



ISOQOL
22nd Annual Conference
VANCOUVER
British Columbia, Canada
OCTOBER 21-24, 2015



FINAL PROGRAM

The Matrix: Quality of Life in Social Context

www.isoqol.org





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Seattle, Washington

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- ☑ Comprehensive Development and Testing of Clinical Outcome Assessment Tools (PROs, ClinROs, ObsROs)
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The Matrix: Quality of Life in Social Context

Welcome to the 22nd Annual Conference of the International Society
for Quality of Life Research — October 21 – 24, 2015

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FINAL PROGRAM

Welcome from the Program Chairs

Welcome to Vancouver!

As Scientific Program Co-chairs, we warmly welcome you at the ISOQOL Annual Conference! The location is beautiful Vancouver, Canada, and our 2015 theme is 'The Matrix – Quality of Life in Social Context'. The focus of the plenaries is on the social dimension of HRQoL – the theory, and the ways we measure and use it in research, practice, and in our interactions with one another.

We're happy that so many of you have registered for the conference and that so many inspiring speakers have accepted our invitation to share their thoughts with us.

We are proud to present the plenary topics to you. These sessions focus on three aspects of the social domain of quality of life. "Not the Usual Suspects" addresses social determinants –particularly socioeconomic factors - as they affect health and quality of life. "The Theory of Everything" - New Models and Measures" presents new and emerging approaches to conceptualize and assess the social dimension, while "The Social Network" provides novel ways of how to use social media in research and knowledge translation. You will note that presenters in these plenaries include both established experts and rising stars, to reflect and inspire ISOQOL's dynamic multigenerational membership.

The fourth plenary showcases "Cutting Edge Research" based on the most innovative and meritorious submitted abstracts.

Those of you who have been to an ISOQOL conference before know its friendly atmosphere. It is very inspiring to meet so many others who are interested in quality of life research, including authors of famous papers, and to share ideas and experiences. Elements such as the mentor-mentee program encourage this exchange and add to the benefits of attending the conference. As this year's conference chairs, we are a living example of what such a meeting may bring: we met when participating in the mentor and mentee program in 2005, we've kept in touch during the intervening years, and now we co-chair this meeting.

We've introduced some new features to enhance the ISOQOL meeting's innovativeness even more and expose attendees to exciting new ways to connect with one another.

One innovation is the use of a digital audience response system during Plenaries to increase audience participation in the discussion – you can register your response via your own smartphone, using wifi that's available in the room.

At this 2015 conference, we are also introducing "Dine-Arounds," small scale dinners on Friday night. Dine-Arounds are a great opportunity to meet someone new, and enjoy an evening of inspiring interaction with your fellow attendees, while experiencing the local Vancouver scene! Sign-up sheets for the Dine-Arounds will be available at the registration desk through Friday, October 23 at 11:30 am, as space permits.

Don't forget to register for the closing dinner on Saturday – if you have not already done so! Enjoy a beautiful view of Vancouver from the rooftop while having a delicious meal with old and new ISOQOL friends. You'll be welcomed by traditional First Nations performers, listen to a jazz singer, and end the evening by dancing the night away with a leading Vancouver deejay! Tickets for the Closing Dinner will be available at the registration desk through Friday, October 23 at 11:30 am, or while supplies last.

When you're in Vancouver, be sure to visit the city and the surrounding areas to take advantage of the incredible cultural and natural attractions of this vibrant part of the world!

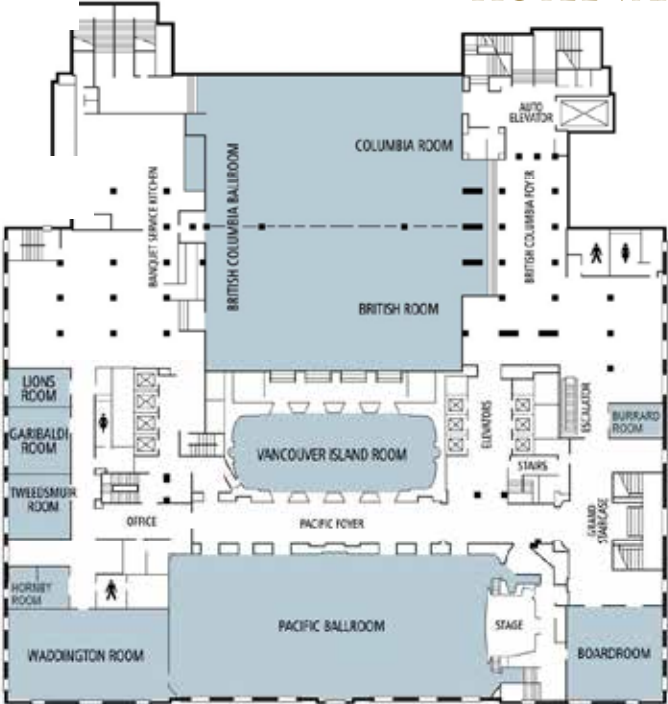
We encourage you to join us in making the 2015 Conference one of the best yet!

Carolyn Gotay and Ida Korfage

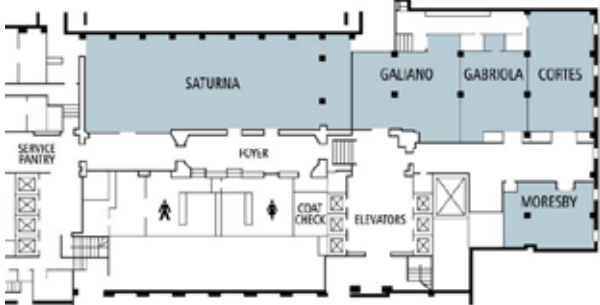


Hotel Floor Plan

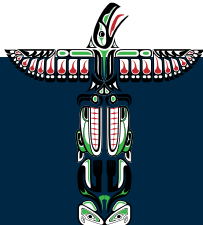
THE *Fairmont*
HOTEL VANCOUVER



Conference Floor



Discovery Floor



Schedule at a Glance

Wednesday, October 21		
9:00 am - 12:00 pm	Morning Workshops (Ticket Required)	
	<i>WK01: An Introduction to Health-Related Quality of Life Assessment</i>	Galiano
	<i>WK02: Death and Missing Data</i>	Gabriola
	<i>WK03: Best Practices for Qualitative Methods for Patient Reported Outcomes Research</i>	Cortes
	<i>WK04: Using innovative methods to inform instrument development and understand patient preferences: how Group Concept Mapping and other creative approaches can be used to capture the experiences and priorities of patients</i>	Moresby Island
	<i>WK05: Implementation of routine Patient Reported Outcome measurement in clinical practice</i>	Saturna
1: 00 pm - 4:00 pm	Afternoon Workshops (Ticket Required)	
	<i>WK06: Introducing the Concept of Response Shift – an Overview of Theory & Methods</i>	Cortes
	<i>WK07: Place Bookmark Here: How to Conceive, Develop, Conduct and Evaluate a Bookmarking Workshop for Identifying Clinically Meaningful Levels of Patient Reported Outcomes (PROs)</i>	Gabriola
	<i>WK08: Improving the design of clinical trials with Patient Reported Outcomes (PROs): guidance for protocol writers</i>	Saturna
	<i>WK09: Clinical Outcomes Assessment (COA) in Rare Disease (RD) – New Perspective on Traditional Methods</i>	Moresby Island
	<i>WK10: Caring about Caregivers: Definitions, Methods and Importance of Evaluating Caregivers' Burden</i>	Galiano
4:30 pm - 6:00 pm	Industry Advisory Committee (IAC) Symposium <i>Bring Your Own Device (BYOD): trends, best practices, challenges.....where do PRO measures go from here?</i>	Saturna
6:00 pm - 7:30 pm	Welcome Reception	British Columbia Ballroom
Thursday, October 22		
7:30 am - 8:30 am	Continental Breakfast for Attendees	Columbia Foyer
7:30 am - 8:25 am	First Time Attendee - Coffee with The Board	Columbia Ballroom
8:30 am - 9:00 am	Welcome from President & Program Committee	Pacific Ballroom
9:00 am - 10:30 am	Plenary - Not the Usual Suspects	Pacific Ballroom
10:35 am - 10:55 am	Thursday Poster Session 1 & Visit with Exhibitors Odd Numbered Posters (1007 - 1101)	British Columbia Ballroom
	<i>Reviews (1007 - 1031); E-Health (1033- 1067); Cancer (1069 - 1101)</i>	
10:55 am - 11:10 am	Outstanding Poster Award Finalist Presentations Session 1 (1001 - 1005)	British Columbia Ballroom
11:20 am - 12:35 pm	Plenary - Cutting Edge Research	Pacific Ballroom
12:35 pm - 1:45 pm	Lunch on your own	
12:35 pm - 1:45 pm	SIG Council Meeting (closed event)	Garibaldi

Schedule at a Glance

1:45 pm - 3:15 pm	Concurrent Oral Sessions	
	<i>Oral Session 101: Quality of Life Constructs</i>	Pacific Ballroom
	<i>Oral Session 102: Quality of Life in Neurological Conditions</i>	Saturna
	<i>Oral Session 103: Quality of Life Across Health Conditions</i>	Waddington
	<i>Oral Session 104: E-Health</i>	Boardroom
	<i>Oral Session 105: Women's Health</i>	Vancouver Island
3:20 pm - 3:40 pm	Thursday Poster Session 2 & Visit with Exhibitors Even Numbered Posters (1008 - 1102)	British Columbia Ballroom
	<i>Kids and Young Adults (1008 - 1038); Diabetes and Kidney (1040 - 1056); Musculoskeletal (1060 - 1084); Mental Health (1086 - 1102)</i>	
3:40 pm - 3:55 pm	Outstanding Poster Award Finalist Presentations Session 2 (1002 - 1006)	British Columbia Ballroom
4:05 pm - 5:35 pm	Concurrent Oral Sessions	
	<i>Oral Session 106: Health Systems and QOL</i>	Pacific Ballroom
	<i>Oral Session 107: Psychometrics</i>	Vancouver Island
	<i>Oral Session 108: Prostate Cancer</i>	Waddington
	<i>Oral Session 109: Mental Health</i>	Boardroom
	<i>Oral Session 110: Population-based Studies</i>	Saturna
6:00 pm - 6:30 pm	<i>New Investigator SIG Tricks of the Trade</i>	Pacific Ballroom
6:30 pm - 7:30 pm	Mentor/Mentee Reception (Pre-registration Required)	British Columbia Ballroom
Friday, October 23		
7:30 am - 8:30 am	Continental Breakfast for Attendees	Columbia Foyer
7:30 am - 8:45 am	Committee & Special Interest Group (SIG) Meetings	
	Child Health SIG Meeting	Waddington
	Health Preference Research SIG Meeting	Saturna
	Ibero America SIG Meeting	Boardroom
	Mixed Methods SIG Meeting	Tweedsmuir
	United Kingdom and Ireland SIG Meeting	Garibaldi
8:00 am - 9:00 am	Breakfast Roundtables (Ticket Required)	Columbia Ballroom
9:00 am - 10:30 am	Plenary - <i>The Theory of Everything</i>' - New Models and Measures	Pacific Ballroom
10:35 am - 10:55 am	Friday Poster Session 1 & Visit with Exhibitors Odd Numbered Posters (2007 - 2097)	British Columbia Ballroom
	<i>Reviews (2007 - 2025); Translation (2027 - 2059); Cancer (2061 - 2097)</i>	
10:55 am - 11:10 am	New Investigator Poster Award Finalist Presentations (2001 - 2005)	British Columbia Ballroom



Schedule at a Glance

11:20 am - 12:35 pm	Concurrent Symposium Sessions	
	<i>Symposium 1: Training Clinicians in How to Use Patient Reported Outcome Measures In Routine Clinical Care</i>	Saturna
	<i>Symposium 2: Patient Reported Outcome (PRO) Assessment in Clinical Practice: PCORI's Perspectives and Case Examples to Advance Research and Clinical Care</i>	Pacific Ballroom
	<i>Symposium 3: Health Preference Research: Enhancing the Relevance of Quality of Life (QOL) Evidence</i>	Vancouver Island
12:35 pm - 1:45 pm	Lunch on your own	
12:35 pm - 1:45 pm	QLR Editorial Board Meeting (closed event)	Garibaldi
1:45 pm - 3:15 pm	Concurrent Oral Sessions	
	<i>Oral Session 201: Multiple Sclerosis</i>	Vancouver Island
	<i>Oral Session 202: Measure Development</i>	Pacific Ballroom
	<i>Oral Session 203: Social Support, Coping and Resilience</i>	Waddington
	<i>Oral Session 204: Cardiac Conditions</i>	Saturna
	<i>Oral Session 205: Meaningful Change</i>	Boardroom
3:20 pm - 3:40 pm	Friday Poster Session 2 & Visit with Exhibitors Even Numbered Posters (2008 - 2102)	British Columbia Ballroom
	<i>Measure Development (2008 - 2062); Response Shift (2064 - 2068); Other Health Conditions (2070 - 2102)</i>	
3:40 pm - 3:55 pm	Student Poster Award Finalist Presentations (2002 - 2006)	British Columbia Ballroom
4:05 pm - 5:35 pm	Concurrent Oral Sessions	
	<i>Oral Session 206: Pulmonary Conditions</i>	Waddington
	<i>Oral Session 207: Health Utilities</i>	Boardroom
	<i>Oral Session 208: Concordance Between Patients and Others</i>	Saturna
	<i>Oral Session 209: Cross-Cultural Research</i>	Pacific Ballroom
	<i>Oral Session 210: Musculoskeletal Conditions</i>	Vancouver Island
5:45 pm - 7:00 pm	Special Interest Group (SIG) Meetings	
	New Investigator SIG Meeting	Waddington
	QOL in Clinical Practice SIG Meeting	Boardroom
	Response Shift SIG Meeting	Tweedsmuir
	Translation and Cultural Adaptation (TCA) SIG Meeting	Garibaldi
7:00 pm	Dine Arounds	Meet in Lobby

Schedule at a Glance

Saturday, October 24		
7:30 am - 8:30 am	Continental Breakfast for Attendees	Columbia Foyer
7:30 am - 8:45 am	Committee & Special Interest Group (SIG) Meetings	
	Industry Advisory Committee (IAC) Meeting	Vancouver Island
	Canada PRO SIG Meeting	Boardroom
	Patient Engagement SIG Meeting	Saturna
	Psychometrics SIG Meeting	Waddington
9:00 am - 10:15 am	ISOQOL Member Business Meeting and Awards Presentation	Pacific Ballroom
10:25 am - 10:45 am	Saturday Poster Session 1 & Visit with Exhibitors Odd Numbered Posters (3003 - 3097)	British Columbia Ballroom
	<i>Clinical Practice: (3003 - 3011); Measure Development (3013 - 3049); Kids and Young Adults (3051 - 3059); International (3061 - 3091); Utilities (3093 - 3097)</i>	
11:00 am - 12:30 pm	Plenary - The Social Network	Pacific Ballroom
12:30 pm - 1:45 pm	Lunch on your own	
1:45 pm - 3:00 pm	Concurrent Symposium Sessions	
	<i>Symposium 4: Developing and Validating Clinician Reported Outcomes: Discussion of Applied Methods</i>	Pacific Ballroom
	<i>Symposium 5: Quality of Life following Stroke, Traumatic Brain Injury and Spinal Cord Injury: Influences of person and environmental factors</i>	Vancouver Island
	<i>Symposium 6: Response shift effects at the item level: Cross-method insights for interpreting change over time</i>	Saturna
3:15 pm - 3:35 pm	Saturday Poster Session 2 & Visit with Exhibitors Even Numbered Posters (3004 - 3100)	British Columbia Ballroom
	<i>Health Economics (3004- 3026); Utilities (3028 - 3038); Health Care Providers (3040 - 3058); Vulnerable Populations (3060 - 3074); Family (3076 - 3100)</i>	
3:45 pm - 5:15 pm	Concurrent Oral Sessions	
	<i>Oral Session 301: Response Shift</i>	Waddington
	<i>Oral Session 302: New Developments in PROMIS</i>	Pacific Ballroom
	<i>Oral Session 303: Behavioral Interventions</i>	Vancouver Island
	<i>Oral Session 304: Quality of Life in Children</i>	Saturna
	<i>Oral Session 305: Aging Worldwide</i>	Boardroom
7:00 pm - 10:00 pm	Closing Dinner (Ticket Required) <i>The Roof, The Fairmont Hotel Vancouver</i>	



General Conference Information

Conference Theme

The Matrix: Quality of Life in Social Context

Target Audience

The 23rd 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 annual conference offers 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 scheduled on Thursday, Friday, and Saturday. These 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. Admission to these sessions is by name badge.

Symposium Sessions

Symposia are didactic or panel presentations that last 90 minutes and are held on Friday and Saturday. Presenters will 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. Admission to these sessions is by name badge. 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. Workshops are selected based on peer-reviewed proposal submissions. Admission to workshops is by paid ticket only and seating is limited.

Industry Advisory Committee Symposium

This session is held on Wednesday and focuses on specific topics with various viewpoints expressed by a panel of experts. This is an invited session and has not been peer reviewed. Pre-registration is required for this session.

Breakfast Roundtables

Breakfast roundtables are informal meetings with up to nine (9) participants to network and discuss mutual interests in your work and field. These are invited sessions and have not been peer reviewed. Admission to breakfast roundtables is by paid ticket only and seating is limited.

Oral Sessions

Oral sessions are offered on Thursday, Friday and Saturday and last 75-90 minutes. They are based on peer-reviewed abstracts clustered around common themes and presented via oral presentations, each of which is approximately 13 minutes in length (10 minute presentation followed by 3 minutes of questions and answers from the audience). Admission to these sessions is by name badge.

Poster Sessions

Poster sessions featuring presentations of peer-reviewed abstracts in thematic groupings will take place on each day during the conference. Poster sessions allow abstract authors to discuss their research with interested colleagues in an informal setting. These sessions are a great way to see the latest research in the field while socializing with colleagues. Admission to the Poster Hall is by name badge.

The poster boards will be positioned vertically and the surface area for poster display will be 2.4 meters wide by 1.2 meters high. The exact poster dimensions are up to poster presenters.

General Conference Information

Poster Numbers

All posters have been assigned a poster number which will correspond to the poster's listing in the final program. Odd numbered posters will be presented in the morning during the daily Session 1, and even numbered posters will be presented in the afternoon during the daily Session 2. Posters should be displayed for the full day in which they are assigned.

Set up and Removal

Presenters are responsible for setting up and removing posters during the assigned set up and removal times. Push pins or an appropriate fastener will be provided. All posters have been assigned a presentation day and time. 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 October 22	Friday October 23	Saturday October 24
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>	10:35 - 10:55 am	10:35 - 10:55 am	10:25 - 10:45 am
Session 2 Presentations <i>Even numbers</i>	3:20 - 3:40 pm	3:20 - 3:40 pm	3:15 - 3:35 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.

Poster Hall Hours

All poster presentations will take place in the British Columbia Ballroom. The Poster Hall will be open daily from **7:00 am – 7:00 pm** from Thursday, October 22 – Saturday, October 24.

Registration Desk

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

Registration Desk Hours

Wednesday, October 21:	7:00 am – 7:00 pm
Thursday, October 22:	7:00 am – 6:30 pm
Friday, October 23:	7:00 am – 5:35 pm
Saturday, October 24:	7:00 am – 5:30 pm

Ticketed Events

A ticket is required for all Workshops, Breakfast Roundtables, and the Closing Dinner. Tickets are available at the Registration Desk while supplies last, through Friday, October 23, at 11:30 am.

Cancellation Policy

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

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.



General Conference Information

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, October 21.

Session Recording

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

Final Program

The 22nd Annual Conference program will be archived online at <http://www.isoqol.org/annual-conference/past-conferences>.



ISOQOL partners with individuals and corporations who share the vision of improving patient outcomes and quality of care.

Become a Friend of ISOQOL

Your gift enables ISOQOL to advance our education program, sponsor scholarships, and advance health-related quality of life and patient-centered outcomes.

**Together We Continue to Advance
Quality of Life Research and Patient Outcomes!**

Please visit the registration desk or our website www.isoqol.org to make a donation.
Thank you for your generous support!

The International Society for Quality of Life Research is a non-profit charitable organization under Section 501(c) 3.

Turn-key study management, PRO administration, data capture and reporting application



Featuring surveys from
PROMIS(r), DSM-5, FACIT(c), RAND(c)
& many more

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
- "Measuring What Matters" Symposium
- Mentor/Mentee Program

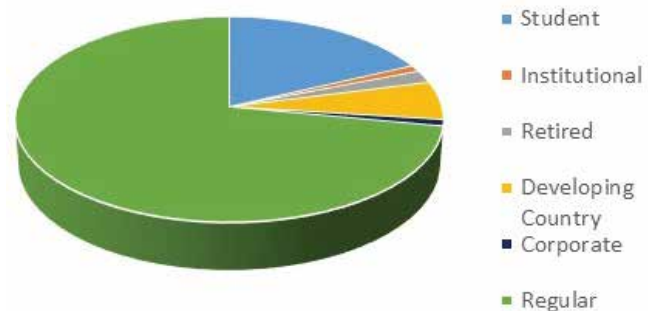
Publications

- *Quality of Life Research Journal*
- *ISOQOL Dictionary of Quality of Life and Health Outcomes Measurement (2015)*
- International Society for Quality of Life Research commentary on the draft European Medicines Agency reflection paper on the use of patient-reported outcome (PRO) measures in oncology studies (2015)
- 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

2015 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

Leadership Opportunities

- ISOQOL Special Interest Groups
- ISOQOL committees and initiatives

Networking & Public Awareness

- Access to ISOQOL Membership Directory and listserv

ISOQOL Leadership



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PhD
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ScD
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Frans Jeroen Oort,
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Michelle Holm



**Program
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2002-2003 Mirjam AG Sprangers, PhD, Netherlands
2001-2002 David Osoba, MD, Canada
2000-2001 Ivan Barofsky, PhD, United States
1998-2000 Sharon Wood-Dauphinee, PhD, Canada
1996-1998 Monika Bullinger, PhD, Germany
1994-1996 Robert Kaplan, PhD, United States
1993-1994 Donald L. Patrick, PhD MSPH, United States

22nd Annual Conference Scientific Program Committee

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Skye Barbic, PhD, Canada – Local Representative
Cynthia Gross, PhD, United States – Mentor/Mentee Program Chair
Nancy Mayo, PhD, Canada – Workshop Chair

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Doris Mwesigire, MD, Uganda

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Peter Fayers, PhD, United Kingdom

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Ana A. Popielnicki, BA, United States – Quality of Life Quarterly Newsletter Editor

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Joan Branin, PhD, United States - Chair

Basic Level Education Program Committee

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Ethan Basch, PhD, United States
William Lenderking, PhD, United States
Nancy Mayo, PhD, Canada – Co-Chair

“Measuring What Matters” Symposium Planning Committee

Sara Ahmed, PhD, Canada – Co-Chair
Steven Blum, PhD, United States – Co-Chair
Claire Snyder, PhD, United States – Board Liaison

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Steven Blum, MBA, MA, United States
Neil Aaronson, PhD, Netherlands
Skye Barbic, PhD, Canada
Roxanne Jensen, PhD, United States

Nominations Committee

Claire Snyder, PhD, United States – Chair
Albert W. Wu, MD MPH, United States
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Response Shift

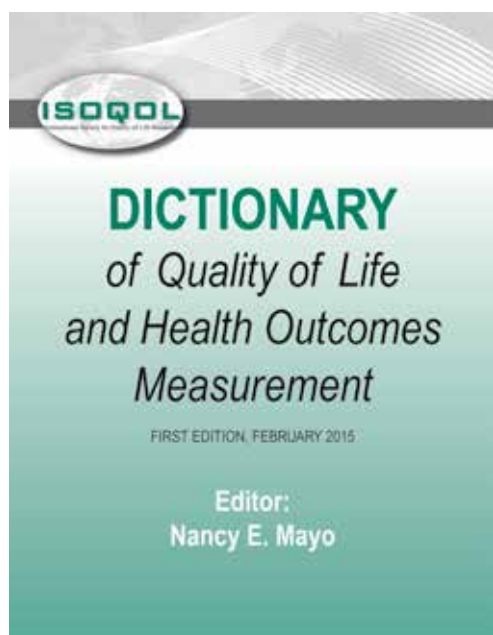
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Awards and Scholarships

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.

Congratulations to the 2015 President's Award recipient –

Carol M. Moinpour, PhD, United States presented by Galina Velikova, MD PhD FRCP

2014 Mirjam AG Sprangers, PhD *presented by Galina Velikova, MD PhD FRCP*

2013 Peter Fayers, PhD *presented by Bryce B. Reeve, PhD*

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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. This is awarded to an ISOQOL member who has shown exceptional leadership skills and potential.

Congratulations to the 2015 Emerging Leader Award recipient –

Bellinda L. King-Kallimanis, PhD, United States

2014 Antonia V. Bennett, PhD

2013 Roxanne Jensen, PhD

2012 Melanie Calvert, PhD

Awards and 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.

Congratulations to the Outstanding Article of the Year (2014 Journal) –

Fayers PM, Hays DR. Don't middle your MIDs: regression to the mean shrinks estimates of minimally important differences. QLR 2014;23(1):1-4.

2014 Finalists

Donneau, A.F., Mauer, M., Coens, C., Bottomley, A., Albert, A.. Longitudinal quality of life data: a comparison of continuous and ordinal approaches. QLR 2014; 23 (10):2873-2881.

Santana, M.-J. and D. Feeny, Framework to assess the effects of using patient-reported outcome measures in chronic care management. Quality of Life Research, 2014. 23(5): p. 1505-1513.

Previous Recipients

- 2013 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.
- 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.



Awards and 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. Student and New Investigator Poster Award Finalists are invited to display their poster throughout the entire conference and present in front of a panel of judges and the attendees at the Annual Conference.

Congratulations to the 2015 New Investigator and Student Presentation Finalists

New Investigator Oral Presentation

John Barile, PhD, University of Hawaii at Manoa, United States

3: Factor Structure of the CDC Healthy Days Core and Symptoms Modules and their Association with Stress, Access to Care, and Social Determinants of Health

Alex Mutebi, PhD, Global Health Economics, United States

205.4: Interpretation of Verbal Descriptors for Response Options Commonly Used in Verbal Rating Scales in Patient-Reported Outcome Instruments

Zheng Li, University of Florida, United States

206.2: The longitudinal relationship between asthma control and quality of life in children: A report from the PROMIS Pediatric Asthma Study

New Investigator Poster Presentation

Eithne Sexton, Trinity College Dublin, Ireland

2001: Does the EQ-5D capture the effect of physical and mental health on subjective well-being among older people?

Kenneth Tang, MSc, McMaster University, Canada

2003: Second-order Confirmatory Factor Analysis of the Work Role Functioning (WRF-26) Questionnaire applied to Firefighters

Rozanne Wilson, PhD, University of Washington, United States

2005: Using Mobile Communication Technology to Improve Social Participation in Frail Elderly Residing in Long-term Care: An Exploratory Group Concept Mapping Study

Student Oral Presentation

Elena Tsangaris, MSc, McMaster University, Canada

202.2: Determining the Psychometric Properties of the CLEFT-Q Using Two Different Sets of Response Options

Gregor Liegl, Mag, Charite - Universitaetsmedizin Berlin, Germany

107.6: Applying a common depression metric to independent samples: Different approaches result in similar score estimates

Guannan Bai, MPH, University Medical Center Rotterdam, Netherlands

105.1: Nausea, vomiting, fatigue and health-related quality of life of women in early pregnancy: The Generation R Study

Awards and Scholarships

Student Poster Presentation

Sneha Shankar, PhD Student, University of British Columbia, Canada

2002: Examining the Factor Structure of General and Health Self-efficacy Scales with Individuals Who are Homeless or Vulnerably Housed


Mohamed Boucekine, Self-perceived Health Assessment Research Unit, France

2004: Detection of Response Shift using a mixed approach combining: k-means and Random Forest methods

Ayesha Mahmud, PhD student, University of Birmingham, United Kingdom

*2006: Outcome reporting in UK-based maternity trials: A Systematic review of randomised controlled trials (The Pro-Maternity group)**

Outstanding Poster Abstract Awards

The top six (6) posters that scored the highest during the abstract review process will be recognized with a ribbon posted on their poster board and are invited to display their poster throughout the entire conference and present in front of a panel of judges and the attendees at the Annual Conference. Each Outstanding Poster Abstract Award Finalist will be designated in the Final Program with a  in front of their poster number and will be acknowledged on a PowerPoint slide at the Awards Presentation during the ISOQOL Members Business Meeting. At this time, the winner will be announced and presented with a framed certificate.

Scholarships

Developing Country Scholarship

Andrea Cueva, Msc, Centro de la Piel, Ecuador

Ranjan Pattnaik, MHS, PhD, Indian Institute of Technology, Kharagpur, India

Andrea L. Monteiro, Msc, Instituto Nacional de Cardiologia, Brazil

New Investigator and Student Scholarship

Andrea Najera Ulloa, MD, Brazil

Guannan Bai, MPH, University Medical Center Rotterdam, Netherlands

John P. Barile, PhD, University of Hawaii at Manoa, United States

Kathrin Fischer, Msc, Charite Universitatsmedizin Berlin, Germany

Venkata NS Jaggumantri, PhD, University of British Columbia, Canada

Patient Engagement Scholarship

Amye L. Leong, MBA, United States

Mario Di Carlo, BA, Canada



Thank you to the 2015 Abstract Reviewers

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Evidera Presentations During ISOQOL

Workshop

An Introduction to Health-Related Quality of Life Assessment
Gelhorn H, Wyrwich K

Oral Presentations

Measurement Properties of the Female Sexual Function Index Desire Domain in Women with Female Sexual Arousal Disorder
Wilson H, Jordan R, Spana C, Revicki D

Validation of a Crosswalk between Measures of Work Role Limitations
Anatchkova M, Kini N, Ware J, Bjorner J

Posters

A Community Sample's Perception of Cause-and-effect Directionality Among Health Domains
Hanmer J, Feeny D, Fischhoff B, Hays R, Hess R, Pilkonis P, Revicki D, Roberts M, Tsevat J, Yu L

Challenges and Opportunities for PROs and Big Data: Applications for the Pharmaceutical Industry
Lenderking W

Development of the PROMIS Nociceptive Pain Scale
Nowinski C, Cella D, Revicki D, Amtmann D, Michaud K, Kallen MA, Askew RL

Evaluating the Reliability and Validity of the ANMS Gastroparesis Cardinal Symptom Index-Daily Diary in Patients with Diabetic and Idiopathic Gastroparesis
Revicki D, Parkman HP

Preference for Pharmaceutical Formulation and Treatment Process Attributes
Stewart KD, Matza LS, Johnston JA, Curtis S, Gelhorn H, Havel H, Sweetana S

Psychometric Assessment of the Functional Assessment of Cancer Therapy/Gynecologic Oncology Group-Neurotoxicity (FACT/GOG-Ntx) Questionnaire in Patients with Relapsed and Refractory Multiple Myeloma (RRMM) Receiving Carfilzomib Treatment
Bacci E, Cocks K, Hurley D, Panjabi S, Revicki D

Qualitative Development of a New Clinician Reported Measure of Multiple Sclerosis Status
Phillips GA, Matza LS, Stewart KD, Jordan JB

Qualitative Equivalence between Paper and Electronic Tablet Versions of 8 PRO Instruments for Osteoarthritis
Eremenco S, Stringer S, Cutts K, Iacobelli M

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Plenary Speakers

Sean Ahrens

San Francisco, CA, United States



Sean Ahrens is an award-winning designer of patient-facing health technology, consultant, and speaker. Sean is a patient with Crohn's Disease and built Crohnology.com, a social network for people with Crohn's & Colitis to track and share what treatments work

for them. He has served as the Co-Principle-Investigator of a PCORI funded Patient Powered Research Network and through which built the OpenPPRN (openpprn.org). Sean won the \$100,000 grand prize in PCORI's Matchmaking App Development Challenge. Sean is a 2x Y-Combinator and RockHealth startup accelerator alum, and studied Computer Science and Business at UC Berkeley.

Frances Chen, PhD

University of British Columbia
Vancouver, BC, Canada



Frances Chen received her A.B. from Harvard University and her Ph.D. from Stanford University. She conducted postdoctoral research at the University of Freiburg, Germany and joined the Department of Psychology at the University of British Columbia in 2013.

Her research investigates how people establish, negotiate, and sustain social relationships. Specifically, Dr. Chen investigates individuals' abilities to approach others and to form relationships, their tendencies to seek and accept social support when distressed, and their effectiveness in dealing with conflict arising from relationships. Her work has been featured in numerous media outlets, including The Globe and Mail, Forbes, Time, NPR, Slate, and The Washington Post.

John P. Barile, PhD

University of Hawaii at Manoa
Manoa, HI, United States



Dr. Barile is an assistant professor at the University of Hawai'i at Mānoa in the Department of Psychology. His research includes the study of social determinants of health-related quality of life with a focus on multiple chronic conditions. This line of research includes the study of individual

level factors, such as socioeconomic status, age and ethnicity, as well as contextual factors, such as housing conditions and community violence. Dr. Barile completed a two-year fellowship at the US Centers for Disease Control and Prevention after earning a doctoral degree in community psychology from Georgia State University and a Bachelor of Science degree in health science from Old Dominion University.

Amylou Dueck, PhD

Mayo Clinic
Scottsdale, AZ, United States



Amylou Dueck, PhD, is the head of biostatistics at Mayo Clinic in Arizona where her primary role is designing and analyzing cancer trials and embedded biomarker and questionnaire-based correlative studies. Her research interests include development of

questionnaires for patient self-reporting of symptoms and statistical analysis methods for patient-reported outcomes (PROs). Dr. Dueck was the study chair of the primary validation study of the US National Cancer Institute's (NCI's) PRO version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) and has collaborated with Ruben Mesa, MD, on validation of the Myeloproliferative Neoplasm Symptom Assessment Form (MPN-SAF). Dr. Dueck is co-vice chair of the Health Outcomes Committee of the Alliance for Clinical Trials in Oncology and statistical representative of NCI's Cancer Care Delivery Research Steering Committee.

Plenary Speakers

Mogens Grønvold, MD

University of Copenhagen
Copenhagen, Denmark



Mogens Grønvold, MD, is Professor of Palliative Care and Quality of Life Research at University of Copenhagen, Denmark, and Head of the Research Unit at Department of Palliative Medicine, Bispebjerg University Hospital in Copenhagen.

Since 1989, his research has focused on the development and application of PRO's in palliative care and oncology. This includes several intervention studies, a national quality of care register including PRO, and international studies such the EU-funded ACTION trial of Advance Care Planning in oncology. Mogens has been a member of the EORTC Quality of Life Group since 1989, was its chair 2011-2014, and is PI for the multinational EORTC CAT Project developing computer-adaptive testing for the 14 dimensions of the EORTC QLQ-C30.

Anatoliy Gruzd, PhD

Ryerson University
Toronto, ON, Canada



Dr. Anatoliy Gruzd is an Associate Professor in the Ted Rogers School of Management at Ryerson University. He is also the Director of the Social Media Lab and a co-editor of a multidisciplinary journal on Big Data and Society published by Sage. Dr. Gruzd's research

initiatives explore how the advent of social media and the growing availability of social big data are changing the ways in which people communicate, collaborate and disseminate information and how these changes impact the social, economic and political norms and structures of modern society. Dr. Gruzd and his lab are also actively developing and evaluating new approaches and tools to support social media data analytics and stewardship. His research and commentaries have been reported across Canada and internationally in various mass media outlets such as Foreign Affairs, Los Angeles Times, Nature.com, The Atlantic, The Globe and Mail, The National Post, The Canadian Press, CBC TV, CBC Radio, CTV and Global TV.

Elizabeth A. Hahn, MA

Northwestern University
Chicago, IL, United States



Elizabeth Hahn is a medical sociologist whose research primarily involves patient-reported outcomes in chronic illnesses, with a focus on underserved populations and health equity. She is a co-investigator on the PROMIS (Patient-Reported Outcomes Measurement Information

System) initiative, and serves as the director of the PROMIS Social Health Workgroup. She is Associate Professor in the Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, and Director of the Outcomes Measurement and Survey Core, a shared resource for the Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

Michael Hayes, PhD

University of Victoria
Victoria, BC, Canada



Dr. Hayes is the Director of Health Research and Education at the University of Victoria, where he is also Director of the School of Public Health and Social Policy, and Director of the Social Dimensions of Health interdisciplinary graduate program. He is a Professor with

appointments in the School of Public Health and Social Policy in the Faculty of Human and Social Development, in the Division of Medical Sciences, and in the Department of Geography in the Faculty of Social Sciences. Prior to joining the faculty at the University of Victoria in July, 2010, he spent 22 years at Simon Fraser University in the Department of Geography and, in 2004, as a founding member of the Faculty of Health Sciences. He was co-founding editor of the journal *Health and Place* and was a non-governmental representative on the Federal-Provincial-Territorial Advisory Committee on Population Health (2001-2006) and a member the Public Health Agency of Canada Expert Advisory Committee on Population Health Promotion (2006-2008). His research interests concern social geographies of health from a life-course perspective. He is particularly interested in health inequities and urban structure, social gradients in health outcomes, disability and public policy. He has also done research on childhood obesity and on newspaper coverage on 'health' in Canada. He has co-edited 3 books.



Plenary Speakers

Allen Heinemann, PhD

Rehabilitation Institute of Chicago
Northwestern University
Chicago, IL, United States



Allen W. Heinemann, PhD, completed his doctoral degree in clinical psychology at the University of Kansas, with a specialty focus in rehabilitation. He has worked at RIC since 1985 where he directs the Center for Rehabilitation Outcomes Research, a rehabilitation-focused health services research unit. He is also professor in the Departments of Physical Medicine and Rehabilitation and Medical Social Sciences at Northwestern University. He co-directs the post-doctoral fellowship program in health services research at Northwestern. His research interests focus on health services research and measurement issues in rehabilitation. He is the author of more than 200 articles in peer-reviewed publications and is the recipient of funding by the National Institute on Disability and Rehabilitation Research, Patient-Centered Outcomes Research Institute, the National Institute on Alcohol Abuse and Alcoholism, Centers for Disease Control and Prevention, the Social Security Administration, the Substance Abuse and Mental Health Services Administration, and private foundations. He is a past president of the American Congress of Physical Medicine and Rehabilitation and the Rehabilitation Psychology division of the American Psychological Association (APA). He serves as co-Editor-in-Chief for the *Archives of Physical Medicine and Rehabilitation*, and is on the editorial boards of several rehabilitation journals. He is the recipient of the APA–Division 22 Roger Barker Distinguished Career Award.

Niels Henrik Hjollund

AmbuFlex@WestChronic
Region Hospital West Jutland
Aarhus University Hospital
Herning, Denmark



Dr. Hjollund has a background in research in occupational and social medicine, where he created a number of cohorts of patients with specific chronic and malignant diseases, which were followed with bimonthly repetitive PRO collection over up to 8 years, with the aim to model long term course and prognosis of symptoms like fatigue, anxiety and depression. Since 2007 he has applied similar data collection methods to the individual patient level and developed a method and a system, AmbuFlex, which enables PRO to be used as the fundament for outpatient follow-up in a number of chronic and malignant diseases.

Marjorie Kagawa Singer PhD MA MN RN FAAN

UCLA School of Public Health and
Department of Asian American Studies Department
Los Angeles, CA, United States



Dr. Kagawa Singer's research focuses on the etiology and elimination of disparities in physical and mental health care outcomes for communities of color, primarily in cancer and with the Asian American and Pacific Islander communities. A major focus of her work is on using mixed-methods to test the cross-cultural equivalence and appropriateness of health behavior theories and measures, and applying the findings to improve the quality of life of diverse population groups. Dr. Kagawa Singer has also published and lectured nationally and internationally on each of these areas.

