

Quality of Life

QUARTERLY

IN THIS ISSUE...

- PAGE 1** President's Message
PAGE 2 ISOQOL Staff Changes
PAGE 3 From the Editor's Desk
PAGE 4 An Interview with President Snyder
PAGE 4 Measuring What Matters – Save the Date
PAGE 5 The 22nd Annual Conference in Review
PAGE 6 Awards Presented at the 2015 Member Business Meeting
PAGE 8 Thank You to the Departing Board Members
PAGE 10 Patient Engagement 2015
PAGE 11 ISOQOL Dictionary Announcement
PAGE 11 Thank You to our 22nd Annual Conference Sponsors
PAGE 13 Members' Corner
PAGE 14 Upcoming Webinars
PAGE 16 ISOQOL Honors Top Reviewers

VOLUME 21 ISSUE 4
Newsletter for
ISOQOL Members
FALL 2015



PRESIDENT'S MESSAGE

Claire Snyder, PhD, Johns Hopkins School of Medicine



Dear Colleagues,
I am honored and humbled to serve as President of the International Society for

Quality of Life Research for the next two years. I have been involved with ISOQOL since 2000, and the professional value is only outweighed by the quality of the personal friendships.

Both the professional and personal benefits of ISOQOL involvement were in action during our recent meeting in Vancouver. With 540 attendees, the annual meeting was a terrific gathering of colleagues where we had the opportunity to explore **"The Matrix: Quality of Life in Social Context."** I want to thank co-chairs Carolyn Gotay and Ida Korfage; committee members Skye Barbic and Simon Pickard; as well as our excellent speakers, moderators, discussants, session chairs, and participants. Special thanks also to our patient partners Amye Leong and

Mario Di Carlo, the Mentor/Mentee chair Cindy Gross, Workshop chair Nancy Mayo, and our sponsors and exhibitors. Finally, hearty congratulations to Galina Velikova for her outstanding tenure as President. It has been a privilege to work with Galina on the Executive Committee over the past year, and ISOQOL has benefited greatly from Galina's service. I hope to continue her excellent work.

With that in mind, I would like to highlight several of the initiatives that I hope we can work on together over the next two years. During this time, ISOQOL will be focusing on two substantive themes, **"Measuring What Matters"** and **"Making Measurement Meaningful."**

Measuring What Matters seeks to address the recurring questions that we face in our professional lives of *"What patient-reported outcomes should I measure?"* and *"What instrument should I use?"* Similarly, Making Measurement Meaningful aims to strengthen the field by addressing questions related to *"What do the PRO scores mean?"* and *"What*

Continued on page 2.



The ISOQOL Newsletter is published four times a year by the International Society for Quality of Life Research.

Newsletter Editor

Ana Popielnicki, BA, USA

Send articles with subject line addressed "Newsletter Submission" to: info@isoqol.org

President

Claire Snyder, PhD, USA

Past-President

**Galina Velikova, MD,
United Kingdom**

Secretary-Treasurer

Cynthia Gross, PhD, USA

Executive Director

Colleen Pedersen, USA

Board Members

Susan J. Bartlett, PhD, Canada

**Melanie Calvert, PhD,
United Kingdom**

David T. Eton, PhD, USA

Lori Frank, PhD, USA

**Mogens Groenvold, MD, PhD,
Denmark**

Anne Klassen, D Phil, Canada

Sandra Nolte, PhD, Germany

**Diana Rofail, PhD CPsychol,
United Kingdom**

**Richard Sawatzky, RN PhD,
Canada**

ADVERTISING INFORMATION

Contact Executive Director,
Colleen Pedersen:
cpedersen@isoqol.org

ISOQOL Executive Office

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

President's Message, Continued from page 1.

is important?" and "How can these results be applied?" Building off the extensive wealth of knowledge and experience within ISOQOL, we aim to develop tools, resources, and initiatives to help our members answer these questions – or at least provide guidance on how to go about answering them.

As a first step in this effort, I am pleased to announce the inaugural Measuring What Matters Symposium, which will be held in the Washington, DC, area July 25-26, 2016. This initial symposium will focus on how to develop and implement a PRO measurement strategy that addresses regulatory requirements while assessing issues that are important to patients and clinicians. In addition to plenary presentations, the symposium will include an interactive component that will provide attendees the opportunity to actively engage with the topic. I want to thank Sara Ahmed and Steven Blum for chairing the first in what we hope will be a series of successful symposia on these topics, and I hope many of you will be able to join us at the meeting.

In addition to our substantive themes, ISOQOL will be working to re-organize and re-invigorate our committee structure. The goals of

this effort include greater engagement of our membership, better alignment of committee efforts with the strategic plan, stronger connections between the Board and committees, improved coordination across committees, and clearer roles for Board members.

Finally, there are two administrative topics that we will be exploring. One is whether, with a higher annual meeting registration fee, we can make membership complimentary for anyone who attends the annual meeting. The second is exploring whether moving our annual meeting dates to a Sunday-Wednesday pattern would afford advantages when contracting with hotels.

