

# Final Program

Assessment, action, and accountability:  
Achieving optimal patient-centered outcomes  
through quality of life research



**ISOQOL**  
**26<sup>th</sup> Annual Conference**

20-23 October 2019  
San Diego, California, USA

    
#ISOQOL19

# Hotel Floor Plan

## Marina Tower Lower Level



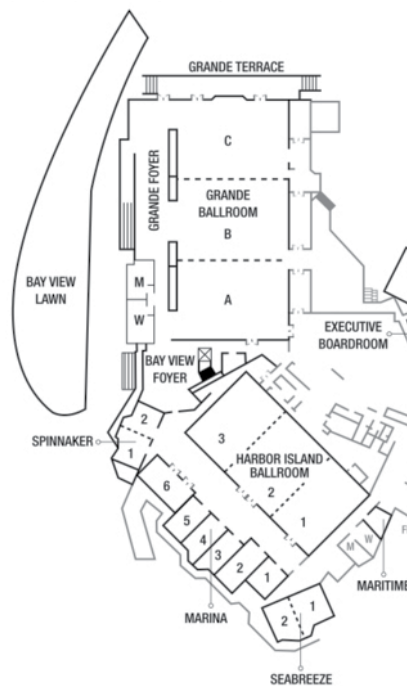
### Conference WiFi Details

Network: sheraton-CONFERENCE  
Access Code: ISOQOL19

After finding the network name, open your internet browser and go to [www.isoqol.org](http://www.isoqol.org). You will be prompted to enter the access code and press "connect".

\*Re-authorize the connection with the access code once every 24 hours, per device.

## Marina Tower Ground Level



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**Assessment, action, and accountability:**  
 Achieving optimal patient-centered outcomes through quality of life research

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## Welcome from the Scientific Program Chairs

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As Scientific Program Co-Chairs, we welcome you to San Diego for the 26<sup>th</sup> Annual Conference of the International Society for Quality of Life Research. The theme for the 2019 conference is "Assessment, Action, and Accountability: Achieving optimal patient-centered outcomes through quality of life research." The annual ISOQOL conference is uniquely positioned to foster an international discussion to advance theory, methods and application of quality of life research in the pursuit of optimal patient-centered outcomes.

You may be wondering "What do they mean by 'achieving optimal patient-centered outcomes'?" We intended that phrase to be provocative to stimulate discussion throughout the conference.

We kick off the scientific program on Monday with the first plenary: "Assessment: The art and science of selecting measures for patient-centered outcomes research." This plenary will discuss the types of measures that can be used as end-points for patient-centered research including PROMs, clinical outcome assessments, and surrogate outcomes and the implications of the choices of outcomes for policy and patient care.

Some of the most innovative and highest-ranked research submitted to ISOQOL this year will be highlighted Monday in the "Cutting Edge Research" plenary. We anticipate a lively session on innovative topics including preferences of clinicians regarding the feedback of PROMs that use modern psychometric techniques, reaching vulnerable populations when implementing PROMs in routine care, and the application of machine learning and artificial neural network analysis to PROM data.

On Tuesday morning, attend the plenary "Action: Theory, methods, and application related to achieving optimal patient-centered outcomes – lessons for Implementation Science." During this session we will focus on how to apply implementation science methods so that we as researchers have the skills to increase the integration of PROM-based research findings in to routine health care in clinical, organizational, and policy settings.

Our final plenary, "Accountability: Counting What Counts" on Wednesday afternoon will offer attendees an opportunity to consider how we can expand the use of PROMs and promote them as endpoints for assessing health care quality, clinical decision making and delivery of patient-centered care at the practice setting, within health care organizations, and between health care systems.

We are excited to offer seven excellent workshops on Sunday that focus on diverse and timely topics ranging from digital storytelling and latent variable measurement invariance to implementation science.

The ISOQOL Awards and Member Business Meeting will be held on Wednesday, 23 October at 10:35 a.m., and everyone is encouraged to attend for the exciting reveal of ISOQOL's new brand and website redesign, along with updates on the strategic plan.

Having lunch at the conference venue was so convenient and helped with networking last year that we're making it a permanent feature of the Annual Conference. Registration includes a buffet lunch Monday - Wednesday served in two shifts.

Just as we're hoping to stretch the boundaries of our scientific field, we encourage you to stretch yourself professionally and socially. We hope you will take advantage of the many opportunities to connect and network, including the Welcome Reception Sunday evening, poster sessions, on-site buffet lunches, and the main social event at the USS Midway Museum on Tuesday evening. We encourage you to engage a first time attendee (you will know them by the hot pink ribbon on their badge), learn what brought them to the meeting, and answer questions they may have about ISOQOL.

San Diego is a vibrant city known for sandy beaches, green spaces, year-round temperate weather, and famous attractions. We simply don't have enough space to do justice to the many wonderful things San Diego has to offer for you to experience following the conference!

Deborah M. Miller, PhD and Kathleen J. Yost, PhD  
2019 Scientific Program Committee Co-Chairs





# Schedule at a Glance

## Sunday, 20 October (pre-conference day)

9:00 AM	4:00 PM	<b>IPRO Course<sup>1</sup></b>	Nautilus 5
9:00 AM	4:00 PM	<b>IPCOR-Pharma Course<sup>1</sup></b>	Marina 3
9:00 AM	12:00 PM	<b>Morning Workshops<sup>1</sup></b>	
		WK2: Theoretical and methodological foundations of latent variable measurement invariance	Nautilus 2
		WK3: Patient-focused endpoints: Defining, developing and analyzing PRO endpoints for optimal interpretability	Nautilus 3
		WK4: Latent Dirichlet Allocation in Analyzing Free-Text Data in Quality Of Life Research	Nautilus 1
1:00 PM	4:00 PM	<b>Afternoon Workshops<sup>1</sup></b>	
		WK5: How Rasch and Classical Test Theory Can Complement Each Other When Assessing the Reliability and Validity of Clinical Outcome Assessments: A Hands-on Workshop	Nautilus 1
		WK6: Digital storytelling: Sharing healthcare experiences as meaningful expression of health-related quality of life	Nautilus 2
		WK7: Clinical outcome assessment in a multi-cultural context: Measurement challenges and solutions	Nautilus 3
		WK8: What is Implementation Science and How Can It Help Us Integrate PROMs into Clinical Practice?	Nautilus 4
4:30 PM	6:00 PM	<b>Concurrent SIG Symposia</b>	
		Patient preferences about health-related quality of life and healthcare: why and how to use them <i>Presented by the Health Preference Research SIG</i>	Nautilus 1
		Integrating the patient perspective throughout the medical product lifecycle: Emerging opportunities <i>Presented by the Industry SIG</i>	Nautilus 2
		How to Write a Competitive Grant Proposal <i>Presented by the New Investigator SIG</i>	Nautilus 3
		Patient engagement with PRO completion in clinical practice: Challenges and solutions <i>Presented by the Patient Engagement SIG and Quality of Life in Clinical Practice SIG</i>	Nautilus 4
6:00 PM	7:30 PM	<b>Welcome Reception</b>	Bayview Lawn

<sup>1</sup>Event requires pre-registration and the purchase of a ticket. <sup>2</sup>Lunch rain location is Nautilus Foyer/Nautilus 4 & 5

## Schedule at a Glance

### Monday, 21 October

7:15 AM	7:45 AM	<b>First Time Attendee - Coffee with Board of Directors</b>	Nautilus 4
7:15 AM	8:00 AM	QLR Editor Business Meeting (closed event)	Marina 6
7:30 AM	10:50 AM	Morning Coffee Service	Grande Foyer
8:00 AM	8:10 AM	<b>Welcome from Scientific Program Co-Chairs</b>	Grande AB
8:10 AM	8:30 AM	<b>President's Address</b>	Grande AB
8:30 AM	10:00 AM	<b>Plenary 1: Assessment: The art and science of selecting measures for patient-centered outcomes research.</b>	Grande AB
10:05 AM	10:45 AM	<b>Monday Poster Session I</b>	Grande C
10:05 AM	10:50 AM	JPRO Editorial Board Meeting (closed event)	Marina 6
10:50 AM	12:00 PM	<b>Plenary 2: Cutting Edge Research</b>	Grande AB
12:00 PM	1:45 PM	Buffet lunch (badge required) Two lunch shifts: 12:05 PM and 1:00 PM	Grande Foyer/ Bayview Lawn <sup>2</sup>
12:05 PM	1:05 PM	<b>Committee/SIG Meetings</b>	
		Australia and New Zealand SIG	Nautilus 4
		New Investigator SIG	Nautilus 1
		QOL in Clinical Practice SIG	Grande AB
		Response Shift SIG	Nautilus 2
		Translation and Cultural Adaptation SIG	Nautilus 3
12:05 PM	1:05 PM	QLR Editorial Board Meeting (closed event)	Marina 6
1:45 PM	3:15 PM	<b>Concurrent Oral Sessions (101-104)</b>	
		101: Health Utilities	Grande AB
		102: Conceptual Approaches to PROM/QOL Assessment	Nautilus 1
		103: Pediatrics	Nautilus 2
		104: PROMs in Clinical Care	Nautilus 3
3:20 PM	4:00 PM	<b>Monday Poster Session II</b>	Grande C
4:05 PM	5:35 PM	<b>Concurrent Oral Sessions (105-108)</b>	
		105: Qualitative Methods	Grande AB
		106: Assessing Change in PROMs	Nautilus 1
		107: E-Health and Mobile Apps	Nautilus 2
		108: Social, emotional, behavioral, and developmental aspects of PROMs	Nautilus 3
5:40 PM	6:20 PM	<b>Tricks of the Trade Presentation</b>	Grande AB
5:35 PM	6:30 PM	Advisory Council of Past Presidents (closed event)	Marina 6
6:30 PM	7:30 PM	<b>Mentor/Mentee Reception<sup>1</sup></b>	Lanai Area/ Shoreline

<sup>1</sup>Event requires pre-registration and the purchase of a ticket. <sup>2</sup>Lunch rain location is Nautilus Foyer/Nautilus 4 & 5



# DATA TELL STORIES.

Let us connect the pieces.



[www.vpgcentral.com](http://www.vpgcentral.com)

## Schedule at a Glance

### Tuesday, 22 October

7:30 AM	8:30 AM	<b>SIG Council Meeting (closed)</b>	Nautilus 1
7:30 AM	8:30 AM	<b>Roundtables<sup>1</sup></b>	
		RT01: How to peer review a paper <i>David Feeny, PhD and Dennis Revicki, PhD</i>	Nautilus 4
		RT02: Measuring Mindfulness and Related Constructs: Lessons Learned from an NCCIH-funded initiative, "COMMENCE" <i>David Victorson, PhD</i>	Nautilus 4
		RT03: Health utility measures for QALY construction <i>Janel Hanmer, MD PhD</i>	Nautilus 4
		RT04: Developing Clinical Outcome Assessments for Regulatory Purposes <i>William Lenderking, PhD</i>	Nautilus 5
		RT05: Integrating patients as partners in clinical research: Perspectives from PCORI <i>Jason Gerson, PhD</i>	Nautilus 5
		RT06: Standardization of PROs and PROMs <i>Caroline B. Terwee, PhD</i>	Nautilus 5
8:15 AM	11:00 AM	Morning Coffee Service	Grande Foyer
8:40 AM	10:10 AM	<b>Plenary 3: Action: Theory, methods, and application related to achieving optimal patient-centered outcomes – lessons from Implementation Science.</b>	Grande AB
10:15 AM	10:55 AM	<b>Tuesday Poster Session I</b>	Grande C
11:00 AM	12:15 PM	<b>Concurrent Symposium Sessions</b>	
		Symposium 1: Unbiased Treatment Effect and Meaningful Change Detection in the Presence of PRO Missing Data: Updating historical practices to improve oncology outcomes	Grande AB
		Symposium 2: Value-Based Health Care and Outcomes Research; a Short Bridge to Close a Long Gap	Nautilus 1
		Symposium 3: "Tell me more": Qualitative and quantitative methods for eliciting supplementary data regarding patient experiences during clinical trials and observational studies	Nautilus 2
		Symposium 4: Novel approaches and solutions to the challenges of measuring health-related domains and concepts across children of a range of ages	Nautilus 3
12:15 PM	2:00 PM	Buffet lunch (badge required) Two lunch shifts: 12:15 PM and 1:10 PM	Grande Foyer/ Bayview Lawn <sup>2</sup>

<sup>1</sup>Event requires pre-registration and the purchase of a ticket. <sup>2</sup>Lunch rain location is Nautilus Foyer/Nautilus 4 & 5



# Schedule at a Glance

## Tuesday, 22 October

12:20 PM	1:20 PM	<b>Committee/SIG Meetings</b>	
		Current Funding Opportunities in QOL Research	Grande AB
		Child Health SIG	Marina 5
		Health Preference Research SIG	Marina 6
		Industry SIG	Nautilus 2
		Mixed Methods SIG	Nautilus 1
		Patient Engagement SIG	Nautilus 3
2:00 PM	3:30 PM	<b>Concurrent Oral Briefs (B201-B204)</b>	
		B201: Patient-centered Outcomes	Grande AB
		B202: Observational Studies	Nautilus 1
		B203: Intervention Studies and Beyond	Nautilus 2
		B204: Measurement Approaches	Nautilus 3
3:35 PM	4:15 PM	<b>Tuesday Poster Session II</b>	Grande C
4:20 PM	5:50 PM	<b>Concurrent Oral Sessions (205-208)</b>	
		205: Validation of New and Existing Measures	Grande AB
		206: Engaging Stakeholders	Nautilus 1
		207: Large Scale Implementation	Nautilus 2
		208: Methodological Investigations	Nautilus 3
6:30 PM	10:30 PM	<b>Experience San Diego Social Event<sup>1</sup></b>	Offsite



<sup>1</sup>Event requires pre-registration and the purchase of a ticket. <sup>2</sup>Lunch rain location is Nautilus Foyer/Nautilus 4 & 5

## Schedule at a Glance

### Wednesday, 23 October

7:30 AM	8:30 AM	<b>Japan SIG Meeting</b>	Nautilus 5
8:00 AM	10:35 AM	Morning Coffee Service	Grande Foyer
8:30 AM	9:45 AM	<b>Concurrent Symposium Sessions</b>	
		Symposium 5: Incorporating quality of life into economic evaluation of cancer therapies: contributions of the Multi-Attribute Utility in Cancer (MAUCa) Consortium	Grande AB
		Symposium 6: Partnering with patients and caregivers in patient centered outcomes research: challenges and solutions	Nautilus 1
		Symposium 7: Improving PROs in Clinical Trials: The PROTEUS Consortium (Patient-Reported Outcomes Tools: Engaging Users & Stakeholders)	Nautilus 2
		Symposium 8: Moving the interpretation of PRO scores forward: MID's et al!	Nautilus 3
9:50 AM	10:30 AM	<b>Wednesday Poster Session I</b>	Grande C
10:35 AM	12:05 PM	<b>ISOQOL Awards and Member Business Meeting</b>	Grande AB
12:05 PM	1:50 PM	Buffet lunch (badge required) Two shifts: 12:05 PM and 1:00 PM	Grande Foyer/ Bayview Lawn <sup>2</sup>
12:10 PM	1:10 PM	<b>Committee/SIG Meetings</b>	
		Canada PRO SIG	Nautilus 1
		Chinese PRO SIG	Marina 5
		Ibero America SIG	Nautilus 2
		Psychometrics SIG	Grande AB
		United Kingdom and Ireland SIG	Nautilus 3
1:50 PM	3:20 PM	<b>Plenary 4: Accountability: Counting What Counts</b>	Grande AB
3:20 PM	4:10 PM	Refreshment break	Grande Foyer
3:25 PM	4:05 PM	<b>Wednesday Poster Session II</b>	Grande C
4:10 PM	5:40 PM	<b>Concurrent Oral Sessions (301-304)</b>	
		301: Caregivers and Other Understudied Populations	Grande AB
		302: Graphical display of PROMs	Nautilus 1
		303: Outcomes of Cancer Treatment	Nautilus 2
		304: Psychometric Methods	Nautilus 3

<sup>1</sup>Event requires pre-registration and the purchase of a ticket. <sup>2</sup>Lunch rain location is Nautilus Foyer/Nautilus 4 & 5

# SAVE THE DATE

27-28 JULY 2020  
WASHINGTON, D.C., USA

**MEASURING  
WHAT MATTERS  
SYMPOSIUM**



*Development and stakeholder  
perspectives of core outcomes sets*





# ISOQOL

INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH

## The Color Palette



The existing ISOQOL green was kept and expanded to include a lighter shade for visual interest. Deep shades of blue were added to symbolize knowledge and integrity. The golden yellow serves as a highlight to provide contrast.

## Graphic Element: The Ribbon



The ribbon is a symbol of connectivity. It serves as a signifier of ISOQOL's mission to connect research to action, scientific study to patient care. It also serves as another indication of ISOQOL's worldwide membership and network.

## Graphic Element: The Lens



The top and bottom of this logo imitate the appearance of a lens. Lenses are used to view or magnify objects - offering the viewer a different perspective. This serves as an allusion to research.



# Introducing our new look and online home.



Inspired by ISOQOL's original logo, the globe shape of this logo is a reference to ISOQOL's international reach. Moving away from a geographically correct map to the abstract makes this logo more technology-friendly.

Visit [WWW.ISOQOL.ORG/REBRAND](http://WWW.ISOQOL.ORG/REBRAND) to learn more about the inspiration behind ISOQOL's new look and website upgrade.

**VISIT [WWW.ISOQOL.ORG](http://WWW.ISOQOL.ORG)**



# General Conference Information

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## Conference Theme

"Assessment, action, and accountability: Achieving optimal patient-centered outcomes through quality of life research"

## Target Audience

The 26th Annual Conference of the International Society for Quality of Life Research provides clinicians, outcomes researchers, surgeons, psychologists, psychometricians, nurses, new investigators, patient partners and other medical professionals with a multidisciplinary forum focused on advancing the science of quality of life and related patient-centered outcomes in health research, care and policy. ISOQOL provides the premier 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 – many included in conference registration and some that require additional purchase to attend. The following descriptions can help attendees understand the features of each session type and select the type of instruction best suited to their educational needs.

## General Scientific Program

### Plenary Sessions

Plenary sessions are scheduled Monday, Tuesday and Wednesday. These sessions are the premier 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 included with registration.*

### Symposium Sessions

Symposia are 90-minute didactic or panel presentations held Tuesday and Wednesday. Presenters will examine important issues from a variety of different perspectives. Presentations and debate among presenters will address alternative solutions, interpretations or point 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 included with registration.*

### Oral Presentations

Oral sessions are 90 minutes long and are offered Monday, Tuesday and Wednesday. Each session is composed of five peer-reviewed abstracts clustered around common themes and presented via oral presentations. Each presentation is approximately 11 minutes in length, plus five minutes of questions and answers from the audience. *Admission included with registration.*

### Oral Briefs

Individual abstracts selected as oral briefs are assigned to an oral brief session. An oral brief session includes up to 10 presenters. After a personal introduction by the moderator, each speaker has 5-7 minutes to present using four slides (maximum). While the rapid pace of oral briefs does not allow for audience Q&A within the session, presenters are encouraged to stay after the conclusion of the session to make themselves available for questions. *Admission included with registration.*

### Poster Presentations

Poster sessions are 40 minutes long and are offered Monday, Tuesday and Wednesday. They feature presentations of peer-reviewed abstracts in thematic groupings. 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 included with registration.*

### Poster Guidelines

Each poster is allocated a horizontal display board that is 48 inches (1.22 m) high by 70 inches (1.78 m) wide. Your printed poster must not exceed the allocated board space. Posters will be mounted on display boards with provided tacks.

### Poster Numbers

All posters are assigned a poster number corresponding to the poster's listing in the final program. Odd-numbered posters will be presented in the morning during the daily Session I, and even-numbered posters will be presented in the afternoon during the daily Session II. Posters should only be displayed on the board with their assigned number and during their assigned session (please refer to the "Poster setup and removal" chart).

# General Conference Information

## Poster Setup and Removal

Presenters are responsible for setting up and removing posters during the assigned setup and removal times. Posters will be mounted on display boards with provided tacks. All posters are assigned a presentation day and time. Posters should be displayed for the full duration in which they are assigned. A detailed schedule of setup and removal times is listed below.

Posters remaining in the hall will be discarded following the close of the conference on 23 October.

	Monday, 21 October	Tuesday, 22 October	Wednesday, 23 October
Session 1 Poster Setup	7:00 am - 10:00 am	7:00 am - 10:00 am	7:30 am - 9:30 am
Session 1 Presentations Odd numbers	10:05 am - 10:45 am	10:15 am - 10:55 am	9:50 am - 10:30 am
Session 1 Poster Removal	11:00 am - 12:00 pm	11:00 am - 12:15 pm	10:30 am - 12:05 pm
Session 2 Poster Setup	1:00 pm - 3:00 pm	1:15 pm - 3:30 pm	1:05 pm - 3:00 pm
Session 2 Presentations Even numbers	3:20 pm - 4:00 pm	3:35 pm - 4:15 pm	3:25 pm - 4:05 pm
Session 2 Poster Removal	4:00 pm - 6:30 pm	4:15 pm - 6:00 pm	4:05 pm - 5:00 pm

## Poster Hall Hours

All poster presentations will take place in Grande Ballroom C. The Poster Hall will be open daily from 7:00 am - 5:00 pm from Monday, 21 October – Wednesday, 23 October.

## Roundtables\*

Roundtables are held on Tuesday morning. Roundtables are informal meetings, with up to nine (9) participants, for networking and discussing mutual interests in a specific work or field. These are invited sessions and have not been peer-reviewed.

## Pre-conference Sessions

### Intro to Patient-Reported Outcomes (IPRO Course)\*

Introduction to Quality of Life and Patient-Reported Outcomes

*Theory, Measurement and Applications*

Collecting and acting upon Patient-Reported Outcomes (PROs) is one of the cornerstones of patient-centered care. PROs include symptoms, some aspects of function, health perception, health related quality of life and quality of life. 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.

The IPRO Course is held Sunday, the pre-conference day. Those that participate in the course will receive a certificate of attendance upon completion of the course evaluation.

### Intro to PCOR for Pharma (IPCOR-Pharma)\*

Introduction to Patient-Centered Outcomes Research (PCOR) for the Pharma/Biotech Industry  
*Using PCOR to Inform Decision Making for Regulators, Payers, Prescribers and Patients*

PCOR is crucial to successful product development in the pharmaceutical/biotechnology industry. PCOR scientists seeking to pursue a career aligned with this industry should understand the product development process, the product lifecycle, the scientific communication process and interactions with key industry stakeholders – both internal and external (i.e., regulators and payers).

This one-day, intensive and interactive educational course offers a curriculum that will provide an introduction to the application of PCOR research specific to the pharma/biotech industry. It will provide attendees with the opportunity to make informed decisions and advance their career with fundamental knowledge of the pharma/biotech industry. Case studies will engage participants and give them a chance to test their new knowledge.

This training is aimed at attendees pursuing a PCOR career or have recently started working in the pharma/biotech industry, looking to gain a better understanding of PCOR-related activities within the pharma/biotech industry (e.g., may currently be working in a Medical Affairs team), pursuing a career in an organization that works closely with the pharma/biotech industry (e.g., regulatory authorities, payer/health technology appraisal organizations, consulting companies) and mentors in academia who are mentoring students in choosing a career path.

