

# Quality of Life

QUARTERLY

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VOLUME 18 ISSUE 3

Newsletter for  
ISOQOL Members  
SUMMER 2012

## ADVERTISING INFORMATION

Contact Marketing Director,  
Jean Wenzel  
jwenzel@isoqol.org



## PRESIDENT'S MESSAGE

Bryce B. Reeve, PhD



Dear ISOQOL Friends,

I am very excited to hear of the great plans for the 19th ISOQOL Annual Conference in Budapest.

You will not want to miss this historic event. The scientific program committee (led by co-chairs Sara Ahmed and Fabio Efficace) have brought together an incredible set of speakers that will cover a broad range of highly informative and cutting edge topics in health-related quality of life (HRQOL) research. Prior to the conference, you can expand your knowledge and skills attending a couple of the highly acclaimed workshops offered. I most enjoy the opportunity to learn about fellow ISOQOL members' research findings during oral presentations and poster sessions, and to meet old friends and make new friends at the meeting. Our conferences always end in a wonderful dinner and party to celebrate a

successful conference and to kick off another exciting year for ISOQOL.

In the previous ISOQOL newsletter, I discussed one of the goals of the April 2012 meeting of the ISOQOL Board of Directors was to begin to develop a short and long term strategic plan for the organization as it relates to ISOQOL's mission to advance the scientific study of HRQOL and other patient-centered outcomes. Our discussions were informed by the contribution of ideas we received through our request to ISOQOL special interest groups, committees, and individual members. We received excellent recommendations of ways to better utilize ISOQOL's existing resources (e.g., website, conferences, newsletters, and the *Quality of Life Research* journal) and great suggestions for expanding ISOQOL into new directions.

One of the exciting new directions for ISOQOL is to provide distance learning opportunities to its members and to the public. Distance learning is made readily available through

*Continued on page 2.*



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

*Newsletter Editor*

**Ana Popielnicki, BA, USA**

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

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*President's Message, Continued from page 1.*

advances in internet technology, and addresses the challenges of conducting more face-to-face workshops due to shrinking travel budgets. While the concept of distance learning is not new and is offered by many other organizations, ISOQOL is in a distinct position to provide high quality educational programs on HRQOL methodology and research strategies, and to encourage active dialog on events or initiatives of importance to its members. One critical area is the application of patient-reported data in the healthcare delivery setting to enhance communication between patients and clinicians and to improve patient care. Webinars are currently being planned to build off the recent release of ISOQOL guidance on this topic. ISOQOL's "User's Guide to Implementing PRO Assessment in Clinical Practice" can be found on the homepage of our website.

The strategic planning session was also informative for the board to identify where there may be gaps in terms of ISOQOL fulfilling its mission. One key stakeholder group that we have not done enough to reach out to is patient advocacy groups. As the healthcare field continues to evolve to become more patient-centered, ISOQOL for close to 20 years has concentrated on how to better capture the experiences and perspectives

of patients and their caregivers. We need to find better ways to connect with patient advocacy groups so they can learn of our work and we can learn of their needs. In addition, it will be the patient advocacy groups' voices that will influence policy makers and funding agencies. The extent that ISOQOL may serve as an advisor to the advocacy groups on better ways to enhance patient participation in research, the better the healthcare field can enhance the care they provide to patients.

There is much more that came from the ISOQOL Board's strategic planning meeting that will come out over the next few months and years. To be successful, these ideas are dependent on your support and contribution. It is your expertise and perspectives that make ISOQOL such a wonderful and vibrant organization. We also rely on you to let us know of important opportunities or collaborations we should be aware of to help fulfill our mission. You are a critical member of ISOQOL and I look forward to working together with you.

Sincerely,

Bryce



## FROM THE EDITOR'S DESK

By: Ana Popielnicki

Dear ISOQOL Family:

I am very pleased to welcome you to our summer edition! We have a rich issue full of wonderful articles, links, and news from all our colleagues and industry stakeholders around the globe.

There are many exciting initiatives, educational opportunities, and strategies being planned by various groups within the Society, with the full support and guidance of our Board of Directors – please see our President's message and a brief report on the BoD meeting of this past April to find out more details and how you can get involved.

