



24TH ANNUAL CONFERENCE

18–21 October 2017
Philadelphia, Pennsylvania

UNITED STATES

Embracing Complexity: Using Patient-Reported Outcomes to Generate Real World Evidence

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Embracing Complexity: Using Patient-Reported Outcomes to Generate Real World Evidence

WELCOME TO THE 24TH ANNUAL CONFERENCE OF THE INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH, 18 – 21 OCTOBER 2017

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Welcome from the Program Chairs

As Scientific Program Co-Chairs, we welcome you to Philadelphia for the 2017 Annual Conference of the International Society for Quality of Life Research. Our theme this year is *“Embracing Complexity: Using Patient-Reported Outcomes to Generate Real World Evidence.”* We believe that this conference provides an important opportunity to celebrate and demonstrate the application of sound scientific principles in the service of reducing the suffering of people with complex health conditions living in an increasingly complex healthcare ecosystem.

Our first plenary, “PROs in Patients with Multiple Chronic Conditions,” will explore the unique challenges for the growing numbers of patients with multiple chronic conditions and the potential for PROs to enhance research and care for these patients. The second plenary session will feature “Cutting Edge Research” – some of the most innovative and highest ranked research submitted to ISOQOL this year. The third plenary, “Communicating PRO Data to Support Complex Decision Making,” will examine opportunities for organizing health care systems to capitalize on the rapidly increasing amount of real-time patient-reported data available in clinical care settings.

In our fourth plenary session, “Past Wisdom for Present Problems,” we take a look back at two influential papers in the field of quality of life research and their current relevance and applications in both research and practice: Bergner’s “Quality of Life, Health Status, and Clinical Research” (1989) and Gill & Feinstein’s “A Critical Appraisal of the Quality-of-Quality of Life Measurements” (1994). Both of these articles provided a critical empirical and theoretical survey of the field over 20 years ago and advanced ideas about what could make the field stronger. How well has our field answered the challenges raised in these papers? What wisdom might they provide for addressing contemporary problems? We have engaged four ISOQOL luminaries to address these questions and to engage one another in debate. If the planning calls for this session are any indication, this will be a spirited and thought-provoking session you won’t want to miss!

Another unique feature of this year’s ISOQOL conference is that we have developed new activities taking advantage of the close proximity to several key U.S. sponsors of quality of life research. Representatives from both private and government organizations have agreed to make themselves available to the attendees in an effort to increase awareness of funding opportunities and to provide guidance regarding successful applications. On Thursday, there will be an open lunchtime panel discussing current funding opportunities in Quality of Life Research. We will also have a “Funder’s Table” located in USS New Jersey, where you can meet with representatives for one-on-one conversations (sign-up required). Finally, our funders have gallantly agreed to allow their name badges to highlight their role with a funding organization, so that you can identify and approach them throughout the conference.

This year’s conference will also feature many of the same excellent programs from prior years to encourage the fun and collegial exchange of ideas. The Mentor/Mentee Program and Roundtables are great opportunities to interact with major influencers in the field in a more informal setting. ISOQOL is continuing our SIG Meetings which provide members with a great outlet to connect with others who share similar interests. On the social side, connect with a small group of attendees and walk to a local restaurant on Friday evening for a dine-around (sign up required).

Have you ever wanted to dine on the oldest and largest square-rigged sailing vessel still afloat? We thought you would. That’s why our Closing Dinner will take place on the Moshulu on Saturday, 21 October at 7:00pm. Tickets for the Closing Dinner will be available at the registration desk through Friday, October 20 at 11:30 am, or while supplies last.

We hope that you enjoy an enjoyable and stimulating time in Philadelphia with colleagues, old and new!

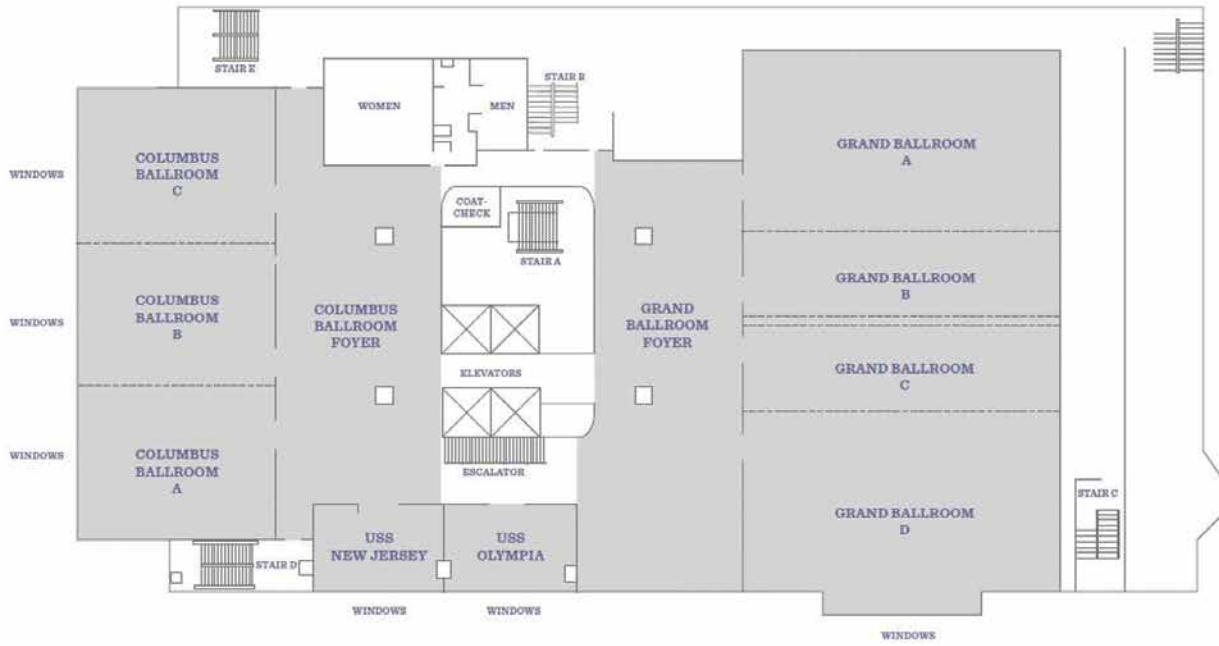
Roxanne Jensen, PhD, and Kevin Weinfurt, PhD
Scientific Program Committee Co-Chairs



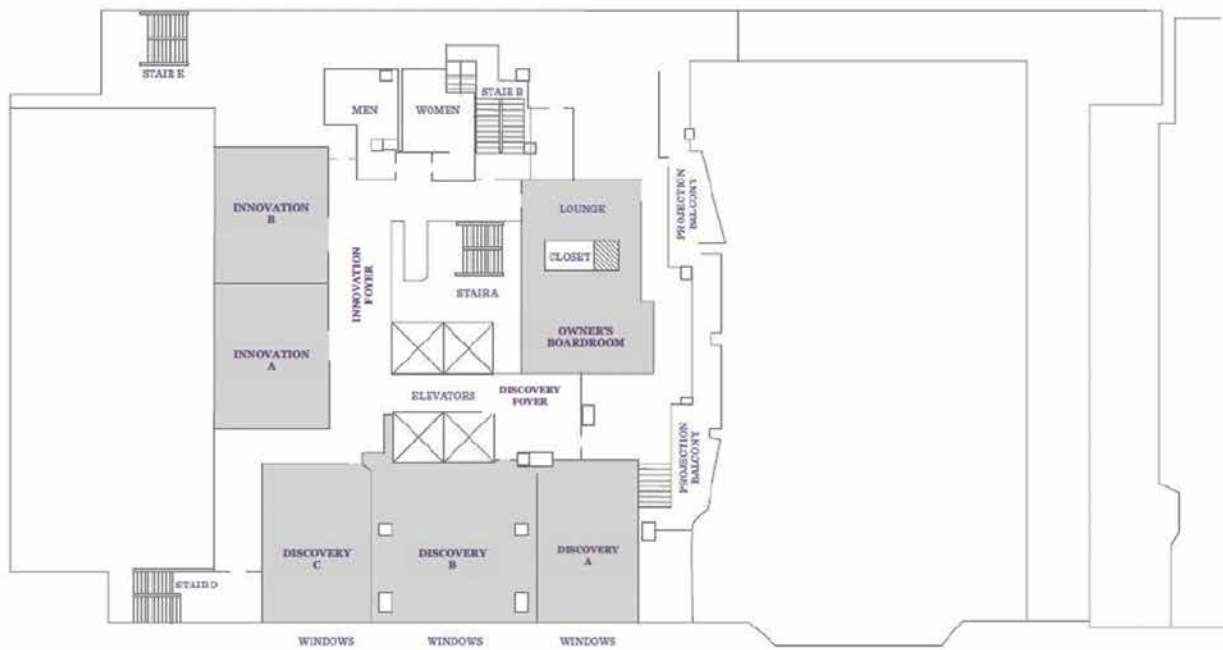
Hotel Floor Plan

Hilton Philadelphia at Penn's Landing Meeting Space

Second Floor



Third Floor



Schedule at a Glance

Wednesday, 18 October		
9:00 am - 4:00 pm	Intro to Patient-Reported Outcomes (IPRO) Course	Discovery A
9:00 am - 12:00 pm	Morning Workshops	
	WK01: An Introduction to Health-Related Quality of Life	Discovery BC
	WK02: Good Practice Guidance for Patient Engagement in Research	Grand ABC
	WK03: Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) – Qualitative Methodological Approaches for Data Collection, Analyses and Reporting	Innovation
	WK04: Interpretation Guidelines to Define Clinical Relevance for Patient-Reported Outcome (PRO) Measures	Grand D
12:00 pm - 1:00 pm	Lunch Break (Ticket Required)	
1:00 pm - 4:00 pm	Afternoon Workshops	
	WK05: Improving the design of clinical trials with PROs: guidance for protocol writers	Grand ABC
	WK06: Introduction to Latent Curve Modeling	Innovation
	WK07: Designing Quality of Life-driven Mobile Information Technologies	Grand D
	WK08: Patient-Reported Outcome (PRO) Measurement in Paediatric Clinical Practice: Special Considerations from Patient and Family Engagement to Implementation	Discovery BC
4:30 pm - 6:00 pm	Industry SIG (I-SIG) Symposium <i>Real-world evidence to support product approval and reimbursement: new frontier?</i>	Grand ABC
6:00 pm - 7:30 pm	Welcome Reception	Columbus Foyer/Grand Foyer

Thursday, 19 October		
7:00 am - 8:00 am	Continental Breakfast	Columbus Foyer/Grand Foyer
7:30 am - 8:00 am	First Time Attendee - Coffee with Board of Directors	Discovery ABC
8:00 am - 8:10 am	Welcome from Co-Chairs/Committee	Grand ABC
8:10 am - 8:30 am	President's Address	Grand ABC
8:30 am - 10:00 am	Plenary - PROs in Patients with Multiple Chronic Conditions	Grand ABC
10:10 am - 10:45 am	Thursday Poster Session I	Columbus Ballroom
10:55 am - 12:05 pm	Plenary - Cutting Edge Research	Grand ABC
12:05 pm - 1:45 pm	Lunch Break (Ticket Required)	Columbus Foyer/Grand Foyer

Schedule at a Glance

Thursday, 19 October		
12:25 pm - 1:30 pm	Committee/SIG/Other Meetings	
	Meet the Funders Meeting	Grand D
	Psychometrics SIG Meeting	Grand ABC
	Canada PRO SIG Meeting	Discovery BC
	United Kingdom and Ireland SIG Meeting	Innovation
	QLR Editorial Board Meeting (closed event)	Discovery A
1:45 pm - 3:15 pm	Concurrent Oral Sessions	
	<i>101: Cancer I</i>	Grand ABC
	<i>102: Statistical Methods</i>	Grand D
	<i>103: Aging Populations</i>	Discovery BC
	<i>104: Child and Adolescent Health</i>	Innovation
3:25 pm - 4:00 pm	Thursday Poster Session II	Columbus Ballroom
4:10 pm - 5:40 pm	Concurrent Oral Sessions	
	<i>105: Meaningful Differences for General Populations</i>	Grand ABC
	<i>106: Rehabilitation and Pain</i>	Grand D
	<i>107: Clinical Conditions 1</i>	Innovation
6:00 pm - 6:30 pm	New Investigator SIG Tricks of the Trade Presentation Simplicity - How to transfer complex research into effective presentations	Grand ABC
6:30 pm - 7:30 pm	Mentor/Mentee Reception (Ticket Required)	Discovery ABC

Friday, 20 October		
7:30 am - 8:30 am	Continental Breakfast	Columbus Foyer/Grand Foyer
7:45 am - 8:45 am	SIG Council Meeting (closed event)	Innovation
7:45 am - 8:45 am	Roundtables	
	<i>RT01 Host: Rachel Hess, MD MS PRO and EHR integration...Notes from the Field</i>	Discovery A
	<i>RT02 Host: Christopher B. Forrest, MD PhD Pediatric Patient-Reported Outcomes</i>	Discovery A
	<i>RT03 Host: Paul Kluetz, MD Beyond U.S. Drug labeling as the Sole Marker of a Successful PRO Strategy in Cancer Trials: Discuss with FDA the Utility of PRO Data in US Regulatory</i>	Discovery A
	<i>RT04 Host: Mogens Groenvold, MD PhD Making EORTC instruments more dynamic</i>	Discovery A
	<i>RT05 Host: Karon F. Cook, PhD But, what does this score mean? Interpreting scores from patient reported outcome measures.</i>	Discovery A
	<i>RT06 Host: Antonia Bennett, PhD New forms of patient generated health data in quality of life research</i>	Discovery A

Schedule at a Glance

Friday, 20 October		
9:00 am - 10:30 am	Plenary - Communicating PRO Data to Support Complex Decision Making	Grand ABC
10:35 am - 11:10 am	Friday Poster Session I	Columbus Ballroom
11:15 am - 12:30 pm	Concurrent Symposium Sessions	
	<i>Symposium 1: Users' Guide for Integrating Patient-Reported Outcomes in Electronic Health Records: Design and Implementation Considerations</i>	Grand ABC
	<i>Symposium 2: Using qualitative methods to explore and define estimates of clinically meaningful change and responders: advantages, challenges and solutions</i>	Grand D
	<i>Symposium 3: Enriching Quality of Life Research Through Appraisal Assessment: Measurement, Theory, and Empirical Evidence</i>	Innovation
12:30 pm - 2:00 pm	Lunch Break (Ticket Required)	Columbus Foyer/Grand Foyer
12:40 pm - 1:45 pm	Committee/SIG Meetings	
	Ibero America SIG Meeting	Discovery A
	Response Shift SIG Meeting	Grand D
	New Investigator SIG Meeting	Discovery BC
	QOL in Clinical Practice SIG Meeting	Innovation
	Translation and Cultural Adaptation SIG Meeting	Grand ABC
2:00 pm - 3:30 pm	Concurrent Oral Sessions	
	<i>201: PROs in Clinical Care</i>	Grand ABC
	<i>202: Cancer II: Measures for General Populations</i>	Grand D
	<i>203: Health Utility Measurement I</i>	Discovery BC
	<i>204: Methodological Advances I</i>	Innovation
3:35 pm - 4:10 pm	Friday Poster Session II	Columbus Ballroom
4:15 pm - 5:45 pm	Concurrent Oral Sessions	
	<i>205: Methods for Trials & Registries</i>	Grand ABC
	<i>206: Cancer III: Prostate and Bladder</i>	Grand D
	<i>207: Clinical Conditions II</i>	Discovery BC
	<i>208: Measurements in General Populations</i>	Innovation
7:00 pm	Dine Arouds	Meet in Lobby

Schedule at a Glance

Saturday, 21 October		
7:30 am - 8:30 am	Continental Breakfast	Columbus Foyer/Grand Foyer
7:30 am - 8:30 am	Australia and New Zealand SIG	Owner's Boardroom
8:30 am - 9:45 am	ISOQOL Member Business Meeting	Grand ABC
9:50 am - 10:10 am	Saturday Poster Session I	Columbus Ballroom
10:15 am - 11:00 am	Awards Presentation/President's Award & 2018 Conference Announcement	Grand ABC
11:00 am - 12:30 pm	Plenary - Past Wisdom for Present Problems	Grand ABC
12:30 pm - 2:00 pm	Lunch Break (Ticket Required)	Columbus Foyer/Grand Foyer
12:40 pm - 1:45 pm	Committee/SIG Meetings	
	Patient Engagement SIG Meeting	Grand D
	Mixed Methods SIG Meeting	Grand ABC
	Health Preference Research SIG Meeting	Discovery BC
	Child Health SIG Meeting	Innovation
	Industry SIG Meeting	Discovery A
2:00 pm - 3:15 pm	Concurrent Symposium Sessions	
	<i>Symposium 4: Putting ISOQOL's PRO User's Guide to the Test: Lessons from Three Real-World Case Studies</i>	Grand ABC
	<i>Symposium 5: Optimizing PROMIS for use with Individuals with Disabilities: Ensuring Condition Specific Validity in a Generic Measurement System</i>	Grand D
	<i>Symposium 6: Adolescents' Mental Wellbeing in China: Positive Contributions of Individual and Contextual Factors</i>	Discovery BC
3:20 pm - 3:40 pm	Saturday Poster Session II	Columbus Ballroom
3:50 pm - 5:20 pm	Concurrent Oral Sessions	
	<i>301: Cancer IV: Head, Neck & Breast</i>	Grand ABC
	<i>302: Methodological Advances II</i>	Grand D
	<i>303: Health Utility Measurement II</i>	Discovery BC
	<i>304: Mental Health</i>	Innovation
7:00 pm - 10:00 pm	Closing Dinner (Ticket Required) Moshulu	Off-site

A Step-By-Step Guide to Using the ISOQOL 2017 Annual Conference Mobile App

Step 1

Follow this link <http://eventmobi.com/isoqol2017conference/> to access and download the app.

Step 2

Save the webpage to your home screen. (Procedure may vary depending on mobile device).

Step 3

Login to the app using your preferred email address to access and personalize your conference schedule.

Step 4

Explore sessions and events through the agenda feature, or search for a specific event or speaker using our search bar.

To learn more about the event app and its features, please visit the registration desk.



General Conference Information

“Embracing Complexity: Using Patient-Reported Outcomes to Generate Real World Evidence”

Target Audience

The 24th 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. Symposia are selected based on peer-reviewed abstract submissions. Admission to these sessions is by name badge.

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.

Intro to Patient-Reported Outcomes (IPRO) Course

This course was developed by the Education Committee and is held on Wednesday, the “Pre-Conference” day of the 24th Annual Conference.

Description:

Collecting and acting upon Patient-Reported Outcomes (PROs) is one of the cornerstones of patient centered care. Choosing the right set of PROs can be challenging as there are many options, each with advantages and disadvantages. This one day, intensive and interactive educational course offers a curriculum that will provide a basic level introduction to the why and how of using PROs in research. Attendees will be given the opportunity to apply their learning throughout the course. This training is aimed at health professionals; medical scientists who are not experts in the use of PROs; consultants; pharmaceutical and medical device representatives; new investigators and research students; policymakers; and other associations and individuals who are interested in acquiring familiarity with the terms and methods of research on PROs.

Those that participate in the course will receive a certificate of attendance, upon completion of the course evaluation. Admission to the IPRO Course is by paid ticket only and seating is limited.

Industry Special Interest Group (I-SIG) 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.

Roundtables

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 roundtables is by paid ticket only and seating is limited.



General Conference Information

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 allocated for display is 94 cm (37 inches) wide by 135 cm (53 inches) tall. Posters must not exceed the allocated space and the exact poster dimensions are up to poster presenters.

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 during their assigned session (please refer to the 'Set up and Removal' chart, at right).

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 session in which they are assigned. A detailed schedule of set up and removal times is listed below.

	Thursday 19 October	Friday 20 October	Saturday 21 October
Morning Poster Set Up	7:00 - 10:00 am	7:00 - 10:00 am	7:00 - 9:00 am
Session 1 Presentations <i>Odd numbers</i>	10:10 - 10:45 am	10:35 - 11:10 am	9:45 - 10:15 am
Morning Poster Removal	11:00 am - 12:00 pm	11:30 am - 12:30 pm	11:30 am - 12:30 pm
Afternoon poster Set Up	1:00 - 3:00 pm	1:30 - 3:00 pm	1:30 - 3:00 pm
Session 2 Presentations <i>Even numbers</i>	3:25 - 4:00 pm	3:35 - 4:10 pm	3:20 - 3:50 pm
Afternoon poster Removal	4:30 - 5:30 pm	4:30 - 5:30 pm	4:00 - 5:00 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 Columbus Ballroom. The Poster Hall will be open daily from 7:00 am – 5:00 pm from Thursday, 19 October – Saturday, 21 October.

Registration Desk

ISOQOL accepts MasterCard, Visa, American Express, and Discover credit cards. Cash transactions may be made in US dollars. 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, 18 October: 7:00 am – 7:00 pm
Thursday, 19 October: 7:00 am – 6:30 pm
Friday, 20 October: 7:00 am – 5:45 pm
Saturday, 21 October: 7:00 am – 5:20 pm



General Conference Information

Boxed Lunch (Wednesday – Saturday)

If you purchased Boxed Lunch via the registration form, you will receive color-coded tickets for each day Boxed Lunch was selected. You are required to present the daily Boxed Lunch Ticket to the hotel staff to pick up your boxed lunch. Boxed Lunch tickets are not available for purchase on-site.

**Please note – Boxed Lunch is non-refundable and is only available for purchase via the registration form prior to the Advance Registration deadline of 11 September.*

Ticketed Events

A ticket is required for the Into to Patient-Reported Outcomes (IPRO) Course, all Workshops, Roundtables, and the Closing Dinner. Tickets are available at the Registration Desk while supplies last, through Friday, 20 October, 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 email 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 emailed the week following the conclusion of the conference.

Evaluations

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

Workshops attendees will receive paper evaluations at the workshops. Workshop evaluations can be returned to the instructor at the conclusion of the workshop or returned to the Registration Desk. Workshop evaluations should be completed and returned on Wednesday, 18 October.

Photography Disclaimer

By registering for the ISOQOL Annual Conference, you give consent to be photographed by ISOQOL staff for purposes of advertising and public display.

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 24th Annual Conference program will be archived online at <http://www.isoqol.org/annual-conference/past-conferences>.



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

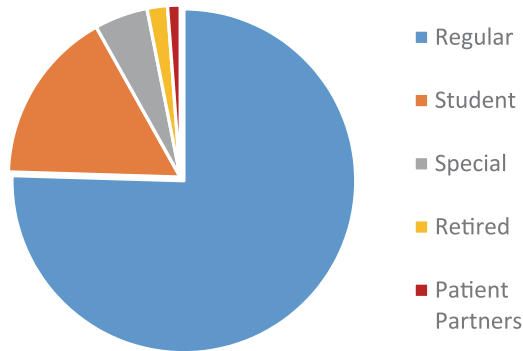
- Special Interest Group's Webinars
- Annual Conference
- Mentor/Mentee Program
- Measuring What Matters Symposium
- Intro to Patient-Reported Outcomes (IPRO) Course – Introduction to Quality of Life and other Patient-Reported Outcomes: Theory, Measurement, and Applications

Publications

- *Journal of Patient Reported Outcomes* (JPRO)
- *Quality of Life Research Journal* (QLR)
- *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)
- User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice Version 2 (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 2016



Benefits of Membership

As a member you belong to a global community of researchers, clinicians, industry professionals, government leaders, patients, and other professionals who share your passion for quality of life research.

ISOQOL membership provides access to a collection of tools, resources, content, development opportunities, and a vibrant community of peers.



Tools and Resources

- Free Access to the online subscription to the *Quality of Life Research Journal* (QLR)
- Discounted print subscription to *Quality of Life Research* (QLR)
- Access to ISOQOL's official open access journal, *Journal of Patient-Reported Outcomes* (JPRO)
- Updates from ISOQOL's newsletter – *Quality of Life Quarterly*
- Discounted access to PRO and QoL Instruments Database



Grow

- Online Education with reduced rates
- Discounted Annual Conference registration
- Discounted Measuring What Matters registration
- Reduced rate for Introductory to Patient-Reported Outcomes (IPRO) Course



Connect

- Serve in leadership roles and sit on ISOQOL Committees and Initiatives
- Participation in Special Interest Groups (SIGs) with access to Teamwork
- Access to ISOQOL membership directory

www.bibliopro.org

- Technical specifications for over **1350 instruments**
- **On-line sublicense application** for over 300 instruments
- **EMPRO** (Evaluating the Measurement of Patient-Reported Outcomes) for a standardized assessment of instruments

BiblioPRO

Virtual library of Patient-Reported Outcomes in Spanish

ISOQOL Leadership

Executive Committee



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Claire Snyder, PhD
United States



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United Kingdom



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Zoe Winters, DPhil MD
United Kingdom

Co-Editors of Journal of Patient-Reported Outcomes



David Feeny, PhD
Canada



Dennis Revicki, PhD
United States

Co-Editors of Quality of Life Research Journal



Jan. R. Boehnke, PhD
United Kingdom



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Netherlands

ISOQOL Office Staff



Executive Director
Colleen Pedersen



Meetings Manager
Marina Shawd



Committees

Advisory Council of Past Presidents

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Byrce Reeve, PhD United States – Co-Chair
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2006-2007 Madeleine T. King, PhD, Australia
2005-2006 Peter Fayers, PhD, United Kingdom
2004-2005 David Feeny, PhD, Canada
2003-2004 Albert W. Wu, MD MPH, United States
2002-2003 Mirjam AG Sprangers, PhD, Netherlands
2001-2002 David Osoba, MD, Canada
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

24th Annual Conference Scientific Program Committee

Roxanne Jensen, PhD, United States – Co-Chair
Kevin Weinfurt, PhD, United States – Co-Chair
Caroline Terwee, PhD, The Netherlands – Symposium Chair
Christopher B. Forrest, MD, PhD, United States – Local Rep.

Audit Committee

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Jose M. Valderas, MD, MPH, PhD, United Kingdom
Claire Snyder, PhD, United States

Education Committee

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William Lenderking, PhD, United States – Co-Chair
Ida J Korforge, PhD, Netherlands – Liaison
Juliana Bredemeier, PhD, Brazil – Mentor/Mentee Program Co-Chair
Maria-Jose Santana, PhD, Canada – Mentor/Mentee Program Co-Chair
Richard Sawatzky, PhD RN, Canada – Webinar Co-Chair
Thomas Willgoss, PhD, United Kingdom – Webinar Co-Chair
Nancy Mayo, PhD, Canada – Workshop Co-Chair
Skye Barbic, PhD OT, Canada – Workshop Co-Chair

Intro to Patient-Reported Outcomes (IPRO) Course

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Nancy E. Mayo, PhD, Canada – Co-Chair
Ida J. Korfage, PhD, Netherlands – Liaison
Jose M. Valderas, MD MPH PhD, United Kingdom
William Lenderking, PhD, United States
Ethan Basch, MD MSc, United States

Nominations Committee

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Sandra Nolte, PhD, Germany
David Eton, PhD, United States
Diana Rofail, PhD, CPsychol, United States

Standards & Best Practices Committee

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Melanie Calvert, PhD, United Kingdom – Chair-Elect
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Quality of Life Quarterly Newsletter Editor

Ana A. Popielnicki, BA, United States

Judging Panels

Scholarships

(New Investigator/Student, Developing Country and Patient Research Partner)

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Sam Salek, PhD RPh FFPM MRPSGB, United Kingdom – Co-Chair
Jose M. Valderas, MD MPH PhD, United Kingdom
Doris Mwesigire, MD Uganda
Andrea Cueva, Ecuador

Emerging Leader Award Committee

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Neil Aaronson, PhD, Netherlands – Co-Chair
Cynthia Gross, PhD, United States
Anne Klassen, DPhil, Canada
Bellinda King-Kallimanis, PhD, United States

Special Interest Groups (SIGs)

Australia

Ljoudmila Busija, PhD, Australia – Chair
Claudia Rutherford, Australia – Chair Elect
Rasa Ruseckaite, Australia – Chair Elect
Rebecca Mercieca-Bebber, PhD candidate Australia – Secretary/Treasurer
Mogens Groenvold, MD PhD, Denmark – Liaison

Canada PRO

Sara Ahmed, PhD, Canada – Co-Chair
Susan Bartlett, PhD, Canada – Co-Chair
Mogens Groenvold, MD PhD, Denmark – Liaison

Child Health

Nancy Young, PhD, Canada – Past Chair
Jeanne Landgraf, MA, United States – Chair
Anne-Catherine Haller, Dipl.-Psych., Germany – Chair Elect
Anne Klassen, DPhil, Canada – Liaison

Health Preference Research

Benjamin M. Craig, PhD, United States – Co-Chair
Richard L. Skolasky, ScD, United States – Co-Chair
Anne Klassen, DPhil, Canada – Liaison

Ibero American

Pedro L. Ferriera, PhD, Portugal – Co-Chair
Monica Avila Pacheco, BPharm MPH, Spain – Co-Chair
Sandra Nolte, PhD, Germany – Liaison

Industry

Josephine M. Norquist, MS, United States – Co-Chair
Emuella Flood, United States – Co-Chair
Diana Rofail, PhD CPsychol, United Kingdom – Liaison

Mixed Methods

Thomas Willgoss, PhD, United Kingdom – Co-Chair
Antoine Regnault, PhD, France – Co-Chair
Anne Klassen, DPhil, Canada – Liaison

New Investigator

Manraj Kaur, PhD, Canada – Co-Chair
Kathrin Fischer, Germany – Co-Chair
David T. Eton, PhD, United States – Liaison

Patient Engagement

Sam Salek, PhD RPh FFPM MRPSGB, United Kingdom – Chair
Kirstie Haywood, DPhil, United Kingdom – Chair Elect
Lori Frank, PhD, United States – Liaison

Psychometrics

Wen-Hung Chen, PhD, United States – Past Chair
Stacie Hudgens, MA (AbD), United States – Chair
RJ Wirth, United States – Chair Elect
Lori Frank, PhD, United States – Liaison

QOL Clinical Practice

Louise Humphrey, MSc, United Kingdom – Chair
Lotte Haverman, PhD, Netherlands – Chair Elect
Zoe Winters, PhD FRCS FCS, United Kingdom – Liaison

Response Shift

Veronique Sebillé, France – Co-Chair
Tolulope Sajobi, PhD, Canada – Co-Chair
Diana Rofail, PhD CPsychol, United Kingdom – Liaison

Translation & Cultural Adaptation

Sonya Eremenco, MA, United States – Chair
Benjamin Arnold, MA, United States – Chair Elect
Susan Bartlett, PhD, Canada – Liaison

United Kingdom and Ireland

Elizabeth Gibbons, MSc, United Kingdom – Co-Chair
John Brazier, PhD, United Kingdom – Co-Chair
Sandra Nolte, PhD, Germany – Liaison



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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 2017 President's Award recipient –

Nancy E. Mayo, PhD presented by Claire Snyder, PhD

- 2016 Carolyn E. Schwartz, ScD, United States *presented by Claire Snyder, PhD*
- 2015 Carol M. Moinpour, PhD, United States *presented by Galina Velikova, MD*
- 2014 Mirjam AG Sprangers, PhD *presented by Galina Velikova, MD*
- 2013 Peter Fayers, PhD *presented by Bryce B. Reeve, PhD*
- 2012 Diane Fairclough, DrPH *presented by Bryce B. Reeve, PhD*
- 2011 Carolyn C. Gotay, PhD *presented by Carol M. Moinpour, PhD*
- 2010 David Feeny, PhD *presented by Diane Fairclough DrPH*
- 2009 Ronald D. Hays, PhD *presented by Neil Aaronson, PhD*
- 2008 David Cella, PhD *presented by Donna Lamping, PhD*
- 2007 Dennis Revicki, PhD *presented by Madeleine T. King, PhD*
- 2006 David Osoba, MD *presented by Peter Fayers, PhD*
- 2005 Neil Aaronson, PhD *presented by David Feeny, PhD*
- 2004 Robert Kaplan, PhD *presented by Albert Wu, MD MPH*
- 2003 John E. Ware, PhD *presented by Mirjam AG Sprangers, PhD*
- 2002 George Torrance, PhD *presented by David Osoba, MD*
- 2001 Donald Patrick, PhD MSPH *presented by Ivan Barofsky, PhD*

Emerging Leader Award – In Honor of Donna Lamping

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

Congratulations to the 2017 Emerging Leader Award recipient – Skye Barbic, PhD OT

- 2015 Bellinda L. King-Kallimanis, PhD
- 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 (2016 Journal)

Shoshani, A., Mifano, K., & Czamanski-Cohen, J. (2016). The effects of the Make a Wish intervention on psychiatric symptoms and health-related quality of life of children with cancer: a randomised controlled trial. *Quality of Life Research*, 25(5), 1209-1218.

2016 Finalists

Janse, M., Sprangers, M. A., Ranchor, A. V., & Fleer, J. (2016). Long-term effects of goal disturbance and adjustment on well-being in cancer patients. *Quality of Life Research*, 25(4), 1017-1027.

Greco, C. M., Yu, L., Johnston, K. L., Dodds, N. E., Morone, N. E., Glick, R. M., ... & Colditz, J. (2016). Measuring nonspecific factors in treatment: item banks that assess the healthcare experience and attitudes from the patient's perspective. *Quality of Life Research*, 25(7), 1625-1634.

Previous Recipients

- 2015 Costa, D.S.J. Reflective, causal, and composite indicators of quality of life: A conceptual or an empirical distinction? *Qual Life Res* 2015; 24: 2057
- 2014 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.
- 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.



Awards and Scholarships

- 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.

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 2017 New Investigator and Student Presentation Finalists

New Investigator Oral Presentation

Kara Schick-Makaroff, PhD, University of Alberta, Edmonton, Alberta, Canada

Cutting Edge Research Plenary: Contextual considerations for introducing an electronic quality of life assessment and practice support system in palliative home care

Oluwagbohunmi Awosoga, PhD, University of Lethbridge, Lethbridge, Alberta, Canada

104.3: Impacts of Caring for Youth with Severe Disabilities on Parents' Quality of Life

Antoine Vanier, MD PhD, INSERM - University of Nantes - University of Tours, Nantes, France

105.1: What are all the proposed methods to estimate the Minimal Clinically Important Difference of a Patient-Reported Outcomes Measure? A systematic review.

New Investigator Poster Presentation

Samantha Anthony, PhD MSW, The Hospital for Sick Children, Toronto, Ontario, Canada

2003: Patient-Reported Outcome Measures within Pediatric Solid Organ Transplantation: A Systematic Review

Derek Kyte, PhD, University of Birmingham, Birmingham, United Kingdom

2005: Systematic Evaluation of Patient-Reported Outcome (PRO) Protocol Content and Reporting in Cancer Clinical Trials: The EPiC Study

Alexander Obbarius, MD, Charité - Universitätsmedizin Berlin, Berlin, Germany

2007: Is Personality Pathology a unidimensional construct? Development of a Personality Pathology Item Bank based on the OPD Structure Questionnaire.

Student Oral Presentation

Josh Biber, MBA, University of Utah, Salt Lake City, Utah, United States

201.4: Comparing automated mental health screening to manual processes in a health care system

Mike Horton, PhD Student, University of Leeds, Leeds, United Kingdom

206.4: The Life After Prostate Cancer Diagnosis (LAPCD) study: Psychometric Evaluation of the Expanded Prostate Cancer Index Composite-26 (EPIC-26) using Rasch Analysis

Emilie Charton, University Hospital of Besançon, Besançon, France

207.2: Time to health-related quality of life score deterioration at 1-year follow-up after immediate latissimus dorsi breast reconstructions: a prospective study in breast cancer

Student Poster Presentation

Lene Kongsgaard Nielsen, Quality of Life Research Center, Odense University Hospital, Odense, Denmark

2004: Health-related quality of life in non-transplant eligible newly diagnosed multiple myeloma patients treated with melphalan/prednisolone plus either thalidomide or lenalidomide; results of the HOVON87/NMSG18 study.