\*Additional purchase required to attend and seating is limited.

# General Conference Information

The IPCOR-Pharma Course is held Sunday, the pre-conference day. Those who participate in the course will receive a certificate of attendance, upon completion of the course evaluation.

## Workshops\*

Workshops are held Sunday, the pre-conference day, in the morning and afternoon. Each three-hour session features numerous presenters focused on a specific topic. Workshops are selected based on peer-reviewed proposal submissions.

## Special Interest Group (SIG) Symposia

Four concurrent symposia hosted by ISOQOL Special Interest Groups (SIGs) are held Sunday, the pre-conference day. These symposia provide educational content related to the special interests and expertise of the groups hosting the session. SIGs have the opportunity to submit a proposal and groups presenting rotate annually to ensure parity and differentiation of content. *Admission included with registration.*

## Registration Desk

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

## Registration Desk Hours

Sunday, 20 October	7:00 am - 7:00 pm
Monday, 21 October	7:00 am - 6:00 pm
Tuesday, 22 October	7:00 am - 5:00 pm
Wednesday, 23 October	7:30 am - 5:00 pm

## Coffee

The conference registration fee includes two coffee breaks daily Monday, Tuesday and Wednesday. Coffee will be served in the Grande Foyer outside the Plenary Room and Poster Hall. The new extended morning coffee break replaces the breakfast offered from previous years.

Day	Morning Coffee Service	Afternoon Coffee Break
Monday, 21 October	7:30 am - 10:50 am	3:15 pm - 4:05 pm
Tuesday, 22 October	8:15 am - 11:00 am	3:30 pm - 4:20 pm
Wednesday, 23 October	8:00 am - 10:35 am	3:20 pm - 4:10 pm

## Lunch

The conference registration fee includes a buffet lunch Monday, Tuesday and Wednesday. Lunch will be served in the Grande Foyer on the ground level with seating outside on the Bayview Lawn. *(In the case of inclement weather, lunch will be served in the Nautilus Foyer on the lower level with seating in Nautilus 4 & 5.)* Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. *\*Your conference name badge is required for entry to the buffet.*

## Lunch Shifts

Day	First Shift	Second Shift
Monday, 21 October	12:05 pm - 12:50 pm	1:00 pm - 1:45 pm
Tuesday, 22 October	12:15 pm - 1:00 pm	1:10 pm - 1:55 pm
Wednesday, 23 October	12:05 pm - 12:50 pm	1:00 pm - 1:45 pm

## Ticketed Events and Name Badge Admission

A paid "ticket" is required for the education courses, workshops, roundtables, and the Experience San Diego Social Event. **Tickets are printed on the back of attendee name badges** and can be added at the Registration Desk while supplies last.

## Cancellation Policy

ISOQOL reserves the right to cancel any session or 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 will be emailed to all presenting authors the week following the conclusion of the conference. Those who require a hard copy may request one at the registration desk following their presentation.

*\*Additional purchase required to attend and seating is limited.*

# General Conference Information

## Evaluations

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

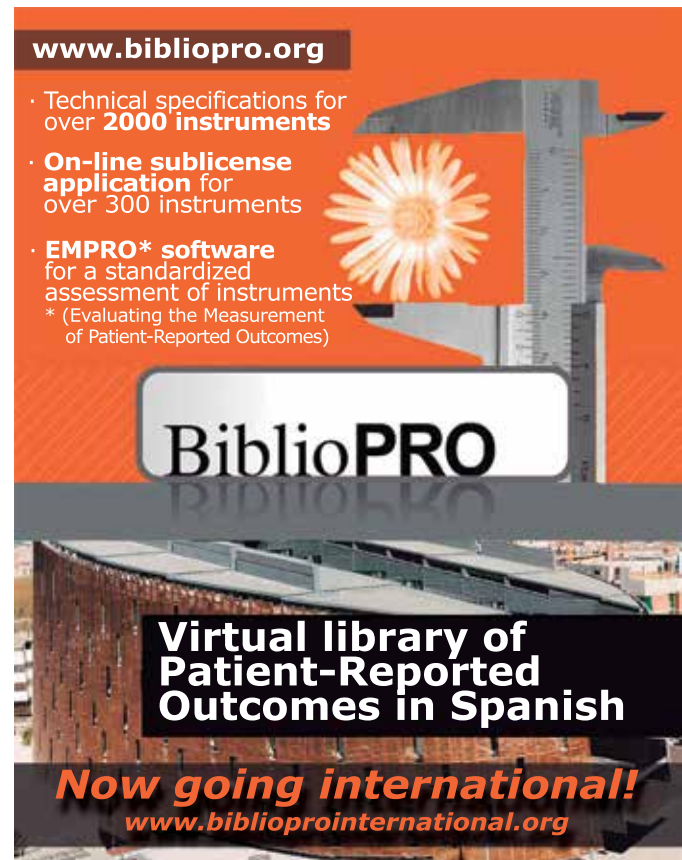
Workshop attendees will receive an evaluation link during the course and are asked to respond before the session concludes.

## Media Disclaimer

By registering for the ISOQOL Annual Conference, you give consent to be photographed/filmed 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.



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- Technical specifications for over **2000 instruments**
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- **EMPRO\* software** for a standardized assessment of instruments  
\* (Evaluating the Measurement of Patient-Reported Outcomes)

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# About ISOQOL

*Advancing health related quality of life research*

The International Society for Quality of Life Research (ISOQOL) is a global community of researchers, clinicians, health care professionals, industry professionals, consultants, and patient research partners advancing health related quality of life research (HRQL). Together, we are creating a future in which patient perspective is integral to health research, care, and policy.

## ISOQOL Membership



### Make the Most of Your Membership

As a member, you choose how you want to utilize the range of resources and benefits available to help you network, learn and advance professionally:

#### Find Your Community

- Connect with fellow members from a range of industries, sectors and fields by joining Special Interest Groups (SIGs) and browsing the Member Directory
- Find fellow professionals in your part of the world by joining a Regional Network
- Take advantage of discounted member registration to join in-person events

#### Develop Your Career

- Volunteer as an abstract reviewer for journals or the Annual Conference
- Participate in mentor/mentee matching at the Annual Conference
- Publish research at a deeply discounted rate in the open-access *Journal of Patient-Reported Outcomes*

- View employment opportunities on the ISOQOL Job Board
- Volunteer as a SIG leader, committee chair, or panel or task force member

#### Learn and Educate

- Participate in webinars and in-person events at the discounted member rate
- Access the PROQOLID database at the discounted member rate
- Influence the educational opportunities available to members by proposing a webinar or volunteering on the Education Committee

#### Stay Informed

- Access the latest research published in both ISOQOL journals
- Receive member-exclusive updates, resources, and volunteer opportunities by email



# ISOQOL Leadership

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## Executive Committee



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**President Elect**  
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Dennis Revicki, PhD  
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David Feeny, PhD  
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## Co-Editors of *Quality of Life Research Journal*



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PhD  
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Colleen Pedersen



**Meetings Manager**  
Marina Shawd



**Communications and  
Membership Manager**  
Samantha Walker



**Membership and  
Programs Coordinator**  
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2009-2010 Diane L. Fairclough, DrPH, United States

2008-2009 Neil K. Aaronson, PhD, Netherlands

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2004-2005 David Feeny, PhD, Canada

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2002-2003 Mirjam AG Sprangers, PhD, Netherlands

2001-2002 David Osoba, MD, Canada

2000-2001 Ivan Barofsky, PhD, United States

1998-2000 Sharon Wood-Dauphinee, PhD, Canada

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1993-1994 Donald L. Patrick, PhD MSPH, United States

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Nalin Payakachat, PhD, United States

### Intro to PCOR for Pharma (IPCOR-Pharma) Course

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Betsy Tschosik, PhD, United Kingdom

### Measuring What Matters

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Jennifer Petersen, MPH, United States

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Maria-Jose Santana, PhD, Canada

Yuelin Li, PhD, United States

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Claudia Rutherford, PhD, Australia

Xin Shelley Wang, MD MPH, United States

### Workshop

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### Scholarship Panel

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

Kirstie Haywood, DPhil BSc (Hons), United Kingdom

Elizabeth Gibbons, PhD, United Kingdom

Marcelo Fleck, MD PhD, Brazil

Ana Maria Rodriguez, PhD, Spain

Laura Pinheiro, PhD, United States

### Emerging Leader Award Panel

Madeleine King, PhD, Australia

Carol Moinpour, PhD, United States

Ida Korfage, PhD, Netherlands

Kevin Weinfurt, PhD, United States

Tom Willgoss, PhD MSc BA, United Kingdom

### Special Interest Groups (SIGs)

#### Australia and New Zealand

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Rasa Ruseckaite, PhD MCompSc, Australia - Chair  
Rebecca Mercieca-Bebber, Australia - Chair Elect  
Natasha Roberts, BN, Australia - Secretary

#### Canada PRO

Sara Ahmed, PhD, Canada - Past Chair  
Ayse Kuspinar, PhD, Canada - Chair  
Nora Fayed, PhD, Canada - Chair Elect

#### Child Health

Jeanie Landgraf, MA, United States - Past Chair  
Nalin Payakachat, PhD, United States - Chair  
Robert Arbuckle, United Kingdom - Chair Elect

#### Chinese PRO

Daniel Fong, PhD, Hong Kong - Chair  
Ji-qian Fang, PhD, China - Chair

#### Health Preference Research

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Manraj Kaur, PhD, Canada - Chair

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Pedro Ferreira, PhD, Portugal - Chair

#### Industry

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Linda Nelsen, MHS, United States - Chair

#### Japan

Kikuko Miyazaki, PhD, Japan - Chair  
Kojiro Shimozuma, MD PhD, Japan - Chair

#### Mixed Methods

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Carla Dias-Barbosa, MSc, United Kingdom - Chair

#### New Investigator

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Laura Pinheiro, PhD, United States - Chair

#### Patient Engagement

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Kate Absolom, PhD, United Kingdom - Chair Elect

#### Response Shift

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Lene Kongsgaard Nielsen, PhD, Denmark - Chair

#### Translation and Cultural Adaptation

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Huda Shalhoub, PhD, United States - Chair  
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Grace Turner, PhD, United Kingdom - Chair Elect

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# Awards and Scholarships

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## President's Award

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

### Congratulations to the 2019 President's Award recipient:

Jordi Alonso, MD PhD presented by Jose M. Valderas, MD MPH PhD

2018 Andrew Bottomley, PhD presented by Jose M. Valderas, MD MPH PhD

2017 Nancy E. Mayo, PhD presented by Claire Snyder, PhD

2016 Carolyn E. Schwartz, ScD presented by Claire Snyder, PhD

2015 Carol M. Moinpour, PhD 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. It will be awarded to an ISOQOL member who has shown exceptional leadership skills and potential in an ISOQOL activity by playing a key role in initiating and/or steering a specific task or project to successful completion.

### Congratulations to the 2019 Emerging Leader Award recipient:

Claudia Rutherford, PhD

2018 Tom Willgoss, PhD MSc BA

2017 Skye P. Barbic, PhD OT

2015 Bellinda L. King-Kallimanis, PhD

2014 Antonia V. Bennett, PhD

2013 Roxanne Jensen, PhD

2012 Melanie Calvert, PhD

## Outstanding Article of the Year Awards

The Outstanding Article of the Year Award recognizes the single best article dedicated to HRQOL research published in *Quality of Life Research* and in the *Journal of Patient-Reported Outcomes* during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQOL research methods or theory.

### Congratulations to the Outstanding Articles of the Year:

#### 2018 *Quality of Life Research* Recipient

Smits, N., van der Ark, L. A., & Conijn, J. M. (2018). Measurement versus prediction in the construction of patient-reported outcome questionnaires: can we have our cake and eat it? *Quality of Life Research*, 27(7), 1673–1682. <https://doi.org/10.1007/s11136-017-1720-4>

## Awards and Scholarships

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### **2018 Journal of Patient-Reported Outcomes Recipient**

Greenhalgh, J., Gooding, K., Gibbons, E., Dalkan, S., Wright, J., Valderas, J., Black, N. (2018). How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *Journal of Patient-Reported Outcomes*, 2:42. <https://doi.org/10.1186/s41687-018-0061-6>

### **2018 Finalists for Quality of Life Research**

Prinsen, C. A. C., Mokkink, L. B., Bouter, L. M., Alonso, J., Patrick, D. L., de Vet, H. C. W., & Terwee, C. B. (2018). COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of Life Research*, 27(5), 1147–1157. <https://doi.org/10.1007/s11136-018-1798-3>

Sawatzky, R., Russell, L. B., Sajobi, T. T., Lix, L. M., Kopec, J., & Zumbo, B. D. (2018). The use of latent variable mixture models to identify invariant items in test construction. *Quality of Life Research*, 27(7), 1745–1755. <https://doi.org/10.1007/s11136-017-1680-8>

### **2018 Finalists for Journal of Patient-Reported Outcomes**

Unger, J.M., Griffin, K., Donaldson, G.W., Baranowski, K.M., Good, M.J., Reburiano, E., Hussain, M., Monk, P.J., Van Veldhuizen, P.J., Carducci, M.A., Higano, C.S., Lara, P.N., Tangen, C.M., Quinn, D.I., Wade III, J.L., Vogelzang, N.J., Thompson, I.M., Moinpour, C.M. Patient-reported outcomes for patients with metastatic castration-resistant prostate cancer receiving docetaxel and atrasentan versus docetaxel and placebo in a randomized phase III clinical trial (SWOG S0421). *Journal of Patient-Reported Outcomes*, 2:27. <https://doi.org/10.1186/s41687-018-0054-5>

Atkinson, T.M., Reeve, B.B., Dueck, A.C., Bennett, A.V., Mendoza, T.R., Rogak, L.J., Basch, E., Li, Y. Application of a bayesian graded response model to characterize areas of disagreement between clinician and patient grading of symptomatic adverse events. *Journal of Patient-Reported Outcomes*, 2:56. <https://doi.org/10.1186/s41687-018-0086-x>

## Student and New Investigator Presentation Awards

Each year, ISOQOL recognizes the best overall oral and poster presentations at the Annual Conference made by full-time students and investigators in the early stages of their career in HRQOL research.

Before the conference, finalists are chosen based on review scores in four categories: student oral presentation, student poster, new investigator oral presentation, and new investigator poster. Each of the finalists is judged during the conference, and one winner is selected for each category to be announced during the ISOQOL Awards & Member Business Meeting.

### **Congratulations to the 2019 New Investigator and Student Presentation Finalists:**

#### **New Investigator Oral Presentation**

Kara Schick-Makaroff, Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada

104.3: *Strategies for incorporating patient-reported outcomes in the care of people with chronic kidney disease (PRO Kidney): A realist synthesis of the evidence*

Lisa Van den Berg, MD, Patient-Reported Outcomes, Value & Experience (PROVE) Center at the Brigham and Women's Hospital, Massachusetts, United States

107.3: *Defining patient recovery following cancer surgery - assessing the feasibility and performance of daily ecological momentary assessments versus the SF-36.*

Minji Lee, Mayo Clinic, Minnesota, United States

205.4: *Confirmatory Factor Analyses and Measurement Invariance of the Patient Experience with Treatment and Self-management (PETS vs. 2.0)—a measure of treatment burden*

#### **New Investigator Poster Presentation**

Rachel Cusatis, PhD, Medical College of Wisconsin, Wisconsin, United States

2003: *Decisional Regret in the first year after Hematopoietic Cell Transplantation*

Gina L. Mazza, Mayo Clinic, Scottsdale, United States

2005: *Monte Carlo Simulations Evaluating the Impact of Missing Data on Between-Arm Comparisons on Summary Measures in Randomized Trials*

Ana Maria Rodriguez-Leboeuf, PhD MSc PT, IQVIA, Quebec, Canada

2007: *Validation of the McGill body image concerns scale for use in head and neck oncology*



## Awards and Scholarships

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### Student Oral Presentation

Ana Maria Moga, Faculty of Medicine, School of Physical & Occupational Therapy, McGill University, Quebec, Canada

*101.2: Towards the development of a preference-based weight-related quality of life (WRQL) index: Proof-of-Concept*

Manrui Zhang, Northwestern University, Illinois, United States

*104.2: Integrating electronic patient-reported outcome (ePRO) systems in clinical practice and its correlation to quality of care*

Sumaya Dano, University of Toronto, Ontario, Canada

*205.5: Measurement characteristics of PROMIS Computer Adaptive Testing (CAT) and ESASr to assess fatigue in Kidney Transplant Recipients*

### Student Poster Presentation

Manraj Kaur, McMaster University, Ontario, Canada

*2004: Examining content validity of BREAST-Q a decade later to determine relevance and comprehensiveness*

Mia Sommer, Department of Hematology, Aalborg, Denmark

*2006: Shared care follow-up of patients with B-cell neoplasias based on tele-care solution and PRO-Data: A feasibility study from the North Denmark Region*

Claire de Vries, Brigham and Women's Hospital, Patient-Reported Outcomes, Value & Experience (PROVE) Center, Massachusetts, United States

*2008: The development of New BODY-Q scales to Measure Outcomes for Patients undergoing Weight Loss surgery*

### Outstanding Poster Abstract Awards

The Outstanding Poster Finalist designation is given to those poster submissions for the Annual Conference that received the highest evaluations during the review process. All submitted posters are automatically considered for this award. Each of the finalists is judged during the conference and one winner is announced during the ISOQOL Awards & Member Business Meeting.

#### Congratulations to the 2019 Outstanding Poster Award Finalists:

Thor Gamst-Klaussen, PhD, UIT The Arctic University of Norway, Tromsø, Norway

*1003: Does the usual activities dimension in EQ-5D-5L measure what it intend to measure?*

Cindy Nowinski, Northwestern University, Chicago, United States

*1004: Evaluating meaningful change in Neuro-QoL CAT-administered item banks among individuals with Multiple Sclerosis at the group level*

Jean-Benoit Hardouin, University of Nantes, University of Tours, INSERM, SPHERE U1246, Nantes, France

*1005: Investigating differential response shift in the measurement of change in physical and mental health in cancer survivors.*

Paul Kamudoni, Global Evidence & Value Development, Merck Healthcare KgaA, Darmstadt, Germany

*1006: Psychometric Properties of a new PROMIS physical function short form for use in relapsing and progressive multiple sclerosis types*

Alexander Obbarius, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Center for Internal Medicine and Dermatology, Department of Psychosomatic Medicine, Berlin, Germany

*1007: The German version of the PROMIS Pain Interference Itembank was found to be a reliable and valid measure in patients with a broad range of rheumatologic conditions*

Zheng Li, PhD MPH CPH, College of Nursing and Health Professions, Valparaiso University, Indiana, United States

*1008: Effects of Ambient Air Pollution and Pollen Exposure on Asthma Control Status: A 26-Week Follow-Up Study*

# Awards and Scholarships

## Developing Country and Student/New Investigator Scholarships

The ISOQOL Travel Scholarship Program was developed to increase the opportunity for members in the early stages of their careers, and for members from developing countries, to attend and present at the Annual Conference by providing funds to help defray the expenses associated with travel to the Annual Conference.

### Congratulations to the 2019 Developing Country Scholarship Recipients:

Adesola Odole, PhD, Nigeria  
Tatiana Nikitina, PhD, Russia  
Allan Berrocal, Costa Rica

### Congratulations to the 2019 Student and New Investigator Scholarship Recipients:

Kyle Kemp, MSc, Canada  
Natasha Roberts, BN (hons), Australia  
Antoinette Davey, MPhil, United Kingdom



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## Patient Research Partner Scholarships

The ISOQOL Patient Research Partner (PRP) Travel Scholarship was developed to contribute to the advancement of patient engagement in outcomes research. This scholarship is awarded to a PRP who has actively contributed to the design, development, delivery and/or evaluation of research projects, as well as participating as a research participant.

### Congratulations to the 2019 Patient Research Partner (PRP) Scholarship Recipients:

Allyson Berent, United States  
Yelak Biru, MSc, United States  
Kristian Ahm Hansen, Denmark

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## Plenary Speakers

### Plenary 1: Assessment: The art and science of selecting measures for patient-centered outcomes research.

Monday, 21 October | 8:30 am - 10:00 am

Sponsored By: EORTC

The goal for this plenary is to stimulate discussion regarding the choice of different types of outcome measures (PROMs, clinical outcome assessments, surrogate outcomes) in patient-centered outcomes research and the implications of those choices for policy and patient care.



**Robert Kaplan, PhD**, Stanford University, Los Angeles, CA, United States

Robert M. Kaplan served as Chief Science Officer at the US Agency for Health Care Research and Quality (AHRQ) and Associate Director for Behavioral and Social Sciences at the National Institutes of Health. He is Distinguished Research Professor at UCLA, and Adjunct Professor of Medicine at Stanford. Kaplan is a past President of five professional organizations including ISOQOL. He is a former Editor-in-Chief of *Health Psychology* and of the *Annals of Behavioral Medicine* and is a member of the National Academy of Medicine. His 20 books and over 550 articles or chapters have been cited over 50,000 times (H-index > 100).



**Paul Kluetz, MD**, U.S. Food and Drug Administration, Silver Spring, MD, United States

Paul Kluetz is a medical oncologist and Deputy Director of the Oncology Center of Excellence (OCE) at the U.S. FDA. His interests include trial design and endpoint selection to expedite drug development and define clinical benefit in oncology trials. In addition to supporting the broader OCE mission, Dr. Kluetz created and directs the OCE's patient-focused drug development program, which has been instrumental in leading FDA efforts to collect, review, analyze and communicate clinical outcome assessment (COA) information such as patient-reported outcomes. Dr. Kluetz remains clinically active, caring for patients and supervising medical residents at the Georgetown University Hospital.

### Plenary 2: Cutting Edge Research

Monday, 21 October | 10:50 am - 12:00 pm

Sponsored By: Vector Psychometric Group, LLC

This plenary session features some of the highest-ranked, most innovative research from ISOQOL abstract submissions. In particular, these abstracts span the research continuum and reflect research that truly "pushes the ISOQOL envelope" in providing new and different ways to look at quality of life.



**Lotte Haverman, PhD**, Emma Children's Hospital – Academic Medical Centre Amsterdam, Netherlands

Dr. Lotte Haverman is the head of the psychosocial research group and a clinical pediatric psychologist of the psychosocial department at the Emma Children's Hospital/Amsterdam University Medical Centers. Her research group focuses on the effectiveness of the use of Patient Reported Outcome Measures (PROMs), including feedback to health care providers, in daily practice including various patient populations (e.g. hemophilia, JIA, HIV, HPN, Nephrology), the development of new PROMS (e.g. Distress Thermometer for Parents), collecting norm data and translating and validating PROMIS item banks into Dutch and psychosocial outcomes of parents, patients and children with chronic illnesses.



**Angela Stover, PhD**, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

Dr. Angela Stover is an assistant professor of health policy and management at the University of North Carolina at Chapel Hill and an associate member of Lineberger Comprehensive Cancer Center. Dr. Stover's research focuses on developing and implementing PROMs in routine care and she has dedicated training in implementation science. She serves as an investigator on PROM studies funded by PCORI, NIH, and CMS in the United States.