As our members strive to fulfill ISOQOL's mission, they are always ready to collaborate when guidance documents reviews and recommendations are needed. Please check out an article from Kathy Wyrwich on the ISOQOL Task Force recent review and input on the Center for Medical Technology Policy (CMTP) draft guidance document (Recommendations for Incorporating Patient-Reported Outcomes into the Design of Clinical

Trials in Adult Oncology). You can also take a look at the final document by clicking the link included in the article.

Our featured article is brought to you by our contributing publication, PharmaVoice. Author Robin Robinson interviews several industry experts and compiles a wealth of information in "Post-approval Studies: More Critical and Challenging Than Ever" – links to the PDF for download, as well as to the current digital edition of PharmaVoice, are accessible in this issue.

In keeping with our patient-centered approach, we bring you an interesting article by Drs. Ahmad and Tsang, posted originally on the HealthAffairs blog and linked here – please see their piece on PROMises, PROMises: Finally, Quality We Really Care About.

We have news and updates about our Annual Conference in Budapest, and an invitation from the Ibero-American Section for their congress

this coming November/December in Brazil – our colleagues Virginia Visconde and Maria Alves are coordinating this event. This issue also brings you an update from the Communications Committee on the website redesign project.

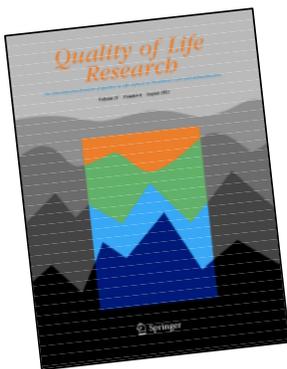
Please look for the list of nominees for Article of the Year from the Quality of Life Research Journal, our traditional Calendar of Events, and various announcements on different activities and ways to contribute.

We are always happy to hear from you – do send your questions, suggestions, submissions and comments to [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line. Now sit back, relax, and happy reading!

Warm regards,



Ana



### CALL FOR ASSOCIATE EDITORS

The journal *Quality of Life Research* is seeking to recruit four new Associate Editors to begin a three-year term by October 1, 2012. Eligible persons will have published scientific works in *Quality of Life Research*, will have served as a reviewer in good standing for the journal, and will be committed to working on our editorial board team to improve the quality and efficiency of manuscript processing as well as the impact of the journal. If interested, please send to the Co-Editors-in-Chief by close of business July 31, 2012, your updated curriculum vitae and a cover letter stating your background in quality of life research, your areas of expertise, and your reasons for seeking the role of Associate Editor for the journal. We are in particular seeking Associate Editors with expertise in utilities, generalists, oral health-related quality of life, neurology, and rehabilitation.

Thank you.

**Carolyn Schwartz, Sc.D., and Dennis Revicki, Ph.D.**  
[carolyn.schwartz@deltaquest.org](mailto:carolyn.schwartz@deltaquest.org)  
[dennis.revicki@unitedbiosource.com](mailto:dennis.revicki@unitedbiosource.com)

## ISOQOL TASK FORCE PROVIDES REVIEW AND INPUT FOR RECENT GUIDANCE DOCUMENT: *RECOMMENDATIONS FOR INCORPORATING PATIENT-REPORTED OUTCOMES INTO THE DESIGN OF CLINICAL TRIALS IN ADULT ONCOLOGY*

Kathy Wyrwich (USA)

In December 2011, the US-based Center for Medical Technology Policy (CMTP) released a draft guidance document titled *Recommendations for Incorporating Patient-Reported Outcomes into the Design of Clinical Trials in Adult Oncology*. Intended to inform decisions by patients, clinicians and payers, the CMTP supports the development of Effectiveness Guidance Documents (EGDs) to provide specific recommendations on the design and reporting of prospective clinical studies, and in this case, the appropriate inclusion of patient-reported outcome measures in the design and implementation of clinical comparative effectiveness research in adult oncology. As stated by the authors, *“These recommendations are intended to set a minimum standard to ensure that data collection allows for examination of patients’ directly reported experiences in diverse studies of treatment effectiveness and outcomes in oncology.”* These draft recommendations were developed through the participation of many important contributors, which included: patient advocacy groups, medical oncologists, pharmaceutical companies, US government agencies, public and private payers, drug

compendia, clinical research entities, statisticians, and academics.

