

# Quality of Life

QUARTERLY

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## VOLUME 18 ISSUE 4

*Newsletter for  
ISOQOL Members*  
FALL 2012

## ADVERTISING INFORMATION

Contact Marketing Director,  
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[jwenzel@isoqol.org](mailto:jwenzel@isoqol.org)



## PRESIDENT'S MESSAGE

*Bryce B. Reeve, PhD*



Dear ISOQOL Friends,

We are at the eve of ISOQOL's 19<sup>th</sup> Annual Conference in Budapest, Hungary. An exciting pro-

gram is planned as we will explore the importance of health-related quality of life (HRQOL) measurement in comparative effectiveness research, eHealth initiatives, clinical practice, and personalized medicine. We will also hear a special presentation from Jan Geissler on the critical role of patient advocacy in cancer research. ISOQOL's core mission is focused on measuring the impact of disease and treatment on patients' lives; thus, building stronger relationships between ISOQOL and patient advocacy groups should be a high priority.

If you are like me, I find the topic areas for all the sessions fascinating and wish I could duplicate myself when concurrent sessions are of-

fered. I encourage conference participants to attend and join one or more special interest group (SIG) meetings: child health, new investigators, psychometrics, quality of life in clinical practice, response shift, and translation and cultural adaptation. The SIGs have been instrumental for ISOQOL to advance the science of HRQOL measurement through the dissemination of publications and reference documents that inform researchers of standards and guidelines for conducting HRQOL research. This has included guidance for using patient-reported data in clinical practice, translation methods for HRQOL questionnaires, incorporating patient-reported outcomes (PROs) in comparative effectiveness research, PRO reporting standards for randomized clinical trials, and standards for PRO measures for use in patient-centered outcomes research.

For the past 19 years, ISOQOL has conducted annual conferences and mid-year meetings to serve as

*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.*

a venue for researchers to share their work and knowledge and for investigators to receive additional education in research methods. Also, ISOQOL's journal, *Quality of Life Research*, published high quality, peer-reviewed research papers and has enjoyed the recognition of an increasing impact factor. The conference and journal will continue to be a high priority for the organization. In addition, ISOQOL is expanding its products and services to the research and healthcare community. The recently released guidance documents noted above are examples of this expansion. A webinar on using PRO measures to improve clinical practice is scheduled for November and other webinars will soon follow. As patient-centered care and patient-centered research gains more prominence throughout the world, ISOQOL will be recognized as a leader in driving

the science. This can only be done through ISOQOL's greatest asset, its members.

So in Budapest, I look forward to listening to the presentations, browsing the posters, and talking to ISOQOL members and attendees in the halls and social events. I hope you all equally enjoy the conference and visit to Budapest. I always walk away from an ISOQOL conference with lots of research ideas and a growing list of new friends. I encourage you, regardless if you attend the conference or not, to contact me or any ISOQOL Board member with any ideas of ways we can advance the field of HRQOL research.

Sincerely,

Bryce



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**BUDAPEST**  
International Society for Quality of Life Research  
**19<sup>th</sup> ANNUAL CONFERENCE**  
October 24-27, 2012

## FROM THE EDITOR'S DESK

By: Ana Popielnicki

Dear ISOQOLers:

Welcome to the Fall edition of *Quality of Life Quarterly*! As always, and thanks to all our contributors (both members and soon-to-be-members!), we have much to share with you in this issue.

As we are all preparing for our Annual Conference at the end of the month, our President's Message focuses on this event and the importance of the work our members are doing around the world. The conference is an excellent venue to share findings, learn about the industry, and enrich our professional and personal perspectives.

We have several contributions, continuing with our commitment to raise awareness and lead the efforts on patient-centered outcomes research, education, and healthcare. Check out a post by Tom Dahlborg – originally posted on HospitalImpact.org: *Compassion vital for better outcomes, care delivery*. Click on the provided link to read the whole article. Also

in this issue, please look for Emily Freeman's article on *Endometriosis and Quality of Life*, based on her work with Canadian women diagnosed with the disease. You can learn more about Dr. Freeman's work in this topic by contacting her directly.

Many thanks to our members Barbara Brandt and Matt Talbert, for their article on *Developing and Translating Clinical Outcomes Assessments*. Reaching the patient and hearing the patient's voice in their own language is vital for data validity and care delivery.