Plenary Speakers

Brennan Spiegel, MD MSHS

Cedars-Sinai Center for Outcomes Research and Education
University of California, Los Angeles
Los Angeles, CA, USA



Dr. Spiegel is the new Director of Health Services Research at the Cedars-Sinai Center for Outcomes Research and Education, Associate Professor of Medicine in the Division of Digestive Diseases, UCLA School of Medicine, the Department of Health Services, UCLA

Fielding School of Public Health, and an attending physician in the Division of Gastroenterology, VA Greater Los Angeles Health Care System. Dr. Spiegel attended Tufts University where he majored in Philosophy and Community Health, and received his M.D. with Alpha Omega Alpha honors from New York Medical College, he received training in internal medicine at Cedars-Sinai Medical Center in Los Angeles, completed a fellowship in Gastroenterology at UCLA, and completed advanced studies in Health Services Research at the UCLA School of Public Health, where he received a Master's Degree in Health Services. Dr. Spiegel and his group are researching new technological innovations to expand care outside of the provider visit, including use of patient-provider electronic portals to support clinical decision making in electronic health records, use of social media as a clinical tool, and a range of wireless biosensors to track physiology remotely and in real time.

Reginald Tucker-Seeley, MA ScM ScD

Dana-Farber Cancer Institute (DFCI)
Harvard T.H. Chan School of Public Health (HSPH)
Boston, MA, United States



Dr. Reginald Tucker-Seeley is an Assistant Professor of Social and Behavioral Sciences in the Center for Community-Based Research at the Dana-Farber Cancer Institute (DFCI), and in the Department of Social and Behavioral Sciences at the Harvard T.H.

Chan School of Public Health (HSPH). He completed master and doctoral degrees at HSPH and a postdoctoral fellowship in cancer prevention and control at HSPH and DFCI. Dr. Tucker-Seeley's research has focused primarily on social determinants of health, such as the association between the neighborhood environment and health behavior; and on individual-level socioeconomic determinants of multimorbidity, mortality, self-rated health, and health self-efficacy. His current work focuses on the development of measures of financial well-being across the cancer continuum, from prevention to end-of-life care. He has funding from the National Cancer Institute (NCI) to develop measures of financial well-being at two points along the cancer continuum: prevention and following diagnosis. Dr. Tucker-Seeley is also committed to community service focused on the elimination of health disparities and serves on the Rhode Island Commission for Health Advocacy and Equity.



Plenary Speakers

Xin Shelley Wang, MD MPH

UT MD Anderson Cancer Center
Houston, TX, United States



Dr. Wang, a clinical research professor in the Department of Symptom Research at The University of Texas MD Anderson Cancer Center, received her medical degree in China and trained there as a medical oncologist. Her research focuses on quantitative interpretation and tool

validation for measuring patient-reported outcomes (PROs), the impact of culture on symptom reporting, the impact of symptom reduction on clinical outcomes in oncology care, and translational research on inflammatory mechanism-driven interventions for symptoms produced by aggressive treatments, such as chemoradiation and major surgery. She is especially interested in measuring and understanding fatigue-related symptom burden. She has published more than 90 papers in peer-reviewed journals, some in high-impact journals.

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At Roche, 85,000 people across 150 countries are pushing back the frontiers of healthcare. Working together, we've become one of the world's leading research-focused healthcare groups. Our success is built on innovation, curiosity and diversity.

The Position

Roche are advertising a uniquely rare opportunity to join the **Patient-Centered Outcomes Research** team at either of our sites in; Welwyn Garden City (UK) and Basel (CH) This role will report directly into the Global Head of Patient-Centered Outcomes Research for Neuroscience.

When joining the **Patient-Centered Outcomes Research** (PCOR) team, the patient (and caregiver's) voice will be central to everything that you do. You will ensure that the patient is at the center of product development and have the opportunity to develop novel innovative endpoints that inform probability of technical success in drug development as well as generate evidence to demonstrate value to enable global market access and reimbursement. The PCOR team provides strategic consultancy and scientific expertise to support partners in functions such as Clinical, Regulatory and Global Pricing and Market Access. The PCOR team is proactively involved in several external initiatives continuously striving to shift the external landscape with a focus on patient relevant endpoints and novel endpoint development intended to assess treatment benefit and treatment burden rigorously and reliably (e.g. CPATH, Brookings, FDA, NIH, ISOQOL etc).

The current open position is within the PCOR Neuroscience team. In this role you will lead the development of PCOR disease area strategies. You will leverage your technical and communication skills to influence your cross functional stakeholders in the business while demonstrating the Roche values of integrity, courage, and passion which is the foundation of our culture.

Who you are

You will preferably have a PhD (or equivalent) in a relevant field along with extensive industry experience. Your vast experience of PCOR will mean that you are well recognised in the field of Outcomes Research. You are someone who thinks out of the box and challenges the status quo. You should have previous mentoring and leadership skills, and be able to form strong partnerships with key stakeholders internally and externally.

If you are proud of contributing and feel you have the commitment to teamwork and innovation that we are seeking, then Roche is the organisation for you. In return we offer a competitive salary plus the excellent benefits you would expect from a blue-chip organisation, including a genuine interest in your development and progression.

For more information or to be considered for this position, please contact Shreeya Patel (Recruiter) at shreeya.patel@roche.com. Alternatively, please visit our careers site: www.roche.com/careers using the reference: **3091689445**

Doing now what patients need next



Scientific Program — Wednesday, October 21

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

9:00 am – 12:00 pm Morning Workshops

(WK01) An Introduction to Health-Related Quality of Life Assessment..... Galiano
Heather Gelhorn, PhD and Kathleen Wyrwich, PhD, Evidera, United States

(WK02) Death and Missing Data..... Gabriola
Diane Fairclough, DrPH, Univ. of Colorado Denver, United States

(WK03) Best Practices for Qualitative Methods for Patient Reported Outcomes Research Cortes
Cicely Kerr, MSc PhD, Oxfordshire, United Kingdom; Helen Kitchen, MSc, Abacus International, United Kingdom; Elizabeth Gibbons, MSc, Health Services Research Unit, Univ. of Oxford; and Catherine Bottomley (nee Golics), MPharm PhD, pH Associates, United Kingdom

(WK04) Using innovative methods to inform instrument development and understand patient preferences: how Group Concept Mapping and other creative approaches can be used to capture the experiences and priorities of patients Moresby Island
Tom Willgoss, PhD, Abacus International, Manchester, United Kingdom; Mary Kane, PhD, Concept Systems, Inc., Ithaca, NY, United States, Helen Kitchen, MSc, Abacus International, Decision Resources Group, Manchester, United Kingdom; and Todd Edwards, PhD, Univ. of Washington, Seattle, WA, United States

(WK05) Implementation of routine Patient Reported Outcome measurement in clinical practice Saturna
Jose M Valderas, MD PhD MPH, Univ. of Exeter, Exeter, United Kingdom; Lotte Haverman, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Netherlands; Anna Beurskens, PhD PT, Maastricht Univ., Maastricht, Netherlands; Sara Ahmed, BSc MSc PhD, McGill Univ., Montreal, QC, Canada, and Zoe E. Winters, MB ChB(Witw) DPhil(Oxon) FRCS FCS, Univ. of Bristol, Bristol, United Kingdom

1:00 pm – 4:00 pm Afternoon Workshops

(WK06) Introducing the Concept of Response Shift – an Overview of Theory & Methods Cortes
Ruth Barclay, PhD MHS BMR (PT), Assistant Professor, Dept. of Physical Therapy, Univ. of Manitoba, Winnipeg, MB, Canada; Bellinda King-Kallimanis, PhD, Pharmerit International, Boston, MA, United States; Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Leah McClimans, PhD, Univ. of South Carolina Columbia, SC, United States

(WK07) Place Bookmark Here: How to Conceive, Develop, Conduct and Evaluate a Bookmarking Workshop for Identifying Clinically Meaningful Levels of Patient Reported Outcomes (PROs) Gabriola
Karon F. Cook, PhD, David Victorson, PhD and David Cella, PhD, Feinberg School of Medicine, Northwestern Univ., Chicago, Illinois, United States; Deborah Miller, PhD, Cleveland Clinic, Cleveland, OH, United States

(WK08) Improving the design of clinical trials with Patient Reported Outcomes (PROs): guidance for protocol writers..... Saturna
Melanie Calvert, PhD, Professor of Outcomes Methodology, Univ. of Birmingham, Birmingham, United Kingdom; Madeleine T. King, PhD, Cancer Australia Chair in Quality of Life, Psycho-oncology Cooperative Research Group (PoCoG), and Rebecca Mercieca-Bebber, Univ. of Sydney, Sydney, Australia; Derek Kyte, MSc, NSPCR Doctoral Researcher, Primary Care & Clinical Sciences, Univ. of Birmingham, Birmingham, United Kingdom

(WK09) Clinical Outcomes Assessment (COA) in Rare Disease (RD) – New Perspective on Traditional Methods Moresby Island
Linda S. Deal, MS, Pfizer, Collegeville, PA, United State; Kathryn Lasch, PhD and Bellinda King-Kallimanis, PhD, Pharmerit International, Cambridge, MA, United States; Paivi H. Miskala, MSPH, PhD, Pharmerit International, Bethesda, MD, United States; R.J. Wirth, PhD; Vector Psychometric Group, LLC, Chapel Hill, NC, United States

(WK10) Caring about Caregivers: Definitions, Methods and Importance of Evaluating Caregivers' Burden Galiano
Antoine Regnault, PhD, Catherine Acquadro, MD, and Khadra Benmedjahed, Mapi, Lyon, France; Caroline Anfray, Mapi Research Trust, Lyon, France; Diana Rofail, PhD CPsychol, Roche Products Limited, Welwyn Garden City, United Kingdom

 Top Outstanding Posters

Scientific Program — Wednesday, October 21

4:30 pm – 6:00 pm

Industry Advisory Committee (IAC) Symposium

Saturna

Bring Your Own Device (BYOD): trends, best practices, challenges...where do PRO measures go from here?

Advances in technology have paved the way for collecting patient-reported data on patients' own personal cell phones and electronic devices. This approach, known as "Bring Your Own Device (BYOD)", has been promoted as a potentially cost effective solution for industry and a convenient option for patients. However, industry sponsors may still be reluctant to utilize this approach in registration trials. The Industry Advisory Committee (IAC) Symposium will address some of the key questions around BYOD, particularly around implementation, compliance, patient acceptance and validation. The symposium will use case studies in order to highlight some of the challenges of BYOD as well as some of the opportunities that it may offer.

Presenters

Emuella Flood, Senior Director-PRO, ICON Clinical Research, United States

Cindy Howry, VP, Product Strategy and Innovation, United States

Alexandra I. Barsdorf, Director, Outcomes & Evidence, Global Health & Value, Pfizer, United States

Panelists

Sonya Eremenco, Director, EPRO New Products, Evidera, United States

Willie Muehlhaussen, D.V.M., Vice President, Head of Innovation, ICON plc, Dublin, Ireland

Mario Di Carlo, BA, Patient Scholar Awardee, Canada

Amye L. Leong, MBA, Patient Scholar Awardee, United States

Moderator

Josephine Norquist, PRO and Study Endpoints Group Lead, Merck Sharp & Dohme, United States

Organizers

Emuella Flood, Senior Director-PRO, ICON Clinical Research, United States; **Josephine Norquist**, PRO and Study Endpoints Group Lead, Merck Sharp & Dohme, United States; **Alexandra I. Barsdorf**, Director, Outcomes & Evidence, Global Health & Value, Pfizer, United States, **Tara Symonds**, Clinical Outcomes Solutions, United Kingdom

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

British Columbia Ballroom

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

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





SAVE THE DATE!

October 23-26, 2016

Vancouver, BC, Canada



38th ANNUAL MEETING



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www.smdm.org**

Scientific Program — Thursday, October 22

7:00 am – 6:30 pm **Registration Desk Open**

7:30 am – 8:25 am **First Time Attendee – Coffee with the ISOQOL Board of Directors** **Columbia Ballroom**

8:30 am – 9:00 am **Welcome and Opening Remarks** **Pacific Ballroom**

Official welcome and opening remarks.

Galina Velikova, MD PhD FRCP, ISOQOL President

Carolyn Gotay, PhD and Ida Korfage, PhD, Scientific Program Co-Chairs

9:00 am – 10:30 am **Not the Usual Suspects** **Pacific Ballroom**

This session focuses on the interface between social factors and quality of life. Talks will investigate social determinants of health, cultural influences on well-being, and how to evaluate the impact of economic factors. The plenary will provide us with better appreciation of how context affects outcomes, and how building this appreciation into our research and practice will lead to a more nuanced and deeper understanding of quality of life.

Speakers

Michael Hayes, PhD, Univ. of Victoria, Victoria, BC, Canada

Reginald Tucker-Seeley, MA ScM ScD, Dana-Farber Cancer Institute (DFCI) Harvard T.H. Chan School of Public Health (HSPH), Boston, MA, United States

Marjorie Kagawa Singer PhD MA MN RN FAAN, Professor, UCLA School of Public Health and Department of Asian American Studies Department, Los Angeles, CA, United States

Co-Chairs

Carolyn Gotay, PhD, Univ. of British Columbia, Vancouver, BC, Canada and Ida Korfage, PhD, Erasmus MC, Rotterdam, The Netherlands

Discussant

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

10:00 am – 5:00 pm **Poster Hall Open** **British Columbia Ballroom**

10:30 am – 11:20 am **Exhibits Open and Refreshment Break** **British Columbia Ballroom**

10:35 am – 10:55 am **Thursday Poster Session 1** **British Columbia Ballroom**

Reviews

(1007) Selecting Patient Reported Outcome Measures for Patients with Abdominal Aortic Aneurysm (AAA): Integrating Systematic Review and Qualitative Evidence Synthesis Methods.

Rosie Duncan, Univ. of Sheffield, Sheffield, United Kingdom; Georgina Jones; Munira Essat; Edith Poku; Patrick Phillips; Helen Buckley Woods; Andrew Booth; Simon Palfreyman; and Jonathan Michaels, Univ. of Sheffield, Sheffield, United Kingdom

(1009) What do Health-Related Quality of Life Questionnaires Designed for Adolescents and Young Adults (AYA) with Cancer Measure? A Systematic Review

Natasha Wickert, McMaster Univ., Hamilton, ON, Canada; Elena Tsangaris, MSc, McMaster Univ., Hamilton, ON, Canada; Samantha Anthony, Hospital for Sick Children, Toronto, ON, Canada; Robert J. Klaassen, Univ. of Ottawa, Children's Hospital of Eastern ON, Ottawa, ON, Canada; Anne Klassen, DPhil, McMaster Univ., Hamilton, ON, Canada

(1011) Systematic Review of Patient-Reported Outcome Measures Used to Assess Symptoms Associated with Heart Failure

Lauren A. Braam, MIH, Health Research Associates, Inc., Seattle, WA, United States; Donald M. Bushnell, MA; and Mona L. Martin, RN MPA, Health Research Associates, Inc., Seattle, WA, United States; Renee F. Pierson, MBA, Janssen Global Services, Raritan, NJ, United States

(1013) Traditional Chinese Medicine Instruments for Quality of Life: a systematic review of psychometric evidence

Changhe Yu, China Academy of Chinese Medical Sciences, Beijing, China; Ya-Nan Sun, PhD, Xuanwu Hospital Capital Medical Univ., Beijing, China; Li-Yun He, PhD; Bao-Yan Liu; and Wen-Jing Bai, PhD, China Academy of Chinese Medical Sciences, Beijing, China

 *Top Outstanding Posters*



Scientific Program — Thursday, October 22

(1015) Carer outcomes in palliative care: a systematic review of the measures and their psychometric properties

Michele Peters, PhD, Univ. of Oxford, Oxford, United Kingdom; Charlotte Michels, MSc, Radboud Univ., Nijmegen, Netherlands; Astrid Adams, MD; and Bee Wee, MD PhD, Oxford Univ. Hospitals Trust, Oxford, United Kingdom; Mary Boulton, PhD, Oxford Brookes Univ., Oxford, United Kingdom

(1017) Using Preference-Based Measures to Improve Care: A Synthesis

David Feeny, PhD, Department of Economics, McMaster Univ., Hamilton, ON, Canada

(1019) Development of a Database of Published Regulatory Recommendations Concerning the Use of Clinical Outcomes Assessments (COAs) in Drug Development: Outcomes InSite

Cecile Perret; and Catherine Acquadro, Mapi Research Trust, Lyon, France.

(1021) Patient Experience with Hereditary Angioedema (HAE): A Review of the Literature

Larissa M. Stassek, MPH, Health Research Associates, Inc., Seattle, WA, United States; Donald M. Bushnell, MA; and Kelly P. McCarrier, PhD, Health Research Associates, Inc, Seattle, WA, United States; Dylan Supina, PhD, Shire Pharmaceuticals, Wayne, PA, United States

(1023) Design, implementation and reporting strategies to reduce the instance and impact of missing patient-reported outcome data: A systematic review

Rebecca Mercieca-Bebber, Univ. of Sydney, Sydney, NSW, Australia; Michael J. Palmer, Queen's Univ., Kingston, ON, Canada; Michael Brundage, MD, MSc, Kingston General Hospital, Queen's Univ., Kingston, ON, Canada; Melanie J. Calvert, PhD, Univ. of Birmingham, Birmingham, United Kingdom; Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia

(1025) Quality of life (QoL) in patients with early laryngeal cancer (LC) treated with transoral laser microsurgery (TLM) or radiotherapy: a systematic review.

Michelle Verelst, Antwerp Univ., Wilrijk, Antwerpen, Belgium; Elien Dewaele; and Pol Specenier, Antwerp Univ. Hospital, Edegem, Belgium

(1031) Challenges in the conversion of quality of life data to utility values

Faraz M. Ali; Richard Kay; and Andrew Y. Finlay, Cardiff Univ., Cardiff, United Kingdom, Sam Salek, PhD RPh FFPM MRPSGB MCMS FESCP, School of Life & Medical Sciences, Univ. of Hertfordshire, Hatfield and Director - Institute for Medicines Development, Cardiff, United Kingdom

E-Health

(1033) COPD Symptom Data - Usability and validation of electronic, tablet-based implementations of the SGRQ-C and CAT questionnaires

Paul O'Donohoe; Karl McEvoy; and Jessica Thilaganathan, CRF Health, London, United Kingdom; Rebecca L. Two, BA (Hons); Abby Cox; and Hayley L. Simpson, BA, PharmaQuest Ltd, Banbury, United Kingdom, Fiona E. Miller, BA (Joint Hons), PharmaQuest Ltd, Banbury, United Kingdom

(1035) The Daily Experience Sampling Questionnaire (DESQ): A New Approach to Measuring Subjective Well-Being

Christine Blome, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1037) Integrating quality of life assessments into acute care for older adults with chronic life-limiting illnesses

Kara Schick-Makaroff, PhD, Univ. of Alberta, Edmonton, AB, Canada; Glenda King, RN, MN, Trinity Western Univ., Vancouver, BC, Canada; Esther Laforest, RN, PhD student, McGill Univ., Montreal, QC, Canada; S. Robin Cohen, PhD, McGill Univ. and Lady Davis Institute, Montreal, QC, Canada; Charlene Neufeld; and Judy Lett, Fraser Health, Vancouver, BC, Canada; James Voth, Intogrey, Vancouver, BC, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada

(1039) Linguistic Validation Of Clinical Outcomes Assessment (COA) Questionnaires Administered via an Interactive Voice Response System (IVRS)

Barbara Brandt, Corporate Translations Inc., East Hartford, CT, United States, Matthew Talbert, Corporate Translations Inc, Chicago, IL, United States; Mary Gawlicki; and Shawn McKown, Corporate Translations Inc., East Hartford, CT, United States

(1041) Open Access telePRO: a website for patient-initiated tele Patient-reported Outcome (telePRO) follow-up in outpatient clinics

Liv Marit Valen Schougaard, RN, MHSc, Regional Hospital West Jutland, Herning, Denmark; Caroline T. Mejdahl, RN, MNSc, Aarhus Univ. Hospital, Aarhus, Denmark; Klaus Hvam Petersen, B. Eng., Regional Hospital West Jutland, Herning, Denmark; Niels Henrik Hjøllund, MD, PhD, AmbuFlex, Herning, Denmark

(1043) Development and Evaluation of Interactive “Life Coaching” App for Enhancing Post-Secondary Students’ Mental Health in Hong Kong

Ka Fai Wong, Assistant Professor, The Open Univ. of Hong Kong, Hong Kong, China



Top Outstanding Posters

Scientific Program — Thursday, October 22

(1047) Successful Integration of Electronic Patient Reported Outcomes to Improve the Quality of Life of Patients with Prostate Cancer in Busy Genitourinary Outpatient Clinics

Alyssa Macedo, MScOT, Univ. Health Network - Princess Margaret Cancer Centre, Toronto, ON, Canada; Doris Howell, Univ. Health Network - Princess Margaret Cancer Centre; Univ. of Toronto, Toronto, Canada; Michael Brundage, MD, MSc, Kingston General Hospital, Queen's Univ., Kingston, ON, Canada; Sarah Stevens, Cancer Care ON, Toronto, Canada; Michael Lima; Anika Petrella; Michael Nesbitt; Fred Cohen; Rupi Purewal; Iryna Tymoshyk; Andrew Bayley; Robert Bristow; Charles Catton; Peter Chung; Saibishkumar Elantholi Parameswaran; Antonio Finelli; Neil Fleshner; Girish Kulkarni; Pdraig Warde, MD; Tran Truong; Terri Stuart-McEwan; and Andrew Matthew, Univ. Health Network - Princess Margaret Cancer Centre; Univ. of Toronto, Toronto, Canada

(1051) Capturing High-Quality Ecological Momentary Assessments by Integrating a Smartphone Application with a Trial Management System

Victor B. Boesen, BSc, Copenhagen Univ. Hospital Rigshospitalet and Gentofte Hospital, Copenhagen, Denmark; Per Cramon, MD; and Stine B. Nissen, M.S. in Psychology, Copenhagen Univ. Hospital Rigshospitalet, Copenhagen, Denmark; Steen J. Bonnema, MD, PhD, DMSc, Odense Univ. Hospital, Odense, Denmark; Jakob B. Bjorner, MD, PhD, QualityMetric; Univ. of Copenhagen, Copenhagen, Denmark; Thea Christoffersen, BSc, Copenhagen Univ. Hospital Rigshospitalet, Copenhagen, Denmark; Ulla Feldt-Rasmussen, MD, DMSc, Copenhagen Univ. Hospital Rigshospitalet, Copenhagen, Denmark; Mogens Groenvold, MD, PhD, DMSc, Univ. of Copenhagen and Bispebjerg Univ. Hospital, Copenhagen, Denmark; Laszlo Hegedus, MD, DMSc, Odense Univ. Hospital, Odense, Denmark; Aase K. Rasmussen, MD, DMSc, Copenhagen Univ. Hospital Rigshospitalet, Copenhagen, Denmark; Torquil Watt, MD, PhD, Copenhagen Univ. Hospital Rigshospitalet and Gentofte Hospital, Copenhagen, Denmark

(1053) Psychosocial, Symptom, and Quality of Life Predictors of Participant Retention in an Internet-Based Symptom Management Study for Women with Recurrent Ovarian Cancer: A Gynecologic Oncology Group (GOG) Trial

Heidi S. Donovan, PhD, RN, Univ. of Pittsburgh School of Nursing, Pittsburgh, PA, United States; Susan M. Sereika, PhD, Univ. of Pittsburgh School of Nursing, Pittsburgh, PA, United States; Sandra Ward, PhD, RN, Univ. of Wisconsin-Madison, Madison, WI, United States; Catherine Bender, PhD, RN, Univ. of Pittsburgh School of Nursing, Pittsburgh, PA, United States; Robert P. Edwards, MD, Univ. of Pittsburgh School of Medicine, Pittsburgh, PA, United States; Judy Knapp, PhD, LCSW, Univ. of Pittsburgh School of Nursing, Pittsburgh, PA, United States; Susan Nolte, PhD, RN, Abington Memorial Hospital, Abington, PA, United States; Michael Spring, PhD, Univ. of Pittsburgh, Pittsburgh, PA, United States; Howard Stein, Univ. of Pittsburgh School of Nursing, Pittsburgh, PA, United States; Joan Walker, MD, Oklahoma Univ. Health Science Center, Oklahoma City, OK, United States; Kristin Zorn, MD, Univ. of Arkansas for Medical Sciences, Little Rock, PA, United States; Lari Wenzel, PhD, Univ. of California-Irvine, Irvine, CA, United States

(1055) A Patient-Centric, Electronic Solution for Capturing Concomitant Medication Usage

Juha Matero; Olli Kotiranta; Nora Ibrahimova; and Paul O'Donohoe, CRF Health, London, United Kingdom, Jessica Thilaganathan, CRF Health, London, United Kingdom

(1057) Patient reported outcomes (PRO) of acceptability with the use of a diabetes mobile application.

Astrid Torbjørnsen, MSc, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway; Lis Ribu, PhD; and Marit Rønnevig, RN MNSc, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway; Astrid Grøttland, BCS, Norwegian Centre for Integrated Care and Telemedicine, Tromsø, Norway; Sølvi Helseth, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway

(1059) Implementation evaluation of a tablet-based waiting room survey of patient reported outcomes in an integrated youth health clinic

Chris G. Richardson, PhD, Univ. of British Columbia/St Paul's Hospital, Vancouver, BC, Canada; Skye P. Barbic, Post-Doctoral Fellow, Faculty of Medicine, Vancouver, BC, Canada; Steve Mathias, MD, FRCPC, Providence Health Care, Vancouver, BC, Canada

(1061) Qualitative Equivalence between Paper and Electronic Tablet Versions of 8 PRO Instruments for Osteoarthritis

Sonya Eremenco, MA, Evidera, Inc., Bethesda, MD, United States; Sonja Stringer, MPH, Evidera, Inc.; Katelyn Cutts; and Michael Iacobelli, Evidera, Inc., Bethesda, MD, United States

(1063) Integrating Patient-Centered Research Methods within User-Centered Design: a Patient-Centered Digital Care Plan

Julie Babione, MSc, W21C Research and Innovation Centre / UCalgary, Calgary, AB, Canada; Marilyn Gill, Patient and Community Engagement Researcher (PaCER); and Maria J. Santana, Univ. of Calgary, AB, Calgary, Canada; Katherine Skora, MS, MPH, CGC, Alberta Health Services, Calgary, Canada; Chloe De Groot, W21C Research and Innovation Centre / UCalgary, Calgary, AB, Canada; Colin Penman, Patient and Community Engagement Researcher (PaCER), Univ. of Calgary, Calgary, AB, Canada; Dilshaan Panjwani; Jill De Groot, MSc; Jaime Kaufman, PhD; William Ghali, MD, FRCPC, MPH; and Peter Sargious, MD, FRCPC, MPH, W21C Research and Innovation Centre / UCalgary, Calgary, Canada

(1065) The Usability and Comparability of an App-based Questionnaire Across a Range of Screen Sizes

Paul O'Donohoe, CRF Health, London, United Kingdom; Juha Matero; Petra Meinander; Antti Heikkila; and Rauha Tulkki-Wilke, CRF Health, London, United Kingdom



Top Outstanding Posters



Scientific Program — Thursday, October 22

(1067) Overcoming oncology study challenges with patient-centric technology

Jessica Thilaganathan; and Karl McEvoy, CRF Health, London, United Kingdom; Paul O'Donohoe, CRF Health, London, United Kingdom; Nora Ibrahimova; and Katie Garner, CRF Health, London, United Kingdom

Cancer

(1069) Social support is associated with mental health and health-related quality of life in breast cancer survivors – results from the German population-based, multiregional CAESAR-Study

Annika Waldmann, Univ. Hospital Schleswig-Holstein, Campus Luebeck, Luebeck, Germany; Maren Bredehoeft, Univ. Hospital Schleswig-Holstein, Campus Luebeck, Luebeck, Germany; Lena Koch-Gallenkamp, German Cancer Research Center (DKFZ), Heidelberg, Germany; Heike Bertram, Cancer Registry of North Rhine-Westphalia (Muenster region), Muenster, Germany; Andrea Eberle, Bremen Cancer Registry, Leibniz Institute for Prevention Research and Epidemiology – BIPS, Bremen, Germany; Bernd Holleczeck, Saarland Cancer Registry, Saarbruecken, Germany; Sieglinde Schmid-Hoepfner, Hamburg Cancer Registry, Hamburg, Germany; Sylke R. Zeissig, Cancer Registry Rhineland-Palatinate, Mainz, Germany; Hermann Brenner; and Volker Arndt, German Cancer Research Center (DKFZ), Heidelberg, Germany

(1075) Development of a Patient-Centric Patient Reported Outcome Instrument to Assess the Quality of Life of Patients Living with Mycosis Fungoides/Sézary Syndrome-Type Cutaneous T-cell Lymphoma (MF/SS-CTCL)

Julia Braverman, PhD, PatientsLikeMe, Cambridge, MA, United States; Auriell N. Towner; and Priya L. Raja, PatientsLikeMe, Cambridge, MA, United States; Magdalena Harrington, PhD, Shire Pharmaceuticals, Cambridge, MA, United States; Kristina F. Simacek, MA, PatientsLikeMe, Cambridge, MA, United States

(1077) Use of the Skin Cancer Quality of Life Impact Tool (SCQOLIT) – A Feasibility Study In Non-melanoma Skin Cancer

Rubeta N. Matin, Consultant Dermatologist, Oxford Univ. Hospitals NHS Trust, Headington, Oxford, United Kingdom; Elizabeth Gibbons, Univ. of Oxford, Oxford, United Kingdom

(1079) Using a Personalized Measure (Patient Generated Index (PGI)) to Identify What Matters to People with Cancer

Ala S. Aburub, MSc, McGill Univ., Montreal, QC, Canada; Bruno Gagnon, M.D., M.Sc, Universite Laval, Laval, QC, Canada; Ana Maria Rodriguez, PHD, McGill Univ., Montreal, QC, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada

(1081) Negative effects on quality of life during Dutch cervical screening program are small

Ida Korfage, PhD, Erasmus MC, Univ. Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Inge M. de Kok, PhD, Erasmus Univ. Medical Center, Rotterdam, Netherlands; Wilbert B. van den Hout, PhD, Leiden Univ. Medical Center, Leiden, Netherlands; Theo J. Helmerhorst, MD, PhD; and J. Dik F. Habbema, PhD; Marie-Louise Essink-Bot, MD PhD, Univ. of Amsterdam, Academic Medical Center, Amsterdam, Netherlands; Marjolein van Ballegooijen, MD PhD, Erasmus Univ. Medical Center, Rotterdam, Netherlands

(1083) Prognostic Value of Health-Related Quality of Life for Death Risk Stratification in Patients with Unresectable Glioblastoma

Brice Paquette, MD, Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon; Department of Digestive Surgery and Liver Transplantation, Univ. Hospital of Besançon France, Besançon, France; Dewi Vernerey; and Amélie Anota, PhD, Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon, Besançon, France; Bruno Chauffert, Prof., Department of Medical Oncology, Univ. Hospital, EA 4666, Amiens, France; Tienhan Sandrine Dabakuyo, PhD, Centre Georges François Leclerc Comprehensive Cancer Centre, Dijon, France; Loïc Feuvret, MD, Department of Radiotherapy, Pitié-Salpêtrière Univ. Hospital, Paris, France; Luc Taillandier, MD, Department of Neurology, Univ. Hospital, Nancy, France; Didier Frappaz, MD, Department of Oncology, Leon Berard Centre for Fight against Cancer, Lyon, France; Hervé Taillia, Department of Neurology, HIA Val de Grace, Paris, France; Roland Schott, Department of Oncology, Paul Strauss Centre for Fight against Cancer, Strasbourg, France; Michel Fabbro, Department of Oncology, Val d'Aurelle Center for Fight against Cancer Montpellier France, Montpellier, France; Isabelle Tennevet, MD, Department of Oncology, Henri Becquerel Center for Fight against Cancer, Rouen, France; Francois Ghiringhelli, Prof., Department of Oncology, GF Leclerc Center for Fight against Cancer, Dijon, France; Chantal Campello, Department of Neurology, Univ. Hospital, Nimes, France; Cécile Dalban, Biostatistics and Quality of life unit, Centre Georges François Leclerc, Dijon, France; Jerome Skrzypski, Biostatistics and Quality of life unit, Centre Georges François Leclerc, Dijon, France; Olivier Chinot, Prof., Department of Neuro-Oncology, Univ. Hospital La Timone, Marseille, France; Franck Bonnetain, Prof., Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon Quality of Life in Oncology National Platform, Besançon, France



Top Outstanding Posters

(1085) Quality of Life (QOL) Results of the UK TACT2 Trial: More Intensive Chemotherapy for Early Breast Cancer (EBC) Has a Measurable Impact on Patient-Reported Symptoms and Functioning (CRUK/05/019)

Galina Velikova, MD PhD, Leeds Institute of Cancer Studies and Pathology Univ. of Leeds, Leeds, United Kingdom; James Morden, ICR-CTSU, Division of Clinical Studies, The Institute of Cancer Research, London, United Kingdom; Peter Barrett-Lee, Academic Breast Unit, Velindre NHS Trust, Cardiff, United Kingdom; David Bloomfield, Sussex Cancer Centre, The Royal Sussex County Hospital, Brighton, United Kingdom; Murrey Brunt, Department of Oncology, Univ. Hospital of North Staffordshire, Stoke-on-Trent, United Kingdom; Peter Canney, Department of Oncology, Beatson Oncology Centre, Glasgow, United Kingdom; Robert Coleman, Academic Unit of Clinical Oncology, Weston Park Hospital, Sheffield, United Kingdom; Susan Russel, Cancer Clinical Trials Unit Scotland (CaCTUS), Edinburgh, United Kingdom; Mark Verrill, Department of Medical Oncology, Northern Centre for Cancer Care, Freeman Hospital, Newcastle upon Tyne, United Kingdom; Andrew Wardley, Department of Medical Oncology, The Christie Hospital NHS Trust, Manchester, United Kingdom; Judith Bliss, ICR-CTSU, Division of Clinical Studies, The Institute of Cancer Research, London, United Kingdom; David Cameron, Edinburgh Cancer Research Centre, Univ. of Edinburgh and NHS Lothian, Edinburgh, United Kingdom



(1087) Clustering based on unsupervised binary trees to define levels of symptom severity in cancer

Pierre Michel, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; Zeinab Hamidou; Laurent Boyer; Badih Ghattas; and Pascal Auquier, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France

(1089) The Experiences of Health-Related Quality of Life in Patients with Non-Specific Symptoms that Undergo a Diagnostic Work-up for Cancer

Ellen Moseholm Larsen, MSCh, PhD Student, Copenhagen Univ. Hospital, Nordsjælland, Hilleroed, Denmark; Bjarne O. Lindhardt, MD, DMSc, Copenhagen Univ. Hospital, Hvidovre, Denmark; Susan Rydahl-Hansen, Associate professor, PhD MScN, Bispebjerg and Frederiksberg Univ. Hospital and Aarhus Univ., Copenhagen, Denmark

(1091) Identification of Patient-Relevant Non-Small Cell Lung Cancer (NSCLC) Symptoms through Semi-Structured Qualitative Interviews

Kelly P. McCarrier, PhD, Health Research Associates, Inc, Seattle, WA, United States; Michael Scanlon; and Mona L. Martin, RN MPA, Health Research Associates, Inc., Seattle, WA, United States; Stephen J. Coons, PhD, Critical Path Institute, Tucson, AZ, United States; Alicyn K. Campbell; and Kendra DeBusk, Genentech, Inc., South San Francisco, CA, United States; Dagmar Kaschinski, Boehringer Ingelheim GmbH, Ingelheim, Germany; Jean Marie Arduino, Merck & Co., Inc., Kenilworth, NJ, United States; Astra M. Liepa, Eli Lilly and Company, Indianapolis, IN, United States; Juliane Lungershausen, Boehringer Ingelheim GmbH, Ingelheim, Germany, On behalf of the Patient-Reported Outcome (PRO) Consortium's Non-Small Cell Lung Cancer Working Group

(1095) Cancer Registry-Linked Data with Patient-Reported Outcomes and Patient Experiences with Care: an Overview of Findings from the Centers for Medicare & Medicaid and National Cancer Institute SEER-MHOS and SEER-CAHPS Data Resources

Erin E. Kent, PhD MS, National Cancer Institute, Rockville, MD, United States; Gigi Yuan, MS; and Marie S. Topor, BS, Information Management Services, Inc., Calverton, MD, United States; Neetu Chawla, PhD MPH, Kaiser Permanente Northern California, Oakland, CA, United States; Sarah Gaillot, PhD; and Kimberly DeMichele, PhD, Centers for Medicare & Medicaid Services, Baltimore, MD, United States

(1097) Incorporating the Patient's Voice into Instrument Development: How Do Patients Describe the Impact of Non-Small Cell Lung Cancer (NSCLC) on their Breathing?

Michael Scanlon, Health Research Associates, Inc., Seattle, WA, United States; Kelly P. McCarrier, PhD, Health Research Associates, Inc, Seattle, WA, United States; Stephen J. Coons, PhD, Critical Path Institute, Tucson, AZ, United States; Mona L. Martin, RN, MPA, Health Research Associates, Inc., Seattle, WA, United States; Alicyn K. Campbell; and Kendra DeBusk, Genentech, Inc., South San Francisco, CA, United States; Juliane Lungershausen; and Dagmar Kaschinski, Boehringer Ingelheim GmbH, Ingelheim, Germany; Jean Marie Arduino, Merck & Co., Inc., Kenilworth, NJ, United States; Astra M. Liepa, Eli Lilly and Company, Indianapolis, IN, United States, On behalf of the Patient-Reported Outcome (PRO) Consortium's Non-Small Cell Lung Cancer Working Group

(1099) Evaluate the Impact of GVHD on Quality of Life, Health, Sexuality and Fatigue of Long Term Survivors after Hematopoietic Stem Cell Transplant (HSCT)

Maribel P. Doro, ISOQOL, Curitiba, Paraná, Brazil; Julita M. Pelaez, Curitiba, Paraná, Brazil; Vaneuza A. Funke, Bone Marrow Transplant, Curitiba, Paraná, Brazil; Iris M. Okumura, Curitiba, Parana, Brazil; Ricardo P. Pasquini, Member of the International Society of Hematology, American Society for Blood and Marrow Transplantation, American Society of Clinical Oncology, International Society for Experimental Hematology; Socie, Curitiba, Paraná, Brazil

(1101) Leukemia treatment strategies: what are the minimally important differences in patient quality of life

Emily McPherson, MA; Sonya Cressman, PhD, MBA; and Paulos Teckle, PhD, BC Cancer Agency, Vancouver, BC, Canada; Dean A Regier, PhD; and Stuart J Peacock, DPhil, Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada; **Alexa Evans, BC Cancer Agency, Vancouver, BC, Canada**




Scientific Program — Thursday, October 22

10:55 am – 11:10 am Outstanding Poster Award Finalist
Presentations Session 1

British Columbia Ballroom

 (1001) Health-Related Quality of Life in CLARINET, a phase III Trial of Lanreotide Autogel 120 mg in Patients with Non-Functioning Entero-Pancreatic neuroendocrine Tumour: Analytical Challenges and Statistical Solutions

Antoine Regnault, Mapi, Lyon, France; Loic Ferrer, INSERM, Université Bordeaux, Bordeaux, France; Jérôme Dinet; and Sylvie Gabriel, IPSEN Pharma, Boulogne, France; Marianne E. Pavel, Universitätsmedizin Berlin, Berlin, Germany; Philippe B. Ruzsniwski, Beaujon Hospital, Clichy, France; Martyn E. Caplin, Royal Free Hospital, London, United Kingdom

 (1003) Use of PROs in clinical guidance for the management of chronic conditions in Primary Care in the United Kingdom

Ian Porter, PhD MSc, Univ. of Exeter Medical School, Exeter, Devon, United Kingdom; Jose M Valderas, MD, PhD, MD, Univ. of Exeter, Exeter, United Kingdom

 (1005) Advancing Patient-Reported Outcome Measures (PROMs) in Canada

Ellis Chow, MBA, Canadian Institute for Health Information, Toronto, ON, Canada; Maria Zaccaria Cho; and Laura L. Faye, Canadian Institute for Health Information, Toronto, ON, Canada; Richard Sawatzky, PhD RN; and Eric K. H. Chan, Ph.D., Trinity Western Univ., Langley, BC, Canada; Greg Webster, Canadian Institute for Health Information, Toronto, ON, Canada

11:20 am – 12:35 pm Cutting Edge Research Plenary

Pacific Ballroom

Plenary sponsored by: Abacus International

This session presents talks based on some of the highest-ranked abstracts from ISOQOL's call for submissions. In particular, these abstracts reflect research that truly "pushes the ISOQOL envelope" in providing new and different ways to look at the field. These innovative presentations span the full quality of life research continuum from biology to health systems.