At the time of this draft document’s release, the EGD’s authors contacted ISOQOL to request a review of this document, and to provide comments and input on the draft guidance. Under the leadership of ISOQOL’s Executive Committee, a short-term task force was quickly formed headed by Board Member Kathy Wyrwich, and an invitation was sent to all ISOQOL members for their volunteer participation in this undertaking to prepare ISOQOL’s formal response. Collin Johnson (UK), Bill Lenderking (USA), Josephine Norquist (USA) and Dennis Revicki (USA) accepted this challenge and its short turnaround time frame. In addition, Carol Moinpour (USA), Bryce Reeves (USA) and Sharon Wood-Dauphinee (Canada) provided a critical review of the Task Force’s response before it was submitted to CMPT. These members demonstrated how ISOQOL’s experience and collective knowledge can be quickly mobilized to provide valuable feedback for important initiatives in our field.

On May 20, 2012, the revised final document was released and is now

available at the CMPT’s website: <http://www.cmtptnet.org/wp-content/uploads/downloads/2012/05/PRO-EGD.pdf>. Developed through an extensive consultative process involving a broad range of experts and stakeholders, including ISOQOL’s formal feedback, the final recommended methods aimed to balance validity with relevance and feasibility, in order to provide decision-makers with a reasonable level of confidence that the intervention improves net health outcomes. In many ways, the May 2012 EGD demonstrates that the ISOQOL Task Force’s input was recognized.

All ISOQOL members are encouraged to review this EGD and its recommendations “intended to improve the process by which studies in adult cancer patients are conducted to provide evidence that is helpful to patients and decision-makers.” The EGD stresses the 15 recommendations in three key areas when incorporating patient-reported outcomes into the design of clinical trials in adult oncology: 1) selection of measures, 2) implementation methods, and 3) data analysis and reporting.

## POST-APPROVAL STUDIES: MORE CRITICAL AND CHALLENGING THAN EVER

By Robin Robinson

### PHASE IV DATA ARE IN HIGH DEMAND BY MORE STAKEHOLDERS.

As the need for post-approval data reaches a critical point, the industry explores the multiple options and struggles to determine which methods are best for collecting and analyzing important data. There are as many ways to collect data with today's real-time technologies as there are data to collect, and not one single process can meet all of the needs of post-approval stakeholders.

Several of our experts point to patient registries as a viable approach and add that both prospective and

retrospective techniques will remain important. Therefore, the best method is not a particular approach but rather a careful evaluation of the fundamental questions to be addressed by each research effort, and an understanding of how the information will be employed. In other words, our experts say, start with the end in mind.

### Finding the Right Approach

In summary:

1. Registries provide opportunity for flexibility and adaptability.
2. Registries have real-world focus.
3. A single approach will not meet every post-approval study requirement.

**\*\* To read the complete article, please click here:** [http://www.pharmavoice.com/pdfs/2012/pv-0612/PV0612\\_PostapprovalStudiesIQ.pdf](http://www.pharmavoice.com/pdfs/2012/pv-0612/PV0612_PostapprovalStudiesIQ.pdf)

**\*\* If you would like to browse PharmaVoice's current digital edition, please click here:** <http://www.pharmavoice.com/content/digitaledition.html?pg=1>

## PROMISES, PROMISES: FINALLY, QUALITY WE REALLY CARE ABOUT

By: Faraz Ahmad & Thomas Tsang

Patient-centered care and patient engagement have become central to the vision of a high value health delivery system. The delivery system is evolving from a fee-for-service transactional payment model to a value-based purchasing model using outcome data and quality improvement and attainment. The Centers of Medicare and Medicaid Services (CMS) and private payers have spurred delivery redesign of networks that focuses on a set of clinical quality measures and patient care experiences along with efficiency measures.

However, the questions we ultimately really care are: "Did I get better? Am I healthier?"

**\*\* To read the complete post, please click on the link below:**

<http://healthaffairs.org/blog/2012/06/25/promises-promises-finally-quality-we-really-care-about/>  
Post by Faraz Ahmad and Thomas Tsang, "PROMises, PROMises: Finally, Quality We Really Care About", Health Affairs Blog, posted by Faraz Ahmad on June 25, 2012 @ 2:14 pm. Copyright ©2010 Health Affairs by Project HOPE – The People-to-People Health Foundation, Inc.