Our indefatigable marketing team, led by Jean Wenzel, has gathered for you as usual the calendar of events for this quarter. Check out all the conferences, educational, and networking opportunities in the October – December Calendar.

We promised you distance learning opportunities, and we are delivering – please see the information on ISOQOL's first webinar, *Using PROMs to Improve Clinical Care*, taking place

on November 5<sup>th</sup>. The webinar will be conducted by Donna Berry and Jan Geissler, and moderated by ISOQOL's Past President Dr. Albert Wu – members and non-members are welcome to participate in this wonderful learning experience.

Our dynamic Executive Director Becky Brandt has updates and news for you on the Annual Conference, the new ISOQOL website, and detailed information on the webinar. Also, please see an ad for the 6<sup>th</sup> Annual Meeting of the Ibero-American Section, this coming November 29 to December 1<sup>st</sup> in Goiás, Brazil.

Your Communications Committee wants to hear from you! Please send your questions, suggestions, submissions, and comments to [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line. Enjoy your reading!

Warm regards,

Ana



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## COMPASSION VITAL FOR BETTER OUTCOMES, CARE DELIVERY

By: Thomas H. Dahlborg, M.S.M., Vice President for Strategy and Project Director for the National Initiative for Children's Healthcare Quality (NICHQ)

I have oft written about the Hippocratic Oath and empathy in healing, and was elated to see the recent article "The Science of Compassion."

As I wrote in "Doctors promise holistic care under Hippocratic Oath," whether you call it "woo woo," squishy, or warm and fuzzy, as the Hippocratic

Oath illustrates, sympathy, understanding, holism and joy in healing are vital for any optimal healing model.

Similarly, the author of "The Science of Compassion" makes the point, "If we say, oh, the practice of compassion is something holy, nobody will listen. If we say, warm-heartedness really reduces your blood pressure, your anxiety,

your stress and improves your health, then people pay attention."

*This post originally appeared on July 3rd, 2012, at the Hospital Impact site ([hospitalimpact.org](http://hospitalimpact.org)), from the FierceHealthCare.com group. To read the complete article, please visit the following link: <http://www.hospitalimpact.org/index.php/2012/07/03/p4076>*



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# BLAZING A TRAIL- HOW CANADIAN WOMEN'S EXPERIENCES WITH ENDOMETRIOSIS CONTRIBUTE TO A PATIENT-CENTERED UNDERSTANDING OF THE DISEASE FOR HEALTHCARE PROVIDERS IN ONTARIO, CANADA

Emily Freeman, PhD—Associate Director, US Medical Bristol-Myers Squibb\*

\*The research discussed in this article was completed while at McMaster University, Hamilton, Ontario Canada. The research and editorial presented in this article are solely those of the author *and* do not necessarily represent those of Bristol-Myers Squibb.

Chronic illnesses such as endometriosis profoundly affect the lives of the people who suffer from such conditions. For women who have been diagnosed with endometriosis, the unpredictability of the symptoms, coupled with limited treatment options and an uncertain future, makes living with this condition physiologically and psychologically challenging. Because endometriosis isn't a very well understood condition -- from the patient's perspective -- my research focused on the experiences of 70 women in Hamilton, Ontario Canada who had been clinically diagnosed with endometriosis using constructivist grounded theory. There has been an enormous amount of research on the science and epidemiology of endometriosis; yet very little research has focused on the needs of patients and the impact on quality of life.

The women identified two specific needs to improve their quality of life and patient-centered care in Ontario: (1) they needed additional information and the opportunity to discuss their disease with healthcare providers and other women with endometriosis, and (2) they recognized a strong need for better communication between women and healthcare providers—the women would like individualized-empathetic care and treatment. The ensuing message—that the healthcare sector needs to shift from thinking about endometriosis as simply a reproductive disease and start examining the interconnections of a woman's lived experience that influence the endometriosis experience—is vitally im-

portant to providing patient-centered care for these women. It also allows the healthcare provider to align better with the patient's values and preferences for treatment, by getting to know what's important to the patient in their daily lives and allowing the patient to share in the decisions related to their care.