Inflammatory Gene SNPs as Predictors of Patient Reported Symptom Related Functioning in Patients with Multiple Myeloma

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

A cluster-randomized study of clinician-patient shared vs standard reporting of symptomatic adverse events using PRO-CTCAE nested in a multicenter trial of multimodal therapy for rectal cancer

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

Factor Structure of the CDC Healthy Days Core and Symptoms Modules and their Association with Stress, Access to Care, and Social Determinants of Health

John P. Barile, PhD, Univ. of Hawaii, Honolulu, HI, United States

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

National implementation of clinical PRO in Denmark

Niels Henrik Hjollund, MD PhD, AmbuFlex, Herning, Denmark

Plenary chaired by Albert Wu, MD MPH, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States

12:35 pm – 1:45 pm Lunch on your own

12:35 pm – 1:45 pm SIG Council Meeting (Closed Event)

Garibaldi

 Top Outstanding Posters

Scientific Program — Thursday, October 22

1:45 pm – 3:15 pm Concurrent Oral Sessions

Oral Session 101: Quality of Life Constructs

Pacific Ballroom

Session Chair: Bellinda L. King-Kallimanis, PhD, United States

1:50 pm – 2:03 pm (101.1) Psychological profiles of attitudes about health: does it make a difference to the self-rating of health and life satisfaction?

Yash J. Jalundhwala, MS, Univ. of Illinois at Chicago, Chicago, IL, United States; A. Simon Pickard, PhD, Univ. of Illinois at Chicago, Chicago, IL, United States

2:04 pm – 2:17 pm (101.2) A single question about a respondent's perceived financial ability to pay monthly bills explains more variance in health utility scores than absolute income and assets questions.

Janel Hanmer, MD, PhD, Univ. of Pittsburgh, Pittsburgh, PA, United States; Dasha Cherepanov, PhD, Partnership for Health Analytic Research, Beverly Hills, CA, United States

2:18 pm – 2:31 pm (101.3) Comparison of QOL between Personalized and "One Size Fits All" Measures

Nancy Mayo, PhD, McGill Univ., Montreal, Canada; Ayse Kuspinar; Ala' S. Arubub; and Carolina Moriello, McGill Univ. Health Centre - RI, Montreal, QC, Canada; Susan C. Scott, McGill Univ. Heath center, Montreal, QC, Canada

2:32 pm – 2:45 pm (101.4) How is Subjective Well-Being related to Quality of Life? Do we need Two Concepts and Measures?

Suzanne M. Skevington, PhD, CPsychol, FBPsS, Univ. of Manchester, Manchester, United Kingdom

2:46 pm – 2:59 pm (101.5) Is there a Relationship between Spiritual Wellbeing (SWB) and QOL? Findings from International Validation of the EORTC QLQ-SWB32

Bella Vivat, Univ. College London, London, United Kingdom; Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Julie Winstanley, Patricia Ritchie Centre for Cancer Care and Research, Sydney, Australia; Juan I. Arraras, Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain; Kath Black, St. Gemma's Hospice, Leeds, United Kingdom; Anne Bredart, Psychiatry and Psychooncology Unit, Institut Curie, Paris, France; Anna Costantini, Psychoncology Unit, Department of Oncological Sciences, Rome, Italy; Sheila Fisher, Leeds Institute of Cancer and Pathology, Univ. of Leeds, Leeds, United Kingdom; Jingbo Guo, Palliative Ward, Shengjing Hospital of China Medical Univ., Liaoning, China; M. Elisa Irarrazaval, Centro Los Juncos, Santiago, Chile; Kunihiro Kobayashi, Department of Respiratory Medicine, Saitama International Medical Centre, Hidaka City, Japan; Renske Kruizinga, Medical Oncology, Academic Medical Centre, Amsterdam, Netherlands; Mariana Navarro, Instituto Nacional de Cancerología, Mexico City, Mexico; Sepideh Omidvari, Health Metrics Research Centre, Iranian Institute for Health Science Research, ACECR & Cancer Research Centre, Cancer Institute of Iran, TUMS, Tehran, Iran; Gudrun Rohde, Faculty of Health and Sport Sciences/Department of Clinical Research, Univ. of Agder and Sorlandet Hospital, Kristiansand, Norway; Samantha Serpentine, Psychoncology Unit, IOV-IRCCS, Padua & Psychoncology Service, Azienda Ulss 3, Bassano del Grappa, Italy; Nigel Spry, Cancer Centre Radiation Oncology, Sir Charles Gairdner Hospital, Nedlands, Australia; Hanneke W. van Laarhoven, Medical Oncology, Academic Medical Centre, Amsterdam, Netherlands; Grace Yang, National Cancer Centre, Singapore, Singapore

3:00 pm – 3:13 pm (101.6) Appraisal assessment in patient-reported outcome research: Methods for uncovering the personal context and meaning of quality of life

Carolyn Schwartz, ScD, Tufts Univ. Medical School; DeltaQuest Foundation, Inc., Oslo and Akershus Univ. College, Concord, MA, United States; Bruce D. Rapkin, PhD, Albert Einstein College of Medicine, Bronx, NY, United States

Oral Session 102: Quality Of Life in Neurological Conditions

Saturna

Session Chair: Cynthia Gross, PhD, United States

1:50 pm – 2:03 pm (102.1) Exploring the relationship between patient-reported improvement in pain, function and satisfaction 12 months after spine surgery

Sara Khor, MSc; and Annie Pugel, MD, Univ. of Washington, Seattle, WA, United States, Danielle C. Lavalley, PharmD, PhD, Univ. of Washington, Seattle, WA, United States; David R. Flum, MD, MPH, Univ. of Washington, Seattle, WA, United States

STUDENT PRESENTATION AWARD FINALIST

2:04 pm – 2:17 pm (102.2) Patient-reported and Performance-based Outcomes in Persons after Mild Traumatic Brain

Nicole von Steinbuechel, Univ. Medical Center Goettingen, Goettingen, Germany; Annette Groeneveld, Univ. Medical Center Goettingen, Goettingen, Germany; Holger Schmidt, Elbekliniken Stade, Stade, Germany; Klaus von Wild, Kvw-Neuroscience Consulting GmbH, Muenster, Germany; Amra Covic; and Joy Backhaus, Univ. Medical Center Goettingen, Goettingen, Germany



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2:18 pm – 2:31 pm (102.3) “When I saw walking, I just kind of took it as wheeling.” A qualitative exploration of how individuals with spinal cord injury perceive mobility-related items in generic health-related quality of life (HRQoL) instruments

Yvonne Anne Michel, Dipl Psych, Univ. of Oslo, Oslo, Norway; Lidia Engel, MSc, Simon Fraser Univ., Vancouver, BC, Canada; Liv Ariane Augestad, MD, PhD, Univeristy of Oslo; Akershus Univ. Hospital, Oslo, Norway; Kim Rand-Hendriksen, Cand.psychol, PhD, Akershus Univ. Hospital; Univ. of Oslo, Oslo, Norway; David G. Whitehurst, PhD, Simon Fraser Univ., Vancouver, BC, Canada

2:32 pm – 2:45 pm (102.4) Impact of bevacizumab added to temozolomide-chemoradiation on time to health-related quality of life deterioration in unresectable glioblastoma: results of a phase II randomized clinical trial

Amélie Anota, PhD, Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon, Besançon, France; Tienhan Sandrine Dabakuyo, PhD, Centre Georges François Leclerc Comprehensive Cancer Centre, Dijon, France; Astrid Pozet, Methodology and Quality of Life in Oncology Unit (EA3181), Univ. Hospital of Besançon, Besançon, France; Brice Paquette, MD, Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon; Department of Digestive Surgery and Liver Transplantation, Univ. Hospital of Besançon, Besançon, France; Loïc Feuvret, MD, Department of Radiotherapy, Pitie-Salpetriere Univ. Hospital, Paris, France; Luc Taillandier, MD, Department of Neurology, Univ. Hospital, Nancy, France; Didier Frappaz, MD, Department of Oncology, Leon Berard Centre for Fight against Cancer, Lyon, France; Hervé Taillia, Department of Neurology, HIA Val de Grace, Paris, France; Roland Schott, Department of Oncology, Paul Strauss Centre for Fight against Cancer, Strasbourg, France; Michel Fabbro, Department of Oncology, Val d'Aurelle Center for Fight against Cancer, Montpellier, France; Isabelle Tennevet, MD, Department of Oncology, Henri Becquerel Center for Fight against Cancer, Rouen, France; Francois Ghiringhelli, Prof., Department of Oncology, GF Leclerc Center for Fight against Cancer, Dijon, France; Cécile Dalban; and Jerome Skrzypski, Biostatistics and Quality of life unit, Centre Georges François Leclerc, Dijon, France; Olivier Chinot, Prof., Department of Neuro-Oncology, Univ. Hospital La Timone, Marseille, France; Bruno Chauffert, Prof., Department of Medical Oncology, Univ. Hospital, EA 4666, Amiens, France; Franck Bonnetain, Prof., Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon Quality of Life in Oncology National Platform, Besançon, France

2:46 pm – 2:59 pm (102.5) Factors influencing health status and quality of life in Canadians living with a traumatic spinal cord

Joel Finkelstein, MD, Sunnybrook Health Sciences Centre, Toronto, ON, Canada; Vanessa K. Noonan, PT, PhD; and Nader Fallah, PhD, Rick Hansen Institute, Univ. of British Columbia, Vancouver, BC, Canada; Chester Ho, MD, Univ. of Calgary, Calgary, AB, Canada; Eve C. Tsai, MD, PhD, The Ottawa Hospital, Ottawa Hospital Research Unit, Univ. of Ottawa, Ottawa, ON, Canada; Carly S. Rivers, PhD, Rick Hansen Institute, Vancouver, BC, Canada; Catherine Truchon, PhD, MScAdm, Institut National d'Excellence en Santé et Services Sociaux (INESSS), Quebec City, QC, Canada; A. G. Linassi, MB, FRCPC, Univ. of Saskatchewan, Saskatoon, SK, Canada; Colleen O'Connell, MD, FRCPC, Stan Cassidy Centre for Rehabilitation, Dalhousie Faculty of Medicine, Fredericton, NB, Canada; Andrea Townson, MD, Univ. of British Columbia, Vancouver, BC, Canada; Henry Ahn, MD, PhD, FRCSC, St. Michael's Hospital, Univ. of Toronto, Toronto, Ontario, Canada; Brian Drew, MD, Hamilton General, McMaster Univ., Hamilton, ON, Canada; Marcel Dvorak, MD, FRCSC, Univ. of British Columbia, Vancouver, BC, Canada; Michael G. Fehlings, MD, PhD, FRCSC, Toronto Western Hospital, Univ. Health Network, Toronto, ON, Canada; Carolyn Schwartz, ScD, Tufts Univ. Medical School; DeltaQuest Foundation, Inc., Oslo and Akershus Univ. College, Concord, MA, United States; Luc Noreau, PhD, Université Laval, Centre for Interdisciplinary Research in Rehabilitation and Social Integration, Quebec City, QC, Canada

Oral Session 103: Quality of Life Across Health Conditions

Waddington

Session Chair: Sara Ahmed, PhD, Canada

1:50 pm – 2:03 pm (103.1) Body Image after Bladder Removal: Are Surgical Reconstructions Delivering Intended Patient-Reported Outcomes?

Scott M. Gilbert, MD, Moffitt Cancer Center, Tampa, FL, United States; Joanna E. Bulkley; and Michael C. Leo, Kaiser Permanente Northwest, Portland, OR, United States; Kim N. Danforth, Kaiser Permanente Southern California, Pasadena, CA, United States; Marilyn L. Kwan, Kaiser Permanente Northern California, Oakland, CA, United States; Robert S. Krouse, Univ. of Arizona, Tucson, AZ, United States; Marcia Grant, City of Hope National Medical Center, Duarte, CA, United States; Chris Wendel, Univ. of Arizona, Tucson, AZ, United States; James V. Davis; Maureen O'Keeffe-Rosetti; and Mark C. Hornbrook, Kaiser Permanente Northwest, Portland, OR, United States; Carmit K. McMullen, Kaiser Permanente Northwest, Portland, OR, United States

2:04 pm – 2:17 pm (103.2) Patient-relevant treatment goals in psoriasis and their association with quality of life

Christine Blome, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ramona Gosau; and Marc Radtke, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Kristian Reich, Dermatologikum Hamburg, Hamburg, Germany; Stephan J. Rustenbach; and Christina Spehr, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Diamant Thaci, Univ. of Lübeck, Lübeck, Germany; Matthias Augustin, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany

2:18 pm – 2:31 pm (103.3) Health-Related Quality of Life (HRQoL) and Patient Experience in Advanced Melanoma: 6-Month Results From the IMAGE Study

Susan D. Mathias, MPH, Health Outcomes Solutions, Winter Park, FL, United States; Srividya Kotapati, Bristol-Myers Squibb, Wallingford, CT, United States; T. Kim Le, Bristol-Myers Squibb, Hopewell, NJ, United States; Javier Sabater, Bristol-Myers Squibb, Madrid, Spain; Amy P. Abernethy, Duke Univ., Durham, NC, United States



Top Outstanding Posters

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2:32 pm – 2:45 pm (103.4) Psychometric Evaluation of Emotional Well-Being in Advanced Basal Cell Carcinoma

Karen Bartley, PhD, MPH, Genentech, San Francisco, CA, United States; Jonathan Gable, MPA; and Stacie Hudgens, MA (ABD), Clinical Outcomes Solutions, Tucson, AZ, United States

2:46 pm – 2:59 pm (103.5) Psychological distress in UK patients with Idiopathic Pulmonary Fibrosis; Use of Emotion Thermometers interpreted within a biopsychosocial constructionist framework

Anne-Marie Doyle, D.Clin.Psy BSc MA, Royal Brompton Hospital London, London, United Kingdom; Caroline Burdett, BA, ISOqol & Royal Brompton Hospital London, London, United Kingdom; Jennifer Gane, Patient Partner RN RHV, Royal Brompton hospital London, London, United Kingdom; Zahra Aden, MSc BSc, NHLI Royal Brompton and Imperial College London, London, United Kingdom; Anne-Marie Russell, MSc RN RHV LPE PGCE, Imperial College London & Royal Brompton Hospital, London, United Kingdom

3:00 pm – 3:13 pm (103.6) “First and foremost battle the virus.” - Patient preferences in antiviral therapy for hepatitis C

Axel Mühlbacher, Professor Health Economics and Healthcare Management, Hochschule Neubrandenburg, Neubrandenburg, Germany; Susanne Bethge, Research Assistant, Hochschule Neubrandenburg, Neubrandenburg, Germany

Oral Session 104: E-Health

Boardroom

Session Chair: *Heidi Donovan, PhD RN, United States*

1:50 pm – 2:03 pm (104.1) Effect of electronic patient reporting of symptoms during cancer treatment: A randomized controlled trial

Ethan Basch, MD, MSc, Univ. of North Carolina, Chapel Hill, NC, United States; Allison Deal, Statistician, Univ. of North Carolina, Chapel Hill, NC, United States; Amylou Dueck, Statistician, Mato Clinic, Scottsdale, AZ, United States; Antonia Bennett, Univ. of North Carolina - Chapel Hill, Chapel Hill, NC, United States; Thomas M. Atkinson, PhD; and Lauren J. Rogak, MA, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Jeff A. Sloan, PhD, Mayo Clinic, Rochester, MN, United States; Deborah Schrag, MD, MPH, Dana-Farber Cancer Institute, Boston, MA, United States

2:04 pm – 2:17 pm (104.2) The integration of a web-based outcome instrument and a graphic analysis tool for real-time, patient-centered outcome data collection and analysis during

Justin E. Bird, MD, Univ. of Texas MD Anderson Cancer Center, Houston, TX, United States; Theresa J. Nalty, PhD, PT, NCS, Univ. of Texas MD Anderson Cancer Center, Houston, TX, United States; Jing He; Alexander N. Penny, PT, DPT; Kristi K. Posey; and Valerae O. Lewis, MD, Univ. of Texas MD Anderson Cancer Center, Houston, TX, United States

2:18 pm – 2:31 pm (104.3) Impact of an Automated Telehealth Cancer Symptom Monitoring and Management System on Symptom Burden and Quality of Life

Kathi Mooney, RN, PhD, FAAN, Univ. of Utah, Salt Lake City, UT, United States; Susan L. Beck, RN, PhD, FAAN, Univ. of Utah, Salt Lake City, UT, United States; Debbie Wujcik, RN, PhD, FAAN, Vanderbilt-Ingram Cancer Center, Nashville, TN, United States; William Dunson Jr., MD, Huntsman Cancer Institute, Salt Lake City, UT, United States; Gary Donaldson, PhD, Univ. of Utah, Salt Lake City, UT, United States

2:32 pm – 2:45 pm (104.4) Electronic Patient Reported Outcomes and Toxicities during Radiotherapy for Head and Neck Cancer

Joshua R. Niska, MD, Mayo Clinic, Scottsdale, AZ, United States; Michele Y. Halyard, MD, Mayo Clinic, Scottsdale, AZ, United States; Angelina D. Tan; and Pamela J. Atherton, Mayo Clinic, Rochester, MN, United States; Samir H. Patel, MD, Mayo Clinic, Scottsdale, AZ, United States; Jeff A. Sloan, PhD, Mayo Clinic, Rochester, MN, United States

Oral Session 105: Women's Health

Vancouver Island

Session Chair: *Sandra Lauck, PhD, Canada*

1:50 pm – 2:03 pm (105.1) Nausea, vomiting, fatigue and health-related quality of life of women in early pregnancy: The Generation R Study

Guannan Bai, MPH, Erasmus MC, Univ. Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Esther H. Groen, PhD; Henriette A. Moll, PhD; Vincent W. Jaddoe, PhD, Erasmus MC; Ida Korfage, PhD; and Hein Raat, PhD, MD, Erasmus MC, Univ. Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands

STUDENT PRESENTATION AWARD FINALIST

2:04 pm – 2:17 pm (105.2) Patient-Reported Neurocognitive Deficits Do Not Always Agree with Objectively-Assessed Neurocognitive Test Scores —Why They Differ as Explained by a Bayesian Latent Regression Item Response Approach

Yuelin Li, PhD., Memorial Sloan Kettering Cancer Center, New York, NY, United States; James C. Root, PhD; Thomas M. Atkinson, PhD; and Tim A. Ahles, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States

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2:18 pm – 2:31 pm (105.3) Validation of the Measure of Ovarian Symptoms and Treatment concerns (MOST), a patient-reported outcome measure (PROM) of symptom burden and subjective benefit with chemotherapy in recurrent ovarian cancer (ROC)

Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia; Martin Stockler; and Rachel O'Connell, NHMRC Clinical Trials Centre, Sydney, Australia; Florence Joly, Centre Francois Baclesse, GINECO, Caen, France; Anne Lanceley, Univ. College London, London, United Kingdom; Felix Hilpert, Klinik für Gynäkologie und Geburtshilfe, UKSH, Kiel, Germany; Aikou Okamoto, Jikei Univ. School of Medicine, Tokyo, Japan; Eriko Aotani, Kitasato Academic Research Organization, Tokyo, Japan; Sandro Pignata, National Cancer Institute, Naples, Italy; Paul Donnellan, Galway Univ. Hospital, Galway, Ireland; Amit Oza, Princess Margaret Hospital, Toronto, Canada; Elisabeth Avall-Lundqvist, Linköping Univ., NSGO, Linköping, Sweden; Jonathan Berek, Stanford Women's Cancer Centre, Stanford, CA, United States; Luke Buizen, NHMRC Clinical Trials Centre, Sydney, Australia; Katrin Sjoquist; and Kim Gillies, NHMRC Clinical Trials Centre, ANZGOG, Sydney, Australia; Phyllis Butow, Psycho-oncology Research Group (PoCoG), Univ. of Sydney, Sydney, Australia; Michael Friedlander, Prince of Wales Hospital, ANZGOG, Sydney, Australia; on behalf of the GCIG Symptom Benefit Study Group, Gynecologic Cancer Intergroup (GCIG)

2:32 pm – 2:45 pm (105.4) Measurement Properties of the Female Sexual Function Index Desire Domain in Women with Female Sexual Dysfunction

Hilary Wilson, Evidera, Bethesda, MD, United States; Dennis Revicki, PhD, Evidera, Bethesda, MD, United States; Carl Spana, Palatin Technologies Inc., Cranbury, NJ, United States; Robert Jordan, Palatin Technologies Inc., Cranbury, NJ, United States

2:46 pm – 2:59 pm (105.5) Modeling Overall Quality of Life in Women with Breast Cancer

Marie-Eve Letellier, McGill Univ., Montreal, QC, Canada; Susan C. Scott, McGill Univ. Health center, Montreal, QC, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada

3:00 pm – 3:13 pm (105.6) Long-term prospective Patient Reported Outcomes (PROs) after types of immediate pedicle back flap (latissimus dorsi) breast reconstruction and adjuvant treatment. Two and three-year post-operative results from the Prospective Trial Management Group

Zoe E. Winters, MB,ChB(Witw), DPhil(Oxon), FRCS, FCS, Univ. of Bristol, Bristol, United Kingdom; Vasiliki Balta; Maryam Afzal; Janet Freeman; and Rebecca Llewellyn-Bennett, Univ. of Bristol, Bristol, United Kingdom; James Cook, Consultant Surgeon, North Bristol NHS Trust, Bristol, United Kingdom; Zenon Rayter, Consultant Surgeon, North Bristol NHS Trust, Bristol, United Kingdom; Rosemary Greenwood, Senior RDS statistician, NIHR Research Design Support, Bristol, United Kingdom; Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia

3:15 pm – 4:05 pm

Exhibits Open and Refreshment Break

British Columbia Ballroom

3:20 pm – 3:40 pm

Thursday Poster Session 2

British Columbia Ballroom

Kids and Young Adults

(1008) What about the patient? Comprehensibility and user acceptance of the Kids-CAT among chronically ill children and adolescents

Kathrin I. Fischer, M.Sc.med., Charite - Universitaetsmedizin Berlin, Berlin, Germany; Dana Barthel, Dipl.-Psych., Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Christiane Otto, PhD, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ute Thyen, MD, Univ. Medical Center Schleswig-Holstein, Lübeck, Germany; Marcus Klein, MD, Univ. Medical Center Schleswig-Holstein, Kiel, Germany; Otto Walter, PhD, MD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Silke Schmidt, Prof., Ernst-Moritz-Arndt Univ. Greifswald, Greifswald, Germany; Holger Muehlan, PhD, Ernst-Moritz-Arndt Univ., Greifswald, Germany; Matthias Rose, MD PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Ulrike Ravens-Sieberer, PhD, MPH, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany

(1010) Development of Parent Proxy and Self-Report Health-Related Quality of Life Instruments for Deaf Children with Cochlear Implants

Michael Hoffman, M.S., Univ. of Miami, Coral Gables, FL, United States; Alexandra L. Quitner, PhD, Univ. of Miami, Coral Gables, FL, United States; Ivette Cejas, PhD, Univ. of Miami Miller School of Medicine, Miami, FL, United States

(1012) Validity and Reliability of a Composite Measure of Disease Severity and Quality Of Life In Children With Atopic Dermatitis for Use in Primary Care.

Andrea Nájera, General Practitioner, Centro de la Piel, Quito, Ecuador; Julia E. Cabezas, Dermatology Resident, Centro de la Piel, Quito, Ecuador; Andrea C. Cueva, Attending Physician/Researcher, Centro de la Piel, Quito, Ecuador; Marcos Serrano, Director-Department of Biostatistics, Hospital Carlos Andrade Marin, Centro de la Piel-Quito, Quito, Ecuador; Santiago A. Palacios, Dermatologist, Centro de la Piel. Univ. Católica, Univ. Central, Quito, Ecuador

(1014) Improving transition of adolescents with chronic health conditions: The impact of an educational program on transition competence and Quality of Life (QoL) according to age

Henriette Golke, Dipl. Psych, Ernst-Moritz-Arndt-Univ. Greifswald, Greifswald, Germany; Carsten Hermann-Garitz, Ernst-Moritz-Arndt-Univ. Greifswald, Greifswald, Germany; Franziska Bomba; and Ute Thyen, MD, Univ. Medical Center Schleswig-Holstein, Lübeck, Germany; Silke Schmidt, Prof., Ernst-Moritz-Arndt Univ. Greifswald, Greifswald, Germany



Top Outstanding Posters

Scientific Program — Thursday, October 22

(1016) Secular Trends in Well-being in Young Swedes: The 'Grow up Gothenburg' studies

Ebba Brann, PhD student, Inst. of Medicine, Sahlgrenska Academy, Univ. of Gothenburg, Gothenburg, Sweden; **Monica Leu, PhD, Inst. of Medicine, Sahlgrenska Academy, Univ. of Gothenburg, Gothenburg, Sweden;** **Agneta Sjöberg, PhD, Department of Food and Nutrition, and Sport Science, Univ. of Gothenburg, Gothenburg, Sweden;** **Aimon Niklasson, MD, PhD;** **Kerstin Albertsson-Wikland, MD, PhD;** and **Lauren Lissner, PhD, Professor, Inst. of Medicine, Sahlgrenska Academy, Univ. of Gothenburg, Gothenburg, Sweden;** **John Chaplin, PhD, AFBPsS, CPsychol., Inst. Clinical Sciences, Sahlgrenska Academy at the Univ. Gothenburg, Gothenburg, Sweden**

(1018) Parent-Child Reporting Discrepancies in Childhood Epilepsy

Nora Fayed, PhD, McMaster Univ., Hamilton, ON, Canada; **Aileen Davis, PhD, Univ. Health Network, Toronto, Canada;** **David Streiner, PhD, McMaster Univ., Hamilton, ON, Canada;** **Peter Rosenbaum, MD, McMaster Univ., Hamilton, ON, Canada;** **Charles E. Cunningham, PhD, McMaster Univ., Hamilton, Canada;** **Gabriel Ronen, MD, MSc, McMaster Univ., Hamilton, ON, Canada**

(1020) Health-Related Quality of Life in Brazilian patients with Osteogenesis Imperfecta: a cross-sectional study using PedsQL™

Ana Paula Vanz, Federal Univ. of Rio Grande do Sul, Porto Alegre, Brazil; **Juliana Van de Sande Lee, Joana Gusmão Hospital, Florianópolis, Brazil;** **Bruna Pinheiro;** **Marina Zambrano;** **Evelise Brizola;** **Neusa Sicca Rocha;** **Ida Vanessa D. Schwartz;** and **Têmis Maria Félix, Federal Univ. of Rio Grande do Sul, Clinical Hospital of Porto Alegre, Porto Alegre, Brazil**

(1022) Quality of Life and Functional Performance of Children Born Preterm at Preschool Age: Longitudinal Study

Martina E. Vieira, Univ. of São Paulo, Univ. of Goiás State, Goiânia, Goiás, Brazil; **Cibelle K. Formiga, Univ. of Goiás State, Goiânia, Goiás, Brazil;** **Maria Beatriz M. Linhares, Univ. of São Paulo, Ribeirão Preto, São Paulo, Brazil**

(1024) Identifying Outcomes for a New Paediatric CFS/ME PROM: A Meta-Ethnography of Qualitative Studies

Roxanne M. Parslow, BSc (HONS), Univ. of Bristol, Bristol, United Kingdom; **Sarah Harris, MSc;** and **Jessica Broughton, MSc, Univ. of Bath, Bath, United Kingdom;** **Alda Alattas;** and **Esther Crawley, BA(Hons), BM BCh, MRCP, FRCPCH, PhD, Univ. of Bristol, Bristol, United Kingdom;** **Kirstie Haywood, Senior Research Fellow, Warwick Medical School, Warwick Univ., Coventry, United Kingdom;** **Alison Shaw, BA, MSc, PhD, Univ. of Bristol, Bristol, United Kingdom**

(1026) The impact of having a child with respiratory insufficiency on the family

Robert J. Graham, Boston Children's Hospital, Boston, MA, United States; **Angie Mae Rodday, Tufts Medical Center, Boston, MA, United States;** **Yudy Muneton-Castano, Boston Children's Hospital, Boston, MA, United States;** **Ruth Ann Weidner;** and **Susan K. Parsons, Tufts Medical Center, Boston, MA, United States**

(1028) Immigrant mothers balancing care for chronically ill or disabled children and labour market participation

Lisbeth G. Kvarme, PhD, Associate Professor, Oslo, Norway; **Elena Albertini-Fruh, RN, Associate Professor, Oslo, Norway;** **Hilde Liden, PhD, Research Professor, Oslo, Norway**

(1036) Quality of life in children with ADHD

Montserrat Hernandez-Martinez, Pediatrician, Primary Care Center Collblanc, CSI, Hospitalet de Llobregat (Spain), L'Hospitalet de Llobregat, Barcelona, Spain; **Nuria Pastor-Hernandez, Psychologist, Univ. of Barcelona, Barcelona, Spain;** **Xavier Pastor-Duran, Pediatrician, Hospital Clinic, Univ. of Barcelona, Barcelona, Spain;** **Cristina Boix-Lluc, Psychologist, Neurology Dep. Hospital Sant Joan de Deu, Esplugues de Llobregat, Barcelona, Spain**

(1038) Ability to predict healthcare utilization using health-related quality of life scores among children with respiratory insufficiency

Angie Mae Rodday, Tufts Medical Center, Boston, MA, United States; **Robert J. Graham, Boston Children's Hospital, Boston, MA, United States;** **Ruth Ann Weidner;** **Norma Terrin;** **Laurel K. Leslie;** and **Susan K. Parsons, Tufts Medical Center, Boston, MA, United States**

Diabetes and Kidney

(1040) How does it feel to donate a kidney?

Kathe Meyer, Oslo Univ. Hospital, Univ. of Oslo, Oslo, Norway; **Anders Hartmann, MD, Oslo Univ. Hospital, Univ. of Oslo, Oslo, Norway;** **Carolyn Schwartz, ScD, Tufts Univ. Medical School;** **DeltaQuest Foundation, Inc., Oslo and Akershus Univ. College, Concord, MA, United States;** **Marit H. Andersen, PhD, Oslo Univ. Hospital, Univ. of Oslo, Oslo, Norway**

(1042) Diabetes - Literacy, Knowledge, Empowerment and Quality of Life

Pedro L. Ferreira, Univ. of Coimbra, Coimbra, Portugal; **Carmina S. Morais;** and **Rui E. Pimenta, CEISUC/ESTSP-IPP, Vila Nova de Gaia, Portugal;** **José M. Boavida, Ministry of Health, Lisboa, Portugal**

(1044) Preference for Pharmaceutical Formulation and Treatment Process Attributes

Katie D. Stewart, MA, Evidera, Bethesda, MD, United States; **Louis S. Matza, PhD, Evidera, Bethesda, MD, United States;** **Joseph A. Johnston, MD, MSc;** and **Sarah Curtis, Eli Lilly and Company, Indianapolis, IN, United States;** **Heather Gelhorn, PhD, Evidera, Bethesda, MD, United States;** **Henry Havel;** and **Stephanie Sweetana, Eli Lilly and Company, Indianapolis, IN, United States**



Top Outstanding Posters



Scientific Program — Thursday, October 22

(1048) Evaluating the Reliability and Validity of the ANMS Gastroparesis Cardinal Symptom Index-Daily Diary in Patients with Diabetic and Idiopathic Gastroparesis

Dennis Revicki, PhD, Evidera, Bethesda, MD, United States; Henry Parkman, MD, Temple Univ. School of Medicine, Philadelphia, PA, United States

(1050) Mediating Role of Psychosocial Support between Mental Health Status and Quality of Life of Type 2 Diabetic Patients

Ranjan Pattnaik, Doctoral Research Fellow, Indian Institute of Technology Kharagpur, Kharagpur, West Bengal, India; Rabindra K. Pradhan, Associate Professor, Indian Institute of Technology Kharagpur, Kharagpur, West Bengal, India

(1052) Relationship between Physical Activity and Health-Related Quality of Life in Alberta's Type 2 Diabetes Population

Danielle Thiel, Univ. of Alberta, Edmonton, AB, Canada; Fatima Al Sayah, PhD, Univ. of Alberta, Edmonton, AB, Canada; Steven Johnson, PhD, Athabasca Univ., Edmonton, AB, Canada; Jeffrey A. Johnson, PhD, Univ. of Alberta, Edmonton, AB, Canada

(1054) Health Literacy and Health-Related Quality of Life in Adults with Type 2 Diabetes: A Longitudinal Study

Fatima Al Sayah, PhD, Univ. of Alberta, Edmonton, AB, Canada; Weiyu Qiu, MS; Jeffrey A. Johnson, PhD, Univ. of Alberta, Edmonton, AB, Canada

(1056) Comparison of Health-Related Quality of Life Between Hemodialysis and Peritoneal Dialysis Patients in Jeddah, Saudi Arabia

Abdulhameed A. Alharbi, MD, MPH, JBCM, Bader Health District, Almadinah Almunawarah, Saudi Arabia; Rajaa M. Alraddadi, MD, ABCM, RICR, Public Health, Jeddah, Saudi Arabia; Alwaleed A. Alharbi, MBBS, King Abdulaziz Univ., Jeddah, Saudi Arabia; Mohammad S. Alghamdi, MD, KFUF(famco), Center of Higher Education, Family and Community Medicine, Jeddah, Saudi Arabia; Yazeed A. Alharbi, King Abdulaziz Univ., Jeddah, Saudi Arabia; Adel M. Ibrahim, MD, MDPH, Public Health, Jeddah, Saudi Arabia

Musculoskeletal

(1060) Differential associations of pain treatment satisfaction and pain-specific psychosocial factors with pain adjustment outcomes among Chinese patients with chronic pain

Wing S. Wong, Dr, The Hong Kong Institute of Education, Hong Kong, China; Richard Fielding, The Univ. of Hong Kong, Hong Kong, China; Steven Wong, Queen Elizabeth Hospital, Kowloon, Hong Kong, Hong Kong, China; Y F. Chow, Queen Elizabeth Hospital, Kowloon, Hong Kong, China; P P. Chen, MBBS, Alice Ho Miu Ling Nethersole Hospital, Tai Po, Hong Kong, China

(1062) Sensitivity to change of the Oxford Hip Score and the Forgotten Joint Score in patients after total hip arthroplasty

Johannes M. Giesinger, Department of Psychiatry and Psychotherapy, Medical Univ. of Innsbruck, Innsbruck, Austria; Jonas Egeter, Medical Univ. of Innsbruck, Innsbruck, Austria; Karlmeirad Giesinger, Kantonsspital St. Gallen, St. Gallen, Switzerland; Hamish Simpson, Royal Infirmary of Edinburgh, Edinburgh, United Kingdom; Colin Howie; and David F. Hamilton, Royal Infirmary of Edinburgh, Edinburgh, United Kingdom

(1064) Therapy adherence and quality of life of patients with rheumatoid arthritis

Michael Koller, Univ. Hospital Regensburg, Regensburg, Germany; Jens U. Ruffer, German Fatigue Society, Cologne, Germany; Karolina Müller; and Florian Zeman, Univ. Hospital Regensburg, Regensburg, Germany; Jens G. Kuipers, Rotes Kreuz Krankenhaus Bremen, Bremen, Germany

(1066) Neuro-QOL scores and number of items required to complete a CAT varies by work status in persons with MS: Implications for clinical implementations of the Neuro-QOL measures.

Deborah Miller, PhD, Cleveland Clinic, Cleveland, OH, United States; Lyla Mourany, Cleveland Clinic, Cleveland, Ohio, United States; Karon F. Cook, PhD, Department of Medical Social Sciences, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; David Victorson, Northwestern Univ., Evanston, IL, United States; Nicolas Thompson; Fan Youran; and Irene Katzan, Cleveland Clinic, Cleveland, OH, United States; David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

(1070) Development of Quality Indicators for Hip and Knee Arthroplasty Rehabilitation

Marie D. Westby, PT, PhD, Univ. of Alberta, Edmonton, AB, Canada; Linda C. Li, PT, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Deborah Marshall, Associate Professor, Univ. of Calgary, Calgary, AB, Canada; Jane Squire Howden, BScN, Edmonton Musculoskeletal Centre, Edmonton, AB, Canada; DWC (Bill) Johnston, MD, FRCS(C); and Allyson Jones, PhD, Univ. of Alberta, Edmonton, AB, Canada

(1072) Path to Participation in People with Multiple Sclerosis

Shahnaz Shahrbanian, PhD, McGill Univ. Buali Sina Univ., Hamedan, Montreal, QC, Canada; Pierre Duquette, Univ. of Montreal, Montreal, QC, Canada; Sara Ahmed, BSc MSc PhD, McGill Univ., Montreal, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada



Top Outstanding Posters

Scientific Program — Thursday, October 22

(1074) Exploring the relationship between demographic and disease related variables and Health-related Quality of Life in patients with Axial Spondyloarthritis

Gudrun Rohde, Faculty of Health and Sport Sciences/Department of Clinical Research, Univ. of Agder and Sorlandet Hospital, Kristiansand, Norway; Kari Hansen Berg, RN, PhD-student, Univ. of Agder, Grimstad, Norway; Anne Proven, Martina Hansens Hospital, Bærum, Norway; Glenn Haugeberg, MD, PhD, Sorlandet Hospital and Norwegian Univ. of Science and Technology, Kristiansand, Norway

(1078) Reproducibility: Reliability and Agreement of Short version of Western Ontario Rotator Cuff Index (Short-WORC) in patients with Rotator Cuff Disorders

Neha Dewan, PhD student, McMaster Univ., Hamilton, ON, Canada; Joy MacDermid, Professor, McMaster Univ., Hamilton, ON, Canada; Norma MacIntyre, Associate professor, McMaster Univ., Hamilton, ON, Canada; Ruby Grewal, Associate Professor, Western Univ., Roth | McFarlane Clinical Research Laboratory, Hand and Upper Limb Centre, London, ON, Canada



(1080) Using routine Patient Reported Outcome Measures to enhance patient decision making: a proof of concept study

Nick Bansback, PhD, Univ. of British Columbia and Centre for Health Evaluation and Outcomes Sciences, Vancouver, BC, Canada; Logan Trenaman, MSc; and Stirling Bryan, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Jeffrey Johnson, PhD, School of Public Health, Univ. of Alberta, Edmonton, AB, Canada

(1084) Linking of the American Academy of Orthopaedic Surgeons Distal Radius Fracture Clinical Practice Guidelines to the International Classification of Functioning Disability and Health (ICF) and ICF Core Sets for Hand Conditions

Saravanan Esakki, PT, McMaster Univ., Hamilton, ON, Canada; SaiPriya Vajravelu, PT; and Joy MacDermid, Professor, McMaster Univ., Hamilton, ON, Canada

Mental Health

(1086) The Relationship Between Body Mass Index, Psychological Distress and Vitality: A Population-Based Study Exploring Mediators and Gender Differences.