## CALENDAR OF EVENTS—JULY

- *July 18 - Jul 21*  
**ECHE 2012 Progress in Health Economics**  
Zurich, Switzerland  
<http://www.eche2012.ch/>
- *July 19 - Jul 20*  
**5th Annual Congress on Access Programs for Investigational and Pre-Launch Drugs**  
Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc12193>
- *July 19-21, 2012*  
**20th Annual Health Forum and the American Hospital Association Leadership Summit 2012**  
San Francisco, CA, USA  
[http://www.healthforum.com/healthforum/html/conferences/12Summit/Sumit\\_home.html](http://www.healthforum.com/healthforum/html/conferences/12Summit/Sumit_home.html)
- *Jul 20 - Jul 21*  
**7th AIDS and Economics Pre-Conference**  
Washington, D.C., USA  
<http://www.healtheconomics.org/conferences/2012/07/20/7th-aids-and-economics.html>
- *Jul 22 - Jul 24*  
**The 2nd Annual California RISE Summit on 'Integrating Risk Adjustment and Quality Measures'**  
Westlake Village, CA, USA  
<http://www.frallc.com>
- *July 22-27*  
**The XIXth International AIDS Conference**  
Washington, DC, USA  
[http://www.who.int/mediacentre/events/meetings/2012/AIDS\\_conference/en/](http://www.who.int/mediacentre/events/meetings/2012/AIDS_conference/en/)
- *Jul 24 - Jul 25*  
**2nd Drug Delivery Global Summit**  
London, UK  
<http://www.appelconsulting.co.uk/events/drug-delivery-1>
- *Jul 24 - Jul 25*  
**The World Health Care Congress on Government Programs and Policy**  
Washington, D.C., USA  
<http://worldcongress.com/>
- *Jul 30 - Jul 31*  
**Dual Eligibles Best Practices Summit**  
Orlando, FL, USA  
<http://www.govhealthit.com/event/dual-eligibles-best-practices-summit>
- *Jul 30 - Jul 31*  
**Pharmaceutical and Biotech Managed Markets and Payer Marketing Strategies Conference**  
Chicago, IL, USA  
<http://www.q1productions.com/managedmarkets/>

## CALENDAR OF EVENTS—AUGUST

- *Aug 2 - Aug 3*  
**The World Congress 10th Annual Health Care Value Congress**  
Boston, MA, USA  
<http://www.worldcongress.com/events/HL12025/index.cfm?confCode=HL12025>
- *Aug 5-8*  
**AHRMM12 Annual Conference & Exhibition**  
San Antonio, TX, USA  
<http://www.arhmm.org>
- *Aug 6 - Aug 7*  
**Oncology Unmet Medical Need Forum**  
Philadelphia, PA, USA  
[http://aloeverajuce.hwize.com/oncology\\_unmet\\_medical\\_need\\_forum\\_6-7\\_august\\_2012\\_philadelphia\\_usa/](http://aloeverajuce.hwize.com/oncology_unmet_medical_need_forum_6-7_august_2012_philadelphia_usa/)
- *Aug 15 - Aug 17*  
**33rd NHESG meeting**  
Kuopio, Finland  
<http://www.healtheconomics.org/conferences/2012/08/15/33rd-nordic-health-eco.html>
- *Aug 27 - Aug 28*  
**4th Annual Pharmaceutical Reimbursement & Market Access Conference**  
Philadelphia, PA, USA  
<http://www.q1productions.com/RxReimb/Home.php>