## Plenary Speakers



**Chris Sidey-Gibbons, PhD**, Brigham and Women's Hospital and Harvard Medical School, Boston, MA, United States

Dr. Sidey-Gibbons is a psychometrician, data scientist, and health services researcher whose principal interests lie in the development and evaluation of computational techniques to enhance the collection, analysis, and reporting of PROMs data in clinical care. Working on both sides of the Atlantic, Dr. Sidey-Gibbons has been Director of Health Assessment and Innovation at the University of Cambridge Psychometrics Center and Co-Director of the Patient-Reported Outcomes, Value, and Experience (PROVE) Center at Brigham and Women's Hospital and Harvard Medical School. He continues to serve as Health Director of the Concerto Platform, an open-source project designed to endow researchers and clinicians with tools to develop and distribute advanced psychometric assessment which encompasses computerized adaptive testing, tailored feedback, and machine learning. Using Concerto, Dr. Sidey-Gibbons has developed a computerized adaptive testing version of the World Health Organization Quality of Life assessment which has been completed by over 15,000 participants in over 100 countries around the globe.



**Todd DeWees, PhD**, Mayo Clinic, Scottsdale, AZ, United States

Dr. DeWees is an Associate Professor of Biostatistics at Mayo Clinic in Arizona and serves as the lead biostatistician for Radiation Oncology across the Mayo Clinic enterprise. He is involved in all aspects of radiation oncology; working with departmental researchers from fields including: biologists, physicists, clinicians, residents, and students. He is responsible for design, monitoring, analysis, interpretation, and reporting for genetic, biological, animal, human, and machine trials. He aids in the design, implementation and publication of grants, prospective, and retrospective trials. Dr. DeWees' research focuses on the optimization and utilization of statistical methodology for clinical data and patient reported outcomes.

### Plenary 3: Action: Theory, methods, and application related to achieving optimal patient-centered outcomes – lessons from Implementation Science.

**Tuesday, 22 October | 8:40 am - 10:10 am**

*Sponsored By: Genentech*

ISOQOL member and non-member conference attendees have made remarkable contributions to the field of patient-reported outcome (PRO) measurement. Increasingly more attention is being placed on implementing PROs in routine clinical practice. This plenary will provide a platform to discuss how patient-centered outcomes research and patient-centered care can be strengthened through Implementation Science.

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**Carl May, PhD**, London School of Hygiene and Tropical Medicine, London, United Kingdom

Professor Carl May is a medical sociologist and health systems scientist with a wide range of research interests across the sociology of health technologies and of human relations in the healthcare systems of the advanced economies. This work has ranged from very applied evaluation studies in health services research (especially in qualitative studies nested within randomised controlled trials) through studies of the social construction of professional-patient relations and different disease entities, to fundamental social science research on the dynamics of human agency under conditions of constraint in implementation science.



**Karen Emmons, PhD**, Harvard T.H. Chan School of Public Health, Boston, MA, United States

Karen Emmons, Ph.D., is a Professor of Social and Behavioral Science at the Harvard-Chan School of Public Health. Her work focuses on community-based approaches to cancer prevention for disadvantaged populations. These efforts target a range of cancer risk factors, including nutrition, physical activity, sun exposure, tobacco and second-hand smoke exposure, and cancer screening. With a passion for community-based implementation science, Dr. Emmons has been actively involved in national efforts to develop implementation research and training programs. As the Faculty Director of the Community Engagement Program for Harvard's Clinical Translational Science Award, she brings this focus to advance evidence-based strategies to improve community health

## Plenary Speakers



**Amy M. Kilbourne, PhD MPH**, U.S. Department of Veterans Affairs, Washington, DC, United States

Amy Kilbourne, PhD, MPH is the Director of the Quality Enhancement Research Initiative (QUERI) for the Veterans Affairs and Professor of Psychiatry at the University of Michigan. Dr. Kilbourne is a national expert in implementation science, partnered-oriented research, and translation of clinical quality improvement intervention findings into actionable policy and practice. She has been widely recognized for her research in multisite implementation intervention trials, development and application of large outcomes databases to improve person-centered care, and integrated physical and mental health care strategies.

### Plenary 4: Accountability: Counting What Counts

Wednesday, 23 October | 1:50 pm - 3:20 pm

Sponsored By: Pfizer

The goal of this plenary is to consider how we can expand the use of PROMs and promote them as endpoints for assessing healthcare quality, clinical decision making, and delivery of patient-centered care.



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

Rachel Hess, MD, MS is a Professor of Population Health Sciences and Internal Medicine, Chief of the Division of Health System Innovation and Research (HSIR) and co-Director of the Utah Center for Clinical and Translational Science at the University of Utah. As a General Internist and Health Services Researcher, Dr. Hess brings a unique perspective of translating research into clinical and policy practice. Dr. Hess's research aims to improve patient-centered outcomes in clinical care. In service of this mission, she seeks to understand determinants of quality of life and how health-related quality of life affects health and cost outcomes.



**Dominick L. Frosch, PhD**, Palo Alto Medical Foundation Research Institute, Palo Alto, CA, United States

Dominick L. Frosch, Ph.D. is Director and Senior Scientist at the Palo Alto Medical Foundation Research Institute. Dr. Frosch's research has focused on advancing patient engagement and patient-centered care for over 20 years. He has published over 120 articles, editorials and chapters in the scholarly literature (h-index=44) and serves as Deputy Editor for the *Journal of General Internal Medicine*. Dr. Frosch received his Ph.D. in clinical psychology with an emphasis on behavioral medicine from the University of California San Diego and completed a fellowship as Robert Wood Johnson Foundation Health & Society Scholar at the University of Pennsylvania.



**Mona Khalid, BSc (Hons) MSc PhD**, International Consortium for Health Outcomes Measurement (ICHOM), London, United Kingdom

Mona Khalid joined ICHOM as the VP of Outcomes Research and Development. Prior to joining ICHOM, Mona spent 10 years in the life sciences industry, leading teams to demonstrate the value of medical interventions. She has joined from Takeda Pharmaceuticals, where she was Global Head of Evidence and Value Generation. Before her tenure in the life sciences industry, she held academic roles at the Institute of Child Health, UCL and at the University of Toronto. She holds a BSc. (Hons) in biology, a MSc. in biomedical science and initiated her PhD in epidemiology.



**7:00 am - 7:00 pm      Registration Desk Open      Bayview Foyer, ground level**

**9:00 am - 4:00 pm      IPRO Course (ticket required)      Nautilus 5, lower level**

**9:00 am - 4:00 pm      IPCOR-Pharma Course (ticket required)      Marina 3, ground level**

**9:00 am - 12:00 pm      Morning Workshops (ticket required)**

**WK02: Theoretical and methodological foundations of latent variable measurement invariance.....Nautilus 2, lower level**

Richard Sawatzky, Trinity Western University, Langley, British Columbia, Canada; Lisa Lix, University of Manitoba, Winnipeg, Manitoba, Canada; Lara Russell, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Tolu Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Bruno Zumbo, PhD, University of British Columbia, Vancouver, British Columbia, Canada

**WK03: Patient-focused endpoints: Defining, developing and analyzing PRO endpoints for optimal interpretability.....Nautilus 3, lower level**

Lysbeth Floden, Clinical Outcomes Solutions, Tucson, AZ, United States; Melanie Bell, PhD, Mel & Enid Zuckerman College of Public Health, University of Arizona, Tucson, AZ, United States; Stacie Hudgens, MA (AbD), Clinical Outcomes Solutions, Tucson, AZ, United States

**WK04: Latent Dirichlet Allocation in Analyzing Free-Text Data in Quality of Life Research..... Nautilus 1, lower level**

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

**12:00 pm - 1:00 pm      Lunch on your own**

*If you purchased a boxed lunch via the registration form, please present your name badge to one of the hotel staff to pick up your boxed lunch in the Nautilus Foyer on the lower level.*

*\*Please note: Boxed lunches are not available for purchase on-site.*

**1:00 pm - 4:00 pm      Afternoon Workshops (ticket required)**

**WK05: How Rasch and Classical Test Theory Can Complement Each Other When Assessing the Reliability and Validity of Clinical Outcome Assessments: A Hands-on Workshop .....Nautilus 1, lower level**

Harman Dhatt, MPH, Apex Health Solutions & University of Arizona College of Pharmacy, Scottsdale, AZ, United States; Stacie Hudgens, MA (AbD), Clinical Outcomes Solutions, Tucson, AZ, United States; Terri Warholak, PhD RPh CPHQ FAPhA, University of Arizona, Tucson, AZ, United States

**WK06: Digital storytelling: Sharing healthcare experiences as meaningful expression of health-related quality of life .....Nautilus 2, lower level**

Elly Park, PhD MScOT, University of Alberta, Edmonton, Alberta, Canada; Mary Forhan, OT PhD, University of Alberta, Edmonton, Alberta, Canada; Allyson Jones, PhD, University of Alberta, Edmonton, Alberta, Canada

**WK07: Clinical outcome assessment in a multi-cultural context: Measurement challenges and solutions ..... Nautilus 3, lower level**

Sonya Eremenco, MA, Critical Path Institute, Tucson, AZ, United States; Mona Martin, RN MPA, Evidera, Inc., Seattle, WA, United States; Helen Doll, MSc DPhil, Clinical Outcomes Solutions, Folkestone, United Kingdom; Antoine Regnault, PhD, Modus Outcomes, Lyon, France; Lori McLeod, PhD, RTI Health Solutions, Research Triangle Park, NC, United States; with contributions from Stacie Hudgens, MA (AbD), Clinical Outcomes Solutions, Tucson, AZ, United States

**WK08: What is Implementation Science and How Can It Help Us Integrate PROMs into Clinical Practice ..... Nautilus 4, lower level**

Angela Stover, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Caroline Potter, PhD, University of Oxford, Oxford, United Kingdom; Natasha Roberts, PhD, Queensland University of Technology, Brisbane, Australia; Amy Cizik, PhD, University of Washington, Seattle, WA, United States; Hedy van Oers, PhD (c), Academisch Medisch Centrum Universiteit van Amsterdam, Amsterdam, Netherlands

**4:30 pm - 6:00 pm      Concurrent SIG Symposia**

These symposia provide educational content related to the special interest and expertise of the groups hosting the session.

**Patient preferences about health-related quality of life and healthcare: why and how to use them Presented by the Health Preference Research SIG.....Nautilus 1, lower level**

Health Preferences Research (HPR) explores how people value different aspects of health-related quality of life and healthcare. Evidence is used to make healthcare and resource allocation decisions; however, this raises the questions of whose preferences should be elicited, and whether preferences differ across populations.

Arguments for each perspective can be made: general population preferences for they do not have vested interests; healthcare professionals preferences for they may better understand the effects of healthcare delivery; patient and healthcare users preferences for the healthcare is provided for them and they have a greater understanding their personal impact.

There is renewed interest in elicitation of patient preferences due to methodology advances in elicitation of experienced utility and of preferences for treatment and healthcare delivery. This symposium will explore recent developments through a presentation of research findings from a panel of experts in the field of HPR and preference-elicitation.

**Integrating the patient perspective throughout the medical product lifecycle: Emerging opportunities**

*Presented by the Industry SIG .....Nautilus 2, lower level*

FDA is developing a series of guidance documents on patient-focused drug development (PFDD) as required under Section 3002 of the 21st Century Cures Act. These guidance documents are to encourage a systematic approach toward inclusion of patient experiences and priorities throughout the medical product lifecycle. The 2019 ISOQOL Annual Meeting Industry Special Interest Group (I-SIG) symposium will focus on how to optimally integrate the patient perspective into clinical development programs throughout the product lifecycle from regulatory, industry and patient perspectives. This session will include dialogue on potential uses of patient experience data and future directions on qualitative and quantitative research. Examples will be used to illustrate, for example, how patient experience data can be used to inform clinical trial design, identification of concepts of interest, selection or development of clinical outcome assessments, patient preference for treatment, benefit-risk assessment, and labeling. Presentations will be followed by a panel discussion including the regulatory, industry and patient representatives and interaction with the audience to discuss the PFDD guidance documents and the practical impact they may have on patients, caregivers, clinicians, and industry.

**How to Write a Competitive Grant Proposal**

*Presented by the New Investigators SIG.....Nautilus 3, lower level*

This symposium will provide in-depth, comprehensive guidance from new and late career investigators who are experienced in how to develop and package a compelling grant application. As New Investigators, grant writing is expected, yet daunting. Many PhD programs fail to properly prepare their graduates to independently embark on this challenging endeavor. This symposium will carefully guide attendees through the critical components of a successful grant proposal (e.g., specific aims, highlighting significance or relevance of the proposed research and its anticipated impact, and developing a realistic budget) and offer opportunities for attendees to ask questions. Our carefully chosen panel consists of internationally-recognized leaders with expertise across health conditions and methodological areas who have demonstrated consistent success in securing external funding. Symposium speakers come from the U.S, Canada, and Germany; and hence will be able to highlight common and uncommon themes for success across different funding organizations and countries.

**Patient engagement with PRO completion in clinical practice: Challenges and solutions**

*Presented by the Patient Engagement and QOL in Clinical Practice SIGs .....Nautilus 4, lower level*

With PROs being increasingly used in clinical practice and patient care, there is an assumption that patients are engaged with their completion and use. But are we doing enough to encourage and support completions of PRO measures? What are the key motivators or obstacles that can influence patient engagement with PRO measures? What have we learned to date about patient engagement that can be applied to shape and guide the successful implementation of PROs into different clinical contexts? How does PRO completion impact patient engagement in self-care? This symposium aims to explore these topics by bringing together insight from members of the ISOQOL Patient Engagement and QOL in Clinical Practice Special Interest Groups. Drawing on firsthand experiences from a collection of PRO initiatives across orthopedics, depression, and oncology, attendees will be invited to consider and discuss approaches that enhance the contribution of patients in ongoing clinical PRO adoption strategies.

**6:00 pm - 7:30 pm      Welcome Reception      Bayview Lawn, ground level**

Begin your time at the conference by visiting with old friends and networking with new friends and colleagues on the Bayview Lawn of the sunny Sheraton San Diego Hotel & Marina. Savor California flavors with provided light hors d'oeuvres or sip on a beverage from the cash bar while taking in panoramic views of the San Diego skyline.

**7:15 pm      Dine Arounds      Meet in hotel lobby**

Social event with pre-registration required

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We are seeking to expand our areas of expertise. ISOQOL members are invited to assist JPRO and QLR in providing high-quality scientific reviews of submitted manuscripts.

# Journal of Patient-Reported Outcomes (JPRO)

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We are excited that the new ISOQOL-sponsored open-access journal has recently been initiated and is now publishing articles online. Please consider JPRO as a publication outlet for your manuscripts on:

- Clinical trial-based PRO results
- Qualitative research
- PROs in clinical practice
- Patient engagement
- Social and behavioral determinants
- Patient-reported experience measures

# Quality of Life Research Journal (QLR)

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For more than 25 years QLR has focused on health-related quality of life aspects of treatment, care and rehabilitation. This subscription-based journal is devoted to the rapid communication of original research, theoretical articles and methodological reports related to the field of quality of life in all the health sciences.



*Learn more about the Journals by visiting  
[www.isoqol.org/journals](http://www.isoqol.org/journals)*



7:00 am - 6:00 pm Registration Desk Open Bayview Foyer, ground level

7:15 am - 7:45 am First Time Attendee - Coffee with ISOQOL Board of Directors Meeting Nautilus 4, lower level

First-time attendees to an ISOQOL Annual Conference are invited to meet the board of directors for an informal networking opportunity over coffee. This is also an opportunity to meet other first-time attendees.

7:15 am - 8:00 am QLR Editor Business Meeting (closed event) Marina 6

8:00 am - 8:10 am Welcome and Opening Remarks Grande Ballroom AB, ground level

Official welcome and opening remarks from scientific program co-chairs.

Deborah Miller, PhD LISW-S and Kathleen J. Yost, PhD, Scientific Program Co-Chairs

8:10 am - 8:30am President's Address Grande Ballroom AB, ground level

8:30 am - 10:00 am Plenary – Assessment: The art and science of selecting measures for patient-centered outcomes research Grande Ballroom AB, ground level

Sponsored By: EORTC

The goal for this plenary is to stimulate discussion regarding the choice of different types of outcome measures (PROMs, clinical outcome assessments, surrogate outcomes) in patient-centered outcomes research and the implications of those choices for policy and patient care.



Chair

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

Speakers

Robert Kaplan, PhD, Stanford University, Los Angeles, CA, United States

Paul Kluetz, MD, U.S. Food and Drug Administration, Silver Spring, Maryland, United States

10:00 am - 10:50 am Break and Exhibits Open Grande Foyer, ground level

10:05 am - 10:50 am JPRO Editorial Board Meeting (closed event) Marina 6

10:05 am - 10:45 am Monday Poster Session I Grande Ballroom C, ground level

Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.

**(1003) Does the usual activities dimension in EQ-5D-5L measure what it intend to measure?**

Thor Gamst-Klaussen, UIT The Arctic University of Norway, Tromsø, Norway

OUTSTANDING POSTER AWARD FINALIST

**(1005) Investigating differential response shift in the measurement of change in physical and mental health in cancer survivors.**

Jean-Benoit Hardouin, University of Nantes, University of Tours, INSERM, SPHERE U1246, Nantes, France

OUTSTANDING POSTER AWARD FINALIST

**(1007) The German version of the PROMIS Pain Interference Itembank was found to be a reliable and valid measure in patients with a broad range of rheumatologic conditions**

Alexander Obbarius, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Center for Internal Medicine and Dermatology, Department of Psychosomatic Medicine, Berlin, Germany

OUTSTANDING POSTER AWARD FINALIST

## Development and Validation of New and Existing Measures

**(1009) Withdrawn**

**(1011) Psychometric Evaluation of New BREAST-Q Scales for the Breast Reconstruction Module**

Elena Tsangaris, Harvard University, Boston, United States

**(1013) Evaluation of construct and structural validity in the Patient Roles and Responsibilities Scale**

Valerie Shilling, University of Sussex, Brighton, United Kingdom

**(1015) Development of a New Patient-Reported Outcome Measure to Evaluate Treatments for Acne and Acne Scarring: The ACNE-Q**

Anne Klassen, McMaster University, Hamilton, Ontario, Canada

**(1017) Spectacles or Refractive Surgery for Myopia: The Patients' Perspectives**

Vijaya Gothwal, L V Prasad Eye Institute, Hyderabad, India

**(1019) Long-Term Conditions Questionnaire (LTCQ) and LTCQ-Carer: new tools for evaluating integrated people-centred services for multi-morbidity and complex care needs including dementia**

Caroline Potter, University of Oxford, Oxford, United Kingdom

**(1021) Identification and recommendations of readability tests for the evaluation of clinical outcome assessments (COAs)**

Nathan Johnson, Endpoint Outcomes, Long Beach, CA, United States

**(1023) Content validity of patient-reported outcome measures used in facial transplant recipients: a systematic literature review**

Zoe Fullerton, Harvard Medical School, Boston, MA, United States

**(1025) Known-groups validity and responsiveness to change of the Patient Experience with Treatment and Self-management (PETS, vs. 2.0) – a patient-reported measure of treatment burden**

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

**(1027) Scoping Review of the Treatment Satisfaction Questionnaire for Medication 15 years after its Development**

Ana Maria Rodriguez-Leboeuf, IQVIA, RWE Patient-Centered Endpoints, Montreal, Quebec, Canada

**(1029) Withdrawn**

**(1031) From Patient Information to Patient Preference Measures in Sarcoma**

Kedar Mate, McGill University/Mayo Clinic, Montreal, Quebec, Canada

**(1033) Psychometric assessment of the PROMIS Scale v1.2 Global Health in the general Dutch population: an Item Response Theory analysis**

Caroline B Terwee, PhD, Amsterdam UMC, Vrije Universiteit Amsterdam, Department of Epidemiology and Biostatistics, Amsterdam Public Health research institute, Amsterdam, Netherlands

**(1035) Measuring patient preferences and treatment benefit in compression therapy: Development of the Patient Benefit Index-Compression (PBI-Comp)**

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

**(1037) Validation of SF-36 version 2 in Brazilian people living with HIV**

Liliane Elze Lins Kusterer, School of Medicine, Federal University of Bahia, Salvador, Bahia, Brazil

**(1039) Psychometric Evaluation of the Canadian version of the Seattle Angina Questionnaire (SAQ-CA)**

Oluwaseyi Lawal, Department of Community Health Sciences, University of Calgary, Calgary, Canada

**(1041) Withdrawn**

## Hematology

**(1043) Patient-reported outcomes can inform the severity of light chain (AL) amyloidosis at diagnosis**

Anita D'Souza, Medical College of Wisconsin, Milwaukee, WI, United States

**(1045) Withdrawn**

**(1047) Validation of PROMIS-29 in adults with haemophilia in the Netherlands**

Erna van Balen, Leiden University Medical Center, Leiden, Netherlands

**(1049) Creating customized patient-reported outcome measures for rare disease clinical trials: application of the EORTC item library to hematological stem cell disorders**

Jill A. Bell, Millennium Pharmaceuticals, Inc., a wholly owned subsidiary of Takeda Pharmaceutical Company Limited, Cambridge, MA, United States

## **(1051) Meaningfulness of HM-PRO scores: Translating the science of PROs into practice**

Paul Kamudoni, Merck KGaA, Darmstadt, Germany

## **(1053) Use of Patient-Reported Outcome Measures in Relapsed/Refractory Multiple Myeloma Studies: A Systematic Review**

Matthew LeBlanc, BSN, Duke University, Durham, NC, United States

## **(1055) Association between psychological factors, and emotional distress and quality of life after allogeneic hematopoietic cell transplantation**

Rika Nakahara, Department of Psycho-oncology, National Cancer Center Hospital, Tokyo, Japan

## **(1057) Quality of life Appraisal processes in patients with multiple myeloma**

Josephine Rahbæk Dueholm, Quality of Life Research Center, Department of Hematology, Odense University Hospital and Faculty of Health Science, University of Southern Denmark, Odense, Denmark

## **(1059) Content validity of the satisfaction and experience questionnaire (SEQ) – multiple myeloma (MM) among patients with relapsed/refractory multiple myeloma**

Emre Yucel, Amgen, Thousand Oaks, CA, United States

## **(1061) Impact of Disease on Patient Functioning in Epstein-Barr Virus Associated (EBV+) Post-Transplant Lymphoproliferative Disease (PTLD) Patients**

Bhumi Trivedi, ZS Associates, Thousand Oaks, CA, United States

## **(1063) Psychological factors of Subjective quality of life in Haemophilia A patients with joint replacements**

Sergei Khrushchev, National Research Center for Hematology, Moscow, Russia

## **Interpreting Scores and Score Differences**

### **(1065) Deriving Meaningful Change Estimates of the National Eye Institute Visual Function Questionnaire-25 in Diabetic Macular Edema Patients**

Brittany Gentile, Genentech, South San Francisco, CA, United States

### **(1067) Establishing clinical thresholds of multi-item tests: An item response theory approach to cut-off scores**

Berend Terluin, Amsterdam UMC, Amsterdam, Netherlands

### **(1069) Group vs Individual Patient Methods: to Estimate Meaningful Change Thresholds: A Simulation Study**

Helen Doll, Clinical Outcomes Solutions, Folkestone, United Kingdom

### **(1071) Time-dependent variation of patient reported outcome (PRO) measurement in patients with chronic conditions: a scoping review**

Antoinette Davey, University of Exeter, Exeter, United Kingdom

### **(1073) Development of a Personalized Minimal Clinically Important Difference: A Qualitative Study**

Salene Jones, Fred Hutchinson Cancer Research Center, Seattle, WA, United States

### **(1075) Severity thresholds for PROMIS across measures and conditions**

Nan Rothrock, Northwestern University, Chicago, United States

### **(1077) A Study about Palliative Care's Practical Use in Clinical Practice in EORTC QLQ-C15-PAL : An Investigation into Minimally Important Difference (MID)**

Kikuko Miyazaki, PhD, Kyoto University, Kyoto, Japan

### **(1079) Improvements in sense of coherence and quality of life of patients undergoing a course of chiropractic care.**

Joel Alcantara, The International Chiropractic Pediatric Association, Los Gatos, CA, United States

### **(1081) Defining estimands for responder analysis of patient-reported outcomes with missing data**

Lysbeth Floden, Clinical Outcomes Solutions, Tucson, AZ, United States

## **Neurology I**

### **(1083) What drives patient's assessment of Quality of Life (QOL) among individuals with advanced Parkinson's disease (PD)?**

Diane Fairclough, Colorado School of Public Health, Denver, CO, United States

## **(1085) Pretesting newly generated items to complement the 39-item Parkinson's disease questionnaire (PDQ)**

David Churchman, PhD, Clinical Outcomes, Oxford University Innovation, Oxford, United Kingdom

**(1087) Withdrawn**

## **(1089) Quality of Life For Persons with Parkinson's Disease Participating in a 6-Month Physical Activity Intervention**

Linda Ehrlich-Jones, PhD RN, Shirley Ryan AbilityLab, Chicago, IL, United States

## **(1091) Patient-Reported and Performance based Outcome after TBI – European Experiences from Center-TBI**

Nicole von Steinbuechel, Institute for Medical Psychology and Medical Sociology, University Medicine Goettingen, Goettingen, Germany

## **(1093) The Psychometric Properties of Mobility Outcome Measures among Individuals with Acquired Brain Injury (ABI): An Umbrella Review**

Rehab Alhasani, McGill University, Montreal, Quebec, Canada

### **Pain**

## **(1095) Change in PROMIS-Preference (PROPr) scores in Chiropractic Patients with Chronic Low Back or Neck Pain**

Ron Hays, PhD, UCLA School of Medicine, Los Angeles, CA, United States

## **(1097) Using an electronic PRO (ePRO) system to support optimal postsurgical pain management following an institutional change in opioid prescribing guidelines**

Kathleen Yost, PhD, Mayo Clinic, Rochester, MN, United States

## **(1099) Validation of the Pain Appraisal Scale (PAS) in spinal fusion surgery patients**

Amy M. Cizik, PhD MPH, University of Washington, Seattle, WA, United States

## **(1101) Subject training clarifies misunderstandings of how to report pain severity in migraine diaries**

Nadeeka Dias, ERT, Boston, MA, United States

**(1103) Withdrawn**

## **(1105) A comparison of differing baseline anchor scores on score distribution in Goal Attainment Scaling**

Chere Chapman, DGI Clinical Inc, Halifax, Nova Scotia, Canada

### **10:50 am - 12:00 pm Plenary – Cutting Edge Research Grande Ballroom AB, ground level**

*Sponsored By: Vector Psychometric Group, LLC*

This plenary session features some of the highest-ranked, most innovative research from ISOQOL abstract submissions. In particular, these abstracts span the research continuum and reflect research that truly "pushes the ISOQOL envelope" in providing new and different ways to look at health related quality of life.