Neha Agnihotri, Norwegian Univ. of Life Science, Ås, Norway, Jocelyne Clench-Aas, Senior Scientist, Norwegian Institute of Public Health, Oslo, Norway; Grete G. Patil, Associate Professor, Norwegian Univ. of Life Sciences, Ås, Norway; Ragnhild B. Nes, Research Scientist, Norwegian Institute of Public Health, Oslo, Norway

(1088) A Proposal for standardization of Health Outcome Measures for Depression and Anxiety

Alexander Obbarius, MD, Charité - Universitätsmedizin Berlin, Berlin, Germany; David Clark, Univ. of Oxford, Oxford, United Kingdom; Anne G. Crocker, Douglas Mental Health Univ. Institute; McGill Univ., Montréal, QC, Canada; Paul Emmelkamp, Netherlands Institute for Advanced Study; The Center for Social and Humanities Research, Jeddah, Saudi Arabia, Wassenaar, Netherlands; Toshi A. Furukawa, Kyoto Univ. Graduate School of Medicine / School of Public Health, Kyoto, Japan; Erik Hedman, Karolinska Institutet, Solna, Sweden; Maria Kangas, Centre for Emotional Health, Department of Psychology, Macquarie Univ., Sydney, Australia; Alain Lesage, Institut universitaire en santé mentale de Montréal & Department of Psychiatry, Univ. of Montreal, Montréal, Canada; Doris M. Mwesigire, Makerere College of Health Sciences, Kampala, Uganda; Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Vikram Patel, London School of Hygiene & Tropical Medicine; Public Health Foundation of India, Sangath, Goa, India; Paul Pilkonis, PhD, Univ. of Pittsburgh, Pittsburgh, PA, United States; Harold A. Pincus, Department of Psychiatry, Columbia Univ., New York, NY, United States; Roberta A. Reis, Univ. Federal do Rio Grande do Sul - Federal Univ. of Rio Grande do Sul, Grupo CNPq - USP - GPEMSA - São Paulo Univ./Health, Sao Paulo, Brazil; Graciela Rojas, Clinical Hospital, Department of Psychiatry, Univ. of Chile, Santiago de Chile, Chile; Cathy Sherbourne, The RAND Corporation, Santa Monica, CA, United States; Caleb Stowell, International Consortium for Health Outcomes Measurement (ICHOM), Boston, MA, United States; Matthias Rose, MD PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany

(1090) Can Religious Coping Predict Clinical Outcome and Quality Of Life In Patients With Panic Disorder? An Open Clinical Trial

Rogério R. Zimpel, MSc, PhD Student, Federal Univ. of Rio Grande do Sul - Brazil, Porto Alegre, Rio Grande do Sul, Brazil; Raquel G. Panzini, PhD; Denise R. Bandeira, PhD; Elizeth Heldt, PhD; and Gisele G. Manfro, PhD, Federal Univ. of Rio Grande do Sul, Porto Alegre, Brazil; Marcelo P. Fleck, PhD, UFRGS, Porto Alegre, Brazil; Neusa S. Rocha, PhD, Federal Univ. of Rio Grande do Sul, Porto Alegre, Brazil

(1092) Quality of life in patients with locked-in syndrome: Evolution over a 6-year period

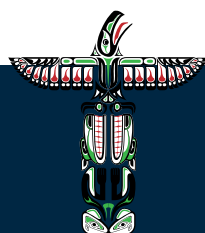
Marie-Christine Rousseau, Fédération des Hôpitaux de Polyhandicap et Multihandicap Hôpital San Salvador, Assistance Publique Hôpitaux de Paris, Paris, France, Karine Baumstarck, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; Marine Alessandrini, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; Thierry Bilette de Villemeur, Fédération des Hôpitaux de Polyhandicap et Multihandicap Hôpital San Salvador, Assistance Publique Hôpitaux de Paris, Paris, France; Pascal Auquier, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France

(1094) Patient-reported health related quality of life is strongly correlated to an objective index of comorbidity: results from a study of elderly U.S. patients

Jesse Cambon, Humana, Louisville, KY, United States; Tristan Cordier, Humana, Atlanta, GA, United States; Lane Slabaugh, PharmD, MBA; Gilbert Haugh; Bill Glasheen; Vipin Gopal, PhD, MBA; and Andrew Renda, MD, MPH, Humana, Louisville, KY, United States



Top Outstanding Posters



Scientific Program — Thursday, October 22

(1098) Development and psychometric testing of the Japanese Version of the 13-item Sense of Coherence Scale-Revised (SOC13-RJ) among Japanese Community-Dwelling Elderly

Junko Sakano, Health and Welfare Science, Okayama Prefectural Univ., Soja, Okayama, Japan; Yuki Yajima, Niimi College, Niimi, Okayama, Japan; Yoshihiko Yamazaki, Nihon Fukushi University, Nagoya, Japan; Asuka Seki, Ajinomoto Co., Inc., Kawasaki, Japan; Kaori Ono, and Naoki Hayashi, Ajinomoto Co., Inc., Kawasaki, Japan

(1100) How Do Recreational Drugs Influence Quality of Life? Extending the WHOQOL-BREF to Assess Substance Users

Elena Swift, MRes, BC Mental Health and Substance Use Services, Vancouver, BC, Canada; Suzanne M. Skevington, PhD, CPsychol, FBPsS, Univ. of Manchester, Manchester, United Kingdom

(1102) Environmental aspects of functioning in people with intellectual disabilities

Juliana Bredemeier, Dean of Psychology Program, UFRGS, FADERGS, Porto Alegre, RS, Brazil; Marilyn Agranonik, Professor, UNISINOS, Porto Alegre, Brazil; Markus Bredemeier, MD, Hospital Conceição, Porto Alegre, Brazil; Tatiana S. Perez, FADERGS, Porto Alegre, Brazil; Marcelo P. Fleck, PhD, UFRGS, Porto Alegre, Brazil

3:40 pm – 3:55 pm

Outstanding Poster Award Finalist
Presentations - Session 2

British Columbia Ballroom

(1002) Quality-Adjusted Life Years (QALY) Loss throughout Remainder of Expected Life Due To Selected Chronic Conditions for U.S. Adults Aged 65 Years and Older

Haomiao Jia, Columbia Univ., New York, NY, United States

(1004) How can Rasch Measurement methods inform a measurement paradigm shift in mental health care?

Skye P. Barbic, Post-Doctoral Fellow, Faculty of Medicine, Vancouver, BC, Canada; Sean A. Kidd, Centre for Addiction and Mental Health, Toronto, ON, Canada; William G. MacEwan, St. Paul's Hospital, Vancouver, Canada; William G. Honer, University of British Columbia, Vancouver, BC, Canada; Kwame McKenzie, Centre for Addiction and Mental Health, Toronto, ON, Canada

(1006) Disease-Specific Calibrations or Disease-Specific Content: Which is Responsible for the Enhanced Sensitivity of Condition-Specific Measures compared to Generic Measures?

San Keller, PhD, American Institutes for Research, Chapel Hill, NC, United States; Manshu Yang, PhD, American Institutes for Research, Chapel Hill, NC, United States

4:05 pm – 5:35 pm

Concurrent Oral Sessions

Oral Session 106: Health Systems and Quality of Life

Pacific Ballroom

Session Chair: Steven Clauser, PhD, United States

4:10 pm – 4:23 pm (106.1) A Breath of Fresh Air: How eCOA Technology Integration Boosts Patient Compliance in Asthma Trials

Jessica Thilaganathan, CRF Health, London, United Kingdom; Antti Heikkila; Juha Matero, CRF Health, London, United Kingdom; Paul O'Donohoe; Karl McEvoy; and Katie Garner, CRF Health, London, United Kingdom

4:24 pm – 4:37 pm (106.2) Development and Use of Patient Reported Outcomes During Early Drug development: An Industry and Academic collaboration

Charles S. Cleeland, PhD, UT MD Anderson Cancer Center, Houston, TX, United States; Loretta Williams, PhD; Tito Mendoza, PhD; and Ferran Prat, PhD, JD, UT MD Anderson Cancer Center, Houston, TX, United States; Brian Cuffel, PhD, Bayer Healthcare Pharmaceuticals, Whippany, NJ, United States; Barrett H. Childs; and Karen N. Keating, Bayer Healthcare Pharmaceuticals, Whippany, NJ, United States

4:38 pm – 4:51 pm (106.3) Patients' and health professionals' understanding of and preferences for graphical presentation styles for individual quality of life scores obtained with the EORTC QLQ-C30

Wilma Kuijpers, The Netherlands Cancer Institute, Amsterdam, Netherlands; Johannes M. Giesinger, Medical Univ. of Innsbruck, Innsbruck, Austria; August Zabernigg, Kufstein County Hospital, Kufstein, Austria; Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Elizabeth Friend, Basingstoke & North Hampshire Hospital, Basingstoke, United Kingdom; Iwona M. Tomaszewska, Jagiellonian Univ. Medical College, Krakow, Poland; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Bernhard Holzner, Medical Univ. of Innsbruck, Innsbruck, Austria

 Top Outstanding Posters

Scientific Program — Thursday, October 22

4:52 pm – 5:05 pm (106.4) Misalignment between cancer patients' values and their care experiences is associated with worse self-reported mental and physical health outcomes

Kathleen J. Yost, Mayo Clinic, Rochester, MN, United States; Marlene Frost, Mayo Clinic, Rochester, MN, United States; Amy Windham, American Institutes for Research, Washington, DC, United States; Sarah Jenkins, Mayo Clinic, Rochester, MN, United States; Kandace Lackore, Mayo Clinic, Rochester, MN, United States; Manshu Yang, PhD, American Institutes for Research, Chapel Hill, NC, United States; San Keller, PhD, American Institutes for Research, Chapel Hill, NC, United States

5:06 pm – 5:19 pm (106.5) Management of Patient-Reported Outcome Alerts: A Cross Sectional Survey

Derek G. Kyte, PhD, Univ. of Birmingham, Birmingham, United Kingdom; Jonathan Ives, PhD; Heather Draper, PhD; and Melanie J. Calvert, PhD, Univ. of Birmingham, Birmingham, United Kingdom

5:20 pm – 5:33 pm (106.6) Do HRQOL Assessments Impact the Development of Cancer Treatments?

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

Oral Session 107: Psychometrics

Vancouver Island

Session Chair: Diane Fairclough, DrPH, United States

4:10 pm – 4:23 pm (107.1) Evaluating the Dimensionality of Complex PROs Using Bifactor Analysis Within an Exploratory Structural Equation Modeling (ESEM) Framework: an Example Using the Patient-reported Scar Evaluation Questionnaire (PR-SEQ)

Rohini Sen, Adelphi Values, Boston, MA, United States; Andreas M. Pleil, Pfizer, Inc., San Diego, CA, United States; Cheryl Coon; and Alan L. Shields, Adelphi Values, Boston, MA, United States

4:24 pm – 4:37 pm (107.2) Improving the measurement of HRQL in dementia: A Rasch Measurement Theory approach

Sarah C. Smith, PhD, London School of Hygiene & Tropical Medicine, London, United Kingdom, A. A. Jolijn Hendriks, PhD, London School of Hygiene & Tropical Medicine, London, United Kingdom; Theopisti Chrysanthaki, PhD, London School of Hygiene & Tropical Medicine, London, United Kingdom; Stefan Cano, PhD, Modus Outcomes, Stofold, United Kingdom; Nick Black, PhD, London School of Hygiene and Tropical Medicine, London, United Kingdom

4:38 pm – 4:51 pm (107.3) PRO development with small samples: An innovative use of repeated measures IRT

R. J. Wirth, Vector Psychometric Group, LLC, Chapel Hill, NC, United States; Carrie Houts, Vector Psychometric Group, LLC, Chapel Hill, NC, United States

5:52 pm – 5:05 pm (107.4) Grooming a CAT: Customizing CAT Administration Rules to Increase Response Efficiencies in Specific Research and Clinical Settings

Michael A. Kallen, PhD, MPH, Northwestern Univ., Feinberg School of Medicine, Missouri City, TX, United States; Karon F. Cook, PhD, Department of Medical Social Sciences; and Richard C. Gershon, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

5:06 pm – 5:19 pm (107.5) A mixture partial credit model for identifying latent classes responsible for differential item functioning

Jean-François Hamel, Assistant professor, Univ. hospital of Angers, Univ. of Nantes, Angers, France; Veronique Sebille, Professor of Biostatistics, Univ. of Nantes, Faculty of Pharmacy, France, Nantes, France; Yves Roquelaure, Professor, Univ. of Angers, Angers, France; Jean-Benoit Hardouin, PhD, Univ. of Nantes, Nantes, France

5:20 pm – 5:33 pm (107.6) Applying a common depression metric to independent samples: Different approaches result in similar score estimates

Gregor Liegl, Mag., Charite - Universitaetsmedizin Berlin, Berlin, Germany; Inka Wahl, Dr. phil., Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Anne Berghoefer, Dr. med.; and Sandra Nolte, PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Christoph Pieh, Dr. med., Danube Univ. Krems, Krems, Austria; Matthias Rose, MD PhD; and Felix Fischer, ScD, Charite - Universitaetsmedizin Berlin, Berlin, Germany
STUDENT PRESENTATION AWARD FINALIST



Scientific Program — Thursday, October 22

Oral Session 108: Prostate Cancer

Waddington

Session Chair: Brent Hollenbeck, MD, United States

4:10 pm – 4:23 pm (108.1) Comparison of patient-reported quality-of-life and complications in men with prostate cancer, between two modes of administration

Rasa Ruseckaite, Monash Univ., Melbourne, Australia; Fanny Sampurno, Monash Univ., Melbourne, Australia; Jeremy L. Millar, Alfred Health, Melbourne, Australia; Sue M. Evans, Monash Univ., Melbourne, Australia

4:24 pm – 4:37 pm (108.2) Reliability and Validity of PROMIS Measures Administered by Telephone Interview in a Prospective, Population-based Study of Men With Localized Prostate Cancer

Caroleen W. Quach, MSPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Michelle M. Langer, PhD; Deborah S. Usinger; Ronald C. Chen, MD, MPH; and Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States

4:38 pm – 4:51 pm (108.3) Comparing the Responsiveness of Two Health-related Quality of Life Instruments in a Phase III Randomized Clinical Trial of Men with Prostate Cancer (NCIC CTG PR.3): The EORTC QLQ-C30+3 with PR17 Trial Specific Checklist versus the FACT-P

Michael Brundage, MD, MSc, Kingston General Hospital, Queen's Univ., Kingston, ON, Canada; Harriet Richardson, PhD, Queen's Univ., Kingston, ON, Canada; Padraig Warde, MD, Univ. Health Network - Princess Margaret Cancer Centre; Univ. of Toronto, Toronto, Canada; Wendy Parulekar, MD; and Bingshu Chen, PhD, NCIC Clinical Trials Group, Queen's Univ., Kingston, ON, Canada; Andrea Bezzak, MD, Princess Margaret Cancer Centre, University Health Network, Toronto, ON, Canada; Yvonne Murray, MSc, NCIC Clinical Trials Group, Queen's Univ., Kingston, ON, Canada

4:52 pm – 5:05 pm (108.4) Five-year follow-up after active surveillance or curative treatment: preliminary quality of life outcomes of men with prostate cancer

Lionne Venderbos, Erasmus Univ. Medical Center, Rotterdam, Netherlands; Monique Roobol; and Chris Bangma, Erasmus Univ. Medical Center, Rotterdam, Netherlands; Ida Korfage, PhD, Erasmus MC, Univ. Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands

5:06 pm – 5:19 pm (108.5) Defining Quality Of Life Outcomes For Advanced Prostate Cancer Trials: Qualitative Interview Results Compared With HRQL Instruments In Current Use

Michael J. Fabricius, MBBS BSc MRCS, Newcastle Univ., Newcastle upon Tyne, United Kingdom; Robert Pickard, MD FRCS (Urol); and Elaine McColl, PhD, Newcastle Univ., Newcastle upon Tyne, United Kingdom

Oral Session 109: Mental Health

Boardroom

Session Chair: Dennis Revicki, PhD, United States

4:10 pm – 4:23 pm (109.1) Patient knows best: patient-reported functionality predicts course of clinical depression

Carlos G. Forero, Researcher, CIBER in Epidemiology y Salud Pública (CIBERESP), Barcelona, Spain; Elena Olariu, Predoc Student, Hospital del Mar Medical Research Institute (IMIM), Barcelona, Spain; Jose Ignacio Castro-Rodríguez, Psychiatrist, Institute of Neuropsychiatry and Addictions (INAD), Parc de Salut Mar., Barcelona, Spain; Gemma Vilagut, Analyst, Hospital del Mar Medical Research Institute (IMIM), Barcelona, Spain; Angels Pont, BSc, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Jordi Alonso, Head, Hospital del Mar Medical Research Institute, Barcelona, Spain

Funding: funded by grants ISCII(P13/00506) and ISCIII(P10/00530) and DIUE of Generalitat de Catalunya (2014SGR748)

4:24 pm – 4:37 pm (109.2) Development of eight item banks to assess specific mental health problems

Philip Batterham, PhD, The Australian National Univ., Acton, ACT, Australia; Matthew Sunderland, PhD; and Natacha Carragher, PhD, Univ. of New South Wales, Randwick, Australia; Alison Cleave, PhD, The Australian National Univ., Acton, Australia

4:38 pm – 4:51 pm (109.3) Impact of Smoking, Physical Inactivity, Heavy Drinking, and Obesity on Health-Related Quality of Life, Life Expectancy, and Quality-Adjusted Life Expectancy among Adults with and without Depression in the U.S.

Haomiao Jia, Columbia Univ., New York, NY, United States; Matthew M. Zack; and William W. Thompson, PhD, U.S. Centers for Disease Control and Prevention, Atlanta, GA, United States

4:52 pm – 5:05 pm (109.4) Development of Dutch Computer Adaptive Tests for Anxiety and Depression using the PROMIS item banks

Gerard Flens, Stichting Benchmark GGZ (SBG) [Benchmark Foundation Mental Health Care], Bilthoven, Netherlands; Niels Smits, Department of Clinical Psychology and Department of Methodology, the EMGO Institute for Health and Care Research, VU Univ. Medical Center, Amsterdam, Netherlands; Caroline B. Terwee, VU Univ. Medical Center, Amsterdam, Netherlands; Edwin de Beurs, Stichting Benchmark GGZ (SBG) [Benchmark Foundation Mental Health Care], Bilthoven, Netherlands



Top Outstanding Posters

Scientific Program — Thursday, October 22

5:06 pm – 5:19 pm (109.5) The BELLA Study: First Results From the Longitudinal Mental Health Module of the German National Health Interview and Examination Survey Among Children and Adolescents
Anne-Catherine Haller, Dipl.-Psych., Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Fionna Klasen, PhD; and Christiane Otto, PhD, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD; and Annett Mierke, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Dana Barthel, Dipl.-Psych., Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ute Ellert, Robert Koch-Institute, Berlin, Germany; Laura Schlepper, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Kathrin I. Fischer, M.Sc.med., Charite - Universitaetsmedizin Berlin, Berlin, Germany; Heike Hoelling, Robert Koch-Institute, Berlin, Germany; Otto Walter, PhD, MD; and Matthias Rose, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Ulrike Ravens-Sieberer, PhD, MPH, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany

Oral Session 110: Population-Based Studies

Saturna

Session Chair: Lori Frank, PhD, United States

4:10 pm – 4:23 pm (110.1) Five year trajectories of Health-Related Quality of Life in Canada's Poorest Postal Code

Skye P. Barbic, Post-Doctoral Fellow, Faculty of Medicine, Vancouver, BC, Canada; Ana Maria Rodríguez, PHD, McGill Univ., Montreal, QC, Canada; Tari Buchanan, University of British Columbia, Vancouver, BC, Canada; William G. MacEwan, St. Paul's Hospital, Vancouver, Canada; William G. Honer, University of British Columbia, Vancouver, BC, Canada

4:24 pm – 4:37 pm (110.2) Exploring the relationships between health-related quality of life and health conditions, costs, resource utilization and quality measures

Eric Havens, MA, Humana, Knoxville, TN, United States; Jonathan Pena, MS; and Lane Slabaugh, PharmD, MBA, Humana, Louisville, KY, United States; Tristan Cordier, MPH, Humana, Atlanta, GA, United States; Andrew Renda, MD, MPH; and Vipin Gopal, PhD, MBA, Humana, Louisville, KY, United States

4:38 pm – 4:51 pm (110.3) Health-Related Quality of Life in Incident, Established, and Long-Term Cases of Chronic Illness: Results from a Population-Based Survey

Lucy Busija, Australian Catholic Univ., Melbourne, Victoria, Australia; Kerrie Sanders; Daniel O'Connor; Geoff Nicholson; Marita McCabe; and Catherine Connaughton, Australian Catholic Univ., Melbourne, Victoria, Australia

4:52 pm – 5:05 pm (110.4) Quality Of Life Independently Predicts Long-Term Vascular Events And Mortality: The Northern Manhattan Study

Mandip S. Dhamoon, MD, MPH, Icahn School of Medicine at Mount Sinai, New York, NY, United States; Consuelo McLaughlin-Mora, MS; Joshua Z. Willey, MD, MS; Ying Kuen Cheung, PhD; and Yeseon P. Moon, MS, Columbia Univ., New York, NY, United States; Ralph L. Sacco, MD, MS, Univ. of Miami, Miami, FL, United States; Mitchell S. Elkind, Columbia Univ., New York, NY, United States

5:06 pm – 5:19 pm (110.5) 1000 Norms Project: Health-related Quality of Life Across the Lifespan

Jennifer N. Baldwin, PhD Student, The Univ. of Sydney, Lidcombe, NSW, Australia; Marnee McKay, PhD Student; Claire Hiller, PhD; Elizabeth J. Nightingale, PhD; Niamh Moloney, PhD; and Joshua Burns, PhD, The Univ. of Sydney, Sydney Children's Hospital Network, Lidcombe, NSW, Australia

6:00 pm – 6:30 pm Tricks of the Trade – Advice for New Investigators in Quality of Life Research

Pacific Ballroom

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

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

David Cella, PhD, Feinberg School of Medicine, Northwestern Univ., Chicago, IL, United States

The "Tricks of the Trade" is intended for New Investigators, but all conference attendees are welcome to attend and to contribute to the discussions.

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

British Columbia Ballroom

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.



Top Outstanding Posters





ISOQOL 2015

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WED, October 21, 2015

Workshop WK10

*Caring about Caregivers:
Definitions, Methods and
Importance of Evaluating
Caregivers' Burden*

When

1:00 – 4:00 PM

Organizer

Antoine Regnault

Instructors

Diana Rofail¹, Antoine Regnault²,
Khadra Benmedjahed², Catherine
Acquadro³, Caroline Anfray³

1: Roche Pharmaceuticals, Welwyn Garden City, UK
2: Mapi PCO, Lyon, France
3: Mapi Research Trust, Lyon, France

THU, October 22, 2015

Poster # 1019 Session 1

*Development of a Database
of Published Regulatory
Recommendations Concerning
the Use of Clinical Outcomes
Assessments (COAs) in Drug
Development: Outcomes InSite*

When

10:35 – 10:55 AM

Presenting Author

Catherine Acquadro

Authors

Cécile Perret, Catherine Acquadro
Mapi Research Trust, Lyon, France

FRI, October 23, 2015

Poster # 2045 Session 1

*Challenges in Translating the
Adult Version of the Transfusion-
Dependent QoL (TranQoL)
Questionnaire into Arabic, French,
Greek, Italian and Turkish*

When

10:35 – 10:55 AM

Presenting Author

Robert J Klaassen

Authors

Cédric Roulliat¹, Robert J.
Klaassen², Dalia Mahmoud³,
Nazilabee Torabully¹

1: Mapi Language Services, Lyon, France
2: Department of Pediatrics, Division of
Hematology/Oncology, University of Ottawa,
Children's Hospital of Eastern Ontario, Canada
3: Celgene, Hematology & Oncology Global
Pricing & Market Access, Summit, NJ, USA

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Upcoming Mapi Group Author Webinars

*A Review of the Epworth
Sleepiness Scale (ESS)*
Dr. Murray Johns
October 28, 2015

*Introducing the TranQoL for
Clinical Research*
Dr. Robert Klaassen
November 10, 2015

Usability Testing of ePRO
Catherine Acquadro, MD
November 24, 2015

Introduction to the Breast-Q™
Dr. Andrea L. Pusic, Dr. Stefan Cano, Dr.
Anne F. Klassen, Allison R. DiLaura
December 16, 2015



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Oral Session 201: Multiple Sclerosis

*Developing the Guy's
Neurological Scale (GNDS) in 28
Languages*

When

1:45 – 3:15 PM

Presenting Author

Catherine Acquadro

Authors

Catherine Acquadro¹, Bing Zhu²,
Alain Nguyen³, Basil Sharrack⁴,
Nazila Torabully³

1: Mapi Research Trust, Lyon, France
2: Biogen, Cambridge, MA, USA
3: Mapi Language Services, Lyon, France
4: Academic Department of Neurology,
Royal Hallamshire Hospital, Sheffield
Teaching Hospitals NHS Foundation
Trust & University of Sheffield, UK

Scientific Program — Friday, October 23

7:00 am – 5:35 pm Registration Desk Open

7:30 am – 8:25 am Special Interest Group (SIG) Meetings

Child Health SIG Meeting Waddington

Health Preference Research SIG Meeting Saturna

Ibero America SIG Meeting Boardroom

Mixed Methods SIG Meeting Tweedsmuir

United Kingdom and Ireland SIG Meeting Garibaldi

8:00 am – 9:00 am Breakfast Roundtables

RT01: Integrating Patients as Partners in Clinical Research

Host: Susan Bartlett, PhD, McGill University, Montreal, QC, Canada

RT02: Measuring HRQL at the General Population Level (an epidemiologist's perspective)

Host: Jordi Alonso, MD PhD, IMIM-Hospital del Mar, Medical Research Institute, Barcelona, Spain

RT03: Operational Issues in Electronic PRO Assessment and Reporting in Clinical Care Settings

Host: Irene Katzan, MD MS, Cleveland Clinic, Cleveland, OH, United States

RT04: Development and validation of clinician-reported outcomes

Host: William Lenderking, PhD, Evidera, Lexington, MA, United States

RT05: Opportunities for research using the SEER-MHOS and SEER-CAHPS linked databases

Hosts: Ron D. Hays, PhD, UCLA Department of Medicine, Division of General Internal Medicine & Health Services Research, Los Angeles, CA, United States and Erin Kent, PhD MS, National Cancer Institute (NCI), Bethesda, MD, United States

RT06: Patient engagement from a governmental perspective

Host: Lena Ring, PhD, Medical Products Agency (MPA) and Uppsala University, Uppsala, Sweden

RT07: Conceptual confusion? Unravelling quality of life, subjective wellbeing and happiness

Host: Suzanne Skevington, PhD, University of Manchester, Manchester, United Kingdom

RT08: Past and Future Applications for Preference-based Measures of Health

Host: Simon Pickard, PhD, University of Illinois at Chicago, College of Pharmacy, Chicago, IL, United States

Breakfast Roundtables are informal meetings with up to nine participants to network and discuss mutual interests in your work and field. A ticket is required for each Breakfast Roundtable.

9:00 am – 10:30 am The Theory of Everything' – New Models and Measures Pacific Ballroom

Plenary sponsored by: Genentech

In this session, we will learn about new ways to think about the social dimension of quality of life in theory and measurement. This will include a theoretical perspective linking biological and behavioural variables and the latest advances in social domain assessment from three major measurement systems. The session will provide both inspiration for the breadth of quality of life and practical tools for moving forward.

Speakers

Frances Chen, PhD, Univ. of British Columbia, Vancouver, BC, Canada

Elizabeth A. Hahn, MA, Northwestern Univ., Chicago, IL, United States

Mogens Grønvold, MD, Univ. of Copenhagen, Copenhagen, Denmark

Allen Heinemann, PhD, Rehabilitation Institute of Chicago, Northwestern Univ., Chicago, IL, United States

Chair

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

Discussant

Jolie Ringash, MD, The Princess Margaret Cancer Centre, Toronto, ON, Canada

 Top Outstanding Posters



FINAL PROGRAM

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Scientific Program — Friday, October 23

10:00 am – 5:00 pm Poster Hall Open British Columbia Ballroom

10:30 am – 11:20 am Exhibits Open and Refreshment Break

10:35 am – 10:55 am Friday Poster Session 1 British Columbia Ballroom

Reviews

(2007) Patient-Reported Outcomes in Randomised Controlled Trials of Head and Neck Cancers: A Systematic Review of Reporting Quality from the PROMOTION Registry

Rebecca Mercieca-Bebber, Univ. of Sydney, Sydney, NSW, Australia; Alessandro Perreca, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Andrew Macann, Department of Radiation Oncology, Auckland Regional Cancer and Blood Service, Auckland City Hospital, Auckland, New Zealand; Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia; Katie Whale, Univ. of Bristol, Bristol, United Kingdom; Salvatore Soldati, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Marc Jacobs, Academic Medical Center, Univ. of Amsterdam, Department of Medical Psychology, Amsterdam, Netherlands; Fabio Efficace, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

(2009) Measuring Outcomes In Young Patients With Conditions Associated With A Facial Difference: Are PRO Instruments Asking The Right Questions?

Natasha Wickert, McMaster Univ., Hamilton, ON, Canada; Karen Wong, MD MSc FRCSC, Hospital for Sick Children, Univ. of Toronto, Toronto, ON, Canada; Mark Mansour, McMaster Univ., Hamilton, ON, Canada; Timothy Goodacre, MBBS BSc FRCS, Univ. of Oxford, Oxford, United Kingdom; Christopher Forrest, MD MSc FRCSC, Hospital for Sick Children, Univ. of Toronto, Toronto, ON, Canada; Andrea Pusic, MD MPH FACS, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Anne Klassen, DPhil, McMaster Univ., Hamilton, ON, Canada

(2011) Digital methodologies in the development of clinical outcome assessments

Chloe Tolley, Adelphi Values Ltd, Cheshire, United Kingdom; Chris Marshall, Adelphi Values Ltd, Cheshire, United Kingdom; Adam Gater; Gavin Dickie; and Sarah Kilgariff, Adelphi Values Ltd, Cheshire, United Kingdom

(2015) The use of patient reported outcome measurements (PROMs) as performance indicators in lung cancer treatment

Majken M. Broenserud, MD, PhD student, Univ. of Southern Denmark and Odense Univ. Hospital, Odense City, Denmark; Erik Jakobsen, MD, MPM, Chief Surgeon, Clinical associate professor, Odense Univ. Hospital, Odense C, Denmark; Liv H. Dørfliinger, Master of Public Health Science (MScPH), Health and Quality Consultant, The Danish Cancer Society, Copenhagen East, Denmark

(2017) The quality of systematic reviews of health-related outcome measurement instruments

Caroline B. Terwee, VU Univ. Medical Center, Amsterdam, Netherlands; Cecilia A. Prinsen, PhD, Amsterdam, Netherlands; Maria G. Ricci Garotti, MSc, Bologna, Italy; Arnela Suman, MSc, Amsterdam, Netherlands; Henrica C. de Vet, VU Univ. Medical Center, Amsterdam, Netherlands; Lidwine B. Mokkink, PhD, Amsterdam, Netherlands

(2019) Content mapping of patient-reported outcomes (PROs) important to patients with non-muscle invasive bladder cancer (NMIBC) against available PRO measures (PROMs)

Claudia Rutherford, PhD, Univ. of Sydney, Sydney, NSW, Australia; Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia; David Smith, PhD, NSW Cancer Council, Sydney, NSW, Australia; Daniel Costa, Dr; Manish Patel, PhD, The Univ. of Sydney, Sydney, NSW, Australia

(2021) Enrolling and Keeping Participants in Self-management Interventions: A Meta-Analysis

Alaa M. Arafah, PhD Candidate, McGill Univ. and King Saud Univ., Montreal, QC, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada

(2023) How do health care providers respond to PROMs data to improve patient care? A realist synthesis

Joanne Greenhalgh; and Sonia Dalkin, Univ. of Leeds, Leeds, United Kingdom; Elizabeth Gibbons, Univ. of Oxford, Oxford, United Kingdom; Nick Black, PhD, London School of Hygiene and Tropical Medicine, London, United Kingdom; Jose M Valderas, MD, PhD, MD, Univ. of Exeter, Exeter, United Kingdom; Judy Wright, Univ. of Leeds, Leeds, United Kingdom; David Meads, Univ. of Leeds, Leeds, United Kingdom; Liz Lingard, North East Quality Observatory System, Newcastle upon Tyne, United Kingdom; Laurence Wood, PPI representative, Leeds, United Kingdom; Jane Jackson, Director, JJ consulting, London, United Kingdom

(2025) A systematic review of Quality of Life measurement in studies investigating treatments of psoriasis

Faraz M. Ali, Clinical Research Fellow, Cardiff Univ., Cardiff, United Kingdom; Andrea C. Cueva, Attending Physician/Researcher, Centro de la Piel, Quito, Ecuador; Ausama A. Atwan, MD, Cardiff Univ. School of Medicine, Cardiff, United Kingdom; Jui Vyas, Cardiff Univ., Cardiff, United Kingdom; Vincent Pignet, Professor of Dermatology, Cardiff Univ. School of Medicine, Cardiff, United Kingdom; Sam Salek, PhD RPH FFPM MRPSGB MCMS FESCP, School of Life & Medical Sciences, Univ. of Hertfordshire, Hatfield and Director - Institute for Medicines Development, Cardiff, United Kingdom; Andrew Y. Finlay, Professor of Dermatology, Cardiff Univ., Cardiff, United Kingdom



Top Outstanding Posters

Scientific Program — Friday, October 23

Translation

(2027) Clinical interpretation of the Chinese version of functional digestive disorders quality of life questionnaire

Zheng-kun Hou, MD, *The First Affiliated Hospital of Guangzhou Univ. of Chinese Medicine, Guang Zhou, China*; **Feng-Bin Liu, MD, The First Affiliated Hospital of Guangzhou Univ. of Chinese Medicine, Guang Zhou, China**, Zhuo-qun Chen, *Guangzhou Univ. of Chinese Medicine, Guangzhou, China*

(2029) The DISABKIDS®-37 Questionnaire for Brazilian children and adolescents with chronic conditions showed cross-cultural Brazilian regions validity

Serlyjane P. Nunes; Jenny Kellma F. Silva; and Fernanda M. dos Anjos, *Universidade Federal Do Maranhão, São Luís, Maranhão, Brazil*; Roberta A. Reis, *Universidade Federal do Rio Grande do Sul, Porto Alegre, Rio Grande Do Sul, Brazil*; Cláudia Fegadolli, *Universidade Federal De São Paulo, São Paulo, Brazil*; Monika Bullinger, *University of Hamburg, Hamburg, Germany*, **Claudia B. dos Santos, Universidade De São Paulo, Ribeirão Preto, São Paulo, Brazil**



(2031) Evaluating the Impact of Defined Difficulty Ratings on Consistency of Translatability

Assessment Results for PRO Measures

Sarah Basse, Health Research Associates, Inc., Seattle, WA, United States; Alexa Chhay; and Mona L. Martin, RN, MPA, *Health Research Associates, Inc., Seattle, WA, United States*

(2033) Challenges Related to the Linguistic Validation of Culturally Sensitive Questions

Fiona E. Miller, BA (Joint Hons), PharmaQuest Ltd, Banbury, United Kingdom; Hayley L. Simpson, BA; and Rebecca L. Two, BA (Hons), *PharmaQuest Ltd, Banbury, United Kingdom*

(2035) Linguistic Validation Interviews in a Pediatric Cerebral Palsy Population: Approaches for Meaningful Feedback

Valeska Kantzer, Health Research Associates, Inc., Mountlake Terrace, WA, United States; Sarah Basse; and Mona L. Martin, RN, MPA, *Health Research Associates, Inc., Seattle, WA, United States*; Thorin L. Geister, PhD, *Merz Pharmaceuticals, Frankfurt am Main, Germany*

(2037) Psychometric Evaluation of the Suicide Ideation Scale in Mentally Ill Korean Patients Dwelling in Communities

Jin Sil Han, MPH, Gimpo Mental Health Center, Gimpo, South Korea; Eun-Hyun Lee, PhD, *Ajou Univ., Suwon, South Korea*; Tong Woo Suh, PhD, *Gimpo Mental Health Center, Gimpo, South Korea*; Chang Hyung Hong, PhD, *Ajou Univ., Suwon, South Korea*

(2039) Gender Differences in Cognitive Debriefing of Clinical Outcomes Assessments (Coa) and the Impact Of the Interviewer

Matthew Talbert, Corporate Translations Inc, Chicago, IL, United States; Barbara Brandt; Carolyn Schulz; Shawn McKown; and Mary Gawlicki, *Corporate Translations, East Hartford, CT, United States*

(2041) Calibration and Validation of the Dutch-Flemish PROMIS Pain Behavior and Pain Interference Item Banks in Patients with Rheumatoid Arthritis

Martine H. Crins, Amsterdam Rehabilitation Research Center | Reade, Amsterdam, Netherlands; Caroline B. Terwee, *VU Univ. Medical Center, Amsterdam, Netherlands*; Rene Westhovens, *Department of Development and Regeneration, Skeletal Biology and Engineering Research Center, KU Leuven, Leuven, Belgium*; Dirkjan van Schaardenburg, *Jan van Breemen Research Institute | Reade, Amsterdam, Netherlands*; Niels Smits, *Department of Clinical Psychology and Department of Methodology, the EMGO Institute for Health and Care Research, VU Univ. Medical Center, Amsterdam, Netherlands*; Johan Joly; Patrick Verschueren; and Kristien van der Elst, *Department of Development and Regeneration, Skeletal Biology and Engineering Research Center, KU Leuven, Leuven, Belgium*; David Cella, PhD, *Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States*; Karon F. Cook, PhD, *Department of Medical Social Sciences, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States*; Joost Dekker, *Department of Rehabilitation Medicine and Department of Psychiatry, VU Univ. Medical Center, Amsterdam, Netherlands*; Maarten Boers, *VU Univ. Medical Center, Amsterdam, Netherlands*; Leo D. Roorda, *Amsterdam Rehabilitation Research Center | Reade, Amsterdam, Netherlands*

(2043) Psychometric validation of the Spanish Manchester-Oxford Foot Questionnaire (MOXFQ) in patients with foot or ankle surgery

Sabine Goldhahn, MD, AO Foundation, Duebendorf, Switzerland; Juan B. Gerstner Garces, MD, *Centro Médico Imbanaco Cali, Cali, Colombia*; Ian Winson, MB ChB FRCS, *Avon Orthopaedic Centre, Southmead Hospital, Westbury on Trym, Bristol, United Kingdom*; Andrew K. Sands, MD, *New York-Presbyterian Hospital – Lower Manhattan Hospital, New York, NY, United States*

(2045) Challenges in Translating the Adult Version of the Transfusion-Dependent QoL (TranQoL) Questionnaire into Arabic, French, Greek, Italian and Turkish

Cedric Roulliat, *Mapi, Lyon, France*, **Robert J. Klaassen, Univ. of Ottawa, Children's Hospital of Eastern ON, Ottawa, ON, Canada**; Dalia Mahmoud, *Celgene, Summit, NJ, United States*; Nazilabee Toraubully, *Mapi, Lyon, France*



Top Outstanding Posters



Scientific Program — Friday, October 23

(2047) Danish translation and linguistic validation of the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Christina Baeksted, PhD Student, MSc in Public Health, Rigshospitalet, Copenhagen Univ. Hospital and Danish Cancer Society, Copenhagen, Denmark; Aase Nissen, MSc Pharm., MPH, Danish Cancer Society, Copenhagen, Denmark; Helle Pappot, MD DMSc, Rigshospitalet, Copenhagen Univ. Hospital, Copenhagen, Denmark; Pernille E. Bidstrup, MA, PhD, Danish Cancer Society Research Center, Copenhagen, Denmark; Sandra A. Mitchell, PhD, CRNP, AOCN, National Cancer Institute, Rockville, MD, United States; Ethan Basch, MD, MSc, Univ. of North Carolina, Chapel Hill, NC, United States; Susanne O. Dalton, MD, PhD, Danish Cancer Society Research Center, Copenhagen, Denmark; Christoffer Johansen, Professor, MD, PhD, Dr Med Sci, Rigshospitalet, Copenhagen Univ. Hospital, Copenhagen, Denmark

(2049) Improving the Reporting quality of Instrument Cross-cultural Adaption: the IRICA statement

Zheng-kun Hou, MD, The First Affiliated Hospital of Guangzhou Univ. of Chinese Medicine, Guang Zhou, China; Feng-bin Liu, MD, The First Affiliated Hospital of Guangzhou Univ. of Chinese Medicine, Guang Zhou, China; Yuan-kun Tan, PhD, Guangzhou Univ. of Chinese Medicine, Guangzhou, China

(2051) Chinese-English Language Equivalence of the Short Form 12-item Health Survey

Daniel Y. Fong, PhD, The Univ. of Hong Kong, Hong Kong SAR, China; Janet Y. Wong, PhD, RN, The Univ. of Hong Kong, Hong Kong SAR, China; Cannas Kwok, Lecturer, Univ. of Western Sydney, Penrith NSW, Australia; Kwok-Fai Lam, The Univ. of Hong Kong, Hong Kong, China

(2055) Professional Proofreading: A New Step in the EORTC Translation Procedure to Further Improve Output Quality

Dagmara Kulis, EORTC, Brussels, Belgium; Cheryl Whittaker, EORTC, Brussels, Belgium; Edite Fiskovica, EORTC, Brussels, Belgium; Eva Greimel, Univ. Hospital Graz, Graz, Austria; Andrew Bottomley, EORTC Headquarters, Brussels, Belgium; Michael Koller, Univ. Hospital Regensburg, Regensburg, Germany

(2057) Why two are better than one: the added value of the second back translation in the EORTC Translation Procedure

Dagmara Kulis, EORTC, Brussels, Belgium; Cheryl Whittaker, EORTC, Brussels, Belgium; Edite Fiskovica, EORTC, Brussels, Belgium; Eva Greimel, Univ. Hospital Graz, Graz, Austria; Andrew Bottomley, EORTC Headquarters, Brussels, Belgium; Michael Koller, Univ. Hospital Regensburg, Regensburg, Germany

(2059) Psychometric Validation of a Hindi Version of Chronic Obstructive Pulmonary Disease Assessment Test (CAT)

Ashutosh N. Aggarwal, Professor, Postgraduate Institute of Medical Education and Research, Chandigarh, India; Isak Lallawmkima, Junior Resident, Postgraduate Institute of Medical Education and Research, Chandigarh, India; Debasish Basu, Professor, Postgraduate Institute of Medical Education and Research, Chandigarh, India

Cancer

(2061) The newly derived four-factor structure of the FACIT-Sp-Ex: Comparing cancer survivors to other cancer/community groups

Hayley S. Whitford, PhD, Cancer Council Australia, Sydney, New South Wales, Australia; The Univ. of Adelaide, Adelaide, South Australia, Australia; Ian Olver, MD, PhD, FRACP, Cancer Council Australia, Sydney, NSW, Australia; Sansom Institute for Health Research, Univ. of South Australia, Adelaide, South Australia, Australia

(2063) Defining responders on the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life questionnaire (30-item core module) (QLQ-C30) subscales

Kim Cocks, KCStats Consultancy, Leeds, United Kingdom; Jacqueline Buchanan, Onyx Pharmaceuticals, Inc., an Amgen subsidiary, South San Francisco, CA, United States

(2065) Utilization of patient reported outcomes (PROs) tools in studies that include pancreatic cancer

Agnes Hong, Pfizer Inc, New York, NY, United States; Giovanni Zanotti, PharmD MSc, Pfizer, New York, NY, United States; Shrividya Iyer, PhD, Pfizer Inc., New York, NY, United States

(2067) Assessment of patient-reported adverse events after discharge from hospital following gastrointestinal cancer surgery: do EORTC disease-specific modules have sufficient coverage to monitor recovery and detect problems early?