## CALENDAR OF EVENTS—SEPTEMBER

- **Sept. 2 - Sept. 4**  
**ISPOR 5th Asia-Pacific Conference**  
Taipei International Convention Center  
Taipei, Taiwan
- **Sept 5 - Sept 8**  
**21st European Workshop on Econometrics and Health Economics**  
Lund, Sweden  
<http://www.york.ac.uk/res/herc/research/ew/index.htm>
- **Sept 10 - Sept 12**  
**17th Annual Summit on the Medicaid Drug Rebate Program & Other Public Sector Reimbursement Programs**  
Chicago, IL, USA  
<http://www.healthcareitnews.com/event/17th-annual-medicaid-drug-rebate-program-summit>
- **Sept 11 - Sept 13, 2012**  
**World Drug Safety Congress Europe**  
London UK  
<http://http://www.terrapinn.com/conference/drug-repositioning/index.stm>
- **Sept 13 - Sept 14**  
**Hospital Management Asia**  
Hanoi, Vietnam  
<http://www.clocate.com/conference/Hospital-Management-Asia-HMA-2012/30620/>
- **Sept 19 - Sept 21**  
**CBI's 15 Annual Registries and Post-Approval Studies Congress**  
Philadelphia, PA, USA  
<http://www.cbinet.com/conference/pc12155>
- **Sept 19 - Sept 20**  
**Reaching, Retaining & Serving Dual Eligible Beneficiaries**  
Scottsdale, AZ, USA  
<http://www.rasociety.org/conference.aspx?ccode=H150>
- **September 20-23, 2012**  
**NAHQ 37th Annual Educational Conference**  
Tampa, FL, USA  
<https://www.ecri.org/Conferences/Pages/NAHQ-2012.aspx>
- **Sept 25 - Sept 28**  
**Digipharm Europe 2012**  
London, UK  
<http://www.healthnetworkcommunications.com/2012/digipharm-europe/workshop-workshop-2-tuesday-25-september.stm>
- **Sept 25 - Sept 28, 2012**  
**The Pharma Marketing Show Europe**  
London, UK  
<http://www.healthnetworkcommunications.com/conference/pharma>
- **Sept 27 - Sept 28**  
**23rd Annual Health Economics Conference: Innovation**  
Stanford, CA, USA  
<http://www.healtheconomics.org/conferences/2012/06/15/call-for-papers-23rd-a.html>
- **Sept 28 - Sept 30**  
**Patient Reported Outcomes and Person Centered Care in Mental Health**  
Washington, D.C., USA  
<http://www.promentalhealth.org/events/proevent.htm>

### BIostatistician II – Cancer Clinical Trials

The American College of Radiology ([www.ACR.org](http://www.ACR.org)) seeks a Biostatistician II to support the Radiation Therapy Oncology Group's Symptom Management Team and to participate in related projects as needed. The candidate must have sufficient educational preparation to conduct prospective and retrospective statistical analyses of clinical trials and be fluent in SAS programming. Individuals with experience in a multi-center clinical trial setting, experience with Quality of Life/Patient Report Outcomes analyses, and dealing with missing data are strongly preferred. MS degree in Statistics and 6+ months of related experience required. Please apply online at [Biostatistician II](http://www.ACR.org), or you may submit your resume and salary history to: [hr@acr.org](mailto:hr@acr.org).

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**Congratulations to the Nominees**  
for the  
*Quality of Life Research Article*  
of the Year Award

The award will be presented during the Business Meeting at the Annual Conference on Friday, October 26.

**Bentley, TKG, et al.**

*Race and gender associations between obesity and nine health-related quality-of-life measures.*  
*Quality of Life Research* (2011) 20: 665-674.

**Brundage, M, et al.**

*Patterns of reporting health-related quality of life outcomes in randomized clinical trials: implications for clinicians and quality of life researchers.*  
*Quality of Life Research* (2011) 20:653 – 664.

**Bushmakin, AG, et al.**

*Applying area-under-the-curve analysis to enhance interpretation of response profiles: an application to sleep quality scores in patients with fibromyalgia.*  
*Quality of Life Research* (2011) 20:491-498.

**Haley, WE, et al.**

*Quality of life after stroke: a prospective longitudinal study.*  
*Quality of Life Research* (2011) 20:799 – 806.

**Hawton, A, et al.**

*The impact of social isolation on the health status and health-related quality of life of older people.*  
*Quality of Life Research* (2011) 20:57-67. Epub 2010 Jul 25.

**Herdman, M, et al.**

*Development and preliminary testing of the new five level version of the EQ-5D.*  
*Quality of Life Research* (2011) 20:1727-1736.

**Lacey, HP, et al.**

*Compared to what? A joint evaluation method for assessing quality of life.*  
*Quality of Life Research* (2011) 20:1169 – 1177.

**Lehmann, V, et al.**

*Suffering in long-term cancer survivors: An evaluation of the PRISM-R2 in a population-based cohort.*  
*Quality of Life Research* (2011) 20:1645-1654.

**Mavranezouli I, et al.**

*Using Rasch analysis to form plausible health states amenable to valuation:  
the development of CORE-6D from a measure of common mental health problems (CORE-OM).*  
*Quality of Life Research* (2011) 20:321 – 333.

