands Cancer Institute; Bernhard Holzner, PhD BE, Univ. Hospital, Innsbruck

(2008) Measuring Functional Domains with the EORTC QLQ-C30 and MDASI in Patients with Cancer

Qiuling Shi, PhD, Univ. of Texas M.D. Anderson Cancer Center, Houston, TX, United States; Xin Shelley Wang, MD MPH; Loretta A. Williams, PhD RN; Tito R. Mendoza, PhD; Robert Z. Orlowski; and Charles S. Cleeland, PhD, UT-MD Anderson Cancer Center

(2010) Understanding the Age-Dependent Cancer Burden on Pretreated Health-Related Quality of Life (HRQOL) of Cancer Patients using the EORTC QLQ-C30: A Pooled Analysis of Randomized Controlled Trials

Chantal Quinten, MSc; Irina Ghislain, MSc; Efsthios Zikos, MS MA, EORTC Headquarters, Brussels, Belgium; Divine Ewane Ediebah, PhD©; Corneel Coens, MSc; and Francesca Martinelli, MSc, EORTC Headquarters; John Maringwa, PhD, Quantative Solutions; Bryce Reeve, PhD, Univ. of North Caroline at Chapel Hill; Jolie Ringash, MD, The Princess Margaret Hospital; Carolyn Gotay, PhD, Univ. of British Columbia, Vancouver BC, Canada; Eva Greimel, PhD, Medical Univ. Graz; Madeleine King, PhD, PoCoG, Univ. of Sydney; Charlie Cleeland, PhD, Univ. of Texas M.D. Anderson Cancer Center; Henning Flechtner, PhD, Univ. of Magdeburg; Joseph Schmucker-Von Koch, Univ. of Regensburg; Martin Taphoorn, MD PhD, VU Medical Center/Medical Center; Joachim Weis, PhD, Univ. of Freiburg; Galina Velikova, MD PhD FRCP, Univ. of Leeds; Andrew Bottomley, PhD, EORTC Headquarters on behalf of EORTC Patient Reported Outcomes and Behavioural Evidence and the EORTC Clinical Groups

(2014) Translating Patient-Reported Outcomes into Decision-Making in Malignant Hematology

Samuel Salek, Cardiff Univ., United Kingdom; Esther Natalie Oliva, Azienda Ospedaliera B-M-M, Hematology Unit; Tatiana I. Ionova, Multinational Center for Quality of Life Research, St. Petersburg; Robert Klaassen, MD, Children's Hospital of Eastern Ontario; Denis A. Fedorenko, PhD, Nat'l Medical Surgical Center, Moscow; Anita Waldmann, Myeloma Patients Europe

Musculoskeletal/Rheumatology

🦋 (2016) Treatment Discontinuation in Rheumatoid Arthritis: A Matter of HRQOL? – Development and Field-Test of a Questionnaire

Sandra Meyer-Moock, Univ. Medicine Greifswald, Germany; Julia Schiffner-Rohe, Pfizer Deutschland; Friedhelm Leverkus, Pfizer Deutschland; Thomas Kohlmann, PhD, Univ. of Greifswald

(2018) Measuring Health-Related Quality of Life (HRQOL) in Patients with Musculoskeletal Infections – A Systematic Review

You-Shan Feng, PhD, Medical Univ. Greifswald, Germany; Dawid Pieper, Witten/Herdecke Univ.; Michaela Eikermann, Witten/Herdecke Univ.; Thomas Kohlmann, PhD, Univ. of Greifswald

(2022) Assessment of Quality of life (QOL) in Postmenopausal Osteoporosis in Poland

Mariola Drozd, Medical Univ. of Lublin, Poland; Monika Szkultecka-Debek, Military Inst. of Medicine, Warsaw; Kazimierz Drozd, Lublin Univ. of Technology; Maria Michalik, AMG Medical Center; Nina Kiepuska, Military Inst. of Medicine, Warsaw

(2024) Ceiling Effect Limits Utility of the Multidimensional Fatigue Inventory to Detect Clinical Meaningful Fatigue in Chronic Fatigue Syndrome

Xin Shelley Wang, MD MPH, Univ. of Texas MD Anderson Cancer Center, Houston, TX, United States; Qiuling Shi, PhD, Univ. of Texas MD Anderson Cancer Center; Suzanne D. Vernon, The CFIDS Association of America

Nephrology/Urology

(2026) Using Analytic Morphomics to Understand Short-Term Convalescence after Bladder Surgery

John M. Hollingsworth, Univ. of Michigan, United States; Jeffrey S. Montgomery, Univ. of Michigan; Scott M. Gilbert, MD, H Lee Moffitt Cancer Center; Michael Engelsbe; Stewart Wang; and Brent Hollenbeck, MD MS, Univ. of Michigan

(2030) Measuring Health-Related Quality of Life in Women with Urinary Incontinence: Reliability and Validity of the Portuguese Version of the King's Health Questionnaire (KHQ)

Rui Soles Goncalves, PhD, Univ. of Coimbra, Portugal; Carla Gabriel; Carina Martins; and António Fernandes Lopes, Alcoitão Health College; Luis Manuel Cavalheiro, PhD; and Pedro L. Ferreira, PhD, Univ. of Coimbra

 Outstanding Poster Abstract Award



Rehabilitation

(2032) Do Environmental Factor Measures Identify Distinct or Common Elements?

Allen W. Heinemann, Northwestern Univ., Chicago, IL, United States; Ana Miskovic; and Alex Wong, PhD, Rehabilitation Institute of Chicago; David Gray; and Holly Hollingsworth, Washington Univ.; Jin-Shei Lai, PhD, Northwestern Univ; Susan Magasi; and Joy Hammel, Univ. of Illinois; David Tulsy, PhD, Kessler Foundation; Elizabeth Hahn, MA; and Sofia Garcia, PhD, Northwestern Univ. Sara Jerousek, Rehabilitation Institute of Chicago, Chicago, IL, United States

(2034) Gender Differences in Physical and Mental HRQOL over the course of One Year after Musculoskeletal Rehabilitation in Germany

Kerstin Mattukat, Martin Luther Univ. Halle-Wittenberg, Germany; Inge Ehlebracht-Koenig, Rehasentrum Bad Eilsen der Deutschen Rentenversicherung Braunschweig-Hannover; Karin Kluge, Teufelsbad Fachklinik Blankenburg; Wilfried Mau, Martin Luther Univ. Halle-Wittenberg

(2036) Confirmatory Factor Analysis and Reliability of the Burn Specific Health Scale – Revised in Burned Adults in Brazil

Noelle O. Freitas; Marina Caltran; Suleimy C. Mazin; Rosana Spadoti Dantas, PhD; and Lidia A. Rossi, PhD, Univ. of São Paulo, Brazil

(2038) Comparative Study of the Quality of Life between People with Vasculogenic Ulcers and the General Population

Beatriz Farias Alves Yamada, Univ. do Estado do Amazonas, Brasil; Vera Lucia CG Santos, PhD; Univ. of São Paulo, Brazil; Carol V. Serna González; Mily CM Ramos; and Danielle C. Soares, Univ. of São Paulo Luciana A. Pacheco, Hospital Darcy Vargas

(2040) How Well Do Environmental Factor Measures Cover the International Classification of Functioning Disability and Health Domains?

Allen W. Heinemann, Northwestern Univ; David Gray, Washington Univ.; Rebecca Simon, Washington Univ.; Brittany Perez, OTR, Univ. at Buffalo, State Univ. of New York; Susan Magasi, Univ. of Illinois; David Tulsy, PhD, Kessler Foundation; Joy Hammel, Univ. of Illinois; Elizabeth Hahn, MA; Sofia Garcia, PhD; and Jin-Shei Lai, PhD, Northwestern Univ., Chicago, IL, United States; Sara Jerousek; and Alex Wong, PhD, Rehabilitation Institute of Chicago

Quality of Care/Patient Satisfaction

(2042) Assessment of Health-Related Quality of Life of the Nurses in the Intensive Care Unit of the City of São Paulo - Brazil.

Luciana S. Costa Santos, Faculdades de Ciências Médicas da Santa Casa de São Paulo, Brazil; Miako Kimura, PhD, Univ. of São Paulo

(2044) Structured Program for Monitoring Patients with Heart Failure and/or Chronic Obstructive Pulmonary Disease: One Year Results

M. Clara Sala Álvarez, RN, Institut Català de la Salut, Barcelona, Spain; Maria Luisa Marti Aguiar; José Luis Del Val Garcia; Mireia Boixadera Vendrell; and Enriqueta Borràs Gallart, Institut Català de la Salut

(2046) Generation of Post-Surgical Concerns and Expectations using Concept Elicitation Interviews with Patients with Thyroid Cancer

Thomas M. Atkinson, PhD, Memorial Sloan Kettering Cancer Center (MSKCC), United States; Elyse Shuk; Dorothy Thomas; Monica M. DiLorenzo; Safina Ali; Jamie S. Ostroff; and Snehal G. Patel, MSKCC

(2048) Assessing Patient-Reported Adverse Outcomes after Hospital Discharge

Barbara M. Okoniewska, Univ. of Calgary, Canada; Katy Eso; Jayna Holroyd-Leduc; Maeve O'Beirne; Ward Flemons; Deborah White; Wrechelle Ocampo; Nancy Clayden; and William A. Ghali, Univ. of Calgary; AJ Forster, MD FRCPC MSc, Univ. of Ottawa; Maria-Jose Santana, PhD, Univ. of Calgary

 Outstanding Poster Abstract Award

Caregivers

(2050) Assessment of Quality of Life in Caregivers of Patients with Mood Disorders in a public outpatient service in the South of Brazil

Mirian Cohen; Ana Flavia da Silva Lima, PhD, Univ. Federal do Rio Grande do Sul; **Sandro R P S Miguel, MD, Institute for Health Technology Assessment, Porto Alegre - Rio Grande Do Sul, Brazil**; Jacques Zimmermann, MD MSc; Luciane N. Cruz, MD, PhD, Federal Univ. of Rio Grande do Sul; Marcelo P. Fleck, MD PhD, Hospital de Clinicas de Porto Alegre

(2052) Quality of Life among Patients with High Grade Gliomas and their Principal Informal Caregivers: A Study of Dyadic Adjustment to an Unfavorable Prognosis Disease

Tanguy Leroy, Aix-Marseille Univ.; Olivier Chinot, Timone Univ. Hospital, Marseille; **Karine Baumstarck, Aix-Marseille Univ., Marseille, France**; Zeinab Hamidou; and Themis Apostolidis, Aix-Marseille Univ.; Pascal Auquier, Univ. Hospital of Marseille

(2054) The Impact of Cancer Patients' Emotional State on Caregivers' Quality of Life

Hui Yu Chan; Haikel A. Lim, BSocSci(Hons); Simon Collinson; and **Rathi Mahendran, National Univ. of Singapore**

(2056) Balancing Filial Piety, Family Obligations, and Personal Goals: Navigating the Cancer Caregiving Terrain

Hui Ying Ng, BA; and Haikel A. Lim, BSocSci(Hons), National Univ. of Singapore; Joanne Chua, National Univ. Hospital; Konstadina Griva; and **Rathi Mahendran, National Univ. of Singapore**

(2058) Quality of Life in Caregivers for Earthquake and Tsunami Disaster Survivors in Fukushima, Japan

Kazunori Tanaka, PhD, Japanese Society of Quality of Life Research, Japan; Yuto Hayashi; Yuto Oiki; Yusuke Tanaka; and Ichiro Nagano, Japanese Society of Quality of Life Research; Yoshihiro Tairako, Touno Sangyou Sinkou Jigyuu Coop; Michiko Kobayashi, MD; and Kozaburo Adachi, MD PhD, Japanese Society of QoL Research; Tomotaka Sobue, MD PhD, Osaka Univ; Takashi Mandai, MD PhD, Japanese Society of QoL Research

Children

(2060) Quality of Life in Minor Siblings of Childhood Leukemia Survivors, Long-Term after Diagnosis: A LEA Study.