Endometriosis is much more complicated than is currently understood by the healthcare system. The women's experiences highlight the need for additional awareness about endometriosis—a well-informed and empathetic medical community is needed to raise awareness of endometriosis in society, so that employers, family, and friends can understand the complexity and dynamic ever-changing nature of the disease. Beginning with the onset of puberty until menopause, which represents roughly 30 years of a woman's life, menstruation is a regular part of women's lives and it has impact on the everyday lives of women. Endometriosis is not just a diagnosis; it is something that a woman will have to live with for the rest of her life in some form or another- having a direct impact on quality of life. In addition, women often do not have anyone to discuss their experience of endometriosis with—given the taboo nature of menstruation, chronic pain, and infertility.

It became clear to me during the research process that the women were asking for the opportunity to ask questions of their healthcare providers and gather more information- because they did not have the opportu-

nity elsewhere in their lives to talk to their family, co-workers, or doctors. I was able to provide an information session with Dr. Warren Foster, a well-known endometriosis researcher at McMaster University who allowed the women to ask questions about the disease. Dr. Foster was able to provide them explanations that helped many of them understand their own situations and answered questions for the women that their own doctors had not taken the time to do.

It was surprising to witness the interaction between the women and Dr. Foster; because the interaction made it clear to me that if more information were available in an understandable format, this would greatly reduce the anxiety and stress that many of these women had experienced. The women knew exactly what they needed and wanted- they wanted empathy, answers, and information, and it was remarkable to watch this unfold during the information session with Dr. Foster.

The women clearly identified the difficulties they faced during their experience and expressed a need to help other women with endometriosis. By sharing their difficulties these women became trailblazers; highlighting the importance of empathy and awareness of the disease by healthcare providers-- to make the journey a much easier one to navigate for future travelers.

*Editor's Note: To learn more about Dr. Freeman's work, please contact her directly at [ecfreeman@gmail.com](mailto:ecfreeman@gmail.com).*



# CLINICAL OUTCOMES ASSESSMENTS: TRANSLATABILITY CONSIDERATIONS AND RECOMMENDATIONS FOR DEVELOPMENT

Barbara A. Brandt, M.A.; Matthew Talbert, M.A.; Corporate Translations, Inc.

The development of Clinical Outcomes Assessments (COAs) intended for use in multinational trials should include careful consideration of readability and translatability of the source document. A highly translatable source will allow for greater achievement of conceptual equivalency while undergoing linguistic validation, resulting in valid data pooling across languages. These important steps can eliminate translation difficulty during harmonization and subsequent cognitive debriefing. It is recommended that the developer collaborate with the language service provider (LSP) during development in order to create a thorough translatability assessment prior to linguistic validation.

When developing COAs for multinational trials, important considerations must be made to ensure ease of translatability and achievement of conceptual equivalency across languages. The LSP should review a preliminary draft of the COA, to identify any potential translatability and readability concerns. This preliminary review, or “face validity,” serves to pinpoint problematic phrasing and concepts, and also to make suggestions for revision prior to translation. Common problems identified during this review may include conceptual overlap in response sets, ambiguity of key concepts, idiomatic items for which direct equivalents may not exist across languages, incomplete instructions, and double-barreled

questions, in which a single question seeks to measure multiple constructs. During this review, the LSP may also make recommendations for minimizing respondent burden. If required, a Flesch-Kincaid readability test can be applied and revisions may be suggested to improve comprehension by a target population. In addition, the LSP will review all questionnaire items and make suggestions for improving the survey methodology, ensuring the source text is optimal for respondent understanding. Identifying and addressing issues such as these early in development saves time and unnecessary expense.

Following the face validity review and instrument revision, a translatability assessment should be completed. This review is carried out by linguists within desired language groups to identify translatability concerns within and across languages, and recommend source revisions to improve translatability. An important outcome of this assessment is to identify items that are culturally-specific, which would potentially yield differing interpretations across languages when translated. According to the ISPOR Patient-Reported Outcomes Translation and Linguistic Validation Good Research Practices Task Force Report, in order to pool data from multicountry studies, cognitive equivalence of PRO measurement concepts should be established (Wild, et. al., 2009). A translatability assessment will

identify idiomatic phrasing, ambiguous concepts, and other areas of a COA with the potential for problematic translation. Idioms such as “put yourself down” and “step on a few toes” can create difficulty in finding equivalent concepts when translated. Some concepts, such as *bother*, have been shown to have a discrepancy in meaning across languages, potentially creating issues with data pooling (Gawlicki, et. al., 2011). Response options where risk of conceptual overlap exists when translated, such as “a little bit” and “somewhat,” may create a challenge in crafting localized response options that are sufficiently distinct.