If you have any feedback on these or other ideas, please submit them to [ISOQOLists](mailto:ISOQOLists@isoqol.org). I look forward to working with you all to advance the scientific study of health-related quality of life and other patient-centered outcomes.

Sincerely,

Claire Snyder, PhD, ISOQOL President



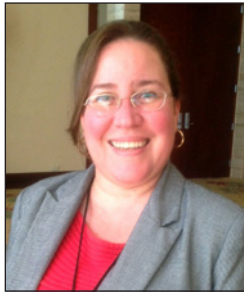
ISOQOL STAFF CHANGES

We would like to welcome Marjorie Struck to the ISOQOL team. Marjorie will be the Program Coordinator for ISOQOL assisting with our social media, newsletter, website, annual meeting and other areas. Please help me welcome Marjorie to ISOQOL.



FROM THE EDITOR'S DESK

By: Ana Popielnicki



Dear ISOQOL Family:

Welcome to this year's last issue of our *Quality of Life Quarterly*!

It was great

seeing you all – and meeting new colleagues – at the Annual Conference in Vancouver last month.

In this issue we have our first President's Message from Dr. Claire Snyder – please check out her article for information on upcoming educational opportunities, projects, and initiatives being planned for this coming year. We are also including a featured article on Dr. Snyder, who I had the opportunity to interview recently – details inside!

The Annual Conference co-chairs, Drs. Carolyn Gotay and Ida Korfage, bring us a comprehensive review of the meeting. Many thanks to both

of them and to the members of the Scientific Program Committee for a wonderful and enriching experience.

The outstanding quality of the published works in our *Quality of Life Research Journal* would not be possible without the collaboration of many dedicated reviewers. The Journal's Co-Editors-In-Chief, Drs. Carolyn Schwartz and Frans Oort, recognize the Top Reviewers of this past year – please read their article in this issue. If you wish to contribute as a reviewer, see details and links there.

Please see news from our Patient Engagement SIG co-chairs, and hear from this year's Patient Engagement Scholars, Amye Leong and Mario Di Carlo, who enthusiastically participated in and actively contributed to several sessions and activities throughout the conference.

Look out for several pertinent announcements – the publication of our Dictionary of Quality of Life and

Health Outcomes Measurement, edited by Dr. Nancy Mayo; staff changes in our Executive Office (welcome, Marjorie!), out two new Special Interest Groups (the Canada-PRO SIG and the Australia SIG, welcome!). Check our webinar announcement, as well as a much-deserved thank you to our departing Board members for their dedicated service.

Do keep in mind that we welcome your questions, comments, or submissions for the 2016 Winter issue! Please send your queries/comments to your Communications Committee at info@isoqol.org with "Newsletter" on your subject line. Enjoy!



Ana Popielnicki
Editor



AN INTERVIEW WITH ISOQOL'S PRESIDENT, DR. CLAIRE SNYDER

By: Ana Popielnicki, Editor

I have been a member of ISOQOL since 2009 – and it was at that year's Annual Conference in New Orleans that I met Claire, when a good mutual friend introduced us at the Welcome Reception. I'm sure she doesn't remember this, but I made it a point to say hi to her every time I came across her from then on, until she might have been convinced we had been friends from childhood ☺

In the following years, I've been privileged to witness Claire's enthusiastic and amazing dedication to our Society. She has served ISOQOL in some capacity for many years now: She has been a member of the Board of Directors, has co-chaired the Annual Conference (coincidentally, the very one where I met her!), was one of the founders of the QOL in Clinical Practice Special Interest

Group, was one of the keynote speakers at the 6th Ibero-America Quality of Life Research Meeting in 2012 in Brazil, has chaired Committees, as well as having presented her research in countless plenary, symposium, oral, and poster sessions.

You will learn more about her in this issue's President's Message, where she talks about all her initiatives and projects for the year. However, I did manage to ask her some general questions that will give you a good snapshot of the whole Claire, not just the Fearless Leader President Claire.

When asked about her favorite part of being our Society's President, Claire quickly stated that it wasn't the "being President" part – just being involved with ISOQOL is what she loves – the important work we do, and most of all the opportunity

to collaborate with such amazing, talented, dedicated, wise, caring, wonderful friends and colleagues all over the world.

What else can I tell you about Claire Snyder? She graciously responded to my silly un-ISOQOL-related questions: She doesn't have a favorite color – but likes different colors for different things: She rarely wears yellow, but likes yellow houses, for example. If she ever gets any free time, she can be found trying out new restaurants, or watching her beloved New Orleans Saints football and Duke Blue Devils basketball teams. Claire is a longtime yoga aficionado, and has recently taken up running.

Now you know a little bit more about our President!



MEASURING WHAT MATTERS

An ISOQOL Symposium

25-26 July 2016

Washington, DC, United States

"Bridging industry regulatory needs with what matters to patients and clinicians."