Julie Berbis, Dept. of Public Health, Medicine Univ., Marseille, France; Gérard Michel, Univ. Hospital of Marseille; Marine Alessandrini; and Camille Vercasson, Aix-Marseilles Univ.; Claire Oudin; Vincent Barlogis; and Hervé Chambost, APHM; Pascal Auquier, Univ. Hospital of Marseille

(2062) Addressing the Rehabilitation Needs of Visually Impaired Young Adults in their Transition to Adulthood: A Patient Record Study

Lisette M. Van Leeuwen, MSc, VU Univ. Medical Center, Amsterdam, Netherlands; Linda Rainey; Ruth Van Nispen, PhD; and Ger Van Rens, VU Univ. Medical Center

(2064) Quality of Life of Caregivers of Asthmatic Children and Adolescents

Maria Alves Barbosa, PhD, Nursing Faculty of Federal Univ. of Goias, Brazil; Isabela C F Fernandes; Karina M. Siqueira; Virginia V. Brasil, PhD; Lizete M A C Oliveira, PhD; Katarinne L. Moraes; Alcides P S Neto; Liege L S Vieira; Jacqueline Andréia B L Cordeiro; and Carla P. Bernardes, Federal Univ. of Goias

(2066) Health-Related Quality Of Life of Children with a Cleft Lip and distress of their Parents

Lotte Haverman, PhD, Emma Children's Hospital /Academic Medical Centre, Amsterdam, Netherlands; Anouck Splinter; and Hedy A. Van Oers, MSc, Emma Children's Hospital/Academic Medical Center; Chantal MAM Van Der Horst; and Martha Grootenhuis, PhD, Academic Medical Center

(2070) Assessing Quality of Life in 5-6 Year Old Children using Illustrations Shown on a Tablet Computer

Tomoaki Kimura, PhD, MOA Health Science Foundation, Atami, Japan; Rika Hayashida, MS, Univ. of Nagasaki; Michiko Kobayashi, MD, Japanese Society of QoL Research; Yoshiteru Maki, Korinkai Kagoshima Clinic; Yuta Okada; Seiya Uchida; and Kiyoshi Yamaoka, MOA Health Science Foundation



SCIENTIFIC PROGRAM

Cross-Cultural Adaptation

(2072) What Does a Decade Matter? The Evolution of Translation Activities in the EORTC Quality of Life Group in the Past 10 Years

Dagmara Kulis, EORTC, Brussels, Belgium; Cheryl Whittaker, EORTC; Eva Elfriede Greimel, PhD, Medical Univ. Graz; Andrew Bottomley, PhD, EORTC Headquarters; Michael Koller, PhD, Center for Clinical Studies, Regensburg

(2074) Cross-Cultural Adaptation and Validation of the Portuguese Version of the Oxford Shoulder Score (OSS)

Carolina Quintal Caldeira, Polytechnic Inst. of Caselo Branco, ESALD; Rui Soles Goncalves, PhD, Univ. of Coimbra, Portugal; Mónica Vieira Rodrigues; and Sabine Cardoso Felícia, Polytechnic Inst. of Castelo Branco, ESALD; Luis Manuel Cavalheiro, PhD; and Pedro L. Ferreira, PhD, Univ. of Coimbra

(2076) Confirmatory Factorial Analysis of the Brazilian-Portuguese version of the Duke Anticoagulation Satisfaction Scale (DASS)

Flávia M. Pelegriño, Univ. of São Paulo; Rejane K. Furuya, Univ. of São Paulo at Ribeirão Preto College of Nursing, Brazil; Eliane Nepomuceno; Suleimy C. Mazin; Lidia A. Rossi, PhD; and Rosana Spadoti Dantas, PhD, Univ. of São Paulo

eHealth

(2078) An Evaluation of the Measurement Equivalence of Electronic Versions of Paper-Based Patient-Reported Outcome Measures

Niloufar Campbell, Cardiff Univ., United Kingdom; Faraz M. Ali, Cardiff Univ; Andrew Finlay, FRCP, Univ. of Wales College of Medicine; Mir-saeed S. Salek, Cardiff Univ.

(2080) Use of BiblioPRO, the Virtual Library of Patient-Reported Outcomes Instruments

Yolanda Pardo; and Montserrat Ferrer, MD PhD MPU, IMIM - Hospital del Mar Medical Research Institute, Barcelona, Spain; and Monica Avila, PharmD, MPH, IMIM; Scientific Committee BiblioPRO, CIBERESP, CIBERSAM, CIBERER

(2082) Mode of Administration of Patient-Reported Outcomes (PROs): A Systematic Review

Claudia Rutherford, PhD, Univ. of Sydney, Australia; Rebecca L. Mercieca-Bebber; and Holly Rice, Univ. of Sydney; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG)

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

(2084) Use of iPads to Assess Health-Related Quality of Life: A Feasibility Study in Outpatient Home Dialysis Clinics

Kara L. Schick Makaroff, PhD RN, Univ. of Alberta, Canada; Anita Molzahn, PhD RN, Univ. of Alberta

(2086) A Web-Based Question Prompt Sheet for the Initial Follow-Up Consultation after Esophageal Cancer Surgery

Marc Jacobs, Academic Medical Center, Amsterdam, Netherlands; Inge Henselmans; Derk Arts; Mark I. Van Berge Henegouwen; Maud Ten Koppel; Suzanne S. Gisbertz; Sjoerd M. Lagarde; Mirjam AG Sprangers, PhD; Hanneke C.J.M. De Haes; and Ellen M. Smets, Academic Medical Center

(2088) EVA-Online: Development and Preliminary Testing of a Guided Online Cognitive Behavioral Therapy (CBT) Program for Breast Cancer Survivors with Climacteric Symptoms

Marieke Van Leeuwen, Netherlands Cancer Institute; Myra S. Hunter, King's College London; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands

PROMIS®

(2090) Diagnostic Performance of Co-Calibrated PHQ-9 and PROMIS® Depression Scales

Sandra D. Griffith, PhD, Cleveland Clinic, Cleveland, OH, United States; Nicolas Thompson, Cleveland Clinic; Paul K. Crane, MD MPH, Harborview Med Ctr; Jaivir S. Rathore, Univ. of Illinois Chicago; Lara Jehi; George E. Tesar; and Irene Katzan, Cleveland Clinic

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(2092) Evaluating PROMIS® Item Content Validity in the Context of HIV Clinical Care

Todd C. Edwards, PhD, Univ. of Washington, Seattle, WA, United States; Rob J. Fredericksen, Univ. of Washington; Leo Morales, MD, PhD, Group Health Research Institute; Rosa Solorio, Univ. of Washington; Frances M. Yang, Georgia Regents Univ.; Heidi M. Crane, Univ. of Washington; Paul K. Crane, MD MPH, Harborview Med Ctr; Donald L. Patrick, PhD MSPH, Seattle Quality of Life Group

(2094) The Psychometric Performance of the PROMIS® Smoking Assessment System: Comparisons of Simulated and Real-data CATs, Short Forms, and Mode of Administration

Brian D. Stucky, PhD, RAND Corporation, United States; Maria O. Edelen, PhD, RAND Corporation; Mark Hansen, UCLA-CRESST; Joan S. Tucker, RAND Corporation; William Shadel, RAND Corporation

(2098) Translation, Cross-Cultural Adaptation and Validation of Mobility Item Bank of Patient-Reported Outcomes Measurement Information System - Pediatric PROMIS® into Portuguese

Nivea M. O. Morales, MD MSc PhD, Federal Univ. of Uberlândia, Brazil; Aline Tavares Duarte; Tania Maria Silva Mendonca; Carlos Henrique Martins Silva, Sr.; and Rogério M C Pinto, Federal Univ. of Uberlândia

(2100) Psychometric Evaluation of the PROMIS® Fatigue Measure in an Ethnically/Racially Diverse Population-Based Sample of Cancer Patients

Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill, United States; Wen-Hung Chen, RTI; Laura C. Pinheiro, Univ. of North Carolina; Molly K. McFatrach, Univ. of North Carolina; Roxanne E. Jensen, PhD, Georgetown Univ.; Jeanne A. Teresi, Columbia Univ. Stroud Center; Arnold L. Potosky, PhD, Georgetown Univ.

Measure Development

(2102) Measuring the Community Re-integration of Burn Injuries in Adults: Conceptual Foundation for Future Development of a Computer Adaptive Test (CAT)

Molly E. Marino, MPH, Boston Univ., United States; Marina Soley Bori, MA; Melinda Rossi, BA; Flor Amaya, MPH; Mary D. Slavin, PhD; and Alan Jette, PhD, Boston Univ.; Colleen Ryan, MD, Massachusetts General Hospital; Amy Acton, RN BSN, The Phoenix Society for Burn Survivors; Jeffrey Schneider, MD, Massachusetts General Hospital; Lewis E. Kazis, ScD, Center for the Assessment of Pharmaceutical Practices

(2104) Impact of Recall Period on the Accuracy of Selected Items from the US National Cancer Institute's Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Tito R. Mendoza, PhD, Univ. of Texas MD Anderson Cancer Ctr., Houston, TX, United States; Antonia V. Bennett, PhD, Univ. of North Carolina at Chapel Hill; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill; Thomas M. Atkinson, PhD; Yuelin Li, PhD; Lauren Rogak, MA, MSKCC; Amylou C. Dueck, PhD, Mayo Clinic; Ethan Basch, MD MSc, Univ. of North Carolina at Chapel Hill; on behalf of the National Cancer Institute PRO-CTCAE Research Group

(2106) Patients with Metastatic Renal Cell Carcinoma (mRCC) on Palliative Cancer Treatment: Relevant Social and Working Life Aspects of Therapy

Sandra Meyer-Mooock, Univ. Medicine Greifswald, Germany; Berit Eberhardt, Das Lebenshaus; Sarah Schmitter; and Rainer Niedtner, Pfizer Deutschland; Viktor Grünwald, Hannover Medical School; Ines Buchholz, Univ. Medicine Greifswald; Christina Claußen, Pfizer Deutschland; Thomas Kohlmann, PhD, Univ. of Greifswald

(2108) Implementation of a PRO, Brief Pain Inventory, in a Large Healthcare System

Thomas E. Elliott, MD, HealthPartners Inst. for Education and Research, Minneapolis, MN, United States; Colleen M. Renier, BS; and Jeanette A. Palcher, Essentia Inst. of Rural Health

🦋 (2110) Development of the Social Activities and Independence Questionnaire in Paediatric Diabetes as part of the DECIDE Randomised Controlled Trial

Timothy El Pickles, BSc (Hons) MSc, Cardiff Univ., United Kingdom; Sue Channon; John Gregory; and Lesley Lowes, Cardiff Univ.

Friday, 17 October



SCIENTIFIC PROGRAM

4:00 pm – 5:30 pm

Concurrent Oral Sessions

Oral Session 206: PROMIS®: New Measures, New Populations

HALL I - C

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

4:05 – 4:18 pm (206.1) Exploratory and Confirmatory Factor Analysis of PROMIS® Pain Quality Version-2 Items

Dennis Revicki, PhD, Evidera, United States; Wen-Hung Chen, RTI; Esi Morgan DeWitt, MD, MSCE, Cincinnati Children's Hospital Medical Center; Cindy Nowinski, MD PhD, Northwestern Univ.; Kaleb Michaud, PhD; and Fred Wolfe, National Data Bank for Rheumatic Diseases; David Cella, PhD, Northwestern Univ.

4:19 – 4:32 pm (206.2) Validation of the PROMIS® Mobility Computer Adaptive Test in Patients with Orthopaedic Trauma to a Lower Extremity

Nan Rothrock, PhD, Northwestern Univ., Chicago, IL, United States; Mark Vrahas, Harvard Orthopedic Trauma Service; Robert V. O'Toole, Univ. of Maryland School of Medicine; Sarah Buono, Northwestern Univ.; Amanda Holmes, Univ. of Maryland School of Medicine; Jordan Morgan, Harvard Orthopedic Trauma Service; Suzanne Morrison, Harvard Orthopedic Trauma Service; Richard Gershon, PhD, Northwestern Univ.