Creating a COA for use in multinational trials requires careful review and consideration during the instrument development phase. The aforementioned steps are recommended for yielding sound and high-quality translations.

## REFERENCES

- Gawlicki M., Brandt, B., McKown, S., Talbert, M. Application of the *Bother* Concept Across Cultures. Poster session presented at: the 18<sup>th</sup> Annual Conference of the International Society for Quality of Life Research; 2011 Oct 26-29; Denver, CO.
- Wild D., Eremenco S., Mear I., et al. Multinational trials – Recommendations on the Translations Required, Approaches to Using the Same Language in Different Countries, and the Approaches to Support Pooling the Data: the ISPOR Patient Reported Outcomes Translation & Linguistic Validation Good Research Practices Task Force Report. *Value in Health* 2009;12:430-440.





## CALENDAR OF EVENTS—OCTOBER

- **Oct 14 - 16**  
**The Sixth Annual Meeting of The PMRG Institute**  
 Sheraton Philadelphia Downtown Hotel, Philadelphia, USA  
<http://www.pmr.org/EventsWebinarsAwards/ThePMRGInstitute2012/tabid/694/Default.aspx>
- **Oct 15 - 17**  
**Investment In Innovation (IN<sup>3</sup>) Medical Device 360° Summit**  
 San Francisco, CA, USA  
<http://www.elsevierbi.com/publications/in-vivo/30/2/in-medical-device-360-2012-london>
- **Oct 16**  
**PROficiency Regional Conference**  
 Copenhagen, Denmark (Oct. 16)  
<http://www.invivodata.com/events/event/proficiency-regional-conference-copenhagen-denmark/>
- **Oct 16 - 19**  
**Market Access World USA**  
 Boston, MA, USA  
<http://www.healthnetworkcommunications.com/conference/market-access-world-usa/index.stm>
- **Oct 17**  
**California Technology Assessment Forum**  
 San Francisco, CA, USA  
<http://www.ctaf.org/>
- **Oct 18**  
**PROficiency Regional Conference**  
 London, England, UK  
<http://www.invivodata.com/events/event/proficiency-regional-conference-london-england-2/>
- **Oct 22 - 24**  
**NORD/DIA US Conference on Rare Diseases & Orphan Products: Shaping the Future Now**  
 Washington D.C., USA  
<http://www.rarediseases.org/news-events/news/nord-dia-2012>
- **Oct 24 - 27**  
**ISOQOL 19th Annual Conference - The Journey of Quality of Life Research: A Path Towards Personalized Medicine**  
 Budapest, Hungary  
<http://www.isoqol.org/2012conference/>
- **Oct 25 - 26**  
**9th Annual Connected Health Symposium**  
 Boston, MA, USA  
[http://symposium.connected-health.org/?utm\\_source=2012+Symposium+Email+to+ALL+July-12-2012&utm\\_campaign=July+Mass+Email&utm\\_medium=email](http://symposium.connected-health.org/?utm_source=2012+Symposium+Email+to+ALL+July-12-2012&utm_campaign=July+Mass+Email&utm_medium=email)
- **Oct 25 - 25**  
**Clinical Trial Endpoints: Methods and Practice in Developing Measurements**  
 Washington D.C., USA  
<http://www.diahome.org/en/Meetings-and-Training/Find-Meetings-and-Training/Meeting-Details.aspx?productID=30490>
- **Oct 26 - 28**  
**7th Asian Conference on Pharmacoepidemiology**  
 Bangalore, India  
<http://www.acpe-india.org/>
- **Oct 27 - 28**  
**Transforming Patient-Centered Research: Building Partnerships and Promising Models**  
 Washington D.C., USA  
<http://www.pcori.org/patient-workshop-interest/>
- **Oct 29 - 30**  
**2nd Annual Pharmaceutical and Medical Device Sales and Marketing Compliance Conference**  
 Chicago, IL, USA  
<http://www.q1productions.com/salescompliance/Index.php#UE9qKHwkxo>
- **Oct 29 - 30**  
**CBI's 7th annual Effective Oncology Benefit Management: A forum for payers**  
 Chicago, IL, USA  
<http://www.cbinet.com/conference/fc12121#UE-AF6Hwkxo>
- **Oct 31 - Nov 3**  
**Second Global Symposium on Health Systems Research**  
 Beijing, China  
<http://www.who.int/alliance-hpsr/hsr-symposium/en/index1.html>