Elaine O'Connell Francischetto, Research Associate; and Kerry Avery, Univ. of Bristol, Bristol, United Kingdom, Galina Velikova, MD PhD, Leeds Institute of Cancer Studies and Pathology Univ. of Leeds, Leeds, United Kingdom; Jane Blazeby, Univ. of Bristol, Bristol, United Kingdom



Top Outstanding Posters

Scientific Program — Friday, October 23

(2069) Psychometric Assessment of the Functional Assessment of Cancer Therapy/Gynecologic Oncology Group-Neurotoxicity (FACT/GOG-Ntx) Questionnaire in Patients with Relapsed and Refractory Multiple Myeloma (RRMM) Receiving Carfilzomib Treatment

Elizabeth Bacci, Evidera, Seattle, WA, United States; Kim Cocks, KCStats Consultancy, Leeds, United Kingdom; Dana Hurley, Onyx Pharmaceuticals, Inc., an Amgen subsidiary, South San Francisco, CA, United States; **Sumeet Panjabi, Onyx Pharmaceuticals, Inc., an Amgen subsidiary, South San Francisco, CA, United States**; Dennis Revicki, PhD, Evidera, Bethesda, MD, United States

(2071) Quality of Life After Patients Progress in Oncology Clinical Trials: The Black Box

Kathryn Lasch, PhD, Pharmerit International, Newton, MA, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; Ethan Basch, MD, MSc, Univ. of North Carolina, Chapel Hill, NC, United States; Jie Zhang, Oncology Franchise Lead, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States; Vasudha Bal, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States; Erica G. Horodniceanu, Pharmerit International, Bethesda, MD, United States; Lavanya Sudharshan, Pharmerit International, Bethesda, MD, United States; Charles S. Cleeland, PhD, UT MD Anderson Cancer Center, Houston, TX, United States

(2073) Using administrative data to identify eligible patients for the Consumer

Assessment of Healthcare Providers and Systems (CAHPS) Survey for Cancer Care Prototype

Kathleen J. Yost, Mayo Clinic, Rochester, MN, United States; Sue Visscher; Marlene Frost; and Sarah Jenkins, Mayo Clinic, Rochester, MN, United States; Christian Evensen, American Institutes for Research, Chapel Hill, MN, United States; Melissa Robertson; James Naessens; Jason Egginton; and Monica Van Such, Mayo Clinic, Rochester, MN, United States

(2075) Assessing Health Related Quality of Life (HQOL) in Mesothelioma: which measures are optimal?

Jason M. Fowler, PhD Fellow, Univ. of Sydney, Concord, NSW, Australia; Janette Vardy, Medical Oncologist, Centre for Medical Psychology and Evidence Based Decision (CeMPED), Univ. of Sydney, Concord, NSW, Australia; Steven Kao; Joe R. Coll; Anne Warby; and Melanie A. Price, Univ. of Sydney, Camperdown, New South Wales, Australia; Haryana Dhillon, Research Fellow, Centre for Medical Psychology & Evidence-based Decision-making, Camperdown, NSW, Australia



(2077) The Cohort Study ProCaSP – Quality of life outcomes of prostate cancer patients after radiotherapy or radical prostatectomy during a follow up period of 24 months

Nora Eisemann, Univ. of Luebeck, Luebeck, Germany; Sandra Nolte, PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Alexander Katalinic, Univ. Luebeck, Luebeck, Germany; Volker Rohde, Justus Liebig Univ. of Giessen & Medical Practice of Urology, Bad Schwartau, Germany; **Annika Waldmann, Univ. Hospital Schleswig-Holstein, Campus Luebeck, Luebeck, Germany**

(2079) The Effects of TCM on Chemotherapy Related Fatigue and Quality of Life in Lung Cancer Patients

Jie You, The Ninth People's Hospital Affiliated to Shanghai Jiao Tong Univ. School of Medicine, Shanghai, China; Tan Xiang-Wen, Shanghai Tianshan Hospital of Traditional Chinese Medicine, Shanghai, China; Chen Xue Fen, Shanghai Univ. of Traditional Chinese Medicine, Shanghai, China; Weiwei Chen, XinHua Hospital Affiliated to Shanghai Jiao Tong Univ. School of Medicine, Shanghai, China; Zheng Chen, Shanghai Univ. of Traditional Chinese Medicine, Shanghai, China; Yuqing Zhang, McMaster Univ., ON, Canada; William Zhang, McMaster Univ., ON, Canada

(2081) The impact of comorbidity on quality of life in elderly patients with chronic myeloid leukemia

Francesco Cottone, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Johannes M. Giesinger, Department of Psychiatry and Psychotherapy, Medical Univ. of Innsbruck, Innsbruck, Austria; Fabio Efficace, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; **Marc Jacobs, Academic Medical Center, Univ. of Amsterdam, Department of Medical Psychology, Amsterdam, Netherlands**

(2083) Health-related quality of life and mammography and Pap test screening: disparity within race/ethnicity groups

Sarah Hobbs; Kimmie Ly; William Gentry; and Connie Rust, South College School of Pharmacy, Knoxville, TN, United States; I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; **Pranav Gandhi, PhD, South College, Knoxville, TN, United States**

(2085) PROMIS Cancer-Specific Reference Values for the US Cancer Population

Roxanne Jensen, PhD, Cancer Prevention and Control Program, Lombardi Comprehensive Cancer Center, Georgetown Univ., Washington, DC, United States; Carol M. Moinpour, PhD, Public Health Sciences Division, Fred Hutchinson Cancer Research Center, Seattle, WA, United States; **Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States**; Tania Lobo, MS, Cancer Prevention and Control Program, Lombardi Comprehensive Cancer Center, Georgetown Univ., Washington, DC, United States; Arnold Potosky, Georgetown Univ., Washington, DC, United States

(2087) Psychosocial Health Among Adolescent and Young Adult Brain Tumor Survivors

David Buchbinder, MD, MSHS, CHOC Children's Hospital & Univ. of California - Irvine, Irvine, CA, United States; **Justin Wilford, PhD, Univ. of California - Irvine, Irvine, CA, United States**; Michelle Fortier, PhD; and Kathryn Osann, PhD, Univ. of California - Irvine, Irvine, CA, United States; Violet Shen, MD; and Lilibeth Torno, MD, CHOC Children's Hospital & Univ. of California - Irvine, Irvine, CA, United States; Leonard Sender, MD, Univ. of California - Irvine, Irvine, CA, United States; Susan K. Parsons, Tufts Medical Center, Boston, MA, United States; Lari Wenzel, PhD, Univ. of California-Irvine, Irvine, CA, United States



Top Outstanding Posters



Scientific Program — Friday, October 23

(2089) Factors determining the change of patient reported outcomes after 24 months follow-up in prostate cancer men, Victoria, Australia

Rasa Ruseckaite, Monash Univ., Melbourne, Australia; Sue M. Evans, Monash Univ., Melbourne, Australia

(2093) Examining the Associations between Cancer Survivorship Status and Health-Related Quality of Life among African-American Female Adults

Selina A. Smith, PhD, MDiv, Georgia Regents Univ., Augusta, GA, United States; Mechelle D. Claridy, MPH, Morehouse School of Medicine, Atlanta, GA, United States; Benjamin E. Ansa, MD, MSCR, Georgia Regents Univ., Augusta, GA, United States; Francesca Damus, MPH, Morehouse School of Medicine, Atlanta, GA, United States; Ernest Alema-Mensah, PhD, DMin, Morehouse School of Medicine, Atlanta, GA, United States; William W. Thompson, PhD, U.S. Centers for Disease Control and Prevention, Atlanta, GA, United States

(2095) Impact of age-related socio-economic and clinical determinants of quality of life among long-term breast cancer survivors

Pegwende Olivia Dialla; and Wai-on Chu, Centre Georges François Leclerc Comprehensive Cancer Centre, Dijon, France; Patrick Roignot, Pathology Centre, Dijon, France; Marie-Christine Bone-Lepinoy, Centre radiotherapie du Parc, Dijon, France; Marie-Laure Poillot; Charles Coutant; and Patrick Arveux, Centre Georges François Leclerc Comprehensive Cancer Centre, Dijon, France, **Tienhan Sandrine Dabakuyo, PhD, Centre Georges François Leclerc Comprehensive Cancer Centre, Dijon, France**

(2097) Value in breast and prostate cancers

Pedro L. Ferreira, Univ. of Coimbra, Coimbra, Portugal; Teresa Sequeira, CEISUC/UFP, Porto, Portugal; Augusta Silveira, CEISUC/UFP, Porto, Portugal; Lara Ferreira, CEISUC/UALG, Faro, Portugal; Carlota Quintal, CEISUC/FEUC, Coimbra, Portugal; Suzete Gonçalves, CEISUC, Coimbra, Portugal; Lurdes Carvalho; Joana Teixeira; and Ana Eberhardt, IPOP, Porto, Portugal

10:55 am – 11:10 am New Investigator Poster Award Finalist Presentations Session

British Columbia Ballroom

(2001) Does the EQ-5D capture the effect of physical and mental health on subjective well-being among older people?

Eithne Sexton, Trinity College Dublin, Dublin, Ireland; Caitriona Cahir, Economic and Social Research Institute, Dublin, Ireland; Tom Fahey, Royal College of Surgeons in Ireland, Dublin, Ireland; Kathleen Bennett, Trinity College Dublin, Dublin, Ireland

(2003) Second-order Confirmatory Factor Analysis of the Work Role Functioning (WRF-26) Questionnaire applied to Firefighters

Kenneth Tang, McMaster Univ., Hamilton, ON, Canada; Joy MacDermid, Professor, McMaster Univ., Hamilton, ON, Canada; Kathryn Sinden, McGill Univ., Montreal, QC, Canada; Rob D'Amico, Hamilton Professional Firefighters Association, Hamilton, ON, Canada; Karen Roche, Hamilton Fire Department, Hamilton, ON, Canada; Colin Grieve, Hamilton Professional Firefighters Association, Hamilton, ON, Canada

(2005) Using Mobile Communication Technology to Improve Social Participation in Frail Elderly Residing in Long-term Care: An Exploratory Group Concept Mapping Study

Rozanne Wilson, PhD, Univ. of Washington, Seattle, WA, United States; Dagmar Amtmann, PhD, Univ. of Washington, Seattle, WA, United States; Jeff Small, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Alex Mihailidis, PhD, P.Eng., Univ. of Toronto, Toronto, ON, Canada

11:20 am – 12:35 pm Concurrent Symposium Sessions

Symposium Session Sponsored by EORTC

Symposium #1: Training Clinicians in How to Use Patient Reported Outcome Measures In Routine Clinical Care

Saturna

Chair: **David Feeny, PhD, Professor, McMaster Univ., Hamilton, Ontario, Canada**

Panelists:

Martha A Grootenhuys, PhD, Professor, Psychosocial Department of the Emma Children's Hospital, Amsterdam, Netherlands
Kate Absolom, PhD, Institute of Oncology, Leeds, United Kingdom

Using patient-reported outcome measures (PROMs) in routine clinical care identifies problems, enhances patient-clinician communication as well communication with and among family members, improves clinical management, and promotes shared decision making. A key issue limiting successful implementation is clinicians' lack of knowledge on how to effectively utilize PROs data in their clinical encounters. Therefore, clinicians need to be trained to interpret PRO data and make it actionable.

The symposium describes three programs training clinicians to use PROMs in routine clinical practice of chronically ill patients, illustrating both successes and obstacles within the implementation process.



Top Outstanding Posters

Scientific Program — Friday, October 23

The symposium includes presentations on: 1) Development and evaluation of an oncologist training program; 2) Training lung transplant specialists to use patient-reported outcome measures in routine clinical practice; 3) Using PRO measures in routine chronic care in paediatrics.

Individual Presentations

Development and Evaluation an Oncologist Training Programme in the Use of Patient- Reported Outcome Data

Galina Velikova, PhD, MD, Professor of Psychosocial and Medical Oncology/Consultant Medical Oncology, Univ. of Leeds, Leeds, United Kingdom

Training Lung Transplant Specialists to Use Patient-Reported Outcome Measures in Routine Clinical Practice

Maria Jose Santana, PhD, Assistant professor, O'Brien Institute for Public Health, Cummings School of Medicine, Univ. of Calgary, Calgary, Canada

The Effectiveness of an Innovative Web-Based Application to Monitor Health-Related Quality of Life in Pediatric Clinical Practice

Lotte Haverman, PhD, Psychosocial Department of the Emma Children's Hospital, Amsterdam, Netherlands

Symposium #2: PRO Assessment in Clinical Practice: PCORI's Perspectives and Case Examples to Advance Research and Clinical Care Pacific Ballroom

Moderators:

Steven Clauser, PhD, PCORI, Washington, DC, United States

Ethan Basch, MD MSc, Cancer Outcomes Research Program, Univ. of North Carolina - Chapel Hill, Chapel Hill, NC, United States

Research studies that involve use of PRO assessment in clinical settings have expanded over the last 5 years and several sustainable and scalable models exist. Despite this, several common challenges to PRO uptake and use remain. Research sponsored by the Patient Centered Outcomes Research Institute (PCORI) and others suggests bridging from research use to clinical use requires awareness of factors that impinge on feasibility of PRO administration, data management, analysis, and interpretation. Methodologic challenges of research use of PRO data, aggregated across samples, differ from the challenges of clinical use which requires both aggregate-level benchmark and/or interpretation guidelines and individual-level reports useful for patients, clinicians, and other end users of the information.

Through case examples and a review of recent PCORI funded research awards, presenters will provide background on the research and real-world clinical challenges PROs are intended to address.

This symposium presents opportunities and challenges common to diverse clinical settings for both research and clinical PRO use, and lessons learned in overcoming those challenges. Through specific examples from different therapeutic areas and patient populations, an action agenda for improving accessibility of PRO data for both research and clinical purposes is forming. This agenda points toward establishing best practices in measure selection, usability testing particularly for administration across different platforms, data management principles useful across settings, and ensuring data interpretation guidelines differentiate between research needs and clinical use.

The examples presented here provide a range of possibilities for increasing the potential for and relevance of PRO assessment for clinical care and research.

Individual Presentations

Integrating PROs into Routine Clinical Care: Perceived Value and Impact

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

Issues in Using Patient-Reported Outcomes for Performance Measurement

Sarah Hudson Scholle, MPH DrPH, National Committee for Quality Assurance, Washington, DC, United States

Integrating PROs into Routine Arthritis Clinical Care: Process and Feasibility

Susan Bartlett, PhD, McGill Univ., Montreal, Quebec, Canada

PCORI's Improving PCOR Methods Program: Building a Patient-Centered Measurement Portfolio

Jason Gerson, PhD, Associate Director, CER Methods, PCORI, Washington, DC, United States



Top Outstanding Posters



Scientific Program — Friday, October 23

Symposium #3: Health Preference Research: Enhancing the Relevance of QOL Evidence

Vancouver Island

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

Panelists:

Scott M. Gilbert, MD, Moffitt Cancer Center, Tampa, FL, United States

Axel Mühlbacher, PhD, Hochschule Neubrandenburg, Neubrandenburg, Germany

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

The relevance of QOL evidence can be enhanced through the systematic assessment of health preferences on measured outcomes using choice experiments. The results of these choice experiments can aid in the dissemination and implementation of comparative QOL evidence by better informing policy makers, providers and patients faced with difficult decisions, such as market access, pricing, guidelines, and treatment choice, respectively. This symposium covers 3 exemplary applications demonstrating how patient preference research enhances QOL evidence: (1) Patient preferences included in decision aids can help navigate their care (BEACON Project; Jeff Sloan); (2) Patient preferences within a cancer center can enhance the summary of clinical QOL evidence (Bladder Cancer Index; Scott Gilbert); and (3) Patient preferences on diagnostic test outcomes (e.g., false positives) can inform health policy (Hepatitis C; Axel Mühlbacher). This patient-centered symposium is most beneficial for researchers interested in understanding and demonstrating the relevance of QOL evidence, particularly in decision making and physician/patient/policymaker communication.

Individual Presentations

Incorporating Patient Preferences on QOL into Routine Clinical Practice: the BEACON Project

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

Clinical Relevance of PROs and Patient Preferences in a Surgical Oncology Clinic

Scott M Gilbert, MD, Moffitt Cancer Center, Tampa, FL, United States

Treatment Preferences of Patients with Metastatic Non-Small Cell Lung Cancer: A Discrete Choice Experiment

Axel C. Mühlbacher, PhD, Hochschule Neubrandenburg, Neubrandenburg, Germany

12:35 pm – 1:45 pm Lunch on your own

12:35 pm – 1:45 pm QLR Editorial Board Meeting (Closed Event)

Garibaldi

1:45 pm – 3:15 pm Concurrent Oral Sessions

Oral Session 201: Multiple Sclerosis

Vancouver Island

Session Chair: Rasa Ruseckaite, Australia

1:50 pm – 2:03 pm (201.1) Development of a multidimensional computerized adaptive test for measuring quality of life for patients with multiple sclerosis: the MuSiQoL-MCAT

Pierre Michel, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; **Karine Baumstarck**, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; and **Pascal Auquier**; **Jean Pelletier**, Departments of Neurology and CRMBM CNRS6612, Timone Univ. Hospital, APHM, Marseille, France; **Anderson Loundou**, Aix-Marseille Univ., EA 3279 – Public Health, Chronic Diseases and Quality of Life - Research Unit, Marseille, France; **Mohamed Boucekine**; **Badih Ghattas**; and **Laurent Boyer**, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France

2:04 pm – 2:17 pm (201.2) Distilling the essence of appraisal: A mixed methods study of people with multiple sclerosis

Bruce D. Rapkin, PhD, Albert Einstein College of Medicine, Bronx, NY, United States; **Carolyn Schwartz, ScD**, Tufts Univ. Medical School; **DeltaQuest Foundation, Inc.**, Oslo and **Akershus Univ. College**, Concord, MA, United States

2:18 pm – 2:31 pm (201.3) A Bayesian methodology to assess psychometric properties of quality of life measures in small sample sizes

Mohamed Boucekine, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; **Pierre Michel**, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France; **Samy Clinchard**, Santé Public, Marseille, France; **Karine Baumstarck**; **Laurent Boyer**; **Anderson Loundou**; **Badih Ghattas**; and **Pascal Auquier**, EA 3279 Self-Perceived Health Assessment Research Unit, School of Medicine, Aix Marseille Université, Marseille, France



Top Outstanding Posters

Scientific Program — Friday, October 23

2:32 pm – 2:45 pm (201.4) Association between Bookmarking-Derived Cut Scores and Self-Classified Cut Scores for Neuro-QOL Measures of Sleep Disturbance, Lower & Upper Extremity Function, and Fatigue in a Sample of Persons with Multiple Sclerosis: Validating Both Approaches

David Victorson, Northwestern Univ., Evanston, IL, United States; Karon F. Cook, PhD, Department of Medical Social Sciences, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Deborah Miller, PhD, Cleveland Clinic, Cleveland, OH, United States; David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

2:46 pm – 2:59 pm (201.5) Interdigitating performance-based tasks and patient reported outcomes to produce a linear hierarchical unidimensional measure of global physical disability in MS

Stanley Hum, PhD (candidate), McGill Univ., Montreal, QC, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada

3:00 pm – 3:13 pm (201.6) Developing the Guy's Neurological Scale (GNDS) in 28 Languages

Catherine Acquadro, Mapi Research Trust, Lyon, France; Bing Zhu, Biogen, Cambridge, MA, United States; Alain Nguyen, Mapi, Lyon, France; Basil Sharrack, Professor, Sheffield Teaching Hospitals NHS Foundation Trust & Univ. of Sheffield, Sheffield, United Kingdom; Nazilabee Torabully, Mapi, Lyon, France

Oral Session 202: Measure Development

Pacific Ballroom

Session Chair: *Wen-Hung Chen, PhD, United States*

1:50 pm – 2:03 pm (202.1) Development of the Preschool Cystic Fibrosis Questionnaire-Revised (CFQ-R)

Alexandra L. Quittner, PhD, Univ. of Miami, Miami, FL, United States; Anjana M. Morris, PhD, MPH, Univ. of Miami, Miami, FL, United States; Claire Wainwright, MD, Lady Cilento Children's Hospital, Brisbane, Australia; Joyce Cheney, Lady Cilento Children's Hospital, Brisbane, Australia

2:04 pm – 2:17 pm (202.2) Determining the Psychometric Properties of the CLEFT-Q Using Two Different Sets of Response Options

Elena Tsangaris, MSc, McMaster Univ., Hamilton, ON, Canada; Karen Wong, MD MSc FRCSC; and Christopher Forrest, MD MSc FRCSC, Hospital for Sick Children, Univ. of Toronto, Toronto, ON, Canada; Karen Harman, MD, McMaster Univ., Hamilton, ON, Canada; Andrea Pusic, MD MPH FACS, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Stefan Cano, PhD, Modus Outcomes, Stotfold, United Kingdom; Timothy Goodacre, MBBS BSc FRCS, Univ. of Oxford, Oxford, United Kingdom; Anne Klassen, DPhil, McMaster Univ., Hamilton, ON, Canada

STUDENT PRESENTATION AWARD FINALIST

2:18 pm – 2:31 pm (202.3) Psychometric development of three new condition-specific questionnaires to measure quality of life (Aneurysm-DQoL), symptoms (Aneurysm-SRQ) and treatment satisfaction (Aneurysm-TSQ) of individuals with abdominal aortic aneurysms.

Jacquelyn Romaine, Health Psychology Research Unit, Royal Holloway, Univ. of London, Egham, Surrey, United Kingdom; George Peach; Matt Thompson; and Robert Hinchliffe, St George's Vascular Institute, London, United Kingdom; Clare Bradley, Health Psychology Research Unit, Royal Holloway, Univ. of London; Health Psychology Research Ltd, Royal Holloway, Univ. of London, Egham, Surrey, United Kingdom

2:32 pm – 2:45 pm (202.4) Development and Psychometric Validation of a PRO Instrument for Obese, Bariatric and Cosmetic Body Contouring Patients: The BODY-Q

Anne Klassen, DPhil, McMaster Univ., Hamilton, ON, Canada; Amy Alderman, MD, Swan Center for Plastic Surgery, Alpharetta, GA, United States; Mark Soldin, MD, St Georges Healthcare NHS Trust, London, United Kingdom; Sam Robson, MD, Temple Medical, Aberdeen, United Kingdom; Manraj Kaur, MSc, McMaster Univ., Hamilton, ON, Canada; Stefan Cano, PhD, Modus Outcomes, Stotfold, United Kingdom; Achilles Thoma, MD, McMaster Univ., Hamilton, ON, Canada; Andrea Pusic, MD MPH FACS, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States

2:46 pm – 2:59 pm (202.5) Validation of a crosswalk between measures of work role limitations

Milena D. Anatchkova, PhD, Univ. of Massachusetts Medical School, Evidera, Lexington, MA, United States; Nisha Kini; and John Ware, PhD, Univ. of Massachusetts Medical School, Worcester, MA, United States; Jakob B. Bjorner, MD, PhD, QualityMetric; Univ. of Copenhagen, Copenhagen, Denmark



Scientific Program — Friday, October 23

3:00 pm – 3:13 pm (202.6) The computer adaptive test (CAT) version of the EORTC QLQ-C30

Morten A. Petersen, *The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Univ. of Copenhagen, Copenhagen, Denmark*; **Neil K. Aaronson**, *The Netherlands Cancer Institute, Amsterdam, Netherlands*; **Juan I. Arraras**, *Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain*; **Wei-Chu Chie**, *Institute of Epidemiology and Preventive Medicine and Department of Public Health, College of Public Health, National Taiwan Univ., Taipei, Republic of Taiwan*; **Thierry Conroy**, *Medical Oncology Department, Institut de cancérologie de Lorraine, Vandoeuvre-lès-Nancy, France*; **Anna Costantini**, *Psychoncology Unit, Department of Oncological Sciences, Rome, Italy*; **Eva-Maria Gampfer**; and **Johannes M. Giesinger**, *Medical Univ. of Innsbruck, Innsbruck, Austria*; **Esther Habets**, *Medical Center Haaglanden, Department of Neurology, The Hague, Netherlands*; **Eva Hammerlid**, *Dept of Otolaryngology Head and Neck Surgery, Sahlgrenska Univ. Hospital, Göteborg Univ., Gothenburg, Sweden*; **Marianne J. Hjermstad**, *Regional Centre for Excellence in Palliative Care, Department of Oncology, Oslo Univ. Hospital, Oslo, Norway*; **Bernhard Holzner**, *Medical Univ. of Innsbruck, Innsbruck, Austria*; **Colin Johnson**, *Surgical Unit, Univ. of Southampton, Southampton, United Kingdom*; **Stein Kaasa**, *Palliative Medicine Unit, Univ. Hospital of Trondheim, Trondheim, Norway*; **Jon H. Loge**, *European Palliative Care Research Centre, Faculty of Medicine, Norwegian Univ. of Science and Technology (NTNU), Trondheim, Norway*; **Susanne Singer**, *Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI), Univ. Medical Centre Johannes Gutenberg Univ., Mainz, Germany*; **Martin Taphorn**, *VU Univ. Medical Center, Department of Neurology, Amsterdam, Netherlands*; **Krzysztof Tomaszewski**, *Department of Anatomy, Jagiellonian Univ. Medical College, Krakow, Poland*; **Galina Velikova**, *MD PhD, Leeds Institute of Cancer Studies and Pathology Univ. of Leeds, Leeds, United Kingdom*; **Irma Verdonck-de Leeuw**, *Clinical Psychology, VU Univ., Amsterdam, Netherlands*; **Teresa Young**, *Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom*; **Mogens Groenvold**, *The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Univ. of Copenhagen, Copenhagen, Denmark*

Oral Session 203: Social Support, Coping and Resilience

Waddington

Session Chair: **Sandra Beurskens**, PhD, Netherlands

1:50 pm – 2:03 pm (203.1) What keeps us healthy in the face of adversity? - Development of a new Stress Resilience Questionnaire (StResQ)

Nina Tamm, *Charité - Universitätsmedizin Berlin, Berlin, Germany*; **Alexander Obbarius**, MD; **Sandra Nolte**, PhD; **Felix Fischer**, ScD; **Kim-Marie**; and **Matthias Rose**, MD PhD, *Charité - Universitätsmedizin Berlin, Berlin, Germany*

2:04 pm – 2:17 pm (203.2) Age and General Self-efficacy Are Directly Associated with Physical Health Related Quality of Life in Norwegian Patients with Neuroendocrine Tumors

Trude Haugland, PhD, *Diakonova Univ. College, Oslo, Norway*; **Astrid K. Wahl**, PhD; and **Dag Hofoss**, PhD, *Univ. of Oslo, Norway, Oslo, Norway*; **Holli DeVon**, PhD, *Univ. of Illinois Chicago, College of Nursing, Chicago, IL, United States*

2:18 pm – 2:31 pm (203.3) Resilience in the Context of Chronic Disease and Disability

Dagmar Amtmann, PhD, *Univ. of Washington, Seattle, WA, United States*; **Aimee M. Verrall**, *Univ. of Washington, Seattle, WA, United States*; **Alexandra L. Terrill**, *Univ. of Utah, Salt Lake City, UT, United States*; **Amanda Smith**; **Arielle Silverman**; **Dawn M. Ehde**; **Kevin Alschuler**; **Mark Jensen**, PhD; **Rozanne Wilson**, PhD; **Kurt Johnson**; and **Ivan Molton**, *Univ. of Washington, Seattle, WA, United States*

2:32 pm – 2:45 pm (203.4) Identifying the Relationship Between Social Support and Quality of Life in a Biobehavioral Cancer Survivorship Trial

Kathryn Osann, PhD, *Univ. of California - Irvine, Irvine, CA, United States*; **Justin Wilford**, PhD, *Univ. of California - Irvine, Irvine, CA, United States*; **Edward Nelson**, MD; **Susie Hsieh**, PhD; and **Jo Tucker**, PhD, *Univ. of California, Irvine, Irvine, CA, United States*; **Bradley J. Monk**, MD, *Univ. of Arizona Cancer Center-Phoenix, Phoenix, AZ, United States*; **Lari Wenzel**, PhD, *Univ. of California-Irvine, Irvine, CA, United States*

2:46 pm – 2:59 pm (203.5) Determinants of health utility among caregivers of individuals with multiple sclerosis (MS)

Namita Joshi, MS, PhD Candidate, *Univ. of Mississippi, San Mateo, CA, United States*; **Rahul Khanna**, PhD; **John P. Bentley**, PhD; and **Donna West-Strum**, PhD, *Univ. of Mississippi, Oxford, MS, United States*; **Glenn A. Phillips**, PhD, *Biogen, Cambridge, MA, United States*; **Matthew Strum**, Pharm D; and **Marie Barnard**, *Univ. of Mississippi, Oxford, MS, United States*

3:00 pm – 3:13 pm (203.6) Does Resilience rest on Relationships? Exploring Social Context and Personal Resources as Moderators of the Effect of Disability on Quality of Life in Older Adults

Eithne Sexton, *Trinity College Dublin, Dublin, Ireland*; **Bellinda King-Kallimanis**, PhD, *Pharmerit, Boston, United States*; **Richard Layte**, *Trinity College Dublin, Dublin, Ireland*; **Anne Hickey**, *Royal College of Surgeons in Ireland, Dublin, Ireland*



Top Outstanding Posters

Scientific Program — Friday, October 23

Oral Session 204: Cardiac Conditions

Saturna

Session Chair: Zoe Winters, United Kingdom

1:50 pm – 2:03 pm (204.1) Change in Individual Trajectories of Change in Patient-Reported Outcomes after Implantable Cardioverter-Defibrillator

Sandra B. Lauck, PhD, St. Paul's Hospital, Vancouver, BC, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada; Joy L. Johnson, PhD; Karin Humphries, DSc; and Pamela A. Ratner, PhD, University of British Columbia, Vancouver, Canada

2:04 pm – 2:17 pm (204.2) Trajectories of Health-Related Quality of Life Following Acute Coronary Syndrome in TRACE-CORE

Lisa Nobel, Univ. of Massachusetts Worcester, Worcester, MA, United States; Jennifer Tjia; Jane Saczynski,; and Molly Waring, Univ. of Massachusetts Worcester, Worcester, MA, United States; Milena D. Anatchkova, PhD, Univ. of Massachusetts Medical School, Evidera, Lexington, MA, United States; Arlene Ash; Catarina Kiefe; and Jeroan Allison, Univ. of Massachusetts Worcester, Worcester, MA, United States

2:18 pm – 2:31 pm (204.3) Patient-centered Outcomes in Treatment of Small Abdominal Aortic Aneurysms - a Qualitative Interview Study

Stephanie M. Tomee, PhD candidate, Leiden Univ. Medical Centre, Leiden, Netherlands; Winifred A. Gebhardt, Associate Professor of Health Psychology; Jan H. Lindeman, Associate professor of Surgery; and Jaap F. Hamming, Professor of Surgery, Leiden Univ. Medical Centre, Leiden, Netherlands

2:32 pm – 2:45 pm (204.4) What Impacts Recovery After Cardiac Surgery? A Mixed Method Approach

Lisa M. Fornaresio, PhD, Inova Heart and Vascular Institute, Falls Church, VA, United States; Sari D. Holmes, PhD; and Niv Ad, MD, Inova Heart and Vascular Institute, Falls Church, VA, United States

2:46 pm – 2:59 pm (204.5) Not so transient: fatigue, psychological and cognitive impairment following transient ischaemic attack (TIA)

Grace M. Moran, Univ. of Birmingham, Birmingham, United Kingdom; Tom Marshall; Melanie J. Calvert, PhD; Max Feltham; and Ronan Ryan, Univ. of Birmingham, Birmingham, United Kingdom

Oral Session 205: Meaningful Change

Boardroom

Session Chair: Madeleine King, PhD, Australia

1:50 pm – 2:03 pm (205.1) Determining meaningful cutpoints for the interference items of the MD Anderson Symptom Inventory

Qiuling Shi, MD, PhD, MD Anderson Cancer center, Houston, TX, United States; Tito Mendoza, PhD, UT MD; Xin Shelley Wang, MD, MPH, MD; and Charles S. Cleeland, PhD, UT MD Anderson Cancer Center, Houston, TX, United States

2:04 pm – 2:17 pm (205.2) A Comparison of Effect Size Measures for Differential Item Functioning Analysis with Ordinal Logistic Regression Techniques in a PROMIS Anxiety Measure

Michelle M. Langer, PhD, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Bryce B. Reeve, PhD; Caroleen W. Quach, MSPH; Deborah S. Usinger; and Ronald C. Chen, MD, MPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States

2:18 pm – 2:31 pm (205.3) Minimal Important Difference (MID) Thresholds for the QOLIE-31-P in Epilepsy Patients with Primary Generalized Tonic-Clonic Seizures (PGTCS)

Stacie Hudgens, MA (ABD), Clinical Outcomes Solutions, Tucson, AZ, United States; Wan Tsong, MS; Anna Forsythe, PharmD, MSc, MBA; Francesco Bibbiani, MD; and Antonio Laurenza, MD, Eisai, Inc., Woodcliff Lake, NJ, United States

2:32 pm – 2:45 pm (205.4) Interpretation of Verbal Descriptors for Response Options Commonly Used in Verbal Rating Scales in Patient-Reported Outcome Instruments

Alex Mutebi, PhD, Amgen, Thousand Oaks, CA, United States; Marion Slack, PhD; and Terri L. Warholak, PhD, Univ. of Arizona, Tucson, AZ, United States; Stacie Hudgens, MA (ABD), Clinical Outcomes Solutions, Tucson, AZ, United States; Stephen J. Coons, PhD, Critical Path Institute, Tucson, AZ, United States

NEW INVESTIGATOR PRESENTATION AWARD FINALIST

2:46 pm – 2:59 pm (205.5) What is a meaningful change? Ask the patient!

Josephine M. Norquist, Merck Sharp & Dohme Corp., North Wales, PA, United States; Tjeerd Korver; and Fang Chen, Merck Sharp & Dohme Corp., North Wales, PA, United States; Rob Arbuckle, Adelphi Values, Cheshire, United Kingdom; Alice Turbull, Adelphi Values, Cheshire, United Kingdom; Allison M. Nguyen, Merck Sharp & Dohme Corp., North Wales, PA, United States



Scientific Program — Friday, October 23

3:15 pm – 4:50 pm Exhibits Open and Refreshment Break

3:20 pm – 3:40 pm Friday Poster Session 2 British Columbia Ballroom

Measure Development

(2008) Comparing patient and proxy agreement concerning impact of dysphagia on patients' quality of life (QoL) as measured by the Dutch version of the Swallowing Quality-of-Life (DSWAL-QoL) questionnaire

Ingeborg Simpelaere, MSc, Univ. College Bruges, AZ Delta Roeselare-Menen, Univ. of Antwerp, Zedelgem, West Flanders, Belgium; Jan Vanderwegen, ENT MD, Saint-Pierre Univ. Hospital, Brussels, Belgium; Gwen Van Nuffelen, Univ. Hospital Antwerp, Antwerp, Belgium; Marc De Bodt, Univ. Hospital Antwerp, Antwerp, Belgium

(2010) A Patient Centred Approach to the development of a Patient Reported Outcome Measure (PROm) in Idiopathic Pulmonary Fibrosis (IPF)

Anne-Marie Russell, MSc RN RHV LPE PGCE, Imperial College London & Royal Brompton Hospital, London, United Kingdom; Anne-Marie Doyle, D.Clin.Psy BSc MA, Royal Brompton Hospital London, London, United Kingdom; Caroline Burdett, BA, ISOQOL & Royal Brompton Hospital London, London, United Kingdom; Jennifer Gane, Patient Partner RN RHV, Royal Brompton Hospital London, London, United Kingdom; Zahra Aden, MSc BSc, NHLI Royal Brompton and Imperial College London, London, United Kingdom; Sharon Fleming, PhD RN, Royal Brompton & Harefield NHS foundation Trust London, London, United Kingdom; Paul Cullinan, MFPHM MD FRCP MRCP MB MSc, Imperial College London and Royal Brompton Hospital London, London, United Kingdom

(2012) A community sample's perception of cause-and-effect directionality among health domains.