Chair

**Kyle Kemp, MSc PhD Candidate**, University of Calgary, Calgary, Alberta, Canada

Speakers

#### **From statistician to clinician: The feedback of PROMIS® CATs within KLIK**

**Lotte Haverman, PhD**, Emma Children's Hospital – Academic Medical Centre Amsterdam, Netherlands

#### **Demographic and symptom differences in PRO-TECT trial (AFT-39) cancer patients electing to complete weekly home patient-reported outcome measures (PROMs) via an automated phone call vs. email: Implications for implementing PROs into routine care**

**Angela Stover, PhD**, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

#### **Predicting patient-reported outcomes following mastectomy and breast reconstruction: application of machine learning techniques to real patient data.**

**Chris Sidey-Gibbons, PhD**, Brigham and Women's Hospital and Harvard Medical School, Boston, MA, United States

#### **Artificial Neural Network Analysis of Patient-Reported Symptomatic Adverse Events utilizing PRO-CTCAE during Proton and Photon Radiation Therapy: Results of a Prospective Registry in a Large-Volume, Multi-Site Practice**

**Todd DeWees, PhD**, Mayo Clinic, Scottsdale, AZ, United States

**12:00 pm - 1:45 pm Buffet lunch break (conference badge required) Grande Foyer & Bayview Lawn\***

12:05 pm – 12:50 pm ..... First Lunch Shift

1:00 pm – 1:45 pm ..... Second Lunch Shift

The conference registration fee includes a buffet lunch served in the Grande Foyer on the ground level. Seating is available in the outdoor Bayview Lawn (\*in inclement weather, the Nautilus Foyer plus Nautilus 4 & 5 will be utilized.) Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. *Entry to the buffet is by name badge.*

**12:05pm - 1:05pm Special Interest Group (SIG) Meetings**

Australia and New Zealand SIG .....Nautilus 4, lower level

New Investigator SIG.....Nautilus 1, lower level

QOL in Clinical Practice SIG..... Grande Ballroom AB, ground level

Response Shift SIG.....Nautilus 2, lower level

Translation and Cultural Adaptation SIG..... Nautilus 3, lower level

**12:05 pm - 1:05 pm QLR Editorial Board Meeting (closed event) Marina 6**

**1:45 pm - 3:15 pm Concurrent Oral Sessions**

*Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.*

**Oral Session 101: Health Utilities Grande Ballroom AB, ground level**

Session Chair: Manraj Kaur, MSc PhD(c), Canada

**1:51 pm – 2:07 pm (101.1) Preferences for quality of life in oncology: are cancer patients and the general population different?**

Nan Luo, National University of Singapore, Singapore, Singapore

**2:08 pm – 2:24 pm (101.2) Towards the development of a preference-based weight-related quality of life (WRQL) index: Proof-of-Concept**

Ana Maria Moga, Faculty of Medicine, School of Physical & Occupational Therapy, McGill University, Montreal, Quebec, Canada

STUDENT ORAL PRESENTATION AWARD FINALIST

**2:25 pm – 2:41 pm (101.3) A hybrid modelling approach for eliciting health state preferences: the Portuguese EQ-5D-5L value set**

Pedro Lopes Ferreira, CEISUC/FEUC 504807285, Coimbra, Portugal

**2:42 pm – 2:58 pm (101.4) Comparative performance of the EuroQol EQ-5D-5L and the CDC Healthy Days measures in assessing population health**

Arto Ohinmaa, PhD, University of Alberta, Edmonton, Alberta, Canada

**2:59 pm – 3:15 pm (101.5) The use of EQ-5D-3L to measure health related quality of life losses due to a technological disaster in Brazil**

Kenya Noronha, PhD, Universidade Federal de Minas Gerais, Belo Horizonte, Brazil

**Oral Session 102: Conceptual Approaches to PROM/QOL Assessment Nautilus 1, lower level**

Session Chair: Carolyn Schwartz, ScD, United States

**1:51 pm – 2:07 pm (102.1) Reporting recommendations for studies on measurement properties of patient-reported outcome measures**

Joel Gagnier, University of Michigan, Ann Arbor, MI, United States



**2:08 pm – 2:24 pm (102.2) Advancing quality-of-life research by deepening our understanding of response shift: A unifying theory of appraisal**

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

**2:25 pm – 2:41 pm (102.3) PRO Measure Profiling Tool (PROMPT): The Development of a Rubric for Optimal Assessment of Patient Reported Outcome Measures in Quality of Life and Additional Domains**

Erin Knight, Center for Program Design and Evaluation, Dartmouth College, Lebanon, NH, United States

**2:42 pm – 2:58 pm (102.4) Time dependent variation of patient reported outcomes: a conceptual model**

Antoinette Davey, University of Exeter, Exeter, United Kingdom

**2:59 pm – 3:15 pm (102.5) Conceptualizing and measuring the needs of young people with mental illness and substance use disorders to transform integrated health services and youth outcomes**

Skye Barbic, The University of British Columbia, Vancouver, British Columbia, Canada

## Oral Session 103: Pediatrics Nautilus 2, lower level

Session Chair: Robert Klaassen, MD, Canada

**1:51 pm – 2:07 pm (103.1) Psychometric Evaluation of the Pediatric Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (Pediatric PRO-CTCAE)**

Bryce Reeve, PhD, Duke University School of Medicine, Durham, NC, United States

**2:08 pm – 2:24 pm (103.2) Advancing the science of pediatric health measurement: A multimethod approach to assessing children's self-report capacity**

Katherine Bevans, Temple University, Philadelphia, PA, United States

**2:25 pm – 2:41 pm (103.3) Evaluating Validity and Clinical Relevance of the PROMIS Itch Questionnaire-Child (PIQ-C)**

David Cella, Northwestern University, Chicago, IL, United States

**2:42 pm – 2:58 pm (103.4) What matters to children and adolescents with lower limb deformities: An international qualitative study informing the development of the LIMB-Q Kids**

Harpreet Chhina, University of British Columbia, Vancouver, British Columbia, Canada

**2:59 pm – 3:15 pm (103.5) A single metric for Pediatric and Adult versions of patient reported outcome measures: illustration in hemophilia**

Antoine Regnault, Modus Outcomes, Lyon, France

## Oral Session 104: PROMs in Clinical Care Nautilus 3, lower level

Session Chair: Roxanne Jensen, PhD, United States

**1:51 pm – 2:07 pm (104.1) Routine provision of information on patient-reported outcomes measures to healthcare providers and patients in clinical practice: a Cochrane systematic review.**

Chris Sidey-Gibbons, PhD, Brigham and Women's Hospital and Harvard Medical School, Boston, MA, United States

**2:08 pm – 2:24 pm (104.2) Integrating electronic patient-reported outcome (ePRO) systems in clinical practice and its correlation to quality of care**

Manrui Zhang, Northwestern University, Chicago, IL, United States

STUDENT ORAL PRESENTATION AWARD FINALIST

**2:25 pm – 2:41 pm (104.3) Strategies for incorporating patient-reported outcomes in the care of people with chronic kidney disease (PRO Kidney): A realist synthesis of the evidence**

Kara Schick-Makaroff, Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

**2:42 pm – 2:58 pm (104.4) Patient participation in symptom management in an acute oncological setting: a naturalistic observation study**

Gen Lin, School of Nursing, Fudan University, Shanghai, China

**2:59 pm – 3:15 pm** (104.5) **Patient-reported outcome (PRO) based follow-up with remote patient monitoring: socio-demographic, individual and disease-related determinants of referral**

Liv Marit Valen Schougaard, AmbuFlex/WestChronic, Herning, Denmark

**3:15 pm - 4:05 pm** Refreshment break and exhibits open Grande Foyer, ground level

**3:20 pm - 4:00 pm** Monday Poster Session II Grande Ballroom C, ground level

*Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.*

**(1004) Evaluating meaningful change in Neuro-QoL CAT-administered item banks among individuals with Multiple Sclerosis at the group level**

Cindy Nowinski, Northwestern University, Chicago, United States

OUTSTANDING POSTER AWARD FINALIST

**(1006) Psychometric Properties of a new PROMIS physical function short form for use in relapsing and progressive multiple sclerosis types**

Paul Kamudoni, Merck KGaA, Darmstadt, Germany

OUTSTANDING POSTER AWARD FINALIST

**(1008) Effects of Ambient Air Pollution and Pollen Exposure on Asthma Control Status: A 26-Week Follow-Up Study**

Zheng Li, College of Nursing and Health Professions, Valparaiso University, Valparaiso, IN, United States

OUTSTANDING POSTER AWARD FINALIST

## E-Health Stakeholder Performance Experience Input on E-PRO

**(1010) Feasibility and acceptability of using the electronic Patient Benefit Index in practice from patients' perspective**

Marina Otten, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

**(1012) Understanding Patient Preference of ePRO Screen Display and Features**

Jenny J. Ly, ERT, Boston, MA, United States

**(1014) Withdrawn**

**(1016) Dialogue cafés with older adults as method for appraising prioritization of technological solutions**

Liv Halvorsrud, Prof MsC PhD, OsloMet – Oslo Metropolitan University, Oslo, Norway

**(1018) Empowering patients: a first step in developing educational videos about PROs in clinical practice**

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

**(1020) Leveraging digital engagement to enhance efficiency and patient-centered care: A case study with the Medicare Annual Wellness Visit**

Elizabeth Austin, University of Washington, Seattle, United States

**(1022) Patients' Perceptions of Value of a Self-Administered Electronic Patient-Reported Outcomes Assessment on Quality of their HIV Care**

Rob Fredericksen, University of Washington, Seattle, WA, United States

**(1024) The use of the KLIK PROM portal in clinical care; the patients' and parents' point of view**

Hedy van Oers, MSc, Amsterdam UMC, University of Amsterdam, Emma Children's Hospital, Psychosocial Department, Amsterdam, the Netherlands

**(1026) Optimizing Outcome Collection in a Student-Run Clinic: Implementation of an Electronically Administered Outcome Measure**

Trevor Staples, University of Utah, Salt Lake City, UT, United States

**(1028) Preferences for the implementation of electronic patient-reported outcome measures in clinical care from the perspective of individuals with chronic pain**

Sara Ahmed, McGill University, Montreal, Quebec, Canada

**(1030) Factors associated with participation in a web-based self-management intervention for lymphoma survivors: Findings from an RCT embedded in the population-based PROFILES registry**

Lonneke van de Poll-Franse, PhD, Netherlands Cancer Institute, Amsterdam, Netherlands

**(1032) Patient, clinicians and trial staff views on the collection of patient-reported adverse events in Early Phase Clinical Trials**

Galina Velikova, University of Leeds, Leeds, United Kingdom

**(1034) Development of the imPROVE Breast Cancer Care: a platform to enable the collection and feedback of patient-reported outcomes data to patients and clinicians.**

Elena Tsangaris, PhD, Patient-Reported Outcomes, Value and Experience (PROVE) Center Brigham and Women's Hospital, Harvard Medical School, Boston, MA, United States

**(1036) Challenges in localization of patient-reported outcomes instruments destined for smartphone applications**

Anna Richards, Vitaccess, Oxford, United Kingdom

**(1038) Factors influencing electronic health literacy in a Teenage and Young Adult (TYA) setting**

Dr Patricia (Trish) Holch, Leeds Beckett University, Leeds, United Kingdom

**(1040) Acceptability of patient-reported outcomes in electronic documentation of health data: Physicians' perspective**

Toni Maria Klein, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

## Endocrinology

**(1042) An integrative review of instruments used to measure physical and psychological symptoms of individuals with neuroendocrine tumors**

Trude Haugland, VID Specialized University, Oslo, Norway

**(1044) Evaluating the validity of the EQ-5D-3L and describing Health-Related Quality of Life (HRQoL) in people living with diabetes and with/without comorbid severe mental illness**

Jan Boehnke, School of Nursing and Health Sciences, University of Dundee, Dundee, United Kingdom

## Gastrointestinal and Genitourinary Cancer

**(1046) Development of a comprehensive patient-reported outcome (PRO) assessment model for patient-centered care in colorectal cancer (CRC): a mixed methods study.**

Claudia Rutherford, The University of Sydney, Sydney, NSW, Australia

**(1048) Patients' Perceived Relevance of Patient Reported Outcome Items in Colorectal Surgery**

Chelsia Gillis, University of Calgary, Calgary, Alberta, Canada

**(1050) Upper Gastrointestinal Cancer Care Coordination (UGICCC) Project: A protocol for a registry-based randomised control trial of symptom monitoring, using patient-reported outcomes, and care coordination integrated into clinical practice.**

Liane Ioannou, Dr, Melbourne, Australia

## Minority/Underserved Populations

**(1052) Concept Elicitation for the Development of Quality Measures in Transgender Health**

Courtney M. Mann, Duke University School of Medicine, Durham, NC, United States

**(1054) Social Capital as Predictor of Quality of Life for Sub-Saharan African Migrants in Germany**

Monika Bullinger, Prof. Dr., University Hospital Hamburg Eppendorf, Hamburg, Germany

**(1056) Determinants of Health Utilities Index Mark 3 among residents of long-term care facilities**

Allyson Jones, PhD, Faculty of Rehabilitation Medicine Physical Therapy, University of Alberta, Edmonton, Alberta, Canada

**(1058) Quality of life (QoL) in Arctic regions: QoL population norms in Chukotka**

Tatiana Nikitina, Multinational Center for Quality of Life Research, Saint-Petersburg, Russia

## **(1060) Development of Physical Functioning Items based on the Patient-Reported Outcomes Measurement Information System (PROMIS®) to be used with Minority Elders**

Sylvia H. Paz, UCLA, Los Angeles, CA, United States

## **(1062) Lessons Learned: Recruiting Research Participants from an Underrepresented Patient Population at a Safety Net Hospital**

Mike Wambua, Hennepin Healthcare Research Institute, Minneapolis, MN, United States

## **Pediatrics and Young Adults I**

### **(1064) Interpretability of PROMIS Pediatric patient-reported outcome scores for children with inflammatory bowel disease**

Julia Schuchard, Children's Hospital of Philadelphia, Philadelphia, United States

### **(1066) Evaluating the association between activity and PROMIS pediatric measures in children with asthma**

Nicole Lucas, Duke University, Durham, NC, United States

### **(1068) Development of a 14-item short-form of the Childhood Atopic Dermatitis Impact Scale (CADIS-SF14)**

Michaela Gabes, Medical Sociology, University of Regensburg, Regensburg, Germany

### **(1070) Improving the care for pediatric transplant patients through integration of patient-reported outcome measures into clinical practice**

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

### **(1072) Understanding of the MD Anderson Symptom Inventory (MDASI) by Adolescents with Cancer**

Loretta A. Williams, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

### **(1074) Health-Related Quality of Life after diagnosis of an infection in children and adolescents in low and middle-income countries: A Systematic Review**

Dibyadyuti Datta, Indiana University School of Medicine, Indianapolis, IN, United States

### **(1076) Chinese translation and validation of pediatric quality of life in neurological disorders (Neuro-QoL)**

Min Li, Norwich University, Northfield, VT, United States

### **(1078) "Social interaction (...) without that then I would probably be miserable": Understanding quality of life in Duchenne muscular dystrophy**

Philip Powell, University of Sheffield, Sheffield, United Kingdom

### **(1080) Psychometric analysis of the Kessler Distress Scale (K10) for young adults receiving integrated health services in British Columbia, Canada.**

Skye Barbic, The University of British Columbia, Vancouver, British Columbia, Canada

### **(1082) *Withdrawn***

### **(1084) Population reference values of the PROMIS Profile 25 in Sweden**

John Chaplin, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden

### **(1086) Adolescents' use of over the counter analgesics: the influence of culture, gender and family; a review**

Siv Skarstein, OsloMet – Oslo Metropolitan University, Oslo, Norway

### **(1088) Are child and adolescent-specific measures used to inform resource allocation decisions? A review of the methods used to generate utility values in NICE technology appraisals for children and adolescents**

Donna Rowen, PhD, University of Sheffield, Sheffield, United Kingdom

### **(1090) Identification of attributes of quality of life among children and adolescents with hearing loss**

Roberta Alvarenga Reis, Federal University of Rio Grande do Sul, Porto Alegre-RS, Brazil

### **(1092) Validation of the Diabetes Mellitus Module DISABKIDS® questionnaire for Brazil**

Claudia Santos, PhD, Department of Maternal-Infant Nursing and Public Health, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil

### **(1094) Methods: for assessing well-being directly from children with severe motor and communication impairment**

Samantha Noyek, Queen's University, Kingston, Ontario, Canada

**PROs in Clinical Trials**

**(1096) Reporting of patient-reported outcomes and quality of life data in oncology drug development trials: a literature review**

Lyna Merzoug, US Food & Drug Administration, Silver Spring, MD, United States;

**(1098) A conceptual framework for patient reported outcome measures in clinical quality registries**

Rasa Ruseckaite, Monash University, Melbourne, Australia

**(1100) The impact of patient-reported outcome (PRO) data from clinical trials: a systematic review and critical analysis**

Samantha Cruz Rivera, University of Birmingham, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom

**(1102) Challenges of using Health-Related Quality of Life Data from Cancer Clinical trials for Retrospective Studies: the EORTC CATAPULT experience**

Madeline Pe, EORTC, Brussels, Belgium

**(1104) Calibrating Rasch measures for assessing treatment effects in a clinical trial setting: Findings from a simulation study**

Angély Loubert, Modus Outcomes, Lyon, France

**Sexual Health**

**(1106) Development and content validation of the IPV-4, a brief patient-reported measure of intimate partner violence for use in HIV care**

Emma Fitzsimmons, University of Washington, Seattle, WA, United States

**(1108) Sexual violence and quality of life: a 30-year prospective cohort study**

Jenna Marie Strizzi, University of Copenhagen, Copenhagen, Denmark

**(1110) No changes in sexual quality of life over a 5 years period in patients with axial spondyloarthritis**

Gudrun Rohde, Faculty of Health and Sport, University of Agder, Norway and Department of Rheumatology, Sorlandet Hospital HF, Kristiansand, Norway

**(1112) Factors influencing safe sex practice in Chinese female emerging adults**

Janet Yuen-Ha Wong, The University of Hong Kong, Hong Kong, S.A.R., Hong Kong

**4:05 pm - 5:35 pm Concurrent Oral Sessions**

*Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.*

**Oral Session 105: Qualitative Methods Grande Ballroom AB, ground level**

Session Chair: Carla Dias-Barbosa, MSc, United Kingdom

**4:11 pm – 4:27 pm (105.1) Obtaining Content for Patient-Reported Experience Measure for Children with Medical Complexity Using Peer Interviewers**

Nora Fayed, Queen’s University, Kingston, Ontario, Canada

**4:28 pm – 4:44 pm (105.2) Taking the “complex” out of complex statistical methods: Plain language knowledge translation resources about PROMS**

Lara Russell, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada

**4:45 pm – 5:01 pm (105.3) The impact of patient-reported outcome data from clinical trials: perspectives from international stakeholders**

Samantha Cruz Rivera, University of Birmingham, Centre for Patient Reported Outcomes Research, Birmingham, United Kingdom

**5:02 pm – 5:18 pm (105.4) Why do bladder cancer patients not use psychosocial services? A qualitative study exploring barriers.**

Elke Rammant, Ghent University, Gent, Belgium

**5:19 pm – 5:35 pm (105.5) Standardizing Quality of life measures in the surgical Treatment of Obesity**

Claire de Vries, Brigham and Women’s Hospital, Patient-Reported Outcomes, Value & Experience (PROVE) Center, Boston, MA, United States



## Oral Session 106: Assessing Change in PROMs Nautilus 1, lower level

Session Chair: Joel Finkelstein, MD, Canada

**4:11 pm – 4:27 pm (106.1) The definition and investigation of the estimation of the Minimal Clinically Important Difference. Extension of the MIDIPRES model for the use of cross-sectional anchors.**

Antoine Vanier, Inserm U1246 SPHERE - University of Nantes, Nantes, France

**4:28 pm – 4:44 pm (106.2) A mixed methods approach to generate meaningful change estimates for the EORTC QLQ-MY20**

Emre Yucel, Amgen, Thousand Oaks, CA, United States

**4:45 pm – 5:01 pm (106.3) Challenges and learnings from using anchoring vignettes to explore health-related quality of life response behavior**