SAVE THE DATE

THE 22ND ANNUAL CONFERENCE IN REVIEW



Several groups of mentors and their mentees meet during the Mentor/Mentee Reception on Thursday night of the Annual Conference.

Vancouver has played the host to the 2010 Winter Olympics, several games of the 2015 Women's Soccer World Cup, and now, ISOQOL's 22nd Annual Conference! The Conference took place last month from October 21-24, 2015, at The Fairmont Hotel – Vancouver. The hotel is located in the center of Downtown Vancouver, just blocks from the beautiful Stanley Park and minutes from delicious Vancouver dining options and entertaining local attractions.

Scientific Committee Co-Chairs, Carolyn Gotay, PhD, University of British Columbia, and Ida Korfage, PhD, Erasmus MC, are to be commended for their passionate work and dedication in coordinating an excellent program centered around the theme, "The Matrix: Quality of Life in Social Context."

The Conference kicked-off in style with a welcome reception, following a day of well-attended workshops. The reception boasted a 21-piece jazz band composed of local musicians, and attendees were able to mingle and network to the sultry sounds of some of the world's best jazz pieces.

The Conference ended with just as much style as it began, as the Closing Dinner was held on The Roof, located on the top floor of The Fairmont Hotel. Saturday evening, attendees were able to hear a representative

from The First Nations speak on the rich culture and history of Vancouver and its people, followed by a local jazz singer. The night ended, in true ISOQOL fashion, with fun and laughter on the dance floor.

Final Conference registration was at an all-time high with 540 registrations and 184 first time ISOQOL attendees. To date, this has been one of our most well-attended conferences!

In total, there were 473 Oral/Poster Abstract submissions, 145 of which were accepted as Oral Presentations and 301 as Posters.

Of the abstracts submitted, several stood out and were judged during the conference to receive the Student and New Investigators Award to both an Oral and a Poster, as well as Outstanding Poster Awards. Award finalists were determined by abstract reviews, but the presentations were judged by a panel of volunteer judges in order to determine the winners.

In fitting with the social theme of the 22nd Annual Conference, the final plenary session on Saturday featured review and discussion of the role of social media on QOL and PRO research. Attendees at the session, as well as throughout the conference, were able to enhance conference engagement using this year's mobile

app, which featured a live polling system, as well as traditional social media platforms such as Twitter and Facebook. Thank you to Shire, our mobile app sponsor. To view some of the photos, discussions, and insights that were shared by attendees, search the hashtag #ISOQOL15.

The Friday night "Dine-Arounds," were another very successful feature of the 2015 Annual Conference. Approximately eight restaurants around the downtown Vancouver area hosted groups of seven or more conference attendees as they dined together, networked, and enjoyed an evening of socializing and good company, very much in-step with the conference theme.

Thank you to all who took the time to complete the post-conference evaluation. Congratulations to Dr. Ronald Hays, the winner of the drawing for the Amazon.com gift card.



The 22nd Annual Conference Co-Chairs, Carolyn Gotay and Ida Korfage, pose together after a very successful day of conference activities.



Past-President Galina Velikova and President Claire Snyder pose for a picture after President Snyder receives the official gavel during the 22nd Annual Awards Ceremony and Member Business Meeting.



A Dine-Around group meets in the lobby of The Fairmont and prepares to venture out to their dining destination.

AWARDS PRESENTED AT THE 2015 MEMBER BUSINESS MEETING

PRESIDENT'S AWARD

The President's Award is presented 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 the value of HRQOL research; promotion or execution of HRQOL research or other scholarly activities; and facilitating or furthering policy initiatives that have an impact on HRQOL.

The 2015 ISOQOL President's Award was presented by President Galina Velikova to Carol M. Moinpour, PhD, United States. Dr. Moinpour has made notable contributions to the field of health-related quality of life research and ISOQOL.



Past-President Carol Moinpour, winner of this year's President's Award, poses with Past-President Diane Fairclough and Past-President David Feeney.

ISOQOL EMERGING LEADER AWARD IN HONOR OF DONNA LAMPING

The Emerging Leader Award recognizes ISOQOL members who have been active in an ISOQOL committee, special interest group (SIG), task force or working group for at least 2 years, and who have shown exceptional leadership skills and potential.

The 2015 recipient of the ISOQOL Emerging Leader Award in Honor of Donna Lamping is Bellinda L. King-Kallimanis, PhD, United States. President Galina Velikova presented the award to Dr. King-Kallimanis at the Awards Presentation during the Members Business Meeting.



Bellinda L. King-Kallimanis receives the Emerging Leader Award - In Honor of Donna Lamping, presented by Madeline King.

ARTICLE OF THE YEAR 2014 IN QUALITY OF LIFE RESEARCH,

Since 2003, ISOQOL has awarded the "Article of the Year" Award to recognize and honor the single best article dedicated to health-related quality of life (HRQL) research published in *Quality of Life Research* journal during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that advance state-of-the-art science in HRQL theory, methods, clinical application, or policy.