Janel Hanmer, MD, PhD, Univ. of Pittsburgh, Pittsburgh, PA, United States; David Feeny, PhD, McMaster Univ., Hamilton, ON, Canada, Hamilton, ON, Canada; Baruch Fischhoff, PhD, Carnegie Mellon Univ., Pittsburgh, PA, United States; Ron D. Hays, PhD, UCLA, Los Angeles, CA, United States; Rachel Hess, MD, MS, Univ. of Utah, Salt Lake City, UT, United States; Paul Pilkonis, PhD, Univ. of Pittsburgh, Pittsburgh, PA, United States; Dennis Revicki, PhD, Evidera, Bethesda, MD, United States; Mark Roberts, MD, MPP, Univ. of Pittsburgh, Pittsburgh, PA, United States; Joel Tsevat, MD, MPH, Univ. of Cincinnati, Cincinnati, OH, United States; Lan Yu, PhD, Univ. of Pittsburgh, Pittsburgh, PA, United States

(2014) Evaluating treatment effect based on Personal Outcomes of Specific Interest (POSI) - A personalized patient-reported outcome strategy

Sravan Jaggamantri, Univ. of British Columbia, Vancouver, BC, Canada; Jean Paul Collet, MD, PhD; and William McKellin, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada; Sylvia Stockler, MD, PhD; and Clara van Karnebeek, MD, PhD, BC Children's Hospital, Vancouver, BC, Canada

(2016) A Framework for Classifying Root Causes of Missing Data for Patient Reported Outcomes in Prospective Studies.

Michael J. Palmer, PhD Candidate, Queen's Univ., Kingston, ON, Canada; Rebecca Mercieca-Bebber; and Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia; Melanie J. Calvert, PhD, Univ. of Birmingham, Birmingham, United Kingdom; Harriet Richardson, PhD, Queen's Univ., Kingston, ON, Canada; Michael Brundage, MD, MSc, Kingston General Hospital, Queen's Univ., Kingston, ON, Canada

(2018) Applying Eran Tal's Model-Based Account of the Epistemology of Measurement to the Short Form-36

Laura Cupples, Univ. of South Carolina, Columbia, SC, United States

(2022) Item banking in Sweden

Bo Palaszewski, Centre of Registers Västra Götaland, Gothenburg, Sweden; Evalill Nilsson, The Research & Development Department of Local Health Care, Region Östergötland, Sweden, Quality Register Center QRC Stockholm, Stockholm, Sweden, Linköping, Sweden; John Chaplin, PhD, AFBPsS, CPsychol., Inst. Clinical Sciences, Sahlgrenska Academy at the Univ. Gothenburg, Gothenburg, Sweden

(2024) Reuniting functioning and wellbeing: The role of the ICF in the development of PROMs

Michaela Dabs; Janika Blömeke; and Rachel Sommer, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Julia Quitmann, researcher, Univ. of Hamburg, Hamburg, Germany; Holger Muehlan, PhD, Ernst-Moritz-Arndt Univ., Greifswald, Germany; Monika Bullinger, Vice Chief of Department, Univ. of Hamburg, Hamburg, Germany

(2026) Qualitative Development of a New Clinician Reported Measure of Multiple Sclerosis Status

Glenn A. Phillips, PhD, Biogen, Cambridge, MA, United States; Louis S. Matza, PhD; Katie D. Stewart, MA; and Jessica B. Jordan, PhD, Evidera, Bethesda, MD, United States

(2028) A PRO surveillance feasibility pilot, the prevalence and correlates of symptoms-related PROs it collected and the quality improvement reports it produced

Tenbroeck Smith, MA, American Cancer Society, Atlanta, GA, United States; Alyssa Troeschel, MPH, American Cancer Society, Atlanta, GA, United States; Kate Castro, RN, MS, AOCN, National Cancer Institute, Rockville, MD, United States; Neeraj Arora, Patient-Centered Outcomes Research Institute, Washington, DC, United States; Kevin Stein, PhD, American Cancer Society, Atlanta, GA, United States; Ryan M. McCabe, PhD, American College of Surgeons, Chicago, IL, United States; Steven Clauser, PhD, MPA, Patient-Centered Outcomes Research Institute, Washington, DC, United States; Elizabeth Ward, PhD, American Cancer Society, Atlanta, GA, United States



Top Outstanding Posters

Scientific Program — Friday, October 23

(2030) Measurement Validation in Patient-Reported Outcomes: Challenges and Opportunities

Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada; Eric K. H. Chan, PhD, Trinity Western Univ., Langley, BC, Canada; Bruno D. Zumbo, PhD, Univ. of British Columbia, Vancouver, Canada; Clifton O. Bingham, MD, Johns Hopkins Univ., Baltimore, MD, United States; William Gardner, Children's Hospital of Eastern ON, Ottawa, Canada; Jeffrey Jutai, Univ. of Ottawa, Ottawa, Canada; Ayse Kuspinar, McGill Univ. Health Centre - RI, Montreal, QC, Canada; Tolulope T. Sajobi, PhD, Departments of Community Health Sciences & Clinical Neurosciences, Univ. of Calgary, Calgary, AB, Canada; Lisa M. Lix, PhD, Univ. of Manitoba, Winnipeg, MB, Canada

(2032) Rasch analysis of Patient-reported Outcomes Measure of Pharmaceutical Therapy for Quality of Life (PROMPT-QoL)

Phantipa Sakthong, Associate Professor, Faculty of Pharmaceutical Sciences, Chulalongkorn Univ., Bangkok, Thailand; Chanadda Chinthammit, Univ. of Arizona, College of Pharmacy, Tucson, AZ, United States

(2034) The McGill Quality of Life Questionnaire-Expanded (MQOL-E) and the Concept of Overall Quality of Life

Lara B. Russell, PhD, Univ. of Victoria & Centre for Health Evaluation and Outcome Sciences, Vancouver, BC, Canada; Anne M. Gadermann, PhD, Univ. of British Columbia, Vancouver, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada; S. Robin Cohen, PhD, McGill Univ. and Lady Davis Institute, Montreal, QC, Canada

(2036) Comparison of Computerized Adaptive Testing and Fixed-Length Short Forms of the Prosthetic Limb Users Survey of Mobility (PLUS-M™)

Dagmar Amtmann, PhD, Univ. of Washington, Seattle, WA, United States; Jiseon Kim, Univ. of Washington, Seattle, WA, United States; Hyewon Chung, Chungnam National Univ., Daejeon, Korea, South; Ryoungsun Park, Univ. of Texas, Austin, TX, United States; Rana Salem; and Brian J. Hafner, Univ. of Washington, Seattle, WA, United States

(2038) Refining Items in the Long-Term Conditions Questionnaire (LTCQ): Cognitive Interviews, Stakeholder Feedback and Translatability Assessment

Caroline Potter, Univ. of Oxford, Oxford, United Kingdom; Cheryl Hunter, Univ. of Leeds, Leeds, United Kingdom; Laura Kelly; Elizabeth Gibbons; Crispin Jenkinson; Ray Fitzpatrick; and Michele Peters, PhD, Univ. of Oxford, Oxford, United Kingdom

(2040) Age-specific factor structures can improve the sensitivity of patient reported outcome measures: evidence from the Grow up Gothenburg study.

Sarah Hitz, MSc, Hamburg Univ. of Applied Sciences, Hamburg, Germany; Ebba Brann, PhD student, Inst. of Medicine, Sahlgrenska Academy, Univ. of Gothenburg, Gothenburg, Sweden; Kerstin Albertsson-Wikland, MD, PhD, Professor, Inst. of Medicine, Sahlgrenska Academy, Univ. of Gothenburg, Gothenburg, Sweden; Zita Schillmöller, PhD, Hamburg Univ. of Applied Sciences, Hamburg, Germany, John Chaplin, PhD, AFBPsS, CPsychol., Inst. Clinical Sciences, Sahlgrenska Academy at the Univ. Gothenburg, Sweden, Gothenburg, Sweden

(2042) Development of thresholds for clinical importance for four key domains of the EORTC QLQ-C30

Johannes M. Giesinger, Department of Psychiatry and Psychotherapy, Medical Univ. of Innsbruck, Innsbruck, Austria; Wilma Kuijpers, The Netherlands Cancer Institute, Amsterdam, Netherlands; Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Krzysztof Tomaszewski, Department of Anatomy, Jagiellonian Univ. Medical College, Krakow, Poland; Elizabeth Friend, Basingstoke & North Hampshire Hospital, Basingstoke, United Kingdom; August Zabernigg, Kufstein County Hospital, Kufstein, Austria; Bernhard Holzner, Medical Univ. of Innsbruck, Innsbruck, Austria; Neil K. Aaronson, The Netherlands Cancer Institute, Amsterdam, Netherlands

(2044) Improving Patient Centered Care: Implementation of PROMIS in a surgical spine practice

Richard L. Skolasky, ScD, Johns Hopkins Univ., Baltimore, MD, United States; David Li; and Brian J. Neuman, MD, Johns Hopkins Univ., Baltimore, MD, United States

(2046) Assessing Meaning & Purpose in Life: Development and Validation of an Item Bank and Short Forms for the NIH PROMIS

John M. Salsman, Wake Forest School of Medicine, Winston-Salem, NC, United States; Crystal L. Park, Univ. of Connecticut, Storrs, CT, United States; Benjamin D. Schalet; and Elizabeth A. Hahn, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Michael F. Steger, Colorado State Univ., Fort Collins, CO, United States; Login George, Univ. of Connecticut, Storrs, CT, United States; Mallory A. Snyder; and David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

(2048) The impact of item format on item information and resulting person parameters in patient-reported outcomes measuring physical function

Gregor Liegl, Mag., Charite - Universitaetsmedizin Berlin, Berlin, Germany; Felix Fischer, ScD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Jakob B. Bjorner, MD, PhD, QualityMetric; Univ. of Copenhagen, Copenhagen, Denmark; James F. Fries, MD, Stanford Univ. School of Medicine, Stanford, CA, United States; Barbara Gandek, PhD, Univ. of Massachusetts Medical School, Worcester, MA, United States; John Ware, PhD, Univ. of Massachusetts Medical School, Worcester, MA, United States; Sandra Nolte, PhD; and Matthias Rose, MD PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany



Scientific Program — Friday, October 23

(2050) Leveraging PROMIS Measures to Build and Pilot the DoD's Pain Assessment Screening Tool and Registry (PASTOR)

Karon F. Cook, PhD, Department of Medical Social Sciences, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Michael A. Kallen, PhD, MPH, Northwestern Univ., Feinberg School of Medicine, Missouri City, TX, United States; Chester (Trip) Buckenmaier, III, Uniformed Services Univ. of the Health Sciences, Rockville, MD, United States; Richard C. Gershon, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

(2052) Psychometric Validation of the Questionnaire on Pain Caused by Spasticity (QPS)

Donald M. Bushnell, MA, Health Research Associates, Inc., Seattle, WA, United States; Thorin L. Geister, PhD, Merz Pharmaceuticals, Frankfurt am Main, Germany; Mona L. Martin, RN, MPA, Health Research Associates, Inc., Seattle, WA, United States; Zhenhuan Liu, MD, Guangzhou Univ. of Traditional Chinese Medicine, Guangdong, Foshan, China; Yang Jie, MD, XiangYaBoAi Rehabilitation Hospital, Changsha City, Hunan, China; Yu-qiong Zhang, MD, MCH Hospital of Dongguan, DongGuan City, GuangDong, China

(2054) Continuity and Change on the AQOL-MHS Over 8 Months

Ligia Chavez, PhD, Univ. of Puerto Rico – Medical Sciences Campus, San Juan, PR, United States; Pedro Garcia; and Nyrma Ortiz, Medical Sciences Campus Univ. of Puerto Rico, San Juan, PR, United States; Patrick Shrout, New York Univ., New York, NY, United States

(2060) Simple web-based IRT score estimation for common metrics: <http://www.common-metrics.org>

Felix Fischer, ScD; and Matthias Rose, MD PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany, Sandra Nolte, PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany

(2062) The Influence of Chronic Illness Treatment and Self-care on Patient Functioning and Well-being: Validating the Impact Scales of a New Measure of Treatment Burden

David T. Eton, Mayo Clinic, Rochester, MN, United States; Kathleen J. Yost; and Jordan K. Rosedahl, Mayo Clinic, Rochester, MN, United States; Mark Linzer; Deborah H. Boehm; and Azra Thakur, Hennepin County Medical Center, Minneapolis, MN, United States; Sara Poplau, Minneapolis Medical Research Foundation, Minneapolis, MN, United States; Roger T. Anderson, Univ. of Virginia School of Medicine, Charlottesville, VA, United States

Response Shift

(2064) Testing Response Shift in the SF-36 Physical Functioning Subscale using Item Response Theory (IRT) Models: Results from the Canadian Multicentre Osteoporosis Study

Lisa M. Lix, PhD, Univ. of Manitoba, Winnipeg, MB, Canada; Xiuyun Wu, Dalhousie Univ., Halifax, NS, Canada; Wilma Hopman, Queen's Univ., Kingston, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada; Tolulope T. Sajobi, PhD, Departments of Community Health Sciences & Clinical Neurosciences, Univ. of Calgary, Calgary, AB, Canada; Juxin Liu, Univ. of Saskatchewan, Saskatoon, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada

(2066) Impact of Response Shift effect on the longitudinal analysis of Health-related quality of life in oncology clinical trials: a simulation study

Amélie Anota, PhD, Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon, Besançon, France; Antoine Barbieri, Biostatistic unit, Institut régional du Cancer de Montpellier (ICM) - Val d'Aurelle, Montpellier; Institut de Mathématiques et de Modélisation de Montpellier, Univ. of Montpellier 2, Montpellier, France; Marion Savina, INSERM, Clinical and Epidemiological Research Unit (CIC-EC 7) – CTD INCa, Institut Bergonié, Bordeaux; INSERM CIC-EC7 Axe Cancer, Université de Bordeaux, Bordeaux, France; Sophie Gourgou-Bourgade, Biostatistic unit, Institut régional du Cancer de Montpellier (ICM) - Val d'Aurelle, Montpellier, France; Franck Bonnetain, Prof., Methodological and Quality of Life in Oncology Unit, EA 3181, Univ. Hospital of Besançon Quality of Life in Oncology National Platform, Besançon, France; Caroline Bascoul-Mollevis, PhD, Biostatistic unit, Institut régional du Cancer de Montpellier (ICM) - Val d'Aurelle, Montpellier, France

(2068) Response shift detection at the item level – A comparison of Item Response Theory and Structural Equation Models-based methods

Myriam Blanchin, PhD, Univ. of Nantes, Nantes, France; Alice Guilleux; Antoine Vanier; and Jean-Benoit Hardouin, PhD, Univ. of Nantes, Nantes, France; Veronique Sebillé, Professor of Biostatistics, Univ. of Nantes, Faculty of PharmacyNantes, France

Other Health Conditions

(2070) Evidence-based Health Education in Asthma - No short-term Effects on Health-related Quality of Life and Satisfaction with Programme but Higher Patient Perceived Trainer Skills

Eva M. Bitzer, Medical Doctor, Senior Public Health Researcher, Univ. of Education Freiburg, Freiburg, Germany; Kathrin Baeuerle; and Janine Feicke, Health Research, Univ. of Education Freiburg, Freiburg, Germany; Wolfgang Scherer, Rehabilitation Centre Utersum, Utersum, Germany; Ulrike Spoerhase, Univ. of Education, Freiburg, Germany

(2072) Symptom alleviation profiles during the last week of life. A register based quality of end-of-life study

Joakim Öhlén, Ersta Sköndal Univ. College, Stockholm, Sweden; Kristofer Arestedt, Linæus Univ., Kalmar, Sweden; Cecilia Håkanson; and Anette Henriksson, Ersta Sköndal Univ. College, Stockholm, Sweden; Carl-Johan Fürst, Lund Univ., Lund, Sweden; Lara Russell, PhD, Univ. of Victoria, Vancouver, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada



Top Outstanding Posters

Scientific Program — Friday, October 23

(2074) Qualitative Research about the Pain Coping Methods of Spinal Cord Injury Patients

Chihyoung Son, Doctor, Korean National Rehabilitation Hospital, Seoul, South Korea; KuemJu Lee; and Sook-Hyun Lee, Korean National Rehabilitation Research Institute, Seoul, South Korea

(2076) Chronic postsurgical pain (CPSP) and Health related quality of Life (HRQoL) in a multicenter cohort study.

Antonio Montes, MD, PhD, Parc de Salut MAR, IMIM (Hospital del Mar Medical Research Institute), Universitat Autònoma de Barcelona, Barcelona, Spain; **Gemma Vilagut, Analyst, Hospital del Mar Medical Research Institute (IMIM), Barcelona, Spain;** Jordi Cantillo, BSc., Parc de Salut MAR, IMIM (Hospital del Mar Medical Research Institute), Universitat Autònoma de Barcelona, Barcelona, Spain; Carlos G. Forero, Researcher, CIBER in Epidemiology y SALud Pública (CIBERESP), Barcelona, Spain; Jordi Alonso, Head, Hospital del Mar Medical Research Institute, Barcelona, Spain; Gisela Roca, MD, PhD, Hospital Universitari Germans Trias i Pujol, Universitat Autònoma de Barcelona, Badalona, Spain; Sergi Sabate, Fundacio Puigvert, Barcelona, Spain; Jaume Canet, Hospital Universitari Germans Trias i Pujol, Universitat Autònoma de Barcelona, Badalona, Spain

(2078) Loss to Follow-up of Participants in a Large, National, Multisite Study of Long Term Outcomes of Burn Injury Survivors

Kara McMullen, Univ. of Washington, Portland, OR, United States; Alyssa Bamer, Univ. of Washington, Denver, CO, United States; Dagmar Amtmann, PhD, Univ. of Washington, Seattle, WA, United States; Radha K. Holavanahalli, Univ. of Texas Southwestern, Dallas, TX, United States; Gretchen J. Carrougher, Univ. of Washington, Seattle, WA, United States; Lynne Friedlander, Spaulding Rehabilitation Hospital, Boston, MA, United States; Nicole Gibran, Univ. of Washington, Seattle, WA, United States; David Herndon, Shriner's Hospital, Galveston, TX, United States; James A. Fauerbach, PhD, Johns Hopkins Univ., Baltimore, MD, United States; Shelley Wiechman, Univ. of Washington, Seattle, WA, United States; Kurt Johnson, Univ. of Washington, Seattle, WA, United States

(2080) Association between nutritional status and quality of life in cirrhotic patients.

Eva Juárez-Hernández, MSc., Medica Sur Clinic & Foundation, Mexico City, Mexico; Cristina Gómez-Gutiérrez, MD; Ylse Gutiérrez-Grobe, MD; Brenda V. Balderas-Garcés, MD; Justo Fernández-Rivero, MD; and Liz N. Toapanta-Yanchapaxi, MD; Maria del Carmen Manzano-Robleda, MD; Sofia Ornelas-Arroyo, MD; Martha H. Uribe-Ramos, MD; Martha H. Ramos-Ostos, MD; Misael Uribe, PhD; Norberto C. Chávez-Tapia, PhD, Medica Sur Clinic & Foundation, Mexico City, Mexico

(2082) Conceptualising and Assessing Bleeding Side-effects of Hormonal Contraception

Pamela Warner, Reader in Medical Statistics, Univ. of Edinburgh, Edinburgh, Scotland, United Kingdom; Hilary O. Critchley, Professor of Reproductive Medicine, Univ. of Edinburgh, Edinburgh, Scotland, United Kingdom

(2084) What is important to cardiac arrest survivors? A qualitative exploration of outcomes

Laura Whitehead, Univ. of Warwick, Coventry, United Kingdom; Gavin Perkins, Professor of Critical Care Medicine, Univ. of Warwick/ Heart of England NHS Foundation Trust, Coventry, United Kingdom; **Kirstie Haywood, Senior Research Fellow, Warwick Medical School, Warwick Univ., Coventry, United Kingdom**

(2086) “They have NO idea what it’s like to live with IBD” The influence of other people’s perceptions on coping with Inflammatory Bowel Disease

Hannah Shucard, Western Washington Univ., Bellingham, WA, United States; Fuschia Sirois, Bishop's Univ., Lennoxville, QC, Canada

(2088) The Relevance of Signs and Symptoms Measured by the Psoriasis Symptom Inventory (PSI) to Patients with Psoriatic Arthritis

Mona L. Martin, RN, MPA, Health Research Associates, Inc., Seattle, WA, United States; Alex Mutebi, PhD, Amgen, Thousand Oaks, CA, United States; Ibrahim Ali, Health Research Associates, Seattle, WA, United States; Alice Gottlieb, Tufts Medical Center, Boston, MA, United States; Philip Mease, Swedish Medical Center, Seattle, WA, United States; David Harrison; and Hema N. Viswanathan, Amgen, Thousand Oaks, CA, United States

(2090) Self-management Behaviors and Psychological and Social Factors Influencing QOL in Patients with Parkinson Disease

Yukako Ando, Nagoya City Univ., Nagoya, Japan; Yoshino Ueki, Nagoya City Univ., Nagoya, Japan; Takemori Yamawaki, Hiroshima City Hospital, Hiroshima, Japan; Itsuko Ozaki, Nagoya City Univ., Nagoya, Japan; Akemi Abe, Hatsuokaichi City Health Center, Hatsuokaichi City, Japan; Akira Inukai, Higashi Nagoya National Hospital, Nagoya, Japan; Ikuko Aiba; and Yufuko Saito, Higashi Nagoya National Hospital, Nagoya, Japan; Katsuhiko Kawaminami, Asaka City Public Health center, Asaka, Japan; Noriyuki Matsukawa, Nagoya City Univ., Nagoya, Japan; Toshio Kobayashi, Hiroshima Univ., Hiroshima, Japan

(2092) Getting on With Your Life With MS: Evaluation plan for a new global self-management workbook

Vanessa Bouchard, McGill Univ., Montreal, QC, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada

(2094) Structural Equation Modeling of the Quality of Life for Patients with Marfan Syndrome

Ju Ryoung Moon, PhD, RN, Samsung Medical Center, Seoul, South Korea; Yong Ae Cho, PhD, RN, Chung-Ang Univ., Seoul, South Korea; June Huh, PhD, MD; I-Seok Kang, MD; and Duk-Kyung Kim, PhD, MD, Samsung Medical Center, Sungkyunkwan Univ. School of Medicine, Seoul, South Korea

(2096) Assessment of Gender Bias in Musculoskeletal Outcome Measures. Methods and Examples

Joy MacDermid, Professor, McMaster Univ., Hamilton, ON, Canada



Top Outstanding Posters



Scientific Program — Friday, October 23

(2098) Self-rated health after stroke - A follow-up study with multiple measurements over a 2 years period
Louise Pape Larsen, MHS, PhD-student, Herning, Denmark; Karin Biering, MHS, PhD, Herning, Denmark; Soeren P. Johnsen, MD, PhD, Aarhus, Denmark; Grethe Andersen, MD, DMSc, Aarhus, Denmark; Niels Henrik Hjollund, MD, PhD, AmbuFlex, Herning, Denmark

(2100) Associations between disease severity and Health-related Quality-of-Life (HRQoL) outcomes in psoriasis patients

Hilde Randa, MSc, PhD-fellow, Aarhus Univ. Hospital and Department of Psychology and Behavioural Science, Aarhus Univ., Aarhus C, Denmark; Peter Jensen, DMSc, Copenhagen Univ. Hospital, Hellerup, Denmark; Lone Skov, Professor, DMSc, Gentofte Hospital, Copenhagen Univ. Hospital, Hellerup, Denmark; Claus Zachariae, Professor, DMSc, Gentofte Hospital, Copenhagen Univ. Hospital, Hellerup, Denmark; Robert Zachariae, Professor, DMSc., MSc, Department of Oncology, Aarhus Univ. Hospital and Department of Psychology and Behavioural Science, Aarhus Univ., Aarhus C, Denmark

(2102) The quality of life in trauma patients at 6 months after injury: a prospective cohort study

Nobuichiro Tamura, MD, Kurashiki central hospital, Kurashiki, Okayama, Japan; Hiroshi Okamoto, MD; Toshie Kaihara; Hayaki Uchino, MD; and Toshio Fukuoka, PhD, Kurashiki Central Hospital, Kurashiki, Okayama, Japan

3:40 pm – 3:55 pm Student Poster Award Finalist Presentations Session British Columbia

(2002) Examining the Factor Structure of General and Health Self-efficacy Scales with Individuals Who are Homeless or Vulnerably Housed

Sneha Shankar, PhD Student, Univ. of British Columbia, Vancouver, Canada; Anita M. Hubley, PhD; and Bruno D. Zumbo, PhD, Univ. of British Columbia, Vancouver, Canada

(2004) Detection of Response Shift using a mixed approach combining: k-means and Random Forest methods

Mohamed Boucekine, School of Medicine, Aix Marseille Université, Marseille, France; Karine Baumstarck; Pierre Michel; and Laurent Boyer, School of Medicine, Aix Marseille Université, Marseille, France; Anderson Loundou, 1. Aix-Marseille Univ., Marseille, France; Badih Ghattas; and Pascal, School of Medicine, Aix Marseille Université, Marseille, France

(2006) Outcome reporting in UK-based maternity trials: A Systematic review of randomised controlled trials (The Pro-Maternity group)*

Ayesha Mahmud, PhD student, Univ. of Birmingham, Birmingham, United Kingdom; Tabassum Khan, Birmingham Women's Hospital, Birmingham, United Kingdom; Sara Kenyon, Univ. of Birmingham, Birmingham, United Kingdom; Kirstie Haywood, Senior Research Fellow, Warwick Medical School, Warwick Univ., Coventry, United Kingdom; Khaled Ismail, Univ. of Birmingham and Birmingham Women's Hospital, Birmingham, United Kingdom

4:05 pm – 5:35 pm Concurrent Oral Sessions

Oral Session 206: Pulmonary Conditions

Waddington

Session Chair: Gail Low, PhD, Canada

4:10 pm – 4:23 pm (206.1) Update of the EORTC questionnaire for assessing quality of life in lung cancer patients (EORTC QLQ-LC13)

Michael Koller, Univ. Hospital Regensburg, Regensburg, Germany; Marianne J. Hjermstad, Regional Centre for Excellence in Palliative Care, Oslo Univ. Hospital, Oslo, Norway; Krzysztof Tomaszewski, Jagiellonian Univ. Medical College, Krakow, Poland; Amelie Harle, The Christie NHS Foundation Trust, Manchester, United Kingdom; Juan I. Arraras, Complejo Hospitalario de Navarra, Pamplona, Spain; Ofir Morag, Chaim Sheba Medical Center, Ramat-Gan, Israel; Cecilia Pompili, St. James's Univ. Hospital, Leeds, United Kingdom; Georgios Ioannidis, Nicosia General Hospital Cyprus, Nicosia, Cyprus; Loukia Georgiou; and Morfo Georgiou, Bank of Cyprus Oncology Centre, Nicosia, Cyprus; Chiara Navarra, Rome, Italy; Wei-Chu Chie, Institute of Epidemiology and Preventive Medicine and Department of Public Health, National Taiwan Univ., Taipei, Republic of Taiwan; Colin Johnson, Univ. of Southampton, Southampton, United Kingdom; Ayje Himpel; Christian Schulz; and Hans-Stefan Hofmann, Univ. Hospital Regensburg, Regensburg, Germany; Dagmara Kulis, EORTC, Brussels, Belgium; Andrew Bottomley, EORTC Headquarters, Brussels, Belgium

4:24 pm – 4:37 pm (206.2) The longitudinal relationship between asthma control and quality of life in children: A report from the PROMIS Pediatric Asthma Study

Zheng Li, Univ. of Florida, Gainesville, FL, United States; Heather Gross; Bryce B. Reeve, PhD; and Darren DeWalt, MD MPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States
NEW INVESTIGATOR OR PRESENTATION AWARD FINALIST



Top Outstanding Posters

Scientific Program — Friday, October 23

4:38 pm – 4:51 pm (206.3) Use of Concept Elicitation Interviews to Determine Potential Differences in Disease-related Symptom Concepts Between Early- Versus Advanced-stage Non-small Cell Lung Cancer (NSCLC) Patients

Thomas M. Atkinson, PhD., Memorial Sloan Kettering Cancer Center, New York, NY, United States; Mona L. Martin, RN, MPA; Kelly P. McCarrier, PhD; and Michael Scanlon, Health Research Associates, Inc., Seattle, WA, United States; Lisa M. Peterson, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Jean Marie Arduino, Merck & Co., Inc., Kenilworth, NJ, United States; Vasudha Bal, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States; Kendra DeBusk, Genentech, Inc., South San Francisco, CA, United States; Dagmar Kaschinski, Boehringer Ingelheim GmbH, Ingelheim, Germany; Astra M. Liepa, Eli Lilly and Company, Indianapolis, IN, United States; Stephen J. Coons, PhD, Critical Path Institute, Tucson, AZ, United States, On behalf of the Patient-Reported Outcome (PRO) Consortium's Non-Small Cell Lung Cancer Working Group

4:52 pm – 5:05 pm (206.4) A matched-samples approach to evaluating the impact of COPD on quality of life, healthcare utilization, and asthma burden.

Brian D. Stucky, PhD, RAND Corporation, Santa Monica, CA, United States; Cathy Sherbourne; and Nicole Eberhart, PhD, RAND Corporation, Santa Monica, CA, United States; Maria O. Edelen, PhD, RAND Corp, Boston, MA, United States

5:06 pm – 5:19 pm (206.5) Quality of Life Trajectory During Surgical Treatment for NSCLC: Preliminary Analysis on Baseline Evaluation on 108 patients.

Cecilia Pompili, St. James's Univ. Hospital, Leeds, United Kingdom; Alberto Sandri, St James Univ. Hospital, Leeds, United Kingdom; Jacintha Lee Mei Ying; and Tadh O'Connor, Univ. of Leeds, Leeds, United Kingdom; John White, St James Univ. Hospital, Leeds, United Kingdom; Sandra Dixon, St James Univ. Hospital, Leeds, United Kingdom; Alessandro Brunelli; and Jonathan Robson, MD, St James's Univ. Hospital, Leeds, United Kingdom

Oral Session 207: Health Utilities

Boardroom

Session Chair: Jeanne Landgraf, MA, United States

4:10 pm – 4:23 pm (207.1) Estimating Health Utility Scores for Children with Autism Using a Mapping Algorithm: Secondary Analysis using NDAR

Nalin Payakachat, PhD, Univ. of Arkansas for Medical Sciences, Little Rock, AR, United States; J Mick Tilford, PhD, Univ. of Arkansas for Medical Sciences, Little Rock, AR, United States

4:24 pm – 4:37 pm (207.2) Validity of the new EQ-5D-5L in a cohort of asthmatic patients in Europe

Gimena Hernández, MD, MPH, IMIM (Hospital del Mar Medical Research Institute), CIBER en Epidemiología y Salud Pública (CIBERESP), Universitat Autònoma de Barcelona, Barcelona, Spain, Monica Avila, BPharm, MPH, IMIM (Hospital del Mar Medical Research Institute), CIBER en Epidemiología y Salud Pública (CIBERESP); Universitat Pompeu Fabra, Barcelona, Spain; Olatz Garin, PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Pompeu Fabra, Barcelona, Spain; Angels Pont, BSc, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), CIBER en Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Alexandra Dima, PhD, Dept of Communication Science, ASCoR, Univ. of Amsterdam, Amsterdam, Netherlands; Laurent Laforest, MD, PhD, Unité de Pharmaco épidémiologie, Faculté d'Odontologie, UMR 5558 CNRS - Université Claude-Bernard Lyon, CHU, Lyon, France; Montse Ferrer, MD, PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), CIBER en Epidemiología y Salud Pública (CIBERESP), Universitat Autònoma de Barcelona, Barcelona, Spain

4:38 pm – 4:51 pm (207.3) Comparison of PROMIS and EQ-5D Quality-adjusted Life Years

John D. Hartman, MA, Moffitt Cancer Center and Univ. of South Florida, Tampa, FL, United States, Benjamin M. Craig, PhD, Moffitt Cancer Center and Univ. of South Florida, Tampa, FL, United States

4:52 pm – 5:05 pm (207.4) A time trade-off-derived value set of the 5-level EQ-5D for Canada

Feng Xie, PhD, McMaster University, Father Sean O'Sullivan Research Centre, St. Joseph's Healthcare, Hamilton, ON, Canada; Eleanor Pullenayegum, PhD, Toronto Hospital for Sick Children, Toronto, ON, Canada; Kathryn Gaebel, McMaster Univ., Hamilton, Canada; Nick Bansback, PhD, Univ. of British Columbia and Centre for Health Evaluation and Outcomes Sciences, Vancouver, BC, Canada; Stirling Bryan, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Arto Ohinmaa, PhD, Univ. of Alberta, Edmonton, AB, Canada; Lise Poissant, PhD, Univ. of Montreal, Montreal, QC, Canada, Jeffrey A. Johnson, PhD, Univ. of Alberta, Edmonton, AB, Canada

5:06 pm – 5:19 pm (207.5) A Comparison of EQ-5D-5L Valuation Data in England and the United Arab Emirates

Koonal K. Shah, Office of Health Economics, London, United Kingdom



Top Outstanding Posters



Scientific Program — Friday, October 23

5:20 pm – 5:33 pm (207.6) Investigating the influence of individual valuation block severity on TTO estimates

Andréa Libório Monteiro, HTA Ms MSc, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil; Marisa Santos, MD, PhD, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil; Monica Cintra, HC-FMRP- USP, Ribeirão Preto, Brazil; Bráulio Santos, MD, MSc, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil; Mônica V. Andrade, PhD; Kenya Noronha, PhD; Luciane N. Cruz, MD PhD; and Suzi Camey, Univ.e Federal de Minas Gerais, Porto Alegre, Brazil; Bernardo Tura, MD PhD, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil

Oral Session 208: Concordance Between Patients and Others

Saturna

Session Chair: Hein Raat, MD PhD MBA, Netherlands

4:10 pm – 4:23 pm (208.1) Individual, linguistic and method-related impact on discrepancies between self- and proxy-reports on health-related quality of life of children and adolescents with chronic conditions

Holger Muehlan, PhD, Ernst-Moritz-Arndt Univ., Greifswald, Germany; Sivan Edelstein, Univ. of Greifswald, Greifswald, Germany; Monika Bullinger, Vice Chief of Department, Univ. of Hamburg, Hamburg, Germany; Silke Schmidt, Prof., Ernst-Moritz-Arndt Univ. Greifswald, Greifswald, Germany

4:24 pm – 4:37 pm (208.2) PROMs and PREMs for Elderly Patients in Acute Care and Their Families: An EMPRO Evaluation

Eric K. H. Chan, PhD, Trinity Western Univ., Langley, BC, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada; Anne M. Gadermann, PhD, Univ. of British Columbia, Vancouver, BC, Canada; S. Robin Cohen, PhD, McGill Univ. and Lady Davis Institute, Montreal, QC, Canada; PROMs PREMs Knowledge Synthesis Team

4:38 pm – 4:51 pm (208.3) Patient Perspective of Treatment Benefit In Clinical Trials: It Never Hurts To Ask – Or Does It?

Alison Greene, MPH; and Christopher Cabanski, PhD, Genentech, South San Francisco, CA, United States, Alison Berryhill-Matsui, MPH, Genentech, South San Francisco, CA, United States

4:52 pm – 5:05 pm (208.4) Cancer and the family: A study of Canadian Chinese-speaking and Anglophone patients and family caregivers

Joyce W. Lee, Univ. of British Columbia and Trinity Western Univ., Vancouver, BC, Canada; Arminee Kazanjian; and Carolyn Gotay, PhD, Univ. of British Columbia, Vancouver, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada

5:06 pm – 5:19 pm (208.5) Developing a Conceptual Framework of Paediatric CFS/ME: The Value of Card Ranking Within Qualitative Interviews

Roxanne M. Parslow, BSc (HONS), Univ. of Bristol, Bristol, United Kingdom; Alison Shaw, BA, MSc, PhD, Univ. of Bristol, Bristol, United Kingdom; Kirstie Haywood, Senior Research Fellow, Warwick Medical School, Warwick Univ., Coventry, United Kingdom; Esther Crawley, BA(Hons), BM BCh, MRCP, FRCPC, PhD, Univ. of Bristol, Bristol, United Kingdom

Oral Session 209: Cross-Cultural Research

Pacific Ballroom

Session Chair: Christine Blome, PhD, Germany

4:10 pm – 4:23 pm (209.1) The Revision and Psychometric Evaluation of WHOQOL-BREF

Jialing Li, Master of Medicine, Sun Yat-Sen Univ.; Guangdong Provincial Center for Disease Control and Prevention, Guangzhou, Guangdong, China; Yuantao Hao, PhD.; Jing Gu, PhD; and Yanxia Zhao, Sun Yat-Sen Univ., Guangzhou, China

4:24 pm – 4:37 pm (209.2) Can the original factor structure of WHOQOL-BREF (English) be replicated in Singapore?

Kok Joon Chong; Yin Bun Cheung; and Eric Yin Hao Khoo, National Univ. of Singapore, Singapore; Khung Keong Yeo, National Heart Centre Singapore, Singapore, Hwee Lin Wee, National Univ. of Singapore, Singapore

4:38 pm – 4:51 pm (209.3) Inuit Version of the Aboriginal Children's Health and Well-Being Measure: Qanuipit?

Karen Baker-Anderson, Executive Director, Ottawa Inuit Children's Centre, Ottawa, ON, Canada, Nancy L. Young, PhD, Laurentian Univ., Sudbury, ON, Canada; Mary Jo Wabano, MHK, Wikwemikong Health Centre, Wikwemikong, ON, Canada; Lynda Brown, BA; Courtney Henderson, BA; Rachel Quinn, BEd; Natlie Lloyd; Christine Kudluk; and Janice Messam, ECE, Ottawa Inuit Children's Centre, Ottawa, ON, Canada

4:52 pm – 5:05 pm (209.4) What Traditional Chinese Medicine told Modern Medicine about health status and Quality of life: content analysis of Traditional Chinese Medicine Instruments for Quality of Life comparing with the WHOQOL and SF-36

Changhe Yu, MD, China Academy of Chinese Medical Sciences, Beijing, China; Ya-Nan Sun, PhD, Xuanwu Hospital Capital Medical Univ., Beijing, China; Li-Yun He, PhD; Wen-Jing Bai, PhD; and Bao-Yan Liu, China Academy of Chinese Medical Sciences, Beijing, China



Top Outstanding Posters

Scientific Program — Friday, October 23

5:06 pm – 5:19 pm (209.5) Assessing the performance of an item bank derived from the World Health Organisation Quality of Life-100 measure for computer adaptive testing across diverse cultures.

Chris Gibbons, PhD CPsychol AFBPsS, NIHR Fellow, Univ. of Manchester, Greater Manchester, United Kingdom

Oral Session 210: Musculoskeletal Conditions

Vancouver Island

Session Chair: *Kathleen Wyrwich, PhD, United States*

4:10 pm – 4:23 pm (210.1) Cutting Edge Solutions to Improving the Efficiency of PRO Measurement: From Real-Data Simulations to Pilot Testing Before and After Total Joint Replacement in a National Registry

John Ware, PhD, Univ. of Massachusetts Medical School, Worcester, MA, United States; Barbara Gandek, PhD; Patricia Franklin, MD; and Celeste Lemay, Univ. of Massachusetts Medical School, Worcester, MA, United States

4:24 pm – 4:37 pm (210.2) Cross-cultural validity of the Animated Activity Questionnaire (AAQ) for assessing activity limitations in patients with hip or knee osteoarthritis.