4:33 – 4:46 pm (206.3) Differential Item Functioning between English Source Version and a German Translation of the PROMIS® Item Bank for Depression

Felix Fischer, PhD, Charité – Universitätsmedizin Berlin, Germany; Inka Wahl, PhD, Univ. Medical Center Hamburg-Eppendorf; Sandra Nolte, PhD, Charité; Elmar Brähler, Leipzig Univ.; Bernd Löwe, Univ. Medical Center Hamburg-Eppendorf & Schön Klinik Hamburg Eilbek; Matthias Rose, MD PhD, Charité

4:47 – 5:00 pm (206.4) Psychometric Properties of the Spanish Version of the Patient-Reported Outcomes Measurement Information System (PROMIS®) Depression Item Bank in a Clinical Sample

Gemma Vilagut, MSc, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain; Carlos Garcia Forero, PhD; Elena Olariu; Jordi Alonso, MD PhD; On Behalf of INSAyD Inv., IMIM-Hospital Del Mar Medical Research Institute

STUDENT PRESENTATION AWARD FINALIST

5:01 – 5:14 pm (206.5) Validation of the Dutch-Flemish PROMIS® Pain Behaviour and Pain Interference Item Banks in Patients presenting for Spinal Manipulative Treatment

Wouter Schuller, EMGO+ Institute for Health and Care Research, Amsterdam, Netherlands; Caroline B. Terwee, PhD; Francisca Galindo-Garre; Niels Smits; Raymond Ostelo; and Henrica C.W. de Vet, Sr., PhD, VU Medical Center

5:15 – 5:28 pm (206.6) The Impact of Dutch- Versus English-Language Calibrations on Theta Estimates of the Dutch-Flemish PROMIS® Pain Behavior and Pain Interference Item Banks

Martine H.P. Crins, Reade | Amsterdam Rehabilitation Research Center, Amsterdam, Netherlands; Niels Smits, VU Univ. Medical Center; Leonard Roorda, MD PhD, Amsterdam, Netherlands; David Cella, PhD, Northwestern Univ.; Karon F. Cook, PhD, Northwestern Univ.; Caroline B. Terwee, PhD, VU Univ. Medical Center

STUDENT PRESENTATION AWARD FINALIST

Oral Session 207: Advancing Mental Health Assessment

HALL I - A

Session Chair: Juan J. Dapuerto, MD PhD, Uruguay

4:05 – 4:18 pm (207.1) What Can Modern Measurement Methods Tell Clinicians about Adaptive Responses of Depression?

Skye P. Barbic, PhD, OT, Univ. of Toronto, Canada; Zachary Durisko, Centre for Addiction and Mental Health, Toronto; Paul W. Andrews, McMaster Univ.

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

Friday, 17 October

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

4:19 – 4:32 pm (207.2) How to Interpret Multidimensional Quality of Life Questionnaire in Schizophrenia ?
Pierre Michel, Aix Marseille Université, Marseille, France; Karine Baumstarck, Aix Marseille Université; Pascal Auquier, Univ. Hospital of Marseille; Anderson Loundou, Self-Perceived Health Assessment Research Unit, Marseille; Julie Berbis, Medicine Univ., Marseille; Christophe Lançon, Aix Marseille Université; Badih Ghattas, Faculté Des Sciences de Luminy, Marseille; Laurent Boyer, PhD, Aix-Marseille Univ.

STUDENT PRESENTATION AWARD FINALIST

4:33 – 4:46 pm (207.3) Low Functional Status as a Predictor of Incident Emotional Disorders: A Population-Based Study

Gabriela Barbaglia Navarro, MD MPH, IMIM - Hospital Del Mar Medical Research Institute, Barcelona, Spain; Ron De Graaf; Margeret Ten Have; and Saskia Van Dorsselaer, The Netherlands Institute of Mental Health and Addiction; Gemma Vilagut, MSc, IMIM; Jordi Alonso, MD PhD, IMIM

4:47 – 5:00 pm (207.4) Factors Associated with Quality of Life in Bipolar Disorder

Sandro R P S Miguel, MD, Institute for Health Technology Assessment, Porto Alegre - Rio Grande Do Sul, Brazil; Luciane N. Cruz, MD, PhD; and Mirian Cohen, Univ. Federal do Rio Grande do Sul; Jacques Zimmermann, MD MSc; Marcelo P. Fleck, MD PhD, Hospital de Clinicas de Porto Alegre; Ana Flávia B S Lima, Univ. Federal do Rio Grande do Sul

5:01 – 5:14 pm (207.5) Patient Health Questionnaire 9 (PHQ-9) use in Primary Care Clinical Practice – Association with Prescription of Antidepressants and Referral to Behavioral Health Specialists

Colleen M. Renier, BS, Essentia Institute of Rural Health, Duluth, MN, United States; Thomas E. Elliott, MD, HealthPartners Institute for Education and Research; Jeanette A. Palcher, Essentia Institute of Rural Health

5:15 – 5:28 pm (207.6) Mindfulness and Health-Related Quality of Life

Cynthia Gross, PhD, Univ of Minnesota, Pharmacy & Nursing, Minneapolis, MN, United States; Maryanne Reilly-Spong, Univ. of Minnesota; Olga Gurvich, Univ. of Minnesota

Oral Session 208: Advancing Preference-Based Measurement Science

SALON 2

Session Chair: Simon Pickard, PhD, United States

4:05 – 4:18 pm (208.1) Construct Validity of SF-6D Health State Utility Values in an Employed Population

Siyam Baxter, PhD Candidate, Univ. of Tasmania, Australia; Kristy Sanderson; Alison Venn; Petr Otahal; and Andrew J. Palmer, Univ. of Tasmania

4:19 – 4:32 pm (208.2) Cross-Sectional Construct Validity of Five Generic Preference-Based Measures in Teens

David Feeny, PhD, McMaster Univ., Canada; Frances L. Lynch; John Dickerson; Gregory Clarke; and Alex MacMillan, The Center for Health Research, Kaiser Permanente Northwest

4:33 – 4:46 pm (208.3) Developing Version 2 of the SF-6D: The Health State Classification System

Brendan Mulhern, Univ. of Sheffield, United Kingdom; John E. Brazier, PhD, Univ. of Sheffield

4:47 – 5:00 pm (208.4) Comparison of an Online Survey and Face-to-Face Interviews for Eliciting Societal Preferences

Donna Rowen, PhD, Univ. of Sheffield, United Kingdom; John E. Brazier, PhD; Anju Keetharuth; and Aki Tsuchiya, Univ. of Sheffield; Angela Robinson, Univ. of East Anglia; Clara Mukuria, PhD, Univ. of Sheffield

5:01 – 5:14 pm (208.5) Does Weighting Matter? Comparing Unweighted vs. Weighted Values in Two Health State Utility Instruments (EQ-5D-5L and 15D)

Admassu Nadew Lamu, Univ. of Tromsø, Norway; Thor Gamst-Klaussen, Univ. of Tromsø; Jeff Richardson, Univ. of Monash; Jan Abel Olsen, PhD, Univ. of Tromsø

5:15 – 5:28 pm (208.6) HYE and ME as Identical Currencies in Preference Studies? A Discrete-Choice Experiment in Type-II-Diabetes

Axel C. Muehlbacher, Hochschule Neubrandenburg, Germany; Susanne Bethge, Hochschule Neubrandenburg

Friday, 17 October

 Outstanding Poster Abstract Award

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Oral Session 209: Adapting Measures Across Languages and Cultures

SALON 4

Session Chair: Hwee-Lin Wee, PhD, Singapore

4:05 – 4:18 pm (209.1) Linguistic Validation of the Spanish Translation of the U.S. National Cancer Institute's Patient- Reported Outcomes Version of the Common Terminology Criteria for Adverse Events

Benjamin J. Arnold, MA, FACITtrans, United States; Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute; Lauren Lent, DHA, MS, FACIT.org and FACITtrans; Tito R. Mendoza, PhD, Univ. of Texas M.D. Anderson Cancer Center; Lauren Rogak, MA, MSKCC; Natalie Barragan, MSKCC; Gordon B. Willis, National Cancer Institute; Mauricio Medina, National Cancer Institute; Suzanne C. Lechner, Univ. of Miami; Jay Harness, St. Joseph Hospital of Orange; Ethan Basch, MD MSc, Univ. of North Carolina - Chapel Hill

4:19 – 4:32 pm (209.2) Translation Methodology for Brazilian Sign Language of the WHOQOL-BREF and WHOQOL-DIS Life Quality Evaluation Instruments

Adriana Ribeiro Freitas, Pontifícia Universidade Católica de Goiás, Brazil; Neuma Chaveiro; Soraya Bianca Reis Duarte; and Maria Alves Barbosa, PhD, Federal Univ. of Goias; Valeska C. Kantzer, Health Research Associates, Inc.; Marcelo P. Fleck, MD PhD, Hospital de Clinicas de Porto Alegre

4:33 – 4:46 pm (209.3) At What Point are Existing Translations Considered to be Outdated?

Valeska C. Kantzer, Health Research Associates, Inc., United States; Yulia Galperina; and Sarah Basse, Health Research Associates, Inc.

4:47 – 5:00 pm (209.4) Feasibility and Application of the Infant Toddler Quality of Life™ (ITQOL) in a Community-Based Sample of Healthy Infants in China

Sheri Volger, MS RD, Nestlé Nutrition, United States; Nicholas P. Hays, Nestlé Nutrition; Robert Northington, Nestlé Nutrition; Meng Mao, Chengdu Women's and Children's Central Hospital; John Ge, Wyeth Nutritional (China) Company Ltd; Jeanne Landgraf, MA, HealthAct CHQ Inc.,

5:01 – 5:14 pm (209.5) Cross-Cultural Adaptation of a Health Measure for Métis Children and Youth

Tara Paquette; Jessica Boulard; Annie Roy-Charland; and Nancy L. Young, PhD, Laurentian Univ. Canada

Oral Session 210: Advancing PROs: Patient-Centered Outcomes Research

HALL I - B

Session Chair: Sara Ahmed, PhD, Canada

4:05 – 4:18 pm (210.1) Patient Involvement in the Development of Patient-Reported Outcome Measures: A Literature Review

Bianca Wiering, TRANZO, Tiburg Univ.; Dolf De Boer, NIVEL, Utrecht, Netherlands; Diana Delnoij, TRANZO, Tiburg Univ.

4:19 – 4:32 pm (210.2) Conversion Mixed Design: A Promising Mixed Methods Research Approach to Patient-Centered Outcome Questions in Clinical Research

Fatoumata Fofana, Mapi; Univ. of Nantes, Lyon, France; Angélique Bonnaud-Antignac, Univ. of Nantes; Alexia Marrel, Mapi; Antoine Regnault, PhD, Mapi HEOR & Strategic Market Access

4:33 – 4:46 pm (210.3) Evaluation of the Patient-Reported Outcome (PRO) Content of Clinical Trial Protocols

Derek Kyte, MSc, Univ. of Birmingham, United Kingdom; Helen Duffy, Univ. of Birmingham; Benjamin Fletcher, Univ. of Oxford; Adrian Gheorghie, Univ. of Birmingham; Rebecca L. Mercieca-Bebber, Univ. of Sydney; Madeleine T. King, PhD, Psycho-oncology Cooperative Research Group (PoCoG); Heather Draper, Univ. of Birmingham; Jonathan CS Ives, PhD, Univ. of Birmingham; Michael Brundage, MD, Queen's Univ.; Jane Blazeby, MD, Univ. of Bristol; Melanie Calvert, PhD, Univ. of Birmingham

4:47 – 5:00 pm (210.4) Patient-Reported Outcomes in Randomized Controlled Trials of Colorectal Cancer Treatment Methodological Quality and Impact on Clinical-Decision-Making

Jonathan R. Rees, MSc PhD FRCS, Univ. of Bristol, United Kingdom; Katie Whale, Univ. of Bristol; Daniel Fish, MSKCC; Peter Fayers, PhD, Univ. of Aberdeen; Valentina Cafaro, GIMEMA; Andrea Pusic, MD MHS FRCS, MSKCC; Jane Blazeby, MD, Univ. of Bristol; Fabio Efficace, PhD, GIMEMA

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

5:01 – 5:14 pm (210.5) Methodological Quality of Patient-Reported Outcomes (PROs) In Breast Cancer Trials According to the CONSORT PRO Extension: Evidence from 122 Trials enrolling over 83,00 patients.