Kyle Kemp, MSc, University of Calgary, Calgary, Alberta, Canada

2006: Night Noise in Hospitals is Linked with Unplanned Readmissions: A Retrospective, Canadian Investigation

Asma Qannas, MS, NJPCA, Philadelphia, Pennsylvania, United States

2008: Impact of Hemodialysis on the Physical and Psychological Well-being among End-Stage Renal Disease Patients in the Gaza-Strip



Awards and Scholarships

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 highlighted in the Final Program 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.

Congratulations to the 2017 Outstanding Poster Award Finalists

Outstanding Poster Finalist Award Session I

Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy
1003: The FA-IPSS(h): A New Index Combining Clinical Data and Patient-Reported Outcomes to Improve Prognostication for Myelodysplastic Syndromes

John Chaplin, PhD, Inst. Clinical Sciences, Sahlgrenska Academy at the University Gothenburg, Sweden, Gothenburg, Sweden
1005: A journey into the future: a focus group analysis of themes related to the quality of life of adolescents with narcolepsy

Talia Miller, MSQ MPH, Health Research Associates, Seattle, Washington, United States
1007: Qualitative Study to Identify Patient-Perceived Impacts of Statin Intolerance

Outstanding Poster Finalist Award Session II

Richard Sawatzky, RN PhD, Trinity Western University, Langley, British Columbia, Canada
1004: The Use of Latent Variable Mixture Models to Identify Invariant Items for the Measurement of Patient-Reported Outcomes

Raymond Baser, MS, Memorial Sloan Kettering Cancer Center, New York, New York, United States
1006: The PROscorer R Package: An Extensible Repository of Open-Source Scoring Functions for Commonly-Used PROs, Designed to Eliminate Scoring Errors and Establish Best Practices for Consistent and Reproducible PRO Scoring

Michelle White, PhD, Optum, Johnston, Rhode Island, United States
1008: A Novel Approach to Measuring Disease Progression in Duchenne Muscular Dystrophy: Results from Clinician Interviews

Scholarships

Developing Country Scholarship

Fredrick Purba, MSc, Indonesia
Wenjje Duan, PhD, China

New Investigator and Student Scholarship

Rebecca Mercieca-Bebber, PhD Candidate, Australia
Nina Deliu, MSc, Italy
Jessica Roydhouse, PhD, United States

Patient Engagement Scholarship

Philip Posner, PhD, United States
Jennifer Bostock, BA, MA, PhD, United Kingdom



Thank you to the 2017 Abstract Reviewers

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Andrew Bottomley, PhD
Andrew Palsgrove, BA
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Barbara Gandek, PhD
Benoit Arnould, PhD
Brittany Lapin, PhD
Canhua Xiao, PhD
Carolyn E. Schwartz, ScD
Chinmay Deshpande
Christine Blome, PhD
Cindy Nowinski, MD PhD
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Lauren Lent, DHA, MS
Ligia M. Chavez, PhD
Lori Frank, PhD
Marcelo P. Fleck, MD PhD
Martha Shumway, PhD
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Nathan A. Pearson, BSc, MSc
Rebecca Mercieca-Bebber
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Juliana Bredemeier, Psychologist,
PhD.
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Robin Pokrzywinski, MHA
Shreekant Parasuraman, PhD
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Plenary Speakers



Jan R. Boehnke

Dundee Centre for Health and Related Research
School of Nursing and Health Sciences
University of Dundee
Dundee, United Kingdom

Jan R. Boehnke is Senior Research Fellow in Evaluation Design and Research Methods at the University of Dundee. He characterises his research as 'psychometric epidemiology', combining contemporary statistical methods with population-sensitive approaches to mental illnesses, their comorbidities, and quality of life. Before joining the Dundee Centre for Health and Related Research, he studied psychology and political sciences and worked for more than a decade as a Co-Investigator on large-scale evaluation projects across mental health, development policy, education, and as a trial statistician in industry, holding positions in Germany (Berlin, Trier, Kassel) and the UK (York). Since 2015 Jan serves on the editorial board of Quality of Life Research and he currently holds a Visiting Senior Research Fellowship at the University of York.



Cynthia Boyd, MD, MPH

Johns Hopkins Bloomberg School of Public Health
Townson, Maryland, United States

Cynthia Boyd, MD MPH is Professor of Medicine, Epidemiology and Health Policy and Management at Johns Hopkins University. Dr. Boyd is trained as a geriatrician, and her research interests focus on people living with multiple chronic conditions. She is a lead investigator on a PCORI methods project titled: "Informing Patient-centered Care for People with Multiple Chronic Conditions," and has led extensive work on this population across the translational path including epidemiology and the design and conduct of clinical trials, methods to develop a synthesis of the evidence base that informs patient-centered care of people with multiple chronic conditions, and how clinical practice guidelines and quality measures can be more relevant to people with multiple chronic conditions.



Helen Burstin, MD, MPH, FACP

National Quality Forum
Washington D.C., United States

Helen Burstin, MD, MPH, FACP is the chief scientific officer (CSO) of the National Quality Forum (NQF), a not-for-profit membership organization that works to catalyze healthcare improvement through quality measurement and

reporting. She provides strategic guidance to all NQF work from the perspective of current and emerging measurement science. She also provides scientific oversight for the evaluation, endorsement and selection of quality measures and the transition to electronic performance measurement.

Prior to her appointment as NQF's CSO, Dr. Burstin served as the organization's senior vice president for performance measurement. Before joining NQF in 2007, Dr. Burstin was the director of the Center for Primary Care, Prevention, and Clinical Partnerships at the Agency for Healthcare Research and Quality. Prior to that, she was an assistant professor at Harvard Medical School and the director of quality measurement at Brigham and Women's Hospital.

Dr. Burstin chaired the Quality Measures Workgroup of the U.S. Department of Health and Human Services' Health IT Policy Committee and was a 2015-2016 Baldrige Executive Fellow. She serves on the board of directors of AcademyHealth.

Dr. Burstin has authored more than 80 articles and book chapters on quality, safety and disparities. She is a professorial lecturer in the Department of Health Policy at George Washington University School of Public Health and a clinical associate professor of medicine at George Washington University, where she serves as a preceptor in internal medicine. She was awarded the Alpha Omega Alpha Medical Voluntary Attending Award from the George Washington School of Medicine.



Karon Cook, PhD

Northwestern University
Houston, Texas, United States

Dr. Karon Cook is Research Professor at the Feinberg School of Medicine, Northwestern University, Chicago, IL. Her work has focused both on applications of modern psychometric approaches and on advancing methodological science. In recent years Dr. Cook has promoted the need for better methods for interpreting scores on health outcome measures. She and her colleagues at Northwestern University have applied approaches developed in educational testing to the interpretation of scores from health measures. This has included applying a "Bookmarking" method to develop cut scores for symptom severity levels (e.g., no problems, moderate, mild, severe) in the context of patient reported outcomes. She has recently applied similar methods in the estimation of thresholds for meaningful change scores. Dr. Cook has served as principle investigator on multiple grants and contracts funded

Plenary Speakers

by National Institutes of Health, Agency for Healthcare Research and Quality, the Department of Defense, and VA Health Services and Rehabilitation Research. She is also known for her efforts in developing accessible webinars and presentations on the science of PROs.



Lynn DeBar, PhD

Center for Health Research
Kaiser Permanente
Seattle, Washington, United States

Lynn DeBar PhD MPH is a senior investigator at the Kaiser Permanente Center for Health Research in Portland Oregon with broad experience studying conditions at the interface of medical and mental health including complex multi-morbidity and chronic pain disorders. Her research has focused on how to optimally address these health issues and behaviors in primary care settings and general medical practices through pragmatic clinical trials adapting evidence-based interventions for use in everyday practice settings including scalable means for the routine collection of patient reported outcomes. Dr. DeBar originally trained as a clinical health psychologist and did her doctoral work at Yale University and received her MPH in biostatistics and epidemiology from Oregon Health & Science University.



Louise Humphrey, MSc

Clinical Outcomes Solutions
Dundee, United Kingdom

Louise Humphrey works for Clinical Outcomes Solutions based in the UK and USA. In her role as Director of Clinical Outcome Assessments (COA), Louise is responsible for providing senior leadership on projects focused on the development, validation and implementation of COAs including participant, observer- and clinician-reported instruments as well as performance measures. She has been involved in measurement development and validation studies for over 10 years, and has experience in a wide variety of therapeutic areas with specific interests in pain, fatigue and women's health issues. Louise leads the strategic development and validation of COA instruments (involving quantitative and qualitative research) on international studies and writes regulatory submission dossiers for those instruments; in addition, she has developed measures for assessing side effects, treatment adherence, satisfaction and caregiver burden. She is also an experienced qualitative interviewer conducting hundreds of patient and clinician interviews.

Prior to joining Clinical Outcome Solutions, Louise was a consultant for the Critical Path Institute's PRO Consortium and between 2013-2015, she led the COA business at Abacus International. Louise was a Director at Adelphi Values (formally MAPI Values) where she worked for seven years in the Endpoint Development and Outcomes Assessment team. She has a First-Class degree in Psychology from the University of Liverpool, UK and an MSc (Dist.) in Social and Organizational Psychology from the University of Exeter, UK.

Louise is an active member of International Society for Pharmacoeconomics and Outcomes Research and International Society for Quality of Life Research (ISOQOL) including ISOQOL's Industry Special Interest Group. She is currently co-chair of ISOQOL's Quality of Life in Clinical Practice Special Interest Group. Louise is an active reviewer for several industry-leading journals and has published research in peer reviewed journals, conference abstracts and presentations.



Madeleine King, BSc(Hons), DipMedStat, PhD

Cancer Australia Chair in Quality of Life
University of Sydney
Sydney, New South Wales, Australia

Professor Madeleine King (BSc(Hons), DipMedStat, PhD) is the Cancer Australia Chair in Cancer Quality of Life (QOL), and Director of the QOL Office at the University of Sydney. She has an eclectic skill set spanning biostatistics, psychometrics, health economics and epidemiology. As a research academic fascinated by the many aspects of PRO science, she has tracked the evolution of PRO science over several decades, contributing to methods for interpreting PROs and incorporating QOL into economic evaluation. In Australia, she advises the national network of Cancer Clinical Trials Groups on best practice for patient-reported outcomes (PROs) in clinical trials. She has a long record of leadership in ISOQOL, and was its president in 2007. She currently co-chairs the ISOQOL task force in Best Practice for PROs in RCTs, which fits well with her commitment to improving the standards of QOL and PRO research in clinical trials, from protocol development through to peer-review reporting.



Bryce Reeve, PhD

Duke University
Durham, North Carolina, United States

Dr. Bryce Reeve is a Professor within the Gillings School of Global Public Health and member of the Lineberger Comprehensive Cancer

Plenary Speakers

Center at the University of North Carolina at Chapel Hill. Dr. Reeve's work focuses on enhancing the application of patient-reported data in clinical research and practice to improve the quality of care for pediatric and adult cancer patients. This includes the development of patient-reported questionnaires using qualitative and quantitative methodologies and integration of patient-reported data in research and healthcare delivery to inform decision-making.

From 2000 to 2010, Dr. Reeve served as Program Director at the U.S. National Cancer Institute. In that role, he was instrumental in the development and support for the PROMIS and the PRO-CTCAE initiatives. He joined UNC in 2010 where he leads an active program conducting research in pediatric and adult populations with cancer and other diseases. He currently serves or has served as PI on two NIH-funded R01 grants, a NIH U01 grant, a NIH U19 grant, a NIH R25 grant, and a PCORI-funded contract.

Dr. Reeve recently served as President of the International Society for Quality of Life Research. He is a member of the ALLIANCE's Health Outcomes Committee. In 2015, he was awarded the John Ware and Alvin Tarlov Career Achievement Prize in Patient-Reported Outcomes Measures. Dr. Reeve loves chocolate and red wine.



Kara Schick-Makaroff

University of Alberta
Edmonton, British Columbia, Canada

Kara Schick-Makaroff is a Can-SOLVE CKD - KRESCENT New Investigator (Canadians

Seeking Solutions & Innovations to Overcome Chronic Kidney Disease; Kidney Research Scientist Core Education & National Training Program), and an Assistant Professor (Faculty of Nursing, University of Alberta, Canada). Her research focus is enhancement of quality of life for people living with chronic and life-threatening illnesses, particularly chronic kidney disease. A major component of Dr. Schick-Makaroff's research involves the routine use of electronic patient-reported outcomes (ePROs) in multidisciplinary care. The goal of her research program is to learn how to best support clinicians and administrators in using ePRO information to enhance quality of life, enrich person-centred care, and improve services for people living with chronic and life-threatening illnesses.



Michael Seid, PhD

UC Department of Pediatrics
Cincinnati, Ohio, United States

Michael Seid, PhD, is Professor of Pediatrics in the UC School of Medicine, Director of Health Outcomes and Quality of Care Research in the Division of Pulmonary Medicine and holds a joint appointment with the James M Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center.

Dr. Seid applies behavioral and social science to answer the question 'What does it take to make sure the right treatment gets to the right child in the right way at the right time, every time?' In this quest, he collaborates broadly with patients and families, clinicians, social scientists, epidemiologists, designers, policy makers, computer engineers and developers, and creatives.

With James Varni, PhD, he was a co-developer of the PedsQL, a widely used generic pediatric health-related quality of life measure. With Peter Margolis, MD PhD, he was co-Principal Investigator of the C3N Project, funded by a Transformative Research Award from the NIH to design and test a new system for transforming chronic care. He is co-PI on the ImproveCareNow PPRN, and a co-I for the National Pediatric Learning Health System CDRN, funded by PCORI, and PI for the Cystic Fibrosis C3N pilot, funded by the CF Foundation. He has been Principal and co-Principal Investigator of numerous large multidisciplinary federally-funded research studies and publishes widely in such journals as Medical Care, HSR: Health Services Research, Archives of Pediatrics and Adolescent Medicine, Pediatrics, BMJ Quality and Safety, the Journal of Ambulatory Pediatrics, and Milbank Quarterly.



Ida Sim, MD, PhD

Department of Medicine
UCSF School of Medicine
San Francisco, California, United States

Ida Sim, MD, PhD is a primary care physician, informatics researcher, and entrepreneur. She is a Professor of Medicine at the University of California, San Francisco, where she co-directs Biomedical Informatics at UCSF's Clinical and Translational Sciences Institute. Her research focuses on computational methods for data sharing and decision making for clinical research and mobile health. She is a co-founder of Open mHealth, a non-profit organization that is building open standards and open source tools for integrating mobile health data. Her mobile health research projects include management of hypertension

Plenary Speakers

and depression in primary care, N-of-1 studies on wellbeing and on chronic pain management, and mobile sensor-driven just-in-time adaptive studies for behavior change. She is also a co-investigator with the Mobile Data to Knowledge NIH Center of Excellence that is building analytic platforms for real-time mobile data analysis. Around clinical trials data, Dr. Sim led the development of the World Health Organization's International Clinical Trials Registry Platform and the first global trial registration policy. She is a co-founder of Vivli, a global clinical trials data sharing platform.

Dr. Sim has served on multiple advisory committees on health information infrastructure for clinical care and research, including committees of the National Research Council and National Academy of Medicine. She is a recipient of the United States Presidential Early Career Award for Scientists and Engineers (PECASE), a Fellow of the American College of Medical Informatics, and a member of the American Society for Clinical Investigation.



Susan M. Smith, MD, MRCRI, MRCGP

HRB Centre for Primary Care Research
RCSI Department of General Practice
Dublin, Ireland

Susan Smith is Professor of Primary Care Medicine in RCSI Medical School and also works as a Family Practitioner at Inchicore Family Doctors in Dublin 8. Her research interests relate to the primary care of patients with chronic conditions with a focus on improving outcomes for patients with multimorbidity and related clinical issues such as medicines management. She has been the lead investigator on several RCTs based in Irish general practice and has recently coordinated the development of a COS for multimorbidity. She has an interest in systematic reviews and is an active author and editor with the Cochrane Collaboration.



Danny Young-Afat, PhD-student

University Medical Center Utrecht
Utrecht, Netherlands

Danny Young-Afat is a PhD-student at the University Medical Center Utrecht (Netherlands). In 2018, he will defend his PhD thesis on 'Patient-centered innovations in breast cancer research and treatment'. During his PhD fellowship, he set up a longitudinal cohort of (currently 1900) breast cancer patients, according to the novel 'cohort multiple Randomized Controlled Trial' design (i.e. UMBRELLA cohort). He has evaluated (ethical) pros and cons of

this new design in the field of oncology. In addition, his research focuses on health apps and patient-reported outcomes. During these past 4 years, he was simultaneously trained as a clinical epidemiologist in the MSc Epidemiology Postgraduate program of the University of Utrecht. In 2016 he completed a research fellowship at Memorial Sloan Kettering Cancer Center (New York), where he developed a computer adaptive testing version of BREAST-Q's 'Satisfaction with Breasts' scale (under supervision of Andrea Pusic and Anne Klassen). He is currently a Plastic and Reconstructive surgery resident (VU University Medical Center, Amsterdam, the Netherlands).



Albert Wu, MD, MPH

Johns Hopkins Bloomberg School of Public Health
Baltimore, Maryland, United States

Albert W. Wu is practicing internist and Professor of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health, with joint appointments in Epidemiology, International Health, Medicine and Surgery, and the Carey Business School. He directs the Center for Health Services and Outcomes Research and PhD Program in Health Services Research. He has been at Johns Hopkins since 1990, where his research and teaching focus on patient outcomes and quality of care. He was President of the International Society for Quality of Life, and has authored over 400 peer review publications. He was the first to study patient-reported outcomes (PRO) in HIV/AIDS clinical trials, including the original Burroughs Wellcome clinical trial of AZT. He founded the Outcomes Committee within the NIH AIDS Clinical Trials Group, which designed and implemented measures of health-related quality of life, symptoms, adherence and cost. He led PRO assessment for multiple national and international trials networks and cohort studies, and helped develop the leading measures in the field, including the MOS-HIV Health Survey, the ACTG HIV Symptom Index, and the ACTG Adherence questionnaires. He was responsible for assessing PRO in the Robert Wood Johnson funded SUPPORT study of seriously ill hospitalized adults, and developed the first clinical models to predict future functional status. He has been a thought leader on the use of PRO data in clinical practice, and incorporation of PRO data into the electronic health record. He earned a BA and MD from Cornell University, and MPH from the University of California, Berkeley.



Scientific Program — Wednesday, 18 October

Wednesday, 18 October

7:00 am – 7:00 pm Registration Desk Open Grand Foyer, 2nd Floor

9:00 am – 4:00 pm IPRO Course (*Ticket Required*) Discovery A, 3rd Floor

9:00 am – 12:00 pm Morning Workshops (*Ticket Required*)

WK01: An Introduction to Health-Related Quality of Life **Discovery BC, 3rd Floor**
Heather Gelhorn, PhD, Evidera, Bethesda, MD, United States; Kathleen Wyrwich, PhD, Eli Lilly & Company, St. Louis, MO, United States

WK02: Good Practice Guidance for Patient Engagement in Research.....**Grand ABC, 2nd Floor**
Kirstie Haywood, DPhil, BSc (Hons), Warwick Medical School, Solihull, United Kingdom; Maarten de Wit, PhD, VU Medical Centre, Zaltbommel, Netherlands; Sophie Staniszewska, DPhil, BSc, Warwick Medical School, Coventry, United Kingdom; Jan Horenjeff, PhD, Patient Research Partner, New York, NY, United States; Sally Crowe, Crowe Associates Ltd., Oxford, United Kingdom; Lori Frank, PhD, Patient-Centered Outcomes Research Institute, Kensington, MD, United States; Sam Salek, PhD, BSc, University of Hertfordshire, Cardiff, United Kingdom

WK03: Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) – Qualitative Methodological Approaches for Data collection, Analyses and Reporting..... **Innovation, 3rd Floor**
Anne Skalicky, MPH, Evidera, Seattle, WA, United States; Susan Magasi, PhD, University of Illinois at Chicago, Chicago, IL, United States; Asha Hareendran, PhD, Evidera, London, United Kingdom

WK04: Interpretation Guidelines to Define Clinical Relevance for Patient-Reported Outcome (PRO) Measures **Grand D, 2nd Floor**
Kim Cocks, PhD, Adelphi Values, Cheshire, United Kingdom; Madeleine King, PhD, University of Sydney, Sydney, Australia; Jammbe Musoro, EORTC HQ, Brussels, Belgium; Corneel Coens, EORTC HQ, Brussels, Belgium; Kate Sully, PhD, Adelphi Values, Cheshire, United Kingdom

12:00 pm – 1:00 pm Lunch Break

If you purchased Boxed Lunch via the registration form, please present your Wednesday Lunch Ticket to one of the hotel staff to pick up your Boxed Lunch in the Columbus Foyer on the second floor.

Please note – Boxed Lunch tickets are **not available for purchase on-site.*



Scientific Program — Wednesday, 18 October

1:00 pm – 4:00 pm Afternoon Workshops (*Ticket Required*)

WK05: Improving the design of clinical trials with PROs:

guidance for protocol writers.....Grand ABC, 2nd Floor
Melanie Calvert, PhD, The University of Birmingham, Birmingham, United Kingdom; **Derek Kyte, PhD**, University of Birmingham, Edgbaston, United Kingdom; **Rebecca Mercieca-Bebber**, The University of Sydney, Sydney, Australia; **Madeleine King, PhD**, University of Sydney, Sydney, Australia

WK06: Introduction to Latent Curve Modeling Innovation, 3rd Floor

James McGinley, PhD, Vector Psychometric Group, Irwin, PA, United States; **R.J. Wirth, PhD**, Vector Psychometric Group, Chapel Hill, NC, United States

WK07: Designing Quality of Life-driven Mobile Information Technologies Grand D, 2nd Floor

Katarzyna Wac, PhD, University of Geneva, Carouge, Switzerland

WK08: Patient Reported Outcome (PRO) Measurement in Pediatric Clinical Practice: Special Considerations from Patient and Family Engagement to Implementation

.....Discovery BC, 3rd Floor
Lotte Haverman, PhD, Emma Children's Hospital – Academic Medical Centre, Amsterdam, Netherlands; **Maria Santana, PhD**, University of Calgary, Calgary, AB, Canada; **Nancy Young, PhD**, Laurier University, Sudbury, ON, Canada; **Samantha Anthony, PhD, MSW**, The Hospital for Sick Children, Toronto, ON, Canada

1:30 pm - 2:30 pm JPRO Editorial Board Meeting (*Closed Event*) Owner's Boardroom, 3rd Floor

4:30 pm – 6:00 pm Industry Special Interest Group (I-SIG) Symposium Grand ABC, 2nd Floor

Real-word evidence to support product approval and reimbursement: new frontier?

The I-SIG symposium will identify what aspects of real world evidence are important for Industry and how patient-centric outcomes from real-world studies fit within the overall product development. An overview of real-world evidence studies, current regulatory and HTA perspectives, and case examples will be presented. A panel discussion will focus on key challenges and potential solutions in this area and future applications for these data.

Moderator:

Josephine Norquist, MS, Merck Sharp & Dohme Corp., North Wales, PA, United States

Speakers:

Will Maier, MPH, PhD, Mapi, London, United Kingdom

Michelle Stewart, PhD, Pfizer Global Development Headquarters, New London, CT, United States

Admission to the I-SIG Symposium is included with the conference registration fee.

6:00 pm – 7:30 pm Welcome Reception Columbus Foyer/Grand Foyer, 2nd Floor

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

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



Scientific Program — Thursday, 19 October

7:00 am – 6:30 pm Registration Desk Open Grand Foyer, 2nd Floor

7:30 am – 8:00 am First Time Attendee – Coffee with the ISOQOL Board of Directors Discovery ABC, 3rd Floor

8:00 am – 8:10 am Welcome and Opening Remarks Grand ABC, 2nd Floor

Official welcome and opening remarks.

Roxanne Jensen, PhD and Kevin Weinfurt, PhD, Scientific Program Co-Chairs

8:10 am – 8:30 am President's Address Grand ABC, 2nd Floor

Claire Snyder, PhD, ISOQOL President

8:30 am – 10:00 am Plenary – PROs in Patients with Multiple Chronic Conditions Grand ABC, 2nd Floor

Plenary sponsored by: EORTC

There is increasing interest in understanding and caring for the growing numbers of people with multiple chronic health conditions. In this plenary session we will explore the challenges for this population and the potential for PROs to enhance research and care for people with multiple chronic conditions.

Chair

Jordi Alonso, MD, PhD, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

Speakers

Cynthia Boyd, MD, MPH, John Hopkins University, Towson, MD, United States

Susan M. Smith, MD, MRCRI, MRCGP, RCSI Dublin, Dublin, Ireland

Lynn DeBar, PhD, Kaiser Permanente Washington Research Institute, Seattle, WA, United States

10:00 am – 11:30 am Poster Hall Open Columbus Ballroom, 2nd Floor

10:00 am – 10:55 am Exhibits Open and Refreshment Break Columbus Foyer/Grand Foyer, 2nd Floor

10:10 am – 10:45 am Thursday Poster Session I Columbus Ballroom, 2nd Floor

(1003) The FA-IPSS(h): a new index combining clinical data and patient-reported outcomes to improve prognostication for myelodysplastic syndromes

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; **Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy**; Gregory Abel, Division of Population Sciences, Dana-Farber Cancer Institute, Harvard Medical School, Boston, MA, United States; Pasquale Niscola, Hematology Unit, Sant'Eugenio Hospital, Roma, Italy; Gianluca Gaidano, Division of Hematology, Department of Translational Medicine, University of Eastern Piedmont, Novara, Italy; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Giovanni Caocci, Department of Medical Sciences, University of Cagliari, Cagliari, Italy; Angel Cronin, Division of Population Sciences, Dana-Farber Cancer Institute, Harvard Medical School, Boston, MA, United States; Luana Fianchi, Institute of Hematology, Catholic University of Sacred Heart, Rome, Italy; Massimo Breccia, Division of Hematology, Department of Cellular Biotechnologies and Hematology, Sapienza University, Rome, Italy; Reinhard Stauder, Department of Internal Medicine V (Hematology and Oncology), Innsbruck Medical University, Innsbruck, Austria; Uwe Platzbecker, Department of Medicine I, University Hospital Dresden Carl Gustav Carus, Dresden, Germany; Giuseppe A. Palumbo, UO Ematologia, AOU Policlinico-V Emanuele, Catania, Italy; Mario Luppi, Hematology, University of Modena, Modena, Italy; Rosangela Invernizzi, Department of Internal Medicine, University of Pavia, IRCCS Policlinico San Matteo Foundation, Pavia, Italy; Micaela Bergamaschi, Clinica Ematologica, IRCCS AOU San Martino IST Genova, Genova, Italy; Lorenza Borin, Department of Hematology, San Gerardo Hospital, Monza, Italy; Anna Angela Di Tucci, Hematology and Bone Marrow Transplantation Unit, Ospedale Oncologico di Riferimento Regionale "Armando Businco", Cagliari, Italy; Huiyong Zhang, Department of Hematology, Affiliated Hospital of Liaoning University of Traditional Chinese Medicine, Shenyang, China; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Franco Mandelli, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Marco Vignetti, Italian Group for Adult Hematologic Diseases (GIMEMA), Data Center and Health Outcomes Research Unit, Rome, Italy

OUTSTANDING POSTER AWARD FINALIST



(1005) A journey into the future: a focus group analysis of themes related to the quality of life of adolescents with narcolepsy

John E. Chaplin, PhD Cpsych, Inst. Clinical Sciences, Sahlgrenska Academy at the University Gothenburg, Sweden, Gothenburg, Sweden; Sarah Hitz, MSc, Hamburg University of Applied Sciences, Hamburg, Germany; Attila Szakács, MD PhD, Institute of Clinical Sciences, University of Gothenburg at Sahlgrenska Academy, Halmstad, Sweden; Niklas Darin, MD PhD, Institute of Clinical Sciences, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden; Tove Hallböök, MD PhD, Institute of Clinical Sciences, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden

OUTSTANDING POSTER AWARD FINALIST

(1007) Qualitative study to identify patient-perceived impacts of statin intolerance

Talia Miller, MPH MSW, Health Research Associates, Seattle, WA, United States; Terry A. Jacobson, MD, National Lipid Association, Jacksonville, FL, United States; Mary Katherine Cheeley, PharmD, National Lipid Association, Jacksonville, FL, United States; Peter H. Jones, MD, National Lipid Association, Jacksonville, FL, United States; Ralph LaForge, MS, National Lipid Association, Jacksonville, FL, United States; Kevin C. Maki, PhD, National Lipid Association, Jacksonville, FL, United States; Mona L. Martin, RN MPA, Health Research Associates, Inc., Seattle, WA, United States; Kelly P. McCarrier, PhD, Health Research Associates, Inc, Seattle, WA, United States; Paul D. Thompson, MD, National Lipid Association, Jacksonville, FL, United States; Jerome D. Cohen, MD, National Lipid Association, Jacksonville, FL, United States

OUTSTANDING POSTER AWARD FINALIST

Advanced Cancer

(1009) Emotional Functioning (EORTC) and involvement in medical decision-making across a multi-country cohort of patients with advanced cancer (n=945).

Ida Korfage, PhD, Erasmus MC, University Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Agnes Van der Heide, Erasmus MC, University Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Lea Jabbarian, MSc, Erasmus MC, Rotterdam, Netherlands; Luc Deliens, PhD, VUB & Ghent University, Brussels, Belgium; Guido Miccinesi, PhD, ISPO Cancer Prevention and Research Institute, Florence, Italy; Urska Lunder, PhD MD, University Clinic for Respiratory and Allergic Diseases Golnik, Golnik, Slovenia; Sheila Payne, PhD, Lancaster University, Lancaster, United Kingdom; Kristian Pollock, PhD, School of Health Sciences, University of Nottingham, Nottingham, United Kingdom; Marijke Kars, PhD, University Medical Center Utrecht, Utrecht, Netherlands; Mogens Groenvold, MD ScD, University of Copenhagen, Copenhagen, Denmark

(1011) Embracing the complexity of religion in relation to Spiritual Wellbeing (SWB): findings from the international validation study of the EORTC QLQ-SWB32

Bella Vivat, PhD, University College London, London, United Kingdom; Teresa Young, BSc, East & North Herts NHS Trust incorporating Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Julie Winstanley, Patricia Ritchie Centre for Cancer Care and Research, Sydney, Australia; Juan I. Arraras, PhD, 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; Fran Boyle, University of Sydney, Sydney, Australia; Anna Costantini, Psychoncology Unit, Department of Oncological Sciences, Rome, Italy; Jingbo Guo, Palliative Ward, Shengjing Hospital of China Medical University, Liaoning, China; M. Elisa Irarrazaval, Calidad de Vida, Santiago, Chile; Kunihiro Kobayashi, Department of Respiratory Medicine, Saitama International Medical Centre, Hidaka City, Japan; Renske Kruizinga, PhD Candidate, 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, Tehran, Iran; Gudrun Rohde, PhD, University of Agder and Sorlandet Hospital, Kristiansand, Norway; Samantha Serpentine, PhD, Psychoncology, IOV-IRCCS, Padua, Italy; Nigel Spry, University of Western Australia Faculty of Medicine Dentistry and Health Sciences, Crawley, Australia; Hanneke W. van Laarhoven, PhD MD, Academic Medical Centre, Amsterdam, Netherlands; Grace Yang, National Cancer Centre Singapore, Singapore, Singapore

(1013) Long-term trends in health-related quality of life in patients with metastatic renal cell carcinoma treated with cabozantinib or everolimus

Paul Williams, MPH BSc, Mapi, Lyon, France; **Florence Marteau, MSc, Ipsen Pharma SAS, Boulogne-Billancourt, France,** Sylvie Gabriel, Ipsen Pharma SAS, Boulogne-Billancourt, France; Jennifer Beaumont, MS, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Milan Mangeshkar, Exelixis, Inc., South San Francisco, CA, United States; John Baer, Exelixis, Inc., South San Francisco, CA, United States; Matthew Hankins, Mapi, London, United Kingdom; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States

(1015) The association between depression and patient-reported health-related quality of life for patients with metastatic breast, lung and colorectal cancer

Adrienne Waldman Casebeer, PhD, MPP, MS, Comprehensive Health Insights, Louisville, KY, United States; Dana Drzayich Antol, MS, Comprehensive Health Insights, Louisville, KY, United States; Sari Hopson, PhD, Comprehensive Health Insights, Louisville, KY, United States; Raya Khoury, MPH, Genentech, South San Francisco, CA, United States; Aparna Parikh, MD, Genentech, South San Francisco, CA, United States; Alisha Stein, RN-NC, MSN, OCN, Genentech, South San Francisco, CA, United States; Todd Michael, PharmD, RPh, Genentech, South San Francisco, CA, United States; Stephen Stemkowski, PhD, MHA, Comprehensive Health Insights, Louisville, KY, United States; Mikele Bunce, PhD, MPH, Genentech, South San Francisco, CA, United States



(1017) The effect of integrative traditional and Western medicine to the symptom burdened and quality of life of elderly patients with advanced non-small cell lung Cancer

Mengjun Shan, MD MAS, Department of Tumor, Longhua Hospital, Shanghai University of Traditional Chinese Medicine, Shanghai, Shanghai, China; Liyuan ZHANG, Affiliated Longhua Hospital, Shanghai University of Traditional Chinese Medicine, Shanghai, China; Dan Fang, MD MS, Department of Tumor, Longhua Hospital, Shanghai University of Traditional Chinese Medicine, Shanghai, China; Jie You, MD PhD, The Ninth People's Hospital Affiliated to Shanghai Jiao Tong University School of Medicine, Shanghai, China

(1019) Estimating minimally important differences for the EORTC QLQ-C15-PAL for terminal cancer patients

Kikuko Miyazaki, PhD, Kyoto University, School of Public Health, Kyoto, Japan; Yoshimi Suzukamo, PhD, Tohoku University Graduate School of Medicine, Sendai, Japan; Masayuki Ikenaga, MD, Yodogawa Christian Hospital, Osaka, Japan; Shozo Ohsumi, MD PhD, National Hospital Organization Shikoku Cancer Center, Matsuyama, Japan; Kojiro Shimozuma, MD, Ritsumeikan University, Kusatsu, Shiga, Japan; Takeo Nakayama, MD PhD, Kyoto University, School of Public Health, Kyoto, Japan

(1021) The influence of spiritual well-being on the QOL perceptions, caregiver role, and caregiving experiences of Hispanic family caregivers of patients with advanced cancer

Lina Mayorga, MPH, Oncology Research + Education Consultants, ROSEMEAD, CA, United States; **Joan J. Branin, PhD, University of La Verne, Pasadena, CA, United States;** Gloria Juarez, Consulting Services, San Pedro, CA, United States

Aging Populations

(1023) *Withdrawn*

(1025) Reducing the effects of moral distress among health professional in long term care facilities in southern Alberta

Oluwagbohunmi Awosoga, PhD, University of Lethbridge, Lethbridge, Alberta, Canada; Em M. Pijl, PhD RN, University of Lethbridge, Lethbridge, Alberta, Canada; Shannon Spenceley, PhD RN, University of Lethbridge, Lethbridge, Alberta, Canada; Brad Hagen, PhD RN, University of Lethbridge, Lethbridge, Alberta, Canada; Barry Hall, PhD, University of Calgary, Southern Alberta Region, Lethbridge, Alberta, Canada

(1027) Advance care planning prevalence study in Australia. Interim findings and protocol

Rasa Ruseckaite, Monash University, Melbourne, Australia; Karen Detering, Advance Care Planning Australia, Austin Health, Melbourne, Australia; Sue M. Evans, Monash University, Melbourne, Australia; Veronica Perera, Advance Care Planning Australia, Austin Health, Melbourne, Australia; Lynne Walker, Advance Care Planning, Australia, Melbourne, Australia; Craig Sinclair, The Rural Clinical School of Western Australia, University of Western Australia, Albany, Australia; Josephine Clayton, Northern Clinical School, HammondCare, Greenwich and Royal North Shore Hospitals, University of Sydney, Sydney, Australia; Linda Nolte, Advance Care Planning Australia, Austin Health, Melbourne, Australia

(1029) Dementia Carers Instrument Development (DECIDE) workstream 1, phase 3: psychometric evaluation

Mike Horton, PhD Student, University of Leeds, Leeds, United Kingdom; Molly Megson, University of Leeds, Leeds, United Kingdom; Paul Kind, University of Leeds, Leeds, United Kingdom; Jan Oyeboode, University of Bradford, Bradford, United Kingdom; Linda Claire, University of Exeter, Exeter, United Kingdom; Hareth Al-Janabi, University of Birmingham, Birmingham, United Kingdom; Carol Brayne, University of Cambridge, Cambridge, United Kingdom; Alan Tennant, BA (Hons) PhD, Swiss Paraplegic Research, Nottwil, Switzerland; Zoe Hoare, Bangor University, Bangor, United Kingdom; Penny Wright, University of Leeds, Leeds, United Kingdom

(1031) Cross-cultural adaptation of pictorial images in the Free and Cued Selective Reminding Test with Immediate Recall (FCSRT-IR) in 29 languages for 24 countries for use in a Mild Cognitive Impairment (MCI) population

Barbara Brandt, MA, Corporate Translations Inc., East Hartford, CT, United States, **Elizabeth Yohe Moore, MPH, Corporate Translations, Inc., Chicago, IL, United States;** Tim Poepsel, PhD, Corporate Translations, Inc., East Hartford, CT, United States; Shawn McKown, MA, Corporate Translations Inc., East Hartford, CT, United States

(1033) Patient and carer well-being in memory clinics: pilot testing the Long-Term Conditions Questionnaire (LTCQ) among people affected by dementia

Caroline M. Potter, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Michele Peters, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Maureen Cundell, Oxford Academic Health Science Network, Oxford, United Kingdom; Rupert McShane, MD, Oxford Academic Health Science Network, Oxford, United Kingdom; Ray Fitzpatrick, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom

(1035) Pain and quality of life in severe dementia

Hanne M. Rostad, MS (PhD Student), Oslo & Akershus University College of Applied Sciences, Oslo, Norway; Martine Puts, PhD, Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada; Milada C. Småstuen, PhD, Oslo & Akershus University College of Applied Sciences, Oslo, Norway; Ellen K. Grov, PhD, Oslo & Akershus University College of Applied Sciences, Oslo, Norway; Inger Utne, PhD, Oslo & Akershus University College of Applied Sciences, Oslo, Norway; Liv Halvorsrud, Oslo and Akershus University College of Applied Sciences, 0130 Oslo, Norway

Scientific Program — Thursday, 19 October

(1037) The role of late-life unemployment on retirement health

Maren Voss, MS, University of Utah, Salt Lake City, UT, United States; Lori L. Wadsworth, PhD, Brigham Young University, Provo, UT, United States; Wendy C. Birmingham, PhD, Brigham Young University, Provo, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Man Hung, PhD, University of Utah, Salt Lake City, UT, United States

(1039) Identity processes among older Norwegians living in urban and rural areas

Mary Kalfoss, Diakonova University College, Oslo, Norway; Gail Low, University of Alberta, Edmonton, Alberta, Canada, **Liv Halvorsrud, Oslo and Akershus University College of Applied Sciences, 0130 Oslo, Norway**

(1041) Are clinical outcome assessment (COA) data important in the evaluation of medicines for the treatment of Alzheimer's disease approved by the FDA and the EMA?