First Place

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

Finalists:

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

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

NEW INVESTIGATOR & STUDENT PRESENTATION AWARDS

New Investigator Oral Presentation Award

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

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

Continued on next page.

New Investigator Poster Presentation Award

Eithne Sexton, Trinity College, Dublin, Ireland

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

Student Oral Presentation Award

Elena Tsangaris, MSc, McMaster University, Canada

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

Student Poster Presentation Award

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

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

OUTSTANDING POSTER ABSTRACT AWARDS

The top six (6) posters that scored the highest during the ISOQOL 22nd Annual Conference abstract review process were recognized with a ribbon posted on their poster board and were invited to display their poster throughout the entire conference and present in front of a panel of judges and the attendees at the Annual Conference.

Outstanding Poster Abstract Award Winner:

Skye P. Barbic, Post-Doctoral Fellow, Faculty of Medicine

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

Outstanding Poster Abstract Award Finalists:

Antoine Regnault; Ian Porter, PhD; Ellis Chow, MBA; Haomiao Jia; San Keller, PhD



PROMIS
HEALTH
ORGANIZATION

SAVE THE DATE

PHO Annual Conference

October 23-24, 2016

Radisson Blu Scandinavia Hotel

Copenhagen

www.promishealth.com

A HUGE THANK YOU

TO OUR DEPARTING ISOQOL BOARD MEMBERS FOR THEIR PROFOUND LEADERSHIP AND DEDICATION.



Andrea Pusic, MD MHS
Memorial Sloan Kettering Cancer Center
New York, NY, United States



Silke Schmidt, PhD
University of Greifswald
Greifswald, Germany



José (Chema) Valderas, MD PhD
University of Oxford
Oxford, United Kingdom



Hwee Lin Wee, PhD
National University of Singapore
Singapore

**AND THE WINNER OF THE 22ND ANNUAL CONFERENCE
EVALUATION SURVEY AMAZON.COM GIFT CARD IS...**

Dr. Ronald Hays!
Congratulations!

ISOQOL CAREER CENTER

EMPLOYERS, THE PERFECT ISOQOL CANDIDATE
COULD BE CLOSER THAN YOU THINK!

Employer Benefits

- Access highly-qualified professional candidates
- Generate high return on recruitment advertisement spending
- Easy-to-use job posting and resume searching capabilities
- Only pay for resumes of interested candidates
- Application tracking and management capabilities
- Access to job board networks for broader job distribution to candidates
- User-friendly template system

jobs.isoqol.org

WE ARE PLEASED TO ANNOUNCE THE ADDITION OF NEW SPECIAL INTEREST GROUPS TO ISOQOL, THE CANADA-PRO SIG AND THE AUSTRALIA SIG!

AUSTRALIA SIG:

The Australia SIG brings together Australian-based researchers in the field of quality of life research. Given geographical remoteness of Australian quality of life researchers from colleagues in the northern hemisphere, the SIG fills a need for a local-based organization of like-minded individuals. We aim to:

- Foster the connections between local researchers
- Provide a forum for exchange of ideas
- Facilitate development of collaborative opportunities
- Promote discussion and dissemination of current and evolving methodologies in quality of life research
- Support emerging local researchers working in the area of quality of life research

Quality of life researchers residing in Australasia and Asia-pacific region are invited to join the Australia SIG.

CANADA-PRO SIG:

The Canada-PRO Special Interest Group members are a diverse group of researchers and clinicians with a common interest in promoting patient reported outcomes (PRO) research and use in Canada. Building on initial efforts of the co-leaders and informal meetings at ISOQOL, we will discuss methodological issues and PRO developments, and generate new ideas to move PRO forward in Canada. Initial goals are to identify priority issues for PRO applications in clinical practice, research, and population monitoring, facilitate networking for Canadian researchers and clinicians, and provide support for students and fellows, new investigators and first time attendees at ISOQOL. Our first meeting will be to develop a shared vision for the group and plan future activity.



PATIENT ENGAGEMENT 2015: TURNING THE 'DREAM' OF PATIENT ENGAGEMENT INTO A REALITY!

Following the success of ISOQOL 2014 in Berlin where ISOQOL hosted its first two Patient Engagement scholars – Anne Lyddiatt and Sam Brace-MacDonnell, the ISOQOL Executive Committee approved an application request from the PE SIG for continued funding for this exciting and pioneering initiative. Following advertisement of the scholarships during Spring 2015, there was yet again an excellent response from the membership, recommending 12 high quality patient applications. The scholarship committee, chaired by Professor Sam Salek and Gloria Juárez, awarded the PE scholarships to two outstanding scholars - Amye Leong and Mario Di Carlo, who, through good humour and rigorous debate made their presence well and truly known throughout the conference.