Janine Topp, University Medical Center Hamburg, Hamburg, Germany

**5:02 pm – 5:18 pm (106.4) Minimally Important Differences for EQ-5D instruments: A Systematic Review of Estimates in Published Literature**

Xuejing Jin, Alberta PROMs and EQ-5D Research and Support Unit (APERSU), School of Public Health, University of Alberta, Edmonton, Alberta, Canada

**5:19 pm – 5:35 pm (106.5) Identifying Responders to Treatment: An Example of Change in the Patient Reported Outcomes Measurement Information System (PROMIS®) Physical Functioning Scale**

Ron Hays, PhD, UCLA School of Medicine, Los Angeles, CA, United States

## Oral Session 107: E-Health and Mobile Apps Nautilus 2, lower level

Session Chair: Sonya Eremenco, MA, United States

**4:11 pm – 4:27 pm (107.1) Translating Clinical and Patient-Reported Data to Shared Decision Reports with Predictive Analytics**

Patricia Franklin, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

**4:28 pm – 4:44 pm (107.2) Reaching for 99% compliance in clinical and post marketing studies**

David Kiger, Datacubed Health, Brooklyn, NY, United States

**4:45 pm – 5:01 pm (107.3) Defining patient recovery following cancer surgery - assessing the feasibility and performance of daily ecological momentary assessments versus the SF-36.**

Lisa van den Berg, Patient-Reported Outcomes, Value & Experience (PROVE) Center at the Brigham and Women's Hospital, Boston, MA, United States

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

**5:02 pm – 5:18 pm (107.4) Validation of activity tracker data as a measure of fatigue, symptom burden, physical function and quality of life in adults receiving taxane therapy for treatment of stage I-III breast cancer**

Antonia Bennett, University of North Carolina, Chapel Hill, NC, United States

**5:19 pm – 5:35 pm (107.5) Novel Application of Natural Language Processing and Machine Learning Techniques to Analyze Qualitative Patient-Reported Outcomes Data: A Report from the PEPR Pediatric Cancer Survivorship Study**

Zhaohua Lu, Department of Biostatistics, St. Jude Children's Research Hospital, Memphis, TN, United States

## Oral Session 108: Social, emotional, behavioral, and developmental aspects of PROMs Nautilus 3, lower level

Session Chair: Tom Willgoss, PhD MSc BA, United Kingdom

**4:11 pm – 4:27 pm (108.1) Waiting in isolation: A qualitative patient researcher led study of the experience of patients waiting for elective surgery**

Marlyn Gill, PaCER Program, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

**4:28 pm – 4:44 pm (108.2) Shared-decision making and adherence: A systematic review and meta-analysis of RCT interventions**

Romualdo Ramos, Medical University of Vienna, Vienna, Austria

**4:45 pm – 5:01 pm (108.3) Evaluation of the Hubley Depression Scale for Older Adults as a screen for depressive disorders in cardiac patients**

Anita Hubley, University of British Columbia, Vancouver, British Columbia, Canada

**5:02 pm – 5:18 pm (108.4) Social difficulties are strongly associated with health-related quality of life (HRQOL) in patients with end stage kidney disease (ESKD)**

Istvan Mucsi, MD PhD, University Health Network, Toronto, Ontario, Canada

**5:19 pm – 5:35 pm (108.5) Considering adolescents as a unique age group: Implications for the design and implementation of Patient-reported outcomes (PROs) for use in adolescents**

Charlotte Panter, Adelphi Values Ltd, Bollington, United Kingdom

## 5:40 pm - 6:20 pm Tricks of the Trade Presentation Grande Ballroom AB, ground level

### How to develop a manuscript that will get published

Speakers

Jan R. Boehnke and Claudia Rutherford, PhD; co-editors-in-chief of *Quality of Life Research*

David Feeny, PhD and Dennis Revicki, PhD co-editors-in-chief of *Journal of Patient-Reported Outcomes*

Getting your manuscript published is exciting but involves many steps, from careful planning at the start of the study and attention to the objectives, research methods, measures, and statistical analysis during protocol development. We are lucky to have our esteemed editors from *Quality of Life Research* and *Journal of Patient-Reported Outcomes* discuss the critical steps that every scholar should take as he or she works to get their own work published. Topics covered in this session will range from articulating clear study objectives, developing a succinct writing style, and effectively conveying results through tables and figures. With an extended Tricks of the Trade session this year, we are sure to have a lively discussion!

Session is presented by the New Investigator SIG and intended for new investigators in the QOL field, however, all researchers are welcome!

## 5:35 pm - 6:30 pm Advisory Council of Past Presidents (closed event) Marina 6

## 6:30 pm - 7:30 pm Mentor/Mentee Reception Lanai Area/Shoreline

*Pre-registration required for the mentor/mentee reception*

The ISOQOL mentoring program promotes career development and provides in-person networking opportunities for students and new investigators within the Society during the Annual Conference. Individuals interested in serving as a mentor will be paired up with students and new investigators that have signed up for the program. This reception provides a forum for conversation, professional networking, and the exchange of knowledge in a relaxed atmosphere. Refreshments will be provided.

*In case of inclement weather, reception will be held in Harbor's Edge Restaurant on the ground level near the hotel lobby.*

Develop your career.

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Recruit Talent. 

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**7:00 am - 5:00 pm    Registration Desk Open    Bayview Foyer, ground level**

**7:30 am - 8:30 am    SIG Council Meeting (Closed Event)    Nautilus 1, lower level**

**7:30 am - 8:30 am    Roundtables (ticket required)**

*Roundtables are informal meetings, with up to nine participants, to network and discuss a select topic related to your work and field. A ticket is required for each roundtable which can be purchased during the registration process. Coffee will be provided.*

**RT01: How to peer review a paper .....Nautilus 4, lower level**

Hosts: David Feeny, PhD and Dennis Revicki, PhD, *Journal of Patient-Reported Outcomes* co-editors-in-chief

**RT02: Measuring Mindfulness and Related Constructs: Lessons Learned from an NCCIH-funded initiative, "COMMENCE" .....Nautilus 4, lower level**

Host: David Victorson, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

**RT03: Health utility measures for QALY construction .....Nautilus 4, lower level**

Host: Janel Hanmer, MD PhD, University of Pittsburgh, Pittsburgh, PA, United States

**RT04: Developing Clinical Outcome Assessments for Regulatory Purposes .....Nautilus 5, lower level**

Host: William Lenderking, PhD, Evidera, Bethesda, MD, United States

**RT05: Integrating patients as partners in clinical research: Perspectives from PCORI .....Nautilus 5, lower level**

Host: Jason Gerson, PhD, PCORI, Washington, D.C., United States

**RT06: Standardization of PROs and PROMs .....Nautilus 5, lower level**

Host: Caroline B. Terwee, PhD, VU, University Medical Center, Amsterdam, Netherlands

**8:40 am - 10:10 am    Plenary 3: Action: Theory, methods, and application related to achieving optimal patient-centered outcomes – lessons from Implementation Science.    Grande Ballroom AB, ground level**

*Sponsored By: Genentech*

ISOQOL member and conference attendees have made remarkable contributions to the field of patient-reported outcome measurement (PROMs). Increasingly more attention is being placed on implementing PROs in routine clinical practice. This plenary will provide a platform to discuss how patient-centered outcomes research and patient-centered care can be strengthened through Implementation Science.



Chair

David A. Chambers, D.Phil.

Speakers

**Carl May, PhD**, London School of Hygiene and Tropical Medicine, London, United Kingdom

**Karen Emmons, PhD**, Harvard T.H. Chan School of Public Health, Boston, MA, United States

**Amy M. Kilbourne, PhD MPH**, U.S. Department of Veterans Affairs, Washington, DC, United States

**10:10 am - 11:00 am    Refreshment Break and Exhibits Open    Grande Foyer, ground level**

**10:15 am - 10:55 am    Tuesday Poster Session I    Grande Ballroom C, ground level**

*Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.*

**(203) Decisional Regret in the first year after Hematopoietic Cell Transplantation**

Rachel Cusatis, Medical College of Wisconsin, Milwaukee, WI, United States

NEW INVESTIGATOR POSTER AWARD FINALIST

**(2005) Monte Carlo Simulations Evaluating the Impact of Missing Data on Between-Arm Comparisons on Summary Measures in Randomized Trials**

Gina L. Mazza, Mayo Clinic, Scottsdale, United States

NEW INVESTIGATOR POSTER AWARD FINALIST

## (2007) Validation of the McGill body image concerns scale for use in head and neck oncology

Ana Maria Rodriguez-Leboeuf, IQVIA, RWE Patient-Centered Endpoints, Montreal, Quebec, Canada

NEW INVESTIGATOR POSTER AWARD FINALIST

## Body Image and Body Satisfaction

(2009) *Withdrawn*

### (2011) Breast reduction surgery improves health-related quality of life in women with breast hypertrophy: a comparison to other surgical interventions

Tamara Crittenden, College of Medicine & Public Health, Flinders University, Bedford Park, Adelaide, Australia

### (2013) Patient-Reported Outcomes in Weight Loss and Body Contouring Surgery: The voice of 1831 patients using the BODY-Q

Lotte Poulsen, Department of Plastic Surgery, Odense University Hospital, Odense C, Denmark

### (2015) The Impact of Radiotherapy on Long-Term Satisfaction and Health Related Quality of Life in Post-mastectomy Breast Reconstruction – An Analysis of 3,265 Patients

Thais Polanco, Memorial Sloan Kettering Cancer Center, New York, NY, United States

### (2017) Normative Data for Interpreting the BODY-Q: Understanding the Value of Weight Loss Surgery

Danny Mou, MD, Brigham and Women's Hospital, Boston, MA, United States

## Caregivers

### (2019) Designing measures of communication ability in individuals with Angelman syndrome

Nicole Lucas, Duke University, Durham, NC, United States

### (2021) Quality of life in mothers of adolescents with chronic pain

Siv Skarstein, OsloMet – Oslo Metropolitan University, Oslo, Norway

### (2023) Quality of life of caregivers of children with Retinoblastoma

Vijaya Gothwal, L V Prasad Eye Institute, Hyderabad, India

### (2025) Training needs and preferences of caregivers reporting seizures in clinical trials

Nadeeka Dias, ERT, Boston, MA, United States

### (2027) The use of social media to capture parental and caregiver understanding of distress associated with fever in infants and young children

Adam Smith, Reckitt Benckiser, Hull, United Kingdom

### (2029) Quality of life (QOL) for parents of infant

Rika Hayashida, University of Nagasaki, Siebold, Nishisonogi-gun, Nagasaki, Japan

(2031) *Withdrawn*

## E-Health Routine Use of ePRO

### (2033) Impact of routine assessment of health related quality of life on the satisfaction with care and the health related quality of life of patients with head and neck cancer

Tienhan Sandrine Dabakuyo-Yonli, Epidemiology and Quality of Life Unit, Georges-François Leclerc Cancer Centre-UNICANCER, DIJON, France

### (2035) Feasibility of electronic reporting of patient-reported outcomes in a fragile and comorbid population during cancer therapy.

Gry Assam Taarnhøj, MD, Department of Oncology, Rigshospitalet, Copenhagen, Denmark

### (2037) Feasibility of Health-related quality of life (HRQoL) assessment for cancer patients using electronic patient-reported outcome (ePRO) in daily clinical practice: A French experience

Sophie Paget-Bailly, PhD, Methodological and Quality of Life Unit, University Hospital of Besançon, F-25000 Besançon, France

### (2039) Acceptability of electronic patient-reported outcomes (PRO) assessments among patients in HIV care

Rob Fredericksen, University of Washington, Seattle, WA, United States

### **(2041) Development and Feasibility of the Use of Electronic Symptom Self-reporting as a Tool for Intensified Disease Monitoring in Lung Cancer in Denmark**

Rasmus Blechingberg Friis, Department of Oncology, Regional Hospital West Jutland, Herning, Denmark

### **(2043) Integration of Patient-reported Outcome Measures in Routine Pediatric Asthma Care Using KidsPRO Program**

Sumedh Bele, University of Calgary, Calgary, Alberta, Canada

### **(2045) Implementing the KLIK PROM portal in transitional care**

Hedy van Oers, MSc, Amsterdam UMC, University of Amsterdam, Emma Children's Hospital, Psychosocial Department, Amsterdam, the Netherlands

**(2047) Withdrawn**

## Healthcare Providers

### **(2049) Quality of Life of the Brazilian Speech, Language and Hearing Sciences students: a study case in South Brazil.**

Roberta Alvarenga Reis, Federal University of Rio Grande do Sul, Porto Alegre-RS, Brazil

**(2051) Withdrawn**

### **(2053) Health Status and Quality of Life of Continuing Care Facilities Workers in Alberta – Canada**

Oluwagbohunmi Awosoga, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada

### **(2055) Public Health - The Voice of Professionals**

Pedro Lopes Ferreira, CEISUC/FEUC 504807285, Coimbra, Portugal

### **(2057) Satisfaction with the Quality of Work Life, according to the level of care in health care workers in Guadalajara, Mexico.**

Raquel González-Baltazar, University of Guadalajara UGU250907MH5, Guadalajara, Jalisco, Mexico

## Methodological Advances in Measure Development & Evaluation I

### **(2059) A novel IRTree Model for identifying extreme response styles using anchoring vignettes**

Molly McFatrigh, MPH, Duke University School of Medicine, Durham, NC, United States

### **(2061) Sample Size Estimation to Support Small Sample Research Designs**

Stacie Hudgens, Clinical Outcomes Solutions, Tucson, AZ, United States

### **(2063) What a difference a day makes: Assessing the impact of Daily Diary completion thresholds on psychometric properties and treatment effects**

Philip Griffiths, Adelphi Values, Bollington, Macclesfield, United Kingdom

**(2065) Withdrawn**

### **(2067) How long is needed to complete a computer adaptive test?: Item-level response time for PROMIS measures**

Rina Fox, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

### **(2069) Quality of Life Psychoperiscope**

Joshua Chiroma Gandhi, University of Jos, Jos, Plateau State, Nigeria

### **(2071) Testing the General Factor of Character Strengths: An Exploratory Bifactor Approach**

Wenjie Duan, Social and Public Administration School, East China University of Science and Technology, Shanghai, China

### **(2073) Measuring quality of health outcome goals using text mining techniques**

Maryam Mozafarina, McGill University, Montreal, Quebec, Canada

### **(2075) Identifying Emotion Symptom Clusters for Children using Multiple Statistical Approaches**

John Peipert, PhD, Department of Medical Social Sciences, Northwestern University, Chicago, IL, United States

### **(2077) Health-Related Quality of Life Measures: Are They Strong Enough to Identify Frailty?**

Mehmet Inceer, McGill University, Montréal, Quebec, Canada



**(2079) Assessing Health-Related Quality of Life (HRQoL) in patients before and after kidney transplantation: exploring measurement invariance using network analysis.**

Line Auneau-Enjalbert, UMR INSERM 1246 SPHERE-Hospital University of Nantes, Nantes, France

## Neurology II

**(2081) What is recovery?-The Perspective of Stroke Survivors**

Nancy Mayo, McGill University, Montreal, Quebec, Canada

**(2083) Assessment of quality of life in individuals with chronic headache. Psychometric properties of the WHOQOL-BREF**

Patrick Brzoska, Witten/Herdecke University, Faculty of Health, School of Medicine, Health Services Research, Witten, Germany

**(2085) Responder definition thresholds of the Migraine-Specific Quality of Life Questionnaire Version 2.1 domains for use in patients with episodic and chronic migraine**

Rebecca Speck, Evidera, Bethesda, MD, United States

**(2087) Educational Resources to Support Implementation of the Spinal Cord Injury-Quality of Life Instruments into Inpatient Rehabilitation**

Linda Ehrlich-Jones, Shirley Ryan AbilityLab, Chicago, IL, United States

**(2089) Cannabis use among individuals living with fibromyalgia**

Nalin Payakachat, BPharm MSc PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

**(2091) Mixed Methods: psychometrics for the development of patient-centered outcome measures in rare diseases: the example of Myasthenia Gravis symptom PROs**

Thomas Morel, UCB Biopharma, Brussel, Belgium

**(2093) The Rett Syndrome Burden of Illness Survey: Results from Cognitive Debriefing Interviews**

Nenad Medic, Parexel Access Consulting, London, United Kingdom

**(2095) Establishing clinical meaningfulness of the 9-Hole Peg Test in the measurement of upper limb impairment in individuals with Friedreich's Ataxia: A qualitative interview study**

Rohini Sen, PhD, Takeda Pharmaceuticals International, Inc., Cambridge, MA, United States

**(2097) Using person-centered PRO assessment to improve the quality of care for people with multiple sclerosis (MS)**

Cindy Nowinski, Northwestern University, Chicago, IL, United States

**(2099) Towards Developing an Ontology for Mobility among Individuals with Acquired Brain Injury (ABI)**

Rehab Alhasani, McGill University, Montreal, Quebec, Canada

## Prostate Cancer

**(2101) *Withdrawn***

**(2103) Distance from exercise centre and ethnicity associated with likelihood of engaging with a hospital-based, structured, group exercise programme for men with prostate cancer in real world data**

Louis Fox, King's College London, London, United Kingdom

**(2105) Comparison of urinary toxicity between patient reported outcomes and physician evaluation in high risk prostate cancer treated with radiotherapy and hormonal therapy: data from a Phase III Trial**

Abdenour Nabid, Centre Hospitalier Universitaire de Sherbrooke, Sherbrooke, Quebec, Canada

**(2107) The treatment and supportive care needs of men with prostate cancer receiving radiation therapy**

Ellie Tsiamis, Monash University, Melbourne, Australia

## Response Shift

**(2109) The long and short of patient-centered assessment: A head-to-head comparison of two measures of appraisal designed for practical use**

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

**(2111) Response shift recalibration profiles in cancer patients: association between coping and profile change**

Mohamed Boucekine, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France

(2113) Validation of a Guttman's Errors based method to detect Response Shift (GERS) at an individual level

Jean-Benoit Hardouin, PhD, INSERM UMR 1246-SPHERE "methodS in Patients reported outcomes and HHealth ResEarch", Nantes, France

## 11:00 am - 12:15 pm Concurrent Symposium Sessions

**Symposium 1:** Unbiased Treatment Effect and Meaningful Change Detection in the Presence of PRO Missing Data: Updating historical practices to improve oncology outcomes  
Grande Ballroom AB, ground level

Sponsored by: *Pharmerit International*

Moderator:

**John Fastenau, PhD**, Janssen, Raritan, NJ, United States

Discussant:

**Scott Komo, DrPH**, US FDA, Silver Spring, MD, United States

Individual Presenters:

**Compliance Rules in Daily Diary Data: Avoiding Reductions in Power and Treatment Efficacy Bias**

**R. J. Wirth, PhD**, Vector Psychometric Group, LLC, Chapel Hill, NC, United States

**Estimating meaningful change in the context of covariate-dependent drop-out**

**Daniel Serrano, PhD**, Pharmerit International, Bethesda, MD, United States

**PROs in Survival Analysis and Detection of Treatment Efficacy**

**Charles Iaconangelo, PhD**, Pharmerit International, Brooklyn, NY, United States



**Symposium 2:** Value-Based Health Care and Outcomes Research; a Short Bridge to Close a Long Gap  
Nautilus 1, lower level

Moderator:

**Katrin Conway**, Mapi Research Trust, Lyon, France

Individual Presenters:

**Use of Patient-Reported Outcome Measures (PROMs) to Evaluate Quality of Care: Challenges and Opportunities**

**Sarah Clifford**, ICON, Los Angeles, CA, United States

**Creating a Standard Set of Outcome Measures for Celiac Disease: the role of COAs across contexts**

**Daniel Leffler, MD**, Takeda Pharmaceuticals, Newton, MA, United States

**ICHOM's methodology for the development and implementation of standard sets to improve quality of care**

**Mona Khalid, BSc (Hons) MSc PhD**, ICHOM, London, United Kingdom

**Sizing the gap and designing the bridge: initial recommendations**

**Benoit Arnould, PhD**, ICON, Lyon, France

**Symposium 3:** "Tell me more": Qualitative and quantitative methods for eliciting supplementary data regarding patient experiences during clinical trials and observational studies  
Nautilus 2, lower level

Moderator:

**Linda Nelsen, MHS**, GlaxoSmithKline, Collegeville, PA, United States

Individual Presenters:

**Listening to the patient: The application and value of qualitative research for gathering patient insights during drug development and evaluation**

**Adam Gater**, Adelphi Values, Macclesfield, United Kingdom

**Challenges, considerations and solutions for implementation of qualitative interviews within clinical research studies: learnings from applications in a range of therapeutic areas**

Linda Nelsen, MHS, GlaxoSmithKline, Collegeville, PA, United States

**“Was it worth it?”: Use of the Patient’s Qualitative Assessment of Treatment (PQAT) to explore direct patients’ experience of drugs received during clinical studies**

Aude Roborel de Climens, PhD, Sanofi, Lyon, France

**Development of a patient-reported questionnaire to measure patient experiences of participating in clinical trials**

Stephanie Manson, PhD, Novartis, East Hanover, NJ, United States

**Symposium 4: Novel approaches and solutions to the challenges of measuring health-related domains and concepts across children of a range of ages Nautilus 3, lower level**

Moderator:

Nalin Payakachat, University of Arkansas for Medical Sciences, Little Rock, AR, United States

Individual Presenters:

**Measuring complex experiences of health-care: the development of an innovative child-reported experience measure using participatory design.**

Malin Berghammer, PhD, Department of Paediatrics, Queen Silvia Children’s Hospital, Gothenburg, Sweden

**Innovative pediatric clinical outcome assessment (COA) administration and reporting strategies**

Diane Turner-Bowker, PhD, Adelphi Values, Boston, MA, United States

**Potential of Behavioral Data as Indicator of Quality of Life and Well-Being in Children: A Longitudinal and Naturalistic Study**

Holger Muehlan, PhD, University of Greifswald, Greifswald, Germany

**Computerised adaptive testing accurately predicts CLEFT-Q scores by selecting fewer, more patient-focused questions.**

Conrad Harrison, University of Oxford, Oxford, United Kingdom

**12:15 pm - 2:00 pm Buffet lunch (conference badge required) Grande Foyer/Bayview Lawn\***

12:15 pm ..... First Lunch Shift

1:10 pm ..... Second Lunch Shift

The conference registration fee includes a buffet lunch served in the Grande Foyer on the ground level. Seating is available in the outdoor Bayview Lawn (\*in inclement weather, the Nautilus Foyer plus Nautilus 4 & 5 will be utilized.) Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. *Entry to the buffet is by name badge.*

**12:20 pm - 1:20 pm Current Funding Opportunities in QOL Research Grande Ballroom AB, ground level**

This session features speakers from government and private funding organizations who will present in an effort to increase awareness of upcoming funding opportunities and to provide guidance regarding successful applications. Each speaker will give an eight minute presentation with time for a question and answer session from the audience.

**12:20 pm - 1:20 pm Special Interest Group (SIG) Meetings**

- Child Health SIG ..... Marina 5, ground level
- Health Preference Research SIG ..... Marina 6, ground level
- Industry SIG ..... Nautilus 2, lower level
- Mixed Methods SIG ..... Nautilus 1, lower level
- Patient Engagement SIG..... Nautilus 3, lower level

## 2:00 pm - 3:30 pm Concurrent Oral Briefs

Presenting authors indicated. The full author listing is available in the *Quality of Life Research* journal supplement.