Caroline Anfray, MA, Mapi Research Trust, Lyon, France; Marie-Pierre Emery, MA, Mapi Research Trust, Lyon, France; Laure-Lou Perrier, MSc, Mapi Research Trust, Lyon, France; Catherine Acquadro, MD, Mapi, Lyon, France

(1043) Presence of generative behavior in older adults in order to improve quality of life in Tijuana, BC, Mexico

Ana Gabriela Magallanes-Rodriguez, PhD, Autonomous University of Baja California, Tijuana, Baja California, Mexico; Ana L. Gonzalez-Celis, National Autonomous University of Mexico (UNAM), Tlalneantla, Estado de Mexico, Mexico; Wendy Samantha Molina Nunez, MA Student, UABC, Tijuana, Mexico; Gloria Georgina Alzina Penalzoa, MA Student, UABC, Tijuana, Mexico; Luis Aguiar Palacios, MA, UABC, Tijuana, Mexico; Julio Martinez Alvarado, PhD, UABC, Tijuana, Mexico

(1045) *Withdrawn*

Cancer: Colorectal

(1047) Development of predictive models for personalized, precision medicine in colorectal cancer using machine learning

Man Hung, PhD, University of Utah, Salt Lake City, UT, United States; Shirley Hon, BS, University of Utah, Salt Lake City, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Eric Hon, University of Utah, Salt Lake City, UT, United States; **Alec R. Hansen, University of Utah, Salt Lake City, UT, United States;** Dominique Nielson, University of Utah, Salt Lake City, UT, United States; Maren Voss, MS, University of Utah, Salt Lake City, UT, United States

(1049) Comparison of dynamic change of quality of life in patients with colon cancer after receiving minimally invasive surgery and open laparotomy

Tzu-Yi Wu, PhD, Academia Sinica, Taipei, Republic of Taiwan; Po-Chuan Chen, MD, National Cheng Kung University Hospital, Tainan, Republic of Taiwan; Jenq-Chang Lee, MD, National Cheng Kung University Hospital, Tainan, Republic of Taiwan; Jung-Der Wang, MD PhD, National Cheng Kung University, Tainan, Republic of Taiwan

(1051) Patient-Reported Outcomes (PROs) in randomized controlled trials of colorectal cancers. methodological quality of reporting over time

Francesco Sparano, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Jonathan Rees, Bristol Centre for Surgical Research, School of Social & Community Medicine, University of Bristol, Bristol, United Kingdom; Jane Blazeby, MD, University of Bristol, Bristol Centre for Surgical Research, School of Social & Community Medicine, Bristol, United Kingdom; Mike Pezold, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Peter Fayers, PhD, University of Aberdeen, Aberdeen, United Kingdom; **Nina Deliu, MSc, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy;** Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; on behalf of GIMEMA and EORTC Quality of Life Group

Gastrointestinal Conditions

(1053) *Withdrawn*

(1055) Development and evaluation of patient-reported outcome measurement for Chinese gastroesophageal reflux disease patients

Zheng-kun HOU, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, GUANG ZHOU, China; Feng-bin LIU, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, GUANG ZHOU, China; Chun-zi YU, Guangzhou University of Chinese Medicine, Guangzhou, China; Ji-ping LI, Guangzhou University of Chinese Medicine, Guangzhou, China; Xin-lin CHEN, Guangzhou University of Chinese Medicine, Guangzhou, China

(1057) Difference in the quality of life of patients being treated with three types of preparation for intestinal cleaning with oral medications for imaging procedures

Martin E. Romero, PhD, Foundation Salutia, Bogotá, Colombia; Juan Pablo Albanes, PhD Candidate, Tecnoquimicas, Cali, Colombia; Yesid Romero, MBA, Fundación Salutia, Bogotá, Colombia; Lina M. Huerfano, MS, Salutia, bogota, Colombia

Measurement Methods

(1059) Patient-oriented measurement of treatment goals and benefits: 10 years' experience with the Patient Benefit Index

Christine Blome, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Stephan J. Rustenbach, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Matthias Augustin, PhD MD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1061) “AI translation systems - are they ready to replace humans?” A comparative study of neural machine translation and human translation in the KDQOL and HADS

Adelina M. Lear, BA (Hons), ICON Plc, Abingdon, United Kingdom; Anna M. Richards, MA, ICON Plc, Abingdon, United Kingdom, **Emuella Flood, ICON Clinical Research, Bethesda, MD, United States**

(1063) Psychometric testing of the Finnish version of the Visual Analogue Scale Foot and Ankle

Jussi P. Repo, MD, University of Helsinki and Helsinki University Hospital, Finland, Helsinki, Uusimaa, Finland; Erkki Tukiainen, MD PhD, University of Helsinki and Helsinki University Hospital, Finland, Helsinki, Finland; Risto P. Roine, MD PhD, Group Administration, University of Helsinki and Helsinki University Hospital, HUS, Finland; Department of Health and Social Management, Research Centre for Comparative Effectiveness and Patient Safety, University of Eastern Finland, Kuopio, Finland, Helsinki, Finland; Hannu Kautiainen, MSc, University of Helsinki and Helsinki University Hospital, Helsinki, Finland; Jan Lindahl, University of Helsinki and Helsinki University Hospital, HUS, Finland, Helsinki, Finland; Outi Ilves, MSc, Department of Health Sciences University of Jyväskylä, Jyväskylä, Finland, Jyvaskyla, Finland; Salme Järvenpää, Central Finland Health Care District, Jyväskylä, Finland, Jyvaskyla, Finland; Arja Häkkinen, University of Jyväskylä, Jyväskylä, Finland, Jyvaskyla, Finland

(1065) Well-being and health-related quality of life: philosophical resources for theory building

Alicia Hall, PhD, Mississippi State University, Mississippi State, MS, United States

(1067) Converting retrospective patient-reported outcomes to momentary versions: cognitive interviewing reveals problems of varying severity with the majority of items

Victor Brun Boesen, MD, Copenhagen University Hospital Rigshospitalet, Copenhagen, Denmark; Stine Birk Nissen, MPsych, University of Copenhagen, Copenhagen, Denmark; Mogens Groenvold, MD ScD, University of Copenhagen, Copenhagen, Denmark; Jakob B. Bjorner, MD PhD, Optum, Johnston, RI, United States; Laszlo Hegedüs, MD ScD, Odense University Hospital, Odense, Denmark; Steen Joop Bonnema, MD ScD, Odense University Hospital, Odense, Denmark; Åse Krogh Rasmussen, MD ScD, Copenhagen University Hospital Rigshospitalet, Copenhagen, Denmark; Ulla Feldt-Rasmussen, MD ScD, Copenhagen University Hospital Rigshospitalet, Copenhagen, Denmark; Torquil Watt, MD ScD, Copenhagen University Hospital Rigshospitalet, Copenhagen, Denmark

(1069) Individualised patient-reported outcome measures: A systematic review

Jaheeda Gangannagaripalli, PhD Student, University of Exeter, Exeter, Devon, United Kingdom; Ian Porter, PhD, University of Exeter, Exeter, Devon, United Kingdom; Daniela G. Bradley, PhD, Nuffield Department of Population Health, University of Oxford, Oxford, Oxford, United Kingdom; Ignacio Ricci-Cabello, PhD, Health Services and Policy Research Group, Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom; Jose M. Valderas, MD PhD, University of Exeter, Exeter, United Kingdom; **Antoinette F. Davey, PhD Student, University of Exeter, Exeter, Devon, United Kingdom**

(1071) Time-dependent variation of PRO measurements in patients with chronic health conditions: A systematic scoping review

Antoinette F. Davey, PhD Student, University of Exeter, Exeter, Devon, United Kingdom; Ian Porter, PhD, University of Exeter, Exeter, Devon, United Kingdom; Colin Green, PhD, University of Exeter, UK, Exeter, United Kingdom; Joe Coombes, BSc Medical Sciences undergraduate student, University of Exeter Medical School, Devon, United Kingdom; Chris Gibbons, PhD, University of Cambridge, Cambridge, United Kingdom; Jose M. Valderas, MD PhD, University of Exeter, Exeter, United Kingdom

(1073) Group comparisons using IRT-based short forms: the impact of score shrinkage

R. J. Wirth, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States; Li Cai, PhD, Vector Psychometric Group, LLC, Los Angeles, CA, United States

(1075) Practical considerations for the Minimal Clinically Important Difference (MCID) determination for Patient Reported Outcomes Measures (PROMs)

Pascal Woaye, MS, University of Nantes, Nantes, France; Antoine Vanier, MD PhD, INSERM - University of Nantes - University of Tours, Nantes, France; Pierre Pottier, MD PhD, University of Nantes, Nantes, France; Myriam Blanchin, PhD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Veronique Sebillle, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France; **Jean-Benoit Hardouin, PhD, University of Nantes, Nantes, France**

Scientific Program — Thursday, 19 October

(1077) Scoring and interpretation of daily diary data in the presence of non-ignorable missing data

Philip Griffiths, PhD, Clinical outcomes solutions, Folkestone, United Kingdom, **Lysbeth L. Floden, PhD Student, Clinical Outcomes Solutions, Tucson, AZ, United States**; Stacie Hudgens, MA, Clinical Outcomes Solutions, Tucson, AZ, United States

(1079) Caregiver outcomes in patient-centered research

Rachel Witsaman, MPH, The Patient Centered Outcomes Research Institute, Washington, DC, United States; Ingrid McDuff, MPH, PCORI, Washington, DC, United States; Mary Kay Margolis, MPH, MHA, PCORI, Washington, DC, United States; Lori Frank, PhD, PCORI, Washington DC, DC, United States

Response Shift

(1081) *Withdrawn*

(1085) Using vignettes to detect response shift in measuring health-related quality of life

Janine Topp, MSc, University Medical Center Hamburg-Eppendorf, Hamburg, Hamburg, Germany; Matthias Augustin, PhD MD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Christine Blome, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1087) What can detect Oort's procedure in terms of size of response shift effect when used in various empirical realistic situations at domain-level? A simulation study.

Antoine Vanier, MD PhD, INSERM - University of Nantes - University of Tours, Nantes, France; Luc Malatier, INSERM - University of Nantes - University of Tours, Nantes, France; Myriam Blanchin, PhD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Jean-Benoit Hardouin, PhD, University of Nantes, Nantes, France; Veronique Sebillé, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France

10:55 am – 12:05 pm Plenary - Cutting Edge Research

Grand ABC, 2nd Floor

Plenary sponsored by: Vector

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.

The cohort multiple randomized controlled trial design – the solution to our problems in oncology?

Danny Young-Afat, PhD-student, University Medical Center Utrecht, Amsterdam, Netherlands

The Mental Health Clustering Tool (MHCT) in NHS England's secondary care: does the available evidence support a payment by results approach?

Jan R. Boehnke, PhD, University of Dundee, Dundee, United Kingdom

Contextual considerations for introducing an electronic quality of life assessment and practice support system in palliative home care

Kara Schick-Makaroff, PhD, RN, University of Alberta, Edmonton, BC, Canada

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

Is newer always better? Comparing traditional and innovative methods to generate a patient-centred conceptual model

Louise Humphrey, MSc, Clinical Outcomes Solutions, Folkestone, United Kingdom

Plenary chaired by **Kathryn Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States**

12:05 pm – 1:45 pm Lunch Break

If you purchased Box Lunch via the registration form, please present your **Thursday Lunch Ticket** to one of the hotel staff to pick up your Boxed Lunch in the Columbus Foyer or Grand Foyer on the second floor.

*Please note – Boxed Lunch tickets are **not** available for purchase on-site.



Scientific Program — Thursday, 19 October

12:25 pm – 1:30 pm Special Interest Group (SIG) and Committee/Task Force Meetings

Meet the Funders MeetingGrand ABC, 2nd Floor
Psychometrics SIG MeetingGrand D, 2nd Floor
Canada PRO SIG MeetingDiscovery BC, 3rd Floor
United Kingdom and Ireland SIG Meeting..... Innovation, 3rd Floor
QLR Editorial Board Meeting (Closed Event)Discovery A, 3rd Floor

1:30 pm – 5:30 pm Poster Hall Open Columbus Ballroom, 2nd Floor

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

Oral Session 101: Cancer I Grand ABC, 2nd Floor

Session Chair: Joan Branin, PhD, United States

1:50 pm – 2:03 pm (101.1) Overall survival results of a randomized trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment

Ethan Basch, MD MSc, University of North Carolina, Chapel Hill, NC, United States; Allison Deal, University of North Carolina, Chapel Hill, NC, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; Antonia V. Bennett, PhD, University of North Carolina, Chapel Hill, NC, United States; Thomas M. Atkinson, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Lauren J. Rogak, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Allison Barz, MD, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Deborah Schrag, MD, Dana-Farber Cancer Institute, Boston, MA, United States

2:04 pm – 2:17 pm (101.2) REPORT-UK (Real-time Electronic Patient Outcome Reporting of adverse events in UK cancer trials) – a feasibility study in a UK oncology setting

Galina Velikova, BMBS(MD) PhD FRCP, University of Leeds, Leeds, United Kingdom; Faye Samy, MS, University of Leeds, Leeds, United Kingdom; Fiona Kennedy, PhD, University of Leeds, Leeds, United Kingdom; Beverly Clayton, RGN/RSCN, BHSc (Hons), University of Leeds, Leeds, United Kingdom; Kate Absolom, PhD, University of Leeds, Leeds, United Kingdom; Elaine O'Connell Francischetto, University of Bristol, Bristol, United Kingdom; Lewis Marston, BA, University of Leeds, Leeds, United Kingdom; Louise Flint off, University of Bristol, Bristol, United Kingdom; Will Crocombe, University of Leeds, Leeds, United Kingdom; Victoria Hiley, University of Leeds, Leeds, United Kingdom; Julia M. Brown, MSc, University of Leeds, Leeds, United Kingdom; Jane Blazeby, MD, University of Bristol, Bristol Centre for Surgical Research, School of Social & Community Medicine, Bristol, United Kingdom

2:18 pm – 2:31 pm (101.3) Patient-reported symptom interference with activity-related and mood-related functioning in patients with advanced cancer in a phase I clinical trials clinic

Goldy C. George, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Tito Mendoza, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Eucharia Iwuayanwu, PHS, MPAS, PAC, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Karen Anderson, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Sarina Piha-Paul, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Aung Naing, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Xin S. Wang, MD MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; David S. Hong, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles S. Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

2:32 pm – 2:45 pm (101.4) Poor social integration impacts fatigue and pain symptoms in survivors of adolescent and young adult cancers

I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; Conor Jones, BS, St. Jude Children's Research Hospital, Memphis, TN, United States; Kumar Srivastava, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; Melissa Hudson, MD, St. Jude Children's Research Hospital, Memphis, TN, United States; Leslie Robison, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; Kevin Krull, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States

2:46 pm – 2:59 pm (101.5) The influence of quality of life on cancer treatment satisfaction and care

Lari Wenzel, University of California, Irvine, Irvine, CA, United States; Dana B. Mukamel, PhD, University of California, Irvine, Irvine, CA, United States; Kathryn Osann, University of California, Irvine, Irvine, CA, United States; Laura Havrilesky, Duke University, Durham, NC, United States; Alexi Wright, Dana Farber Cancer Institute, Boston, MA, United States; Joan Walker, Oklahoma University Health Science Center, Oklahoma City, OK, United States; Ronald Alvarez, Vanderbilt University, Nashville, TN, United States; Linda Van Le, University of North Carolina, Raleigh, NC, United States; Katina Robison, Brown University, Providence, RI, United States; Leslie Randall, University of California, Irvine, Irvine, CA, United States; Mark Wakabayashi, City of Hope, Duarte, CA, United States; Lisa Sparks, Chapman University, Orange, CA, United States; Susie Hsieh, University of California, Irvine, Irvine, CA, United States; Aditi Wahi, MPH, University of California, Irvine, Irvine, CA, United States; Heather Ladd, University of California, Irvine, Irvine, CA, United States; Joseph Lipscomb, Emory University, Atlanta, GA, United States; David Cohn, Ohio State University, Columbus, OH, United States



Scientific Program — Thursday, 19 October

Oral Session 102: Statistical Methods

Discovery BC, 3rd Floor

Session Chair: Antoine Regnault, PhD, France

1:50 pm – 2:03 pm (102.1) Accuracy of latent class item response theory models for measurement invariance: a simulation study

Tolulope T. Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Richard Sawatzky, PhD, Trinity Western University, Langley, British Columbia, Canada; Lara Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Juxin Liu, University of Saskatchewan, Saskatoon, Canada; Bruno D. Zumbo, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Lisa M. Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada

2:04 pm – 2:17 pm (102.2) Longitudinal IRT for scale development with small samples

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

2:18 pm – 2:31 pm (102.3) Longitudinal modeling of item response data: a comparison of two approaches

James McGinley, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States; Carrie R. Houts, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States

2:32 pm – 2:45 pm (102.4) Cognitive appraisal processes are relevant to patients' assessment of clinically important change: What predicts worse outcomes after spine surgery?

Joel A. Finkelstein, MD MSc, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada; Jie Zhang, MPH, DeltaQuest Foundation, Inc., Concord, MA, United States; Bruce D. Rapkin, PhD, Albert Einstein College of Medicine, Bronx, NY, United States; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., Tufts University Medical School, Concord, MA, United States

2:46 pm – 2:59 pm (102.5) The Minimal Important Change (MIC), based on ROC-analysis or predictive modeling, needs to be adjusted for ceiling effects

Berend Terluin, PhD MD, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, The Netherlands, Amsterdam, Netherlands; Cheryl D. Coon, PhD, Outcometrix, Tucson, AZ, United States; Lina Holm Ingelsrud, PhD Candidate, Copenhagen University Hospital Hvidovre, Copenhagen, Denmark; Johannes C. van der Wouden, PhD, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, The Netherlands; Caroline B. Terwee, PhD, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, Netherlands

Oral Session 103: Aging Populations

Grand D, 2nd Floor

Session Chair: Belinda King-Kallimanis, PhD, United States

1:50 pm – 2:03 pm (103.1) Introducing electronic quality of life assessments in hospital palliative care: A micro-meso-macro framework

Marian Krawczyk, PhD, Centre for Health Evaluation & Outcome Sciences (CHEOS), Vancouver, British Columbia, Canada; Kara Schick-Makaroff, PhD, University of Alberta, Edmonton, Alberta, Canada; Esther Laforest, PhD Candidate, McGill University, Montreal, Quebec, Canada; S. Robin Cohen, PhD, McGill University and Lady Davis Institute, Montreal, Quebec, Canada; Kelli Stajduhar, PhD, University of Victoria, Victoria, British Columbia, Canada; Sheryl Reimer-Kirkham, PhD, Trinity Western University, Langley, British Columbia, Canada; Joakim Öhlén, PhD, Institute of Health and care sciences Gothenburg University, Gothenburg, Sweden; Richard Sawatzky, PhD, Trinity Western University, Langley, British Columbia, Canada

2:04 pm – 2:17 pm (103.2) Adaptation and validation of the veterans RAND 12-item health survey (VR-12) for long-term residential care

Rozanne Wilson, PhD, Trinity Western University, Langley, British Columbia, Canada; Lena Cuthbertson, British Columbia Ministry of Health/ Providence Health Care, Vancouver, British Columbia, Canada; Lara Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Lillian Parsons, Providence Health Care, Vancouver, British Columbia, Canada; Richard Sawatzky, PhD, Trinity Western University, Langley, British Columbia, Canada

2:18 pm – 2:31 pm (103.3) Using Patient-Reported Outcomes Measurement Information System (PROMIS®) physical functioning items with elderly minorities

Sylvia H. Paz, PhD, UCLA, Los Angeles, CA, United States; Loretta Jones, Doctor of Ministry, Healthy African American Families, Los Angeles, CA, United States; Ron D. Hays, PhD, UCLA, Los Angeles, CA, United States

2:32 pm – 2:45 pm (103.4) Frailty from a modern measurement perspective: if the shoe fits ..

Nancy Mayo, PhD, McGill University, Montreal, Quebec, Canada; Jose Morais, McGill University, McGill University Health Centre, Montreal, Canada; Kedar Mate, PhD(c), McGill University, Montreal, Quebec, Canada; Sabrina Figueiredo, McGill University, Montreal, Canada; Mylene Aubertin-Leheudre, PhD, University of Quebec and Montreal, Montreal, Quebec, Canada; Mohammad Auais, PhD, Queens University, Kingston, Ontario, Canada; Julio F. Fiore Jr, PhD MSc, McGill University, Montreal, Quebec, Canada; Carolina Moriello, MSc, McGill University Health Centre - RI, Montreal, Quebec, Canada; Susan C. Scott, McGill University Health Center, Montreal, Quebec, Canada

Thursday, 19 October



Scientific Program — Thursday, 19 October

2:46 pm – 2:59 pm (103.5) The University of Washington resilience scale: comparison to the general US population

Dagmar Amtmann, PhD, University of Washington, Seattle, WA, United States; Alyssa M. Bamer, MPH, University of Washington, Denver, CO, United States; Fraser D. Bocell, PhD, University of Washington, Seattle, WA, United States; Kevin N. Alschuler, PhD, University of Washington, Seattle, WA, United States; Dawn M. Ehde, PhD, University of Washington, Seattle, WA, United States; Mark P. Jensen, PhD, University of Washington, Seattle, WA, United States; Kurt Johnson, PhD, University of Washington, Seattle, WA, United States; Arielle Silverman, PhD, University of Washington, Seattle, WA, United States; Amanda E. Smith, BS, University of Washington, Seattle, WA, United States; Alexandra L. Terrill, PhD, University of Utah, Salt Lake City, UT, United States; Ivan Molton, PhD, University of Washington, Seattle, WA, United States

Oral Session 104: Child and Adolescent Health

Innovation, 3rd Floor

Session Chair: Anne Klassen, DPhil, Canada

1:50 pm – 2:03 pm (104.1) Trajectories of QOL discrepancy for children with epilepsy and their parents

Nora Fayed, PhD, QUEENS University, Kingston, Ontario, Canada; Lisa Avery, Avery Information Services, Peterborough, Ontario, Canada; David Streiner, McMaster University, Hamilton, Ontario, Canada; Mark A. Ferro, PhD, University of Waterloo, Waterloo, Ontario, Canada; Michael H. Boyle, PhD, McMaster University, Hamilton, Ontario, Canada; Peter Rosenbaum, McMaster University, Hamilton, Ontario, Canada; Charles E. Cunningham, McMaster University, Hamilton, Canada; Gina Glidden, PhD Candidate, McGill University, Montreal, Quebec, Canada; Lucyna Lach, PhD, McGill University, Montreal, Quebec, Canada; Gabriel Ronen, McMaster University, Hamilton, Ontario, Canada

2:04 pm – 2:17 pm (104.2) Psychometric properties of the Participation and Activity Inventory for visually impaired children and youth 3-6 years (PAI-CY 3-6): a proxy questionnaire

Ellen Elsmann, PhD Candidate, VU University Medical Center, Amsterdam, Netherlands; Ruth Van Nispen, PhD, VU University Medical Center, Amsterdam, Netherlands; Ger Van Rens, MD PhD, VU University Medical Center, Amsterdam, Netherlands

2:18 pm – 2:31 pm (104.3) Impacts of caring for youth with severe disabilities on parents' quality of life

Tamer S. Mohammed, MD MSc, University of Lethbridge, Lethbridge, Alberta, Canada, Oluwagbohunmi Awosoga, PhD, University of Lethbridge, Lethbridge, Alberta, Canada

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

2:32 pm – 2:45 pm (104.4) Comparison of self-reports and parent proxy-reports on the quality of life and function of children with lower limb deformities

Angela Eugenio, University of British Columbia, Vancouver, British Columbia, Canada, Harpreet Chhina, MSc, University of British Columbia, Vancouver, British Columbia, Canada; Anthony Cooper, MBChB, FRCS, University of British Columbia, Vancouver, British Columbia, Canada

2:46 pm – 2:59 pm (104.5) Risk and protective factors of health-related quality of life in children and adolescents: results of the longitudinal BELLA-study

Ulrike Ravens-Sieberer, PhD MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Christiane Otto, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Anne-Catherine Haller, Dipl Psych, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ann-Katrin Meyrose, MSc, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Heike Hoelling, Robert Koch-Institute, Berlin, Germany; Franziska Reiss, PhD Student, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Fionna Klasen, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

3:15 pm – 4:10 pm Exhibits Open and Refreshment Break

Columbus Foyer/Grand Foyer, 2nd Floor

3:25 pm – 4:00 pm Thursday Poster Session II

Columbus Ballroom, 2nd Floor

(1004) The use of latent variable mixture models to identify invariant items for the measurement of patient-reported outcomes

Richard Sawatzky, PhD, Trinity Western University, Langley, British Columbia, Canada; Lara Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Tolulope T. Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Lisa M. Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; Jacek A. Kopec, MD PhD, University of British Columbia, Vancouver, British Columbia, Canada; Bruno D. Zumbo, PhD, University of British Columbia, Vancouver, British Columbia, Canada

OUTSTANDING POSTER AWARD FINALIST

(1006) The PROscorer R package: an extensible repository of open-source scoring functions for commonly-used PROs, designed to eliminate scoring errors and establish best practices for consistent and reproducible PRO scoring

Raymond E. Baser, MS, Memorial Sloan Kettering Cancer Center, New York, NY, United States

OUTSTANDING POSTER AWARD FINALIST



(1008) A novel approach to measuring disease progression in Duchenne muscular dystrophy: results from clinician interviews

Michelle K. White, PhD, Optum, Johnston, RI, United States; Dana Martin, PharmD, Sarepta Therapeutics, Cambridge, MA, United States; Mindy Leffler, Casimir Trials, LLC, Bellevue, WA, United States; Chelsea Macary, Sarepta Therapeutics, Cambridge, MA, United States; Kaitlin Rychlec, Optum, Johnston, RI, United States; Asia Sikora Kessler, PhD, Optum, Johnston, RI, United States; Chris Jones, PhD, CJ Strategy and Communications, Boston, MA, United States; Mark Kosinski, MA, Optum, Johnston, RI, United States

OUTSTANDING POSTER AWARD FINALIST

Child and Adolescent Health

(1010) *Withdrawn*

(1012) Validity of the EQ-5D-Y in children and adolescents with diabetes

Karina Mayoral, Student Master in Public Health, Health Services Research Group. Hospital del Mar Research Institute, Barcelona, Spain; Marc Marti-Pastor, MD MPH, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain; Gimena Hernandez, PhD, Hospital del Mar Research Institute, Barcelona, Catalonia, 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; 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 (UPF), Barcelona, Spain; Luis Rajmil, I'IMIM (Institut Hospital del Mar d'Investigacions Mèdiques), Barcelona, Spain; **Montse Ferrer, MD PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain**

(1014) Parental functioning after induction treatment of their child with acute lymphoblastic leukemia

Lindsay M. Steur, MD, VU University medical center, Amsterdam, Netherlands; Niki Rensen, BSc, VU University medical center, Amsterdam, Netherlands; Martha A. Grootenhuis, PhD, Princess Máxima Center for pediatric oncology, Utrecht, Netherlands; Natasha K. van Eijkelenburg, MD PhD, Princess Máxima Center for pediatric oncology, Utrecht, Netherlands; Inge M. van der Sluis, MD PhD, Sophia Children's Hospital Erasmus medical center, Rotterdam, Netherlands; Maroeska te Loo, MD PhD, Amalia Children's Hospital Radboud University medical center, Nijmegen, Netherlands; Cor van den Bos, MD PhD, Emma Children's Hospital Academic medical center, Amsterdam, Netherlands; Wim J. Tissing, MD PhD, Beatrix Children's Hospital University medical center Groningen, Groningen, Netherlands; Gerardus J. Kaspers, PhD MD, VU University medical center, Amsterdam, Netherlands; Raphaële R. van Litsenburg, MD PhD, VU University medical center, Amsterdam, Netherlands

(1016) Trajectory of self-reported HRQoL in children and adolescents with type 1 diabetes over 6 months

Kathrin I. Fischer, MSc, Charité - Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Dana Barthel, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Christiane Otto, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ute Thyen, PhD, University Medical Center Schleswig-Holstein, Lübeck, Germany; Marcus Klein, PhD, University Medical Center Schleswig-Holstein, Kiel, Germany; Otto Walter, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Ulrike Ravens-Sieberer, PhD MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

(1018) App development for monitoring the ARCA (Asthma Research Children and Adolescent) cohort

Sara Calpe, IMIM (Institut Hospital del Mar d'Investigacions Mèdiques), Barcelona, Spain; Karina Mayoral, Student Master in Public Health, Health Services Research Group. Hospital del Mar Research Institute, Barcelona, Spain; **Marc Marti-Pastor, MD MPH, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain;** CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), 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 (UPF), 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; Gimena Hernández, MD MPH, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona, Bellaterra, Spain, Barcelona, Spain; Montse Ferrer, MD PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain



(1020) Infant Cleft Observer Outcomes (ICOO): identification of observable signs of health and well-being in infants with clefts

Todd Edwards, University of Washington, Seattle, WA, United States; Laura Stueckle, Seattle Children's Hospital, Seattle, WA, United States; Meredith Albert, Shriners Hospital - Chicago, Chicago, IL, United States; Cassandra Aspinall, Seattle Children's Hospital, Seattle, WA, United States; Suzel Bautista, University of Illinois - Chicago, Chicago, IL, United States; Claudia Crilly Bellucci, University of Illinois - Chicago, Chicago, IL, United States; Kathleen Kapp-Simon, University of Illinois - Chicago, Chicago, IL, United States; Solange Mecham, University of Washington, Seattle, WA, United States; Donald Patrick, PhD, University of Washington, Seattle, WA, United States; Janine Rosenberg, University of Illinois - Chicago, Chicago, IL, United States; Carrie Heike, Seattle Children's Hospital, Seattle, WA, United States

(1022) Qualitative insights to health related quality of life among US and Canadian based children with lower limb deformities

Harpreet Chhina, MSc, University of British Columbia, Vancouver, British Columbia, Canada; Anne F. Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada; Jacek A. Kopec, MD PhD, University of British Columbia, Vancouver, British Columbia, Canada; Natasha M. Longmire, McMaster University, Hamilton, Ontario, Canada; John L. Oliffe, PhD RN, University of British Columbia, Vancouver, British Columbia, Canada; Anthony Cooper, MBChB, FRCS, University of British Columbia, Vancouver, British Columbia, Canada

(1024) Understanding and measuring needs of youth with mental illness: a patient-and family-oriented research collaboration to “generate real world evidence”

Skye P. Barbic, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Adelena Leon, BSc, University of British Columbia, Vancouver, British Columbia, Canada; Steve Mathias, Providence Health Care, Vancouver, British Columbia, Canada; Sarah Irving, BA, Providence Health, Vancouver, British Columbia, Canada; Tamara Throssell, Family Smart Consultant, Family Smart, Vancouver, British Columbia, Canada; Stephanie Gillingham, MSW, Foundry, Vancouver, British Columbia, Canada; Oluseyi Oyedele, PhD, Foundry, Vancouver, British Columbia, Canada; Ian Manion, PhD Cpsych, The Royal Ottawa, Ottawa, Ontario, Canada

(1026) Cross-cultural adaptation of the AQOL-MHS

Ligia M. Chavez, PhD, University of Puerto Rico – Medical Sciences Campus, San Juan, PR, United States; Ernesto M. Magallón-Neri, PhD, University of Barcelona, Barcelona, Spain

(1028) Dutch norms for the Strengths and Difficulties Questionnaire (SDQ) – parent form for children aged 2-18 years

Heleen Maurice-Stam, PhD, Academic Medical Center/Emma Children's Hospital, Amsterdam, Netherlands; Lotte Haverman, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Amsterdam, Netherlands; Anouck Splinter, MSc, researcher, Amsterdam, Netherlands; **Hedy van Oers, MSc, Psychologist/PhD student, Amsterdam, Netherlands;** Sasja Schepers, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Amsterdam, Netherlands; Martha A. Grootenhuis, PhD, Princess Máxima Center for pediatric oncology, Utrecht, Netherlands

(1030) Similar low Health Related Quality of Life scores among children on dialysis and renal transplanted children: An international study

Anouck Splinter, MSc, researcher, Amsterdam, Netherlands; Lidwien Tjaden, MD PhD, Emma Children's Hospital, Amsterdam, Netherlands; **Lotte Haverman, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Amsterdam, Netherlands;** Martha A. Grootenhuis, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands; Jaap Groothoff, MD PhD, Emma Children's Hospital, Amsterdam, Netherlands

(1032) Health and use of early intervention/special education of Native Hawaiian and Pacific Islander children with developmental disabilities: United States, 2014

Nalin Payakachat, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; Christopher R. Long, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; Marie-Rachelle Narcisse, PhD, University of Arkansas for Medical Sciences Northwest Campus, Fayetteville, AR, United States; Pearl A. McElfish, PhD, University of Arkansas for Medical Sciences Northwest Campus, Fayetteville, AR, United States

(1034) Quality of Life (QOL) questionnaire for schoolchildren (Part 3)

Rika Hayashida, RN MSN, University of Nagasaki, Siebold, Nishisonogun, Nagasaki, Japan; Michiko Kobayashi, MD, Japanese Society of Quality of Life Research, Kobe, Japan; Takashi Mandai, MD PhD, Japanese Society of Quality of Life Research, Kobe, Japan

(1036) Health-Related Quality of Life and suicidal behaviors among adolescents from an extreme region of Chile

Carlos A. Hidalgo-Rasmussen, PhD, University of Guadalajara, University of Playa Ancha, Cd. Guzman, Jalisco, Mexico; Maria Jacqueline Rojas, PhD, University of Playa Ancha, Viña del Mar, Chile; Fabiola Vilugron, Doctoral Student, University of Playa Ancha, Quilpue, Chile; Viridiana Chavez-Flores, Doctoral Student, University of Guadalajara, Cd. Guzman, Jalisco, Mexico; Libia Y. Yanez-Peñuñuri, Doctoral Student, University of Guadalajara, Cd. Guzman, Jalisco, Mexico

(1038) Health Related Quality of Life during treatment in adolescents aged 12-18 years with cancer

Martha A. Grootenhuis, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands; Sasja Schepers, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Amsterdam, Netherlands; Max van Noesel, MD PhD, Princess Maxima Centre for Pediatric Oncology, Utrecht, Netherlands; Kelly van Bindsbergen, MS (PhD Student), Princess Maxima Center for Pediatric Oncology, Utrecht, Netherlands; Hanneke de Ridder, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands; Raphaële R. van Litsenburg, MD PhD, VU University Medical Center, Amsterdam, Netherlands; Maureen Bult-Mulder, Princess Maxima Centre for Pediatric Oncology, Utrecht, Netherlands; Hans Merks, Emma Children's Hospital AMC, Amsterdam, Netherlands; Chris Verhaak, Amalia Children's Hospital, Nijmegen, Netherlands

(1040) *Withdrawn*

(1042) Validity of the NarQoL: comparing a disease specific and a generic instrument in a population of adolescents with narcolepsy.