Amye and Mario participated in a range of activities including as panel members on the IAC symposium and contributors to the Clinical Practice and Young Investigators SIGs – and of course, to the Patient Engagement SIG! In addition, they truly contributed to the liveliness of the two breakfast round-table meetings chaired by Susan Bartlett and Lena Ring, undoubtedly enriching the outcomes of the sessions!

The PE SIG meeting was supported by many and an enthusiastic debate followed the presentations prepared by the PE SIG co-chairs, Sam Salek and Kirstie Haywood. The session closed with clear words of wisdom from our PE scholars, encouraging ISOQOL in the further development of its PE activities. It is clear that there is much passion, experience and expertise pertaining to PE within the ISOQOL membership, and

a great potential for forging strong alliances with external groups undertaking and leading in similar activities. The PE SIG is looking forward to developing strong and sustainable programmes of work which will benefit both the ISOQOL membership and wider community.

It was clear through feedback to both Amye and Mario, and to members of the PE SIG, that ISOQOL participants valued the contribution and presence of our PE scholars. It is hoped that, following the positive report of the PE Taskforce and support from the ISOQOL Board of Directors, this initiative and a number of other short-, medium-, and long-term PE activities

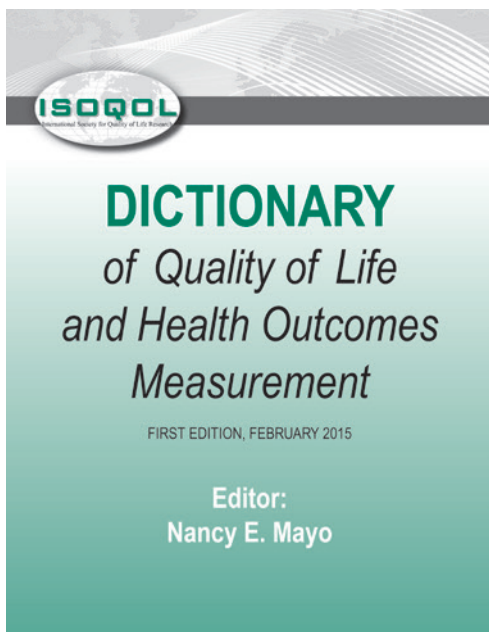
will build on the success of the last two years. In doing so, the PE SIG will seek to continue to work together with our past and future PE scholars in realising the dream of Patient Engagement being fully embraced by ISOQOL and its membership, becoming fully integrated into all activities of the organisation.

“Patients truly wish to partner with researchers for the common good of all parties” (Mario Di Carlo).

Sam Salek, Kirstie Haywood, Amye Leong, Mario Di Carlo



Patient Partners Amye Leong and Mario di Carlo pose with Kirstie Haywood and Patient Engagement SIG Chair Sam Salek.



WE ARE PLEASED TO ANNOUNCE THE PUBLICATION OF THE ISOQOL DICTIONARY OF QUALITY OF LIFE AND HEALTH OUTCOMES MEASUREMENT!

Over 600 definitions of terms related to quality of life and health outcomes measurement, study design, and analysis are covered, along with over 350 references. Look up a term, or read the Dictionary from A to Z to see the vast array of terms and concepts that apply to this important field.

Many thanks to Editor Nancy E. Mayo, PhD, for her dedication and hard work on this publication.

Purchase your e-version or print version now at www.isoqol.org. All profits go to support ISOQOL's activities to advance the scientific study of quality of life and other patient-centered outcomes.

THANK YOU TO OUR 22ND ANNUAL CONFERENCE SPONSORS





Validated translations of PRO instruments equal validated results.

Corporate Translations' state-of-the-art linguistic validation process is modeled after the FDA guidance document and the ISPOR Good Practice Guidelines for the translation and validation of PRO instruments. As pioneers in linguistic validation, we have developed an array of support services designed to help our clients utilize PRO instruments in their global clinical trials. Corporate Translations has completed over 10,000 PRO instrument translations in a wide range of languages and therapeutic areas. That's why we are the preferred supplier of ISO 9001:2008 translation and linguistic validation solutions to the world's leading life science companies.

www.corptransinc.com
1-855-727-6003

Face Validation | Harmonization | Back Translation | Cognitive Debriefing | ePRO Consultation

WELCOME TO OUR NEWEST ISOQOL MEMBERS

Sayako Akiyama
 Kimberly E. Alexander, PhD
 Andreas Auensen, MD
 Rania A. Azmi
 Jennifer N. Baldwin
 Vasiliki Balta
 Nick Bansback
 Fraser D. Bocell, PhD
 Jan R. Boehnke
 Patrick Bonnet
 Mohamed Boucekine
 Jason Brunetta
 Wei Chen
 Lung-I Cheng, PhD
 Chanadda Chinthammit,
 BSPHarm, MS
 Nicole Cook
 Tristan A. Cordier, MPH
 Nadia Corsini
 Krister Cromm
 Laura M. Cupples, MA
 Kristen Davidge
 Chinmay Deshpande
 Jacob Devine
 Anne-Marie Doyle
 Jiqian Fang
 Kate M. Fennell
 Gerard Flens
 Derek Ford
 Lisa M. Fornaresio, PhD
 Jared Foster
 Simone Freitag, PhD
 Sabina M. Gasper
 Haleh Ghavami
 Henriette Golke
 Jing Gu
 Chun Hao