Oral briefs offer the distinct opportunity to give a short verbal presentation in a group setting. After a personal introduction by the moderator, each speaker has 5-7 minutes to present using four slides (maximum). While the rapid pace of oral briefs does not allow for audience Q&A within the session, presenters are encouraged to stay after the conclusion of the session to make themselves available for questions.

### Oral Brief B201: Patient-centered outcomes Grande Ballroom AB, ground level

Brief Chair: Cindy Nowinski MD PhD, United States

#### 2:05 pm – 2:13 pm (B201.1) Content and face validity of a nephrology PRO questionnaire used as a decision aid in clinical practice

Birgith Grove, PhD student, AmbuFlex, Herning, Denmark

#### 2:13 pm – 2:21 pm (B201.2) Development of a Questionnaire to Assess Worry about Affording Healthcare in an International Sample

Salene Jones, Fred Hutchinson Cancer Research Center, Seattle, WA, United States

#### 2:21 pm – 2:29 pm (B201.3) Identifying trigger items from the Patient Roles and Responsibilities Scale

Lesley Fallowfield, University of Sussex, Brighton, United Kingdom

#### 2:29 pm – 2:37 pm (B201.4) Quality of life (QoL) for people with rare diseases: Challenges and examples from a study pre-testing the UK-PSC-QoL, a provisional QoL tool for people with primary sclerosing cholangitis (PSC) in the UK

Elena Marcus, MSc, University College London, London, United Kingdom

#### 2:37 pm – 2:45 pm (B201.5) Responsiveness of standard spine outcome tools: Do they measure up?

Joel Finkelstein, MD, Sunnybrook HSC, Toronto, Ontario, Canada

#### 2:45 pm – 2:53 pm (B201.6) FDA Analysis: Relationship between time-to-deterioration in cough, dyspnea, and/or pain in chest to clinical endpoints in non-small cell lung cancer (NSCLC) trials

Jonathon Vallejo, FDA, North Bethesda, MD, United States

#### 2:53 pm – 3:01 pm (B201.7) A Prospective, Randomized Trial of Patient-Reported Outcome Measures to Drive Management Decisions in Oncology

Joselle Cook, Mayo Clinic, Rochester, MN, United States

#### 3:01 pm – 3:09 pm (B201.8) Patient Reported Outcome Measures (PROMs) in Pancreatic Cancer: A Systematic Review

Ashika Maharaj, Monash University, Melbourne, Australia

#### 3:09 pm – 3:17 pm (B201.9) FDA overview of statistical analysis of patient-reported outcomes in lung cancer clinical trials approved between January 2008 and December 2017

Mallorie Fiero, U.S. Food and Drug Administration, Silver Spring, MD, United States

#### 3:17 pm – 3:25 pm (B201.10) Assessing how a child with cancer functions using patient-reported and objective physical activity data

Molly McFatrach, Duke University School of Medicine, Durham, NC, United States

### Oral Brief B202: Observational Studies Nautilus 1, lower level

Brief Chair: Lotte Haverman, PhD, Netherlands

#### 2:05 pm – 2:13 pm (B202.1) Pain interference and influencing factors in Chinese children with cancer

Lei Cheng, School of Nursing, Fudan University, Shanghai, China

#### 2:13 pm – 2:21 pm (B202.2) The disruptiveness of itchiness: the impact of one symptom on quality of life in psoriasis

Vanina L. Taliercio, Department of Dermatology, University of Utah, Salt Lake City, UT, United States

#### 2:21 pm – 2:29 pm (B202.3) Characteristics of Highly-Symptomatic Atrial Fibrillation Patients in Clinical Practice: Results: from the Utah mEval Program.

Brian Zenger, University of Utah, Salt Lake City, UT, United States

**2:29 pm – 2:37 pm (B202.4) Research Designs for Optimizing Data Collected from Multiple Sources in Real-World Populations**

Stacie Hudgens, Clinical Outcomes Solutions, Tucson, AZ, United States

**2:37 pm – 2:45 pm (B202.5) The Magnitude of Proxy-Introduced Bias across Eight Domains of Health**

Brittany Lapin, Cleveland Clinic, Cleveland, United States

**2:45 pm – 2:53 pm (B202.6) Examining the impact of different data collection modes for patient-reported outcome measures**

Ellie Tsiamis, Monash University, Melbourne, Australia

**2:53 pm – 3:01 pm (B202.7) Birth weight and quality of life in midlife: A 50-year follow-up study of 2,079 individuals in Denmark**

Emilie Rune Hegelund, University of Copenhagen, Copenhagen, Denmark

**3:01 pm – 3:09 pm (B202.8) Associations of personality with quality of life and satisfaction with life in a longitudinal study with 30-year follow-up**

Cathrine Lawaetz Wimmelmann, University of Copenhagen, Copenhagen, Denmark

**3:09 pm – 3:17 pm (B202.9) Residual Effects and Complications of Health Following Thrombotic Thrombocytopenic Purpura (TTP)**

Deirdra Terrell, University of Oklahoma Health Sciences Ctr, Oklahoma City, OK, United States

**3:17 pm – 3:25 pm (B202.10) Acceptability of patient-reported outcomes in electronic documentation of health data: Patients' perspective**

Toni Maria Klein, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

**Oral Brief B203: Intervention Studies and Beyond Nautilus 2, lower level**

Brief Chair: Paivi Miskala, MSPH PhD, United States

**2:05 pm – 2:13 pm (B203.1) "You know it's not just a waste of time, somebody's looking at it." Patient engagement with online symptom reports during chemotherapy (eRAPID) – The importance of clinician use of data**

Galina Velikova, MD PhD FRCP, University of Leeds, Leeds, United Kingdom

**2:13 pm – 2:21 pm (B203.2) Improvements in quality of life in patients attending chiropractic care: the use of the PROMIS-29 and PROMIS global health**

Joel Alcantara, The International Chiropractic Pediatric Association, Los Gatos, CA, United States

**2:21 pm – 2:29 pm (B203.3) Advance care planning in patients with advanced cancer: results from the European 6 country, cluster-randomized ACTION trial**

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

**2:29 pm – 2:37 pm (B203.4) Patient Reported Outcome (PRO) in the monitoring of adverse events in patients receiving immunotherapy for melanoma – a randomized clinical trial**

Lærke K. Tolstrup, Odense University Hospital, Odense, Denmark

**2:37 pm – 2:45 pm (B203.5) Designing a PRO Feedback Report for patients after knee arthroplasty - simplicity for better comprehensibility**

Kathrin Fischer, MSc, Charité Universitätsmedizin Berlin, Berlin, Germany

**2:45 pm – 2:53 pm (B203.6) Establishing anchor-based minimally important differences (MID) for the EORTC QLQ-C30 scales across multiple cancer sites**

Jamme Z. Musoro, European Organisation for Research and Treatment of Cancer, Brussels, Belgium

**2:53 pm – 3:01 pm (B203.7) Understanding Patient Preference of ePRO Screen Display and Features**

Jenny J. Ly, ERT, Boston, MA, United States

**3:01 pm – 3:09 pm (B203.8) Differences between Self- and Proxy-Reported Health Utilities in the Pediatric Populations: A Systematic Review and Meta-Analysis**

Minghui Li, PhD, University of Tennessee Health Science Center, Memphis, TN, United States



**3:09 pm – 3:17 pm (B203.9) Enablers and barriers to implementing patient-reported outcome measures (PROMs) in clinical settings: a meta-review of reviews**

Claudia Rutherford, PhD, The University of Sydney, Sydney, NSW, Australia

**3:17 pm – 3:25 pm (B203.10) Impact of a smartphone application on health-related quality of life for adolescents and young adults with cancer.**

Helle Pappot, Rigshospitalet, University Hospital of Copenhagen, Copenhagen, Denmark

## Oral Brief B204: Measurement Approaches Nautilus 3, lower level

Brief Chair: Frances Yang, PhD, United States

**2:05 pm – 2:13 pm (B204.1) Assessing the engagement of children and families in selecting patient-reported outcomes (PROs) and developing their measures (PROMs)**

Samantha Noyek, MSc, Queen's University, Kingston, Ontario, Canada

**2:13 pm – 2:21 pm (B204.2) Understanding the Patient Experience in Follicular Lymphoma (FL), Relapsed/Refractory FL (R/R FL), and Relapsed/Refractory Diffuse Large B-Cell Lymphoma (R/R DLBCL)**

Dasha Cherepanov, PhD, Millennium Pharmaceuticals, Inc., a wholly owned subsidiary of Takeda Pharmaceutical Company Limited, Cambridge, MA, United States

**2:21 pm – 2:29 pm (B204.3) Using Item Response Theory to construct a health classification system and select health states for valuation for the Preference-Based Index from the Recovering Quality of Life (ReQoL) outcome measure**

Anju Keetharuth, PhD, University of Sheffield, Sheffield, United Kingdom

**2:29 pm – 2:37 pm (B204.4) Health benefits of new cycle-path construction: Cost-effectiveness analysis with a Markov model**

Admassu N. Lamu, PhD, University of Bergen, Bergen, Norway

**2:37 pm – 2:45 pm (B204.5) Does knowledge of treatment assignment affect patient-reported outcomes? An evaluation of open-label bias in multiple myeloma**

Jessica Roydhouse, PhD, US Food and Drug Administration, Silver Spring, United States

**2:45 pm – 2:53 pm (B204.6) The validity and responsiveness of the EORTC QLU-C10D and HUI-3 in colorectal cancer patients**

Helen Mctaggart-Cowan, PhD, Faculty of Health Sciences, Simon Fraser University, Burnaby, British Columbia, Canada

**2:53 pm – 3:01 pm (B204.7) Psychometric evaluations of the 15-item geriatric depression scale and recommendations for the adoption of a shortened version.**

Mian Wang, PhD, Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC, United States

**3:01 pm – 3:09 pm (B204.8) Mapping Expanded Prostate Cancer Index Composite to EQ-5D Utility Weights to Inform Economic Evaluations in Prostate Cancer: Secondary Analysis of NRG/RTOG 0415**

Rahul Khairnar, MS, BPharm, University of Maryland, Baltimore, Baltimore, MD, United States

**3:09 pm – 3:17 pm (B204.9) Timing of patient-reported outcome assessment of transient symptomatic toxicities from cancer treatment seem to matter - findings from a Nordic phase II trial in relapsed multiple myeloma patients**

Henrik Rode Eshoj, PhD, Quality of Life Research Center, Department of Hematology, Odense University Hospital and OPEN Odense Patient data Explorative Network, Odense University Hospital, Odense, Denmark

**3:17 pm – 3:25 pm (B204.10) The agreement of pain relief responders defined by various pain severity items from the Brief Pain Inventory**

Qiuling Shi, PhD, University of Texas MD Anderson Cancer Center, Houston, United States

## 3:30 pm - 4:20 pm Refreshment Break and Exhibits Open Grande Foyer, ground level

## 3:35 pm - 4:15 pm Tuesday Poster Session II Grande Ballroom C, ground level

Presenting authors indicated. The full author listing is available in the *Quality of Life Research* journal supplement.

### **(2004) Examining content validity of BREAST-Q a decade later to determine relevance and comprehensiveness**

Manraj Kaur, PT MSc PhD(c), McMaster University, Hamilton, Ontario, Canada

STUDENT POSTER AWARD FINALIST

### **(2006) Shared care follow-up of patients with B-cell neoplasias based on tele-care solution and PRO-Data: A feasibility study from the North Denmark Region**

Mia Sommer, RN MHS PhD student, Department of Hematology, Aalborg, Denmark

STUDENT POSTER AWARD FINALIST

### **(2008) The development of New BODY-Q scales to Measure Outcomes for Patients undergoing Weight Loss surgery**

Claire de Vries, PhD, Brigham and Women's Hospital, Patient-Reported Outcomes, Value & Experience (PROVE) Center, Boston, MA, United States

STUDENT POSTER AWARD FINALIST

## Elders/Older Adults

### **(2010) Development of a short version of Social Provisions Scale for community-dwelling elderly individuals: an item response theory approach.**

Junko Sakano, Okayama Prefectural University, Okayama, Japan

### **(2012) The use of PROMIS Physical Function scores to predict response to physical therapy intervention in older adults.**

Anne Thackeray, University of Utah, Salt Lake City, UT, United States

### **(2014) The association between sleep disorders, health-related quality of life, and healthcare resource utilization for patients with a disability**

Dana Drzayich Antol, Humana Healthcare Research, Cleveland, OH, United States

### **(2016) Measuring Symptom Burden in Geriatric Oncology with MD Anderson Symptom Inventory (MDASI) in Chinese Cancer Patients and Survivors**

Qiuling Shi, PhD, MDACC, Houston, TX, United States

### **(2018) *Withdrawn***

### **(2020) Psychometric properties of a Health-Related Quality of Life Measure of Well-Being in the National Health and Aging Trend Study**

Frances Yang, Medical College of Georgia, Kansas City, United States

## Engaging Stakeholders Measure Development and Use

### **(2022) *Withdrawn***

### **(2024) Patients' Preferences of Patient Reported Outcomes Symptom Measurement**

Meagan Whisenant, The University of Texas MD Anderson Cancer Center, Houston, United States

### **(2026) The role of context and label in participants' quantitative interpretation of common quality of life PROM response options**

Philip Powell, University of Sheffield, Sheffield, United Kingdom

### **(2028) Bringing patients and health researchers closer together: patient involvement in a study on patient-reported outcomes in cancer consultations**

Pernille Skovlund, PhD student, Experimental Clinical Oncology, Department of Oncology, Aarhus University Hospital, Aarhus N, Denmark

### **(2030) Measuring What Matters: Developing a Patient-Centered Engagement Rubric for Quality Measurement**

Patrick Campbell, PharmD PhD, Pharmacy Quality Alliance, Alexandria, VA, United States

### **(2032) What aspects of health and quality of life are important to people?**

Mathieu Janssen, PhD, Section Medical Psychology and Psychotherapy, Erasmus MC, Rotterdam, Netherlands

### **(2034) Application of patient-centric methods in clinical outcomes assessment research; patient feedback from a qualitative interview study in Crohn's disease**

Helen Kitchen, MSc, DRG Abacus, Manchester, United Kingdom

### **(2036) Alignment of Various Healthcare Experience Surveys with Newly Developed Patient-Centered Quality Indicators (PC-QIs)**

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

### **(2038) Methods, value and application of Delphi panels in rare disease populations: a case study overview**

Nicola Williamson, Adelphi Values Ltd, Bollington, United Kingdom

## General Cancer

### **(2040) Content comparison of unmet needs self-report measures used in patients with head and neck cancer (HNC): a systematic review**

Chindhu Shunmuga Sundaram, The University of Sydney, Sydney, NSW, Australia

### **(2042) Phase III development of an EORTC QOL cancer survivorship assessment strategy: pretesting of provisional questionnaires**

Lonneke Van de Poll-Franse, PhD, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands

### **(2044) Seeking a Mutual Understanding of Health-Related Quality of Life Domains: Mapping the EORTC QLQ-C30 onto the WHO-ICF**

Claire Piccinin, EORTC, Brussels, Belgium

### **(2046) Understanding and Acceptability of the MD Anderson Symptom Inventory in Patients with Cancer**

Loretta A. Williams, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

### **(2048) Assessment of Financial Toxicity in Cancer Patients and Survivors: A Scoping Review of Patient-Reported Outcome Measures (PROMs)**

Caitlin Biddell, University of North Carolina at Chapel Hill, Gillings School of Global Public Health, Chapel Hill, NC, United States

### **(2050) "Was it worth it?" as a novel, patient-centered metric of the tolerability of cancer therapy**

Gita Thanarajasingam, Division of Hematology, Mayo Clinic, Rochester, MN, United States

### **(2052) Health information Need Correlated with Quality of Life among Cancer Patients Receiving Chemotherapy: A cross-sectional study in Egypt**

Naglaa Youssef, College of Nursing, Princess Nourah bint Abdulrahman, Riyadh, Saudi Arabia

### **(2054) Development of standard EORTC CAT Core short forms**

Morten Petersen, The Research Unit, Department of Palliative Medicine, Bispebjerg og Frederiksberg Hospital, Copenhagen NV, Denmark

### **(2056) Non-small cell lung cancer: Insights into patient and caregiver experiences**

Susan Jones, Janssen Pharmaceuticals, Inc, Titusville, NJ, United States

### **(2058) Are the quality of life structures different in cancer patients with different levels of severity?**

Yoshimi Suzukamo, Tohoku University, Sendai, Japan

### **(2060) Measurement of outcomes perceived by patients (PRO) with cancer through the EORTC QLQ C30 in Colombia**

Martin Romero, Grupo Proyectame, Bogota, Colombia

### **(2062) Evaluating the use of patient-reported outcome measures for improving inter-rater reliability of common terminology criteria for adverse event ratings**

Bernhard Holzner, Medical University of Innsbruck, Innsbruck, Austria

### **(2064) Long-term Patient Reported Outcomes following Post-mastectomy Breast Reconstruction: An 8-year Examination of 3,268 Patients**

Meghana Shamsunder, Memorial Sloan Kettering Cancer Center, New York, NY, United States

## Pediatrics and Young Adults II

**(2066) Measuring quality of life in Duchenne muscular dystrophy (DMD): A systematic review of content and structural validity using COSMIN**

Jill Carlton, University of Sheffield, Sheffield, United Kingdom

**(2068) The development of an observer-reported outcome (ObsRO) measure to assess the signs and impact of fever distress in infants and young children**

Adam Smith, Reckitt Benckiser, Hull, United Kingdom

**(2070) Parental illness, life satisfaction and the influence of class-mate relationships**

Sanne Ellegaard Jørgensen, University of Southern Denmark Department: Danish National Institute of Public Health, Copenhagen, Denmark

**(2072) So, tell me about your item bank: Characterizing PROMIS pediatric item banks to better inform computer adaptive testing and short form administration.**

Michael Kallen, Northwestern University, Missouri City, United States

**(2074) Validation of Patient Reported Outcome Measurement Information System (PROMIS) measures for children with type 1 diabetes**

Ashima Singh, Medical College of Wisconsin, Milwaukee, WI, United States

**(2076) Overcoming Measurement Challenges in Rare Diseases: An Example from the Development of the Heck-Laurin Pediatric Multiple Sclerosis Index (PedsMSI)**

Nikki Ow, McGill University, Montreal, Quebec, Canada

**(2078) Nonrestorative Sleep was Associated with Quality of Life in Chinese Adolescents**

Daniel Fong, The University of Hong Kong, Hong Kong, Hong Kong

**(2080) *Withdrawn***

**(2082) Validation of the pediatric Patient-Reported Outcomes Measurement Information System (PROMIS®) Fatigue, Sleep-Related Impairment and Sleep Disturbance Item banks in the general Dutch population.**

Michiel Luijten, MSc, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Psychosocial Department, Amsterdam, Netherlands

**(2084) Responsiveness of PROMIS® Pediatric measures to changes in health-related quality of life among children and adolescents undergoing treatment for cancer.**

Courtney M. Mann, Duke University School of Medicine, Durham, NC, United States

**(2086) PRO Assessment in Brazil - A scoping review on the adoption of the DISABKIDS® methodology for translation and validation of PROs instruments**

Beatriz Conacci, Bachelor, Department of General and Specialized Nursing, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil

**(2088) Keeping a PRO Instrument Alive – The International Pediatric DISABKIDS Initiative**

Monika Bullinger, Prof. Dr., University Hospital Hamburg Eppendorf, Hamburg, Germany

**(2090) Implementing the AQOL-MHS in clinical practice: getting from bedside to bedside**

Ligia M. Chavez, University of Puerto Rico, San Juan, Puerto Rico

## Rheumatic and Orthopedic Conditions

**(2092) Stressful Life Events are Common in the Year Prior to RA Onset and are Associated with Worse Symptoms and QOL**

Nicole Andersen, McGill University, Montreal, Quebec, Canada

**(2094) Interrelationship among physical activity pattern, self-reported fatigue, pain and quality of life in female older adults being managed for knee osteoarthritis**

Omoyemi Ogwumike, PhD, UNIV. OF IBADAN, Ibadan, Nigeria

**(2096) *Withdrawn***

**(2098) A Mixed Methods psychometrics program for the development of a measure of Fatigue in SLE**

Thomas Morel, UCB Biopharma, Brussels, Belgium

## **(2100) Derivation via Scoring Service of PROMIS® Fatigue Scores Based on FACIT-Fatigue Scores from Phase 3 trials with Sarilumab for the Treatment of Rheumatoid Arthritis (RA)**

Clifton Bingham III, Johns Hopkins University, Baltimore, MD, United States

**(2102) Withdrawn**

## **(2104) Testing for Response Shift at the Population Level in a Canadian Longitudinal Cohort Study**

Lisa Lix, University of Manitoba, Winnipeg, Manitoba, Canada

## **(2106) What is behind the “mobility” dimension of the EQ-5D? An exploratory analysis in patients following total hip/knee replacement**

Xuejing Jin, School of Public Health, University of Alberta, Edmonton, Alberta, Canada

## **(2108) Usage and content comparison of outcome measures used to evaluate outcome of total shoulder arthroplasty: A structured review with ICF-linking**

Ze Lu, Roth|McFarlane Hand & Upper Limb Centre, St Joseph's Hospital London care, London, Ontario, Canada

## **(2110) Content validity and feasibility of frequently used health-related quality of life measures in older people with hip fracture: a qualitative study**

Magdalena Brandl, Medical Sociology, University of Regensburg, Regensburg, Germany

**(2112) Withdrawn**

## **(2114) Reliability of a specific questionnaire to evaluate the quality of life in people with knee and hip osteoarthritis in Colombia**

Eliana-Isabel Rodríguez-Grande, MSc. Physical therapist, Escuela de Medicina y Ciencias de la Salud, Universidad del Rosario, Bogota, Colombia

### **4:20 pm - 5:50 pm Concurrent Oral Sessions**

*Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.*

#### **Oral Session 205: Validation of New and Existing Measures**

**Grande Ballroom AB, ground level**

Session Chair: David Eton, PhD, United States

#### **4:26 pm – 4:42 pm (205.1) International validation of the updated EORTC module for assessing quality of life in patients with lung cancer**

Michael Koller, University Hospital Regensburg, Regensburg, Germany

#### **4:43 pm – 4:59 pm (205.2) Measuring function: Introducing the EORTC QLQ-F17 Core Function Questionnaire**

Mogens Groenvold, University of Copenhagen, Copenhagen, Denmark

#### **5:00 pm – 5:16 pm (205.3) Development of a new measure of health literacy: Preliminary results of item analysis**

Jacek Kopec, University of British Columbia, Vancouver, British Columbia, Canada

#### **5:17 pm – 5:33 pm (205.4) Confirmatory Factor Analyses and Measurement Invariance of the Patient Experience with Treatment and Self-management (PETS vs. 2.0)—a measure of treatment burden**