**Peyre, H, et al.**

*Missing data methods for dealing with missing items in quality of life questionnaires:  
A comparison by simulation of personal mean score, full information maximum likelihood,  
multiple imputation, and hot deck techniques applied to the SF-36 in the French  
2003 decennial health survey.*  
*Quality of Life Research* (2011) 20:287-300.

**Schüz, B, et al.**

*What do people include when they self-rate their health?  
Differential associations according to health status in community-dwelling older adults.*  
*Quality of Life Research* (2011) 20:1573-1580.

**Varni JW, et al.**

*The PedsQLTM Infant Scales: feasibility, internal consistency reliability,  
and validity in healthy and ill infants.*  
*Quality of Life Research* (2011) 20:45 – 55.



## COMMUNICATIONS COMMITTEE REPORT: WEBSITE REDESIGN

*Communications Committee / Website Redesign Team*

The Communications Committee has been hard at work on redesigning the ISOQOL website. The new site will provide ISOQOL members with a greater ease of use, additional features, and a brand new look and feel. Guiding this renovation is the Committee's purpose as approved by the Board of Governors:

*The Communications Committee uses the newsletter, website and other methods to inform membership about upcoming educational events, board activities and other information of interest to the membership.*

The members of the web redesign team include Co-Chairs Deborah M. Miller (US), Chair of the Communications Committee, Bellinda King-Kallimanis (Ireland), Chair of the New Investigator SIG, as well as Stefan Cano (UK), ISOQOL

board member, Joanne Greenhalgh (UK) ISOQOL board member and Chair of the Membership Committee, and ISOQOL Staff Members Rebecca Brandt, Executive Director, and Adam DeMarie.

The short term goal for this project is to update the website, using feedback from our membership obtained during the 2010 Membership Survey, so that it better matches the latest standards and trends in web design and function. In the longer term, the redesign team is looking for the site to serve as an introduction to the public about our field, explaining what exactly members of our profession have to offer those outside it. These two goals are driven by the desire to provide value to ISOQOL's members, interacting with you in the ways that you are most comfortable. Overall

we hope that this redesign will move ISOQOL towards greater public and member engagement, a resource for academics and clinicians to remain current with developments in our multi-disciplinary field.

The redesign has outlined the content to be included on the new site, developed a framework to organize it, and worked with a team of web designers to create a visual template that complements both. Looking ahead, we will be writing the content for the new site, as well as developing some procedures for the governance of the site after it launches (at the direction of the board). We expect the redesigned site to be operational before the Annual Conference this year and we look forward to hearing your feedback about it.

### FIND ISOQOL ON FACEBOOK AND TWITTER!



### ISOQOL BOARD OF DIRECTORS ELECTION

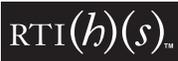
All ISOQOL members are eligible to vote in the 2012 election of new board members. Membership will be electing the President-elect, along with four new Directors. If you have not already voted, please click here to place your vote before 20 July. <http://isoqol.execinc.com/edibo/Election2012>

## ISOQOL BOARD OF DIRECTORS MEETING REPORT

By: Rebecca Brandt, CAE, Executive Director

The ISOQOL Board of Directors met in Chicago, IL USA in April. The meeting provided an opportunity for the board to participate in strategic conversations about the future of ISOQOL. There were many discussions about the development of partnerships with like-minded organizations and progress reports from ISOQOL task forces. Key outcomes include:

- Online learning opportunities will be available for ISOQOL members in 2012.
- New efforts will be discussed with the *Quality of Life Research* publisher to promote important science being reported in our journal.
- Carolyn Schwartz, ScD and Dennis Revicki, PhD were reappointed for a 3-year term as co-editors-in-chief of *Quality of Life Research*.
- An ISOQOL Publication Policy was approved. This policy will cover all articles being written by ISOQOL committees, task forces and SIGs.
- Chapters continue to be transitioned to Sections. A policy for the creation of a section is in development.
- Barcelona, Spain was approved as the venue for the 2014 annual conference.
- A new ISOQOL website will be launched in 2012.