Rika Hayashida, MS
 Jeffrey C. Henne
 Alejandra Herrera
 Agnes Hong, PharmD
 Zheng-kun Hou
 Anita M. Hubley
 Stanley Hum
 Amjad Hussain
 Sylvi Irawati
 Haku Ishida
 Tsuguo Iwatani
 Annikka Jensen, PhD
 Haomiao Jia
 Rebecca A. Johnson
 Namita Joshi, PhD
 Tom Karagiannis, PharmD
 Fiona Kennedy, PhD
 Rahul Khanna
 Naomi B. Knoble, PhD
 Michael Koller
 Rajesh V. Kumar, DNB
 Lisbeth G. Kvarme, PhD
 Jessica L. Lawson, MSc, MA
 Jennifer Le-Rademacher
 Joyce W. Lee
 Zheng Li, PhD, MPH
 Guiping Liu, PhD
 Hawys Lloyd-Hughes
 Alyssa Macedo
 Fong Yiu Mak
 Rajiv Mallick
 MaryKay Margolis, PhD
 Janet McCabe, RN, MEd, PhD
 Nathan McClure
 Sean Mikles
 Fiona E M Miller, BA (Joint Hons)
 Paivi Miskala

Tempei Miyaji
 Carolina Moriello, MSc
 Arto Ohinmaa
 Yuichi Oi
 Krystallia Pantiri
 Louise Pape Larsen, MHSc
 Sunju Park
 Sheryl M. Pease, MBA, PMP
 Kjell I. Pettersen, MD PhD
 Laura C. Pinheiro, MPH
 Ian Porter, PhD
 Caroline M. Potter, DPhil
 Angela P. Presson, PhD
 Kim Rand-Hendriksen, PhD
 Hilde Randa, MSc
 Leo D. Roorda
 Michael Scanlon
 Liv Marit Valen Schougaard
 Rohini Sen
 Sneha Shankar
 Takeru Shirowa, PhD
 Hannah Shucard
 Matthew F. Sidovar
 Jeffrey L. Solomon
 Chihyoung Son, MD PhD
 Matt Stiefel
 David S. Sugano, Dr.PH.
 Jessica A. Thilaganathan
 Chloe Tolley
 Natasha Wickert, MSc
 Alex Wong, PhD, DPhil
 Jie You, MD PhD
 Yu Yulan
 Chong Zhang
 Jun Zou



UPCOMING WEBINARS

CLINICAL OUTCOMES ASSESSMENT IN A MULTI-CULTURAL CONTEXT: MEASUREMENT CHALLENGES AND RECOMMENDATIONS

Thursday, 17 December 2015 at 11:00 am - 12:30 pm EST (90 minutes)

Presented by: The Psychometric and Translation & Cultural Adaptation Special Interest Groups (SIGs)

Clinical Outcome Assessment (COA) in an international study requires particular caution due to the differences in language, culture, education, and standards of care. These differences are likely to be sources of variability in measurement outcomes. If not adequately managed, this variability can potentially jeopardize the accurate capture of the targeted concepts, and make the demonstration of treatment benefit more difficult. Cross-cultural equivalence of COAs used in international studies is, therefore, of particular importance. The webinar will present the challenges and discuss possible solutions related to this question.

A certain amount of cross-cultural variation can be prevented using qualitative methods during the development and translation of a COA. Content can be considered from a cross-cultural perspective using multi-cultural patient interviews and techniques such as Translatability Assessment. Evaluation of cross-cultural equivalence of a measure has traditionally been accomplished using quantitative methods. These methods include investigation of differential item functioning and measurement invariance. Once data have been collected and evaluated quantitatively, further investigation can be conducted qualitatively to focus on specific areas of variability that raise questions about equivalency or comparability. Once the cross-cultural equivalence of a COA used in a multicultural study has been tested and variability addressed using both qualitative and quantitative methods, a more clear demonstration of a treatment benefit can be ascertained with confidence in the results.

These topics and methods for early qualitative and quantitative evaluation will be described, using examples, by speakers from both the Translation and Cultural Adaptation and the Psychometrics Special Interest Groups of ISOQOL. The presentation will be followed by an interactive Q&A session during which the speakers will address questions from the audience.

LEARNING OBJECTIVES:

- To anticipate potential measurement issues related to cultural differences in the context of a multi-cultural study
- To outline a strategy to investigate cross-cultural equivalence of COAs using appropriate quantitative and qualitative methods

FEATURED PRESENTERS:

Stacie Hudgens, MA (AbD) Managing Partner, Strategic Lead for Clinical Outcome Solutions

Antoine Regnault, PhD Research Director for Mapi

Lori McLeod, PhD Head, Psychometrics for RTI Health Solutions

Mona Martin, RN MPA Executive Director for Health Research Associates Inc.