Wilfred F. Peter, VU Univ. Medical Center, Amsterdam, Netherlands; Henrica C. de Vet; Maarten Boers; and Jaap Harlaar, VU Univ. Medical Center, Amsterdam, Netherlands; Leo D. Roorda, Amsterdam Rehabilitation Research Center, Reade, Amsterdam, Netherlands; Rudolf W. Poolman; and Vanessa A. Scholtes, Onze Lieve Vrouwe Gasthuis, Amsterdam, Netherlands; Martijn Steultjens, Glasgow Caledonian Univ., Glasgow, United Kingdom; Ewa M. Roos, Institute of Sports Science and Clinical Biomechanics, Odense, Denmark; Francis Guillemin, Univ. of Lorraine, Nancy, France; Maria G. Benedetti, Istituto Ortopedico Rizzoli, Bologna, Italy; Antonio Escobar, Basurto Univ. Hospital, Bilbao, Spain; Hanne S. Dagfinrud, National Advisory Unit for rehabilitation in rheumatology, Oslo, Norway; Caroline B. Terwee, VU Univ. Medical Center, Amsterdam, Netherlands

4:38 pm – 4:51 pm (210.3) Pooling Outcome Data across Multi-attribute Utility Measures: Feasibility in Rheumatoid Arthritis and Hip Arthroplasty

Sheri L. Pohar, BScPharm, MSc, PhD, CADTH, Ottawa, ON, Canada; Chris Cameron, PhD; Srabani Banerjee, PhD; and Michelle Mujoomdar, PhD, CADTH, Ottawa, ON, Canada

4:52 pm – 5:05 pm (210.4) Total knee replacement provides joint pain and function improvement but are patients overall happy?

Allyson Jones, PhD, Univ. of Alberta, Edmonton, AB, Canada; Andrea Barbo, MD Anderson Center, Houston, TX, United States; Glenn Landon; and Sherwin Siff, St Luke's Episcopal Hospital, Houston, TX, United States; Maria Suarez-Almazor, MD PhD, MD Anderson Center, Houston, TX, United States

5:06 pm – 5:19 pm (210.5) The Performance and Association Between Patient-Reported and Performance-based measures of Physical Functioning in Research on Individuals with Arthritis

Laura C. Pinheiro, MPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Leigh F. Callahan, PhD, School of Medicine, Thurston Arthritis Research Center, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Lloyd J. Edwards, PhD, Gillings School of Global Public Health, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Rebecca J. Cleveland, PhD, School of Medicine, Thurston Arthritis Research Center, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States

5:45 pm – 7:00 pm Special Interest Group (SIG) Meetings

New Investigator SIG Meeting

Waddington

Quality of Life (QOL) in Clinical Practice (CP) SIG Meeting

Boardroom

Response Shift SIG Meeting

Tweedsmuir

Translation and Cultural Adaptation (TCA) SIG Meeting

Garibaldi

7:00 pm Dine-Arounds

Social Event *pre-registration required

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Scientific Program — Saturday, October 24

7:00 am – 5:30 pm Registration Desk Open

7:30 am – 8:25 am Committee and Special Interest Group (SIG) Meetings

Industry Advisory Committee (IAC) Meeting Vancouver Island

Canada PRO SIG Meeting Boardroom

Patient Engagement SIG Meeting Saturna

Psychometrics SIG Meeting Waddington

9:00 am – 10:15 am ISOQOL Member Business Meeting and Awards Presentation Pacific Ballroom

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

ISOQOL Awards

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

2015 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 British Columbia Ballroom

10:15 am – 11:00 am Refreshment Break in Poster Hall

10:25 am – 10:45 am Saturday Poster Session 1 British Columbia Ballroom

Clinical Practice

(3003) PRO feedback in a clinical practice setting: What patient-reported information do pediatric oncology providers find helpful?

Lotte Haverman, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Netherlands; Sasja Schepers, Emma Children's Hospital, Academic Medical Center, Amsterdam, Netherlands; Sima Zadeh, International Cancer Institute at the National Institute of Health, Bethesda, MD, United States; Martha Grootenhuis, Prof, Emma Children's Hospital, Academic Medical Center, Amsterdam, Netherlands; Wiener Lori, International Cancer Institute at the National Institute of Health, Bethesda, MD, United States

(3005) The Use of PRO Measures in the Clinical Setting from a Clinician Perspective

Michele Halyard, MD, Mayo Clinic, Scottsdale, AZ, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; Louise Humphrey, PhD, Clinical Outcomes Assessment Abacus International, Manchester, United Kingdom; Anna Beurskens, PhD, PT, Maastricht Univ., Maastricht, Netherlands; Jeff A. Sloan, PhD, Mayo Clinic, Rochester, MN, United States

(3007) Current Practices in Patient-Reported Outcome (PRO) Data Collection in Trials: A Survey of UK trial staff and management

Derek G. Kyte, PhD, Univ. of Birmingham, Birmingham, United Kingdom; Jonathan Ives, PhD; Heather Draper, PhD; and Melanie J. Calvert, PhD, Univ. of Birmingham, Birmingham, United Kingdom

(3009) Payer Perspectives of Patient Reported Outcomes Data: An Online Assessment

Susan L. Hogue; Andrew P. Brogan; Carla DeMuro; and Amy Barrett, RTI Health Solutions, Research Triangle Park, NC, United States, Lori McLeod, PhD, RTI Health Solutions, Research Triangle Park, NC, United States; Denise D'Alessio; and Vasudha Bal, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States

(3011) Challenges and Opportunities for PROs and Big Data: Applications for the Pharmaceutical Industry

William R. Lenderking, PhD, Evidera, Lexington, MA, United States

 Top Outstanding Posters



Measure Development

(3013) Using cognitive interviews to assess and refine the Coeliac Disease Assessment Questionnaire (CDAQ)
Helen Crocker, MSc, and Crispin Jenkinson, Univ. of Oxford, Oxford, United Kingdom, Michele Peters, PhD, Univ. of Oxford, Oxford, United Kingdom

(3015) How Much Change Really Matters? Development and Comparison of Two Novel Approaches to Defining Clinically Important Differences in Fatigue Scores

Karon F. Cook, PhD, Department of Medical Social Sciences, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Michael A. Kallen, PhD, MPH, Northwestern Univ., Feinberg School of Medicine, Missouri City, TX, United States; David Victorson, Northwestern Univ., Evanston, IL, United States; Deborah Miller, PhD, Cleveland Clinic, Cleveland, OH, United States

(3017) Development of Novel Patient-Reported Outcomes (PRO) Instruments to Assess Atopic Dermatitis Signs, Symptoms and Impacts

Christina Curry, MSc., Genentech, Inc., South San Francisco, CA, United States; Martha Gauthier; Mary Lynn Cala; Shayna Egan; Brooke Witherspoon; and Christopher Evans, Endpoint Outcomes, Boston, MA, United States; Kristina Fitzgerald, MPH, Genentech Inc., South San Francisco, CA, United States

(3019) Psychometric properties of the Patient-Reported Outcomes Measure of Pharmaceutical Therapy for Quality of Life (PROMPT-QoL)

Phantipa Sakthong, Associate Professor, Faculty of Pharmaceutical Sciences, Chulalongkorn Univ., Bangkok, Thailand; Pattarin Sukarnjanaset.; Nontapat Sonsa-ardjit; and Wipaporn Munpan, Faculty of Pharmaceutical Sciences, Chulalongkorn Univ., Bangkok, Thailand

(3021) Title: Reliability of the Aboriginal Children's Health and Well-Being Measure (ACHWM)

Nancy L. Young, PhD, Laurentian Univ., Sudbury, ON, Canada; Mary Jo Wabano, MHK, Wikwemikong Health Centre, Wikwemikong, ON, Canada; Koyo Usaba, MHK, Laurentian Univ., Sudbury, ON, Canada; Debbie Mishibinijima, BA, Wikwemikong Health Centre, Wikwemikong, ON, Canada; Tricia A. Burke, BA, Laurentian Univ., Sudbury, ON, Canada

(3023) An Early Look: A Mixed Methods Study to Examine the Feasibility, Preliminary Psychometric Performance, and Early Construct Validity of the CLEFT-Q

Karen Wong, MD MSc FRCSC, Hospital for Sick Children, Univ. of Toronto, Toronto, ON, Canada; Elena Tsangaris, MSc, McMaster Univ., Hamilton, ON, Canada; Christopher Forrest, MD MSc FRCSC, Hospital for Sick Children, Univ. of Toronto, Toronto, ON, Canada; Karen Harman, MD, McMaster Univ., Hamilton, ON, Canada; Andrea Pusic, MD MPH FACS, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Stefan Cano, PhD, Modus Outcomes, Stotfold, United Kingdom; Timothy Goodacre, MBBS BSc FRCS, Univ. of Oxford, Oxford, United Kingdom; Anne Klassen, DPhil, McMaster Univ., Hamilton, ON, Canada

(3025) Establishing Content Validity for the National Eye Institute's Visual Function Questionnaire (VFQ-25) in Intermediate, Posterior, and Panuveitis

Jacob Devine, ICON Plc, San Francisco, CA, United States; Kellee Howard, MSc, MA, ICON Plc, San Francisco, CA, United States; Martha Skup, PhD; Jingdong Chao, PhD; and Arijit Ganguli, MBA, PhD, AbbVie Inc, Chicago, IL, United States; John Sheppard, MD, Departments of Ophthalmology & Microbiology, Eastern Virginia Medical School and Virginia Eye Consultants, Norfolk, VA, United States

(3027) Initial Development of Patient-Reported Outcome Measures for Children, Adolescents and Adults with Primary Ciliary Dyskinesia: The QOL-PCD

Alexandra L. Quittner, PhD, Univ. of Miami, Miami, FL, United States; Margaret Leigh, MD, Univ. of North Carolina - Chapel Hill, Chapel Hill, NC, United States; Tom Ferkol, MD, Washington Univ. in St. Louis, St. Louis, MO, United States; Sharon Dell, MD, Univ. of Toronto, Toronto, ON, Canada; Anjana M. Morris, PhD, MPH, Univ. of Miami, Miami, FL, United States; Laura Behan, MSc; and Jane Lucas, BM, PhD, Univ. of Southampton, Southampton, United Kingdom

(3029) Development of a patient reported measure to assess perceived RT inconvenience: Phase I (conceptual framework) and Phase II (issue generation)

Puma Sundaresan, Radiation Oncologist; and Christopher Milross, The Univ. of Sydney, Sydney, NSW, Australia; Martin Stockler, NHMRC Clinical Trials Centre, Sydney, NSW, Australia; Daniel Costa, Dr, The Univ. of Sydney, Sydney, NSW, Australia, Madeleine King, PhD, Univ. of Sydney, Sydney, NSW, Australia

(3031) Health related Quality of Life in Narcolepsy: validation of the DISABKIDS-Narcolepsy Module

John Chaplin, PhD, AFBPsS, CPsychol., Inst. Clinical Sciences, Sahlgrenska Academy at the Univ. Gothenburg, Sweden, Gothenburg, Sweden; Attila Szakács, MD, Institute of Clinical Sciences, Sahlgrenska Academy, Halmstad County Hospital, Halmstad, Sweden; Niklas Darin, MD, Institute of Clinical Sciences, Sahlgrenska Academy, Univ. of Gothenburg, Gothenburg, Sweden; Tove Hallböök, MD, Institute of Clinical Sciences, Sahlgrenska Academy, Univ. of Gothenburg. 3Lund Child and Youth Habilitation Center, Lund, Sweden



Top Outstanding Posters

(3033) Integrating the Child's Voice in Adverse Event Reporting in Oncology Trials: Cognitive Interview Findings from the Multisite Pediatric PRO-CTCAE Initiative

Bryce B. Reeve, PhD, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Molly McFatrach, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Justin N. Baker, St. Jude Children's Research Hospital, Memphis, TN, United States; David R. Freyer, Children's Hospital Los Angeles, Los Angeles, CA, United States; Joshua Gagne, Dana-Farber Cancer Institute/Boston Children's Hospital, Boston, MA, United States; Jami S. Gattuso; and Deborah Gibson, St. Jude Children's Research Hospital, Memphis, TN, United States; Racquel E. Kohler, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Alyssa Levine, Dana-Farber Cancer Institute/Boston Children's Hospital, Boston, MA, United States; Selena Lollar; and Jane Lukshis, Palmetto Health Children's Hospital, Columbia, SC, United States; Jennifer W. Mack, Dana-Farber Cancer Institute/Boston Children's Hospital, Boston, MA, United States; Christa Martens, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Catriona Mowbray, Children's National Health System, Washington, DC, United States; Diana Palma, Children's Hospital Los Angeles, Los Angeles, CA, United States; Laura C. Pinheiro, MPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Lillian Sung, The Hospital for Sick Children, Toronto, ON, Canada; Sarah C. Taddei, Dana-Farber Cancer Institute/Boston Children's Hospital, Boston, MA, United States; Deborah Tomlinson, The Hospital for Sick Children, Toronto, ON, Canada; Mia Waldron, Children's National Health System, Washington, DC, United States; Meaghann Weaver, Children's National Health System/St. Jude Children's Research Hospital, Memphis, TN, United States; Jennifer Wind, Dana-Farber Cancer Institute/Boston Children's Hospital, Boston, MA, United States; Janice Withycombe, Palmetto Health Children's Hospital, Columbia, SC, United States; Pamela S. Hinds, Children's National Health System, Washington, DC, United States

(3035) Design of the HIV Dependent Quality of Life (HIVDQoL) questionnaire and HIV Symptom Rating Questionnaire (HIVSRQ).

Jacquelyn Romaine, Health Psychology Research Unit, Royal Holloway, Univ. of London, Egham, Surrey, United Kingdom; Janet Bayfield, Health Psychology Research Unit, Royal Holloway, Univ. of London, Egham, Surrey, United Kingdom; Rosalind Plowright, Health Psychology Research Ltd, Royal Holloway, Univ. of London; Health Psychology Research Unit, Royal Holloway, Univ. of London, Egham, Surrey, United Kingdom; Miranda Murray, Viiv Healthcare, London, United Kingdom; Clare Bradley, Health Psychology Research Unit, Royal Holloway, Univ. of London; Health Psychology Research Ltd, Royal Holloway, Univ. of London, Egham, Surrey, United Kingdom

(3037) Item Generation for the Long-Term Conditions Questionnaire (LTCQ): Qualitative Interviews with Patients

Caroline Potter, Univ. of Oxford, Oxford, United Kingdom; Cheryl Hunter, Univ. of Leeds, Leeds, United Kingdom; Laura Kelly; Elizabeth Gibbons; Crispin Jenkinson; and Angela Coulter, Univ. of Oxford, Oxford, United Kingdom; Julien Forder, Univ. of Kent and London School of Economics and Political Science, Canterbury, United Kingdom; Ann-Marie Towers, Univ. of Kent, Canterbury, United Kingdom; Ray Fitzpatrick; and Michele Peters, PhD, Univ. of Oxford, Oxford, United Kingdom

(3039) Validity and Responsiveness of Short Version of Western Ontario Rotator cuff Index (Short-WORC) in patients with Rotator Cuff Pathology

Neha Dewan, PhD student, McMaster Univ., Hamilton, ON, Canada; Joy MacDermid, Professor; and Norma MacIntyre, Associate professor, McMaster Univ., Hamilton, ON, Canada; Ruby Grewal, Associate Professor, Western Univ., Roth | McFarlane Clinical Research Laboratory, Hand and Upper Limb Centre, London, ON, Canada

(3041) Using a Personalized Measure to Capture QOL in People with HIV

Nancy Mayo, PhD, McGill Univ., Montreal, Canada; Carolina Moriello, McGill Univ. Health Centre - RI, Montreal, QC, Canada; Lesley K. Fellows, Dr.; and Marie-Josée Brouillette, Dr., McGill Univ., Montreal, QC, Canada; Susan C. Scott, McGill Univ. Health Center, Montreal, QC, Canada

(3043) Preliminary Measurement Properties of the Pain Assessment for Lower Back-Impacts Questionnaire (PAL-I): Development Using a Mixed-Methods Approach

Donald M. Bushnell, MA, Health Research Associates, Inc., Seattle, WA, United States; Kelly P. McCarrier, PhD, Health Research Associates, Inc., Seattle, WA, United States; Abhilasha Ramasamy, Forest Research Institute, Jersey City, NJ, United States; Hiltrud Liedgens, Grunenthal GmbH, Aachen, Germany; Lauren A. Braam, MIH; and Mona L. Martin, RN, MPA, Health Research Associates, Inc., Seattle, WA, United States; Steven I. Blum, GlaxoSmithKline (with Forest Research Institute at time of study), Collegeville, PA, United States

(3045) Preliminary Measurement Properties of the Pain Assessment for Lower Back-Symptoms (PAL-S): Development and Evaluation through a Mixed-Methods Approach

Kelly P. McCarrier, PhD, Health Research Associates, Inc, Seattle, WA, United States; Donald M. Bushnell, MA, Health Research Associates, Inc., Seattle, WA, United States; Abhilasha Ramasamy, Forest Research Institute, Jersey City, NJ, United States; Hiltrud Liedgens, Grunenthal GmbH, Aachen, Germany; Lauren A. Braam, MIH; and Mona L. Martin, RN, MPA, Health Research Associates, Inc., Seattle, WA, United States; Steven I. Blum, GlaxoSmithKline (with Forest Research Institute at time of study), Collegeville, PA, United States

(3047) Measurement Properties of a New Claudication Symptom Instrument (CSI)

Todd Edwards, PhD, Univ. of Washington, Seattle, WA, United States; Danielle C. Lavalley, PharmD, PhD.; Alexander Clowes, MD; and Beth Devine, PhD, PharmD, Univ. of Washington, Seattle, WA, United States; Ellen Thomason, MD, MPH, Providence Health Services, Seattle, WA, United States; David R. Flum, MD, MPH; and Mark Meissner, MD, Univ. of Washington, Seattle, WA, United States; Skye P. Barbic, Post-Doctoral Fellow, Faculty of Medicine, Vancouver, BC, Canada; Donald Patrick, PhD, MSPH, Univ. of Washington, Seattle, WA, United States

(3049) Content development of a patient-reported outcome instrument for the measurement of the primary signs and symptoms chronic plaque psoriasis

April Armstrong, Univ. of Colorado, Denver, CO, United States; Murali Sundaram, AbbVie Inc., North Chicago, IL, United States; Catherine Foley; Farrah Pompilus; and Jonathan Stokes, Adelphi Values, Boston, MA, United States; Alan L. Shields, Adelphi Values, Boston, MA, United States



Top Outstanding Posters



Scientific Program — Saturday, October 24

Kids and Young Adults

(3051) Application of the EQ-5D-Y in a clinical study: how children and adolescents with chronic conditions assess health-related quality of life

Kathrin I. Fischer, M.Sc.med., Charite - Universitaetsmedizin Berlin, Berlin, Germany; Dana Barthel, Dipl.-Psych.; and Christiane Otto, PhD, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ute Thyen, MD; and Marcus Klein, MD, Univ. Medical Center Schleswig-Holstein, Kiel, Germany; Otto Walter, PhD, MD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Silke Schmidt, Prof.; and Holger Muehlan, PhD, Ernst-Moritz-Arndt Univ., Greifswald, Germany; Matthias Rose, MD PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Ulrike Ravens-Sieberer, PhD, MPH, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany

(3053) Chronic conditions and health-related quality of life in school-aged children: findings from a large population-based study in the Netherlands

Guannan Bai, MPH, Erasmus MC, Univ. Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Marieke H. Herten, PhD, Statistics Netherlands, Heerlen, Limburg Province, Netherlands; Jeanne M. Landgraf, MA, HealthActCHQ Inc, Boston, MA, United States; Ida Korfage, PhD; and Hein Raat, PhD, MD, Erasmus MC, Univ. Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands

(3055) Quality of life and alcohol consumption behaviors by gender among first-year students of a Chilean Univ.

Carlos A. Hidalgo-Rasmussen, Researcher, Univ. de Guadalajara, Univ. de Playa Ancha, Cd. Guzmán, Jalisco, Mexico; María Jacqueline Rojas, Researcher, Univ. de Playa Ancha, Viña del Mar, Chile; Fabiola Vilugrón, Professor, Univ. de Playa Ancha, Quilpué, Chile; Verónica Pastén, Professor, Univ. de Playa Ancha, Viña del Mar, Chile



(3059) Longitudinal associations among asthma control, sleep problems, and health-related quality of life in children with asthma: A report from the PROMIS Pediatric Asthma Study

Zheng Li, Univ. of Florida, Gainesville, FL, United States; Heather Gross; Bryce B. Reeve, PhD; and Darren DeWalt, MD MPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States

International

(3061) Defining the Values for Patient Engagement (PE) in Health-Related Quality of Life (HRQoL) Research: An International Perspective

Kirstie Haywood, Senior Research Fellow, Warwick Medical School, Warwick Univ., Coventry, United Kingdom; Sam Salek, PhD RPh FPPM MRPSGB MCMS FESCP, School of Life & Medical Sciences, Univ. of Hertfordshire, Hatfield and Director - Institute for Medicines Development, Cardiff, United Kingdom; Anne Lyddiatt, Patient Research Partner, OMERACT, Cochrance Collaboration., London, Canada; Samantha Brace-McDonnell, Patient Research Partner, Warwick Medical School, Warwick Univ., Coventry, United Kingdom; Sophie Staniszevska, Warwick Medical School, Warwick Univ., Coventry, United Kingdom

(3067) Quality of Life in Residents for Earthquake, Tsunami and Radiation Disaster in Fukushima, Japan

Rika Hayashida, Univ. of Nagasaki, Siebold, Nishisonogigun, Nagasaki, Japan; Takashi Mandai; Ayako Tsukihashi; Hiroshi Shimagami; Akihiro Yamamoto; Li-sa Chang; and Taiji Omura, Japanese Society of Quality of Life Research, Kobe, Japan; Yoshihiro Tairako, Tounou Sangyou Sinkou Jigyuu Cooperation, Iwaki, Fukushima, Japan; Shinichi Suzuki, Kashima Hospital, Iwaki, Fukushima, Japan; Yoshie Tada, Narahamachi, Iwaki Office, Iwaki, Fukushima, Japan; Ichirou Nagano; Kouki Kaketaka; Shuuto Yamashita; Masaya Kusuda; Atsuhiko Fukuoka; Haruyasu Fujita; Souichirou Maruyama; Michiko Kobayashi; and Kouzaburo Adachi, Japanese Society of Quality of Life Research, Kobe, Japan; Tomotaka Sobue, Graduate School of Medicine, Osaka Univ., Osaka, Japan

(3069) Purpose in Life and Personal Growth: Predictors of Quality of Life in Mexican Elders

Ana L. Gonzalez-Celis, Psychology, National Autonomous Univ. of Mexico (UNAM), Tlalneapantla, Estado de Mexico, Mexico; Juana Gomez-Benito, Psychology, Univ. of Barcelona, Barcelona, Spain; Margarita Maldonado-Saucedo, ITESO, Univ. Western Institute of Technology and Higher Education, Tlaquepaque, Jalisco, Mexico; Maria E. Vidaña-Gaytan, Autonomous Univ. of Ciudad Juárez, Ciudad Juarez, Chihuahua, Mexico; Ana G. Magallanes-Rodriguez, Autonomous Univ. of Baja California, Tijuana, Baja California, Mexico; Margarita Chavez-Becerra, National Autonomous Univ. of Mexico (UNAM), Tlalneapantla, Estado de Mexico, Mexico; Edgardo Ruiz-Carrillo, Psychology, National Autonomous Univ. of Mexico (UNAM), Tlalneapantla, Estado de Mexico, Mexico

(3071) Evaluating a Methodology for providing Individualized Feedback on Quality of Life and its Importance in Community and Primary Care, using the WHOQOL-BREF

Suzanne M. Skevington, PhD, CPsychol, FBPsS, Univ. of Manchester, Manchester, United Kingdom; Alison Llewellyn, Consultant Health Psychologist, Univ of Bath, Bristol, United Kingdom

(3073) Parent's experiences of neonatal care in England: a large scale postal survey

Jenny King, Picker Institute Europe, Oxford, United Kingdom; Amy Tallett; Sarah-Ann Burger; Tamara van Doorn, Picker Institute Europe, Oxford, United Kingdom

(3083) Spiritual and Religious Coping and Quality of Life Among Older Adults: Brazilian study

Luciano Vitorino, Paulista School of Nursing, Federal Univ. of São Paulo - UNIFESP., Itajuba, Minas Gerais, Brazil; Gail Low, Associate Professo, Univ. of Alberta, Edmonton, AB, Canada; Lucila Amaral Vianna, Full Professor, Federal Univ. of São Paulo – UNIFESP, Sao Paulo, Brazil



Top Outstanding Posters

Scientific Program — Saturday, October 24

(3085) Adapting to Aging among Norwegian Elders

Mary Kalfoss, Professor, Diakonova Univ. College, Oslo, Norway; Liv Halvorsrud, Associate Professor, Oslo & Akershus Univ. College of Applied Sciences, Oslo, Norway, Gail Low, Associate Professor, Faculty of Nursing, Univ. of Alberta, Edmonton, AB, Canada

(3087) Impact of socio-economic factors on oral health related quality of life in Japanese population

Mariko Naito, DDS, PhD, Nagoya Univ. Graduate School of Medicine, Nagoya, Japan; Yoshimi Suzukamo, PhD, Tohoku Univ. Graduate School of Medicine, Sendai, Japan; Tatsuro Miyake, DDS, PhD, Baika Woman's Univ., Ibaraki, Japan; Kenji Wakai, MD, PhD, Nagoya Univ. Graduate School of Medicine, Nagoya, Japan

(3089) Health Related Quality of Life in a community dwelling elderly sample in Brazil

Andréa Libório Monteiro, HTA Ms MSc, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil; Bruna Veras, MSc; and Juliana Peixoto, MSc, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil; Sandra Furtado, MSc; and Helio Furtado, MSc, Prefeitura do Rio de Janeiro – SESQV, Rio de Janeiro, Brazil; Marisa Santos, MD, PhD, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil

(3091) Disparities in quality of life and mental distress: A comparison of Chinese heterosexual and homosexual populations

Janet Y. Wong, PhD, RN, The Univ. of Hong Kong, Hong Kong SAR, China; Daniel Y. Fong, PhD, The Univ. of Hong Kong, Hong Kong SAR, China

Utilities

(3093) Validity of the EQ-5D-Y in a cohort of asthmatic children in Europe

Gimena Hernández, MD, MPH, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain, CIBER en Epidemiología y Salud Pública (CIBERESP), Spain, Universitat Autònoma de Barcelona, Bellaterra., Barcelona, Spain; Monica Avila, BPharm, MPH, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain, CIBER en Epidemiología y Salud Pública (CIBERESP), Spain, Universitat Pompeu Fabra, Barcelona, Spain; Olatz Garin, PhD, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain, CIBER en Epidemiología y Salud Pública (CIBERESP), Spain, Universitat Pompeu Fabra, Barcelona, Spain; Angels Pont, BSc, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain, CIBER en Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Alexandra Dima, PhD, Dept of Communication Science, ASCoR, Univ. of Amsterdam, Amsterdam, Netherlands; Laurent Laforest, MD, PhD, Unité de Pharmacologie, Faculté d'Odontologie, UMR 5558 CNRS - Université Claude-Bernard Lyon, CHU, Lyon, France; Montse Ferrer, MD, PhD, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain, CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona, Bellaterra, Barcelona, Spain

(3095) Using the Health Utilities Index to Improve Chronic-Care Management

Maria Jose Santana, PhD, O'Brien Institute for Public Health, Calgary, AB, Canada

(3097) Further Evidence on EQ-5D-5L Preference Inversion: A Brazil/US Collaboration

Benjamin M. Craig, PhD, Moffitt Cancer Center and Univ. of South Florida, Tampa, FL, United States; Marisa Santos, MD, PhD; and Andréa Libório Monteiro, HTA Ms MSc, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil

11:00 am – 12:30 pm The Social Network

Pacific Ballroom

The proliferation of technology to connect us and expand our networks with others continues to have a profound impact on society. Our Society is not immune to these influences. This plenary features speakers who are at the forefront of this new era. They will share their insights for how to use social media in research, clinical care, and building connections between research, clinical practice, patients and the public.

Speakers

Anatoliy Gruz, PhD, Ryerson Univ., Toronto, ON, Canada

Brennan Spiegel, MD, MSHS, Cedars-Sinai Center for Outcomes Research and Education, Univ. of California, Los Angeles, Los Angeles, CA, USA

Sean Ahrens, San Francisco, CA, United States

Chair

Melanie Calvert, PhD, The Univ. of Birmingham, Birmingham, United Kingdom

Discussant

Chris G. Richardson, PhD, Univ. of British Columbia and Providence Health Care, Vancouver, BC, Canada



Top Outstanding Posters



Scientific Program — Saturday, October 24

12:30 pm – 1:45 pm Lunch on your own

1:45 pm – 3:00 pm Concurrent Symposium Sessions

Symposium #4: Developing and Validating Clinician Reported Outcomes: Discussion of Applied Methods

Pacific Ballroom

Moderator: **Louise Humphrey, MSc**, Abacus International, Manchester, United Kingdom

Panelists:

Emuella Flood, ICON PRO, Bethesda, MD, USA

Linda Abetz-Webb, Patient-Centred Outcomes Assessment (P-COA), Cheshire, United Kingdom

Cicely Kerr, MSc PhD, Oxfordshire, Oxford, United Kingdom

Stacie Hudgens, MA ABD, Clinical Outcomes Solutions, Tucson, AZ, USA

Clinician-Reported Outcomes (ClinROs) fall under the umbrella term of Clinical Outcomes Assessments (COAs) and provide clinician insight into “a patient’s symptoms, overall mental state, or the effects of a disease or condition on how the patient functions” (FDA Guidance for Industry 2009). ClinROs are particularly important for capturing treatment benefit for patients unable to self-report or for concepts which require training and expertise to make the evaluation. Within the regulatory framework, ClinROs must be fit-for-purpose within the context of use to support product labeling. Currently, there is no specific guidance on ClinROs published by regulatory agencies, and a critical need within the field is to understand applied, practical methods that are specifically appropriate for the development and psychometric testing of these instruments. Utilizing learnings from Patient-Reported Outcomes and Health-Related Quality of Life measure development and experiences in developing and applying ClinROs, this symposium intends to address this critical need and engage participants by providing real world examples of applied methodological considerations for ClinROs, including practical challenges, evaluation of existing ClinROs and development of new ClinROs.

Individual Presentations

ClinROs: History and importance, regulatory guidance, selection and applied development methods.

Emuella Flood, ICON PRO, Bethesda, MD, United States

Pediatric ClinROs: Special considerations and recommendations for pediatric ClinRO development methods

Linda Abetz-Webb, Patient-Centred Outcomes Assessment, Cheshire, United Kingdom

ClinROs: Applied methods for evaluating content validity of ClinROs

Cicely Kerr, MSc PhD, Oxfordshire, Oxford, United Kingdom

ClinRO Psychometric Validation: Analytic and research design considerations

Stacie Hudgens, MA (ABD), Clinical Outcomes Solutions, Tucson, AZ, United States

Symposium #5: Quality of Life following Stroke, Traumatic Brain Injury and Spinal Cord Injury: Influences of person and environmental factors

Vancouver Island

Moderator: **Allen Heinemann, PhD**, Feinberg School of Medicine Northwestern Univ., Chicago, IL, United States

The quality of life of persons living in the community with physical disabilities can be influenced by a variety of person and environment factors. This symposium reports findings from a large-scale study that recruited a community sample of people with stroke, traumatic brain injury and spinal cord injury. The aims of this symposium are to: (1) Describe the influence of health literacy on quality of life following stroke, traumatic brain injury and spinal cord injury; (2) Discuss how economic quality of life reflects resources and disability burden in a community sample; (3) Discuss the acceptability of outcome measurement for persons with disability; (4) Illustrate the relationships between emotional functioning and quality of life in a community sample of persons with disabilities; and (5) Model social aspects of quality of life as a function of cognition and motor performance in a community sample of persons with disabilities.



Top Outstanding Posters

Scientific Program — Saturday, October 24

Individual Presentations

Computer-based Measurement of Health Literacy, Functional Literacy, Cognitive Abilities and Patient-Reported Outcomes Among English-speaking Adults with Functional Limitations Due to Spinal Cord Injury, Stroke or Traumatic Brain Injury

Elizabeth A Hahn, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

New PRO scales to measure economic quality of life (ECQ)

David S. Tulsky, Univ. of Delaware, Newark, DE, United States

Finding a Focus for Social Aspects of Quality of Life with Neurological Disorders: Cognitive, Emotional, and Environmental Factors

Alex Wong, Washington Univ. School of Medicine, St Louis, MO, United States

Reasonable accommodations affect the validity of scores on the NIH Toolbox Cognition Battery among people with neurological disabilities

Susan Magasi, Univ. of Illinois at Chicago, Chicago, IL, United States

Health Disparities in Health-Related Quality of Life Among Individuals with Disabilities

Noelle Carozzi, Univ. of Michigan, Ann Arbor, MI, United States

Symposium #6: Response shift effects at the item level: Cross-method insights for interpreting change over time

Saturna

Chair: Véronique Sébille, ScD, EA 4275, Faculty of Pharmacy, Univ. of Nantes, Nantes, France

Discussant:

Carolyn E. Schwartz, ScD, On behalf of the ISOQOL Response Shift Special Interest Group, DeltaQuest Foundation, Inc., Concord, MA; Tufts Univ. School of Medicine, Boston, MA, United States

Interpreting change in patient-reported outcomes (PRO) can be obfuscated by response shift (RS). RS research focuses on subscale scores combining several items. It can be hypothesized that the prevalence and magnitude of RS effects at item-level may influence RS detection and true change estimation and that item-level analysis could help getting more insight into RS interpretation. Different RS detection methods may perform differently in identifying item-level RS effects. This symposium presents five studies of item-level RS detection methods to investigate these unanswered questions in different disease populations.

Qualitative and quantitative analyses examine RS effects at item-level and their impact on interpreting change in PRO. Dr. Huang presents item-level structural equation modelling (SEM) analyses of pediatric patients. Dr. Verdam presents SEM analyses for item-level RS detection in cancer patients undergoing radiotherapy. Dr. Blanchin presents Guttman errors and Item Response Theory (IRT) models to identify individual- and item-level RS in chronically ill patients. Dr. Hardouin presents non-parametric IRT for item-level RS detection.

Thentest assumptions were not supported in qualitative analyses. Preliminary analyses suggest that item-level RS effects were detected in quantitative analyses. Item-level RS effects had a small to moderate impact on true change estimation. The discussant will present results of a SIG survey examining the expected implications of item-level RS effects. This symposium provides a range of methods and implications for detecting item-level RS effects.

Individual Presentations

Assessing item-level response shift related to the change of health state on the NIH PROMIS Paediatric Scales: A Report from the NIH PROMIS Paediatric Asthma Study

I-Chan Huang, PhD, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, Memphis, TN, United States

Item-level response shift detection using structural equation modeling

Mathilde GE Verdam, MSc, Academic Medical Centre and Child Development and Education, Univ. of Amsterdam, Amsterdam, The Netherlands

A Guttman errors based method for response shift detection at the individual and item levels

Myriam Blanchin, PhD, EA 4275 SPHERE "bioStatistics, Pharmacoepidemiology and Human Sciences Research Team", Faculty of Pharmacy, Univ. of Nantes, Nantes, France

Use of Non parametric Item Response Theory to detect Item-level Response Shift

Jean-Benoit Hardouin, ScD, EA 4275 SPHERE "bioStatistics, Pharmacoepidemiology and Human Sciences Research Team", Faculty of Pharmacy, Univ. of Nantes, Nantes, France



Top Outstanding Posters



Scientific Program — Saturday, October 24

3:00 pm – 3:45 pm Refreshment Break in Poster Hall

3:15 pm – 3:35 pm Saturday Poster Session 2

British Columbia Ballroom

Health Economics

(3004) Face to face comparison between EQ-5D-5L and the traditional EQ-5D-3L in Catalan general population

Marc Marti-Pastor, Teaching Unit of Preventive Medicine and Public Health, PSMAR-UPF-ASPB, Barcelona, Spain; Angels Pont, BSc, IMIM (Hospital del Mar Medical Research Institute), and CIBER en Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Olatz Garin, PhD, IMIM (Hospital del Mar Medical Research Institute), CIBER en Epidemiología y Salud Pública (CIBERESP), Universitat Pompeu Fabra, Barcelona, Spain; Ricard Tresserras, Antonia Medina; and Oriol Garcia, Direcció General de Planificació i Recerca en Salut. Departament de Salut. Generalitat de Catalunya, Barcelona, Spain; Montse Ferrer, MD PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), CIBER en Epidemiología y Salud Pública (CIBERESP), Universitat Autònoma de Barcelona, Barcelona, Spain, Carlos G. Forero, Researcher, CIBER in Epidemiology y SAIdud Pública (CIBERESP), Barcelona, Spain

(3006) An examination of generic health status estimates in the context of spinal cord injury: is there a case for standardizing the framing of mobility-related questions?

David G. Whitehurst, PhD, Simon Fraser Univ., Vancouver, BC, Canada; Nicole Mittmann, PhD, Sunnybrook Health Sciences Centre, Toronto, Canada; Vanessa K. Noonan, PT, PhD, Rick Hansen Institute, Univ. of British Columbia, Vancouver, BC, Canada; Marcel Dvorak, MD; and Stirling Bryan, PhD, Univ. of British Columbia, Vancouver, BC, Canada

(3008) Validity of Standard Gamble utilities in patients referred for aortic valve replacement

Amjad I. Hussain, Medical doctor, Oslo Univ. Hospital, Oslo, Norway; Andrew Garratt, Institute of Health Management and Health Economics, Oslo, Norway; Lars Gullestad, prof, Oslo Univ. Hospital, Oslo, Norway; Kjell I. Pettersen, OUS, Oslo, Norway

(3010) A New Valuation Method: Direct Elicitation of Personal Utility Functions for EQ-5D

Nancy J. Devlin, Professor, Office of Health Economics, London, United Kingdom; Koonal K. Shah, Office of Health Economics, London, United Kingdom; Brendan Mulhern, Univ. of Technology Sydney, Sydney, NSW, Australia; Ben van Hout, Univ. of Sheffield, Sheffield, United Kingdom

(3012) Anchoring bias in EQ-5D valuation based on face-to-face time trade-off interviews

Kim Rand-Hendriksen, Cand.psychol, PhD, Akershus Univ. Hospital; Univ. of Oslo, Oslo, Norway; Liv Ariane Augestad, MD, PhD, Univeristy of Oslo; Akershus Univ. Hospital, Oslo, Norway; Nan Luo, PhD, National Univ. of Singapore, Singapore

(3014) Testing the 'non-stopping' time trade-off procedure for valuation of the EQ-5D-5L health states: a study of two countries

Nan Luo, PhD, National Univ. of Singapore, Singapore, Singapore; Kim Rand-Hendriksen, Cand.psychol, PhD; and Liv Ariane Augestad, MD, PhD, Univeristy of Oslo; Akershus Univ. Hospital, Oslo, Norway

(3016) Determinants of Health Preferences in the Canadian EQ-5D-5L Valuation Study

Fatima Al Sayah, PhD, Univ. of Alberta, Edmonton, AB, Canada; Nick Bansback, PhD, Univ. of British Columbia and Centre for Health Evaluation and Outcomes Sciences, Vancouver, BC, Canada; Stirling Bryan, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Arto Ohinmaa, Univ. of Alberta, Edmonton, Canada; Eleanor Pullenayegum, PhD, Toronto Hospital for Sick Children, Toronto, ON, Canada; Feng Xie, PhD, McMaster Univerity, Father Sean O'Sullivan Research Centre, St. Joseph's Healthcare, Hamilton, ON, Canada; Jeffrey A. Johnson, PhD, Univ. of Alberta, Edmonton, AB, Canada

(3018) Exploring the role of disease labels on general population preferences

Helen McTaggart-Cowan, Canadian Centre for Applied Research in Cancer Control, Vancouver, BC, Canada; Dean A Regier, PhD; and Stuart J Peacock, DPhil, Canadian Centre for Applied Research in Cancer Control, Vancouver, BC, Canada

(3024) Quality of life in Diabetes mellitus type I adults in Brazil

Monica Cintra, Medical coordinator, HC-FMRP- USP, Ribeirão Preto, Brazil; Stella Carletti, MD, INC, Rio de Janeiro, Brazil; Andréa Libório Monteiro, HTA Ms MSc, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil; Marcelo Goulart, INC, Rio de Janeiro, Brazil; Bernardo Tura, MD PhD, Instituto Nacional de Cardiologia, Rio de Janeiro, Brazil; Marisa Santos, MD, PhD, Instituto Nacional de Cardiologia, Rio de Janeiro Area, Brazil

(3026) Does EQ-5D-5L Account for the Impact of Limitations in Activities of Daily Livings (ADLS) on Social Care Outcomes, Capabilities and Well-Being?