## CALENDAR OF EVENTS—NOVEMBER & DECEMBER

- **Nov 1 - 2**  
**DISRUPTORS: Revolutionizing Drug/Dx Reimbursement**  
Philadelphia, PA, USA  
<http://realendpoints.com/symposium/>
- **Nov 1 - 2**  
**Real Endpoints Symposium**  
Philadelphia, PA, USA  
<https://realendpoints.ontrackevents.com/register.cfm>
- **Nov 3 - 7**  
**ISPOR 15th Annual European Congress**  
Berlin, Germany  
<http://www.ispor.org/Events/Main.aspx?eventId=39>
- **Nov 8 - 9**  
**9th Health and Ageing Conference on Genetics and Insurance**  
Stockholm, Sweden  
[http://www.genevaassociation.org/Conference\\_Events/Programmes.aspx](http://www.genevaassociation.org/Conference_Events/Programmes.aspx)
- **Nov 12 - 13**  
**Achieving Excellence in HEDIS Measures and Quality Management**  
Nashville, TN, USA  
<http://www.healthcare-conferences.com/conference.aspx?ccode=H152A>
- **Nov 12 - 13**  
**The Strategies and Tactics of Pricing**  
Stockholm, Sweden  
<http://www.pricingsolutions.com/index.php/en/component/content/article/206>
- **Nov 13 - 14**  
**Health Insurance Exchange Congress**  
Chicago, IL, USA  
<http://www.iirusa.com/hix/welcome.xml>
- **Nov 13 - 14**  
**Medicare Readmissions and Transitions of Care**  
Nashville, TN, USA  
<http://www.allconferences.com/conferences/2012/20120829143224/>
- **Nov 22 - 24**  
**1st Congress of Health Economics**  
Ankara, Turkey  
<https://www.healtheconomics.org/conferences/5603-1st-congress-of-health-economics/>
- **Nov 26 - 29**  
**Healthcare World Asia**  
Singapore  
<http://www.terrapinn.com/conference/healthcare-world-asia/index.stm>
- **Nov 26 - 28**  
**Pharmaccess Leaders Forum 2012**  
Berlin, Germany  
<http://www.pharmaccessleadersforum.com/>
- **Nov 27 - 28**  
**2nd Pharmacovigilance Global Summit**  
London, UK  
[http://www.appelconsulting.co.uk/events.php?prop\\_id=184](http://www.appelconsulting.co.uk/events.php?prop_id=184)
- **Nov 27 - 30**  
**World Generic Medicines Congress Americas 2012**  
Washington D.C, USA  
<http://www.eventseye.com/fairs/f-world-generic-medicines-congress-americas-14767-1.html>
- **Nov 28 - 30**  
**Medical Device Leaders Forum**  
Berlin, Germany  
<http://www.medicaldeviceleadersforum.com/>
- **Nov 29 - 30**  
**Health Insurance Exchanges Summit**  
Las Vegas, NV, USA  
<http://www.healthcare-conferences.com/conference.aspx?ccode=H155>
- **Nov 29 - 30**  
**Real World Data & Health Outcomes**  
Boston, MA, USA  
<http://www.eyeforpharma.com/real-world-data-and-health-outcomes/>
- **Nov 29 - December 1**  
**The 6th Ibero-American Quality of Life Congress**  
San Marino Suite Hotel  
Goiânia, Goiás, Brazil  
<http://www.equippeeventos.net/isoqol/>
- **Nov 30 - 30**  
**The Myth of Average: Why Individual Patient Differences Matter**  
Washington D.C., USA  
<http://www.regonline.com/builder/site/Default.aspx?EventID=1129899>
- **Dec 3 - 4**  
**Health Economics for Non-Health-Economists**  
Brussels, Belgium  
<http://www.celforpharma.com/pharma-management/training/pharma-health-economics-course.html>
- **Dec 3 - 5**  
**International Summit on GMP & GCP: USA, Europe, Japan, Asia Pacific**  
Philadelphia, PA, USA  
<http://www.omicsonline.org/gmp-gcp2012/cfa.php>
- **Dec 4 - 6**  
**Health Technology Assessment World Europe**  
London, UK  
<http://www.healthnetworkcommunications.com/conference/health-technology-assessment/index.stm>