Sonya Eremenco, MA Director, ePRO New Products for Evidera, Inc.



Continued on next page.

RESPONSE SHIFT: A REVIEW OF THE LITERATURE

Date: Thursday, 14 January, 2016 at 11:00 am – 12:30 pm EST

Response shift (RS) refers to changes in an individual's self-evaluation of his/her health status and quality of life because of changes in internal standards, values, or concepts. According to Sprangers and Schwartz (1999), there are three types of RS: (a) recalibration (change in internal standards of measurements), (b) reprioritization (change in prioritization of component domains constituting the target construct), and (c) reconceptualization (redefinition of the target construct). RS has been investigated in a number of medical conditions where the diagnosis, or treatment, or other factors may act as catalysts that induce change in an individual's self-perceptions of health status and quality of life. It has been shown that response shift could influence assessments of treatment effects and changes in patients' health status and quality of life over time.

A number of methods for measuring and detecting response shift have been developed and tested. Our research team conducted a scoping review on the literature on response shift. In this webinar, based on the results of our scoping review, participants will learn about the literature on response shift, the different types of response shift, the different statistical methods for detecting response shift, and future directions of research in the field.

LEARNING OUTCOMES/OBJECTIVES:

- Participants will learn about the results of our scoping review of the response shift literature
- Participants will be able to explain the potential influence that response shift has on the assessment of treatment effects, as well as assessment of changes in patients' health status and quality of life over time
- Participants will be able to critically evaluate and consider the different commonly used statistical methods of response shift
- Participants will be able to describe the role of response shift in measurement validation (with an emphasis on the modern theories of measurement validity).

FEATURED PRESENTERS:

Rick Sawatzky, PhD, RN, Associate Professor and Canada Research Chair, School of Nursing, Trinity Western University

Tolu Sajobi, PhD, Assistant Professor, Department of Community Health Sciences, University of Calgary

Eric Chan, PhD, Research Associate, School of Nursing, Trinity Western University

Ronak Brahmabhatt, MBBS, MPH



HEALTH UTILITIES INDEX® (HUI®)

**Leading multi-domain instrument for
PROs, QALYs, RCTs, CEAs, CUAs and more ...**

**For reliable, valid and responsive measurement of
health status and HRQL.**

**Domains of vision, hearing, speech, ambulation, dexterity,
emotion, cognition, pain & discomfort.**

Recognized by authorities worldwide.

www.healthutilities.com

ISOQOL HONORS TOP REVIEWERS

By Carolyn E. Schwartz, Sc.D.^{1,2}, and Frans J. Oort, Ph.D.³ — Co-Editors-in-Chief, *Quality of Life Research*

“Nothing is a waste of time if you use the experience wisely.” — Auguste Rodin

So much of what matters in our path as researchers depends on the good will and generosity of others. When we are students, studying and training to be professionals, we rely on our mentors to shape and guide us. Once we have completed this training and find positions in our field, we rely on more seasoned faculty or colleagues to help us navigate and make good decisions on how to spend our time, in what directions to invest our efforts, and with whom to build collaborations. Once we have data to report, we rely on kind editors and anonymous reviewers to help us on our way to achieving what is in fact our key commodity: publications in peer-reviewed professional journals.

With the increasing numbers of journals, the demand for reviewers has become particularly acute. As editors, we can attest to a precipitously declining reviewer-acceptance rate: too many competing demands make many decline invitations to review. This lengthens the review process considerably: at present, we are finding that we have to invite about ten reviewers to get two to agree to review a manuscript.

At *Quality of Life Research*, ISOQOL’s frontline journal in the field of patient-reported outcomes, we are looking into ways to acknowledge and reinforce reviewers for their efforts on the journal and in the field. As a first step in this path, we initiated this year at the ISOQOL annual meeting a new badge ribbon for our top reviewers. This ribbon graced the ISOQOL conference badge for all to see (and envy, we hope). Those top reviewers are shown in Table 1. These are people who reviewed at least six manuscripts in the past year, and provided on-time and high-quality reviews. The journal’s top functioning is in large part due to their efforts.

As a next step, we will modify the role of our International Advisory Board to be a core of experts in the field who commit to reviewing at least six manuscripts per year on time and with high-quality reviews. We are also looking into possible venues for training so that more potential reviewers know how to do a review properly and efficiently. If you have ideas about the best venue for such a training program, please contact us directly (carolyn.schwartz@deltaquest.org and oort.qolr@uva.nl).

If you would like to step up as a top reviewer for *Quality of Life Research*, please go to the journal website (<http://www.editorialmanager.com/qure/default.aspx>) and register as a reviewer; and/or update your profile to make sure your contact information is correct, and your areas of expertise are up-to-date. This will help us to find you.

And thank you to the 70 people listed in Table 1. We are very grateful for your efforts...