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy; Yeliz Cemal, MSKCC; Andrea Pusic, MD MHS FRCSC, MSKCC; Peter Fayers, PhD, Univ. of Aberdeen; Alfonso Picocchi, GIMEMA Data Center; Jonathan R. Rees, MSc PhD FRCS, Univ. of Bristol; Jane Blazeby, MD, Univ. of Bristol

5:15 – 5:28 pm (210.6) Routine Clinical Quality of Life Measurement for Head and Neck Cancer Patients: Example from a Province-Wide Oncology Initiative

Jolie Ringash, MD, The Princess Margaret Cancer Centre, Toronto, Canada; Alyssa Macedo; Madeline Li; Terri Stuart-McEwan; and Anita Archer, The Princess Margaret Cancer Centre; Andrew Hope; Brian O'Sullivan; and John Waldron, The Princess Margaret Cancer Centre and The Univ. of Toronto

5:45 pm – 6:30 pm Special Interest Group (SIG) Meetings

Ibero America SIG Meeting	SALON 4
New Investigator SIG Meeting	SALON 2
Psychometrics SIG Meeting	HALL I - C

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Friday, 17 October



SCIENTIFIC PROGRAM

Saturday, 18 October

7:00 am – 4:00 pm Registration Desk Open

7:30 am – 8:45 am Committee & Special Interest Group (SIG) Meetings

Child Health SIG Meeting

SALON 2

QOL in Clinical Practice SIG Meeting

HALL I – C

Translation & Cultural Adaptation (TCA) SIG Meeting

SALON 4

9:00 am – 10:15 am ISOQOL Member Business Meeting and Awards Presentation

HALL I – AB

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:

2014 President's Award

Emerging Leader Award – In Honor of Donna Lamping

Outstanding Article of the Year Award

New Investigator and Student Presentation Awards

10:00 am – 4:00 pm Poster Hall Open

Hall II

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

10:25 am – 10:45 am Saturday Poster Session 1

HALL II

Breast and Prostate Cancer

(3001) Quality of Life in Long Term Premenopausal Early Stages Breast Cancer Survivors - Determinants of Future Perspective and Global QOL

Juan Ignacio Arraras, PhD, Servicio Navarro de Salud, Spain; Jose Juan Illarramendi; Esteban Salgado; Susana De La Cruz; Gemma Asin; and Ana Manterola, Complejo Hospitalario de Navarra; Berta Ibañez, REDISSEC; Uxue Zarandona, Complejo Hospitalario de Navarra; Koldo Cambra, REDISSEC; Miguel Angel Dominguez, Complejo Hospitalario de Navarra

(3003) Quality of Life Following Mastectomy and Breast Reconstruction: Learning From The QUEST Feasibility Randomised Trials (CRUK /08/027).

Zoe E. Winters, University of Bristol, United Kingdom; Clare Griffin; Judith Mills; and Penny Hopwood, Institute of Cancer Research; Natalie Bidad; and Lindsay MacDonald, Univ. College London; Philip Turton, Leeds NHS Trust; Robert Horne, Univ. College London; Judith Bliss, Institute of Cancer Research

(3005) Patient-Reported Outcomes (PROs) and Treatment Decision-Making in Ductal Carcinoma in Situ (DCIS) of the Breast: A Systematic Review

Claudia Rutherford, PhD, QOL Office, University of Sydney, Australia; Madeleine T. King, PhD, PoCoG; On Behalf of the DCIS PRO Collaborative Group, QOL Office, Univ. of Sydney

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(3007) Determinants of Quality of Life among Long-Term Breast Cancer Survivors

Wai-on Chu; and **Pegdwende Olivia Dialla**, Centre Georges François Leclerc Comprehensive Cancer Centre, Dijon, France; Patrick Roignot, Pathology Centre, Dijon; Marie-Christine Bone-Lepinoy, Centre Radiothérapie Du Parc, Dijon; Marie-Laure Poillot; Charles Coutant; Patrick Arveux; and Tienhan Sandrine Dabakuyo, PharmD PhD, Centre Georges-Francois Leclerc

(3009) Health-Related Quality of Life in Men Undergoing Radical Prostatectomy and the Relationship with Psychosocial Factors: Preliminary Data

Livia Cristina de Resende Izidoro; Glaucia B. Soares; Tamires C. Vieira; Fabiana Souza Orlandi, PhD; Priscilla Hortense; and **Anamaria A. Napoleao**, PhD, Federal University of São Carlos, Brazil

(3011) Domains of Improvements in Quality of Life after Testosterone Recovery for High Risk Prostate Cancer Patients Treated with Long Term Androgen Deprivation Therapy

Abdenour Nabid, MD, FRCP(C), Centre Hospitalier Universitaire de Sherbrooke, Canada; Nathalie Carrier, Centre Hospitalier Univ. de Sherbrooke; André-Guy Martin, Hôtel-Dieu de Québec; Jean-Paul Bahary, MD, FRCP, Centre Hospitalier de L'Univ. de Montreal; Luis Souhami, Centre Univ. de Santé McGill; Marie Duclos, Centre Univ. de Santé McGill; Francois Vincent, Centre Hospitalier Régional de Trois-Rivières; Sylvie Vass, CSSS de Chicoutimi; Boris Bahoric, Hôpital Général Juiif; Robert Archambault, Hôpital de Gatineau

Endocrinology/Diabetes/Obesity

(3013) The Relationship between Fitness and Health-Related Quality of life and the mediating role of Self-Determined Motivation in Adolescents with Overweight

Kirsti Riiser, Oslo & Akershus University College of Applied Sciences, Oslo, Norway; Yngvar Ommundsen, Norwegian School of Sport Sciences; Milada C. Smaastuen; Knut Løndal; Nina Misvær; and Sølvi Helseth, PhD, Oslo & Akershus Univ. College of Applied Sciences

(3015) Quality of Life and Health Habits in Patients With or Without Type 2 Diabetes

Jose Guadalupe Salazar Estrada, Sr., Psic, PhD, Universidad de Guadalajara, Mexico; Norma A. Ruvalcaba, II; and Gustavo Hidalgo-Santacruz, MA, Univ.de Guadalajara

(3017) Quality of Life in Patients with Benign Non-Toxic Goitre as Compared to the General Population: Baseline and 6 Months Post-Treatment

Per Cramon, MD, Copenhagen University Hospital, Denmark; Åse K. Rasmussen, Copenhagen Univ. Hospital Rigshospitalet; Jakob B. Bjorner, MD PhD, QualityMetric; Steen J. Bonnema, Odense Univ. Hospital; Daniel M. Frenzl, Univ. of Massachusetts Medical School; Mogens Groenvold, MD, PhD, Univ. of Copenhagen; Laszlo Hegedüs, Odense Univ. Hospital; Ulla Feldt-Rasmussen; and Torquil Watt, MD PhD, Copenhagen Univ. Hospital

(3019) Impact of Irritable Bowel Syndrome with Constipation on Health-Related Quality of Life Among Commercially Insured Patients in the United States

Judith J. Stephenson, HealthCore Inc.; Jessica Buono, Forest Laboratories; **William M. Spalding**, Ironwood Pharmaceuticals; Qian Cai, HealthCore Inc; Hiangkiat Tan, HealthCore Inc; Robyn Carson, MPH, Forest Research Institute; Jalpa A. Doshi, Univ. of Pennsylvania

(3021) Contribution of Significant Life Events to HRQOL Assessment in a Haemophilia Sample

Jean St-Louis, CHU Sainte Justine; **Robert Klaassen**, MD, Children's Hospital of Eastern Ontario, Canada; Nancy L. Young, PhD, Laurentian Univ.; Diana Urajnik, Laurentian Univ.; Stephanie Cloutier, L' Hôpital de L'Enfant-Jésus; Bruce Ritchie, Univ. of Alberta; Margaret Warner, Royal Victoria Hospital; Francine Menard, CHU Sainte Justine; Georges E. Rivard, Hôpital Ste-Justine; Victor Blanchette, Hospital for Sick Children

Mental Health

🦋 (3023) Measuring Recovery Orientation in People with Serious Mental Illness: Application of Modern Methods to Reveal the Shortcomings of Revised Scales in Mental Health

Skye P. Barbic, PhD, OT, University of Toronto, Canada; Sean Kidd, Centre for Addiction and Mental Health, Toronto; Maria O'Connell, Yale Univ.; Kwame McKenzie, Wellesley Institute; Larry Davidson, Yale Univ.

🦋 (3027) Construct Validation of the Adolescent Mental Health Continuum-Short Form (MHC-SF) in Japanese and Norwegian High School Students

Junko Sakano, Okayama Prefectural University, Japan; Eva Langeland, Bergen Univ. College; Ragnhild Sollesnes, Bergen Univ. College; Yuki Yajima, Niimi College; Shin-ichiro Sasahara, Univ. of Tsukuba; Yoshihiko Yamazaki, Nihon Fukushi Univ.

🦋 Outstanding Poster Abstract Award

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SCIENTIFIC PROGRAM

(3031) The Impact of Second Generation Antipsychotics on Psychosocial Functioning in Bipolar Disorder

Omer Aydemir, Celal Bayar University, Izmir, Turkey; Pinar Cetinay-Aydin, Bakirkoy Mazhar Osman Research and Training Hospital; Demet Gulec-Oyeckin, Onsekiz Mart Univ.; Seref Gulseren, Ataturk Research and Training Hospital; Gulperi Putgul-Koybasi, Menemen State Hospital; Hasan Sahin, Bayindir State Hospital

Pulmonary

(3033) Does the Smoking Cessation Improve the Smoker's Quality of Life?

Yuto Hayashi, Japanese Society of Quality of Life Research, Hyogo, Japan; Ryo Yoshioka; Kazunori Tanaka, PhD; Yusuke Tanaka; and Yuto Oiki, Japanese Society of QoL Research; Yuko Takahashi, MD PhD, Nara Women's Univ.; Michiko Kobayashi, MD, Japanese Society of QoL Research; Tomotaka Sobue, MD PhD, Osaka Univ.; Takashi Mandai, MD PhD, Japanese Society of QoL Research

(3035) Self-Perceived Sleep Quality and Quantity in Adult Subjects with Asthma in a Real World

Setting: Findings from the Costeasma Study

Pedro Ojeda, Clínica de Asma Y Alergia Dres; Verónica Sanz de Burgoa, Pfizer, S.L.U.; Javier Rejas, Pfizer, S.L.U., Madrid, Spain

(3037) Development of E-Versions of the Asthma Quality of Life Questionnaire (Standardised)

[AQLQ(S)] in Twenty (20) Languages for Use on Handheld Devices

Elizabeth Juniper, MCSP, MSc, McMaster Univ. Med Ctr; Géraldine Grataloup, Mapi; Catherine Acquadro, Mapi Research Trust, Lyon, France

(3039) Identifying Important Domains of HRQOL for Patients with COPD: The Perspective of Healthcare Professionals

Muirne CS Paap, University of Twente, Netherlands; Christina Bode; and Lonneke Lenferink, Univ. of Twente; Caroline B. Terwee, PhD, VU Univ. Medical; Job Van Der Palen, Medisch Spectrum Twente

(3041) Combining Disease-Relevant and Disease-Attributed Measures to Assess HRQOL in Patients with COPD in the Netherlands and Canada

Muirne CS Paap, Univ. of Twente; Sara Ahmed, PhD, McGill University, Montreal, Canada; Owis J. Eilayyan, McGill Univ.; Caroline B. Terwee, PhD, VU Univ. Medical Center; Job Van Der Palen, Medisch Spectrum Twente

(3043) A Prospective Observational Study of the Impact of Chronic Obstructive Pulmonary Disease (COPD) on Health-Related Quality of Life (HRQOL) of Patients Receiving Indacaterol

Paul Jones, MD PhD, St. George's Univ. of London; Monica Hadi, pH Associates Ltd, Marlow; Ruth Uden, pH Associates Ltd, Marlow; Anzal Qurbain, Novartis Pharmaceuticals Ltd

Children

(3045) Impact of Gastrointestinal Problems on Children with Autism Spectrum Disorders and their Caregivers

Nalin Payakachat, BPharm, MS, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; J. Mick Tilford, PhD, Univ. of Arkansas for Medical Sciences; Erica Kovacs, Columbia Univ. Medical Center; Jeffrey M. Pyne, Univ. of Arkansas for Medical Science; Karen A. Kuhlthau, PhD, Center for Child and Adolescent Health Research and Policy, Boston

(3047) Health-Related Quality of Life and its Possible Determinants among Mothers of Children with Cerebral Palsy

Nivea M. O. Morales, MD MSc PhD, Federal University of Uberlândia, Brazil; Ludmilla Rabelo Guimarães; Carlos Henrique Martins Silva, Sr.; Anaísa R. Amorim; Rogerio R. Morales, MD; Rogério M C Pinto, Federal Univ. of Uberlândia

(3049) Improving Transition of Adolescents with Chronic Health Conditions from Pediatric to Adult Healthcare Services: The Effects of an Educational Program on Self-Management and Health-Related Quality of Life (HRQOL).