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## 2012 ANNUAL CONFERENCE – ENGAGE

Whether or not you are attending the Annual Conference in Budapest, Hungary next week will not prevent you from engaging with attendees and speakers. We offer a LinkedIn page for the conference (search for “2012 ISOQOL Annual Conference”), a Twitter account (@ISOQOL) and a Facebook page. The LinkedIn page will provide a venue for discussions about presentations or posters between those at the meeting and those that are not. The ISOQOL Twitter account will offer live nuggets of information about what is happening real-time at the conference. Post photos from the conference and provide feedback on sessions by posting on our Facebook page.

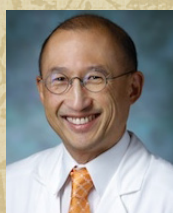
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**BUDAPEST**  
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- Supervise Data Collection and Analysis: Identifies sources and obtains information from knowledgeable individuals, reference texts, on-line databases, and other research sources. 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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## UPCOMING WEBINAR: USING PATIENT-REPORTED OUTCOME MEASURES TO IMPROVE CLINICAL CARE

The Clinical Practice Special Interest Group is excited to launch ISOQOL's first webinar on November 5, 2012 at 11 AM ET. The webinar will explore how to use patient-reported outcome measures (PROMs) to effectively improve patient care. In 2011, a task force of ISOQOL members led by Claire Snyder, PhD, wrote the "User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice" which was published in *Quality of Life Research*, November 2011. The webinar will expand upon this User's Guide into practical applications of engaging in PROMs.

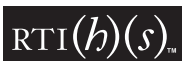
At the conclusion of the webinar all participants will understand how to incorporate the use of PROMs into

routine patient care; how to select the appropriate measure(s) to use; how to interpret the results; and how to ultimately make these results actionable.

Donna L. Berry, PhD, RN, AOCNÂ, FAAN, an associate Professor at Harvard Medical School and director of the Phyllis F. Cantor Centre for Research in Nursing & Patient Care Services at Dana-Farber Institute, will discuss her successes in engaging PROMs within clinical settings. She will also discuss the use of PROMs in the aid of clinical decision-making and what to expect when they are implemented. Mr. Jan Geissler, director of the European Patients' Academy on Therapeutic Innovation (EUPATI), will describe the ben-

efits and burdens as perceived by patients. ISOQOL is also pleased to welcome Mr. Geissler to the Annual Conference in Budapest for a special presentation, *Patient Advocates in Cancer Research: European Patients' Perspectives*. ISOQOL Past President, Dr. Albert Wu, will serve as moderator for the webinar.

Registration for the webinar is now open. Visit [www.isoqol.org](http://www.isoqol.org) to listen to a podcast by Dr. Albert Wu and to register for the webinar. ISOQOL members are able to register for \$75US and student members can register for \$20US. The webinar will be available for a fee-on-demand after the live event.



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# Call for Papers

The Editors of *Quality of Life Research* are planning a special series to highlight effective use of quantitative methodologies to improve quality of life research. We are seeking papers that exemplify excellent science on various methodologies or topics, including but not limited to:

- Application of linear growth curve models for analyzing clinical trial data
- Application of bifactor models for examining general and specific factor structures within QOL domains
- Methods for handling missing data in statistical analyses of prospective QOL data
- Applications of unidimensional and multidimensional item response theory (IRT) models for analyses of health outcome data
- Applying differential item functioning (DIF) testing to evaluate measurement equivalence of QOL measures.
- Dyadic data analysis in QOL research
- Application of structural equation modeling (SEM) for evaluating construct validity of QOL measures or examining relationships among QOL variables.
- Using latent class analysis (cluster analysis) or latent profile analysis to identify classes (clusters or profiles) of individuals with similar (or different) QOL profiles and underlying factors associated with these classes (clusters or profiles).