1 DeltaQuest Foundation, Inc., Concord, MA, USA
2 Tufts University School of Medicine, Boston, MA, USA
3 University of Amsterdam, Amsterdam, The Netherlands

TABLE 1. TOP REVIEWERS FOR QUALITY OF LIFE RESEARCH		
Name		Institution
Jenny	Abanto	University of Sao Paulo
Edimansyah	Abdin	Institute of Mental Health
Jordi	Alonso	IMIM-Hospital del Mar Research Institute, Barcelona, Spain; CIBER de Epidemiology Salud Pública (CIBERESP), Spain; Dpt. Experimental and Health Sciences, Pompeu Fabra University (UPF), Barcelona, Spain;
Reza	Amini	University of North Texas
Adin-Cristian	Andrei	Northwestern University
Thiago	Ardenghi	universidade federal de santa maria-rs
Alarico	Ariani	Azienda Ospedaliero Universitaria di Parma - Ospedale Maggiore di Parma

Continued on next page.

ISOQOL Honors Top Reviewers, Continued from previous page.

Juan Ignacio	Arraras	Complejo Hospitalario de Navarra
Chris	Barker	Chris Barker Statistical Planning And Analysis Services, Inc
Ivan	Barofsky	The Quality of Life Institute
Melissa	Benton	University of Colorado, Colorado Springs
Christine	Blome	University Medical Center Hamburg-Eppendorf
Jan	Boehnke	University of York
Kholoud	Bokhary	University of New South Wales; King Saud University
W. Jeff	Bryson	Alabama Psychological Services Center
Julio	Cabrero-Garcia	University of Alicante
Joseph	Cappelleri	Pfizer Inc
Sungkun	Cho	Chungnam National University
Daniel	Costa	University of Sydney
M.	Dempster	Queen's University Belfast
Michael	Edwards	The Ohio State University
David	Ellard	Coventry University
David	Feeny	McMaster University
Erin	Fekete	University of Indianapolis
Eva	Fenwick	University of Melbourne
Barbara	Gandek	University of Massachusetts Medical School
Pranav	Gandhi	University of Florida
Laura	Gibbons	University of Washington
Eva	Grill	Ludwig-Maximilians-Universit MÄnchen
Ron	Hays	UCLA Department of Medicine
Axel	Hirsch	Retired
Steven	Hoffman	University of Texas at San Antonio
Wilma	Hopman	Kingston General Hospital
Hsien-Yu	Hsia	Jin-Wen University of Science and Technology
Pilar	Isla Pera	University of Barcelona (Spain)
Donna	Jeffe	Washington University School of Medicine
Angelos	Kassianos	University of Cambridge
Anna	Kieszkowska-Grudny	European Health Centre Otwock
Henrik	Lauridsen	Faculty of Health Science, University of Southern Denmark
Christopher	Lee	BC Cancer Agency
Michael	Lensing	Oslo University Hospital
Ling-Yi	Lin	National Cheng Kung University
Chaojie	Liu	La Trobe University
Cameron	McIntosh	Public Safety Canada

Continued on next page.

ISOQOL Honors Top Reviewers, Continued from previous page.

Wieneke	Mokkink	VU University Medical Center Amsterdam
Peter	Newcombe	University of Queensland
Sandra	Nolte	Charité - Universitätsmedizin Berlin
Antonio	Oliveira	Centro Hospitalar Gaia-Espinho
Muirne	Paap	University of Oslo
Geraldine	Padilla	University of California San Francisco
Helen	Parsons	The University of Warwick
Brigida	Patricio	School of Allied Health Technologies, Polytechnic Institute of Porto
Nalin	Payakachat	University of Arkansas for Medical Sciences College of Pharmacy
Thomas	Perneger	Geneva University Hospitals
JÁrg	Richter	Center for Child and Adolescent Mental Health
Christopher	Sampson	University of Nottingham
Veronique	Sebille	University of Nantes, Faculty of Pharmacy
Cathy	Sherbourne	RAND
Vasily	Shuvaev	Russian Research Institute Hematology and Transfusiology
Susanne	Singer	University Medical Centre Mainz
Richard	Skolasky	Johns Hopkins University School of Medicine
Caroline	Terwee	VU University Medical Center
Nada	Tomasovic Mrcela	Eko oporaba
James	Varni	Texas A&M University
Per	Wandell	Karolinska Institutet
Carlos	Wong	The University of Hong Kong
Penny	Wright	University of Leeds
Susan	Yount	CORE, Evanston Northwestern Healthcare and Robert H. Lurie Comprehensive Cancer Center, Northwestern University, Chicago, IL
Hatice	Zahran	Centers for Disease Control and Prevention





ISOQOL
23rd Annual Conference
19-22 October 2016
COPENHAGEN

DENMARK



**Abstract Submission
Deadlines:**

Workshop & Symposium
Submission—29 January

Oral & Poster Abstract
Submission—18 April

isoqol.org