Minji Lee, Mayo Clinic, Rochester, MN, United States

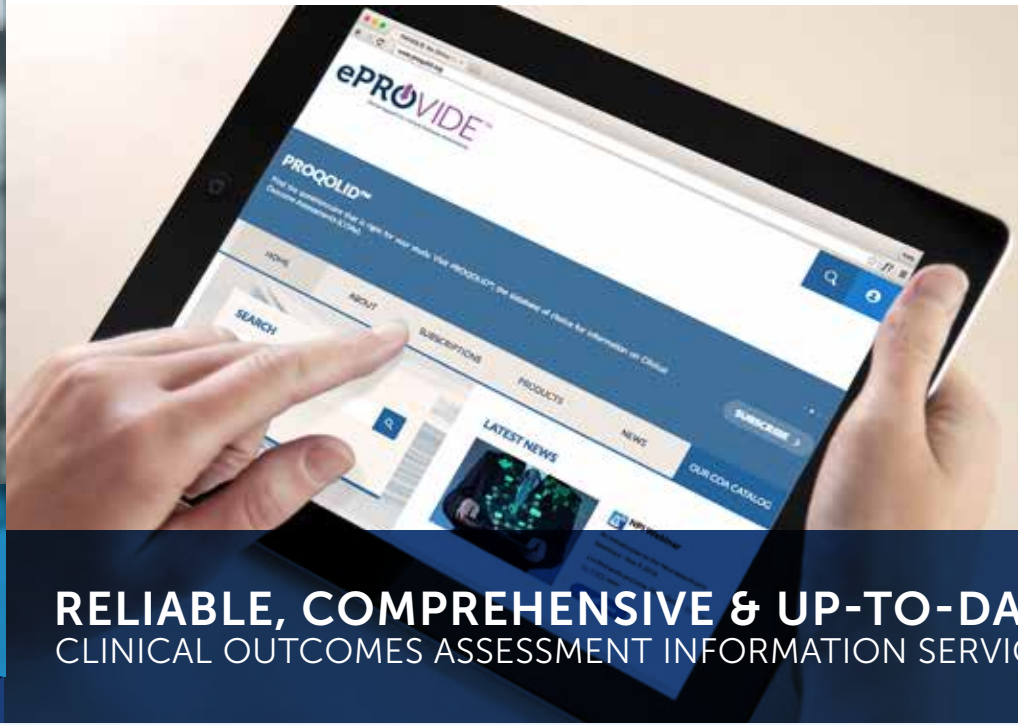
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#### **5:34 pm – 5:50 pm (205.5) Measurement characteristics of PROMIS Computer Adaptive Testing (CAT) and ESASr to assess fatigue in Kidney Transplant Recipients**

Sumaya Dano, University of Toronto, Toronto, Ontario, Canada

STUDENT ORAL PRESENTATION AWARD FINALIST





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**Oral Session 206: Engaging Stakeholders Nautilus 1, lower level**

Session Chair: Hilary Wilson, PhD, United States

**4:26 pm – 4:42 pm (206.1) Partnering with Patients/Parent Partners and Stakeholders on Development of Live Yes Insights – an online personal health record to track arthritis-related Patient Reported Outcomes longitudinally**

Karen Schifferdecker, Dartmouth College, Lebanon, NH, United States

**4:43 pm – 4:59 pm (206.2) Optimising Patient and Public Involvement in Patient Reported Outcome Measure (PROM) development**

Jill Carlton, University of Sheffield, Sheffield, United Kingdom

**5:00 pm – 5:16 pm (206.3) Patient-reported outcome measures in the encounter between patient and clinician – a multi-perspective qualitative study**

Caroline Mejdahl, AmbuFlex/WestChronic, Regional Hospital West Jutland, Herning, Herning, Denmark

**5:17 pm – 5:33 pm (206.4) Early cancer detection on reserve: An indigenous led peer to peer qualitative study of the experience of people living within an Indigenous community with their cancer diagnoses and treatment**

Tawnya Crowshoe, PaCER Program, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

**5:34 pm – 5:50 pm (206.5) Building Effective Patient Engagement In Drug Development: An example Based On People With MS Collaborating With A Pharmaceutical Company**

Paul Kamudoni, Global Evidence & Value Development, Merck Healthcare KgaA, Darmstadt, Germany

**Oral Session 207: Large Scale Implementation Nautilus 2, lower level**

Session Chair: Sandy Mitchell, PhD CRNP AOCN, United States

**4:26 pm – 4:42 pm (207.1) Clinical use of PROs in cancer care and related staff attitudes at 18 U.S. cancer centers**

Tenbroeck Smith, American Cancer Society, Atlanta, GA, United States

**4:43 pm – 4:59 pm (207.2) Implementing a Successful Large Scale Patient Reported Outcomes Program**

Rachel Sisodia, Massachusetts General/Partners Healthcare, Boston, MA, United States

**5:00 pm – 5:16 pm (207.3) Development of a Veteran-Centered Measure of Healthcare Engagement**

Benjamin Schalet, Northwestern Feinberg School of Medicine, Chicago, IL, United States

**5:17 pm – 5:33 pm (207.4) Optimizing Workflows in the Patient Portal to Collect the Patient Health Questionnaire for Clinical Practice**

Courtney Segal, University of Washington, Seattle, WA, United States

**5:34 pm – 5:50 pm (207.5) Practical guidelines for the electronic implementation of Patient-Reported Outcomes (PROs)**

Caroline Anfray, Mapi Research Trust, Author Collaboration, Lyon, France

**Oral Session 208: Methodological Investigations Nautilus 3, lower level**

Session Chair: Susan Bartlett, PhD, Canada

**4:26 pm – 4:42 pm..... (208.1) New complementary perspectives for inpatient physical function assessment: Matched patient-reported and clinician-reported short-form measures from the PROMIS Adult Physical Function Item Bank.**

Michael Kallen, Northwestern University, Missouri City, United States

**4:43 pm – 4:59 pm (208.2) Patient-initiated versus fixed-interval patient-reported outcome-based follow-up in outpatients with epilepsy: a pragmatic randomized controlled trial**

Liv Marit Valen Schougaard, AmbuFlex/WestChronic, Herning, Denmark

**5:00 pm – 5:16 pm** (208.3) **Development of a Composite Scoring Algorithm for the National Cancer Institute's Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)**

Amylou C Dueck, PhD, Alliance Statistics and Data Center, Mayo Clinic, Scottsdale, AZ, United States

**5:17 pm – 5:33 pm** (208.4) **Using PROs in clinical trials: what should I know about "estimands"?**

Rachael Lawrance, Adelphi Values, Bollington, United Kingdom

**5:34 pm – 5:50 pm** (208.5) **Using latent class models to examine heterogeneity in response shift**

Richard Sawatzky, Trinity Western University, Langley, British Columbia, Canada

**6:30 pm – 10:30 pm** **Experience San Diego Social Event (ticket required)**

**USS Midway Museum**

The USS Midway is a retired US Navy aircraft carrier that is now permanently docked in San Diego, and serves as a naval aviation museum. Attendees have the unique opportunity to experience what it was like to live and work on a Navy ship, including the chance to sit in the cockpit of several helicopters and planes, walk through the sleeping bunks, and hear from veterans who experienced this life firsthand. The view from the Flight Deck provides a stunning view of both the San Diego bay and the city skyline, which is especially striking at night.

*Tickets are required for this event.*



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*-Jordi Alonso, MD, PhD*

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7:30 am - 5:00 pm Registration Desk Open Bayview Foyer, ground level

7:30 am - 8:30 am Japan SIG Meeting Nautilus 5, lower level

8:30 am - 9:45 am Concurrent Symposium Sessions

**Symposium 5:** Incorporating quality of life into economic evaluation of cancer therapies: contributions of the Multi-Attribute Utility in Cancer (MAUCa) Consortium  
Grande Ballroom AB, ground level

Moderator

**Madeleine King, PhD**, University of Sydney, Sydney, Australia

*Submitted on behalf of the EORTC Quality of Life Group and the MAUCa Consortium*

Individual Presentations:

**Valuations of the QLU-C10D and FACT-8D: Canadian illustrations**

**Helen McTaggart-Cowan**, Faculty of Health Sciences, Simon Fraser University, Burnaby, British Columbia, Canada; *presented on behalf of the Canadian MAUCa Team*

**United States Utility Algorithm for the EORTC QLU-C10D and the FACT-8D: Multi-Attribute Utility Measures Based on Cancer-Specific Quality of Life Instruments**

**Dennis Revicki, PhD**, Evidera, Bethesda, MD, United States

**EORTC QLU-C10D valuation studies in various European countries – findings and outlook**

**Georg Kemmler, PhD**, Department of Psychiatry, Psychotherapy and Psychosomatics, Medical University of Innsbruck, Innsbruck, Austria

**UK utility weights for the cancer-specific EORTC QLU-C10D: Why, how and when to use?**

**Donna Rowen, PhD**, University of Sheffield, Sheffield, United Kingdom

**Symposium 6:** Partnering with patients and caregivers in patient centered outcomes research: challenges and solutions Nautilus 1, lower level

Moderator:

**Tom Keeley**, GSK, Uxbridge, United Kingdom

Discussants:

**Marilyn Metcalfe, PhD**, GlaxoSmithKline, Research Triangle Park, NC, United States

*Submitted on behalf of GlaxoSmithKline*

Individual Presentations:

**Online patient communities: listening to the voice of the patient to optimise the study protocol to be used in a clinical study**

**Bethany Metcalfe**, Join the Dots, Manchester, United Kingdom

**Engagement of a Patient Advisory Group as partners to guide the design, conduct and interpretation of concept elicitation and cognitive debriefing interviews during Patient-Reported Outcome research studies**

**Charlotte Panter, MSc BSc (Hons)**, Adelphi Values, Manchester, United Kingdom

**Engagement with caregivers during the development and implementation of a survey to evaluate the impact of a rare neurodevelopmental disorder**

**Kate Williams, PhD**, Acaster Lloyd Consulting, London, United Kingdom

**Patients as Research Pioneers: a patient's perspective on how to achieve effective use of PROs through engaging patients as partners**

**Yelak Biru, MS CS**, International Myeloma Foundation, Bentonville, AR, United States

## Symposium 7: Improving PROs in Clinical Trials: The PROTEUS Consortium (Patient-Reported Outcomes Tools: Engaging Users & Stakeholders) Nautilus 2, lower level

Moderator:

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

Individual Presentations:

### Tools to optimize PROs in clinical trials

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

### Strategies for implementing and disseminating the tools to optimize PROs in clinical trials

Michael Brundage, MD MSc, Queen's Cancer Research Institute, Kingston, Ontario, Canada

## Symposium 8: Moving the interpretation of PRO scores forward: MIDs et al! Nautilus 3, lower level

Moderators:

Bellinda King-Kallimanis, PhD, US FDA, Silver Spring, MD, United States

Kathleen Wyrwich, PhD, Eli Lilly & Company, St. Louis, MO, United States

Individual Presentations:

### Estimating meaningful change: A practical example using existing datasets and prospective patient interview

Kim Cocks, PhD, Adelphi Values, Cheshire, United Kingdom

### Critical insights from a large systematic review of anchor-based minimal important difference (MID) estimates for patient-reported outcome measures (PROMs)

Tahira Devji, PhD, McMaster University, Hamilton, Ontario, Canada

### Effect of reliability on bias and precision of the ROC-based MID, predictive MID, and adjusted MID

Berend Terluin, MD PhD, Amsterdam UMC, Amsterdam, Netherlands

### Issues in Measuring Change and MIDs

Geoff Norman, PhD, McMaster University, Dundas, Ontario, Canada

## 9:45 am - 10:35 am Refreshment Break Grande Foyer, ground level

## 9:50 am - 10:30 am Wednesday Poster Session I Grande Ballroom C, ground level

Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.

## Breast Cancer

### (3003) Oral care to prevent oral mucositis and the health-related quality of life in estrogen receptor-positive metastatic breast cancer patients treated with everolimus (Oral Care-BC): a randomized controlled phase III trial

Mariko Naito, PhD, Hiroshima University, Hiroshima, Japan

### (3005) Exploring the differential experience of psychological-related symptom and quality of life outcomes for breast cancer patients undergoing chemotherapy: a latent class analysis

Changrong Yuan, Fudan University, Shanghai, China

### (3007) Identification of breast cancer survivors with high symptom burden

Meagan Whisenant, The University of Texas MD Anderson Cancer Center, Houston, United States

### (3009) *Withdrawn*

### (3011) Health-related Quality of Life in elderly HER2+ metastatic breast cancer patients comparing pertuzumab plus trastuzumab without or with metronomic chemotherapy in the randomized phase II clinical trial EORTC 75111-10114

Corneel Coens, MSc, EORTC Headquarters, Brussels, Belgium



### **(3013) Patients' experience of communication and handling of symptomatic adverse events in breast cancer patients receiving adjuvant chemotherapy**

Helle Pappot, MD DMSc, Rigshospitalet, University Hospital of Copenhagen, Copenhagen, Denmark

### **(3015) Identification of fatigue patterns and risk factors for breast cancer patients undergoing chemotherapy in China: a latent class analysis**

Qingmei Huang, Fudan University, Shanghai, China

**(3017) Withdrawn**

## **Dermatology**

### **(3019) Agreement of daily and weekly mean scores in a chronic plaque psoriasis population in a Phase 2 clinical trial**

Benjamin Banderas, Adelphi Values, Boston, MA, United States

### **(3021) Quality of life in patients with psoriasis: a qualitative content analysis of online portals**

Marina Otten, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

### **(3023) How pain impacts quality of life in psoriasis: an inadequately addressed symptom**

Vanina L. Taliercio, MD MS, Department of Dermatology, University of Utah, Salt Lake City, UT, United States

### **(3025) The psychosocial impact of psoriasis**

Aaron M. Secrest, MD PhD, Department of Dermatology, University of Utah, Salt Lake City, UT, United States

### **(3027) Which PROMs to use when assessing pruritus? An update of a systematic review**

Janine Topp, University Medical Center Hamburg, Hamburg, Germany

### **(3029) Real-time patient-reported outcomes in dermatology: proof of concept in patients treated with isotretinoin**

Aaron M. Secrest, Department of Dermatology, University of Utah, Salt Lake City, UT, United States

## **Gastrointestinal and Liver Conditions**

**(3031) Withdrawn**

### **(3033) Responsiveness and minimal important changes of the CHBQOL instrument in patients with chronic hepatitis B**

Lin Zhu, Zhejiang University School of Public Health, Hangzhou, China

### **(3035) Social media review to explore the disease journey of patients with Hepatitis B Virus infection**

Aiste Guobyte, Clinical Outcomes Solutions, Chicago, IL, United States

### **(3037) Early Cognitive Improvement One Month after Liver Transplant Measured by the NIH Toolbox**

John Peipert, PhD, Department of Medical Social Sciences, Northwestern University, Chicago, IL, United States

**(3039) Withdrawn**

### **(3041) Work-Health-Personal Life Conflict of New Chronic Hepatitis B Patients in China: A Qualitative Study**

Ying Jing Zheng, Institute of Social and Family Medicine, School of Public Health, Zhejiang University 866 Yuhangtang Road, Xihu District, Hangzhou, Zhejiang Province, China

**(3043) Withdrawn**

## **Health Utilities**

### **(3045) Predicting EQ-5D utilities from the MacNew heart disease quality of life questionnaire**

Admassu N. Lamu, University of Bergen, Bergen, Norway

### **(3047) Association between self-reported health and 30-day readmission or death after discharge from hospital**

Fatima Al Sayah, University of Alberta, Edmonton, Alberta, Canada

### **(3049) Preference-based mapping between the Dutch EQ-5D5L, CarerQoL-7D, and ASCOT**

Milad Karimi, Erasmus University Rotterdam, Rotterdam, Netherlands

**(3051) Is EQ-5D-5L better over time? A head-to-head comparison of responsiveness of the EQ-5D-3L and EQ-5D-5L**

Ines Buchholz, Institute for Community Medicine, Department Methods, University Medicine Greifswald, Greifswald, Germany

**(3053) The striking similarity between preference weights for quality of life dimensions and mortality weights: Another way of thinking about scoring health indices?**

Nancy Mayo, McGill University, Montreal, Quebec, Canada

**(3055) How to capture fluctuating health impairments in people with multiple sclerosis: Development of an intensive longitudinal assessment of the EQ-5D-5L**

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

**(3057) Withdrawn**

**(3059) A vision 'bolt-on' to EQ-5D is more responsive than EQ-5D in patients undergoing cataract surgery**

Mathieu Janssen, PhD, EuroQol Research Foundation, Rotterdam, Netherlands

**(3061) Construct validity of Health Utilities Index Mark 2 and 3 among residents in long-term care facilities**

Allyson Jones, PhD, Faculty of Rehabilitation Medicine Physical Therapy, University of Alberta, Edmonton, Alberta, Canada

**(3063) Extending the QALY project in the United States: face and content validity of items for a new preference-based measure**

A. Simon Pickard, University of Illinois, Chicago, Chicago, IL, United States

### Methodological Advances in Measure Development & Evaluation II

**(3065) Interpreting Disease Symptoms: Item-level Analysis Methodology**

Lysbeth Floden, PhD, Clinical Outcomes Solutions, Tucson, AZ, United States

**(3067) Testing relationships between clinical and non-clinical variables in cutaneous lupus erythematosus: A structural equation model of quality of life**

Motolani Ogunsanya, College of Pharmacy, University of Oklahoma Health Sciences Center, Oklahoma City, OK, United States

**(3069) Implementation of different versions of Oort's Structural Equation Modeling approach in a Stata command.**

Bastien Perrot, PhD, UMR INSERM 1246 SPHERE, Nantes, France

**(3071) Combined Psychotherapeutic-Pharmacopsychometric Triangle for Integrated Measurement-Based Care and Quality of Life Assessment**

Joshua Chiroma Gandhi, University of Jos, Jos, Plateau State, Nigeria

**(3073) Accuracy of Latent Class Item Response Theory Models for Examining Heterogeneity in Ordinal Patient-Reported Outcomes Data**

Tolu Sajobi, University of Calgary, Calgary, Alberta, Canada

**(3075) PRO estimands and missing data**

Melanie Bell, Mel & Enid Zuckerman College of Public Health, University of Arizona, Tucson, AZ, United States

**(3077) Recommendations on the most suitable PROMs for the treatment of patients with obesity: a systematic review**

Danny Mou, Brigham Women's Hospital, Boston, MA, United States

**(3079) Personalised felicitemetrics. ACSA, a self-anchoring uniscale based on life experience, may circumvent several biases.**

Jan L Bernheim, Vrije Universiteit Brussel, Brussels, Belgium

**(3081) Assessing health-related quality of life through pictorial items. An overview of the state of the art**

Patrick Brzoska, Witten/Herdecke University, Faculty of Health, School of Medicine, Health Services Research, Witten, Germany

**(3083) BODY-Q Bariatric Module: Developing a Novel PROMS for Bariatric Surgery Patients**

Danny Mou, Brigham Women's Hospital, Boston, MA, United States

## Quality Indicators/Care Experience

### **(3085) Risk Modeling of Hospital Re-admissions Using Machine Learning**

Man Hung, PhD, Roseman University of Health Sciences College of Dental Medicine, South Jordan, UT, United States

### **(3087) Development and Testing of a Patient-Reported Outcome Measure for Use with Emergency Department Patients who are Discharged Home**

Dorcas Beaton, PhD, St. Michael's Hospital, Toronto, Ontario, Canada

### **(3089) A Machine Learning Approach to Predict Risk of 30-Day Readmission: Insights from Hospital Experience Surveys completed by Patients Living with Chronic Conditions**

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

### **(3091) The Impact of Collecting Patient-Reported Outcome Measures on Visit Satisfaction in Rheumatology Clinics**

Brittany Lapin, Cleveland Clinic, Cleveland, United States

### **(3093) Changes in the quality of life of the patients seen in an Integrated Health Services Organization of a Health Maintenance Organization in Colombia**

Martin Romero, Grupo Proyectame, Bogota, Colombia

### **(3095) *Withdrawn***

## Renal Disease and Nephrology

### **(3097) Linking SF-36 scores to PROMIS T-Scores in renal transplant recipients**

Intan Purnajo, Terasaki Research Institute, Los Angeles, CA, United States

### **(3099) The Prognostic Value of Patient-Reported Physical Function for Living Donor Kidney Transplant Outcomes**

John Peipert, PhD, Department of Medical Social Sciences, Northwestern University, Chicago, IL, United States

### **(3101) Ethnicity is associated with social difficulties in patients with end stage kidney disease (ESKD)**

Istvan Mucsi, MD PhD, University Health Network, Toronto, Ontario, Canada

### **(3103) Relationship between health-related quality of life domains and clinical outcomes in chronic kidney disease (CKD): an observational cohort study**

Olalekan Lee Aiyegbusi, University of Birmingham, Birmingham, United Kingdom

### **(3105) Validation of the PROMIS Preference scoring system (PROPr) in patients with End-Stage Kidney Disease (ESKD)**

Jing Zhang, Multi-organ transplant program, University Health Network and University of Toronto, Toronto, Ontario, Canada

### **(3107) Assessing the Patient's Perspective in End-stage Kidney Disease – Baseline Results from the CONVINCE Trial**

Kathrin Fischer, Charité Universitätsmedizin Berlin, Berlin, Germany

## 10:35 am - 12:05 pm ISOQOL Awards and Member Business Meeting Grande Ballroom AB, ground level

The Awards and Member Business Meeting includes award presentations, leadership transition, and official ISOQOL business. Since membership dues are included in the conference registration, all Annual Conference attendees are members and are encouraged to attend this session.

Recipients of the following awards will be announced:

2019 President's Award

Emerging Leader Award – In Honor of Donna Lamping

New Investigator and Student Presentation Awards

Outstanding Article of the Year Awards

Travel Scholarships

## 12:05 pm - 1:50 pm Buffet lunch (conference badge required) Grande Foyer/Bayview Lawn\*

12:05 pm ..... First Lunch Shift

1:00 pm ..... Second Lunch Shift

The conference registration fee includes a buffet lunch served in the Grande Foyer on the ground level. Seating is available in the outdoor Bayview Lawn (\*in inclement weather, the Nautilus Foyer plus Nautilus 4 & 5 will be utilized.) Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. Entry to the buffet is by name badge.

## 12:10 pm - 1:10 pm Special Interest Group (SIG) Meetings

Canada PRO SIG .....Nautilus 1, lower level

Chinese PRO SIG..... Marina 5, ground level

Ibero America SIG.....Nautilus 2, lower level

Psychometrics SIG.....Grande Ballroom AB, ground level

United Kingdom and Ireland SIG .....Nautilus 3, lower level

## 1:50 pm - 3:20 pm Plenary – Accountability: Counting What Counts Grande Ballroom AB, ground level

The goal of this plenary is to consider how we can expand the use of PROMs and promote them as endpoints for assessing health care quality, clinical decision making, and delivery of patient-centered care.

Sponsored by: Pfizer

Chair:

Janel Hanmer, MD PhD, University of Pittsburgh Department of Medicine, Pittsburgh, PA, United States

Speakers:

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

Dominick L. Frosch, PhD, Palo Alto Medical Foundation Research Institute, La Jolla, CA, United States

Mona Khalid, BSc (Hons) MSc PhD, ICHOM, London, United Kingdom



## 3:20 pm - 4:10 pm Refreshment Break Grande Foyer, ground level

## 3:25 pm - 4:05 pm Wednesday Poster Session II Grande Ballroom C, ground level

Presenting authors indicated. The full author listing is available in the Quality of Life Research journal supplement.