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## 2012 ISOQOL ANNUAL CONFERENCE

### **BUDAPEST, HUNGARY 24-27 OCTOBER REGISTRATION NOW OPEN**

With Budapest's striking landscape, relaxing river and beautiful architecture you will be pushed towards new discoveries both during the conference sessions and beyond. Join fellow health-related quality of life researchers, clinicians, and industry professionals in sharing research through workshops, symposia and engaging poster presentations. A host of networking receptions and breaks will allow you plenty of time to catch up with old friends and to make new connections.

### **SIG MEETINGS**

Each Special Interest Group (SIG) will be holding its annual meeting in Budapest. All ISOQOL members are invited to join a SIG and engage with

activities throughout the year. Please see our online schedule of events for a full listing of dates and times the SIGs will be meeting.

### **PLENARY SESSIONS**

*Comparative Effectiveness Research and Patient-Centered Outcomes Research* will be presented by Ethan Basch, MD MSc, Memorial Sloan-Kettering Cancer Center, Chair, Patient-Centeredness Workgroup, Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI), Andrew Vallance-Owen MBA FRCS Ed, Chairman, UK Department of Health's PROMs Stakeholder Group and Albert W. Wu, MD MPH, Johns Hopkins Bloomberg School of Public Health. The session will be chaired by Neil K. Aaronson, PhD.

*From Clinical Trials to Clinical Practice: Towards Bridging the Gap* will be presented by Michael Brundage, MD, Cancer Research Institute at Queen's University, Ontario, Canada and Chair of the CONSORT PRO 2012 Executive and ISOQOL Reporting Guidelines Task Force, Paul Jacobsen, PhD H. Lee Moffitt Cancer Center & Research Institute & University of South Florida, Tampa, FL, USA and Holger J. Schünemann, MD, PhD, MSc, FRCP(C) McMaster University Health Sciences Centre, Hamilton, ON, Canada. The session will be chaired by Melanie Calvert, PhD and Fabio Efficace, PhD.

*Innovations in eHealth* will be presented by Paul Wicks, PhD, Patients Like Me and Martha Grootenhuis, PhD Emma Children's Hospital, Academic Medical Center, Amsterdam, The Netherlands. The

## **EpidM Introduces Winter Courses in Epidemiology January 14-25, 2013**



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For more information please visit: [www.epidm.nl/wintercourses](http://www.epidm.nl/wintercourses)



## 2012 ISOQOL ANNUAL CONFERENCE—CONTINUED

session will be chaired by Sara Ahmed, PhD and Bernhard Holzner, PhD BE.

*Paving the Path Towards Personalized Medicine* will be presented by Per Hall, Karolinska Institute, Stockholm, Sweden, Donald E. Morisky, ScD ScM MPH, UCLA School of Public Health, Los Angeles, CA, USA and William E. Narrow, MD MPH, DSM-5 Task Force, American Psychiatric Association. The session will be chaired by Juan J. Dapuerto, MD, PhD and Mirjam AG Sprangers, PhD.

To read additional information about our speakers, please visit <http://www.isoqol.org/2012conference/schedule.php>

### WORKSHOPS AND LUNCHEON ROUNDTABLES

Thirteen different workshops will offer attendees an opportunity to dive deep into a topic meeting specific educational needs. Titles of workshops include *Interpreting Utility (Preference-Based) Measures of Health-Related Quality of Life, Assessing Health Outcomes in a Global Clinical Research Setting: Challenges and Solutions to Manage Cultural Variability and Improving the Reporting of Patient Reported Outcomes in Clinical Trials*. Luncheon roundtable discussions will allow attendees time to discuss an area of mutual interest with a veteran in the field. Pre registration is required for all workshops and for luncheon roundtables. Topics include *Cancer Survivorship, Innovations in Modern*

*Psychometrics* and a roundtable focused on the needs of students and new investigators, *CVs, Resumes, and Cover Letters, Oh My!*

### HOST HOTEL

All of scientific content for the conference will be held at the Budapest Marriott Hotel. All guest rooms have a view of the Danube River and the hotel is located in the city center, near Parliament, Buda Castle, and restaurants and shopping. The views at night of the Royal Palace from the hotel are particularly breathtaking! We are pleased to offer a discounted room rate of 120€ per night for bookings taking place prior to 1 September. The ISOQOL room rate cannot be guaranteed after this date. Please make your reservation through the ISOQOL website.