John E. Chaplin, PhD Cpsych, Inst. Clinical Sciences, Sahlgrenska Academy at the University Gothenburg, Sweden, Gothenburg, Sweden; Attila Szakács, MD PhD, Institute of Clinical Sciences, University of Gothenburg at Sahlgrenska Academy, Halmstad, Sweden; Tove Hallböök, MD PhD, Institute of Clinical Sciences, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden; Niklas Darin, MD PhD, Institute of Clinical Sciences, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden

(1044) Longitudinal changes in Health Related Quality of Life in children with migrant backgrounds

Ester Villalonga-Olives, PhD, University of Maryland, Baltimore, MD, United States; Ichiro Kawachi, PhD, Harvard T.H. Chan School of Public Health, Boston, MA, United States; Josué Almansa, PhD, University of Groningen, Groningen, Netherlands; Nicole von Steinbüchel, PhD, University Medical Center Goettingen, Goettingen, Germany

(1046) Comparisons of measurement properties between the PROMIS computerized adaptive tests and short-forms among children with asthma

I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; Chelsea Young, BS, St. Jude Children's Research Hospital, Memphis, TN, United States; Darren DeWalt, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

(1048) Patient-provider engaged evaluation in Child Medical Complexity care

Nora Fayed, PhD, QUEENS University, Kingston, Ontario, Canada; Astrid Guttman, PhD MD, The Hospital for Sick Children, Toronto, Ontario, Canada; Nathalie Major, MD, Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada; Julia Orkin, MD, The Hospital for Sick Children, Toronto, Ontario, Canada; Eyal Cohen, PhD, Queen's University, Kingston, Ontario, Canada

(1050) Quality of life in adolescent's exposure to intimate partner violence of parents from Mexico

Libia Y. Yanez-Peñuñuri, Doctoral Student, University of Guadalajara, Cd. Guzman, Jalisco, Mexico; Carlos A. Hidalgo-Rasmussen, PhD, University of Guadalajara, University of Playa Ancha, Cd. Guzman, Jalisco, Mexico; Norma A. Ruvalcaba Romero, PhD, University of Guadalajara, Ciudad Guzmán, Jalisco, Mexico

(1052) Predictors of self-reported health-related quality of life according to the EQ-5D-Y in chronically ill children and adolescents with asthma, diabetes and juvenile arthritis: longitudinal results

Ulrike Ravens-Sieberer, PhD MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Dana Barthel, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Fionna Klasen, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Ann-Katrin Meyrose, MSc, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Marcus Klein, PhD, University Medical Center Schleswig-Holstein, Kiel, Germany; Ute Thyen, PhD, University Medical Center Schleswig-Holstein, Lübeck, Germany; Christiane Otto, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1054) Translation and psychometric testing of the Chinese version of Measure Yourself Medical Outcome Profile (MYMOP)

Fan Zhang, the affiliated hospital of LNUOTCM, Liaoning, China; Yue Xu, Liaoning University of Traditional Chinese Medicine, Shenyang, China; Zhihui Chen, Liaoning University of Traditional Chinese medicine, Shenyang, China; Yue Liu, The Affiliated Hospital of LNUOTCM, Shenyang, China; Dezhao Kong, The Affiliated Hospital of LNUOTCM, Shenyang, China; Yupeng Pei, Liaoning University of Traditional Chinese Medicine, Shenyang, China; Shi Zhang, The Affiliated Hospital of LNUOTCM, Shenyang, China; Yang Wang, The Affiliated Hospital of LNUOTCM, Shenyang, China; Zhe Zhang, The Affiliated Hospital of LNUOTCM, Shenyang, China; Guanlin Yang, Liaoning University of Traditional Chinese Medicine, Shenyang, China

(1056) – (1064) *Withdrawn*



Musculoskeletal & Rheumatic Conditions

(1066) An alternative approach to implementing PROMs

Elizabeth Gibbons, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Ray Fitzpatrick, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom

(1068) Health-related quality of life after below knee amputation stump salvage using free latissimus dorsi flap is comparable to that of local flap coverage

Jussi P. Repo, MD, University of Helsinki and Helsinki University Hospital, Finland, Helsinki, Uusimaa, Finland; Risto P. Roine, MD PhD, Group Administration, University of Helsinki and Helsinki University Hospital, HUS, Finland; Department of Health and Social Management, Research Centre for Comparative Effectiveness and Patient Safety, University of Eastern Finland, Kuopio, Finland, Helsinki, Finland; Erkki Tukiainen, MD PhD, University of Helsinki and Helsinki University Hospital, Finland, Helsinki, Finland

(1070) Use of early Patient-Reported Outcome Measures to predict one year health outcomes following lumbar laminectomy with arthrodesis

Taylor E. Purvis, BA, Johns Hopkins University, Baltimore, MD, United States; Brian J. Neuman, Johns Hopkins University, Baltimore, MD, United States; Lee H. Riley, III, Johns Hopkins University, Baltimore, MD, United States; Richard L. Skolasky, Johns Hopkins University, Baltimore, MD, United States

(1072) Identifying key domains of Health-related Quality of Life for individuals with LBP: persons' perspective

Owis Eilayyan, McGill University, Montreal, Quebec, Canada; Amede Gogovor, MSc, McGill University, Montreal, Quebec, Canada; Regina Visca, McGill University, Montreal, Quebec, Canada; Nancy Mayo, PhD, McGill University, Montreal, Quebec, Canada; Sara Ahmed, McGill University, Montreal, Canada

(1074) Improvement in physical but not mental Health-Related Quality of Life observed in Axial Spondyloarthritis patients over a 5-year period.

Gudrun Rohde, PhD, University of Agder and Sorlandet Hospital, Kristiansand, Norway; Kari Hansen Berg, University of Agder, Grimstad, Norway; Anne Proven, Martina Hansens Hospital, Bærum, Norway; Glenn Haugeberg, Martina Hansens Hospital and Sorlandet Hospital and Norwegian University of Science and Technology, Kristiansand, Norway

(1076) A systematic review of the psychometric properties of patient-reported outcome measures for use in patients with anterior cruciate ligament injuries

Joel Gagnier, MS MD PhD, University of Michigan, Ann Arbor, MI, United States; Ying Shen, MPH candidate, University of Michigan, Ann Arbor, MI, United States

(1078) *Withdrawn*

(1080) Large variation in pain, functioning and joint awareness in patients being satisfied with outcome after total joint arthroplasty

Karlmeinrad Giesinger, Kantonsspital St. Gallen, St.Gallen, Switzerland; Deborah J. MacDonald, University of Edinburgh, Edinburgh, United Kingdom; David F. Hamilton, Royal Infirmary of Edinburgh, Edinburgh, United Kingdom; Fanny L. Loth, MSc, Medical University of Innsbruck, Innsbruck, Tirol, Austria; Johannes M. Giesinger, PhD, Medical University of Innsbruck, Innsbruck, Austria

(1082) The reliability, central tendency, and variability of the RAND SF36 in patients attending care in a chiropractic PBRN

Joel Alcantara, Doctor of Chiropractic, International Chiropractic Pediatric Association, San Jose, CA, United States; Jeanne Ohm, Doctor of Chiropractic, International Chiropractic Pediatric Association, Media, PA, United States; Junjoe Alcantara, Doctor of Chiropractic, Alcantara Chiropractic, Pasig City, Luzon, Philippines

(1084) "I Just Want My Life Back": reducing fatigue and improving function are critical targets for improving participation and HRQL in rheumatoid arthritis

Alexandra Sirois, BSc, McGill University, Montreal, Quebec, Canada; Nathan Chiarlitti, BSc, McGill University, Montreal, Quebec, Canada; Michelle Jones, Johns Hopkins University, Baltimore, MD, United States; Clifton O. Bingham, MD, Johns Hopkins University, Baltimore, MD, United States; Susan J. Bartlett, PhD, McGill University, Montreal, QC, Quebec, Canada

Qualitative Methods & Stakeholder Engagement

(1086) Natural Language Processing (NLP) of verbatim Patient-Reported Outcomes highlights functional ability as important to patients

Jennifer L. Purks, BS, Georgetown University, Washington, DC, United States; Michael Harris, MA, Georgetown University, Washington, DC, DC, United States; Karen E. Anderson, MD, Georgetown University, Washington, DC, United States; Ira Shoulson, MD, Georgetown University, Washington, DC, United States

(1088) Collaborating with Ethno-Cultural Communities for Person-Centred Outcome Research: approaches to engagement

Kimberly Manalili, MPH, University of Calgary, Calgary, Alberta, Canada; Vic Lantion, MD, Ethno-Cultural Council of Calgary, Calgary, Alberta, Canada; Fartoon Siad, MSc, University of Calgary, Calgary, Alberta, Canada; **Maria J. Santana, PhD, University of Calgary, Calgary, Alberta, Canada**

(1090) The ISOQOL Patient Engagement Task Force: purpose, process and outcomes

Cynthia Chauhan, Research Advocacy Network, Wichita, KS, United States; **Cynthia R. Gross, PhD, University of Minnesota College of Pharmacy & School of Nursing, Minneapolis, MN, United States**; Lori Frank, PhD, PCORI, Washington DC, DC, United States; Carol M. Moinpour, PhD, Public Health Sciences Division, Fred Hutchinson Cancer Research Center, Seattle, WA, United States; Colleen Pedersen, ISOQOL, Milwaukee, WI, United States; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands

(1092) Exploratory analysis of the effectiveness of cognitive debriefing during usability testing of questionnaire format migration

Rebecca Prince, BA, Corporate Translations, Inc., Bloxham, Banbury, United Kingdom; **Elizabeth Yohe Moore, MPH, Corporate Translations, Inc., Chicago, IL, United States**; Barbara Brandt, MA, Corporate Translations Inc., East Hartford, CT, United States; Tim Poepsel, PhD, Corporate Translations, Inc., East Hartford, CT, United States; Shawn McKown, MA, Corporate Translations Inc., East Hartford, CT, United States

(1094) Qualitative methods of patient-reported outcome measure development

Loretta A. Williams, PhD, APRN, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Tito Mendoza, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Qiuling Shi, MD PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Xin S. Wang, MD MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Oluwatosin Bamidele, MBBS, MPH, MBA, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles S. Cleeland, PhD, The University of Texas UT MD Anderson Cancer Center, Houston, TX, United States

(1096) Compassionate interviewing: Engaging empathically with seriously ill participants for patient-reported outcomes (PRO) instrument development and regulatory/health technology assessment (HTA) submissions.

Angela Stroupe, MA, Pharmerit International, Newton, MA, United States; Laure Delbecq, PhD, Pharmerit International, Rotterdam, Netherlands; Caroline Seo, BSc, Pharmerit, International, Newton, MA, United States; Jacqueline Figueredo, BA, Pharmerit, International, Newton, MA, United States; Kirsten Glynn, MPH, Pharmerit, International, Newton, MA, United States; France G. Sowell, PhD, Pharmerit, International, Bethesda, MD, United States; Nicole Clarke, MPH, Pharmerit, International, Bethesda, MD, United States; Kathryn Lasch, PhD, Pharmerit International, Newton, MA, United States

(1098) *Withdrawn*

Concurrent Oral Sessions 4:10 pm – 5:40 pm

Oral Session 105: Meaningful Differences for General Populations

Grand ABC, 2nd Floor

Session Chair: Ben Schalet, United States

4:15 pm – 4:28 pm (105.1) What are all the proposed methods to estimate the minimal clinically important difference of a patient-reported outcomes measure? A systematic review.

Antoine Vanier, MD PhD, INSERM - University of Nantes - University of Tours, Nantes, France; Anna Toscano, PhD Student, University of Turin; University of Nantes, University of Tours, INSERM, Nantes, France; Veronique Sebillé, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Jean-Benoit Hardouin, PhD, University of Nantes, Nantes, France

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

4:29 pm – 4:42 pm (105.2) Evaluation of responder definitions: a comparison of nonparametric methods

Lysbeth L. Floden, PhD Student, Clinical Outcomes Solutions, Tucson, AZ, United States; Melanie Bell, PhD, University of Arizona, Tucson, AZ, United States; Stacie Hudgens, MA, Clinical Outcomes Solutions, Tucson, AZ, United States

4:43 pm – 4:56 pm (105.3) What impacts the stability of anchor-based responder definitions?

Shanshan Qin, PhD, RTI-HS, Research Triangle Park, NC, United States; Theresa Coles, PhD, RTI-HS, Research Triangle Park, NC, United States; Lauren Nelson, PhD, RTI-HS, Research Triangle Park, NC, United States; Valerie Williams, PhD, RTI-HS, Research Triangle Park, NC, United States; Nicole Williams, BS, RTI-HS, Research Triangle Park, NC, United States; Lori McLeod, PhD, RTI Health Solutions, Research Triangle Park, NC, United States



Scientific Program — Thursday, 19 October

4:57 pm – 5:10 pm (105.4) Minimally clinically important differences of PROMIS measures vary by symptom, direction, and level of disease activity in rheumatoid arthritis

Susan J. Bartlett, PhD, McGill University, Montreal, QC, Quebec, Canada; Michelle Jones, Johns Hopkins University, Baltimore, MD, United States; Clifton O. Bingham, MD, Johns Hopkins University, Baltimore, MD, United States

5:11 pm – 5:24 pm (105.5) Evidence-based approach to determine meaningful change in HRQOL scores of the EORTC QLQ-C30 in adjuvant melanoma cancer: on Behalf of the EORTC Melanoma Group and EORTC Quality of Life Group.

Jamme Musoro, EORTC Headquarters, Brussels, Belgium; Corneel Coens, EORTC Headquarters, Brussels, Belgium; Divine E. Ediabah, PhD, Amsterdam Medical Center, Amsterdam, The Netherlands, Amsterdam, Netherlands; Alexander Eggermont, Institut Gustave Roussy, Paris, France, Paris, France; Henning Flechtner, Magdeburg Universitätsklinik, Magdeburg, Germany; Eva Greimel, PhD, University Hospital Graz, Graz, Austria; Mogens Groenvold, MD PhD DSci, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, University of Copenhagen, Copenhagen, Denmark; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Jaap Reijneveld, VUMC, Amsterdam, Netherlands; Egbert F. Smit, Netherlands Cancer Institute, Amsterdam, The Netherlands, Amsterdam, Netherlands; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Stupp Roger, University Hospital Zurich, Zurich, Switzerland, Zurich, Switzerland; Martin Taphoorn, Medical Center Haaglanden, the Hague, Netherlands; Galina Velikova, BMBS(MD) PhD FRCP, University of Leeds, Leeds, United Kingdom; Efsthios Zikos, EORTC Headquarters, Brussels, Belgium; Yvonne Brandberg, Karolinska Institutet Solna, Stockholm, Sweden; Kim Cocks, PhD, Adelphi Values Ltd, Bollington, United Kingdom; Andrew Bottomley, PhD, EORTC Headquarters, Brussels, Belgium

Oral Session 106: Rehabilitation and Pain

Grand D, 2nd Floor

Session Chair: Dagmar Amtman, PhD, United States

4:15 pm – 4:28 pm (106.1) Quality of life and adaptation in people with spinal cord injury: recalibration response shift effects five years post-injury

Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc., Tufts University Medical School, Concord, MA, United States; Carly S. Rivers, Rick Hansen Institute, Vancouver, British Columbia, Canada; Vanessa K. Noonan, Rick Hansen Institute, University of British Columbia, Vancouver, British Columbia, Canada; Joel A. Finkelstein, MD MSc, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada; for the RHSCIR Network, Rick Hansen Institute, Vancouver, British Columbia, Canada

4:29 pm – 4:42 pm (106.2) Trajectories in social participation among community dwelling adults with multiple sclerosis

Ayse Kuspinar, PhD, McMaster University, Hamilton, Ontario, Canada; Nancy Mayo, PhD, McGill University, Montreal, Quebec, Canada

4:43 pm – 4:56 pm (106.3) Prospective validation of a short version of MSQOL-54 (MSQOL-29) and mode equivalence of electronic and paper-based administration

Rosalba Rosato, PhD, Università di Torino, Turin, Italy; Silvia Testa, University of Turin, Turin, Italy; Paolo Confalonieri, Istituto Neurologico Carlo Besta, Milan, Italy; Maria Grazia Grasso, Fondazione S. Lucia, Rome, Italy; Ilaria Rossi, IRCCS S. Lucia Foundation, Rome, Italy; Francesco Schiavelli, Regional Referral Multiple Sclerosis Centre (CReSM), University Hospital San Luigi Gonzaga, Orbassano, Italy; Francesco Patti, Ospedale Garibaldi, Catania, Catania, Italy; Erika Pietrolongo, Imaging and Clinical Sciences, G. d'Annunzio University of Chieti-Pescara, Chieti, Italy; Clara G. Chisari, University Hospital Policlinico Vittorio Emanuele, Catania, Italy; Anna Toscano, PhD Student, University of Turin; University of Nantes, University of Tours, INSERM, Nantes, France; Barbara L. Loera, University of Turin, Turin, Italy; Antonio Bertolotto, Centro Riferimento Regionale Sclerosi Multipla (CReSM) and Azienda Ospedaliera Universitaria San Luigi Gonzaga, Orbassano, Italy; Andrea Giordano, Istituto Neurologico Carlo Besta, Milan, Italy; Ambra Giovannetti, Foundation IRCCS Neurological Institute C. Besta, Milan, Italy; Alessandra Lugaresi, University of Chieti and Pescara, Chieti, Italy; Alessandra Solari, Istituto Neurologico Carlo Besta, Milan, Italy

4:57 pm – 5:10 pm (106.4) Evaluating different patterns of chronic pain through PROs - applying latent class analysis to visual analogue scales

Alexander Obbarius, MD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Nina Obbarius, Dipl Psych, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Felix Fischer, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Gregor Liegl, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany



Scientific Program — Thursday, 19 October

5:11 pm – 5:24 pm (106.5) Assessing condition-specific health-related quality of life in lateral epicondylar tendinopathy: a systematic and standardised comparison of available instruments

Jonathan P. Evans, MBBS, University of Exeter, Exeter, Devon, United Kingdom; Christopher M. Smith, MBBS, Royal Devon & Exeter Hospital, Exeter, United Kingdom; Ian Porter, PhD, University of Exeter, Exeter, Devon, United Kingdom; Jaheeda Gangannagaripalli, PhD Student, University of Exeter, Exeter, Devon, United Kingdom; Charlotte Bramwell, PhD Student, University of Exeter, Exeter, Devon, United Kingdom; Antoinette F. Davey, PhD Student, University of Exeter, Exeter, Devon, United Kingdom; Vicki Goodwin, PhD, University of Exeter, Exeter, United Kingdom; Jose M. Valderas, MD PhD, University of Exeter, Exeter, United Kingdom

Oral Session 107: Clinical Conditions I

Innovation, 3rd Floor

Session Chair: Sara Ahmed, PhD, Canada

4:15 pm – 4:28 pm (107.1) Using creative and therapeutic activities to improve dialysis patients' health-related quality of life

Guillermo Pedreira Robles, Registered Nurse, Hospital del Mar, Barcelona, Barcelona, Spain; Ana vasco Gómez, Registered Nurse, Hospital del Mar, Barcelona, Spain; Cristina herrera Morales, Registered Nurse, Hospital del Mar, Barcelona, Spain; Yaiza Martínez Delgado, Registered Nurse, Hospital del Mar, Barcelona, Spain; Tai mooi Ho Wong, Registered Nurse, Hospital del Mar, Barcelona, Spain; Ernestina Junyent Iglesias, Registered Nurse, Hospital del Mar, Barcelona, Spain

4:29 pm – 4:42 pm (107.2) Psychometric Properties of the Kidney Disease Quality of Life (KDQOLTM) 36-item short-form survey (KDQOL-36) in the United States

John D. Peipert, PhD, David Geffen School of Medicine, UCLA, Los Angeles, United States; Peter M. Bentler, PhD, UCLA, Los Angeles, CA, United States; Kristi Klicko, Medical Education Institute, Madison, WI, United States; Ron D. Hays, PhD, UCLA, Los Angeles, CA, United States

4:43 pm – 4:56 pm (107.3) Patient-reported outcomes as predictors of mortality, initiation of dialysis and transplantation in patients with chronic kidney disease: a prospective cohort study

Birgith E. Grove, MSc, AmbuFlex/WestChronic, Herning, Denmark; Niels Henrik Hjollund, Professor, PhD, Hospital Unit West Jutland / Aarhus University, Herning, Denmark; Liv Marit Valen Schougaard, PhD Student, AmbuFlex, Herning, Denmark; Per R. Ivarsen, MD PhD, Department of Nephrology, Aarhus University Hospital, Aarhus N, Denmark

4:57 pm – 5:10 pm (107.4) Standardised Translation of the King's Sarcoidosis Questionnaire (KSQ) into eleven languages

Surinder Biring, MB ChB (Hons) MD, King's College Hospital, London, United Kingdom; Hannah Fletcher, MSc, King's College Hospital, London, United Kingdom; Timothy Tully, MD, King's College Hospital, London, United Kingdom; Amit S. Patel, MD, King's College Hospital, London, United Kingdom; Susanna Kullberg, MD, Karolinska Institute, Stockholm, Sweden; Nesrin Mogulkoc, MD, Ege University Hospital, Izmir, Turkey; Anna Dubaniewicz, MD, Medical University of Gdansk, Gdansk, Poland; Gianluca Cotta, MD, Hospital de la Santa Creu i Sant Pau, Barcelona, Spain; Akio Niimi, MD, Nagoya City University Graduate School of Medical Sciences, Nagoya, Japan; Wei-Jie Guan, PhD, Guangzhou Institute of Respiratory Disease, Guangzhou, China; Dominique Valeyre, MD, Avicenne Hospital, APHP, Bobigny, France; Diego Castillo Villegas, MD, Hospital de la Santa Creu i Sant Pau, Barcelona, Spain; Carlos A. Pereira, MD, Paulista School of Medicine, Federal University of São Paulo, São Paulo, Brazil; Catherine Acquadro, MD, Mapi, Lyon, France; Robert Baughman, MD, University of Cincinnati, Cincinnati, OH, United States

5:11 pm – 5:24 pm (107.5) Impact of employment status on health-related quality of life for people living with autoimmune conditions

Leslie Beth Herbert, PhD, Health Union, Philadelphia, PA, United States; Amna Rizvi, MPH, Health Union, Philadelphia, PA, United States

Thursday, 19 October



Scientific Program — Thursday, 19 October

6:00 pm – 6:30 pm Tricks of the Trade Presentation

Grand ABC, 2nd Floor

Complexity - How to transfer complex research into effective presentations

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.

Speakers:

Karon F. Cook, PhD, Northwestern University, Houston, TX, United States

Christopher Gibbons, University of Cambridge, Cambridge, United Kingdom

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

6:30 pm – 7:30 pm Mentor/Mentee Reception (Ticket Required)

Discovery ABC, 3rd Floor

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

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

Thursday, 19 October



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Scientific Program — Friday, 20 October

7:00 am – 5:45 pm Registration Desk Open Grand Foyer, 2nd Floor

7:45 am – 8:45 am SIG Council Meeting (Closed Event) Innovation, 3rd Floor

7:45 am – 8:45 am Roundtables (Ticket Required) Discovery A, 3rd Floor

RT01: PRO and ERH integration...Notes from the Field

Hosted by Rachel Hess, MD MS, University of Utah, Salt Lake City, UT, United States

RT02: Pediatric Patient-Reported Outcomes

Hosted by Christopher B. Forrest, MD PhD, The Children's Hospital of Philadelphia, Philadelphia, PA, United States

RT03: Beyond U.S. drug labeling as the sole marker of a successful PRO strategy in Cancer trials: discuss with FDA the utility of PRO data in US Regulatory

Hosted by Paul Kluetz, MD, Food and Drug Administration, Silver Spring, MD, United States

RT04: Making EORTC instruments more dynamic

Hosted by Mogens Groenvold, MD PhD, University of Copenhagen, Copenhagen, Denmark

RT05: But, what does this score mean? Interpreting scores from patient reported outcome measures.

Hosted by Karon F. Cook, PhD, Northwestern University, Houston, TX, United States

RT06: New forms of patient generated health data in quality of life research

Hosted by Antonia Bennett, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

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

9:00 am – 10:30 am Plenary – Communicating PRO Data to Support Complex Decision Making Grand ABC, 2nd Floor

Plenary sponsored by: Bayer

In this session we are focusing on the rapidly increasing amount of real-time of patient-reported outcomes available in clinical care settings, and discussing the future using this information both for the patient and at the system level.

Speakers

Ida Sim, MD, PhD, UCSF School of Medicine, San Francisco, CA, United States

Helen Burstin, MD, MPH, FACP, National Quality Forum, Washington, DC, United States

Michael Seid, PhD, UC Department of Pediatrics, Cincinnati, OH, United States

Chair

Roxanne Jensen, PhD, Johns Hopkins University, Baltimore, MD, United States

10:00 am – 12:00 pm Poster Hall Open Columbus Ballroom, 2nd Floor

10:30 am – 11:15 am Exhibits Open and Refreshment Break Columbus Foyer/Grand Foyer, 2nd Floor

10:35 am – 11:10 am Friday Poster Session I Columbus Ballroom, 2nd Floor

(2003) Patient-reported outcome measures within pediatric solid organ transplantation: a systematic review

Samantha J. Anthony, PhD MSW, The Hospital for Sick Children, Toronto, Ontario, Canada; Hayley Stinson, MSW, The Hospital for Sick Children, Toronto, Ontario, Canada; Tanya Lazor, MSW, The Hospital for Sick Children, Toronto, Ontario, Canada; Katarina Young, BHS, The Hospital for Sick Children, Toronto, Ontario, Canada; Maria J. Santana, PhD, University of Calgary, Calgary, Alberta, Canada; Jennifer Stinson, RN-EC PhD CPNP, The Hospital for Sick Children, Toronto, Ontario, Canada; Lori West, MD DPhil, University of Alberta, Edmonton, Alberta, Canada

NEW INVESTIGATOR POSTER AWARD FINALIST



(2005) Systematic evaluation of Patient-Reported Outcome (PRO) protocol content and reporting in cancer clinical trials: the EPiC study

Derek G. Kyte, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Ameeta Retzer, PhD, University of Birmingham, Birmingham, United Kingdom; Thomas Keeley, PhD, Parexel International, London, United Kingdom; Khaled Ahmed, PhD, University of Birmingham, Birmingham, United Kingdom; Jo Armes, PhD, Kings College London, London, United Kingdom; Julia M. Brown, MSc, University of Leeds, Leeds, United Kingdom; Lynn Calman, PhD, University of Southampton, Southampton, United Kingdom; Chris Copland, NCRI Psychosocial Oncology and Survivorship CSG, York, United Kingdom; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Anna Gavin, PhD, Queen's University Belfast, Belfast, United Kingdom; Adam Glaser, BSc (HONS) MBBS DM MRCP FRCPC, University of Leeds, Leeds, United Kingdom; Diana M. Greenfield, PhD, Sheffield Teaching Hospital NHS Foundation Trust, Sheffield, United Kingdom; Anne Lanceley, PhD, University College London, London, United Kingdom; Rachel M. Taylor, PhD, University College London Hospitals NHS Foundation Trust, London, United Kingdom; Galina Velikova, BMBS(MD) PhD FRCP, University of Leeds, Leeds, United Kingdom; Michael Brundage, MD MSc, Kingston General Hospital, Queen's University, Kingston, Ontario, Canada; Rebecca Mercieca-Bebber, University of Sydney, Sydney, NSW, Australia; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom

NEW INVESTIGATOR POSTER AWARD FINALIST

(2007) Is personality pathology a unidimensional construct? Development of a personality pathology item bank based on the OPD structure questionnaire.

Alexander Obbarius, MD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Nina Obbarius, Dipl Psych, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Gregor Liegl, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Felix Fischer, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

NEW INVESTIGATOR POSTER AWARD FINALIST

Cardiovascular Disease

(2009) Identifying research priorities relating to the long-term impact of TIA and minor stroke

Grace Turner, PhD, University of Birmingham, Birmingham, United Kingdom; Tom Marshall, PhD, Institute for Applied Health Research, Birmingham, United Kingdom; Jonathan Mathers, PhD, University of Birmingham, Birmingham, West Midlands, United Kingdom; Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom

(2011) Increasing capture of patient-reported outcomes in trauma research

Grace Turner, PhD, University of Birmingham, Birmingham, United Kingdom; Anita Slade, PhD, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; Derek G. Kyte, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Karen Piper, PhD, Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Antonio M. Belli, MD, University of Birmingham, Birmingham, United Kingdom

(2013) Assessing Health-Related Quality of Life (HRQOL) in survivors of cardiac arrest: a systematic review of patient-reported outcome measures

Kirstie Haywood, DPhil. BSc (Hons), Royal College of Nursing Research Institute, Warwick Medical School, Warwick University, Coventry, United Kingdom; Nathan Pearson, PhD Student, Warwick Medical School, Warwick University, Coventry, United Kingdom; Laurie J. Morrison, MD MSc FRCPC, Li Ka Shing Knowledge Institute, St Michaels Hospital, Toronto, Ontario, Canada; Maaret Castrén, MD FRCPC, Helsinki University Central Hospital, Helsinki, Finland; Gisela Lilja, OT, Skåne University Hospital; Lund University, Lund, Sweden; Gavin Perkins, University of Warwick, Coventry, United Kingdom

(2015) The development and evaluation of the traditional Chinese medicine (TCM) diagnosis scale of coronary heart disease (CHD) angina pectoris of spleen deficiency and phlegm turbid syndrome

Fan Zhang, the affiliated hospital of LNUTCM, Liaoning, China; Yue Xu, Liaoning University of Traditional Chinese Medicine, Shenyang, China; Zhihui Chen, Liaoning University of Traditional Chinese medicine, Shenyang, China; Yue Liu, The Affiliated Hospital of LNUTCM, Shenyang, China; Dezhao Kong, The Affiliated Hospital of LNUTCM, Shenyang, China; Yupeng Pei, Liaoning University of Traditional Chinese Medicine, Shenyang, China; Shi Zhang, The Affiliated Hospital of LNUTCM, Shenyang, China; Yang Wang, The Affiliated Hospital of LNUTCM, Shenyang, China; Zhe Zhang, The Affiliated Hospital of LNUTCM, Shenyang, China; Guanlin Yang, Liaoning University of Traditional Chinese Medicine, Shenyang, China

Scientific Program — Friday, 20 October

Health Utility Measurement

(2017) EQ-5D-5L valuation study for Portugal

Pedro L. Ferreira, PhD, CEISUC/FEUC, Coimbra, Portugal; Patricia Antunes, PhD Student, CEISUC, Coimbra, Portugal; Lara N. Ferreira, PhD, CEISUC & University of Algarve, Faro, Portugal; Luis N. Pereira, PhD, University of the Algarve - CIEO & CEISUC, Faro, Portugal

(2019) Quality of life asymmetries based on the residence

Pedro L. Ferreira, PhD, CEISUC/FEUC, Coimbra, Portugal; Patricia Antunes, PhD Student, CEISUC, Coimbra, Portugal; Lara N. Ferreira, PhD, CEISUC & University of Algarve, Faro, Portugal; Luis N. Pereira, PhD, University of the Algarve - CIEO & CEISUC, Faro, Portugal

(2021) Brachytherapy versus External Beam Radiation Treatment with early stage breast cancer: impact on Quality of Life

Alec R. Hansen, University of Utah, Salt Lake City, UT, United States; Maren Voss, MS, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Dominique Nielson, University of Utah, Salt Lake City, UT, United States; Man Hung, PhD, University of Utah, Salt Lake City, UT, United States

(2023) Canadian population norms for the QLU-C10D, a new cancer-specific utility instrument

Helen McTaggart-Cowan, PhD, Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Richard Norman, PhD, Curtin University, Perth, Australia; A. Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States; Dean A Regier, PhD, Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada; Stuart J Peacock, D. Phil., Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada; on behalf of the Canadian MAUCa Team, Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada

(2025) Mapping two depression scales (DASS-21 and K10) onto each of eight different value sets for EQ-5D-5L

Thor Gamst-Klaussen, MA PhD Student, University of Tromsø, Tromsø, Norway; Admassu N. Lamu, Doctoral Student, University of Tromsø, Tromsø, Norway; Gang Chen, PhD, Monash University, Clayton, Victoria, Australia; Jan A. Olsen, BA (Hons) PhD, University of Tromsø, Tromsø, Norway

(2027) Estimating a Dutch value set for the paediatric preference-based CHU-9D using a discrete choice experiment with duration

Donna Rowen, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom; Brendan Mulhern, University of Technology Sydney, Sydney, NSW, Australia; Katherine Stevens, PhD, University of Sheffield, Sheffield, United Kingdom; Erik Vermaire, PhD, TNO Child Health, Leiden, Netherlands

(2029) Creating a preference-based scoring system for the Health Status Classification System - Preschool (HSCS-PS)

Charlene Rae, MS (PhD Student), McMaster University, Hamilton, Ontario, Canada; William Furlong, MSc, McMaster University, Dundas, Ontario, Canada; **David Feeny, PhD, Department of Economics, McMaster University, Hamilton, Ontario, Canada, Hamilton, Ontario, Canada;** Ronald D. Barr, MD, McMaster University, Hamilton, Ontario, Canada

(2031) Eye tracking to explore attendance in health-state descriptions

Anna Selivanova, PhD Student, University of Groningen, University Medical Center Groningen, Groningen, Groningen, Netherlands; Paul F. Krabbe, PhD, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands., Groningen, Netherlands

(2033) Quantifying the uncertainty in the PROMIS® Preference (PROPr) scoring system

Barry Dewitt, PhD Student, Carnegie Mellon University, Pittsburgh, PA, United States; Alexander Davis, PhD, Carnegie Mellon University, Pittsburgh, PA, United States; Baruch Fischhoff, PhD, Carnegie Mellon University, Pittsburgh, PA, United States; Mark Roberts, MD MPP, University of Pittsburgh, Pittsburgh, PA, United States; Janel Hanmer, MD PhD, University of Pittsburgh, Pittsburgh, PA, United States

(2035) What does the “usual activities” dimension of the EQ-5D measure?