Stefanie Hahm, University of Greifswald, Germany; Carsten Herrmann, Ernst-Moritz-Arndt-Univ.; Franziska Bomba, Univ. of Luebeck; Ute Thyen, MD, Universitaetsklinikum Schleswig-Holstein; Silke Schmidt, PhD, Univ. of Greifswald

 Outstanding Poster Abstract Award

SCIENTIFIC PROGRAM

(3051) Legal Guardian's Proxy Ratings of Health-Related Quality of Life and HIV Stigma for their Children Living with Early-Acquired HIV Infection: A Comparative Study

Lise-Lott Rydstrom, Karolinska Institutet, Sweden; Britt-Marie Ygge, Karolinska Hospital; Lars Naver, Karolinska Univ. Hospital; Maria Wiklander, PhD, Karolinska Institutet; Lars E. Eriksson, PhD, Karolinska Institutet

(3053) Satisfaction with Life and Psychological Distress in Children as a Function of Parental Life Satisfaction and Psychological Distress

Jocelyne M.R. Clench-Aas, PhD, Norwegian Inst. of Public Health, Oslo, Norway; Ragnhild Bang Nes, Norwegian Inst. of Public Health

Population Health

(3055) Measuring Well-Being: Psychometrics, Conceptual Consistency and the Plausibility of a Gold Standard

Myles-Jay A. Linton, BSc, Univ. of Exeter, United Kingdom; Antonieta Medina-Lara, BSc(Hons), MSc, PhD, Univ. of Exeter Medical School

(3057) Safety, Health and Quality of Life in Personal and Organizational Level in the Manufacturing Industry

Jose Guadalupe Salazar Estrada, Sr., Psic, PhD, Universidad de Guadalajara, Mexico; Norma S. Figueroa Villaseñor; and Raquel Gonzalez-Baltazar, PhD, Univ. of Guadalajara

(3059) Sense of Coherence among Japanese White Collar Workers Participating in "Salutogenic Café" - A Six Months Follow-Up Study

Shin-ichiro Sasahara, University of Tsukuba, Japan; Junko Sakano, Okayama Prefectural Univ.; Eva Langeland; and Ragnhild Sollesnes, Bergen Univ. College; Yuichi Oi; Kazuya Usami; Shun Suzuki; Yasuhito Hirai; and Hidetoshi Kaneko, Univ. of Tsukuba; Yoshihiko Yamazaki, Nihon Fukushi Univ.

(3061) Perceived Neighborhood Environment and Adults Health in Three Tunisian Cities

Khaled Hassine, ANCSEP / Ministry of Health, Tunisia; Thouraya Annabi-Attia, ANCSEP / Ministry of Health

(3065) How Experience Immigrant Parents of disabled or Chronically Ill Children their Own Health and Quality of Life?

Lisbeth G. Kvarme, PhD, Oslo and Akershus University College, Oslo, Norway; Elena Albertini Früh, II; and Liv Halvorsrud, Oslo and Akershus Univ. College of Applied Science; Hilde Liden, IV, Institutt for Samfunnsforskning

(3067) Quit Smoking is Associated with Better Health-Related Quality of Life in the Spanish General Population

Alfonso De Lossada, Pfizer, S.L.U.; Javier Rejas, Pfizer, S.L.U., Madrid, Spain

Cross-Cultural Adaptation

(3069) The Translatability of Fatigue Across Languages

Barbara A. Brandt, MA, Corporate Translations, Inc.; Shawn McKown, MA, Corporate Translations, Inc., United States; Matthew Talbert, Corporate Translations, Inc.; Mary C. Gawlicki, MBA, Corporate Translations, Inc.

(3073) Reporting of Methods Used for Translations of Pediatric Patient-Reported Outcomes (PRO)

Mika Nokela, Covance Market Access; Anna-Karin Berger, PhD, Covance Market Access; Anders P. Ingelgård, PhD Docent, Covance

(3077) The Stroke Impact Scale: Validation of the French Version

Sylvia Cael, University of Dijon, France; Pierre Decavel, CHU Besancon; Christine Binquet, Univ. Hospital, Inserm; Charles Bénaim, CHU Dijon; Marc Puyraveau; Morgane Chotard; Thierry Moulin; and Bernard Parratte, CHU Besancon; Yannick Béjot, CHU Dijon; Mariette Mercier, Univ. Hospital of Besancon

(3079) Recommended Guidelines for Accepting Changes that Affect Existing Translations

Rosanna Sze, Health Research Associates, Inc.; Valeska C. Kantzer, Health Research Associates, Inc., United States

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Patient-Centered Research

(3083) Engaging Patients in Developing Outcome Measures - Does Context of Use Drive Methodological Decisions?

Anne Skalicky, MPH, Evidera; Susan Magasi, Univ. of Illinois; Asha Hareendran, PhD, Evidera, United Kingdom

(3085) Symptom Distress Profiles in Hospitalized Patients in Sweden – A Point Prevalence Survey

Ingela Henoeh, University of Gothenburg, Sweden; Richard Sawatzky, PhD RN, Trinity Western Univ.; Hanna Falk; Isabel Fridh; and Eva Jakobsson Ung, Univ. of Gothenburg; Elisabeth Kenne Sarenmalm, Skaraborg Hospital; Anneli Ozanne, Univ. of Gothenburg; Joakim Öhlén, Ersta Sköndal Univ. College; Kristin Falk, Univ. of Gothenburg

(3087) Hidden Pathways of Chronic Illness: A Patient-Generated Study

Sandra Zelinsky, University of Calgary, Canada; Nancy Marlett; and Svetlana Shklarov, Univ. of Calgary

Utilities/Cost-Effectiveness Methods

(3089) Domains Associated with Changes in Quality of Life Related to Health (HRQOL): A Method Based on Preference

Martin Romero, MD PhD(c), Universidad Nacional de Colombia; Nelson Alvis-Guzman; and Jannina Alvis-Zakzuk, Universidad de Cartagena; Ruben Marrugo; Lina Huerfano; and Maritza Sanabria, Fundacion Salutia

(3091) Fifth Wheel: Evidence of Disagreements Between Health Scales and Preferences in the EQ-5D

Benjamin M. Craig, PhD, H. Lee Moffitt Cancer Center & Research Inst., Tampa, FL, United States

Statistical Analysis of PROs

(3097) The Empowerment Scale: A Factor Analysis to Determine Multi- or Unidimensionality

Jane Kass-Wolff, University of Colorado Anschutz Medical Campus, United States; Karen H. Sousa, RN PhD, Univ. of Colorado Denver

(3099) The Analysis of Multivariate Longitudinal Data: An Application of the Longitudinal Three-Mode Model in Health-Related Quality of Life Data

Mathilde Verdam, University of Amsterdam, Netherlands; F. J. Oort, Univ. of Amsterdam; Y. M. Van Der Linden, Leiden Univ. Medical Centre; Mirjam AG Sprangers, PhD, Academic Medical Center

(3101) The Influence of a Monetary Incentive on (Online) Response, Response Time, and Quality of Life Outcomes

Nicole J. Horevoorts, MA, Tilburg University, Netherlands; Simone Oerlemans, Comprehensive Cancer Center Netherlands; Floortje Mols; and Pauline Vissers, Tilburg Univ.; Lonneke Van de Poll-Franse, Comprehensive Cancer Center South

(3103) Response Shift Associated with the Pediatric Health Status Change on the Rating of Asthma-Specific Quality of Life: An Item-Level Analysis

Pranav Gandhi, PhD, South College School of Pharmacy, Knoxville, TN, United States; Darren DeWalt, MD MPH, Univ. of North Carolina, Chapel Hill; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc.; I-Chan Huang, PhD, Univ. of Florida

(3105) Semantic Primes: A Possible Way to Avoid Response Shift?

Antoine Vanier, MD, University Pierre Et Marie Curie Paris, France; Alain Leplège, MD, PhD, Univ. of Paris Diderot; Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes; Veronique Sebillé, ScD, Univ. of Nantes; Bruno Falissard, Univ. Paris-Sud and Univ. Paris-Descartes

(3107) Sample Size Determination when Conducting a Confirmatory Factor Analysis (CFA): How Sample Size, Scale Characteristics, Data Characteristics and Estimation Methods Affect Fit Indexes?

Emmanuelle Anthoine, Univ. of Nantes; Leila Moret, Univ. Hospital of Nantes; Veronique Sebillé, ScD, University of Nantes, France; Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes

SCIENTIFIC PROGRAM

11:00 am – 12:30 pm **Plenary Session: Well-Being and Mental Health Measurement Opportunities** **HALL I – AB**

Plenary session sponsored by Shire.

The importance of mental health for well-being, and vice-versa, has been both conceptually and empirically recognized. Nevertheless, there is still a gap between such recognition and its translation into measurement applied to individual and public health.

This plenary session will address different perspectives about how mental health and well-being could be both understood and integrated conceptually and why they could be considered promising measurements for clinical settings and health economics.

Speakers

Carol D. Ryff, PhD, Director, Institute on Aging, Marie Jahoda Professor of Psychology, University of Wisconsin-Madison, United States

David Cella, PhD, Feinberg School of Medicine, Northwestern University, United States

John Brazier, PhD, School of Health and Related Research (ScHARR), University of Sheffield, United Kingdom

Plenary chaired by **Jordi Alonso, MD PhD**, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain and **Marcelo Fleck, MD PhD**, Hospital de Clinicas de Porto Alegre Brazil

12:30 pm – 1:30 pm **Lunch Buffet – Served in Poster Hall**

12:30 pm – 1:30 pm **Committee Meeting** **SALON 3**

SIG Leader Council

1:45 pm – 3:15 pm **Concurrent Symposium Session**

Symposium #4: Quality of Life and Cancer Prevention **SALON 2**

Moderator: Carolyn Gotay, PhD, University of British Columbia, Vancouver, Canada

Cancer is one of the most prevalent chronic and fatal diseases worldwide, yet at least half of all cancer cases could be prevented. This symposium presents information about the effects of a four different cancer prevention interventions on HRQOL and other outcomes.

This symposium will provide attendees with a novel perspective on the uses and contributions of HRQOL assessment, going beyond assessing well-being in patients with a diagnosed illness, toward contributing to health in the general population.

INDIVIDUAL PRESENTATIONS

A Sleep Intervention to Improve Quality of Life (QOL) and Sleep in Shiftworkers at Increased Risk of Breast Cancer

Carolyn Gotay, PhD, Cancer Prevention Centre, Univ. of British Columbia, Vancouver, Canada

Quality Of Life and HPV Vaccine

Ida J. Korfage, Erasmus MC - University Medical Centre Rotterdam, Netherlands

Health-Related Quality of Life Outcomes in Prostate Cancer Prevention Clinical Trials

Carol M. Moinpour, PhD, Fred Hutchinson Cancer Research Center, Seattle, WA, United States

Health-Related Quality Of Life (HRQOL) Following Prophylactic Mastectomy and Reconstruction

Andrea Pusic MD, MHS, FRCSC, Memorial Sloan-Kettering Cancer Center, New York, NY, United States

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SCIENTIFIC PROGRAM

Symposium# 5: Ambulatory Monitoring and Mobile Assessment of Quality of Life

SALON 4

Moderator: Silke Schmidt, PhD, Ernst-Moritz-Arndt-University, Greifswald, Germany

Discussant: Mogens Grönvold, MD PhD, Dept. of Public Health, Section of Health Services Research, Copenhagen, Denmark

Ambulatory monitoring and mobile assessment of quality of life are emerging areas in clinical studies and scientific research. Due to technological developments, remote assessment of patient-reported outcomes has become more accessible and easy-to-use.

The symposium aims to provide an overview on several methodological challenges that are related to ambulatory monitoring and mobile assessment of quality of life, e.g. different assessment approaches, investigating temporal stability, adopting retrospective measures, implementing adaptive testing.