### CLOSING DINNER ON SATURDAY

Our closing dinner celebration will take place during a dinner cruise along the Danube River. Enjoy delightful entertainment and a delicious dinner with your colleagues and friends. Tickets for the event may be purchased through your registration.

### THANK YOU

ISOQOL would like to thank our conference sponsors for their support. During your time at the conference, please make sure to stop by and visit with our exhibitors. They are anxious to hear about your experiences and to learn the best ways to partner with experts in the field.



### PATIENT-REPORTED OUTCOMES SENIOR SCIENTIST

*This position can be located in either the U.S. or Europe (This position can also be based remotely)*

The Senior Scientist manages client engagements, directing the collection and analysis of primary and secondary data and formulating strategic advice for clients. This individual is responsible for managing teams of consultants, and collaborating with managers in other divisions on consulting projects.

As a Senior Scientist your daily job duties would include the following:

- Manage PRO engagements including PRO development and validation, with appropriate scientific rigor to meet the client's needs.
- Understand Client Requirements: Participates in defining how the assignment will be performed and the deliverables that will be presented by the Firm.
- Prepare Proposals: Reviews and revises draft proposals that respond to client requirements following standard formats used for previous engagements.
- Supervise Data Collection and Analysis: Identifies sources and obtains information from knowledgeable individuals, reference texts, on-line databases, and other research sources. Evaluates data using quantitative methods as necessary to allow appropriate inferences and conclusions to be drawn.
- Review Summaries: Reviews and advises on analyses of key points, patterns, and trends found in data.
- Develop Findings and Recommendations: Assists in using information and data to prepare specific findings and recommendations, which are appropriate to client requirements.
- Interface with Internal Project Management and Client: May meet with client to review work plan, schedule meetings, describe data sources, explain patterns observed in data, and indicate how findings and recommendations were developed.
- Prepare and Present Deliverables: Prepares written memos, correspondence, and reports; conducts in-person presentations for clients.
- Evaluate Engagement: Participates in the evaluation of client engagements to review the original work plan, budget, consultant contributions, client responses, and the potential for future work.
- Generate Repeat Business: Establishes business relationship with clients that results in repeat business for the Firm.
- Train and Mentor Staff: Act as a mentor to less experienced consulting staff, orienting them on firm policies and career development objectives.

**Required Education for the Senior Scientist position includes:**

- Typically holds a doctoral degree in business administration, public health management, clinical science, health services research, health economics, psychology, or other relevant discipline from an outstanding program at a distinguished university.
- Knowledge of psychometrics is critical for this position, both from the practical and conceptual level, for classical and modern (latent modeling and IRT) psychometrics.

**Required Experience/Skills for the Senior Scientist position includes:**

- Several years of successful relevant research and/or consulting experience at Covance or in a similar environment and meets the performance criteria outlined by the Firm.
- Experience writing and reviewing code for psychometrics in SAS, Mplus (or similar latent modeling software), and IRT code in general.
- Strong communication, organization and analytical skills.

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## ISOQOL GLOBAL NEWS: ACTIVITIES OF THE IBERO-AMERICAN SECTION

We are celebrating the **6th Ibero-America Quality of Life Research Meeting**, with the theme **“Usefulness for Clinical Practice”**, from November 29 to December 1st, 2012, in the Federal University of Goiás, located in West-Central Brazil. We invite all professionals interested in studies on Health-Related Quality of Life to participate. We are currently accepting abstract submissions (deadline of August 31st, 2012) —[www.equippeeventos.net/isoqol](http://www.equippeeventos.net/isoqol). The event will include conferences, round tables, pre-congress courses,

and presentations. We have confirmed the participation of renowned Ibero-America colleagues, and from the USA and Canada, Drs. Claire Snyder and Sara Ahmed.

### GOIÂNIA

It is the capital of the state of Goiás, located in the central plateau of Brazil, 209 KM (~ 130 milies) from Brazilia, the country’s capital. With a population of 1,318,148 Goiás is among the seven Brazilian cities with the best quality of life – it takes pride in charming its denizens and visitors.

### SPONSORS/COORDINATION:

- International Society for Quality of Life Research (ISOQOL) Ibero-American Section
- Federal University of Goiás (UFG)
- Multi-disciplinary Group in Quality of Life Studies / UFG (GMPQV/UFG)
- Center for Research on Paradigm Care and Quality of Life (NEPAQ)
- Federal University of Goiás



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