Shelby Huffman, University of Alberta, Edmonton, Alberta, Canada; Fatima Al Sayah, PhD, University of Alberta, Edmonton, Alberta, Canada, **Arto Ohinmaa, PhD, University of Alberta, Edmonton, Alberta, Canada;** Jeffrey A. Johnson, PhD, University of Alberta, Edmonton, Alberta, Canada

(2037) The impact of happiness and demographic on EQ-5D-5L C-TTO and DCE values: happy people trade off

Fredrick D. Purba, PhD Candidate, Erasmus MC University Medical Center, Rotterdam, Netherlands; Joke A. Hunfeld, PhD, Erasmus MC University Medical Center , Rotterdam, Netherlands; Aulia Iskandarsyah, PhD, Padjadjaran University, Faculty of Psychology , Jatinangor, Indonesia; Titi S. Fitriana, M.Psi, YARSI University, Jakarta, Indonesia; Sawitri S. Sadarjoen, PhD, Padjadjaran University, Faculty of Psychology, Jatinangor, Indonesia; Jan Passchier, PhD, VU University, Amsterdam, Netherlands; Jan J. Busschbach, PhD, Erasmus MC University Medical Center, Rotterdam, Netherlands

(2039) Test-retest reliability of discrete choice experiments for valuations of QLU-C10D health states

Eva Gamber, PhD, Medical University of Innsbruck, Innsbruck, Tyrol, Austria, Fanny L. Loth, MSc, Medical University of Innsbruck , Innsbruck, Tyrol, Austria; Bernhard Holzner, PhD, Medical University of Innsbruck, Innsbruck, Austria; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Virginie Nerich, Besançon University Hospital, Besançon, France; Richard Norman, PhD, Curtin University, Perth, Australia; Rosalie Viney, PhD, University of Technology Sydney (UTS), Sydney, NSW, Australia; **Georg Kemmler, Innsbruck Medical University, Innsbruck, Tyrol, Austria**

PROMIS

(2041) Psychometrics and crosswalks of the PROMIS measures

Man Hung, PhD, University of Utah, Salt Lake City, UT, United States; Tom Greene, PhD, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; **Maren Voss, MS, University of Utah, Salt Lake City, UT, United States**; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Charles L. Saltzman, MD, University of Utah, Salt Lake City, UT, United States

(2043) Health outcomes in the era of technology

Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Maren Voss, MS, University of Utah, Salt Lake City, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; **Man Hung, PhD, University of Utah, Salt Lake City, UT, United States**

(2045) The impact of disease-related differential item functioning on the comparison of PROMIS Physical Function scores between cardiology and rheumatology patients

Gregor Liegl, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Felix Fischer, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Frank Buttgereit, MD, Charité – Universitätsmedizin Berlin, Berlin, Germany; Fabian Knebel, MD, Charité – Universitätsmedizin Berlin, Berlin, Germany; Andreas Stengel, MD, Charité – Universitätsmedizin Berlin, Berlin, Germany; Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

(2047) Utility of the PROMIS instruments in orthopaedics

Man Hung, PhD, University of Utah, Salt Lake City, UT, United States; Charles L. Saltzman, MD, University of Utah, Salt Lake City, UT, United States; Tom Greene, PhD, University of Utah, Salt Lake City, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Maren Voss, MS, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Andrew Tyser, MD, University of Utah, Salt Lake City, UT, United States

(2049) Health utility in patients undergoing spine surgery: derivation and validation of a conversion equation using Patient Outcomes Reporting Measurement Information System (PROMIS) health domains

Richard L. Skolasky, Johns Hopkins University, Baltimore, MD, United States; Brian J. Neuman, Johns Hopkins University, Baltimore, MD, United States; Lee H. Riley, III, Johns Hopkins University, Baltimore, MD, United States

(2051) Evaluation of measurement equivalence across child self-reports and parent proxy-reports of PROMIS pediatric Health-Related Quality of Life

Ania Filus, PhD, University of Southern California, Los Angeles, CA, United States; Stefan Schneider, PhD, University of Southern California, Los Angeles, CA, United States

(2053) Calibration of the Dutch-Flemish PROMIS item banks ability to participate in social roles and activities and satisfaction with social roles and activities in patients undergoing rehabilitation and in the general population

Caroline B. Terwee, PhD, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, Netherlands; Albere Köke, PhD, Zuyd University of Applied Science, Heerlen, Netherlands; Eva de Schipper, BSc, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, Netherlands; Martine H. Crins, Amsterdam Rehabilitation Research Center, Reade, Amsterdam, Netherlands; Thomas Klausch, PhD, Department of Epidemiology & Biostatistics, VU University Medical Center, Amsterdam, Netherlands; Rob Smeets, PhD, Maastricht University, Maastricht, Netherlands; Henrica de Vet, PhD, VU University Medical Center, Amsterdam, Netherlands; Leo D. Roorda, MD PhD, Amsterdam Rehabilitation Research Center, Reade, Amsterdam, Netherlands

(2055) Self-rated health of the Dutch general population as compared to the US general population as measured with eleven PROMIS item banks

Martine H. Crins, Amsterdam Rehabilitation Research Center, Reade, Amsterdam, Netherlands; **Caroline B. Terwee, PhD, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, Netherlands**; Toufik Agaroud, VU University Medical Center, Amsterdam, Netherlands; Henrica de Vet, PhD, VU University Medical Center, Amsterdam, Netherlands; Maarten Boers, VU University Medical Center, Amsterdam, Netherlands; Rene Westhovens, Department of Development and Regeneration, Skeletal Biology and Engineering Research Center, KU Leuven, Leuven, Belgium; Gerard Flens, Stichting Benchmark GGZ (SBG) [Benchmark Foundation Mental Health Care], Bilthoven, Netherlands; Edwin de Beurs, Stichting Benchmark GGZ (SBG) [Benchmark Foundation Mental Health Care], Bilthoven, Netherlands; Joost Dekker, Department of Rehabilitation Medicine and Department of Psychiatry, VU University Medical Center, Amsterdam, Netherlands; Leo D. Roorda, MD PhD, Amsterdam Rehabilitation Research Center | Reade, Amsterdam, Netherlands

(2057) Short forms to measure pain catastrophizing and pain related self-efficacy

Dagmar Amtmann, PhD, University of Washington, Seattle, WA, United States; Alyssa M. Bamer, MPH, University of Washington, Denver, CO, United States; Kendra Liljenquist, PhD, University of Washington, Seattle, WA, United States; Mark P. Jensen, PhD, University of Washington, Seattle, WA, United States; Dennis C. Turk, PhD, University of Washington, Seattle, WA, United States



(2059) The PROMIS general satisfaction with sexual life scale: a validation replication study

Stephanie Hullman, PhD, RUSH Medical Center, Chicago, IL, United States; Douglas O. Williams, BS BA, University of Sydney, University of Sydney, NSW, Australia; Angela Ballard, BSc, The University of Sydney, Sydney, Australia; Haryana M. Dhillon, PhD, University of Sydney, Sydney, NSW, Australia; Phyllis Butow, Psycho-oncology Research Group (PoCoG), University of Sydney, Sydney, Australia; Ilona Juraskova, PhD, University of Sydney, Sydney, NSW, Australia; Kim Hobbs, BSW MA, Westmead Hospital, Westmead, NSW, Australia; Kevin McGeechan, PhD, University of Sydney, Sydney, NSW, Australia; Catalina Lawsin, PhD, RUSH Medical Center, Chicago, IL, United States; **Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia**

(2061) Responsiveness of the PROMIS® Pediatric Global Health (PGH-7) measure to improvements in acute asthma

Brandon D. Becker, MPH PhD, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Joseph Zorc, MD, Children's Hospital of Philadelphia, Philadelphia, PA, United States; James Guevara, MD MPH, Children's Hospital of Philadelphia, Philadelphia, PA, United States; JeanHee Moon, PhD, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Mitchell Maltenfort, PhD, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Ramya Pratiwadi, MEd, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Christopher B. Forrest, MD PhD, Children's Hospital of Philadelphia, Philadelphia, PA, United States

(2063) Testing the measurement and score equivalence of paper-, web-, and interactive voice response system-based versions of PROMIS and other simple patient-reported measures

MINJI LEE, PhD, Mayo Clinic, ROCHESTER, MN, United States; Timothy J. Beebe, PhD, University of Minnesota, Minneapolis, MN, United States; **Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States**; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; David T. Eton, PhD, Mayo Clinic, Rochester, MN, United States; Marlene H. Frost, PhD, Mayo Clinic, Rochester, MN, United States; Paul Novotny, BS MS, Mayo Clinic, Rochester, MN, United States; Jeff A. Sloan, PhD, Mayo Clinic, Rochester, MN, United States

(2065) Linking the PROMIS and ASCQ-Me pain measures

Michelle Langer, PhD, American Institutes for Research, Chapel Hill, NC, United States; San Keller, American Institutes for Research, Chapel Hill, NC, United States

PROs in Clinical Practice

(2067) Recommendations for presenting patient-reported outcomes data to patients and clinicians: results from a modified-Delphi consensus process

Michael Brundage, MD MSc, Kingston General Hospital, Queen's University, Kingston, Ontario, Canada; Elissa Bantug, MHS, Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD, United States; Katherine C. Smith, PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States; Bernhard Holzner, PhD, Medical University of Innsbruck, Innsbruck, Austria; Yonaira Rivera, MPH, 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 Delphi Panel, Various, Various, MD, United States

(2069) Is health-related quality of life (HRQOL) a suitable measure of patient decision aid effectiveness: a systematic review sub-analysis?

Claudia Rutherford, PhD, University of Sydney, Sydney, NSW, Australia; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Intissar Souli, PhD Candidate, University of Ottawa, Ottawa, Ontario, Canada; Dawn Stacey, PhD, University of Ottawa, Ottawa, Ontario, Canada

(2071) *Withdrawn*

(2073) Use of Quality of Life instruments in clinical practice in the Andalusian Public Health System

Miguel Rodríguez-Barranco, PhD, Andalusian School of Public Health, Granada, Granada, Spain; **Antonio Olry de Labry Lima, PhD, Andalusian School of Public Health, Granada, Granada, Spain**; María del Carmen Valcárcel-Cabrera, BS, Andalusian School of Public Health, Granada, Granada, Spain; Eva Martín-Ruiz, MSc, Andalusian School of Public Health, Granada, Granada, Spain; Pablo Sánchez-Villegas, MSc, Andalusian School of Public Health, Granada, Granada, Spain; Juan Manuel Jiménez-Martín, PhD, Andalusian School of Public Health, Granada, Granada, Spain; Diego Rodero-Pulido, BS, Andalusian School of Public Health, Granada, Granada, Spain; Joan Carles March-Cerdá, PhD, Andalusian School of Public Health, Granada, Granada, Spain

(2075) Measuring treatment goals and benefits: defining threshold values regarding clinical needs for actions from patients' perspective

Rachel Sommer, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Maximilian Kleimaker, University of Hamburg, Hamburg, Germany; Christine Blome, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(2077) Use of KLIK in adult care: Implementation of electronic Patient Reported Outcomes in clinical practice.

Hedy van Oers, MSc, Psychologist/PhD student, Amsterdam, Netherlands; Martha A. Grootenhuis, PhD, Princess Máxima Center for pediatric oncology, Utrecht, Netherlands; Lotte Haverman, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Amsterdam, Netherlands

Scientific Program — Friday, 20 October

(2079) Quantifying the patient experience with patient-reported outcome measures

Brittany Lapin, PhD MPH, Cleveland Clinic, Cleveland, OH, United States; Joceyln Bautista, MD, Cleveland Clinic, Cleveland, OH, United States; Charles Bae, MD, Cleveland Clinic, Cleveland, OH, United States; Irene Katzan, Cleveland Clinic, Cleveland, OH, United States

(2081) Bundle payment in health services delivery

Man Hung, PhD, University of Utah, Salt Lake City, UT, United States; Alec R. Hansen, University of Utah, Salt Lake City, UT, United States; Maren Voss, MS, University of Utah, Salt Lake City, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; **Dominique Nielson, University of Utah, Salt Lake City, UT, United States**

(2083) Electronic patient-reported outcomes: Do current guidance address issues encountered in practice?

Paul Williams, MPH BSc, Mapi, Lyon, France; Alexandre Itani, BA, Mapi, Lyon, France; Vanessa Brunel, MA, Mapi, Lyon, France; Piero Bindi, MA, Mapi Research Trust, Lyon, France; Marie-Pierre Emery, MA, Mapi Research Trust, Lyon, France; Catherine Acquadro, MD, Mapi, Lyon, France; Elan Josielewski, PhD, Mapi, Yardley, PA, United States; **Caroline Anfray, MA, Mapi Research Trust, Lyon, France**

(2085) m-PRIAS: an e-health technology for men on active surveillance for prostate cancer

Lionne Venderbos, PhD, Erasmus University Medical Center, Rotterdam, Netherlands; Monique Roobol, PhD, Erasmus University Medical Center, Rotterdam, Netherlands

(2087) Health related quality of life (HRQOL) assessment for patients with advanced renal cell carcinoma (mRCC) treated with tyrosine inhibitor (TKI) using electronic patient reported outcome (PRO) in daily clinical practice in France

Guillaume Mouillet, MD, University Hospital Jean Minjot, Besançon, France; Astrid Pozet, University Hospital Jean Minjot, Besançon, France; Joëlle Fritsch, University Hospital Jean Minjot, Besançon, France; Ikram Es-Saad, MSc, University Hospital Jean Minjot, Besançon, France; Sophie Paget-Bailly, PhD, University Hospital Jean Minjot, Besançon, France; Audrey Foubert, MSc, University Hospital Jean Minjot, Besançon, France; Diane Berthod, , University Hospital Jean Minjot, Besançon, France; **Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France**; Antoine Thierry-Vuillemin, MD PhD, University Hospital Jean Minjot, Besançon, France; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France

11:15 am – 12:30 pm Concurrent Symposium Sessions

Symposium 1: **Users' Guide for Integrating Patient-Reported Outcomes in Electronic Health Records: Design and Implementation Considerations**

Grand ABC, 2nd Floor

Moderator:

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

Discussants:

Ashley Smith, PhD, MPH, National Cancer Institute, Bethesda, MD, United States

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

Submitted on Behalf of the PRO-EHR Users' Guide Steering and Working Group

The "Users' Guide for Integrating Patient-Reported Outcomes in Electronic Health Records" was developed in response to increasing interest in and demand for guidance on how PROs can be incorporated into EHRs. The Users' Guide for integrating PROs in EHRs builds on the ISOQOL "Users' Guide for Assessing Patient-Reported Outcomes in Clinical Practice," but focuses specifically on considerations associated with EHR integration, including technological and applied topics. Similar to the ISOQOL Users' Guide, the PRO-EHR Users' Guide addresses the key issues (formulated as questions) related to integrating PROs in EHRs, and rather than recommending one "right" approach, provides a range of options, along with their relative advantages and disadvantages. By providing multiple options, organizations can evaluate which approach(es) fit best for their environment. Each section of the PRO-EHR Users' Guide also identifies information gaps/research questions and useful references/resources. A multi-disciplinary Steering Group of stakeholders advised on the overall project strategy, developed the list of key issues involved in integrating PROs in EHRs, and helped identify experts to address the questions. The question list was circulated for comment before being finalized. For each question, two experts with complementary backgrounds and expertise were selected, forming the Working Group. The PRO-EHR Users' Guide was circulated for stakeholder comment prior to finalization. This session will provide an overview of the PRO-EHR Users' Guide and present two abstracts highlighting the design and implementation issues. Design issues include approaches used for integrating PROs in EHRs, governance, training, target populations, outcomes of interest, and PRO



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measure selection. Implementation issues include the mode and frequency of PRO administration, reporting results, responding to issues, pooling data, and ethical/legal considerations.

Individual Presentations

Integrating Patient-Reported Outcomes in Electronic Health Records: Design Considerations

Michele Halyard, Mayo Clinic, Scottsdale, AZ, United States

Integrating Patient-Reported Outcomes in Electronic Health Records: Implementation Considerations

Irene Katzan, Cleveland Clinic, Cleveland, OH, United States

Symposium 2: Using qualitative methods to explore and define estimates of clinically meaningful change and responders: advantages, challenges and solutions

Grand D, 2nd Floor

Moderator:

Rob Arbuckle, Adelphi Values Ltd, Cheshire, United Kingdom

Establishing what constitutes clinically meaningful change at the patient-level on Clinical Outcome Assessments (COA) is important to aid interpretation of COA data by patients, clinicians, regulators and payers. It's increasingly recognized that only using statistical methods to do so is insufficient. Instead, taking a patient-centric, mixed methods approach, researchers are recommended to also use qualitative methods to obtain the perspectives of patients, caregivers and healthcare professionals regarding what constitutes meaningful and important score change. However, despite consensus around the value of qualitative exploration of meaningful change, there remain many unsolved challenges related to their implementation and interpretation. This symposium will provide attendees with a comprehensive overview of qualitative methods that can be used to establish clinically meaningful change and serve as a forum to discuss challenges associated with conduct and interpretation. Case studies from multiple disease areas and with a variety of respondent-types (children, caregivers and clinicians) will be presented and discussed.

Individual Presentations

Qualitatively exploring clinically meaningful change on Clinical Outcome Assessments – overview of methods, challenges and considerations

Hannah Staunton, MSc, Roche, Welwyn Garden City, United Kingdom

Novel approaches to qualitatively exploring clinically meaningful change in a pediatric population

Rob Arbuckle, Adelphi Values Ltd, Cheshire, United Kingdom

Qualitative Exit Interviews with Psychologists and Parents/Caregivers to Help Inform Clinically Meaningful Change Thresholds on an Observer-reported Clinician Administered Measure and a Performance Outcome Measure in Down Syndrome

Tom Willgoss, PhD, Roche Products Ltd., Welwyn Garden City, United Kingdom

A mixed methods approach to establishing clinically meaningful change using patient-reported outcome and observer-reported outcome data

Linda Nelsen, GlaxoSmithKline, Collegeville, PA, United States

Optimizing Multiple Raters in the Generation of Anchors for Evaluating Meaningful Change

Claire Burbridge, Clinical Outcomes Solutions, Folkestone, United Kingdom

Symposium 3: Enriching Quality of Life Research Through Appraisal Assessment: Measurement, Theory, and Empirical Evidence

Innovation, 3rd Floor

Moderator:

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

Discussants:

Karon F. Cook, PhD, Northwestern University, Houston, TX, United States

Recent work on patient-reported outcomes (PROs) focuses on precise, brief measures, which generally convey little about what an individual's rating actually means. Individual differences in appraisal are important and relevant to PRO research. Building on response shift theory and Tourangeau's work on the psychology of survey response, substantial advances in appraisal assessment have made it increasingly feasible to measure these cognitive



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processes efficiently in manners highly amenable to quantitative and mixed methods analyses. This symposium will summarize these advances and summarize how studying cognitive appraisal processes has enhanced quality of life (QOL) research in chronic and life-threatening illness. The symposium will include four papers: 1. The first will describe the theoretical model underlying appraisal assessment, as well as the evolution of appraisal assessment over the past decade. These tools range from using mixed methods (qualitative and quantitative) to long- and short-form versions of close-ended quantitative measures. He will present an overview of a body of empirical work showing how appraisal processes can enhance observational QOL studies and can reveal important response shift effects. 2. The second will present an analysis of treatment burden in a separate sample of 446 heterogeneous chronically ill patients, and how appraisal and other individual differences play a role in modifying the impact of treatment burden on QOL. 3. The third will present results of a longitudinal cohort study of bladder cancer patients, comparing the QOL outcomes for two types of diversion surgery, and examining how appraisal processes play a role in these outcomes. 4. The fourth will present analyses examining the relationship between appraisal, personality, and QOL, and looking at resilience in a heterogeneous sample of ~4000 chronically ill patients. The study documents that appraisal mediates the relationship between resilience and QOL. Our Discussant will bridge notions from appraisal research with those from Item Response Theory and other sophisticated psychometric models, and will discuss the implications of findings for outcomes assessment of resilience and resilience-building interventions.

Individual Presentations

Appraisal Theory and Measurement

Bruce Rapkin, PhD, Albert Einstein College of Medicine, Bronx, NY, United States

What role do person factors play in modifying the impact of treatment burden in chronic illness?

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

Resilience to health challenges is related to different ways of thinking: Mediators of physical and emotional quality of life in a heterogeneous rare-disease cohort

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

Understanding the impact of radical cystectomy and urinary diversion in patients with bladder cancer: Treatment outcomes clarified by appraisal processes

Bernard H. Bochner, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States

12:30 pm – 2:00 pm Lunch Break

If you purchased Box Lunch via the registration form, please present your **Friday Lunch Ticket** to one of the hotel staff to pick up your Boxed Lunch in the Grand Foyer and Columbus Foyer on the second floor.

*Please note – Boxed Lunch tickets are **not** available for purchase on-site.

12:40 pm – 1:45 pm Special Interest Group (SIG) Meetings

Ibero America SIG Meeting	Discovery A, 3 rd Floor
Response Shift SIG Meeting	Grand D, 2 nd Floor
New Investigator SIG Meeting	Discovery BC, 3 rd Floor
QOL in Clinical Practice SIG Meeting	Innovation, 3 rd Floor
Translation and Cultural Adaptation SIG Meeting	Grand ABC, 2 nd Floor

1:45 pm – 5:30 pm Poster Hall Open

Columbus Ballroom, 2nd Floor

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2:00 pm – 3:30 pm Concurrent Oral Sessions

Oral Session 201: PROs in Clinical Care

Grand ABC, 2nd Floor

Session Chair: Louise Humphrey, MSc, United Kingdom

2:05 pm – 2:18 pm (201.1) Stakeholder perceptions of facilitators and Barriers for PRO-based performance measures in five U.S. healthcare systems

Angela M. Stover, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Randall Teal, MA, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Maihan Vu, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Arlene Chung, MD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Jennifer Jansen, MPH, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Ethan Basch, MD MSc, University of North Carolina, Chapel Hill, NC, United States

2:19 pm – 2:32 pm (201.2) How does PROMs feedback work as a quality improvement strategy? Lessons from the feedback of other forms of performance data

Joanne Greenhalgh, University of Leeds, Leeds, United Kingdom; Sonia M. Dalkin, PhD, Northumbria University, Newcastle upon Tyne, United Kingdom; Elizabeth Gibbons, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Judy Wright, University of Leeds, Leeds, United Kingdom; Nick Black, MD, London School of Hygiene and Tropical Medicine, London, United Kingdom; Jose M. Valderas, MD PhD, University of Exeter, Exeter, United Kingdom; David Meads, University of Leeds, Leeds, United Kingdom

2:33 pm – 2:46 pm (201.3) Reviewing mental health in oncology

Josh Biber, MBA, University of Utah, Salt Lake City, UT, United States; Rachel Hess, MD MS, University of Utah, Salt Lake City, UT, United States; Howard Weeks, MD, University of Utah, Salt Lake City, UT, United States; Jenny Reese, MPA, University of Utah Medical Group, Salt Lake City, UT, United States

2:47 pm – 3:00 pm (201.4) Comparing automated mental health screening to manual processes in a health care system

Josh Biber, MBA, University of Utah, Salt Lake City, UT, United States; Rachel Hess, MD MS, University of Utah, Salt Lake City, UT, United States; Howard Weeks, MD, University of Utah, Salt Lake City, UT, United States; Jenny Reese, MPA, University of Utah Medical Group, Salt Lake City, UT, United States

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3:01 pm – 3:14 pm (201.5) Assessing the impact of computer-adaptive administration, tailored feedback, and response prediction on the user engagement and perceived acceptability of quality of life assessment.

Chris Gibbons, PhD, University of Cambridge, Cambridge, United Kingdom

Oral Session 202: Cancer II: Measures for General Populations

Grand D, 2nd Floor

Session Chair: Galina Velikova, MD, PhD, FRCP, United Kingdom

2:05 pm – 2:18 pm (202.1) First results of a 15,000 person population survey to establish European norm data for the EORTC Computer-Adaptive Test QLQ-CAT

Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Gregor Liegl, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Morten A. Petersen, MSc, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, University of Copenhagen, Copenhagen, Denmark; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Anna Costantini, Psychoncology Unit, Department of Oncological Sciences, Rome, Italy; Peter Fayers, PhD, University of Aberdeen, Aberdeen, United Kingdom; Mogens Groenvold, MD ScD, University of Copenhagen, Copenhagen, Denmark; Bernhard Holzner, PhD, Medical University of Innsbruck, Innsbruck, Austria; Colin D. Johnson, MChir FRCS, Surgical Unit, University of Southampton, Southampton, United Kingdom; Georg Kemmler, Innsbruck Medical University, Innsbruck, Tyrol, Austria; Krzysztof Tomaszewski, MD PhD, Health Outcomes Research Unit, Department of Gerontology, Geriatrics and Social Work, Faculty of Education, Ignatianum Academy, Krakow, Poland; Annika Waldmann, PhD, University Luebeck, Luebeck, Germany; Teresa Young, BSc, East & North Herts NHS Trust incorporating Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

2:19 pm – 2:32 pm (202.2) Selection of anchors for the EORTC QLQ-C30 scales in adjuvant melanoma studies: on Behalf of the EORTC melanoma Group and EORTC Quality of Life Department

Frederic Fiteni, MD PhD, EORTC, Brussels, Belgium; Jammbe Musoro, EORTC Headquarters, Brussels, Belgium; Corneel Coens, EORTC Headquarters, Brussels, Belgium; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Alexander Eggermont, Institut Gustave Roussy, Paris, France, Paris, France; Andrew Bottomley, PhD, EORTC Headquarters, Brussels, Belgium; Yvonne Brandberg, Karolinska Institutet Solna, Stockholm, Sweden



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2:33 pm – 2:46 pm (202.3) Responsiveness of PROMIS short-form symptom measures and analogous LASA and PRO-CTCAE single-item rating scales in cancer patients

Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States; David T. Eton, PhD, Mayo Clinic, Rochester, MN, United States; Paul Novotny, BS MS, Mayo Clinic, Rochester, MN, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; Timothy J. Beebe, PhD, University of Minnesota, Minneapolis, MN, United States; Marlene H. Frost, PhD, Mayo Clinic, Rochester, MN, United States; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States; Jennifer Beaumont, MS, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Susan Yount, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Jeff A. Sloan, PhD, Mayo Clinic, Rochester, MN, United States

2:47 pm – 3:00 pm (202.4) Establishing a common metric for patient-reported outcomes in cancer patients: Linking PROMIS, LASA, and PRO-CTCAE

Minji Lee, PhD, Mayo Clinic, Rochester, MN, United States; Benjamin D. Schalet, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States; Kathleen J. Yost, PhD, Mayo Clinic, Rochester, MN, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; Paul Novotny, BS MS, Mayo Clinic, Rochester, MN, United States; Susan Yount, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Jeff A. Sloan, PhD, Mayo Clinic, Rochester, MN, United States

3:01 pm – 3:14 pm (202.5) Development of thresholds for clinical importance for the EORTC quality of life measures

Fanny L. Loth, MSc, Medical University of Innsbruck, Innsbruck, Tirol, Austria; Bernhard Holzner, PhD, Medical University of Innsbruck, Innsbruck, Austria; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Juan I. Arraras, PhD, Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; John Ramage, Department of Gastroenterology and Hepatology, Hampshire Hospitals NHS Foundation Trust, Basingstoke, United Kingdom; Mogens Groenvold, MD PhD DSci, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, University of Copenhagen, Copenhagen, Denmark; Jacobien M. Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Morten A. Petersen, MSc, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, University of Copenhagen, Copenhagen, Denmark; Krzysztof Tomaszewski, MD PhD, Health Outcomes Research Unit, Department of Gerontology, Geriatrics and Social Work, Faculty of Education, Ignatianum Academy, Krakow, Poland; Teresa Young, BSc, East & North Herts NHS Trust incorporating Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Johannes M. Giesinger, Medical University of Innsbruck, Innsbruck, Austria

Oral Session 203: Health Utility Measurement I

Innovation, 3rd Floor

Session Chair: Zoe Winters, DPhil, FRCS, FCS, United Kingdom

2:05 pm – 2:18 pm (203.1) Preference-based measure from the CDC's HRQOL-4 versus SF-6D among U.S. Medicare beneficiaries

Haomiao Jia, Columbia University, New York, NY, United States; Erica I. Lubetkin, MD MPH, CUNY School of Medicine, New York, NY, United States

2:19 pm – 2:32 pm (203.2) Cooking from scratch: developing an algorithm to guide the construction of a de novo condition-specific multi-attribute health status utility classification system

Teresa Tsui, MSc, PhD (student), Toronto Health Economics and Technology Assessment (THETA) Collaborative, Toronto, Ontario, Canada; Nicholas Mitsakakis, PhD, University Health Network, Toronto, Ontario, Canada; Joanna Bielecki, BSc, MSt, Toronto Health Economics and Technology Assessment (THETA) Collaborative, Toronto, Ontario, Canada; Aileen Davis, PhD, University Health Network, Toronto, Ontario, Canada; Maureen Trudeau, MD FRCPC, Sunnybrook Odette Cancer Centre, Toronto, Ontario, Canada; Karen Bremner, BSc, Toronto General Hospital Research Institute, Toronto, Ontario, Canada; Murray D. Krahn, MD, MSc, FRCPC, Toronto Health Economics and Technology Assessment (THETA) Collaborative, Toronto, Ontario, Canada

2:33 pm – 2:46 pm (203.3) The EORTC QLU-C10D utility project – interim evaluation and comparison across countries

Georg Kemmler, Innsbruck Medical University, Innsbruck, Tyrol, Austria; Eva Gamper, PhD, Medical University of Innsbruck, Innsbruck, Tyrol, Austria; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Richard Norman, PhD, Curtin University, Perth, Australia; Virginie Nerich, Besançon University Hospital, Besançon, France; Bernhard Holzner, PhD, Medical University of Innsbruck, Innsbruck, Austria

2:47 pm – 3:00 pm (203.4) Omitted dimensions in mapping algorithms: predicting EQ-5D-3L utilities from GHQ-12 scores in English general population data

Jan R. Boehnke, PhD, University of Dundee, Dundee, United Kingdom; Qi Wu, MSc, University of York, York, United Kingdom; Steve Parrott, PhD, University of York, York, United Kingdom; Simon Gilbody, PhD, University of York, York, United Kingdom

3:01 pm – 3:14 pm (203.5) Eliciting Systemic Lupus Erythematosus (SLE) patients' benefit-risks preferences for corticosteroid use

Xinyi Ng, PhD, University of Maryland, Baltimore, MD, United States; Marcy Fitz-Randolph, DO, PatientsLikeMe, Cambridge, MA, United States; Robert Beardsley, PhD, University of Maryland Baltimore, Baltimore, MD, United States; Laurence Magder, PhD, University of Maryland Baltimore, Baltimore, MD, United States; C. Daniel Mullins, PhD, University of Maryland Baltimore, Baltimore, MD, United States; Susan dosReis, PhD, University of Maryland Baltimore, Baltimore, MD, United States



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Oral Session 204: Methodological Advances I

Discovery BC, 3rd Floor

Session Chair: Diane Fairclough, DrPH, United States

2:05 pm – 2:18 pm (204.1) The prognostic value of cancer-related fatigue on overall survival in patients with advanced NSCLC: application of Continuous Time Markov Chains on symptom research

Ting Yu Chen, MS, MD Anderson Cancer Center, Houston, TX, United States; Qiling Shi, MD PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Wenyaw Chan, PhD, The University of Texas Health Science Center at Houston, Houston, TX, United States; Xin S. Wang, MD MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Tito Mendoza, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles S. Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

2:19 pm – 2:32 pm (204.2) Modelling strategies to improve estimates of prognostic factors analyses with patient reported outcomes: a simulation study.

Nina Deliu, MSc, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Gary S. Collins, PhD, Centre for Statistics in Medicine, University of Oxford, Oxford, United Kingdom; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Kristel Van Steen, PhD, GIGA-R Medial Genomics Unit, University of Liège, Liège, Belgium; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States; Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

2:33 pm – 2:46 pm (204.3) A generic method for PRO based individual prognosis in chronic diseases

Niels Henrik Hjollund, Professor, PhD, Hospital Unit West Jutland / Aarhus University, Herning, Denmark

2:47 pm – 3:00 pm (204.4) Comparing patient-reported outcomes of satisfied and not-satisfied total knee arthroplasty patients: an analysis of differential item functioning

Lara B. Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Richard Sawatzky, PhD, Trinity Western University, Langley, British Columbia, Canada; Laurie Goldsmith, PhD, Simon Fraser University, Burnaby, British Columbia, Canada; Lisa M. Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; Tolulope T. Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Anne M. Gadermann, University of British Columbia, Vancouver, British Columbia, Canada; Stirling Bryan, University of British Columbia, Vancouver, British Columbia, Canada

3:01 pm – 3:14 pm (204.5) Treatment of missing data in clinical registries: a comparison of approaches for estimating change in patient-reported outcomes

Lisa M. Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; Lisa Zhang, University of Manitoba, Winnipeg, Manitoba, Canada; Olawale Ayilara, University of Manitoba, Winnipeg, Manitoba, Canada; Tolulope T. Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Richard Sawatzky, PhD, Trinity Western University, Langley, British Columbia, Canada; Eric Bohm, University of Manitoba, Winnipeg, Manitoba, Canada

3:30 pm – 4:15 pm Exhibits Open and Refreshment Break

Columbus Foyer/Grand Foyer, 2nd Floor

3:35 pm – 4:10 pm Friday Poster Session II

Columbus Ballroom, 2nd Floor

(2004) Health-related quality of life in non-transplant eligible newly diagnosed multiple myeloma patients treated with melphalan/prednisolone plus either thalidomide or lenalidomide; results of the HOVON87/ NMSG18 study.