INDIVIDUAL PRESENTATIONS

Enhancing the Sensitivity of Quality of Life Measurement by Taking the Trait-State Distinction and Response Shift into Account

Mirjam AG Sprangers, PhD, Academic Medical Center, Univ. of Amsterdam, Netherlands

The Impact of Ambulatory Health Monitoring and Changing Health Conditions on Health-Related Cognitions

Holger Muehlan, PhD, Ernst-Moritz-Arndt-University, Greifswald, Germany

Computerized Adaptive Tests for Ambulatory Monitoring

Sandra Nolte, PhD, Charité – University Medicine Berlin, Germany

Mobile Assessment of Quality of Life in Children via Computerized-Adaptive Testing - Application and Acceptance of the Kids-CAT Tool

Dana Barthel, Dipl.-Psych., University Medical Center Hamburg-Eppendorf, Hamburg, Germany

Symposium #6: An International Consensus Process to Identify Priorities in Child-Reported Outcomes Research

HALL I-A

Organizer & Moderator: Anne Riley, PhD, Johns Hopkins University, Baltimore, MD, United States

This symposium will discuss an international consensus process that included child health experts representing a variety of countries and stakeholders. This process was conducted to achieve an international consensus on the top research priorities to advance the science of child reported outcomes (CROs) about their health related quality of life (HRQOL).

INDIVIDUAL PRESENTATIONS

Advances and Innovations in Assessment Methods for Child Reported Outcome Research and Applications

Jeanne M. Landgraf, MA, HealthAct CHQ Inc., Boston, MA, United States

Recommendations for Advancing Child Reported Outcome (CRO) Measurement Across the Lifecourse

Monika Bullinger, PhD, Institute for Medical Psychology, Hamburg University, Germany

State of the Art and Needed Research to Advance the Science of Clinically Meaningful Change in CRO Scores

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

Advances Needed for Distinguishing True Change in Health from Changes Due to Other Causes

Hein Raat, MD PhD MBA, Erasmus MC - University Medical Centre Rotterdam, Netherlands

Critique and Considerations of the CRO Research Agenda Identified through the ISOQOL CHIG Consensus Process

Discussant: Katherine B. Bevans, PhD, The Children's Hospital of Philadelphia, PA, United States

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SCIENTIFIC PROGRAM

Symposium #7: 2014 PROMIS® Update: News, Expanded Pediatric Item Banks, International, and Industry Developments

HALL I - B

Organizer & Moderator: **Joan E. Broderick, PhD**, Univ. of Southern California, United States

The Patient-Reported Outcomes Measurement System (PROMIS®), a National Institutes of Health (US) initiative, has developed a contemporary and innovative approach to the measurement of physical health, mental health, and social quality of life for children and adults. Those attending this symposium will hear an update on the development side of PROMIS® initiatives and what is on the horizon. Consideration of advantages of PROMIS® for global research will be discussed.

INDIVIDUAL PRESENTATIONS

PROMIS®: Current Status, Recent Developments and Future Plans

David Cella, PhD, Feinberg School of Medicine, Northwestern University, Chicago, IL, United States

Advancing the PROMIS® Pediatric Patient-Reported Outcome Portfolio: New Measures and Methods

Christopher B. Forrest, MD PhD, The Children's Hospital of Philadelphia, PA, United States

Who is the Norm? Hurdles on the Way to an International Standardization of PRO Assessments

Matthias Rose, MD PD, Charité – University Medicine Berlin, Germany

The Case for an International PROMIS® Initiative

Jordi Alonso, MD PhD, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain

Sharing the progress of the PROMIS® Industry Interest Committee

Tara Symonds, PhD, United Kingdom

Symposium 8: Monitoring Patient-Reported Outcome Alerts in Clinical Trials and Routine Practice: An Expert Panel Discussion of Current Knowledge and Priority Areas for Research

HALL I - C

Chair: **Michael Brundage, MD**, Queen's University, Kingston, Canada

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

In this symposium panelists will introduce the concept of 'PRO Alerts', identify ethical and logistical considerations for their management and share the latest evidence on current management practices based on survey findings from >600 trialists. The panelists will consider PRO Alerts in the context of the National Cancer Institute's PRO-CTCAE initiative to develop a standardized patient-centered approach to adverse event reporting in clinical trials and will discuss how this approach has been applied to routine clinical care using the 'real-world' example of e-RAPID.

By the end of the symposium attendees will have a clear understanding of the issues facing researchers, clinicians and Institutional Review Boards in relation to PRO Alerts, the options currently available for use in different contexts and priority areas for future research.

INDIVIDUAL PRESENTATIONS

Introduction to PRO Alerts in Trials

Melanie Calvert, PhD, Univ. of Birmingham, United Kingdom

Current Practices in Patient-Reported Outcome (PRO) Alert Management in Clinical Trials

Derek Kyte, MSc, Univ. of Birmingham, United Kingdom

PRO Alerts in the Context of the National Cancer Institute's PRO-CTCAE Initiative to Develop a Standardized Patient-Centered Approach to Adverse Event Reporting in Clinical Trials

Sandra A. Mitchell, PhD CRNP AOCN, National Cancer Institute, United States

Development of an integrated online toxicity reporting and management system for oncology: eRAPID (Electronic patient self-Reporting of Adverse-events: Patient Information and aDvice)

Galina Velikova, MD PhD FRCP, Univ. of Leeds, Psychosocial Oncology Clinical Practice Research Group, St James's Institute of Oncology, Leeds, United Kingdom



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3:15 pm – 4:00 pm

Exhibits Open and Refreshment Break

3:25 pm – 3:45 pm

Saturday Poster Session 2

HALL II

Breast and Prostate Cancer

(3004) Validation of the French Version of the Impact of Cancer Version 2 (IOCv2) Questionnaire on a Breast Cancer Survivors Population

Myriam Blanchin, Univ. of Nantes, France; Sarah Dauchy; and Alejandra Cano, Institut Gustave Roussy; Anne Brédart, Institut Curie; Neil K. Aaronson, PhD, The Netherlands Cancer Institute; Jean-Benoit Hardouin, PhD ScD, Univ. of Nantes

(3006) Quality of Life and Symptom Concerns in Breast Cancer Survivors Receiving Hormonal Therapy

Gloria Juarez, PhD RN MSN, City of Hope, Duarte, CA, United States; Joan J. Branin, PhD, Univ. of La Verne

(3008) Health-Related Quality of Life and Health Utilities in Prostate Oncology

Pedro L. Ferreira, PhD, Univ. of Coimbra, Portugal; Teresa Sequeira, CEISUC/UFPA; Joana Teixeira, UFP Hospital; Lurdes Carvalho, Portuguese Oncology Institute; Augusta Silveira, CEISUC/UFPA

(3012) Validation of the French Version of Expanded Prostate Cancer Index Composite (EPIC) for Assessment of Health-Related Quality of Life, According to Item Response Theory and Classical Analyses

Anne-Sophie Mariet, Univ. of Franche-Comté, Besançon, France; Amélie Anota, Quality of Life in Oncology Platform, France; Anne-Valérie Guizard, Centre Francois Baclesse; Pascale Grosclaude, Centre Claudius Régaud; Michel Velten, College of Medicine, Strasbourg; Mariette Mercier, Univ. Hospital of Besançon

Endocrinology/Diabetes/Obesity

(3016) Health-Related Quality Of Life in the Cluster Types of Metabolic Syndrome Components among Korean Population

Younghwa Baek, Korea Institute of Oriental Medicine (KIOM), Daejeon, Korea; Kihyun Park; Jonghyang Yoo; Siwoo Lee; and Eunsu Jang, KIOM

(3018) Applying an Ambulatory Monitoring Approach to Investigate the Relationship between Well-Being and the Menstrual Cycle

Maxi Rahn, Univ. of Greifswald; Pinar Kueucuekbalaban, Greifswald, Germany; Tim Rostalski; Holger Muehlan; and Silke Schmidt, PhD, Univ. of Greifswald

(3020) Health-Related Quality of Life among Patients With Chronic Constipation in a Commercially Insured Sample of United States Adults

Qian Cai, HealthCore Inc; Jessica Buono, Forest Laboratories; William M. Spalding, Ironwood Pharmaceuticals; Judith J. Stephenson, HealthCore Inc.; Hiangkiat Tan, HealthCore Inc.; Robyn Carson, MPH, Forest Research Institute; Jalpa A. Doshi, Univ. of Pennsylvania

Mental Health

(3022) Resilience in Couples Facing a Psychiatric Disorder Acts as a Protective Factor against Psychological Distress and Impaired Quality of Life

Marco Pereira, Universidade de Coimbra, Portugal; Stephanie Alves; and Sara Rodrigues, Univ. of Coimbra; Catarina Janeiro; and Isabel Narciso, Univ. of Lisbon; Maria C. Canavarró, Univ. of Coimbra; Frank M. Dattilio, Harvard Medical School

(3024) Using the Random Forest Method to Detect a Response Shift in the Quality of Life of Patients Suffering from Schizophrenia: A Cohort Study

Mohamed Boucekine, Self-Perceived Health Assessment Research Unit, Marseille, France; Anderson Loundou, Self-Perceived Health Assessment Research Unit; Badih Ghattas, Faculté Des Sciences de Luminy; Pierre Michel, Aix Marseille Université; Patricia Minaya Flores, MA, Laboratoire de Sante Publique; Karine Baumstarck, Aix Marseille Université; Pascal Auquier, Univ. Hospital of Marseille; Laurent Boyer, PhD, Aix-Marseille Univ.; Mondher Toumi, MD, Lundbeck SA

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(3026) Literature Review of the Psychometric Properties of the Edinburgh Postnatal Depression Scale (EPDS)

Rachel M. Wiens; Hillary L. McBride; and Marvin J. McDonald, Trinity Western Univ.; Daniel W. Cox, Univ. of British Columbia; Eric K. H. Chan, PhD, Trinity Western Univ., Canada

(3028) Quality of Life (QOL) Questionnaire for Schoolchildren (part 2)

Rika Hayashida, MS, Univ. of Nagasaki, Japan; Michiko Kobayashi, MD, Japanese Society of Quality of Life Research; Minako Chibu, Saiseikai Nagasaki Hospital; Takashi Mandai, MD PhD, Japanese Society of Quality of Life Research

🦋 (3030) Quality of Life in a Community Sample of Young Cocaine and/or Heroin Users: The Role of Mental Disorders

Antonia Domingo-Salvany, PhD, IMIM, Barcelona, Spain; Marcela Chahua, Instituto de Salud Carlos III; Albert Sánchez-Niubò; and Marta Torrens, IMIM; Luis Sordo; and M José Bravo, Instituto de Salud Carlos III; M Teresa Brugal, Agència de Salut Pública de Barcelona

Pulmonary

(3040) Using the Three Step Test Interview to Understand How the SGRQ-C is Interpreted by COPD Patients

Muirne CS Paap, Univ. of Twente, Netherlands; Christina Bode; and Lukas Lange, Univ. of Twente; Job Van Der Palen, Medisch Spectrum Twente

Children

(3044) Correlates of Cross-Sectional and Longitudinal Health-Related Quality of Life among Children with Autism Spectrum Disorders

Karen A. Kuhlthau, PhD, Center for Child and Adolescent Health Research and Policy, Boston, MA, United States; Erin McDonnell, Massachusetts General Hospital; Daniel Coury, Nationwide Children's Hospital; Eric Macklin, Massachusetts General Hospital

(3046) Distress in Parents of a Child with Down Syndrome

Hedy A. Van Oers, MSc, Emma Children's Hospital/Academic Medical Center, Amsterdam, Netherlands; Jan Pieter Marchal; Lotte Haverman, PhD; Heleen Maurice-Stam, MSc; Paul AS Van Trotsenburg; and Martha Grootenhuis, PhD, Emma Children's Hospital/Academic Medical Center

(3048) Quality of Life of Children and Adolescents with Chronic Kidney Failure Undergoing Hemodialysis: Construction of the Specific DISABKIDS® Module

Isabella S. Abreu, Universidade de São Paulo, Brazil; Maria Fernanda Cabral Kourrouski; Lucila Castanheira Nascimento; and Regina Aparecida Garcia de Lima, Univ. of São Paulo; Monika Bullinger, PhD, Hamburg Univ.; Claudia Benedita dos Santos, PhD, MISP-EERP-USP

(3054) Maternal Well-Being, Stress and Symptoms of Depression in New Mothers in the Context of Counseling

Julia Hannah Quitmann, Univ. Medical Center Hamburg-Eppendorf, Germany; Anja Rohenkohl, Univ. Medical Center Hamburg-Eppendorf; Dagmar Brandt, Von Anfang an e.V.; Monika Bullinger, PhD, Hamburg Univ.