To participate in this call, please submit a **letter of intent** with draft title, contact information and institution for all co-authors, and abstract (250 word maximum). A subset of these letters of intent will be invited for full manuscript. We expect to publish 4-6 manuscripts.

Anticipated timeline:

Letter of Intent	February 1, 2013
Manuscripts invited based on screening of letters of intent	March 1, 2013
Manuscripts due	June 3, 2013
Anticipated publication of special section	Fall 2013

Please email to:

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

Deadline for submission of Letter of Intent:  
February 1, 2013



## Postdoctoral Fellowship: Applications of Patient-Reported Outcome Measures Northwestern University

Position is for a 2 year post-doctoral fellowship with Dr. David Cella in the Department of Medical Social Sciences (MSS) Feinberg School of Medicine, Northwestern University. The fellowship will occur in the context of an innovative NIH funded study "PROSetta Stone," designed to determine actionable thresholds (PRO endpoints) as meaningful indicators of improvement or decline in therapeutic efficacy and effectiveness from the patient's perspective. The postdoc will work closely with Dr. Cella to craft and oversee a systematic implementation plan for PRO application and dissemination, coordinate and participate in scientific products from the study, and direct a range of scientific activities to promote PRO usability and adoption in clinical and clinical research communities. Candidate must be conversant in multiple relevant areas in order to catalyze PRO applications among diverse stakeholders. Training as many of the following areas is optimal: comparative effectiveness research, clinical trials, basic psychometrics, program development, health information technology and/or dissemination science. Completion of doctorate prior to start of the position is required. Start date flexible. To apply, email materials (including a CV, 3 letters of recommendation and a statement of research interests to Dr. David Cella, c/o Julie Kay ([julie-kay@northwestern.edu](mailto:julie-kay@northwestern.edu))). Applicants considered until the position is filled. [www.mss.northwestern.edu/Careers/](http://www.mss.northwestern.edu/Careers/)

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**MARK YOUR CALENDAR: UPCOMING WEBINAR**

**INCORPORATING PATIENT REPORTED OUTCOMES  
INTO COMPARATIVE EFFECTIVENESS RESEARCH**

**WEDNESDAY, DECEMBER 12  
2 PM ET**

**Speakers:** Bryce Reeve, PhD (ISOQOL President) and Charles Turkelson, PhD (Center for Medical Technology Policy), Sara Ahmed, PhD (McGill University), Ethan Basch, MD MSc (University of North Carolina), Lori Frank, PhD (Patient-Centered Outcomes Research Institute)