## Cross-Cultural Adaptation

### (3004) Linguistic validation of a novel, patient-centric, eCOA for dementia clinical trials: Translation from English to French

Chere Chapman, DGI Clinical Inc, Halifax, Nova Scotia, Canada

### (3006) Withdrawn

### (3008) Development of the Chinese Version of the Youth Quality of Life Instrument -Research Version (YQOL-R)

Hong-Mei Wang, PhD, Department of Social Medicine of School of Public Health and Department of Pharmacy of the First Affiliated Hospital Zhejiang University School of Medicine, Hangzhou, China

### (3010) Cross-cultural Adaptation and Validation of the Portuguese-version of the Pediatric Functional Assessment of Chronic Illness Therapy Fatigue (peds-FACIT-F)

Carlos Silva, Faculdade de Medicina da Universidade Federal de Uberlandia, Uberlandia, Brazil

### (3012) Withdrawn

### (3014) Road to comprehensibility: development and translation of the EORTC IADL-BN32 questionnaire

Dagmara Kulis, MA, EORTC, Brussels, Belgium

### **(3016) Cognitive debriefing methodology used in linguistic validation of the Kiddie Schedule for Affective Disorders and Schizophrenia**

Carter Cassedy, ICON Clinical Research, Durham, NC, United States

### **(3018) Understanding the concept and context of “condition” and its cross-cultural harmonization during the translation and linguistic validation of the FACT-BI-Cys.**

Benjamin Arnold, MA, FACITrans, Ponte Vedra, FL, United States

### **(3020) Going Up 2 Flights and Mopping: Harmonizing Cross-Cultural Issues for FACIT-Dyspnea**

Emily Parks-Vernizzi, MFA, FACITrans, Clifton Park, NY, United States

### **(3022) Different responses to subjective health between Korea and US**

Eunjeong Kang, Soonchunhyang University, Asan, South Korea

## **E-Health Smartphone Apps and Wearables**

### **(3024) The patient's voice. Innovation in the localisation methodology of real-world evidence 'Bring Your Own Device' smartphone apps for quality of life observational studies.**

Anna Richards, MA, Vitaccess, Oxford, United Kingdom

### **(3026) A novel approach to using machine learning algorithms for fraud detection in real world data from wrist worn wearable devices**

Willie Muehlhausen, Dublin City University, Dublin, Ireland

### **(3028) An innovative online approach to qualitative research in patients with primary Sjögren's syndrome**

Linda Nelson, Value Evidence and Outcomes, Patient Centered Outcomes, GSK, Upper Providence, PA, United States

### **(3030) Feasibility study of smartphone-enabled, peer reported outcomes assessment in healthy individuals**

Allan Berrocal, University of Geneva, Quality of Life Technologies Lab (Switzerland), Geneva, Switzerland

## **Head and Neck Cancer**

### **(3032) A systematic review of psychological distress measures for people diagnosed with head and neck cancer (HNC)**

Chindhu Shunmuga Sundaram, The University of Sydney, Sydney, Australia

### **(3034) NCCN-FACT Head and Neck Symptom Index-22 (NFHNSI-22) Reduced for Efficient, Patient-centered Drug Development**

Kimberly A. Webster, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

### **(3036) The patients' preference of a Patient-Reported Outcome questionnaire- selection of a PRO questionnaire for patients undergoing radiotherapy for head and neck cancer**

Cecilie Holländer-Mieritz, Rigshospitalet, Department of Oncology, Copenhagen, Denmark

### **(3038) Prospective Outcomes and Support Initiative (POSI) for Gyne and Head and Neck Radiotherapy Patients in British Columbia: Patient Completion and Clinician Use**

Regina Tam, BC Cancer Surrey, Surrey, British Columbia, Canada

## **Mental Illness/Mental Health**

### **(3040) Health-related quality of life associated with Hamilton Rating Scale for Depression remission and response in postpartum depression**

Margaret Gerbasi, Sage Therapeutics, Cambridge, MA, United States

### **(3042) Screening for anxiety and depressive symptoms using the EQ-5D-3L post-hospital discharge**

Arto Ohinmaa, PhD, University of Alberta, Edmonton, Alberta, Canada

**(3044) Withdrawn**

**(3046) Withdrawn**

### **(3048) Development of an item bank and a computerized adaptive testing to evaluate respect and dignity in psychiatry: the PREMIUM project**

Sara Fernandes, Aix-Marseille Univ, School of medicine Timone, Marseille, France



**Engaging patients** throughout the drug development process to better understand their experiences, preferences, and outcomes.



## Scientific Presentations During **ISOQOL**



### WORKSHOP

Clinical Outcome Assessment in a Multi-Cultural Context: Measurement Challenges and Solutions

**Martin ML**, Hudgens S, Regnault A, Eremenco S, McLeod L



### SYMPOSIUM

United States Utility Algorithm for the EORTC QLU-C10D and the FACT-8D: Multi-Attribute Utility Measures Based on Cancer-Specific Quality of Life Instruments

**Revicki DA**, Norman R, Viney R, Pickard AS, Mercieca-Bebber R, Shaw J, Cella D, King MT



### ORAL PRESENTATION

Understanding the Patient Experience in Follicular Lymphoma (FL), Relapsed/Refractory FL (R/R FL), and Relapsed/Refractory Diffuse Large B-Cell Lymphoma (R/R DLBCL)

Bell JA, Cherepanov D, **Revicki D**, **Speck RM**, **Swett L**, Stumpo K, Rong Y, Gordon LI

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### **(3050) Assessing the validity of diabetes-related psychosocial patient-reported outcome measures in people living with diabetes and severe mental illnesses**

Jan Boehnke, School of Nursing and Health Sciences, University of Dundee, Dundee, United Kingdom

### **(3052) The relationship of mood and sleep status with self-perceived quality of life and symptom severity for clients with mental illness in Taiwan**

Ay Woan Pan, School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan

### **(3054) Meaning in life as a protection against loneliness. Exploring empirical studies and theory.**

Anna Paldam Folker, PhD, University of Southern Denmark, Copenhagen, Denmark

### **(3056) Why the pass for university entrance examination does not improve the Quality of Life (QOL) for the successful candidate?**

Rika Hayashida, University of Nagasaki, Siebold, Nishisonogi-gun, Nagasaki, Japan

## PRO Measurement Harmonization Standardization

### **(3058) *Withdrawn***

### **(3060) Improving standards of patient reported outcomes analysis: matching statistical methods to key research objectives – a SISAQOL initiative**

Corneel Coens, EORTC, Brussels, Belgium

### **(3062) Development of robust and feasible international standard sets of health outcome measurements**

Mona Khalid, BSc (Hons) MSc PhD, ICHOM, London, United Kingdom

### **(3064) Mapping functions, measurement instruments, and rare diseases: challenges and solutions**

Benoit Arnould, ICON plc, Lyon, France

### **(3066) Improving the PRO components of clinical trial protocols: Implementation of the SPIRIT-PRO through educational workshops**

Rachel Campbell, PhD, University of Sydney, Faculty of Science, School of Psychology, Sydney, NSW, Australia

### **(3068) Review of core outcome sets for key inflammatory conditions: a comparison of studies indexed in COMET, ICHOM and international regulatory guidance**

Olalekan Lee Aiyegbusi, University of Birmingham, Birmingham, United Kingdom

### **(3070) When to Select Clinician Reported Outcome an evaluation of the existing evidence and suggestions for future use**

Nenad Medic, PhD, PAREXEL, London, United Kingdom

## Pulmonary

### **(3072) Patient-Reported Outcome Measures in Cystic Fibrosis**

Rasa Ruseckaite, Monash University, Melbourne, Australia

### **(3074) Identifying the Need for a Disease-Specific Health Related Quality of Life Instrument for Patients with Chronic Hypersensitivity Pneumonitis**

Kerri Aronson, Weill Cornell Medical College, Division of Pulmonary and Critical Care, New York, NY, United States

## Qualitative Methods

### **(3076) When is enough evidence enough? A retrospective analysis of data from patient reported outcome (PRO) cognitive debriefing studies on change-to-survey thresholds**

Michelle White, Optum, Johnston, RI, United States

### **(3078) Evaluation of content validity of the Near Activity Visual Questionnaire-Presbyopia (NAVQ-P) in presbyopia subjects**

Adam Gater, Adelphi Values, Bollington, Macclesfield, United Kingdom

### **(3080) What response processes can tell us about positively and negatively worded and keyed items**

Anita Hubley, University of British Columbia, Vancouver, British Columbia, Canada

**(3082) Health-related quality of life after hand transplantation: Preliminary analysis from focus groups of multi-disciplinary transplantation team members**

Callie Tyner, University of Delaware, Newark, DE, United States

**(3084) A qualitative study exploring patients' perspectives on ease of understanding, interpretation and completion of the Uterine Fibroid Daily Bleeding Diary (UF-DBD)**

Claudia Haberland, Bayer AG, Berlin, Germany

**(3086) Patient-centered methods: Considerations for exploring sensitive topics during patient interviews to develop clinical outcome assessment (COA) measures**

Chris Marshall, DRG Abacus, Clinical Outcomes Assessment, Manchester, United Kingdom

**(3088) Withdrawn**

**(3090) Patient experience using a Patient-reported Outcome Measure for Self-management**

Maria J Santana, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

**(3092) Withdrawn**

## 4:10 pm - 5:40 pm Concurrent Oral Sessions

Presenting authors indicated. The full author listing is available in the *Quality of Life Research* journal supplement.

### Oral Session 301: Caregivers and Other Understudied Populations Grande Ballroom AB, ground level

Session Chair: Joan Griffin, PhD, United States

**4:16 pm – 4:32 pm (301.1) Understanding hemophilia caregiver burden: Does appraisal buffer the impact of hemophilia on caregivers?**

Carolyn Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, United States

**4:33 pm – 4:49 pm (301.2) Development and validation of the Caregiver Roles and Responsibilities Scale**

Valerie Shilling, University of Sussex, Brighton, United Kingdom

**4:50 pm – 5:06 pm (301.3) Differences in Fear of Falling, Self-efficacy and Anxiety among Community-dwelling Elderly Individuals with Knee Osteoarthritis**

Adesola Odole, College of Medicine, University of Ibadan, Ibadan, Nigeria

**5:07 pm – 5:23 pm (301.4) The effect of frailty on Quality of Life in elderly patients after hip fracture: a longitudinal study**

Marc van de Ree, Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands

**5:24 pm – 5:40 pm (301.5) Mapping Services to Needs for First Nations Children's in Canada Using Rasch Analysis**

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

### Oral Session 302: Graphical display of PROMs Nautilus 1, lower level

Session Chair: Claire Snyder, PhD, United States

**4:16 pm – 4:32 pm (302.1) A Novel Approach of Using Graphical Representation of EQ-5D-3L Dimensions, Levels, and Health States for Illiterate Respondents in Valuation Studies – An Example from Morocco**

Fatima Al Sayah, University of Alberta, Edmonton, Alberta, Canada

**4:33 pm – 4:49 pm (302.2) Developing a Computer Adaptive Version of the Animated Activity Questionnaire (AAQ-CAT)**

Leo D. Roorda, Amsterdam Rehabilitation Research Center | Reade, Amsterdam, Netherlands

**4:50 pm – 5:06 pm (302.3) Does scrolling affect measurement equivalence of electronic patient-reported outcome measures? Results of a quantitative equivalence study**

Saeid Shahraz, ICON PLC, Boston, MA, United States

**5:07 pm – 5:23 pm (302.4) Heat map visualization of daily patient-reported dysmenorrhea pain in Japanese patients treated with ethinylestradiol/drospirenone: a randomized controlled study**

Sayako Akiyama, MPH, Markt Access, Bayer Yakuin, Ltd., Tokyo, Japan

**5:24 pm – 5:40 pm (302.5) R Shiny and Flexdashboards: Interactive Patient Reported Quality of Life Tracking for Increasing Protocol Adherence**

Michael A Golafshar, Mayo Clinic, Scottsdale, AZ, United States

## Oral Session 303: Outcomes of Cancer Treatment Nautilus 2, lower level

Session Chair: Brittany Lapin, PhD MPH, United States

**4:16 pm – 4:32 pm (303.1) The Prospective Impact of Radical Cystectomy and Urinary Diversions on the Health-Related Quality of Life of Bladder Cancer Patients**

Thomas Atkinson, Memorial Sloan Kettering Cancer Center, New York, United States

**4:33 pm – 4:49 pm (303.2) Identifying Cancer Survivors Most At-Risk for High Symptom Burden: The Role of Age at Diagnosis and Physical Activity**

Elizabeth Siembida, National Cancer Institute, Rockville, MD, United States

**4:50 pm – 5:06 pm (303.3) Symptom Burden of Patients with Metastatic Solid Tumors Receiving Pembrolizumab in an Early Phase Trial**

Tito Mendoza, University of Texas MD Anderson Cancer Center, Houston, United States

**5:07 pm – 5:23 pm (303.4) Evaluating time to physical function deterioration in multiple myeloma**

Jessica Roydhouse, US Food and Drug Administration, Silver Spring, MD, United States

**5:24 pm – 5:40 pm (303.5) Barriers and facilitators to physical activity in men with prostate cancer: a mixed methods systematic review**

Louis Fox, King's College London, London, United Kingdom

## Oral Session 304: Psychometric Methods Nautilus 3, lower level

Session Chair: Lori McLeod, PhD, United States

**4:16 pm – 4:32 pm (304.1) Stratification of Spine Patients based on Clinical Profiles of PROMIS Domains**

Irene Katzan, Cleveland Clinic, Cleveland, United States

**4:33 pm – 4:49 pm (304.2) Comparison of Unidimensional and Multidimensional Item Response Theory Scoring for NeuroQOL Pediatric Emotion Measures**

Jin-Shei Lai, Northwestern University, Chicago, United States

**4:50 pm – 5:06 pm (304.3) Latent class analysis of fatigue and its association with quality of life and inflammation in patients with head and neck cancer who have undergone definitive radiation**

Canhua Xiao, Yale University, Orange, CT, United States

**5:07 pm – 5:23 pm (304.4) Discovering patient clusters and their unique quality of life profiles with the Infinite Relational Model**

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

**5:24 pm – 5:40 pm (304.5) Scoring methods: History, practices, and pragmatic implications for different options**

David Andrae, Endpoint Outcomes, Austin, United States

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## Exhibitors

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ISOQOL would like to thank the following organizations for exhibiting at the 26th Annual Conference.

### Exhibit #5

BrightOutcome develops patient-centered healthcare applications designed to enhance lives and improve patient health outcomes. Our web apps and Healthcare IT solutions include stand-alone web portals, Web Services (WS) integration with EHR/EMR and legacy Health IT systems, and custom implementation projects.



### Exhibit #7

PROMIS® (Patient-Reported Outcomes Measurement Information System) is a set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. It can be used with the general population and with individuals living with chronic conditions.



### Exhibit #2

Our mission at FACIT is to provide a voice for patients worldwide. Scientifically aligned with our partners at the Department of Medical Social Sciences at Northwestern University, FACIT.org and FACITtrans are uniquely positioned to provide cutting-edge health outcomes measurement science to the academic and the pharmaceutical research communities. FACIT.org serves as the licensor of the widely-used Functional Assessment of Chronic Illness Therapy system of questionnaires. FACITtrans provides multilingual translation services and linguistic validation to the research community.



### Exhibit #6

RWS has a long and successful heritage dating back to 1958. Over the last 60 years, the company has established itself as the world leader in translation and localization, intellectual property support solutions and life sciences language services. Our specialist divisions work together to deliver high-quality, complex services in a reliable and flexible manner to meet the diverse needs of a global client base.



### Exhibit #3

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.



### Exhibit #1

Springer is a leading publisher of books, journals, electronic products and considered the largest Open Access publisher. Visit the Springer booth where we will be highlighting ISOQOL's two journal publications: Quality of Life Research (Impact Factor: 2.488) and Open Access Journal of Patient-Reported Outcomes. For more information please visit [www.springer.com](http://www.springer.com) and [www.springeropen.com](http://www.springeropen.com).





# ISOQOL Education Courses

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- hospitals
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### **Introduction to Quality of Life and Patient-Reported Outcomes**

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# 2020 ABSTRACT SUBMISSION ANNOUNCEMENT

In an effort to ensure an appropriate balance between theory, methods and application at the ISOQOL Annual Conference, there will be a major change to the primary abstract categories for the 2020 submission process.

## NEW PRIMARY ABSTRACT CATEGORIES

### **Theoretical Work**

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Abstracts in this category use theory to advance the understanding of HRQOL phenomena. Such work might include novel efforts to explain known associations or relationships observed in the literature; modifications or extensions to theories that are routinely or historically used in HRQOL research and applications; or applications of an established theory from another field to HRQOL phenomena. Abstracts in this category should not be presenting new data (including qualitative or formative work) or meta-analyses, but may reference published data in support of a theory.

### Example Titles

- Comparative Analysis of Philosophical Conceptions of Well-Being in Different Health Status Measures
- A Dialogic Approach to Assessing Quality of Life
- Toward a Theoretical Model of Quality-of-Life Appraisal: Implications of Findings from Prior Studies of Response Shift
- Hermeneutics as a 'lens' in the interpretation of patient-reported outcome measures

## Methodological

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Work in this category reports on qualitative or quantitative methods for developing and evaluating patient-reported health status, as well as methods for analyzing and interpreting scores from such measures of health assessments. While the work might feature a particular disease area or measure, the primary aim of the work is to present a method rather than present findings about a particular measure or population.

### Example Titles

- Triangulating estimates of meaningful change or difference in patient-reported outcomes: application of a correlation-based weighting procedure
- Mind the (inter-rater) gap. An empirical investigation of self-reported and proxy-reported quality of life in the derivation of childhood utility values for economic evaluation
- Handling informative drop-out in longitudinal analysis of health-related quality of life: Application on data from the oesophageal cancer clinical trial PRODIGE5/ACCORD17
- Accommodating heterogeneity to improve measurement validity in large population health surveys
- Correspondence between Q-Sort and Individual Interviews for Concept Elicitation

## Application: Clinical Research

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Abstracts in this category use patient-centered measures to better understand the nature, prevention, treatment and management of different health conditions. Approaches used in this category could include qualitative or quantitative, randomized or non-randomized, cross-sectional or longitudinal, and meta-analyses.

## Example Titles

- Psychometric properties of DEMQOL and DEMQOL-Proxy in people with dementia: a Rasch based analysis
- Health-related quality of life of Dutch children and adolescents with a chronic health condition aged 6 to 18 years
- A randomized implementation study to evaluate an ePRO system for monitoring adverse events after discharge following major abdominal cancer surgery
- Developing a conceptual framework for a new patient-reported outcome measure for children with eczema: A qualitative study of children and parents
- Phase I and II development of an EORTC QOL cancer survivorship assessment strategy: issue generation and construction of provisional questionnaires
- Factors associated with community ambulation in adults aged 45-85 – the Canadian Longitudinal Study on Aging

## **Application: Clinical Care Applications**

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Abstracts in this category include reports of efforts to integrate the patient's voice more effectively into clinical encounters. Examples include descriptions of experiences implementing a standardized PRO collection system in a single clinic, reports of the development of a streamlined questionnaire battery for patients to complete prior to visits, and efforts to develop better reports for clinicians of patients' PRO data over time. It is expected that abstracts in this category are more descriptive in nature with limited sample sizes. Larger and/or randomized studies should be categorized as Clinical Research.

## Example Titles

- The Process of Capturing Patient-Reported Outcomes Electronically to Improve Dermatologic Care
- Bridging the gap between research and daily practice: optimization and implementation of mHeath tool PsyMate™ in primary care
- Development of a patient education program for patients undergoing body contouring after massive weight loss
- Clinical Application and Usage of Patient Reported Outcome Measures in an Orthopaedic Outpatient Setting

## Application: Policy

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Abstracts in this category focus on issues relevant to the requirement, development and large-scale (e.g., Health System, Government) application of patient-reported outcomes in health care practice, regulatory, and population/surveillance settings. Abstracts may include program evaluation, case studies and economic analyses.

## Example Titles

- Embedding patient and public involvement within the Centre for Patient Reported Outcomes Research
- Common Issues Encountered in Regulatory Review of the Development of Clinical Outcome Assessments
- Can Patient-Reported Outcomes Assessment Be Brought to Scale? Lessons from a Statewide PRO-focused Quality Improvement Initiative
- Stakeholder Perspectives on the Use of Patient-Generated Health Data to Transform Healthcare

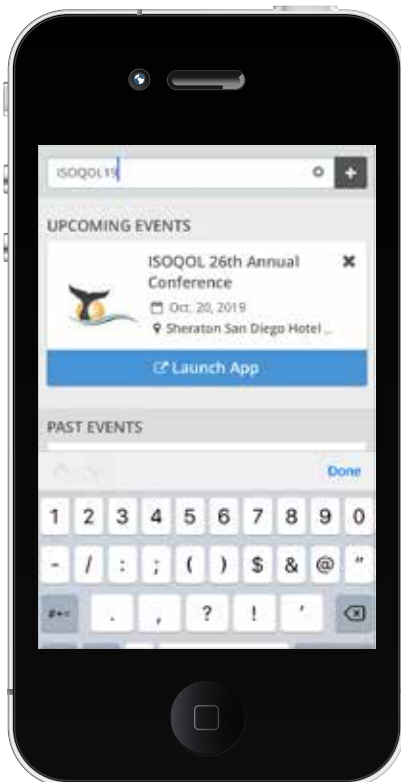




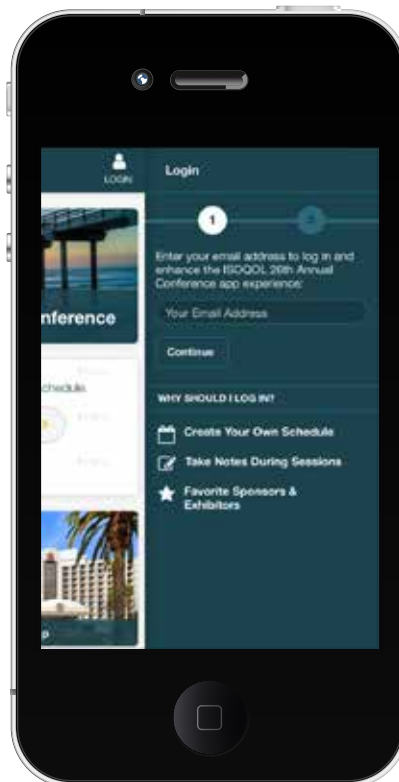
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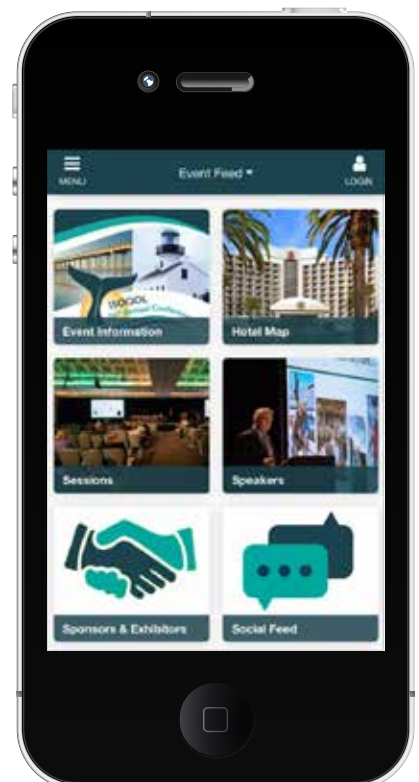
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# Save the Date

Abstract Submission Deadlines:

Workshop & Symposium Submission - 20 January 2020

Oral, Oral Brief & Poster Abstract Submission - 6 April 2020



**ISOQOL 2020**  
Prague, Czech Republic

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