Population Health

(3056) Quality of Life of Globally Mobile Employees: What Harms, What Helps and What is the Role of accompanying Partners?

Herbert Fliege, PhD, Health Service, Federal Foreign Office of Germany; Heiko Rüger; Stine Waibel; and Silvia Ruppenthal, Federal Institute for Population Research; Maria M. Bellinger, Federal Foreign Office, Berlin, Germany

(3058) Effects of Private Insurance Mandates on Racial Disparities in Health and Family Outcomes for Children with Autism

Pratik Doshi, Arkansas Children's Hospital; Nalin Payakachat, BPharm, MS, PhD, Univ. of Arkansas for Medical Sciences, United States; Dennis Kuo; Songthip Ounpraseuth; and J. Mick Tilford, PhD, Univ. of Arkansas for Medical Sciences

(3060) Validation of the General Oral Health Assessment (GOHAI) Index into Japanese adults

Mariko Naito, DDS, PhD, Nagoya Univ. Graduate School of Medicine, Japan; Yoshimi Suzukamo, PhD, Tohoku Univ.; Shino Suma; Sayo Kawai; Rieko Okada; Asahi Hishida; Emi Morita; Nobuyuki Hamajima; and Kenji Wakai, Nagoya Univ.

(3062) A Proposal to Improve Health-Related Quality of Life in the Population of Aguachica (Colombia)

Ethman A. Torres, MBA, Universidad Santo Tomas, Floridablanca, Colombia; Davyanis Vargas, Univ. Santo Tomas

🦋 Outstanding Poster Abstract Award



SCIENTIFIC PROGRAM

(3064) Health-Related Quality of Life and its Association with Mammography use in a Nationally Representative US Sample

Erica Y. Lee; Jeffery L. Kibert, II; Whitney Jordan; William M. Gentry; and Michael B. Bottorff, South College School of Pharmacy; I-Chan Huang, PhD, Univ. of Florida; Pranav Gandhi, PhD, South College School of Pharmacy, Knoxville, TN, United States

(3066) Validity of the Aboriginal Children's Health and Well-Being Measure (Aaniish Naa Gegii)

Nancy L. Young, PhD, Laurentian Univ., Canada; Mary-Jo Wabano; and Brenda Pangowish, Wikwemikong Health Centre; Melanie Trotter; and Koyo Usuba, MS, Laurentian Univ.

Cross-Cultural Adaptation

(3070) Are "Lively" and "Full of Pep" Similar or Different Concepts? Challenges in Translating These Terms in Seven Languages

Irène Gil Campos, Mapi; Caroline Anfray, Mapi, Lyon, France; Catherine Acquadro, Mapi Research Trust

(3072) French Adaptation and Psychometric Validation of the Expanded Prostate Cancer Index Composite Questionnaire for Health-Related Quality of Life of Prostate Cancer Patients

Anne-Sophie Mariet, Univ. of Franche-Comté, Besançon, France; Amélie Anota, Quality of Life in Oncology Platform, France; Philippe Maingon, Centre George François Leclerc; Florence Joly, Centre François Baclesse; Jean-François Bosset, Besançon Univ. Hospital; Anne-Valérie Guizard, Centre François Baclesse; Michel Velten, College of Medicine, Strasbourg; Mariette Mercier, Univ. Hospital of Besançon

(3074) The Importance of the Additional Proofreading Step and its Impact on Subsequent Linguistic Validation Steps

Beng Li Ting; Linda See; and Grace Gao, Health Research Asia; Valeska C. Kantzer, Health Research Associates, Inc.; Mona L. Martin, RN MPA, Health Research Associates, Inc.

(3076) Developing the Coeliac Disease Assessment Questionnaire (CDAQ): An assessment of translatability

Helen Crocker, MSc, Univ. of Oxford, United Kingdom; Hayley Simpson; and Rebecca L. Two, BA, PharmaQuest Ltd; Crispin Jenkinson, Health Services Research Unit; Michele Peters, PhD, Univ. of Oxford

(3078) The Concept of Neurological Reserve in a Norway: Cultural and Social Differences Revealed by Cognitive Interviewing

Inger Utne, Oslo & Akershus Univ. College of Applied Sciences, Oslo, Norway; Liv Halvorsrud; and Randi Andenas, PhD, Oslo & Akershus Univ. College; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc.

Patient-Centered Research

(3080) Update of the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID): Integration of the New COA Taxonomy-The ClinRO Example

Laure-Lou Perrier; Katrin Conway, BA; and Catherine Acquadro, Mapi Research Trust, Lyon, France

(3082) Partners in Research: Patients Leading Research Initiatives on Health Experiences

Svetlana Shklarov, Univ. of Calgary Canada; Nancy Marlett; Deborah Marshall; and Maria-Jose Santana, PhD, Univ. of Calgary; Tracy Wasylak, Alberta Health Services

(3084) Patient Retention and Response in Longitudinal Patient-Reported Outcomes Studies Using a Telephone Interactive Voice Response System

Loretta A. Williams, PhD RN; and Qiuling Shi, PhD, Univ. of Texas MD Anderson Cancer Center, Houston, TX, United States; Tito R. Mendoza, PhD; Araceli Garcia-Gonzalez; Patricia Ault; Nazim Ali; and Jorge E. Cortes, Univ. of Texas MD Anderson Cancer Center; Jonathan C. Trent, II, Univ. of Miami Sylvester Comprehensive Cancer Center; Dejka M. Araujo; and Charles S. Cleeland, PhD, Univ. of Texas MD Anderson Cancer Center

(3086) Functionality and Feedback: A Protocol for a Realist Synthesis of the Collation, Interpretation and Utilization of PRO Data to Improve Patient Care

Joanne Greenhalgh, PhD; and Sonia Dalkin, Univ. of Leeds, United Kingdom; Judy Wright, Univ. of Leeds; Nick Black, MD, London School of Hygiene and Tropical Medicine; Jose M. Valderas, MD MPH PhD, Univ. of Exeter; Elizabeth J. Gibbons, MSc, Univ. of Oxford; David Meads, Univ. of Leeds; Laurence Wood, PPI representative, Univ. of Leeds; Chris Mills, Leeds West CCG; Ray Pawson, Univ. of Leeds

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Utilities/Cost-Effectiveness Methods

(3090) Non-Trading Response on Time Trade-Off Responses: Individual's Values or Logic Violation?

Andréa L. Monteiro, MSc, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil; Monica A C T Cintra, MD, PhD; Marcelo Goulart; Bráulio Santos; and Bernardo R. Tura, National Inst. of Cardiology Brazil; Luciane N. Cruz, MD, PhD; and Suzy A. Camey, Federal Univ. of Rio Grande do Sul; Monica V. Andrade, Federal Univ. of Minas Gerais; Kenya Noronha, Univ. Federal de Minas Gerais; Marisa Santos, MD, Instituto Nacional de Cardiologia Brazil

(3092) Tablet Versus Paper Questionnaire: EQ-5D Quality of Life Questionnaire Comparison for the Brazilian Population.

Angela M. Bagattini, Federal Univ. of Rio Grande do Sul, Porto Alegre, Brazil; Patricia K. Ziegelmann; and Ana Flávia B S Lima, Univ. Federal do Rio Grande do Sul; Sandro R P S Miguel, MD, Inst. for Health Technology Assessment; Monica V. Andrade, Federal Univ. of Minas Gerais; Kenya Noronha, Univ. Federal de Minas Gerais; Marisa Santos, MD; and Monica A C T Cintra, MD, PhD, National Inst. of Cardiology Brazil; Carisi Polanczyk; and Luciane N. Cruz, MD PhD, Federal Univ. of Rio Grande do Sul

(3094) Mapping of the OAB-SF Questionnaire onto EQ-5D for Overactive Bladder Patients in Spain

Miguel A. Ruiz, Universidad Autónoma de Madrid, Spain; Laura L. Gutiérrez, Universidad Autónoma de Madrid; Javier Rejas, Pfizer

(3096) Breast Cancer: Health Utilities and Health-related Quality of Life

Pedro L. Ferreira, PhD, Univ. of Coimbra, Portugal; Augusta Silveira, CEISUC/UFP; Ana Eberhardt, ICBAS; Isabel Sequeira, IPOP; Teresa Sequeira, CEISUC/UFP

Statistical Analysis of PROs

(3098) Latent Heterogeneity of Factorial Structure as a Source of Model Misfit in Confirmatory Factor Analysis

Ljoudmila Busija, PhD, Deakin Univ., Australia; Marita Mc Cabe; Matthew Fuller-Tyszkiewicz; and John Reynolds, Deakin Univ.

(3100) Perceived Own Health State and Health Assessments of Case-Vignettes – Is There a Connection?

Andreas Hinz, Univ. of Leipzig, Germany; Winfried Häuser, Klinikum Saarbruecken, Germany; Heide Glaesmer, Univ. of Leipzig; Rüyä-Daniela Kocalevent, Univ. Medical Center Hamburg; Elmar Brähler, Leipzig Univ.

(3104) Response Shift Detection at Item-Level in Longitudinal Patient-Reported Outcomes Studies with an Optimal SEM-Based Method – A Simulation Study

Alice Guilleux, Univ. of Nantes, France; Myriam Blanchin, Univ. of Nantes; Antoine Vanier, MD, Univ. Pierre Et Marie Curie Paris; Jean-Benoit Hardouin, PhD ScD; and Veronique Sebille, ScD, Univ. of Nantes

(3106) MF-SAF: Re-Validation of Psychometric Properties Based on Rasch Model, and Approaches to Exploit Multi-Day Measurements to Improve Measurement Properties

Lothar T. Tremmel, Incyte Corp, United States

4:00 pm – 5:30 pm

Concurrent Oral Sessions

Oral Session 301: Advancing Measurement in Cognitive and Neurological Disorders HALL I - A

Session Chair: Lori Frank, PhD, United States

4:05 – 4:18 pm (301.1) Quantifying Cognition in HIV by Combining Patient Report and Neuropsychological Testing Using Rasch Analysis: The Shoe Fits

Nancy E. Mayo, PhD, McGill Univ. Health Centre, Montreal, Canada; Lisa R. Palladini, Msc (c), Division of Clinical Epidemiology, Montreal, QC, Canada; Marie-Josée Brouillette, McGill Univ.; Lois Finch, McGill Univ.; Lesley Fellows, McGill Univ.

4:19 – 4:32 pm (301.2) The Effects of Cognition on Patient Activation and Subsequent Patient-Reported Outcomes among Patients with Co-Occurring Physical and Mental Health Disorders

Kimberly Case, PhD, Univ. of Florida, United States; Sara Jo Nixon, PhD; Martin Wegman; Robert Prather; Jill Herndon, PhD; Keith Muller, PhD; Jason Lee; I-Chan Huang, PhD; and Elizabeth Shenkman, PhD, Univ. of Florida

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4:33 – 4:46 pm (301.3) Health-Related Quality of Life after Mild, Moderate and Severe Traumatic Brain Injury: Patterns and Predictors of Suboptimal Functioning During the First Year after Injury

Annemieke C. Scholten, Erasmus Univ. Medical Centre, Rotterdam, Netherlands; J A. Haagsma, Erasmus Univ. Medical Centre; T MJC Andriessen, Radboud Univ. Medical Center; P E. Vos, Slingeland Hospital; Ewout Steyerberg; E F. Van Beeck; and S Polinder, Erasmus Univ. Medical Centre

4:47 – 5:00 pm (301.4) An Empirical Based Model of Dementia Specific Quality of Life – Results of a Meta-Synthesis of Qualitative Studies

Martin Nikolaus Dichter, MScN, German Center for Neurodegenerative Disease (DZNE); Rebecca Palm; and Margareta Halek, DZNE; Sabine Bartholomeyczik, Witten/Herdecke Univ.; Gabriele Meyer, Martin-Luther-Univ.