Lene Kongsgaard Nielsen, PhD Student, Quality of Life Research Center, Odense University Hospital, Odense, Denmark; Claudia Stege, VU University Medical Center, Amsterdam, Netherlands; Birgit Witte, VU University Medical Center, Amsterdam, Netherlands; Bronno van der Holt, HOVON Data Center, Rotterdam, Netherlands; Ulf-Henrik Mellqvist, Section of Hematology and Coagulation, Gotheborg, Sweden; Morten Salomo, Rigshospitalet, Copenhagen, Denmark; Mark-David Levin, Albert Schweitzer Hospital, Dordrecht, Netherlands; Markus Hansson, Skåne University Hospital, Lund, Sweden; Torben Plesner, Vejle Hospital, Vejle, Denmark; Damian Szatkowski, Førde Central Hospital, Førde, Norway; Einar Haukås, Stavanger University Hospital, Stavanger, Norway; Peter Gimsing, Rigshospitalet, Copenhagen, Denmark; Pieter Sonneveld, Erasmus Medical Center Cancer Center, Rotterdam, Netherlands; Niels Abildgaard, Quality of Life Research Centre, Odense University Hospital, Odense, Denmark; Anders Waage, St Olavs Hospital and Norwegian University of Science and Technology and KG Jebsen Myeloma Research Center, Trondheim, Norway; Sonja Zweegman, VU University Medical Center, Amsterdam, Netherlands

STUDENT POSTER AWARD FINALIST



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(2006) Night noise in hospitals is linked with unplanned readmissions: a retrospective, Canadian investigation

Kyle Kemp, MSc, University of Calgary, Calgary, Alberta, Canada; Hude Quan, MD PhD, University of Calgary, Calgary, Alberta, Canada; Maria J. Santana, PhD, University of Calgary, Calgary, Alberta, Canada

STUDENT POSTER AWARD FINALIST

(2008) Impact of hemodialysis on the physical and psychological well-being among end-stage renal disease patients in the Gaza-Strip

MohamedRaed S. Elshami, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Enas F. Alaloul, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Bettina Böttcher, MD, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; **Asma I. Qannas, MSc, Philadelphia University, Philadelphia, PA, United States**

STUDENT POSTER AWARD FINALIST

Cancer: General Measurement

(2010) Sustained employability and health-related quality of life in cancer survivors up to four years after diagnosis

Saskia F. Duijts, PhD, VU University Medical Center / The Netherlands Cancer Institute, Amsterdam, Netherlands; Jacobien M. Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Peter van Muijen, MD PhD, VU University Medical Center, Amsterdam, Netherlands; Allard J. van der Beek, PhD, VU University Medical Center, Amsterdam, Netherlands

(2012) Psychometric validity of the Japanese version of Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Kanako Azuma, BS, Tokyo Medical University Hospital, Tokyo, Japan; Takashi Kawaguchi, PhD, Tokyo University of Pharmacy and Life Sciences, Tokyo, Japan; Tempei Miyaji, MSc, The University of Tokyo, Tokyo, Japan; Motohiko Sano, PhD, Saitama Medical Center, Saitama Medical University, Saitama, Japan; Soan Kim, MSc, Juntendo University Nerima Hospital, Tokyo, Japan; Yosuke Kawahara, MSc, Toshiba General Hospital, Tokyo, Japan; Ayako Torii, MSc, Tokyo Medical University Hospital, Tokyo, Japan; Yuri Yamada, BS, Tokyo Medical University Hospital, Tokyo, Japan; Taiki Hirata, BS, Tokyo Medical University Hospital, Tokyo, Japan; Keiichiro Ishibashi, PhD, Saitama Medical Center, Saitama Medical University, Saitama, Japan; Atsushi Okubo, BS, Juntendo University Nerima Hospital, Tokyo, Japan; Ethan Basch, MD MSc, University of North Carolina, Chapel Hill, NC, United States; Takuhiro Yamaguchi, PhD, Tohoku University Graduate School of Medicine, Miyagi, Japan

(2014) Generation of evidence to support the content validity of legacy quality of life instruments: EORTC QLQ-C30 case study

Kim Cocks, PhD, Adelphi Values Ltd, Bollington, United Kingdom; Chloe Tolley, BSc, Adelphi Values Ltd, Bollington, Cheshire, United Kingdom; Laura Grant, MSc, Adelphi Values Ltd, Bollington, Cheshire, United Kingdom; Sally Wheelwright, PhD, University of Southampton, Southampton, United Kingdom; Krzysztof Tomaszewski, MD PhD, Health Outcomes Research Unit, Department of Gerontology, Geriatrics and Social Work, Faculty of Education, Ignatianum Academy, Krakow, Poland; Mogens Groenvold, MD ScD, University of Copenhagen, Copenhagen, Denmark; Andrew Bottomley, PhD, EORTC Headquarters, Brussels, Belgium; Deborah Fitzsimmons, PhD, Swansea University, Swansea, United Kingdom; Galina Velikova, BMBS(MD) PhD FRCP, University of Leeds, Leeds, United Kingdom; Simone Oerlemans, PhD MSc, Netherlands Comprehensive Cancer Organisation, Utrecht, Netherlands; Juan I. Arraras, PhD, Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Colin D. Johnson, MChir FRCS, Surgical Unit, University of Southampton, Southampton, United Kingdom

(2016) Statistical methods to determine the minimal clinically important difference in Health-Related Quality of Life questionnaires in cancer: a systematic literature review

Célia Touraine, PhD, Montpellier Cancer Institute, Montpellier, France; Ahmad Ousmen, Doctoral Student, Methodology and quality of life unit in oncology, CHRU Besançon, France., BESANCON, Franche comté, France; Nina Deliu, MSc, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Anne Bredart, Psychiatry and Psychooncology Unit, Institut Curie, Paris, France; Caroline Bascoul-Mollevi, PhD, Biostatistic unit, Institut régional du Cancer de Montpellier (ICM) - Val d'Aurelle, Montpellier, France, Montpellier, France; Amélie Anot, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France



(2018) Discordance of adverse event assessment between clinicians and patients using the CTCAE and PRO-CTCAE questionnaires in Japan

Motohiko Sano, PhD, Saitama Medical Center, Saitama Medical University, Saitama, Japan; Takashi Kawaguchi, PhD, Tokyo University of Pharmacy and Life Sciences, Tokyo, Japan; Tempei Miyaji, MSc, The University of Tokyo, Tokyo, Japan; Kanako Azuma, BS, Tokyo Medical University Hospital, Tokyo, Japan; Soan Kim, MSc, Juntendo University Nerima Hospital, Tokyo, Japan; Yosuke Kawahara, MSc, Toshiba General Hospital, Tokyo, Japan; Yoko Sano, BS, Tokyo Medical University Hospital, Tokyo, Japan; Tomohide Shimodaira, MSc, Tokyo Medical University Hospital, Tokyo, Japan; Takayuki Seki, MSc, Tokyo Medical University Hospital, Tokyo, Japan; Keiichiro Ishibashi, PhD, Saitama Medical Center, Saitama Medical University, Saitama, Japan; Min KwiSeon, BS, Juntendo University Nerima Hospital, Tokyo, Japan; Ethan Basch, MD MSc, University of North Carolina, Chapel Hill, NC, United States; Takuhiro Yamaguchi, PhD, Tohoku University Graduate School of Medicine, Miyagi, Japan

(2020) Challenges and training needs of study coordinators responsible for administration of patient-reported outcome questionnaires in cancer trials

Rebecca Mercieca-Bebber, University of Sydney, Sydney, NSW, Australia; Derek G. Kyte, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Martin Stockler, NHMRC Clinical Trials Centre, Sydney, NSW, Australia; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia

(2022) Pre-Testing of the EORTC satisfaction with cancer care core questionnaire and outpatient module

Anne Bredart, Psychiatry and Psychooncology Unit, Institut Curie, Paris, France; **Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France;** Teresa Young, BSc, East & North Herts NHS Trust incorporating Mount Vernon Cancer Centre, Northwood, Middlesex, United Kingdom; Krzysztof Tomaszewski, MD PhD, Health Outcomes Research Unit, Department of Gerontology, Geriatrics and Social Work, Faculty of Education, Ignatianum Academy, Krakow, Poland; Juan I. Arraras, PhD, Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain; Hugo Moura De Albuquerque Melo, Institute of Integrative Medicine, Recife, Brazil; Heike Schmidt, Medizinische Fakultät der Martin Luther Universität Halle Wittenberg, Halle, Germany; Elizabeth Friend, Basingstoke & North Hampshire Hospital, Basingstoke, United Kingdom; Mia Bergenmar, Karolinska Institutet, Karolinska University Hospital, Stockholm, Sweden; Anna Costantini, Psychooncology Unit, Department of Oncological Sciences, Rome, Italy; Vassilios Vassiliou, BOC Oncology Centre, Lefkosia, Cyprus; José Hureaux, CHU Angers, Angers, France; Frederic Marchal, Institut de Cancérologie de Lorraine, Vandœuvre-lès-Nancy, France; Iwona M. Tomaszewska, Jagiellonian University Medical College, Krakow, Poland; Wei-Chu Chie, Institute of Epidemiology and Preventive Medicine and Department of Public Health, College of Public Health, National Taiwan University, Taipei, Republic of Taiwan; John Ramage, Department of Gastroenterology and Hepatology, Hampshire Hospitals NHS Foundation Trust, Basingstoke, United Kingdom; Ariane Beaudeau, Institut Curie, Paris, France; Eveline Bleiker, Netherlands Cancer Institute, Amsterdam, Netherlands; Dagmara Kulis, EORTC, Brussels, Belgium; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands

(2024) Predictive staging of breast cancer using lymph node ratio

Dominique Nielson, University of Utah, Salt Lake City, UT, United States; Yushan Gu, BS, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Maren Voss, MS, University of Utah, Salt Lake City, UT, United States; Alec R. Hansen, University of Utah, Salt Lake City, UT, United States; Man Hung, PhD, University of Utah, Salt Lake City, UT, United States

(2026) Concordance between patient reported and clinical outcomes in randomized controlled trials (RCTs) of cancer treatment

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Francesco Sparano, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Peter Fayes, PhD, University of Aberdeen, Aberdeen, United Kingdom; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Jonathan Rees, Bristol Centre for Surgical Research, School of Social & Community Medicine, University of Bristol, Bristol, United Kingdom; Nina Deliu, MSc, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Alfonso Piciocchi, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Edoardo La Sala, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Alissa Haas, Indiana University, Bloomington, IN, United States; Jacobien M. Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Wenna Wang, Guangdong Medical University, Dongguan, China; Mike Pezold, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Sarah Fuzesi, Memorial Sloan Kettering Cancer Center, New-York, NJ, United States; Sumit Isharwal, Memorial Sloan Kettering Cancer Center, New York, NY, United States; John Yeung, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Chonghua Wan, PhD, School of Humanities and Management, Research Center on Quality of Life and Applied Psychology, Guangdong Medical University, DongGuan, Guangdong, China; Jane Blazeby, MD, University of Bristol, Bristol Centre for Surgical Research, School of Social & Community Medicine, Bristol, United Kingdom; on behalf of GIMEMA and EORTC Quality of Life Group.

(2028) Differences in Patient Reported Outcomes for smoking-related cancers by smoking status post-diagnosis

Scott Gummerson, Georgetown University, Baltimore, MD, United States; Vasiliki Zotou, Georgetown University, Washington, DC, United States; Tania Lobo, MS, Georgetown University, Washington, DC, United States; Roxanne E. Jensen, PhD, Georgetown University, Washington, DC, United States

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(2030) Type and magnitude of EORTC QLQ-C30 outcomes in cancer clinical trials.

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Francesco Sparano, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Peter Fayers, PhD, University of Aberdeen, Aberdeen, United Kingdom; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Alissa Haas, Indiana University, , Bloomington, IN, United States; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Nina Deliu, MSc, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Jonathan Rees, Bristol Centre for Surgical Research, School of Social & Community Medicine, University of Bristol, Bristol, United Kingdom; Jacobien M. Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Wenna Wang, Guangdong Medical University, Dongguan, China; Sarah Fuzesi, Memorial Sloan Kettering Cancer Center, New-York, NJ, United States; Sumit Isharwal, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Chonghua Wan, PhD, School of Humanities and Management, Research Center on Quality of Life and Applied Psychology, Guangdong Medical University, DongGuan, Guangdong, China; Jane Blazeby, MD, University of Bristol, Bristol Centre for Surgical Research, School of Social & Community Medicine, Bristol, United Kingdom; on behalf of GIMEMA and EORTC Quality of Life Group.

(2032) Development of a new patient-reported outcome instrument for skin cancer: FACE-Q skin cancer

Erica H. Lee, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Anne F. Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada; Stefan J. Cano, PhD, Modus Outcomes, Letchworth Garden City, United Kingdom; Kishwer S. Nehal, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States

(2034) *Withdrawn*

(2036) Cancer and Quality of Life research: 50 years of progress

Carolyn C. Gotay, PhD, University of British Columbia, Vancouver, British Columbia, Canada

Measurement in General Populations

(2038) *Withdrawn*

(2040) Factors influencing successful uptake of Advance Care Planning

Rasa Ruseckaite, Monash University, Melbourne, Australia; Karen Detering, Advance Care Planning Australia, Austin Health, Melbourne, Australia; Sue M. Evans, Monash University, Melbourne, Australia; Veronica Perera, Advance Care Planning Australia, Austin Health, Melbourne, Australia; Linda Nolte, Advance Care Planning Australia, Austin Health, Melbourne, Australia

(2042) Quality of work life and burnout syndrome in workers of a health institution in Guadalajara, Mexico

Raquel Gonzalez-Baltazar, PhD, University of Guadalajara, Guadalajara, Jalisco, Mexico; Silvia G. Leon-Cortes, PhD, University of Guadalajara, Guadalajara, Jalisco, Mexico; Monica I. Contreras-Estrada, PhD, University of Guadalajara, Guadalajara, Jalisco, Mexico; Gustavo Hidalgo-Santacruz, Master in Public Health, MD, University of Guadalajara, Guadalajara, Jalisco, Mexico; Brenda J. Hidalgo-Gonzalez, Gestalt Psychotherapist, University of Guadalajara, Guadalajara, Jalisco, Mexico

(2044) *Withdrawn*

(2046) *Withdrawn*

(2048) Developing person-centred quality indicators informed by the patient voice

Kimberly Manalili, MPH, University of Calgary, Calgary, Alberta, Canada; Fartoon Siad, MSc, University of Calgary, Calgary, Alberta, Canada; Vic Lantion, MD, Ethno-Cultural Council of Calgary, Calgary, Alberta, Canada; Maria J. Santana, PhD, University of Calgary, Calgary, Alberta, Canada

(2052) Is there the possibility on QOL prediction in residents who had to move from temporary dwelling to reconstruction house after earth quake, tsunami and radiation disaster in Fukushima, 2011, Japan?

Rika Hayashida, RN MSN, University of Nagasaki, Siebold, Nishisonogigun, Nagasaki, Japan; Shinichi Suzuki, Kashima Hospital, Iwaki, Fukushima, Japan; Taiji Omura, Japanese Society of Quality of Life Research, Kobe, Japan; Takuya Itou, Hospital, Iwaki city, Japan; Ayako Tsukihashi, Japanese Society of Quality of Life Research, Kobe, Japan; Hiroshi Shimagami, Japanese Society of Quality of Life Research, Kobe, Japan; Akihiro Yamamoto, Japanese Society of Quality of Life Research, Kobe, Japan; Li-sa Chang, Japanese Society of Quality of Life Research, Kobe, Japan; Yoshihiro Tairako, Tounou Sangyou Sinkou Jigyuu Cooperation, Iwaki, Fukushima, Japan; Ichirou Nagano, Japanese Society of Quality of Life Research, Kobe, Japan; Yoshie Tada, Narahamachi, Iwaki Office, Iwaki, Fukushima, Japan; Michiko Kobayashi, MD, Japanese Society of Quality of Life Research, Kobe, Japan; Haruyasu Fujita, Japanese Society of Quality of Life Research, Kobe, Japan; Kouzaburo Adachi, Japanese Society of Quality of Life Research, Kobe, Japan; Atsuhiko Fukuoka, Japanese Society of Quality of Life Research, Kobe, Japan; Tomotaka Sobue, Graduate School of Medicine, Osaka University, Osaka, Japan; YOSHIFUMI NODA, company, Kobe, Japan; Atsuo Okada, Japanese Society of Quality of Life Research, Kobe, Japan; Hideyuki Miyauchi, Japanese Society of Quality of Life Research, Kobe, Japan; Takashi Mandai, MD PhD, Japanese Society of Quality of Life Research, Kobe, Japan



(2054) Known-groups validity of the Long-Term Conditions Questionnaire (LTCQ): a measure for potential use in integrated care

Caroline M. Potter, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Laurie Batchelder, PhD, Personal Social Services Research Unit, University of Kent, Canterbury, Kent, United Kingdom; Louise Geneen, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Diane Fox, Personal Social Services Research Unit, University of Kent, Canterbury, United Kingdom; Laura Kelly, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Elizabeth Gibbons, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Crispin Jenkinson, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Karen Jones, PhD, Personal Social Services Research Unit, University of Kent, Canterbury, Kent, United Kingdom; Julien Forder, PhD, University of Kent and London School of Economics and Political Science, Canterbury, United Kingdom; Ray Fitzpatrick, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Michele Peters, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom

(2056) Measurement invariance of the SF12v2 between its English and Chinese versions in Chinese adults

Daniel Y. Fong, PhD, The University of Hong Kong, Hong Kong SAR, Hong Kong SAR, China; Edmond P. Choi, PhD Candidate, The University of Hong Kong, Hong Kong, China; Cannas Kwok, PhD, University of Western Sydney, Penrith NSW, Australia; Janet Y. Wong, PhD, The University of Hong Kong, Hong Kong, Hong Kong SAR, China

(2058) Quality of Life of sugar cane cutters in the harvest and intercrop periods

Celmo C. Porto, PhD, Federal University of Goiás, Goiânia, Brazil; Maria A. Barbosa, RN PhD, Federal University of Goiás, Goiânia, Goiás, Brazil, **Suelen M. Nogueira, Doctoral Student, University Federal of Goiás - UFG, Goiânia, Brazil**

(2060) How do immigrant parents of children with complex health needs manage to cope?

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

(2062) Comparing mental health to physical functioning

Josh Biber, MBA, University of Utah, Salt Lake City, UT, United States; Rachel Hess, MD MS, University of Utah, Salt Lake City, UT, United States; Howard Weeks, MD, University of Utah, Salt Lake City, UT, United States; Jenny Reese, MPA, University of Utah Medical Group, Salt Lake City, UT, United States

(2064) The relationship of material and social deprivation with health status

Hilary Short, University of Alberta, Edmonton, Alberta, Canada; Fatima Al Sayah, PhD, University of Alberta, Edmonton, Alberta, Canada; **Arto Ohinmaa, PhD, University of Alberta, Edmonton, Alberta, Canada;** Jeffrey A. Johnson, PhD, University of Alberta, Edmonton, Alberta, Canada

(2066) *Withdrawn*

(2068) Multiple complexities: perspectives from children's health and well-being assessment in Canadian Aboriginal communities

Nancy L. Young, PhD, Laurentian University, Sudbury, Ontario, Canada; Mary Jo Wabano, MS/MA, Naandwechige Gamig Wikwemikong Health Centre, Wikwemikong, Ontario, Canada; Marnie M. Anderson, BSc, Laurentian University, Sudbury, Ontario, Canada; Trisha Trudeau, BA, Naandwechige Gamig Wikwemikong Health Centre, Wikwemikong, Ontario, Canada; Jon McGavock, PhD, University of Manitoba, Winnipeg, Ontario, Canada; Jenna Stacey, BA, University of Manitoba, Winnipeg, Ontario, Canada

(2070) Development of two short versions of the Patient Reported Experiences and Outcomes of Safety in Primary Care (PREOS-PC) questionnaire: PREOS-PC Compact and PREOS-PC-6

Luke Mounce, PhD, Health Services & Policy Research Group, University of Exeter Medical School, University of Exeter, Exeter, UK., Exeter, United Kingdom; Jaheeda Gangannagaripalli, PhD Student, University of Exeter, Exeter, Devon, United Kingdom; Ignacio Ricci-Cabello, PhD, Health Services and Policy Research Group, Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom; Anthony J. Avery, MBBS, MBChB, BMedSci, School of Medicine, Division of Primary Care, University of Nottingham, Nottingham, UK., Nottingham, United Kingdom; **Jose M. Valderas, MD PhD, University of Exeter, Exeter, United Kingdom**

(2072) Validation of the Canadian Personal Recovery Outcome Measure for the emergency department

Adelena Leon, BSc, University of British Columbia, Vancouver, British Columbia, Canada; David Barbic, MD FRCP, St. Paul's Hospital, Department of Emergency Medicine, Vancouver, British Columbia, Canada; Skye P. Barbic, PhD, University of British Columbia, Vancouver, British Columbia, Canada

(2074) Modernizing the 14-Item treatment satisfaction questionnaire for medication using Rasch measurement theory

Ana Maria Rodríguez, PhD MSc, McGill University, QuintilesIMS, Montreal, Quebec, Canada; Alban Fabre, PhD MSc, QuintilesIMS, Paris, France; Eric Gemmen, PhD MSc, QuintilesIMS, Washington, DC, United States; Louise Parmenter, PhD MPH, QuintilesIMS, Reading, United Kingdom

(2076) Development and psychometric testing of a short form of the Patient-Reported Outcomes Measure of Pharmaceutical Therapy for Quality of Life

Phantipa Sakthong, PhD, Faculty of Pharmaceutical Sciences, Chulalongkorn University, Bangkok, Thailand

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Mixed Methods

(2078) Deriving quality of life issues in primary sclerosing cholangitis (PSC): a strategy for systematic reviewing and identification of potentially relevant issues

Elena Marcus, PhD Student, University College London, London, United Kingdom; Douglas Thorburn, MBChB MRCP MD, The Royal Free NHS Foundation Trust, London, United Kingdom; Paddy Stone, MA MD FRCP, University College London, London, United Kingdom; Bella Vivat, PhD, University College London, London, United Kingdom

(2080) Techniques for the psychometric evaluation of Clinical Outcomes Assessment (COA) measures used in rare disease

Diane M. Turner-Bowker, PhD, Adelphi Values, Boston, MA, United States; Rohini Sen, PhD, Adelphi Values, Boston, MA, United States; Laura Morrissey, MPH, Adelphi Values, Boston, MA, United States; Masami Kelly, MA, Adelphi Values, Boston, MA, United States; Kas Severson, MFA, Adelphi Values, Boston, MA, United States; Leighann Litcher-Kelly, PhD, Adelphi Values, Boston, MA, United States

(2082) An assessment of psychosocial determinants of health-related quality of life (HRQOL) among adults with hemophilia in the United States

Ruchitbhai Shah, PhD, Pharmerit International, Bethesda, MD, United States; John P. Bentley, University of Mississippi, Oxford, MS, United States; Benjamin Banahan, PhD, The University of Mississippi, University, MS, United States; Amit Patel, PhD, Medical Marketing Economics, Oxford, MS, United States; Erin Holmes, PhD, The University of Mississippi, University, MS, United States; Marie Barnard, University of Mississippi, Oxford, MS, United States; Rahul Khanna, University of Mississippi, Oxford, MS, United States

(2084) Assessment of Health-Related Quality of Life in hospitalized adults with sickle cell disease Vaso-Occlusive Crisis

Kimberly S. Esham, MD, Tufts Medical Center, Boston, MA, United States; Angie Mae Rodday, PhD MSc, Tufts Medical Center, Boston, MA, United States; Ruth Ann Weidner, MBA, Tufts Medical Center, Boston, MA, United States; Rachel J. Buchsbaum, MD, Tufts Medical Center, Boston, MA, United States; Hedy P. Smith, MD PhD, Boston Medical Center, Boston, MA, United States; Susan K. Parsons, MD, Tufts Medical Center, Boston, MA, United States

(2086) Living with Axial Spondyloarthritis (AxSpA) and fatigue: “drunk with tiredness”.

Nathan Pearson, PhD Student, Warwick Medical School, Warwick University, Coventry, United Kingdom; Jon Packham, MD PhD, Keele University, Staffordshire, United Kingdom; Liz Tutton, PhD, Warwick Medical School, University of Warwick, Coventry, United Kingdom; Jane Martindale, PhD, Wrightington Wigan and Leigh NHS Foundation Trust, Lancaster, United Kingdom; George Strickland, Wrightington, Wigan and Leigh NHS Foundation Trust, Wigan, England, Wigan, United Kingdom; Jean Thompson, Wrightington, Wigan and Leigh NHS Foundation Trust, Wigan, England, Wigan, United Kingdom; Kirstie Haywood, DPhil. BSc (Hons), Royal College of Nursing Research Institute, Warwick Medical School, Warwick University, Coventry, United Kingdom

(2088) Quality of life in syndromic craniosynostosis.

Sara Pérez, PhD Candidate, Complutense University of Madrid, Madrid, Spain

(2090) *Withdrawn*

Urologic Conditions

(2092) Narrative review of existing PRO Measures in bladder pain syndrome

Lars Joensson, BS, Grunenthal GmbH, Aachen, Germany; Sandeep Duttagupta, PhD, CBPartners, New York, NY, United States; Paul Nash, PhD, CBPartners, San Francisco, CA, United States; Min Yang, BS, CBPartners, New York, NY, United States

(2094) An Appraisal of PRO Measures for Vulvodynia from Stakeholder Perspectives: A Qualitative Analysis

Lars Joensson, BS, Grunenthal GmbH, Aachen, Germany; Sandeep Duttagupta, PhD, CBPartners, New York, NY, United States; Paul Nash, PhD, CBPartners, San Francisco, CA, United States; Min Yang, BS, CBPartners, New York, NY, United States

(2096) Validation of the Spanish version pelvic organ prolapse/urinary incontinence sexual questionnaire (PISQ-12) in Chilean women

Claudia C. Flores-Espinoza, PhD(c), Escuela de Enfermería de Pontificia Universidad Católica de Chile, Santiago, Santiago de Chile, Chile; Vera L. Santos, PhD, Escola de Enfermagem da Universidade de São Paulo, Sao Paulo, Sao Paulo, Brazil

4:15 – 5:45 pm

Concurrent Oral Sessions

Oral Session 205: Methods for Trials and Registries

Grand D, 2nd Floor

Session Chair: Carol Moynour, PhD, United States

4:20 pm – 4:33 pm (205.1) Determining number of patient interviews in qualitative research for PRO development as a clinical trial endpoint and suitable for a regulatory submission

Professor Chris Barker, PhD, Statistical Planning And Analysis Services, Inc., San Carlos, CA, United States



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4:34 pm – 4:47 pm (205.2) Measurement equivalence across technologies - a new approach to support BYOD concepts

Willie Muehlhausen, DVM, ICON plc, Nenagh, Tipperary, Ireland; Bill Byrom, PhD, ICON plc, Dublin, Ireland; Barbara Skerritt, ICON plc, Dublin, Ireland; Emuella Flood, ICON Clinical Research, Bethesda, MD, United States; Marie Mc Carthy, MSc, ICON plc, Dublin, Ireland

4:48 pm – 5:01 pm (205.3) Feasibility and added value of multiple baseline symptom assessments in early-phase clinical trials

Tito Mendoza, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Goldy C. George, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Loretta A. Williams, PhD, APRN, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Qiuling Shi, MD PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Aung Naing, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; David S. Hong, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles S. Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

5:02 pm – 5:15 pm (205.4) Time to quality of life improvement as a method for longitudinal analysis of treatment efficacy

Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

5:16 pm – 5:29 pm (205.5) Guidance on the inclusion of Patient-Reported Outcomes (PROs) in clinical trial protocols: the SPIRIT-PRO extension

Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Derek G. Kyte, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Rebecca Mercieca-Bebber, University of Sydney, Sydney, NSW, Australia; Anita Slade, PhD, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; An-Wen Chan, PhD, University of Toronto, Toronto, Ontario, Canada; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia

Oral Session 206: Cancer III: Prostate and Bladder

Discovery BC, 3rd Floor

Session Chair: Michael Brundage, MD, Canada

4:20 pm – 4:33 pm (206.1) Men undergoing active surveillance for localized prostate present the best short-term quality of life outcomes.

Laura Sayol, IMIM (Institut Hospital del Mar d'Investigacions Mèdiques), 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 (UPF), 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; Ferran Guedeà, Catalan Institute of Oncology, L'Hospitalet de Llobregat, Barcelona, Spain; Cristina Gutiérrez, Catalan Institute of Oncology, Hospitalet de Llobregat, Barcelona, Spain; Montse Ventura, Catalan Institute of Oncology, Hospitalet de Llobregat, Barcelona, Spain; Marc Martí-Pastor, MD MPH, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain; Montse Ferrer, MD PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain

4:34 pm – 4:47 pm (206.2) NRG Oncology/RTOG 0415, hypofractionation in patients with low-risk prostate cancer: are patient reported outcomes the practice change tipping point?

Stephanie L. Pugh, PhD, NRG Oncology, Philadelphia, PA, United States; W R. Lee, MD, Duke University Medical Center, Durham, NC, United States; James Dignam, PhD, NRG Oncology, Philadelphia, PA, United States; Daniel Low, PhD, UCLA, Los Angeles, CA, United States; Gregory P. Swanson, MD, University of Texas Health Science Center at San Antonio, San Antonio, TX, United States; Amit B. Shah, MD, WellSpan Health York Cancer Center, York, PA, United States; David P. D'Souza, MD, London Regional Cancer Program, London, Ontario, Ontario, Canada; Jeff M. Michalski, MD, Washington University, St. Louis, MO, United States; Ian S. Dayes, MD, McMaster University Juravinski Cancer Center, Hamilton Health Science, Hamilton, Ontario, Canada; Samantha A. Seaward, MD, Kaiser Permanente Northern California, Santa Clara, CA, United States; Paul L. Nguyen, MD, Dana-Farber/Harvard Cancer Center, Boston, MA, United States; William A. Hall, MD, Medical College of Wisconsin, Milwaukee, WI, United States; Thomas M. Pisansky, MD, Mayo Clinic, Scottsdale, AZ, United States; Yuhchyan Chen, MD, University of Rochester, Rochester, NY, United States; Howard M. Sandler, MD, Cedars-Sinai Medical Center, Los Angeles, CA, United States; Benjamin Movsas, MD, Henry Ford Hospital, Detroit, MI, United States; Deborah W. Bruner, PhD RN, Emory University, Atlanta, GA, United States



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4:48 pm – 5:01 pm (206.3) Observational longitudinal study of pain in men with metastatic castrate-resistant prostate cancer: aim 1. Rates of pain palliation and pain progression as indicated by self-reported daily pain and analgesic use

Antonia V. Bennett, PhD, University of North Carolina, Chapel Hill, NC, United States; Marwan Shouery, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Mian Wang, PhD, University of North Carolina, Chapel Hill, NC, United States; Young E. Whang, MD, University of North Carolina, Chapel Hill, NC, United States; Matthew Milowsky, MD, University of North Carolina, Chapel Hill, NC, United States; Sarah Drier, MPH, University of North Carolina, Chapel Hill, NC, United States; Phillip Carr, University of North Carolina, Chapel Hill, NC, United States; Julie N. Graff, MD, Oregon Health and Sciences University, Portland, OR, United States; Michael J. Morris, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Howard I. Scher, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Celestia S. Higano, MD FACP, Seattle Cancer Care Alliance, Seattle, WA, United States; Tomasz M. Beer, MD, Oregon Health and Sciences University, Portland, OR, United States; Michael A. Carducci, MD, Johns Hopkins Medical Institutions, Baltimore, MD, United States; Ethan Basch, MD MSc, University of North Carolina, Chapel Hill, NC, United States

5:02 pm – 5:15 pm (206.4) The Life After Prostate Cancer Diagnosis (LAPCD) study: psychometric evaluation of the Expanded Prostate Cancer Index Composite-26 (EPIC-26) using Rasch Analysis

Mike Horton, PhD Student, University of Leeds, Leeds, United Kingdom; Amy Downing, University of Leeds, Leeds, United Kingdom; Paul Kind, University of Leeds, Leeds, United Kingdom; Eila Watson, Oxford Brookes University, Oxford, United Kingdom; Hugh Butcher, University of Leeds, Leeds, United Kingdom; Richard Wagland, University of Southampton, Southampton, United Kingdom; Luke Hounscome, Public Health England, Bristol, United Kingdom; Peter Selby, University of Leeds, Leeds, United Kingdom; Anna Gavin, PhD, Queen's University Belfast, Belfast, United Kingdom; Adam Glaser, BSc (HONS) MBBS DM MRCP FRCPC, University of Leeds, Leeds, United Kingdom; Penny Wright, University of Leeds, Leeds, United Kingdom

STUDENT ORAL PRESENTATION AWARD FINALIST

5:16 pm – 5:29 pm (206.5) A mixed methods study to develop a conceptual framework for patient-reported outcomes in non-muscle invasive bladder cancer

Claudia Rutherford, PhD, University of Sydney, Sydney, NSW, Australia; Daniel Costa, PhD, Pain Management Research Institute, Royal North Shore Hospital, St Leonards NSW, Sydney, NSW, Australia; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; David Smith, NSW Cancer Council, Sydney, NSW, Australia; Manish Patel, University of Sydney, Sydney, Australia

Oral Session 207: Clinical Conditions II

Innovation, 3rd Floor

Session Chair: I-Chan Huang, PhD, United States

4:20 pm – 4:33 pm (207.1) Chinese patient-reported experience of living with chronic hepatitis B

Lin Zhu, PhD Candidate, Zhejiang University School of Public Health, Hangzhou, China; Ying Li, MPH, Zhejiang University School of Public Health, Hangzhou, China; Xiao Cheng, MPH candidate, Zhejiang University School of Public Health, Hangzhou, China; Mengna Song, MPH candidate, Zhejiang University School of Public Health, Hangzhou, China; Jingxia Kong, PhD Candidate, Zhejiang University School of Public Health, Hangzhou, China; Hongmei Wang, PhD, Zhejiang University School of Public Health, Hangzhou, Zhejiang Province, China

4:34 pm – 4:47 pm (207.2) Time to health-related quality of life score deterioration at 1-year follow-up after immediate latissimus dorsi breast reconstructions: a prospective study in breast cancer

Emilie Charton, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Amélie Anot, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Zoe E. Winters, PhD, Breast Cancer Surgery Patient Reported and Clinical Outcomes Research Group, School of Clinical Sciences, University of Bristol, and Division of Surgery and Interventional Sciences, University College London, Bristol, United Kingdom

STUDENT ORAL PRESENTATION AWARD FINALIST

4:48 pm – 5:01 pm (207.3) Health-related quality of life of lung transplant survivors: improvement lasts up to 15 years

Ahmad Shahabeddin Parizi, MD MPH, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands, Groningen, Netherlands; Paul F. Krabbe, PhD, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands, Groningen, Netherlands; Erik A. Verschuuren, MD PhD, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands, Groningen, Netherlands; Rogier A. Hoek, MD, Erasmus MC-University Medical Center, Rotterdam, the Netherlands, Rotterdam, Netherlands; Hanneke J. Kwakkel-van Erp, MD PhD, University Medical Center Utrecht, Utrecht, the Netherlands, Utrecht, Netherlands; Michiel E. Erasmus, MD PhD, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands, Groningen, Netherlands; Wim van der Bij, MD PhD, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands, Groningen, Netherlands; Karin M. Vermeulen, PhD, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands., Groningen, Netherlands

5:02 pm – 5:15 pm (207.4) Identification of COPD severity phenotypes and their relationship to symptom-defined exacerbation recovery: a latent class analysis

Lindsey T. Murray, PhD, Evidera, Bethesda, MD, United States



Scientific Program — Friday, 20 October

5:16 pm – 5:29 pm (207.5) Psychometric findings and normative values for the CLEFT-Q based on 2,434 children and young adult patients with cleft lip and/or palate from 12 countries

Anne F. Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada; Karen Wong Riff, Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada; Natasha M. Longmire, McMaster University, Hamilton, Ontario, Canada; Asteria Albert, Hospital Sant Joan de Déu, Barcelona, Spain; Stephen B. Baker, Inova Children's Hospital, Falls Church, VA, United States; Stefan J. Cano, PhD, Modus Outcomes, Letchworth Garden City, United Kingdom; Andrew J. Chan, Flinders Medical Centre, Bedford Park, Australia; Douglas J. Courtemanche, University of British Columbia, Vancouver, British Columbia, Canada; Marieke Dreise, University Medical Center Groningen, Groningen, Netherlands; Jesse A. Goldstein, University of Pittsburgh Medical Center, Pittsburgh, PA, United States; Timothy Goodacre, University of Oxford, Oxford, United Kingdom; Karen Harman, McMaster University, Hamilton, Ontario, Canada; Montserrat Munill, Hospital Vall d'Hebron, Barcelona, Spain; Mirta Palomares Aguilera, Fundación Gantz, Santiago, Chile; Petra Peterson, Karolinska University Hospital, Stockholm, Sweden; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Rona Slator, Birmingham Children's Hospital, Birmingham, United Kingdom; Mia Stierman, LUNDS University, Lund, Sweden; Elena Tsangaris, McMaster University, Hamilton, Ontario, Canada; Sunil S. Tholpady, Indiana University School of Medicine, Indianapolis, IN, United States; Federico Vargas, Fundación Operación Sonrisa, Bogotá, Colombia; Christopher Forrest, Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada

Oral Session 208: Measurement in General Populations

Grand ABC, 2nd Floor

Session Chair: Fabio Efficace, PhD, Italy

4:20 pm – 4:33 pm (208.1) PROMIS-29 V2.0 physical and mental health summary scores

Ron D. Hays, PhD, UCLA, Los Angeles, CA, United States; Karen L. Spritzer, BS, UCLA, Los Angeles, CA, United States; Benjamin D. Schalet, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States

4:34 pm – 4:47 pm (208.2) Trajectory and predictors of health-related quality of life during pregnancy: The Generation R Study

Guannan Bai, PhD Candidate, Erasmus MC, University Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Hein Raat, MD PhD, Erasmus MC, University Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Vincent W. Jaddoe, MD PhD, Erasmus MC, University Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands; Eva Mautner, PhD, Medical University of Graz, Graz, Austria; Ida Korfage, PhD, Erasmus MC, University Medical Center Rotterdam, Rotterdam, South Holland Province, Netherlands

4:48 pm – 5:01 pm (208.3) Improving single-item generic health survey measures

John E. Ware, Jr., PhD, University of Massachusetts Medical School, Worcester, MA, United States; Barbara Gandek, PhD, University of Massachusetts Medical School, Worcester, MA, United States

5:02 pm – 5:15 pm (208.4) Multi-morbidity as a predictor of quality of life

Michele Peters, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Laura Kelly, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Caroline M. Potter, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Crispin Jenkinson, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Louise Geneen, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Elizabeth Gibbons, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Julien Forder, PhD, University of Kent and London School of Economics and Political Science, Canterbury, United Kingdom; Ray Fitzpatrick, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom

5:16 pm – 5:29 pm (208.5) Calibration of the Dutch-Flemish PROMIS fatigue item bank in the Dutch general population

Leo D. Roorda, MD PhD, Amsterdam Rehabilitation Research Center | Reade, Amsterdam, Netherlands; Martine H. Crins, Amsterdam Rehabilitation Research Center | Reade, Amsterdam, Netherlands; Eva de Schipper, BSc, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, Netherlands; Thomas Klausch, PhD, Department of Epidemiology & Biostatistics, VU University Medical Center, Amsterdam, Netherlands; Caroline B. Terwee, PhD, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, Netherlands

7:00 pm Dine Arounds

Social Event *pre-registration required





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Scientific Program — Saturday, 21 October

7:00 am – 5:20 pm Registration Desk Open Grand Foyer, 2nd Floor

7:30 am – 8:30 am Australia and New Zealand SIG Meeting Owner's Boardroom, 3rd Floor

8:30 am – 9:45 am ISOQOL Member Business Meeting Grand ABC, 2nd Floor

This event will focus on the business of the Society including the official leadership transition.