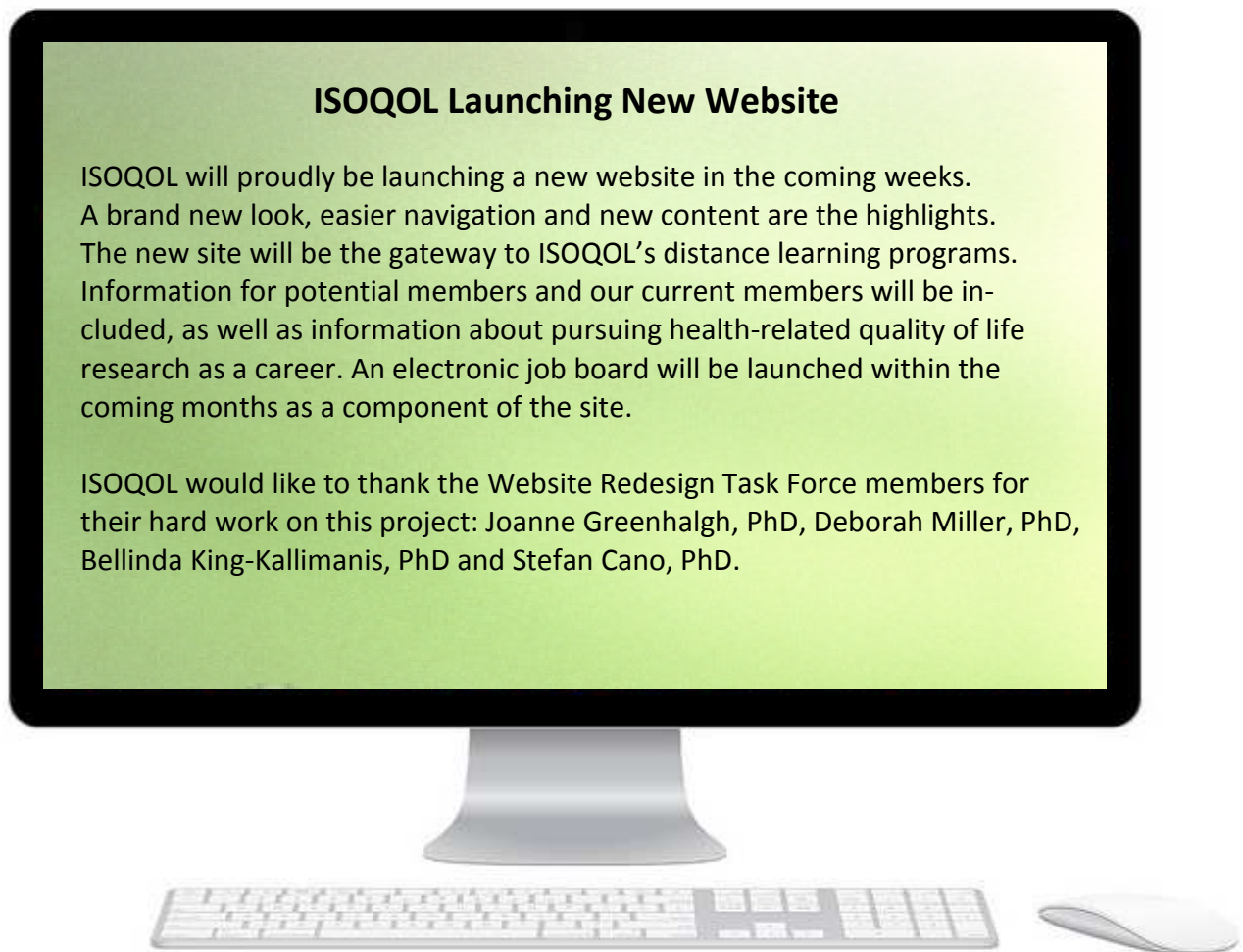
**This webinar is complimentary.** Pre-registration is required. Watch for an e-mail announcement regarding registration opening in late October.



**ISOQOL Launching New Website**

ISOQOL will proudly be launching a new website in the coming weeks. A brand new look, easier navigation and new content are the highlights. The new site will be the gateway to ISOQOL's distance learning programs. Information for potential members and our current members will be included, as well as information about pursuing health-related quality of life research as a career. An electronic job board will be launched within the coming months as a component of the site.

ISOQOL would like to thank the Website Redesign Task Force members for their hard work on this project: Joanne Greenhalgh, PhD, Deborah Miller, PhD, Bellinda King-Kallimanis, PhD and Stefan Cano, PhD.





# ISOQOL 20<sup>TH</sup> ANNUAL CONFERENCE



October 9–12, 2013 **MIAMI, FLORIDA, USA**



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## Abstract Deadlines

Workshop and Symposium Abstract Submission  
Deadline: **Friday, February 1, 2013**

Oral and Poster Presentation Abstract Submission  
Deadline: **Friday, April 12, 2013**

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**6th IBEROAMERICAN MEETING ON QUALITY OF LIFE RESEARCH**  
**6ª REUNIÃO IBEROAMERICANA DE QUALIDADE DE VIDA**  
**Goiânia - Goiás - Brazil - 11/29 to 12/01/2012**  
**San Marino Suite Hotel**



We are celebrating the 6th Ibero-American Meeting on Quality of Life Research, with the theme “Measuring Quality of Life: Applications in 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. The event will include conferences, round tables and pre-congress courses. We have confirmed the participation of Drs. Claire Snyder from the USA, and Sara Ahmed from Canada, as well as renowned Ibero American colleagues.

**SPONSORS/COORDINATION:**

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

**CONTACT:** Equipe Eventos. Rua 06, 370- sala 206. Setor Oeste - Goiânia/ Goiás. Brazil CEP: 74.115-070  
Phone: 55(62)3945-1374. [www.equipeeventos.net/isoqol](http://www.equipeeventos.net/isoqol)



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