5:01 – 5:14 pm (301.5) Evaluation of the Patient Health Questionnaire (PHQ-9) Depression Scale for Differential Item Functioning according to Demographics and Disease Severity Across Neurological Diseases: Results from the Cleveland Clinic Neurological Institute

Irene Katzan, Cleveland Clinic, United States; Sandra D. Griffith, PhD; Lara Jehi; Hubert Fernandez; Erik Pioro; and Stewart Tepper, Cleveland Clinic; Paul K. Crane, MD MPH, Harborview Med Ctr

5:15 – 5:28 pm (301.6) Quality of Life Assessments in Persons with Spinal Cord Injury with Neurogenic Bowel and Bladder

Denise G. Tate, PhD, Univ. of Michigan, United States; Martin Forchheimer, Univ. of Michigan; David Tulskey, PhD, Kessler Foundation; Pamela A. Kisala; Gianna Rodriguez; Anne Cameron; and Anthony Chiodo, Univ. of Michigan

Oral Session 302: Assessing Well-Being and Health Across Cultures

SALON 4

Session Chair: Cynthia Gross, PhD, United States

4:05 – 4:18 pm (302.1) DIF Analysis to Tease out Average Differences in Mental Well-Being in Scotland and Catalonia

Carlos Garcia Forero, PhD, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain; Nuria Duran Adroher; Pere Castellví; and Gemma Vilagut, MSc, IMIM; Sarah Stuart-Brown, Univ. of Warwick; Jordi Alonso, MD PhD, IMIM

4:19 – 4:32 pm (302.2) Correlates of Mental Well-Being: A Cross-Country Analysis in Scotland and Catalonia

Nuria Duran Adroher, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain; Carlos Garcia Forero, PhD; Pere Castellví; and Jordi Alonso, MD PhD, IMIM

4:33 – 4:46 pm (302.3) Assessment of the Psychometric Equivalence of the PROMIS® Anxiety Item Bank and its German Translation

Inka Wahl, PhD, Univ. Medical Center Hamburg-Eppendorf, Germany; Joshua Rutsohn, Northwestern Univ.; David Cella, PhD, Northwestern Univ.; Bernd Löwe, Univ. Medical Center Hamburg-Eppendorf & Schön Klinik Hamburg Eilbek; Matthias Rose, MD PhD, Charité; Elmar Brähler, Leipzig Univ.; Paul Pilkonis, Univ. of Pittsburgh School of Medicine; Benjamin Schalet, Northwestern Univ.

4:47 – 5:00 pm (302.4) Psychometric Validation of an EORTC Measure of Spiritual Well-Being in Patients with Advanced Cancer

Teresa E. Young, BSc, Mount Vernon Hospital, United Kingdom; Bella Vivat, PhD, Health Sciences and Social Care; Julie B. Winstanley, PhD, Univ. of Sydney; Juan Ignacio Arraras, PhD, Servicio Navarro de Salud; Anne Bredart, PhD, Institut Curie; Anna Costantini, Sant'Andrea Hospital. Sapienza Univ. of Rome; Sheila E. Fisher, PhD MBCh FRCS, Univ. of Leeds; Jingbo Guo, Shenyang; M Eliza Irarrazaval, Instituto Oncologico Fundacion Arturo Lopez Perez; Kunihiko Kobayashi, MD, PhD, Saitama International Medical Center; Kruizinga R., MA, AMC, Univ. of Amsterdam; Hanneke W.M. van Laarhoven, MD PhD; AMC, Univ. of Amsterdam; Navarro M., Instituto Nacional de Cancerologia; Omidvari S., Mental Health, IHSR (Health Metric Research Center), ACECR & Cancer Research Center, TUMS, Iran; Rohde G.E., Univ. of Agder & Sorlandet Hospital; Serpentine S., Az. Psycho-Oncology Service/Palliative Care Unit; Yang G.M., National Cancer Centre Singapore, on behalf of EORTC Quality of Life Group

5:01 – 5:14 pm (302.5) Quality of Life of People Living with HIV/AIDS: A Cross-Country Comparison Study of Finland and Portugal

Nuno Nobre, Univ. of Helsinki, Finland; Marco Pereira, Univ. de Coimbra; Maria C. Canavarro, Univ. of Coimbra; Jussi Sutinen, Aurora Hospital, Helsinki; Harri Sintonen, Univ. of Helsinki; Risto P. Roine, Univ. of Helsinki

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5:15 – 5:28 pm (302.6) Quality of life of Japanese and Austrian Mothers: Differences and Impact Factors in East-Asia and Central Europe

Eva Mautner, Medical Univ. Graz, Austria; Chie Ashida, Hiroshima Univ; Eva Elfriede Greimel, PhD; Uwe Lang; Christina Kolman; and Daniela Alton, Medical Univ. of Graz; Wataru Inoue, Hiroshima Univ.

Oral Session 303: Advancing Measurement of Physical and Mental Health in General Populations

SALON 2

Session Chair: Caroline B. Terwee, PhD, Netherlands

4:05 – 4:18 pm (303.1) Inpatients Experience Response Shifts between Admission and Discharge from Psychosomatic Ward

Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Germany; Annett Mierke; and Matthias Rose, MD PhD, Charité

4:19 – 4:32 pm (303.2) Characterizing the Unwell-Beings in England

Antonietta Medina-Lara, BSc(Hons) MSc, PhD, Univ. of Exeter Medical School, United Kingdom; Ruben E. Mujica-Mota, BSc MSc PhD, Univ. of Exeter

4:33 – 4:46 pm (303.3) Satisfaction with Life and Mental Distress in People Living Alone or with a Partner.

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

4:47 – 5:00 pm (303.4) Common Patterns of Morbidity and Multi-Morbidity and their Impact on Health-Related Quality of Life: Evidence from a National Survey

Ruben E. Mujica-Mota, BSc MSc PhD, Univ. of Exeter, United Kingdom; Martin Roberts, Univ. of Exeter; Gary Abel, Univ. of Cambridge; Mark Elliott, RAND Corporation; Georgios Lyrtzopoulos; and Martin Roland, Univ. of Cambridge; John Campbell, Univ. of Exeter

5:01 – 5:14 pm (303.5) Health-Related Quality of Life and Well-Being

Clara Mukuria, PhD, Univ. of Sheffield, United Kingdom; John E. Brazier, PhD, Univ. of Sheffield

5:15 – 5:28 pm (303.6) The impact of peer benchmarking: results from The PROFILE (Patient-Reported Outcomes: Feedback Interpretation and Learning Experiment) Trial and qualitative interviews with surgeons

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

Oral Session 304: Advancing Measurement in Children

HALL I - B

Session Chair: Gabriel M. Ronen, MD MSc, Canada

4:05 – 4:18 pm (304.1) How Qualitative Methods Can Be Used to Ensure Content Validity in a PRO Instrument for Patients with Cleft Lip and/or Palate who Vary by Age and Culture: Development of the CLEFT-Q

Elena Tsangaris, McMaster Univ., Canada; Karen W.Y. Wong, MD MSc FRCSC; and Christopher R. Forrest, MD, The Hospital For Sick Children; Andrea Pusic, MD MHS FRCSC, MSKCC; Stefan J. Cano, PhD CPsychol AFBPsS, Plymouth Univ.; Tim Goodacre, Oxford Radcliffe Hospitals; Anne Klassen, D Phil, McMaster Univ.

4:19 – 4:32 pm (304.2) Model Testing of the Children's Quality of Life Questionnaire

Shulamith Kreitler, Tel-Aviv Univ., Israel; Michal M. Kreitler; and Yasmin Alkalay, Tel-Aviv Univ.

4:33 – 4:46 pm (304.3) Development and Validation of a Generic Scale for use in Transition Programs to Measure Self-Management Skills in Adolescents with Chronic Health Conditions: The TRANSITION-Q

Anne Klassen, D Phil, McMaster Univ., Canada; Christina Grant; Ronald Barr, MD; Herbert Brill; Gabriel M. Ronen, MD, MSc; Constantine Samaan; Abbey Schlatman; Elena Tsangaris; Uma Athale; Natasha Wickert; and Jan Willem Gorter, McMaster Univ.

4:47 – 5:00 pm (304.4) Rasch Analysis of the PedsQL 3.0 Diabetes Module

Timothy El Pickles, BSc (Hons) MSc, Cardiff Univ., United Kingdom; Rebecca Playle; KerENZA Hood; and Jonathan Gillard, Cardiff Univ.

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(304.5) WITHDRAWN

5:01 – 5:14 pm (304.6) Global Mobility and Quality of Life in Accompanying Children

Maria M. Bellinger, Federal Foreign Office, Berlin, Germany; Heiko Rüger; Stine Waibel; and Silvia Ruppenthal, Federal Institute for Population Research; Herbert Fliege, PhD, Federal Foreign Office of Germany

Oral Session 305: Evaluating Impact of Cancer on Quality of Life

HALL I - C

Session Chair: Carolyn C. Gotay, PhD, Canada

4:05 – 4:18 pm (305.1) Relationship between Quality of Life, Distress, and Immune Biomarkers among Cancer Survivors

Lari Wenzel, PhD, Univ. of California, Irvine United States; Kathryn Osann, PhD; Susie Hsieh; Jo Anne Tucker; and Edward Nelson, Univ. of California, Irvine

4:19 – 4:32 pm (305.2) Psychiatric Morbidity and Survival Following Oesophageal Cancer Surgery

Anna Wikman, Karolinska Institutet, Stockholm, Sweden; Ylva V. Hellstadius, Molecular Medicine and Surgery; Mohammed A. Johar, BSc.(Hons) MSc.; and Pernilla Lagergren, Karolinska Institutet

4:33 – 4:46 pm (305.3) Healthcare-Related Financial Distress is Associated with Symptoms in US Adult Cancer Survivors

Arnold L. Potosky, PhD; and Roxanne E. Jensen, PhD, Georgetown Univ., Washington, DC, United States; Grace Zhou, Georgetown Univ.; Carol M. Moinpour, PhD, Fred Hutchinson Cancer Research Center

(305.4) WITHDRAWN

4:47 – 5:00 pm (305.5) Quality of Life Spillover among Spouses With and Without Cancer

Kristin Litzelman, National Cancer Institute, United States

5:01 – 5:14 pm (305.6) A Longitudinal Study on the Impact of Active Surveillance for Prostate Cancer on Anxiety and Distress Levels

Lionne DF Venderbos, Erasmus Univ. Medical Center, Rotterdam, Netherlands; Roderick CN Van Den Bergh; Monique J. Roobol; and Fritz H. Schröder, Erasmus Univ. Medical Center; Marie-Louise Essink-Bot, PhD, Univ. of Amsterdam; Chris H. Bangma; Ewout Steyerberg; and Ida J. Korfage, PhD, Erasmus Univ. Medical Center

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7:00 pm – 10:00 pm Closing Dinner

Spiegelsaal (Mirror Hall), Clärchens Ballhaus
Auguststraße 24, 10117 Berlin, Germany

The Closing Dinner will be held at **Spiegelsaal (Mirror Hall)** in the Clärchens Ballhaus. Clärchens Ballhaus is one of few remaining, original Weimar-era dancehalls to survive World War II and to still be in operation to this day.

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Exhibit #5

BrightOutcome develops innovative healthcare information technology solutions to produce better and brighter outcomes for patients in a variety of clinical contexts. Our PRO/HIT foundation allows us to assist researchers and clinicians to **measure** the health-related information of their patient/subject populations; **inform** clinicians of their patients' health status, needs and concerns, and, **empower** patients/public to know and track their health status.



Exhibit #4

FACIT.org licenses the functional assessment of chronic illness therapy instruments. FACITtrans provides multilingual translations services to the research community.



Exhibit #2

The Mapi Group is a service provider to the global healthcare industry. We help people who are shaping tomorrow's health outcomes by offering strategic, insightful solutions for successful market access in our ever-changing healthcare environment. From the inception of the Mapi Group four decades ago, the patient has been at the center of our concerns. Our company has developed around the increasing need for patient understanding and centrality, providing valuable insights to the healthcare industry on which strategic directions should be based.



Exhibit #1

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- Comparative Effectiveness Research
- Scientific Communications

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