**Please note – only ISOQOL Members may attend the Member Business Meeting unless invited by ISOQOL Leadership.*

9:45 am – 12:00 pm Poster Hall Open Columbus Ballroom, 2nd Floor

9:45 am – 10:15 am Refreshment Break Columbus Foyer/Grand Foyer, 2nd Floor

9:45 am – 10:15 am Saturday Poster Session I Columbus Ballroom, 2nd Floor

Cancer: Breast

(3003) The effect of spirituality on the Quality of Life among breast cancer female patients with mastectomy in the Gaza-Strip

MohamedRaed S. Elshami, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Enas F. Alaloul, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Israa M. Awad, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Huda N. Abu Nemer, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Esraa S. Khader, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Alaa A. Alhelu, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Heba S. Baraka, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; **Asma I. Qannas, MSc, Philadelphia University, Philadelphia, PA, United States**; Bettina Böttcher, MD, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Khamis A. Elessi, MD, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel

(3005) Impact of mastectomy on Quality of Life among breast cancer female patients in the Gaza-Strip

Enas F. Alaloul, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; MohamedRaed S. Elshami, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Alaa A. Alhelu, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Heba S. Baraka, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Esraa S. Khader, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Huda N. Abu Nemer, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Israa M. Awad, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Bettina Böttcher, MD, Faculty of Medicine at the Islamic University of Gaza, Gaza, Gaza-Strip, Israel; Khamis A. Elessi, MD, Faculty of Medicine at Islamic University of Gaza, Gaza, Gaza-Strip, Israel; **Asma I. Qannas, MSc, Philadelphia University, Philadelphia, PA, United States**

(3007) Understanding key symptoms, side effects, and impacts of HR+ and HER2- advanced breast cancer: qualitative patient interviews

Nina Galipeau, MA, Adelphi Values, Boston, MA, United States; Brittany Klooster, MPH, Adelphi Values, Boston, MA, United States; **Meaghan Krohe, PhD, Adelphi Values, Chicago, IL, United States**; Derek Tang, PhD, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States; Sarah Dillard, MS, Adelphi Values, Boston, MA, United States; Sophie Higgins, MPH, Adelphi Values, Boston, MA, United States; Tania Small, MD, Novartis Pharmaceutical Corporation, East Hanover, NJ, United States; Dennis A. Revicki, PhD, Evidera, Bethesda, MD, United States; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States

(3009) Long-term survival prediction from Health-related Quality of Life in breast cancer patients: a prospective cohort study

Tran Thi Xuan Mai, PhD Student, Graduate School of Cancer Control and Policy, National Cancer Center, Goyang, Korea, South; Lee Eun Sook, PhD MD, Research Institute and Hospital, National Cancer Center, Goyang, Korea, South; Chang Yoonjung, PhD MD, Graduate School of Cancer Science and Policy, National Cancer Center, Goyang, Korea, South; Cho Hyunsoon, PhD, Graduate School of Cancer Science and Policy, National Cancer Center, Goyang, Korea, South; Choi Jin Hyuk, MD, Research Institute and Hospital, Goyang, Korea, South; Lee Myung Kyung, PhD, Kyungook National University, Daegu, Korea, South; Kang Hyokjo, MD, Research Institute and Hospital, National Cancer Center, Goyang, Korea, South; Jung So Youn, MD, Research Institute and Hospital, National Cancer Center, Goyang, Korea, South; Yun Young Ho, PhD MD, Institute of Health Policy and Management, Seoul, Korea, South

(3011) Identification of response shift at the item level on quality of life changes in breast cancer and melanoma patients using Rasch family models – what is the impact of covariates?

Veronique Sebille, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Karima Hammam, MD MSc, Université de Nantes, Université de Tours, INSERM, Nantes, France; Angélique Bonnaud-Antignac, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Myriam Blanchin, PhD, Université de Nantes, Université de Tours, INSERM, Nantes, France

Scientific Program — Saturday, 21 October

(3013) Locus of control and coping as predictors of the change of Health-Related Quality of Life over time in breast cancer and melanoma patients

Anna Toscano, PhD Student, University of Turin; University of Nantes, University of Tours, INSERM, Nantes, France; Myriam Blanchin, PhD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Angélique Bonnaud-Antignac, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Veronique Sebillé, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France

(3015) Investigating methodology of Patient-Reported Outcomes data analysis in breast cancer randomized clinical trials

Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; **Frederic Fiteni, MD PhD, EORTC, Brussels, Belgium;** Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Francesco Sparano, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Sarah Fuzesi, Memorial Sloan Kettering Cancer Center, New-York, NJ, United States; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy

(3017) Withdrawn

(3019) Withdrawn

(3021) Translatability assessment of the EORTC breast cancer questionnaire QLQ-BR23 update

Dagmara Kulis, EORTC, Brussels, Belgium; Cheryl Whittaker, EORTC, Brussels, Belgium; Andrew Bottomley, PhD, EORTC Headquarters, Brussels, Belgium; Vesna Bjelic-Radisic, MBBS, Medical University Graz, Graz, Austria; Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

(3023) Withdrawn

(3025) Comparison of trajectories of anxiety and depression using PROMIS and EORTC instruments in breast cancer patients during and after neoadjuvant chemotherapy

Yuying Chen, BS, University of California San Francisco, San Francisco, CA, United States; Roxanne E. Jensen, PhD, Georgetown University, Washington, DC, United States; Christina Yau, PhD, University of California San Francisco, San Francisco, CA, United States; Amy J. Chien, MD, University of California San Francisco, San Francisco, CA, United States; Hope Rugo, MD, University of California San Francisco, San Francisco, CA, United States; Laura E. Esserman, MD MBA, University of California San Francisco, San Francisco, CA, United States, Michelle Melisko, MD, University of California San Francisco, San Francisco, CA, United States

(3027) Breast cancer outcomes assessed in PCORI-funded patient-centered comparative clinical effectiveness research: comparison to a defined core outcome set

Mary Kay Margolis, MPH, MHA, PCORI, Washington, DC, United States; Ingrid McDuff, MPH, PCORI, Washington, DC, United States; Vadim Gershteyn, MPH, PCORI, Washington, DC, United States; Lori Frank, PhD, PCORI, Washington DC, DC, United States

(3029) The impact of symptom concerns on the quality of life of breast cancer survivors receiving hormone replacement therapy

Gloria Juarez, Consulting Services, San Pedro, CA, United States; **Joan J. Branin, PhD, University of La Verne, Pasadena, CA, United States;** Lina Mayorga, MPH, Oncology Research + Education Consultants, ROSEMEAD, CA, United States

(3031) Exploration of Patient-Reported Outcomes (PRO) in metastatic breast cancer clinical studies

Lijun Zhang, PhD, FDA, Silver Spring, MD, United States; Jiayi Zhou, FDA, Silver Spring, MD, United States

Mental Health

(3033) Association of gay-related discrimination with mental health in men who have sex with men

Marc Marti-Pastor, MD MPH, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain; Montse Ferrer, MD PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain; Ju Park, ScB, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States; Christine Ogbue, PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States; Colin Flynn, PhD, Maryland Department of Health and Mental Hygiene, Baltimore, MD, United States; Danielle German, PhD, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States



Scientific Program — Saturday, 21 October

(3035) Initial validation of a new content valid stress resilience item bank

Nina Obbarius, Dipl Psych, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Felix Fischer, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Alexander Obbarius, MD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Sandra Nolte, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Gregor Liegl, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Kim Hinkelmann, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; **Kathrin Fischer, Charité - Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany**

(3037) A critical assessment of service user involvement in designing the ReQoL PROM

Andrew Grundy, BA (Hons), University of Nottingham, Nottingham, United Kingdom; **Anju Keetharuth, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom**; Jill Carlton, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom

(3039) Relationship between sense of coherence and psycho-physiological reactivity to acute mental stress.

Junko Sakano, PhD, Okayama Prefectural University, Soja, Okayama, Japan; Yoichi Sawada, PhD, Okayama Prefectural University, Okayama, Japan; Yuki Yajima, PhD, Niimi College, Niimi, Okayama, Japan; Hisashi Okata, MA PhD Student, Okayama Prefectural University, Okayama, Japan; Atsushi Ueda, MA, Okayama Prefectural University, Okayama, Japan; Rina Yoneyama, Okayama Prefectural University, Okayama, Japan; Shinichiro Sasahara, University of Tsukuba, Tsukuba -City, Ibaraki pref., Japan

(3041) A prescription for quality of life for patients with mental illness presenting to the emergency department

Adelena Leon, BSc, University of British Columbia, Vancouver, British Columbia, Canada; David Barbic, MD FRCPC, St. Paul's Hospital, Department of Emergency Medicine, Vancouver, British Columbia, Canada; William G. MacEwan, St. Paul's Hospital, Vancouver, Canada; Qadeem Salehmohamed †, BSc, University of British Columbia, Vancouver, British Columbia, Canada; Skye P. Barbic, PhD, University of British Columbia, Vancouver, British Columbia, Canada

(3043) Patient reported outcomes in patients with cognitive diversity.

Sara Pérez, PhD Candidate, Complutense University of Madrid, Madrid, Spain; Javier Gonzalez Marques, PhD, Complutense University of Madrid, Madrid, Spain; Jose Hinojosa Mena Bernal, PhD, Hospital Universitario del Niño Jesús, Madrid, Spain

(3045) Quality of life and dating violence among Mexican Junior High School Students

Libia Y. Yanez-Peñuñuri, Doctoral Student, University of Guadalajara, Cd. Guzman, Jalisco, Mexico; Carlos A. Hidalgo-Rasmussen, PhD, University of Guadalajara, University of Playa Ancha, Cd. Guzman, Jalisco, Mexico; Cesar A. Rey Anacona, PhD, Universidad Tecnológica y Pedagógica de Colombia, Tunja, Boyacá, Colombia

(3047) Maternal mental health and Patient-Reported Outcomes: identifying at-risk pregnant and postpartum patients

Howard Weeks, MD, University of Utah, Salt Lake City, UT, United States; Rachel Hess, MD MS, University of Utah, Salt Lake City, UT, United States; Josh Biber, MBA, University of Utah, Salt Lake City, UT, United States, **Jenny Reese, MPA, University of Utah Medical Group, Salt Lake City, UT, United States**

(3049) Validity and reliability of Chinese version of Spiegel scale in the population of Primary Insomnia

Chang-He Yu, Dongzhimen Hospital, Beijing University of Chinese Medicine, Beijing, China; Shiyang Yan, PhD, Institute of Basic Research in Clinical Medicine, China Academy of Chinese Medical Sciences, Beijing, China; Wen-Jing Bai, PhD, China Academy of Chinese Medical Sciences, Beijing, China; Yan Liu, China Academy of Chinese Medical Sciences, Beijing, China; Ya-Nan Sun, Xuanwu Hospital Capital Medical University, Beijing, China; Runshun Zhang, Guang'anmen Hospital of China Academy of Chinese Medical Sciences, Beijing, China; Yanhong ZHANG, PhD, Institute of Basic Research in Clinical Medicine, China Academy of Chinese Medical Sciences, Beijing, China; Jia Liu, Institute of Basic Research in Clinical Medicine of China Academy of Chinese Medical Science, Beijing, China; Li-Yun He, PhD, China Academy of Chinese Medical Sciences, Beijing, China; Bao-Yan Liu, China Academy of Chinese Medical Sciences, Beijing, China; Xi-you Wang, Dongzhimen Hospital, Beijing University of Chinese Medicine, Beijing, China; Chang-Xin Liu, Dongzhimen Hospital, Beijing University of Chinese Medicine, Beijing, China

Mixed Clinical Conditions II

(3051) Engaging patients, caregivers, and physicians to understand the burden of illness of geographic atrophy

Jordana K. Schmier, MA, Exponent, Alexandria, VA, United States; Yamina Rajput, MS, Genentech, Inc., South San Francisco, CA, United States; Rishi P. Singh, MD, Cole Eye Institute, Cleveland Clinic, Cleveland, OH, United States; Sunil S. Patel, MD PhD, West Texas Retina Consultants, Abilene, TX, United States; Jared S. Nielsen, MD, Wolfe Eye Clinic, West Des Moines, IA, United States



(3053) Withdrawn

(3055) Health-Related Quality of Life assessment in pulmonary TB patients

Saniya Saleem, MA MSc, The Indus Hospital, New York, NY, United States; Aryn Malik, MPH, Interactive Research Development, Karachi, Pakistan; Asma Ghulam, Interactive Research Development, Karachi, Pakistan; Junaid Ahmed, Interactive Research Development, Karachi, Pakistan; Hamidah Hussain, MD, The Indus Hospital, Karachi, Pakistan

(3057) Withdrawn

(3059) The importance of validation and refinement in PROM development: using the HASMID questionnaire, a measure of self-management in diabetes

Jill Carlton, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom; Donna Rowen, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom; Jackie Elliott, PhD, University of Sheffield, Sheffield, United Kingdom

(3061) Item reduction and validation of the Chinese version of Diabetes Quality-of-Life Measure (DQOL)

Xuejing Jin, PhD, University of Alberta, Edmonton, Alberta, Canada; Gordon G. Liu, PhD, Peking University, Beijing, China; Hertzell Gerstein, MD MSc, McMaster University, Hamilton, Ontario, Canada; Mitchell Levine, MD MSc, McMaster University, Hamilton, Ontario, Canada; Kathleen Steeves, MA, McMaster University, Hamilton, Ontario, Canada; Haijing Guan, MSc, Peking University, Beijing, China; Hongchao Li, MSc, China Pharmaceutical University, Nanjing, China; Feng Xie, PhD, McMaster University, Hamilton, Ontario, Canada

(3063) Ethnographic research to understand the lived experience of geographic atrophy

Elizabeth Tschosik, PhD, Genentech, Inc., South San Francisco, CA, United States; Sobha Sivaprasad, MD, Moorfields Eye Hospital, London, United Kingdom; Audrey Kapre, MS, Genentech, Inc., South San Francisco, CA, United States; Ivan Suñer, MD, Retina Associates of Florida, Tampa, FL, United States; Robyn Guymier, MBBS PhD, Centre for Eye Research Australia, University of Melbourne, Melbourne, Australia; Antonia Joussem, MD PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Paolo Lanzetta, MD, University of Udine, Udine, Italy; Daniela Ferrara, MD PhD, Genentech, Inc., South San Francisco, CA, United States

(3065) Impact of visual impairment on quality of life and participation of young adults aged 18-25 years

Ellen Elsmann, PhD Candidate, VU University Medical Center, Amsterdam, Netherlands; Ger Van Rens, MD PhD, VU University Medical Center, Amsterdam, Netherlands; Ruth Van Nispen, PhD, VU University Medical Center, Amsterdam, Netherlands

(3067) Challenges in translating the Mini Asthma Quality of Life Questionnaire (Mini AQLQ) into Tigrigna for Ethiopia

Elizabeth Juniper, MSc, McMaster University, Hamilton, Ontario, Canada; Tesfay Mehari, B.Pharm MSc.Pharm RPh, Mekelle University, Mekelle, Ethiopia; Joanna Burgos, MA, Mapi, Lyon, France; **Catherine Acquadro, MD, Mapi, Lyon, France**

(3069) Oral health related quality of life in patients with hiv

Ana Gabriela Magallanes-Rodriguez, PhD, Autonomous University of Baja California, Tijuana, Baja California, Mexico; Luis Aguiar Palacios, MA, Autonomous University of Baja California, Tijuana, Mexico; Julio Martinez Alvarado, PhD, Autonomous University of Baja California, Tijuana, Mexico; Agustin Negrete C, PhD, Autonomous University of Baja California, Tijuana, Mexico; Leslie Zamarripa, MA Student, Autonomous University of Baja California, Tijuana, Mexico

(3071) Quality of life related with health effects in type 2 diabetic patients treated with psyconeuroimmuno-therapy

Martin E. Romero, PhD, Fundación Salutia, Bogotá, Colombia; Yesid Romero, MBA, Fundación Salutia, Bogotá, Colombia; Duvan Gallo, BA, Fundación Salutia, Bogotá, Colombia; Lilibiana Useche, MD, Christus Sinergia, Cali, Colombia; Maria F. Gualdrón, MD MS, Christus Sinergia, Cali, Colombia; Pamela A. Alfonso, MD MSc, Fundación Salutia, Bogotá, Colombia; Lina M. Huerfano, MS, Salutia, Bogotá, Colombia

(3073) The associations between dysphagia symptoms and quality of life in institutionalized elderly

Mariko Naito, PhD DMD, Nagoya University Graduate School of Medicine, Nagoya, Japan; Yoshimi Suzukamo, PhD, Tohoku University Graduate School of Medicine, Sendai, Japan; Wataru Fujii, PhD DMD, Kyushu Dental University, Kitakyushu, Japan; Yuhei Matsuda, DH, Kyushu Dental University, Kitakyushu, Japan

Nephrology

(3075) Psychological intervention in patients with chronic renal disease in haemodialysis

Guillermo Pedreira Robles, Registered Nurse, Hospital del Mar, Barcelona, Barcelona, Spain; Yaiza Martínez Delgado, Registered Nurse, Hospital del Mar, Barcelona, Spain; Ana vasco Gómez, Registered Nurse, Hospital del Mar, Barcelona, Spain; Cristina Herrera Morales, Registered Nurse, Hospital del Mar, Barcelona, Spain; Ernestina Junyent Iglesias, Registered Nurse, Hospital del Mar, Barcelona, Spain



Scientific Program — Saturday, 21 October

(3079) The use of electronic Patient-Reported Outcomes (ePROs) in the management of patients with advanced chronic kidney disease – a pilot/feasibility study for a randomised controlled trial

Derek G. Kyte, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Paul Cockwell, FRCPC, University Hospitals Birmingham NHS Foundation Trust, Birmingham, United Kingdom; Mary Dutton, MSc, University Hospitals NHS Foundation Trust, Birmingham, United Kingdom; Helen Eddington, University Hospitals NHS Foundation Trust, Birmingham, United Kingdom; Gabby Hadley, University Hospitals NHS Foundation Trust, Birmingham, United Kingdom; Natalie Ives, University of Birmingham, Birmingham, United Kingdom; Tom Marshall, PhD, Institute for Applied Health Research, Birmingham, United Kingdom; Stephanie Stringer, University Hospitals NHS Foundation Trust, Birmingham, United Kingdom; Marie Valente, University of Birmingham, Birmingham, United Kingdom; Elizabeth Brettell, University of Birmingham, Birmingham, United Kingdom; Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom

(3081) *Withdrawn*

(3083) Using Patient Reported Outcome measures (PROs) to promote quality of care and safety in the management of patients with end stage renal disease (ESRD) requiring treatment with haemodialysis.

Nicola E. Anderson, MSc, University of Birmingham, Birmingham, United Kingdom; Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Paul Cockwell, FRCPC, University Hospitals Birmingham NHS Foundation Trust, Birmingham, United Kingdom; Mary Dutton, MSc, University Hospitals NHS Foundation Trust, Birmingham, United Kingdom; Derek G. Kyte, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom

(3085) Psychometric properties of living donor kidney transplant decision-making measures among dialysis patients

John D. Peipert, PhD, David Geffen School of Medicine, UCLA, Los Angeles, United States; Amy D. Waterman, PhD, David Geffen School of Medicine, UCLA, Los Angeles, CA, United States; Ron D. Hays, PhD, UCLA, Los Angeles, CA, United States

(3087) Comparison of quality of life in pre-emptive and dialyzed patients on waiting list for kidney transplantation. Exploring differential item functioning using Rasch Measurement Theory Models.

Line Enjalbert, PhD Student, University of Nantes, Nantes, France; **Jean-Benoit Hardouin, PhD, University of Nantes, Nantes, France;** Magali Giral, ITUN, NANTES, France; Aurelie Meurette, ITUN CHU de Nantes, NANTES, France; Veronique Sebille, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France

10:15 am – 11:00 am Awards Presentation & 2018 Annual Conference Announcement

Grand ABC, 2nd Floor

The first portion of this event will be the presentation of the ISQOOL Awards. The second portion of this event will be the 2018 Annual Conference Announcement.

ISOQOL will present the following awards at Awards Presentation:

2017 President's Award

Outstanding Article of the Year Award

New Investigator and Student Presentation Awards

Outstanding Poster Award

Emerging Leader Award

Travel Scholarships



Scientific Program — Saturday, 21 October

11:00 am – 12:30 pm Plenary – Past Wisdom for Present Problems Grand ABC, 2nd Floor

Plenary sponsored by: Roche

In this session, we take a look back at two influential papers in the field of quality of life research and their current relevance and applications in both research and practice: Bergner’s “Quality of Life, Health Status, and Clinical Research” (*Med Care* 1989;27[3]:S148-S156) and Gill & Feinstein’s “A Critical Appraisal of the Quality-of-Quality of Life Measurements” (*JAMA* 1994;272:619-626). Both of these articles provided a critical empirical and theoretical survey of the field over 20 years ago and advanced ideas about what could make the field stronger. How well has our field answered the challenges raised in these papers? What wisdom might they provide for addressing contemporary problems?

Speakers

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

Madeleine King, BSc(Hons), DipMedStat, PhD, University of Sydney, Sydney, Australia

Bryce Reeve, PhD, Duke University, Durham, NC, United States

Karon F. Cook, PhD, Northwestern University, Houston, TX, United States

Chair

Kevin Weinfurt, PhD, Duke University, Durham, NC, United States

12:30 pm – 2:00 pm Lunch Break

If you purchased Box Lunch via the registration form, please present your **Saturday Lunch Ticket** to one of the hotel staff to pick up your Boxed Lunch in Grand Foyer or Columbus Foyer on the second floor.

*Please note – Boxed Lunch tickets are **not** available for purchase on-site.

12:40 pm – 1:45 pm Special Interest Group (SIG) Meetings

Patient Engagement SIG MeetingGrand D, 2nd Floor

Mixed Methods SIG Meeting.....Grand ABC, 2nd Floor

Health Preference Research SIG MeetingDiscovery BC, 3rd Floor

Child Health SIG Meeting Innovation, 3rd Floor

Industry SIG MeetingDiscovery A, 3rd Floor

1:45 am – 5:00 pm Poster Hall Open Columbus Ballroom, 2nd Floor



Scientific Program — Saturday, 21 October

2:00 pm – 3:15 pm Concurrent Symposium Sessions

Symposium 4: Putting ISOQOL's PRO User's Guide to the Test: Lessons from Three Real-World Case Studies

Grand ABC, 2nd Floor

Moderator:

Louise Humphrey, MSc, Clinical Outcomes Solutions, Manchester, United Kingdom

In 2011, volunteers from ISOQOL developed the PRO User's Guide to help clinicians use PRO measures in clinical practice. The Guide is structured around nine key considerations. In 2013, members from ISOQOL's Clinical Practice Special Interest Group (CP-SIG) began creating a Supplement to contextualize information in the Guide through real-world case studies. This symposium will present three of the case studies included in the Supplement. The case studies offer perspectives about successful PRO strategies and lessons learned.

Individual Presentations

An Overview of ISOQOL's PRO User's Guide

Louise Humphrey, MSc, Clinical Outcomes Solutions, Manchester, United Kingdom

Implementation of electronic Patient Reported Outcomes in pediatric daily clinical practice: the KLIK experience

Lotte Haverman, PhD, Emma Children's Hospital - Academic Medical Center, Amsterdam, Netherlands

Real-world challenges and solutions for the selection and implementation of disease-specific PROs based on patient preferences.

Sara Ahmed, PhD, McGill University, Montreal, QC, Canada

AmbuFlex – experiences of PRO-based clinical decision-making

Liv Marit Valen Schougaard, PhD Student, AmbuFlex, Herning, Denmark

Symposium 5: Optimizing PROMIS for use with Individuals with Disabilities: Ensuring Condition Specific Validity in a Generic Measurement System

Grand D, 2nd Floor

Moderator:

David Tulskey, PhD, University of Delaware, Newark, DE, United States

The Patient Reported Outcomes Measurement Information System (PROMIS) item banks have been designed for the general population and scores have been standardized to a sample reflective of the demographics of the US population (2000 census). One of the main advantages of PROMIS is that the use of CAT and IRT allow for assessment across a broad range of each underlying construct. Most important is that PROMIS item banks are relevant and appropriate for individuals with a wide variety of health conditions. There are, however, some cases in which additional item banks are needed for a specific medical population and/or modifications to the existing item banks are needed. For instance, this occurs when testing individuals with disabilities and some specific items are not relevant to the individual (ambulation items to individuals who are unable to walk). Alternatively, important aspects of Quality of Life may not be represented in a general measurement system. This symposium will provide examples when such modification or expanded item bank development is needed to enhance a measurement system like the PROMIS. The session will include: 1) a presentation on the need for additional emotional functioning measures for individuals who have had traumatic injury 2) a talk providing examples of how a construct means different things to different populations and thus requiring condition specific calibrations (e.g., sexual functioning in individuals with spinal cord injury vs. traumatic brain injury), and 3) a presentation describing how sub-banks are needed to measure a construct (e.g., measures of ambulation, basic mobility, wheelchair mobility, self-care, and fine motor as a finer grain approach to physical functioning in individuals with spinal cord injury). The final talk will present a statistical methodology for preserving the PROMIS metric even if alternate calibrations are utilized. This could be applied in a wide variety of situations including recalibration in unique subpopulations or translated item banks.

Individual Presentations

Development of Item Banks to Measure Resilience and Grief following Traumatic Injury

Keith Bredemeier, PhD, University of Delaware, Newark, DE, United States



Scientific Program — Saturday, 21 October

Deconstruction of Physical Functioning for Special Populations: An Illustration with Spinal Cord Injury

Pamela Kisala, MA, University of Delaware, Newark, DE, United States

Optimizing PROMIS for Special Populations: A New Methodology to Transform Condition Specific Calibrated PROMIS Item Banks to the General Population PROMIS Metric

Aaron Boulton, PhD, University of Delaware, Newark, DE, United States

Measuring Sexual Functioning in individuals with Spinal Cord and Traumatic Brain Injuries

David Tulska, PhD, University of Delaware, Newark, DE, United States

Symposium 6: Adolescents' Mental Wellbeing in China: Positive Contributions of Individual and Contextual Factors

Discovery BC, 3rd Floor

Moderator:

Wenjie Duan, PhD, Wuhan University, Wuhan, Hubei, China

Psychologists, educators, social workers, and other health professionals have conducted series of studies and interventions to facilitate adolescents' health-related quality of life outcomes. Many factors have been determined as contributors to adolescents' mental wellbeing in previous literatures, including individual factors (e.g., traits and cognitive style) and contextual factors (e.g., neighborhood economic characteristics and physical environment). In this section, our team members summarized some on-going studies to illustrate that how and why these individual and contextual factors can affect mental wellbeing of adolescents. The first study used meta-analysis to evaluate the effects of mindfulness-based stress reduction programs for using in youth depression. The second study present the role of neighborhood and community characteristics on mental health among Chinese youth using a nationally representative and multilevel data. The third study developed a single section character strengths-based cognitive intervention to reduce anxiety and promote flourishing on freshman. The final study proposed a theoretical model of character strengths-based mindfulness program, which may help individuals to be mindful one's character strengths for enhancing wellbeing. The implications and limitations of these studies were also discussed.

Individual Presentations

Social Inclusion and Quality of Life among Chinese Migrant Adolescents

Xiaoqing Tang, PhD, Zhongnan University of Economics and Law, Wuhan, China

A Systematic Review and Meta-Analysis of the Effects of Mindfulness-Based Stress Reduction on Youth Depression

Tingting Liu, PhD, Wuhan University, Wuhan, Hubei, China

Neighborhood and Mental Health of Chinese Youth

Ying Liang, PhD, Wuhan University, Wuhan, Hubei, China

Does being Mindful of Your Character Strengths Enhance Psychological Wellbeing? A Longitudinal Mediation Analysis

Wenjie Duan, PhD, Wuhan University, Wuhan, Hubei, China

3:15 pm – 3:50 pm Refreshment Break

Columbus Foyer/Grand Foyer, 2nd Floor

3:20 pm – 3:50 pm Saturday Poster Session II

Columbus Ballroom, 2nd Floor

Cancer: Mixed Sites

(3004) Examining the symptoms and quality of life improvements with durable response in patients with carcinoid syndrome from the TELESTAR open-label extension

David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States; Jennifer Beaumont, MS, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Florence Marteau, MSc, Ipsen Pharma SAS, Boulogne-Billancourt, France; Marion Feuille, PharmD, Ipsen Pharma SAS, Boulogne-Billancourt, France; Sylvie Gabriel, Ipsen Pharma SAS, Boulogne-Billancourt, France; John Ramage, Department of Gastroenterology and Hepatology, Hampshire Hospitals NHS Foundation Trust, Basingstoke, United Kingdom; Marianne Pavel, Charité – Universitätsmedizin Berlin, Berlin, Germany; Dieter Hörsch, Zentralklinik Bad Berka, Bad Berka, Germany; Matthew H. Kulke, Dana-Farber Cancer Institute, Boston, MA, United States

(3006) Pain intensity and quality of life in patients with neuroendocrine tumors; a cross sectional study

Trude Haugland, PhD RN, Diakonova University College, 0130 Oslo, Norway

Saturday, 21 October



(3008) Comparison of the traditional 3 levels EuroQol with the 5 levels in patients with urological cancers

Víctor Zamora-Ruiz, Student, IMIM (Institut Hospital del Mar d'Investigacions Mèdiques), Barcelona, Spain; Marc Martí-Pastor, MD MPH, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), 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; 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 (UPF), Barcelona, Spain; **Gemma Vilagut, MSc, IMIM (Hospital del Mar Medical Research Institute), Barcelona**; CIBER en Epidemiología y Salud Pública (CIBERESP), Madrid; Pompeu Fabra University (UPF), Barcelona, Spain; Albert Frances, Hospital del Mar, Barcelona, Spain, Barcelona, Spain; Yolanda Z. Pardo, PhD, IMIM Hospital del Mar, Barcelona, Spain; Montse Ferrer, MD PhD, Health Services Research Unit, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain; CIBER en Epidemiología y Salud Pública (CIBERESP), Spain; Universitat Autònoma de Barcelona (UAB), Barcelona, Spain; EMPARO CU, IMIM - Hospital del Mar, Barcelona, Spain

(3010) Development of HM-PRO, a haematology specific Patient-Reported Outcome Measure: content validation

Pushpendra Goswami, PhD Student, School of Life & Medical Sciences, University of Hertfordshire, Hatfield, Hertfordshire, United Kingdom; **Sam Salek, PhD BSc, School of Life & Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom**; Tatyana Ionova, University Clinic and Multinational Centre for Quality of Life Research, Saint-Petersburg, Russia; Esther Oliva, Azienda Ospedaliera, Reggio Calabria, Italy; Jonathan Kell, Cardiff and Vale University Health Board, Cardiff, United Kingdom; Marina Karakantza, Leeds Teaching Hospital NHS Trust, Leeds, United Kingdom; Saad Al-Ismael, Singleton Hospital, ABM University Health Board, Swansea, United Kingdom; Graham P. Collins, Oxford University Hospitals NHS Trust, Oxford, United Kingdom; Stewart McConnell, Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom; Catherine Langton, Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom; Daniel M. Jennings, Royal Surrey County Hospital NHS Foundation Trust, Guildford, Surrey, United Kingdom; Roger Else, Patient Research Partner, Milton Keynes, United Kingdom; Adele K. Fielding, University College London, Cancer Institute, London, United Kingdom

(3012) Sleep problems after induction therapy in children with acute lymphoblastic leukemia and their association with quality of life and fatigue

Lindsay M. Steur, MD, VU University medical center, Amsterdam, Netherlands; Martha A. Grootenhuys, PhD, Princess Máxima Center for pediatric oncology, Utrecht, Netherlands; Natasha K. van Eijkelenburg, MD PhD, Princess Máxima Center for pediatric oncology, Utrecht, Netherlands; Inge M. van der Sluis, MD PhD, Sophia Children's Hospital Erasmus medical center, Rotterdam, Netherlands; Maroeska te Loo, MD PhD, Amalia Children's Hospital Radboud University medical center, Nijmegen, Netherlands; Cor van den Bos, MD PhD, Emma Children's Hospital Academic medical center, Amsterdam, Netherlands; Wim J. Tissing, MD PhD, Beatrix Children's Hospital University medical center Groningen, Groningen, Netherlands; Gerardus J. Kaspers, PhD MD, VU University medical center, Amsterdam, Netherlands; Raphaële R. van Litsenburg, MD PhD, VU University Medical Center, Amsterdam, Netherlands

(3014) Routine collection of patient reported outcome measures in lung cancer - experiences from a Danish pilot study