Clara Mukuria, PhD, Univ. of Sheffield, Sheffield, United Kingdom; John Brazier, PhD, Univ. of Sheffield, Sheffield, South Yorkshire, United Kingdom; Tessa Peasgood, PhD, Univ. of Sheffield, Sheffield, United Kingdom



Top Outstanding Posters

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Utilities

(3028) Time Trends in the Health Utilities Index Mark 3 Attributes in the General Population of Canada, 2000-2010

Jacek A. Kopec, *Univ. of British Columbia, Vancouver, Canada*; Eric C. Sayre, *Arthritis Research Canada, Vancouver, Canada*; Philippe Fines, *Statistics Canada, Montreal, Canada*; Anya Okhmatovskaia, *McGill Univ., Montreal, Canada*; William M. Flanagan, *Statistics Canada, Ottawa, Canada*; Michael C. Wolfson, *Univ. of Ottawa, Ottawa, Canada*

(3030) Performance of the EQ-5D-5L in a large community-based survey

Yash J. Jalundhwala, *MS, Univ. of Illinois at Chicago, Chicago, IL, United States*, A. Simon Pickard, *PhD, Univ. of Illinois at Chicago, Chicago, IL, United States*

(3032) Developing and testing national tariff for EQ-5D-5L in Japan with special reference to statistical methods to obtain QOL score

Shinya Saito, *Medicine, Okayama Univ., Okayama, Japan*; Takeru Shirowa, *National Institute of Public Health, Wako, Saitama, Japan*; Shunya Ikeda, *International Univ. of Health and Welfare, Ohtawara, Tochigi, Japan*; Shinichi Noto, *Niigata Univ. of Health and Welfare, Niigata, Japan*; Ataru Igarashi, *The Univ. of Tokyo, Tokyo, Japan*; Takashi Fukuda, *National Institute of Public Health, Wako, Saitama, Japan*; Kojiro Shimozuma, *Ritsumeikan Univ., Kusatsu, Shiga, Japan*

(3034) German utility weights for the EORTC QLQ-C30 – first results of a general population survey using discrete choice experiments

Georg Kemmler, *Statistician, Innsbruck Medical Univ., Innsbruck, Tyrol, Austria*; Eva-Maria Gamper, *Medical Univ. Innsbruck, Innsbruck, Austria*; Virginie Nerich, *Besaçon Univ. Hospital, Besaçon, France*; Richard Norman, *Curtin Univ., Perth, Australia*; Madeleine King, *PhD, Univ. of Sydney, Sydney, NSW, Australia*; Bernhard Holzner, *Medical Univ. of Innsbruck, Innsbruck, Austria*

(3036) Valuing the SF-6D Version 2 in Canada

Nick Bansback, *PhD, Univ. of British Columbia and Centre for Health Evaluation and Outcomes Sciences, Vancouver, BC, Canada*; Brendan Mulhern, *Univ. of Technology Sydney, Sydney, NSW, Australia*; Richard Sawatzky, *PhD RN, Trinity Western Univ., Langley, BC, Canada*; John Brazier, *PhD, Univ. of Sheffield, Sheffield, South Yorkshire, United Kingdom*; David G. Whitehurst, *PhD, Simon Fraser Univ., Vancouver, BC, Canada*

(3038) Instrument-defined estimates of minimally important difference in EQ-5D-5L index score for Canadian, Chinese and Spanish scoring algorithms

Nathan S. McClure, *MSc, Univ. of Alberta, Edmonton, AB, Canada*; Fatima Al Sayah, *PhD, Univ. of Alberta, Edmonton, AB, Canada*; Feng Xie, *PhD, McMaster University, Father Sean O'Sullivan Research Centre, St. Joseph's Healthcare, Hamilton, ON, Canada*; Nan Luo, *PhD, National Univ. of Singapore, Singapore*; Jeffrey A. Johnson, *PhD, Univ. of Alberta, Edmonton, AB, Canada*

Health Care Providers



(3040) Development of a feedback form for routine clinical use of PROs in Primary Care for patients with multimorbidity

Ian Porter, *Dr, Univ. of Exeter Medical School, Exeter, Devon, United Kingdom*; Jose M Valderas, *MD, PhD, MD, Univ. of Exeter, Exeter, United Kingdom*

(3042) Presenting PRO Results from Comparative Research Studies in Clinical Practice to Inform Treatment Decision-Making: Making Pictures Speak More Clearly to Patients and Clinicians

Michael Brundage, *MD, MSc, Kingston General Hospital, Queen's Univ., Kingston, ON, Canada*; Elissa Bantug, *MHS, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States*; Elliott Tolbert, *Mr., Johns Hopkins School of Medicine, Baltimore, MD, United States*; Katherine C. Smith, *PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States*; Claire Snyder, *PhD, Division of General Internal Medicine, Johns Hopkins School of Medicine, Baltimore, MD, United States, PRO Data Presentation Stakeholder Advisory Board*



(3044) Presenting Individual Patient PRO Data in Clinical Practice: Making Line Graphs “in Line” with Patient and Clinician Understanding

Claire Snyder, *PhD, Division of General Internal Medicine, Johns Hopkins School of Medicine, Baltimore, MD, United States*; Katherine C. Smith, *PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States*; Emily Little, *MPH, Johns Hopkins School of Medicine, Baltimore, MD, United States*; Elissa Bantug, *MHS, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States*; Michael Brundage, *MD, MSc, Kingston General Hospital, Queen's Univ., Kingston, ON, Canada, PRO Data Presentation Stakeholder Advisory Board*

(3046) Evaluation of electronic patient-reported outcome data used in real-time with nurses and patients.

Kara Schick-Makaroff, *PhD, Univ. of Alberta, Edmonton, AB, Canada*; Anita Molzahn, *RN, PhD, FCAHS, Univ. of Alberta, Edmonton, AB, Canada*

(3048) Weight Bias Among Healthcare Providers: Quality of Life Implications for Patients with Obesity

Mary Forhan, *OT Reg(AB) PhD, Univ. of Alberta, Edmonton, AB, Canada*; Jacqueline Torti, *MHP*; and Allyson Jones, *PhD, Univ. of Alberta, Edmonton, AB, Canada*



Top Outstanding Posters



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(3050) Developing tools for use in clinical practice - a methodological approach

Chloe Tolley, Adelphi Values Ltd, Cheshire, United Kingdom; Rebecca Hall, Adelphi Values Ltd, Cheshire, United Kingdom; Kevin Mills, Adelphi Values Ltd, Cheshire, United Kingdom; Bryan Bennett, Adelphi Values Ltd, Cheshire, United Kingdom, **Chris Marshall, Adelphi Values Ltd, Cheshire, United Kingdom**

(3054) The Distress Assessment and Response Tool (DART) at the Princess Margaret Cancer Centre: How to Engage Clinicians

Alyssa Macedo, MScOT, Univ. Health Network - Princess Margaret Cancer Centre, Toronto, ON, Canada; Madeline Li, MD PhD FRCP(C); Gary Rodin, MD; Sabira Bagha, MSW; and Yvonne Leung, PhD, Univ. Health Network, Toronto, ON, Canada; Lindsay McColl, Univ. of Toronto, Toronto, ON, Canada; Alexis Twiddy, Univ. of Toronto, Toronto, ON, Canada; Kathy Davison, RN, BAS, MHS, Univ. Health Network, Toronto, ON, Canada; Terri Stuart-McEwan, Univ. Health Network - Princess Margaret Cancer Centre; Univ. of Toronto, Toronto, Canada

(3056) Quality of Work Life perception and Mental Health in nursing staff

Raquel Gonzalez-Baltazar, Univ. of Guadalajara, Guadalajara, Jalisco, Mexico; Gustavo Hidalgo-Santacruz; Silvia G. Leon-Cortes; Monica I. Contreras-Estrada; and Brenda J. Hidalgo-Gonzalez, Univ. of Guadalajara, Guadalajara, Jalisco, Mexico

(3058) Future Rehabilitation Professionals' Knowledge, Skills and Attitudes Towards Self-Management Support: Helping Future Clinicians to Help Patients.

Sabrina Figueiredo, PhD Candidate, McGill Univ., Montreal, Canada; Nancy Mayo, PhD, McGill Univ., Montreal, Canada; Alike Thomas, PhD, McGill Univ.; Jewish Rehabilitation Hospital, Montreal, Canada

Vulnerable Populations

(3060) Content Validation of a Quality of Life Measure for Individuals Who Are Homeless and Vulnerably Housed

Lara B. Russell, PhD, Univ. of Victoria & Centre for Health Evaluation and Outcome Sciences, Vancouver, BC, Canada; Anita M. Hubley, PhD, Univ. of British Columbia, Vancouver, Canada

(3062) Measuring health-related quality of life in homeless and vulnerably housed adults: A validation study

Anita M. Hubley, PhD, Univ. of British Columbia, Vancouver, Canada; Bruce MacLaurin, MSW, MSc, Univ. of Calgary, Calgary, AB, Canada; Susan Farrell, PhD, Royal Ottawa Mental Health Centre & Univ. of Ottawa, Ottawa, ON, Canada; Anne M. Gadermann, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Alina Turner, PhD, Turner Research and Strategy & Univ. of Calgary, Calgary, AB, Canada; Katrina Milaney, PhD, Univ. of Calgary, Calgary, AB, Canada; Wendy Muckle, RN, BScN, MHA, Ottawa Inner City Health, Inc., Ottawa, ON, Canada



(3064) Effect of Health Promotion Seminars Using Traditional Drum Performance on the QOL and Physical Status of Japanese Community Elderly

Toshio Kobayashi, Hiroshima Univ., Hiroshima, Japan; Akemi Furuyashiki; Suzumi Okuda; and Kousuke Yabase, Hiroshima Univ., Hiroshima, Japan

(3068) Subjective Age, Age Satisfaction, and Self-Rated Health in Adults Who Are Homeless or Vulnerably Housed

Ayumi Sasaki, Univ. of British Columbia, Vancouver, Canada; Anita M. Hubley, PhD; and Anne M. Gadermann, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Lara Russell, PhD, Univ. of Victoria, Vancouver, Canada; Anita Palepu, Professor, Univ. of British Columbia, Vancouver, BC, Canada

(3070) Recommendations from the field: Interviewing and retaining homeless and vulnerably housed participants in longitudinal health research

Sophie Ma Zhu, Univ. of British Columbia, Vancouver, BC, Canada; Roxanne Joyce, Providence Health Care Research Institute & Univ. of British Columbia, Vancouver, BC, Canada; Anne M. Gadermann, PhD, Univ. of British Columbia, Vancouver, BC, Canada; Julia Gerlitz, Univ. of British Columbia & Providence Health Care Research Institute, Vancouver, BC, Canada; Meagan Stowe; and Julie Parrell, Providence Health Care Research Institute, Vancouver, BC, Canada; Anita M. Hubley, PhD; and Anita Palepu, Professor, Univ. of British Columbia, Vancouver, BC, Canada

(3072) Does Socioeconomic Inequality Moderate the Reduction in Vitality, Life Satisfaction and Increased Psychological Distress in those Suffering from Chronic Illness? A Population-Based Study on Possible Pathways.

Jocelyne Clench-Aas, Senior Scientist, Norwegian Institute of Public Health, Oslo, Norway; Neha Agnihotri, Norwegian Univ. of Life Science, As, Norway; Ragnhild B. Nes, Research Scientist, Norwegian Institute of Public Health, Oslo, Norway

(3074) The relationship between physical disability and overall health-related quality of life of residents in long-term care facilities

Allyson Jones, PhD, Univ. of Alberta, Edmonton, AB, Canada; David Feeny, PhD, Department of Economics, McMaster Univ., Hamilton, ON, Canada; Susan Slaughter; and Adrian Wagg, Univ. of Alberta, Edmonton, AB, Canada



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Family

(3076) Developing a measure of hemophilia caregiver impact

Carolyn Schwartz, ScD, Tufts Univ. Medical School; DeltaQuest Foundation, Inc., Oslo and Akershus Univ. College, Concord, MA, United States; Adi Eldar-Lissai, M.S., MBA, PhD, Biogen, Cambridge, MA, United States

(3078) Psychometric Properties of the Diabetes Self-care Efficacy Scale

Sravanti Ghosh, Senior Research Fellow, Indian Statistical Institute, Kolkata, West Bengal, India; Debdulal Dutta Roy, Assistant Professor, Indian Statistical Institute, Kolkata, West Bengal, India

(3080) Cultural Influences on the Caregiver Role, Caregiving Experiences and Perceptions of QOL of Hispanic Family Caregivers of Patients with Advanced Cancer

Gloria Juarez, PhD, RN, Consulting Services, San Pedro, CA, United States; Joan J. Branin, PhD, Univ. of La Verne, Pasadena, CA, United States; Lina Mayorga, PhD MPH CHES, City of Hope, Duarte, CA, United States

(3082) Elderly patient and caregiver involvement in the quality improvement of cancer care pathways

Asiong Jie, MD, PhD, Atrium-Orbis Medical Centre Heerlen, and Zuyd Univ. of Applied Sciences, Heerlen, Netherlands; Inge Melchior, PhD, Zuyd Univ. of Applied Sciences and Atrium-Orbis Medical Centre Heerlen, Heerlen, Netherlands; Albine Moser, PhD, MPH, RN, Zuyd Univ. of Applied Sciences, Heerlen, Netherlands; Marja Veenstra, PhD, House of Care, Sittard, Netherlands; Esther Stoffers, PhD, House of Care, Sittard, Netherlands

(3086) Empowerment for whom? Comparison of attitudes towards disability among people with disability, caregivers and the public

Chun Hao, Sun Yat-sen Univ., Guangzhou, China; Qiaolan Zheng; Jing Gu, PhD; and Yuantao Hao, PhD Sun Yat-sen Univ., Guangzhou, Guangdong, China

(3090) Quality of Life (QoL) Questionnaire for Mothers of Schoolchildren

Rika Hayashida, Univ. of Nagasaki, Siebold, Nishisonogigun, Nagasaki, Japan; Michiko Kobayashi; and Takashi Mandai, Japanese Society of Quality of Life Research, Kobe, Japan

(3096) Living Well? Examining Quality-of-life and Associated Care Needs among Families of Children with Medical Complexity

Janet McCabe, RN, MEd, PhD, Univ. of Saskatchewan, Prince Albert, SK, Canada; Jennifer Kryworuchko, PhD, RN, CNCC(C); and Janet Gaunt, RN, Univ. of Saskatchewan, Saskatoon, SK, Canada

(3098) The Quality of Life and Experience of the Family Caregivers for Stroke Patients admitted on Korean National Rehabilitation Hospital

Chihyoung Son, Doctor, Korean National Rehabilitation Hospital, Seoul, South Korea; Jung Hwan Kim, Korean National Rehabilitation Hospital, Seoul, South Korea; Hyun-Jeong Im, Korean National Rehabilitation Center, Seoul, South Korea; Jeong-A Yu, Korean National Rehabilitation Hospital, Seoul, South Korea; KuemJu Lee; and JiEun Lee, Korean National Rehabilitation Research Institute, Seoul, South Korea; Bum Suk Lee, Korean National Rehabilitation Hospital, Seoul, South Korea; Hyun Choi, Korean National Rehabilitation Research Institute, Seoul, South Korea

(3100) Predictors of quality of life of family caregivers of drug addicts

Susane F. Cosentino, Assistant Professor, Federal Univ. of Santa Maria / CESNORS, Brazil, Palmeira das Missões/RS, Rio Grande do Sul, Brazil; Luciano Vitorino, Paulista School of Nursing, Federal Univ. of São Paulo - UNIFESP, Itajuba, Minas Gerais, Brazil; Leila G. de Brizola Perdonssini, Nurse in Family Health Strategy, Specialist, Palmeira das Missões, Rio Grande do Sul, Brazil; Maria Helena Souza, Adjunct Professor, Federal Univ. of Rio de Janeiro, Palmeira das Missões, Rio Grande do Sul, Brazil; Lucila Amaral Vianna, Full Professor, Federal Univ. of São Paulo - UNIFESP, Sao Paulo, Brazil

3:45 pm – 5:15 pm Concurrent Oral Sessions

Oral Session 301: Response Shift

Waddington

Session Chair: Carolyn Schwartz, ScD, United States

3:50 pm – 4:03 pm (301.1) Minimal impact of response shift for SF-12 mental and physical health status in the homeless and vulnerably housed: An item-level multi-group analysis

Anne M. Gadermann, PhD, Univ. of British Columbia, Vancouver, Canada; Richard Sawatzky, PhD RN, Trinity Western Univ., Langley, BC, Canada; Anita Palepu, Professor; Anita M. Hubley, PhD; and Bruno D. Zumbo, PhD, Univ. of British Columbia, Vancouver, Canada; Tim Aubry, Professor, Univ. of Ottawa, Ottawa, Canada; Susan Farrell, PhD, Royal Ottawa Mental Health Centre & Univ. of Ottawa, Ottawa, ON, Canada; Stephen Hwang, Professor, Univ. of Toronto, Toronto, Canada



Top Outstanding Posters



Scientific Program — Saturday, October 24

4:04 pm – 4:17 pm (301.2) Response shift in patients receiving a pre-emptive kidney transplant compared to similar recipients having experienced a short dialysis period: study protocol for a prospective, observational, multicenter controlled study

Veronique Sebillé, Univ. of Nantes, Faculty of Pharmacy, France, Nantes, France; Jean-Benoit Hardouin, PhD; Angelique Bonnaud-Antignac; and Philippe Tessier, Univ. of Nantes, Nantes, France; Magali Giral, ITUN, Nantes, France; Yohann Foucher, Univ. of Nantes, Nantes, France; Aurelie Meurette, ITUN CHU de Nantes, Nantes, France

4:18 pm – 4:31 pm (301.3) Response Shift and Perceptions of Quality of Life Following Neurogenic Bowel and Bladder in Persons with Spinal Cord Injury

Denise G. Tate, Professor, Univ. of Michigan Medical School, Ann Arbor, MI, United States; Edward Rohn, Research Associate, Univ. of Michigan, Ann Arbor, MI, United States; Colette Duggan, Senior Research Associate, Detroit Medical Center/ Rehabilitation Institute of Michigan, Detroit, MI, United States; Roxane Madrid, Research Assistant, Univ. of Michigan, Ann Arbor, MI, United States; Martin Forchheimer, Senior Research Associate, Univ. of Michigan, Ann Arbor, MI, United States; Emily Zafiroff, Research Assistant, Univ. of Michigan, Ann Arbor, MI, United States

4:32 pm – 4:45 pm (301.4) Evaluation of the Oort's procedure for response shift detection at item level – a simulation study

Alice Guilleux, Univ. of Nantes, Nantes, France; Myriam Blanchin, PhD, Univ. of Nantes, Nantes, France; Jean-Benoit Hardouin, PhD, Univ. of Nantes, Nantes, France; Veronique Sebillé, Professor of Biostatistics, Univ. of Nantes, Faculty of Pharmacy, France, NANTES, France

4:46 pm – 4:59 pm (301.5) Identification of response shift in the Manitoba Follow-up Study: at the individual and item level

Maryam A. Alshammari, Univ. of Manitoba, Winnipeg, Canada; Robert Tate, PhD; Donna Collins, MSc; and Ruth Barclay, PhD, Univ. of Manitoba, Winnipeg, Canada

Oral Session 302: New Developments in PROMIS

Pacific Ballroom

Session Chair: *Caroline Terwee, PhD, Netherlands*

3:50 pm – 4:03 pm (302.1) Use of Scale Linkage to Determine Performance of PRO-PMs Assessed with Different Patient-Reported Outcome Measures

Irene Katzan, Cleveland Clinic, Cleveland, OH, United States; Fan Youran; and Sandra D. Griffith, Cleveland Clinic, Cleveland, OH, United States; Paul Crane, Univ. of Washington, Seattle, WA, United States; Nicolas Thompson; and Deborah Miller, PhD, Cleveland Clinic, Cleveland, OH, United States; David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

4:04 pm – 4:17 pm (302.2) Development of the PROMIS Nociceptive Pain Scale

Cindy J. Nowinski, MD, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Dennis Revicki, PhD, Evidera, Bethesda, MD, United States; Dagmar Amtmann, PhD, Univ. of Washington, Seattle, WA, United States; Kaleb Michaud, PhD, Univ. of Nebraska Medical Center, Omaha, NE, United States; Michael A. Kallen, PhD, MPH, Northwestern Univ., Feinberg School of Medicine, Missouri City, TX, United States; Robert Askew, PhD, MPH, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

4:18 pm – 4:31 pm (302.3) Extending PROMIS and Neuro-QOL to Huntington Disease: New Measures of Chorea, Speech and Swallowing Difficulties, and End of Life Concerns

Noelle Carlozzi, Univ. of Michigan, Ann Arbor, MI, United States; Jin-Shei Lai, Northwestern Univ., Chicago, IL, United States; Stephen Schilling, Univ. of Michigan, Ann Arbor, MI, United States; Elizabeth A. Hahn, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Anna Kratz, Univ. of Michigan, Ann Arbor, MI, United States; Nancy Downing; and Jane Paulsen, Univ. of Iowa, Cedar Rapids, IA, United States; Martha Nance, Park Nicollet, Golden Valley, MN, United States; Praveen Dayalu, Univ. of Michigan, Ann Arbor, MI, United States; Joel Perlmutter, Washington Univ., St. Louis, MO, United States; Michael McCormack, Rowan Univ., Glassboro, NJ, United States; Kimberly Quaid, Indiana Univ., Indianapolis, IN, United States; Christopher Ross, Johns Hopkins Univ., Baltimore, MD, United States; Susan Perlman, UCLA, Los Angeles, CA, United States; Jennifer Miner, Univ. of Michigan, Ann Arbor, MI, United States; Stacey Barton, Washington Univ., St. Louis, MO, United States; Humberto Marin, Rutgers Univ., Piscataway, NJ, United States; Michael Geschwind, UCSF, San Francisco, CA, United States; Stephen Rao, Cleveland Clinic, Cleveland, OH, United States; Richard C. Gershon, PhD; and David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

4:32 pm – 4:45 pm (302.4) Validation of PROMIS Scales in Adolescents and Young Adults with Special Health Care Needs: A Report from the PROMIS Linking Study

Carrie R. Howell, St. Jude Children's Research Hospital, Memphis, TN, United States; Heather Gross; Bryce B. Reeve, PhD; and Darren DeWalt, MD MPH, Univ. of North Carolina at Chapel Hill, Chapel Hill, NC, United States; I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States



Top Outstanding Posters

Scientific Program — Saturday, October 24

4:46 pm – 4:59 pm (302.5) Refinement and Validation of a General Self-Efficacy Item Bank and Short Form for the NIH PROMIS

John M. Salsman, Wake Forest School of Medicine, Winston-Salem, NC, United States; Thomas V. Merluzzi, Univ. of Notre Dame, Notre Dame, IN, United States; Benjamin D. Schalet, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States; Crystal L. Park, Univ. of Connecticut, Storrs, CT, United States; Elizabeth A. Hahn; Mallory A. Snyder; and David Cella, PhD, Northwestern Univ. Feinberg School of Medicine, Chicago, IL, United States

Oral Session 303: Behavioral Interventions

Vancouver Island

Session Chair: Carol Moinpour, PhD, United States

3:50 pm – 4:03 pm (303.1) Health Behavior Change Counseling improves rehabilitation engagement and leads to better functional outcomes following lumbar spine surgery

Richard L. Skolasky, ScD, Johns Hopkins Univ., Baltimore, MD, United States; Anica M. Maggard; David Li; Lee H. Riley, III, MD; and Stephen T. Wegener, PhD, Johns Hopkins Univ., Baltimore, MD, United States

4:04 pm – 4:17 pm (303.2) Effects of Lifestyle Interventions on Quality of Life in Breast Cancer Patients

Haleh Ghavami, PhD., Urmia Univ. of Medical Sciences, Urmia, Azarbayjane Gharbi, Iran; Neriman Akyolcu, PhD., Istanbul Univ., Istanbul, Turkey

4:18 pm – 4:31 pm (303.3) Exploring the Relationship of Psychosocial Determinants in the Context of a Weight Loss Intervention

Jessica L. Lawson, MSc, M.A., Yeshiva Univ., Hoboken, NJ, United States; Elizabeth Seng; and Charles Swencionis, Yeshiva Univ., New York, NY, United States; Judith Wylie-Rosett, Einstein School of Medicine, New York, NY, United States

4:32 pm – 4:45 pm (303.4) Patient-reported outcomes and the use of a diabetes diary mobile application to attain lifestyle changes for persons with type 2 diabetes

Heidi Holmen, MSc, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway; Astrid Torbjørnsen, MSc; and Lis Ribu, PhD, Oslo and Akershus Univ. College of Applied Sciences, Oslo, Norway

4:46 pm – 4:59 pm (303.5) Sense of coherence (SOC) among Japanese white collar workers participating in “Salutogenic Café”. A six months follow-up study investigating development of SOC and the use of new skills.

Shinichiro Sasahara, Occupational Psychiatry, Univ. of Tsukuba, Tsukuba-City, Ibaraki pref., Japan; Junko Sakano, Health and Welfare Science, Okayama Prefectural Univ., Soja, Okayama, Japan; Eva Langeland; and Ragnhild Sollesnes, Univ. College of Bergen, Bergen, Norway; Yuichi Oi; and Kazuya Usami, Univ. of Tsukuba, Tsukuba-City, Japan; Yoshihiko Yamazaki, Nihon Fukushi University, Nagoya, Japan; Ichiyo Matsuzaki, Univ. of Tsukuba, Tsukuba, Japan

5:00 pm – 5:13 pm (303.6) Examining the association between modifiable health behaviors and health-related quality of life among U.S. adults.

William W. Thompson, PhD, U.S. Centers for Disease Control and Prevention, Atlanta, GA, United States; Vincent Campbell, PhD, Center for Disease Control & Prevention, Atlanta, GA, United States; John P. Barile, PhD, Univ. of Hawaii, Honolulu, HI, United States; Gloria L. Krahn, PhD, Oregon State Univ., Corvallis, OR, United States

Oral Session 304: Quality of Life in Children

Saturna

Session Chair: I-Chan Huang, PhD, United States

3:50 pm – 4:03 pm (304.1) Health related quality of life in children and adolescents born with esophageal atresia - Use of focus groups in the development of a condition-specific questionnaire

Michaela Dellenmark-Blom, Quality Manager, The Queen Silvia Children's Hospital, Sahlgrenska Univ. Hospital, Gothenburg, Sweden; John Chaplin, PhD, AFBPsS, CPsychol., Inst. Clinical Sciences, Sahlgrenska Academy at the Univ. Gothenburg, Sweden, Gothenburg, Sweden; Linus Jönsson, Pediatric Surgeon; Vladimir Gatzinsky, Pediatric Surgeon; and Kate Abrahamsson, Pediatric Surgeon, The Queen Silvia Children's Hospital, Sahlgrenska Univ. Hospital, Gothenburg, Sweden

4:04 pm – 4:17 pm (304.2) Quality of Life in Children is associated with Severity of Atopic Dermatitis and with Depressed Mood: A Cross Sectional Study

Andrea Nájera, General Practitioner, Centro de la Piel, Ecuador., Quito, Ecuador; Andrea C. Cueva, Attending Physician/Researcher, Centro de la Piel, Quito, Ecuador; Julia E. Cabezas, Dermatology Resident, Centro de la Piel, Quito, Ecuador; Santiago A. Palacios, Dermatologist, Centro de la Piel. Univ. Católica. Univ. Central, Quito, Ecuador; Marcos Serrano, Director-Department of Biostatistics, Hospital Carlos Andrade Marin, Centro de la Piel-Quito, Quito, Ecuador



Scientific Program — Saturday, October 24

4:18 pm – 4:31 pm (304.3) Quality of Life in Childhood Epilepsy: A KIDSCREEN Comparison with Typical Children and Children with Cerebral Palsy

Meron Mezgebe, BHS, Mercer Univ., Atlanta, GA, United States; Gileh-Gol Akhtar-Danesh, BHS, McMaster Univ., Hamilton, ON, Canada; David Streiner, PhD; Nora Fayed, PhD; and Peter Rosenbaum, MD, McMaster Univ., Hamilton, ON, Canada, **Gabriel Ronen, MD, MSc, McMaster Univ., Hamilton, ON, Canada**

4:32 pm – 4:45 pm (304.4) Administration of the first German-speaking Computer Adaptive Test for assessing health-related quality of life in children and adolescents in a clinical sample: study design, methods and first validation results of the Kids-CAT study

Dana Barthel, Dipl.-Psych., Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Christiane Otto, PhD, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD; and Kathrin I. Fischer, M.Sc.med., Charite - Universitaetsmedizin Berlin, Berlin, Germany; Ute Thyen, MD, Univ. Medical Center Schleswig-Holstein, Lübeck, Germany; Marcus Klein, MD, Univ. Medical Center Schleswig-Holstein, Kiel, Germany; Otto Walter, PhD, MD; and Felix Fischer, ScD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Silke Schmidt, Prof., Ernst-Moritz-Arndt Univ. Greifswald, Greifswald, Germany; Holger Muehlan, PhD, Ernst-Moritz-Arndt Univ., Greifswald, Germany; Matthias Rose, MD PhD, Charite - Universitaetsmedizin Berlin, Berlin, Germany; Ulrike Ravens-Sieberer, PhD, MPH, Univ. Medical Center Hamburg-Eppendorf, Hamburg, Germany

Oral Session 305: Aging Worldwide

Boardroom

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

3:50 pm – 4:03 pm (305.1) General Health Perception Indicates Service Needs Post-Hospitalization Among Vulnerable Seniors

Sabrina Figueiredo, PhD Candidate, McGill Univ., Montreal, Canada; Alicia Rosenzweig, McGill Univ.; Jose Morais, MD, PhD, McGill Univ., McGill Univ. Health Centre; and Nancy Mayo, PhD, McGill Univ., Montreal, Canada

4:04 pm – 4:17 pm (305.2) Quality of Life among Senior Citizens in Bhutan: associations with adverse childhood experiences and recent stressful life events

Nidup Dorji, PhD Candidate, Khesar Gyalpo Univ. of Medical Sciences of Bhutan, Thimphu, Bhutan, Brisbane, Queensland, Australia; Michael Dunne, Professor; and Charlotte Seib, Lecturer, Queensland Univ. of Technology, Brisbane, Queensland, Australia; Sibnath Deb, Professor, Pondicherry Univ., Puducherry, Tamil Nadu, India

4:18 pm – 4:31 pm (305.3) Psychological risk factors and resources for early frailty detection in older adults

Simone Freitag, Ernst-Moritz-Arndt Univ. Greifswald, Greifswald, Germany; Silke Schmidt, Prof., Ernst-Moritz-Arndt Univ. Greifswald, Greifswald, Germany

4:32 pm – 4:45 pm (305.4) Health-related Quality of Life during Progression of Alzheimer's disease based on Latent Growth Curve Model

Hongmei Yu, Shanxi Medical Univ., Taiyuan, China; Yanbo Zhang, Shanxi Medical Univ., Taiyuan, China

4:46 pm – 4:59 pm (305.5) How can we interpret proxy reports of HRQL when it is no longer possible to obtain a self-report from people with dementia?

Sarah C. Smith, PhD, London School of Hygiene & Tropical Medicine, London, United Kingdom; A. A. Jolijn Hendriks, PhD; and Theopisti Chrysanthaki, PhD, London School of Hygiene & Tropical Medicine, London, United Kingdom; Stefan Cano, PhD, Modus Outcomes, Stofold, United Kingdom; Nick Black, PhD, London School of Hygiene and Tropical Medicine, London, United Kingdom

5:00 pm – 5:13 pm (305.6) Exploring the impact of the built environment on older adults' quality of life

Lidia Engel, MSc, Simon Fraser Univ., Vancouver, BC, Canada; Maureen C. Ashe, PhD; Anna Chudyk, MSc; and Heather A. McKay, PhD, The Univ. of British Columbia; David G. Whitehurst, PhD, Simon Fraser Univ.; and Stirling Bryan, PhD, Univ. of British Columbia, Vancouver, BC, Canada

7:00 pm – 10:00 pm

Closing Dinner

The Roof at The Fairmont Hotel Vancouver

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The Closing Gala Dinner will be held at **The Roof** located on the 15th floor of Fairmont Hotel Vancouver and offers panoramic views of snow-capped mountains, the Point Grey peninsula and the Strait of Georgia.

This restaurant first debuted in 1939 when the hotel first opened, and the venue became a national icon known for its dinner and dancing. It also served as an unconventional studio for CBC Radio who aired a weekly show from under the famous green copper roof for many years. As a nod to the Fairmont Hotel Vancouver's 75th anniversary, the space was re-launched to a new generation.

You will have a chance to hear musical performances from First Nations performers and a local musician, and to dance the night away with the help of one of Vancouver's leading deejays!

Tickets are required for this event.



Top Outstanding Posters

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Exhibitors

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Exhibit #2

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 #6

The Canadian Institute for Health Information (CIHI) (www.cihi.ca) is an independent, not-for-profit organization that provides essential information on Canada's health system and the health of Canadians. Our stakeholders use our broad range of health databases, measurements and standards, together with our evidence-based reports and analyses, in their day-to-day decision-making. We protect the privacy of Canadians by ensuring the confidentiality, integrity and availability of our health care information.



Exhibit #7

Concept Systems, Inc.'s mission is to support high quality research for improved individual and community wellbeing. Our unique blend of consulting and technology-supported methodologies empower organizations to capture and synthesize the voices of individuals, producing group knowledge for decisions and assessments. We are the expert in Group Concept Mapping (GCM), an adaptable tool for quality of life practitioners that has been widely used in Public Health and Healthcare for over 25 years. The methodology allows for refinement of patient reported outcomes, organization and prioritizing of programs and initiatives, and development of assessment structures.



Exhibit #3

Our mission at FACIT is to provide a voice for patients worldwide. Scientifically aligned with our partners at the Department of Medical Social Sciences at Northwestern University, FACIT.org and FACITtrans are uniquely positioned to provide cutting-edge health outcomes measurement science to the academic and the pharmaceutical research communities. FACIT.org serves as the licensor of the widely-used Functional Assessment of Chronic Illness Therapy system of questionnaires. FACITtrans provides multilingual translation services and linguistic to the research community. Stop by FACIT's table and allow us to show you all the NIH item banking collaborations in which we are privileged to serve.



Sponsors and Exhibitors



Exhibit #1

Health Research Associates celebrates its 20th year in business, specializing in the development, testing and preparation of Clinical Outcome Assessment tools (COAs) for use in clinical trials and other research studies. HRA skills include qualitative research, observational studies, validation and equivalency studies, translatability assessment, and linguistic validation.



Exhibit #5

Mapi Group™ has over 40 years of experience supporting Life-Science companies in utilizing Patient Reported Outcomes measures, Value communications and Commercialization support, Strategic Regulatory Services, and gathering Real-World Evidence on Pharmaceuticals, Biologicals, and Medical devices. Mapi Group is the premier provider of Health Research and Commercialization services to Life-Science companies. <http://www.mapigroup.com>.



Exhibit #4

Pharmerit International conducts worldwide research in the field of Health Economics and Outcomes Research. We help define, build, and communicate your product's clinical, humanistic, and economic value through a wide range of services tailored to your specific needs. Our global experts specialize in the assessment, development or modification, and psychometric validation of PRO measures and preference elicitation.

Exhibit Hall Layout

British Columbia Ballroom

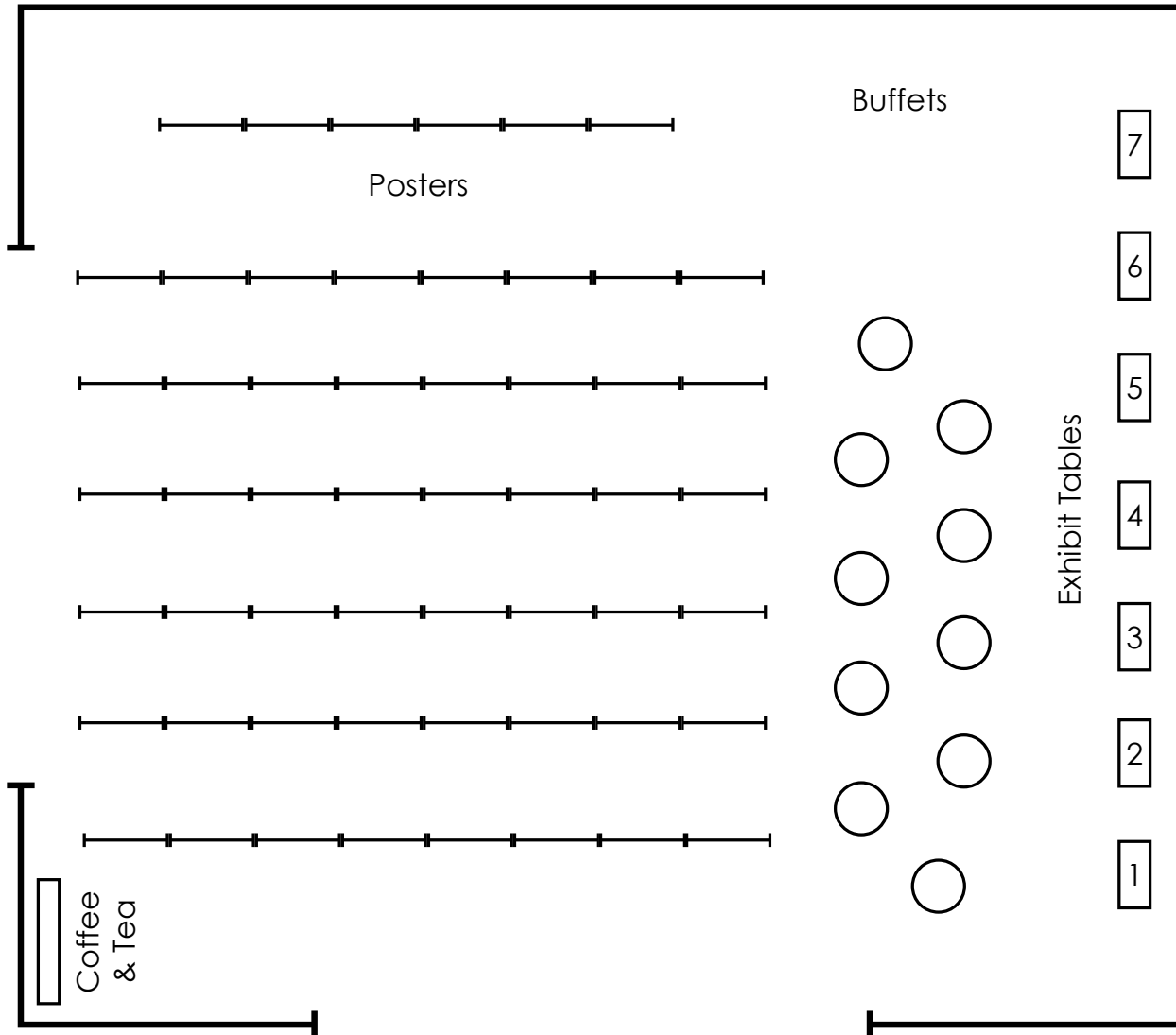


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