Majken M. Broenserud, MD, Odense Patient Data Exploratory Network (OPEN), Odense University Hospital/Institute of Clinical Research, University of Southern Denmark, Odense, Denmark, Odense City, Denmark; Maria Iachina, PhD, Center for Clinical Epidemiology and Research Unit of Clinical Epidemiology, Odense University Hospital, Odense, Denmark, Odense City, Denmark; Liv H. Dørfliinger, MPH, Steno Diabetes Center Copenhagen, Copenhagen, Denmark; Erik Jakobsen, MD, The Danish Lung Cancer Registry, Department of Thoracic Surgery, Odense University Hospital, Odense, Denmark, Odense C, Denmark; Mogens Groenvold, MD PhD DSci, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, University of Copenhagen, Copenhagen, Denmark

(3016) Using FACT-G and PROMIS-29 to evaluate the association between duration of somatostatin analog use and quality of life in patients with carcinoid syndrome in the United States

Jennifer Beaumont, MS, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Lynn Huynh, MPH MBA DrPH, Analysis Group, Inc., Boston, MA, United States; Daniel M. Halperin, MD, Department of Gastrointestinal Medical Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Beilei Cai, PhD, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States; Todor Totev, BSc, Analysis Group, Inc., Boston, MA, United States; Rachel Bhak, MS, Analysis Group, Inc., Boston, MA, United States; Mei S. Duh, MPH ScD, Analysis Group, Inc., Boston, MA, United States; Maureen P. Neary, MS PhD, Novartis Pharmaceuticals Corporation, East Hanover, NJ, United States; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States

(3018) Investigation of long-term trend and determinants of quality of life in bladder cancer survivors

Tzu-Yi Wu, PhD, Academia Sinica, Taipei, Republic of Taiwan; Yuh-Shyan Tsai, MD PhD, National Cheng Kung University, Tainan, Republic of Taiwan; Fat-Ya Ou, BS, National Cheng Kung University, Tainan, Republic of Taiwan; Chien-Hui Ou, MD, National Cheng Kung University, Tainan, Republic of Taiwan; Hong-Lin Cheng, MD, National Cheng Kung University Hospital, Tainan, Republic of Taiwan; Tzong-Shin Tzai, MD, Tainan Municipal An-Nan Hospital, Tainan, Republic of Taiwan; Wen-Horng Yang, MD, National Cheng Kung University Hospital, Tainan, Republic of Taiwan; Jung-Der Wang, MD PhD, National Cheng Kung University, Tainan, Republic of Taiwan

(3020) Major depressive disorder in the elderly patients with multiple myeloma using SEER-Medicare Health Outcomes Survey

Naleen Raj Bhandari, MS, University of Arkansas for Medical Sciences, Little Rock, AR, United States; Nalin Payakachat, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

Scientific Program — Saturday, 21 October

(3022) Qualitative study to identify patient-perceived impacts of locally advanced cutaneous

Talia Miller, MPH MSW, Health Research Associates, Seattle, WA, United States; Jonathan S. Zager, MD, Moffitt Cancer Center, Tampa, FL, United States; Chad Gwaltney, PhD, ERT, Pittsburgh, PA, United States; Linda Fippin, MS, Provectus Biopharmaceuticals, Knoxville, TN, United States; Stephanie Hansen, RN CCRP, Provectus Biopharmaceuticals, Knoxville, TN, United States; David Sarson, PhD, Provectus Biopharmaceuticals Australia Pty Limited, Waitara, Australia; Robert H. Andtbacka, MD, Huntsman Cancer Institute, Salt Lake City, UT, United States; John F. Thompson, MD, Melanoma Institute Australia, Sydney, Australia; Michael Sadler, PhD, ERT, Pittsburgh, PA, United States; Mona L. Martin, RN MPA, Health Research Associates, Inc., Seattle, WA, United States; Eric Wachter, PhD, Provectus Biopharmaceuticals, Knoxville, TN, United States

(3024) Exploring the prognostic ability of Health-Related Quality of Life on survival for older adults with lung cancer

Laura C. Pinheiro, PhD MPH, Weill Cornell Medicine, New York, NY, United States; Bryce B. Reeve, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

(3026) Health-related quality of life of community thyroid cancer survivors in Hangzhou, China

Ting Wang, MPH, Zhejiang University School of Public Health, Hangzhou, Zhejiang Province, China; Minmin Jiang, PhD, Zhejiang University School of Public Health, Hangzhou, Zhejiang Province, China; Yanjun Ren, MPH, Hangzhou Center for Disease Control and Prevention, Hangzhou, Zhejiang Province, China; **Hongmei Wang, PhD, Zhejiang University School of Public Health, Hangzhou, Zhejiang Province, China**

(3028) Benefits of an enhanced recovery program after surgery for gastrointestinal cancer: clinical and patient perspectives

Xin S. Wang, MD MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Qiuling Shi, MD PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Valerie Shelton, RN MA, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Bob Massey, PhD RN, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

(3030) Minimal clinically important difference for the EORTC QLQ-C30 and QLQ-BN20 questionnaires in glioblastoma patients using several distribution and anchor-based methods

Ahmad Ousmen, Doctoral Student, Methodology and quality of life unit in oncology, CHRU Besançon, France, BESANCON, Franche comté, France; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Bruno Chauffert, Department of Medical Oncology, University Hospital, EA 4666, Amiens FRANCE, AMIENS, France; Loic Feuvret, Department of Radiotherapy, Pitie-Salpetriere University Hospital, Paris, paris, France; Luc Taillandier, Department of Neurology, University Hospital, Nancy FRANCE, NANCY, France; Didier Frappaz, Department of Oncology, Leon Berard Centre for Fight against Cancer, Lyon FRANCE, LYON, France; Hervé Taillia, Department of Neurology, HIA Val de Grace, Paris FRANCE, PARIS, France; Roland Schott, Department of Oncology, Paul Strauss Centre for Fight against Cancer, Strasbourg FRANCE, Strasbourg, France; François Ducray, Department of Neurology, University Hospital, Lyon, France, Lyon, France; Michel Fabbro, Department of Oncology, Val d'Aurelle Center for Fight against Cancer Montpellier FRANCE, MONTPELLIER, France; Isabelle Tennevet, Department of Oncology, Henri Becquerel Center for Fight against Cancer, Rouen FRANCE, ROUEN, France; Francois Ghiringhelli, Department of Oncology, GF Leclerc Center for Fight against Cancer, Dijon FRANCE, DIJON, France; Jean-Sébastien Guillamo, Department of Neurology, University Hospital, Caen, France, caen, France; Xavier Durando, Department of Oncology, Jean Perrin Center for Fight against Cancer, Clermont-Ferrand, France, Clermont-ferrand, France; Daniel Castera, Clinique Saint Pierre, Perpignan, France, PERPIGNAN, France; Marc Frenay, Department of Oncology, Antoine Lacassagne Center for Fight against Cancer, Nice, France, Nice, France; Chantal Campello, Department of Neurology, University Hospital, Nimes FRANCE, NIMES, France; Jerome Skrzypski, Biostatistics and Quality of life unit, Centre Georges François Leclerc, Dijon, France, dijon, France; Olivier CHINOT, Department of Neuro-Oncology, University Hospital La Timone, Marseille, France, marseille, France; Franck Bonnetain, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France

(3034) Retrospective evaluation of PRO/QoL in lung cancer patients

Xiaoping Jiang, PhD, FDA, Silver Spring, MD, United States; Umaporn Siangphoe, PhD, FDA, Silver Spring, MD, United States

Dermatologic Conditions

(3036) Development of a disease-specific Quality of Life (QOL) measure for patients with cutaneous lupus erythematosus: a pilot study

Motolani Ogunsanya, PhD, University of Oklahoma Health Sciences Center, Oklahoma City, OK, United States; Carolyn Brown, PhD, Health Outcomes and Pharmacy Practice Division, Austin, TX, United States; Andrew Hudson, Medical Student, University of Texas Southwestern Medical Center, Dallas, TX, United States; Linda Hynan, PhD, University of Texas Southwestern Medical Center, Dallas, TX, United States; Benjamin Chong, MD, University of Texas Southwestern Medical Center, Dallas, TX, United States



(3038) Patient-reported outcome measures in pruritus (itch): a systematic review of measurement properties

Dominic Schoch, MD, University Medical Center Hamburg, Hamburg, Germany; Rachel Sommer, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Matthias Augustin, PhD MD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sonja Ständer, MD, University Hospital of Münster, Münster, Germany; **Christine Blome, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany**

(3040) ACNE-Q is a new Patient Reported Outcome instrument that measures appearance-related concerns

Natasha M. Longmire, McMaster University, Hamilton, Ontario, Canada; Trisia Breitkopf, McMaster University, Hamilton, Ontario, Canada; Bhoomika Piplani, McMaster University, Hamilton, Ontario, Canada; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Maureen O'Malley, Ancaster Dermatology Centre, Ancaster, Ontario, Canada; Shari Lipner, Weill Cornell Medicine, New York City, NY, United States; Karen Wong Riff, Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada; **Anne F. Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada**

(3042) Demonstrating equivalence of the electronic and paper-based versions of the Dermatology Life Quality Index (DLQI)

Faraz M. Ali, Cardiff University, Cardiff, United Kingdom; Nutjaree Johns, Khon Kaen University, Khon Kaen, Thailand; Vincent Piguet, Cardiff University, Cardiff, United Kingdom; Andrew Y. Finlay, Cardiff University, Cardiff, United Kingdom; **Sam Salek, PhD BSc, School of Life & Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom**

(3044) HRQOL before and after intensive treatment in children with skin diseases

Lynn Blaauboer, MSc, Emma Children's Hospital, Academic Medical Centre, Amsterdam, Netherlands; **Lotte Haverman, PhD, Emma Children's Hospital, Academic Medical Center, Amsterdam, Amsterdam, Netherlands**; Pina Middeldamp-Hup, MD PhD, Academic Medical Centre, Amsterdam, Netherlands; Martha A. Grootenhuys, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands

(3046) Translation and linguistic validation of the Psoriasis Symptom Scale (PSS) for use with plaque psoriasis patients

Emily Parks-Vernizzi, BFA, FACITtrans, Elmhurst, IL, United States; **Benjamin Arnold, MA, FACITtrans, Elmhurst, IL, United States**; Anne M. Rentz, MSPH, Evidera, Bethesda, MD, United States; Anne M. Skalicky, MPH, Evidera, Seattle, WA, United States; Dagmar Kaschinski, Boehringer Ingelheim GmbH, Ingelheim, Germany

(3048) An international qualitative study to development a new Patient-Reported Outcome instrument for chronic wounds: The WOUND-Q

Emiel van Haren, MD, Memorial Sloan Kettering Cancer Center, New York City, NY, United States; Anne F. Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada; Lotte Poulsen, MD, University of Southern Denmark, Odense, Denmark, Odense, Denmark; Natasha M. Longmire, McMaster University, Hamilton, Ontario, Canada; Bhoomika Piplani, McMaster University, Hamilton, Ontario, Canada; Maarten Hoogbergen, MD PhD, Catharina Hospital Eindhoven, Eindhoven, Netherlands; Lee Squitieri, MD, University of California, Los Angeles, Los Angeles, CA, United States; Karen Cross, MD PhD, St. Michael's Hospital, and Scientist at Keenan Research Centre, Toronto, Ontario, Canada; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States

Methods for Clinical Trials

(3050) Incorporating usability and feasibility testing of electronic Patient-Reported Outcome Measures as part of clinical trial development: an example from chronic pain trials

Lucy Abraham, MSc, Pfizer Ltd., Tadworth, Surrey, United Kingdom; Adam Gater, MSc, Adelphi Values Ltd., Bollington, Cheshire, United Kingdom; Chloe Tolley, BSc, Adelphi Values Ltd, Bollington, Cheshire, United Kingdom; Charlotte Panter, MSc, Adelphi Values Ltd., Bollington, Cheshire, United Kingdom; Paul O'Donohoe, MSc, CRF Health, London, United Kingdom; **Kate Sully, PhD, Adelphi Values Ltd., Bollington, Cheshire, United Kingdom**

(3052) A systematic scoping review of the Australian New Zealand Clinical Trials Registry for trials with patient-reported outcome and proxy-rated endpoints

Rebecca Mercieca-Bebber, University of Sydney, Sydney, NSW, Australia; Ailsa Langford, Australian New Zealand Clinical Trials Registry, NHMRC Clinical Trials Centre, University of Sydney, NSW 2006., Sydney, nsw, Australia; Claudia Rutherford, PhD, University of Sydney, Sydney, NSW, Australia; Lucy Busija, PhD, Australian Catholic University, Melbourne, Victoria, Australia; Melissa Tinsley, NSW Agency for Clinical Innovation, Sydney, Australia; Natasha Roberts, Royal Brisbane and Women's Hospital (RBWH), Brisbane, Australia; Jessica K. Roydhouse, PhD, Brown University School of Public Health, Providence, RI, United States; Michelle Wilson, Auckland City Hospital, Auckland, New Zealand; Margaret-Ann Tait, MSc, University of Sydney, Sydney, Australia; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Elizabeth Vodicka, Pharmaceutical Outcomes Research and Policy Program, University of Washington, USA, Washington, WA, United States; Beth Devine, University of Washington, Seattle, WA, United States

(3054) What evidence suggests a relationship between patient age and missing PRO data on Randomized Clinical Trials (RCTs)?

Michael J. Palmer, PhD Candidate, Queen's University, Kingston, Ontario, Canada; Rebecca Mercieca-Bebber, University of Sydney, Sydney, NSW, Australia; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Melanie J. Calvert, PhD, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom; Harriet Richardson, PhD, Queen's University, Kingston, Ontario, Canada; Michael Brundage, MD MSc, Kingston General Hospital, Queen's University, Kingston, Ontario, Canada

(3056) Quality of Patient-Reported Outcome (PRO) reporting in Randomized Controlled Trials (RCTs) over time. Evidence from 480 RCTs from 2004 to 2016

Fabio Efficace, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Neil K. Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Francesco Sparano, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Mirjam Sprangers, PhD, Department of Medical Psychology, Academic Medical Centre/University of Amsterdam, Amsterdam, Netherlands; Peter Fayers, PhD, University of Aberdeen, Aberdeen, United Kingdom; Andrea L. Pusic, MD, Memorial Sloan-Kettering Cancer Center, New York City, NY, United States; Alissa Haas, Indiana University, Bloomington, IN, United States; Alfonso Piciocchi, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Edoardo La Sala, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Amélie Anota, PhD, French National Platform Quality of Life and Cancer, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Francesco Cottone, PhD, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Nina Deliu, MSc, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Jonathan Rees, Bristol Centre for Surgical Research, School of Social & Community Medicine, University of Bristol, Bristol, United Kingdom; Jacobien M. Kieffer, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Wenna Wang, Guangdong Medical University, Dongguan, China; Mike Pezold, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Sarah Fuzesi, Memorial Sloan Kettering Cancer Center, New-York, NJ, United States; Sumit Isharwal, Memorial Sloan Kettering Cancer Center, New York, NY, United States; John Yeung, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Chonghua Wan, PhD, School of Humanities and Management, Research Center on Quality of Life and Applied Psychology, Guangdong Medical University, DongGuan, Guangdong, China; Jane Blazeby, MD, University of Bristol, Bristol Centre for Surgical Research, School of Social & Community Medicine, Bristol, United Kingdom; on behalf of GIMEMA and EORTC Quality of Life Group

(3058) Quality appraisal of Clinician-Reported Outcome questionnaires in China

Jue-lian Wang, China, Guangzhou, China; **Zheng-kun HOU, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, GUANG ZHOU, China;** Feng-bin LIU, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, GUANG ZHOU, China

(3060) Bias arising from the use of patient reported outcomes measures

Joel Gagnier, MS MD PhD, University of Michigan, Ann Arbor, MI, United States

(3062) Estimating longitudinal changes in Health-Related Quality of Life in coronary artery disease: a comparison of longitudinal models

Oluwagbohunmi Awosoga, PhD, University of Lethbridge, Lethbridge, Alberta, Canada; Maria J. Santana, PhD, University of Calgary, Calgary, Alberta, Canada; Danielle Southern, MSc, University of Calgary, Calgary, Alberta, Canada; Anita Brobbey, MS (PhD Student), University of Calgary, Calgary, Alberta, Canada; Mingshan Lu, PhD, University of Calgary, Calgary, Alberta, Canada; Hude Quan, MD PhD, University of Calgary, Calgary, Alberta, Canada; Colleen Norris, PhD, University of Alberta, Edmonton, Alberta, Canada; Matthew James, MD PhD, University of Calgary, Calgary, Alberta, Canada; Lisa M. Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; **Tolulope T. Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada**

(3064) An FDA example of patient-reported Physical Function (PF) analysis in cancer clinical trials

Marian Strazzeri, MS, FDA/CDER, Silver Spring, MD, United States; Laura Lee Johnson, PhD, FDA/CDER, Silver Spring, MD, United States; Rajeshwari Sridhara, PhD, FDA/CDER, Silver Spring, MD, United States; Paul Kluetz, MD, FDA/CDER, Silver Spring, MD, United States; Scott Komo, DrPH, FDA/CDER, Silver Spring, MD, United States

(3066) Do we need to consider instruments as a whole when we migrate to additional technology platforms?

An introduction to a new approach of widgets.

Willie Muehlhausen, DVM, ICON plc, Nenagh, Tipperary, Ireland; Bill Byrom, PhD, ICON plc, Dublin, Ireland; Barbara Skerritt, ICON plc, Dublin, Ireland; Marie Mc Carthy, MSc, ICON plc, Dublin, Ireland

3:50 pm – 5:20 pm **Concurrent Oral Sessions**

Oral Session 301: Cancer IV: Head, Neck and Breast

Discovery BC, 3rd Floor

Session Chair: Michelle Mollica, PhD, MPH, RN, OCN, United States

3:55 pm – 4:08 pm (301.1) Using patient-reported functional impairment to quantify tolerability of radiotherapy in patients with head and neck cancer

Qiuling Shi, MD PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Brandon Gunn, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Xin S. Wang, MD MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Tito Mendoza, PhD, The University of Texas UT MD Anderson Cancer Center, Houston, TX, United States; David Rosenthal, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles S. Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States



Scientific Program — Saturday, 21 October

4:09 pm – 4:22 pm (301.2) HPV status is associated with fatigue at one year post IMRT for patients with head and neck cancer

Canhua Xiao, PhD, Emory University, Atlanta, GA, United States; Jonathan J. Beitler, MD, Emory University, Atlanta, GA, United States; Kristin A. Higgins, MD, Emory University, Atlanta, GA, United States; Nabil F. Saba, MD, Emory University, Atlanta, GA, United States; Dong M. Shin, MD, Emory University, Atlanta, GA, United States; Linh Kha Huynh, BS, Emory University, Atlanta, GA, United States; Toby Glazer, BS, Emory University, Atlanta, GA, United States; Andrew H. Miller, MD, Emory University, Atlanta, GA, United States; Deborah W. Bruner, PhD RN, Emory University, Atlanta, GA, United States

4:23 pm – 4:36 pm (301.3) Performance of patient-reported dysphagia instruments in a phase III clinical trial of concurrent systemic and radiation therapy for locally advanced head and neck cancer: the Canadian cancer trials group HN.6 trial

Jolie Ringash, MD, The Princess Margaret Cancer Centre and the University of Toronto, Toronto, Ontario, Canada; Rosemary Martino, PhD, The University of Toronto, Toronto, Ontario, Canada; Bingshu Chen, Canadian Cancer Trials Group, Queen's University, Kingston, Ontario, Canada; John Waldron, MD, The Princess Margaret Cancer Centre and the University of Toronto, Toronto, Ontario, Canada; Lillian Siu, MD, The Princess Margaret Cancer Centre and the University of Toronto, Toronto, Ontario, Canada; Alexander Montenegro, MSc, The Canadian Cancer Trials Group and Queen's University, Kingston, Ontario, Canada; Amy Short, MSc, St. Paul's Hospital, Saskatoon, Saskatchewan, Canada; Andrea Gomes, MSc, The Princess Margaret Cancer Centre, Toronto, Ontario, Canada; Colette Nault, MSc, The Ottawa Hospital, Ottawa, Ontario, Canada; Wendy Parulekar, MD, Canadian Cancer Trials Group, Queen's University, Kingston, Ontario, Canada

4:37 pm – 4:50 pm (301.4) Patient and provider perceptions of real-time quality of life measures during head and neck radiotherapy

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

4:51 pm – 5:04 pm (301.5) Identification of response shift at a subgroup level in cancer-related fatigue in breast cancer patients

Myriam Blanchin, PhD, Université de Nantes, Université de Tours, INSERM, Nantes, France; Maxime Salmon, Université de Nantes, Université de Tours, INSERM, Nantes, France; Christine Rotonda, PhD, Université de Lorraine, Metz, France; Francis Guillemin, MD PhD, University of Lorraine, Nancy, France; **Veronique Sebillle, ScD, Université de Nantes, Université de Tours, INSERM, Nantes, France**

Oral Session 302: Methodological Advances II

Grand ABC, 2nd Floor

Session Chair: Antonia Bennett, PhD, United States

3:55 pm – 4:08 pm (302.1) Cross-walks between Patient-Reported Health Outcome Measures – are results general or country specific?

Jakob B. Bjorner, MD PhD, Optum, Johnston, RI, United States; Pankaj A. Patel, PharmD, Kantar Health, New York, NY, United States; Asia Sikora Kessler, PhD, Optum, Johnston, RI, United States; Michelle K. White, PhD, Optum, Johnston, RI, United States

4:09 pm – 4:22 pm (302.2) Development of a self-report measure of cognitive ability for HIV: The Communicating Cognitive Concerns Questionnaire (C3Q)

Sorayya Askari, PhD, McGill University, Montreal, Quebec, Canada; Lesley K. Fellows, McGill University, Montreal, Quebec, Canada; Marie-Josée Brouillette, McGill University, Montreal, Quebec, Canada; **Nancy Mayo, PhD, McGill University, Montreal, Quebec, Canada**

4:23 pm – 4:36 pm (302.3) Can we improve respondents' understanding of what should be the basis for pain intensity ratings? Evidence from the ACTION PROTECCT Training System

Shannon M. Smith, PhD, University of Rochester School of Medicine & Dentistry, Rochester, NY, United States; Dagmar Amtmann, PhD, University of Washington, Seattle, WA, United States; Robert L. Askew, PhD, Stetson University, DeLand, FL, United States; Claudia Ramirez, MD, University of Rochester School of Medicine & Dentistry, Rochester, NY, United States; Dennis C. Turk, PhD, University of Washington, Seattle, WA, United States; Robert H. Dworkin, PhD, University of Rochester School of Medicine & Dentistry, Rochester, NY, United States

4:37 pm – 4:50 pm (302.4) How much is too much? Predictors of patient response burden in the completion of patient-reported outcome assessments

Thomas M. Atkinson, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Carolyn E. Schwartz, ScD, DeltaQuest Foundation, Inc.; Tufts University Medical School, Concord, MA, United States; Leah Goldstein, LMSW, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Iliana Garcia, MPH, Albert Einstein College of Medicine, Bronx, NY, United States; Daniel F. Storfer, BA, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Yuelin Li, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Jie Zhang, MPH, DeltaQuest Foundation, Inc., Concord, MA, United States; Bernard H. Bochner, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Bruce D. Rapkin, PhD, Albert Einstein College of Medicine, Bronx, NY, United States

Saturday, 21 October



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TOOLS MATTERS.

Scientific Program — Saturday, 21 October

4:51 pm – 5:04 pm (302.5) Are propensity scores useful when trying to compare proxy and patient reports of care experience?

Jessica K. Roydhouse, PhD, Brown University School of Public Health, Providence, RI, United States; Roeue Gutman, PhD, Brown University School of Public Health, Providence, RI, United States; Nancy L. Keating, MD MPH, Harvard Medical School, Boston, MA, United States; Vincent Mor, PhD, Brown University School of Public Health, Providence, RI, United States; Ira B. Wilson, MD MS, Brown University School of Public Health, Providence, RI, United States

Oral Session 303: Health Utility Measurement II

Innovation, 3rd Floor

Session Chair: Richard Skolasky, ScD, United States

3:55 pm – 4:08 pm (303.1) United States Valuation of the EQ-5D-5L

Benjamin M. Craig, PhD, University of South Florida, Tampa, FL, United States; Kim Rand-Hendriksen, PhD, Akershus University Hospital; University of Oslo, Oslo, Norway

4:09 pm – 4:22 pm (303.2) Predicting EQ-5D index scores from PROMIS Profile 29 in the United Kingdom, France, and Germany

Christoph P. Klapproth, MD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Alain Leplege, Université Paris Diderot, Paris, France; Chris Gibbons, PhD, University of Cambridge, Cambridge, United Kingdom; Joel Coste, MD PhD, Hotel Dieu, Assistance Publique-Hôpitaux de Paris, Paris, France; Jose M. Valderas, MD PhD, University of Exeter, Exeter, United Kingdom; Matthias Rose, MD PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany; Felix Fischer, PhD, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

4:23 pm – 4:36 pm (303.3) Estimating the Canadian utility weights for the cancer-specific preference-based instrument, QLU-C10D

Helen McTaggart-Cowan, PhD, Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada; Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Kelvin Chan, MD MSc, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada; Daniel Costa, PhD, Pain Management Research Institute, Royal North Shore Hospital, St Leonards NSW, Sydney, NSW, Australia; Jeffrey Hoch, PhD, University of California Davis, Davis, CA, United States; Richard Norman, PhD, Curtin University, Perth, Australia; Nicole Mittmann, PhD, Sunnybrook Health Sciences Centre, Toronto, Canada; Natasha Leighl, MD, Princess Margaret Cancer Centre, Toronto, Ontario, Canada; A. Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States; Dean A Regier, PhD, Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada; Rosalie Viney, PhD, University of Technology Sydney (UTS), Sydney, NSW, Australia; Stuart J Peacock, D. Phil., Canadian Centre for Applied Research in Cancer Control, Vancouver, British Columbia, Canada

4:37 pm – 4:50 pm (303.4) Mapping the cancer-specific EORTC QLQ-C30 onto the EQ-5D-5L and SF-6D

Admassu N. Lamu, Doctoral Student, University of Tromsø, Tromsø, Norway; Martin J. Mwamba, UiT, Bodø, Norway; Jan A. Olsen, BA (Hons) PhD, University of Tromsø, Tromsø, Norway

4:51 pm – 5:04 pm (303.5) Development of United Kingdom value set for EORTC QLU-C10D: multi-attribute utility classification for the EORTC-QLQ-C30

Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia; Richard Norman, PhD, Curtin University, Perth, Australia; Rebecca Mercieca-Bebber, University of Sydney, Sydney, NSW, Australia; Donna Rowen, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom; Patrick Bonnet, Abbie, North Chicago, IL, United States; David Cella, PhD, Northwestern University, Feinberg School of Medicine, Department of Medical Social Sciences, Chicago, IL, United States; A. Simon Pickard, PhD, University of Illinois at Chicago, Chicago, IL, United States; John E. Brazier, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom; Rosalie Viney, PhD, University of Technology Sydney (UTS), Sydney, NSW, Australia; Dennis A. Revicki, PhD, Evidera, Bethesda, MD, United States

Oral Session 304: Mental Health

Grand D, 2nd Floor

Session Chair: Ron Hays, PhD, United States

3:55 pm – 4:08 pm (304.1) Validation of the Patient Reported Outcomes Measurement Information System (PROMIS®) anxiety measures in psychiatric patients

Kathryn Sophie Bazo, MPH, University Pompeu Fabra, Barcelona, Spain; Gemma Vilagut, MSc, IMIM (Hospital del Mar Medical Research Institute), Barcelona; CIBER en Epidemiología y Salud Pública (CIBERESP), Madrid; Pompeu Fabra University (UPF), Barcelona, Spain; Elena Olariu, Hospital del Mar Medical Research Institute (IMIM), Barcelona, Spain; Jose Ignacio Castro-Rodríguez, Institute of Neuropsychiatry and Addictions (INAD), Parc de Salut Mar, Barcelona, Spain; Jordi Alonso, PhD, IMIM (Hospital del Mar Medical Research Institute), Barcelona; CIBER en Epidemiología y Salud Pública (CIBERESP), Madrid; Pompeu Fabra University (UPF), Barcelona, Spain; Carlos G. Forero, PhD, CIBER en Epidemiología y Salud Pública (CIBERESP), Madrid; IMIM (Hospital del Mar Medical Research Institute), Barcelona; Pompeu Fabra University (UPF), Barcelona, Spain



Scientific Program — Saturday, 21 October

4:09 pm – 4:22 pm (304.2) Validation of the PHQ-9 as a screen for depression in the emergency department

Skye P. Barbic, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Adelena Leon, BSc, University of British Columbia, Vancouver, British Columbia, Canada; William G. MacEwan, St. Paul's Hospital, Vancouver, Canada; David Barbic, MD FRCP, St. Paul's Hospital, Department of Emergency Medicine, Vancouver, British Columbia, Canada

4:23 pm – 4:36 pm (304.3) Health related quality of life of treatment resistant depression patients in the STAR*D study

Allitia DiBernardo, MD, Janssen, Titusville, NJ, United States; Xiwu Lin, PhD, Janssen, Titusville, NJ, United States; Qiaoyi Zhang, MD, Janssen, Titusville, NJ, United States; Jim Xiang, PhD, Janssen, Titusville, NJ, United States; Lang Lu, MS, Janssen, Raritan, NJ, United States; Carol Janieson, PhD, Janssen, Titusville, NJ, United States; Kwan Lee, PhD, Janssen, Titusville, NJ, United States; Gang Li, PhD, Janssen, Titusville, NJ, United States

4:37 pm – 4:50 pm (304.4) Intimate partner sexual violence among Chinese emerging adults: prevalence, correlates, mental health and quality of life outcomes

Janet Y. Wong, PhD, The University of Hong Kong, Hong Kong, Hong Kong SAR, China; Edmond P. Choi, PhD Candidate, The University of Hong Kong, Hong Kong, China; Daniel Y. Fong, PhD, The University of Hong Kong, Hong Kong SAR, Hong Kong SAR, China

4:51 pm – 5:04 pm (304.5) Spouse depression and patient-reported outcomes: embracing complexity through understanding cancer patient and spouse dynamics

Kristin Litzelman, PhD, University of Wisconsin-Madison, Madison, WI, United States; Abiola Keller, MPH PhD, Marquette University, Madison, WI, United States; Lori DuBenske, PhD, University of Wisconsin-Madison, Madison, WI, United States; Amye Tevaarwerk, MD, University of Wisconsin-Madison, Madison, WI, United States

7:00 pm – 10:00 pm Closing Dinner (Ticket Required)

Moshulu

The ISOQOL Closing Dinner will be held at Moshulu, the world's oldest and largest square rigged sailing vessel still afloat. The ship was built by William Hamilton and Company on the River Clyde in Glasgow, Scotland in 1904. The largest remaining original windjammer, she is currently the only restaurant venue on a Tall Ship today.

Tickets are required for this event.



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Exhibit #6

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Exhibit #7

Mapi Research Trust is a non-profit organization promoting the use of Clinical Outcomes Assessments

(COAs) in studies, and encouraging exchanges in the Patient-Centered Outcomes field between academics, pharmaceutical companies, and international organizations around the world. Through two unique databases (PROQOLID & PROLabels), developed and constantly updated by Mapi Research Trust research professionals, we not only exchange the latest health outcomes information, but also create vital links among those at every level of Patient-Centered Outcomes studies. We maintain the world's largest library devoted exclusively to Clinical Outcomes Assessments (COA), and make its wealth of information available to those who need it most.



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Exhibit #1

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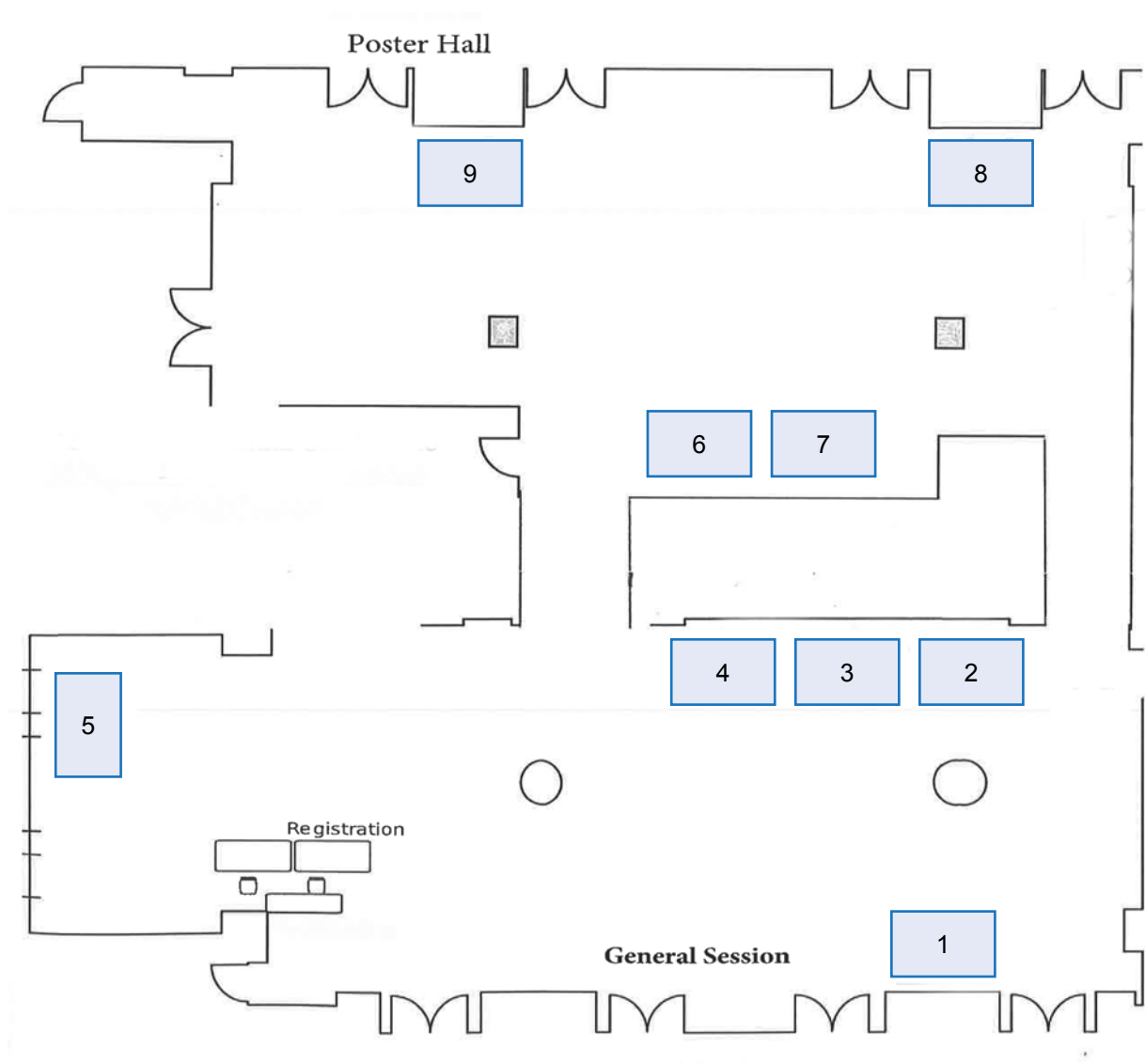
publisher. Visit the Springer booth where we will be highlighting ISOQOL's two journal publications: Quality of Life Research (Impact Factor: 2.334) and the newly launched Open Access Journal of Patient-Reported Outcomes. For more information please visit www.springer.com and www.springeropen.com.



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ISOQOL 24th Annual Conference Exhibit Layout

Hilton Philadelphia at Penn's Landing – Second Floor



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Design and testing of measurement approaches

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Design and testing of measurement approaches/ Psychometric test development methods (classical, modern, DIF)

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Intervention studies (e.g. RCTs, natural experiments)

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Intervention studies (e.g. RCTs, natural experiments)/Health policy

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E-Health / Technology (The application of technology for the delivery of clinical information, care and services.)

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Scale (PSS) for Use with Plaque Psoriasis Patients

*Parks-Vernizzi E, Arnolod B, **Rentz A, Skalicky A, Kaschinski D***

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