

Quality of Life

QUARTERLY

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VOLUME 19 ISSUE 1

Newsletter for
ISOQOL Members
WINTER 2013

ADVERTISING INFORMATION

Contact Marketing Director,
Jean Wenzel
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PRESIDENT'S MESSAGE

Bryce B. Reeve, PhD



Happy New Year ISOQOL!

The start of 2013 represents the mid-term of my two-year service as ISOQOL President. It

is a time for me to reflect back over the past year and strategize for the future of the organization. ISOQOL has made great strides in 2012, positioning itself to lead the field in patient-centered outcomes research and healthcare delivery.

ISOQOL extended its educational mission in 2012 by offering two webinars. The first was on *Using Patient-Reported Outcomes Measures to improve Clinical Practice*. In the webinar, Donna Berry and Albert Wu discussed the issues, challenges, and benefits for directly incorporating routine patient feedback through standardized PRO measures for enhancing clinician-patient communication and decision making. Serving as patient advocate, Jan Geissler provided the patient per-

spective on this technology with the hope that better communication will result in better health outcomes. The second webinar was on *Incorporating Patient-Reported Outcomes into Comparative Effectiveness Research*. In this webinar, Sara Ahmed and Ethan Basch summarized the recommendations from two recently released guidance documents (one from ISOQOL and the other from the Center for Medical Technology Policy), and Lori Frank provided an overview of the Patient-Centered Outcomes Research Institute (PCORI) and the role of patient engagement in research. Both webinars are archived and can be viewed on ISOQOL's website www.isoqol.org.

In addition, ISOQOL published in 2012 four expert guidance documents (with one in press) to advance the field of HRQOL measurement. These include: 1) a paper led by the ISOQOL Translation & Cultural Adaptation SIG on *The process of reconciliation: evaluation of guidelines for translating quality-of-life questionnaires* (Koller et al., 2012. Expert Review of
Continued on page 2.



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

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Ana Popielnicki, BA, USA

Send articles with subject line addressed "Newsletter Submission" to:
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President's Message, Continued from page 1.

Pharmacoeconomics and Outcomes Research); 2) a paper led by the ISOQOL Industry Advisory Committee on *Methods for interpreting change over time in patient-reported outcome measures* (Wyrwich et al. 2012, Quality of Life Research); 3) an ISOQOL sponsored paper on *The use of patient-reported outcomes (PRO) within comparative effectiveness research: implications for clinical practice and health care policy* (Ahmed et al, 2012. Medical Care); and 4) the ISOQOL sponsored paper, *ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research* (Reeve et al, in press, Quality of Life Research). More guidance documents will be coming out in 2013. I encourage all SIGs and committees to strategize on other ISOQOL guidance documents to address key research gaps in the field.

ISOQOL's flagship journal, *Quality of Life Research*, published high quality papers and received recognition in 2012 in the form of its high ranking among similar health journals and rising impact score. My sincere gratitude goes to the Co-Editors in Chief (Dennis Revicki and Carolyn Schwartz) and the Associate Editors for their time, hard work, and expert oversight of the journal.

The highlight of 2012 was ISOQOL's 19th Annual Scientific Conference held in Budapest, Hungary. With the backdrop of Budapest's Castle Hill visible from the conference rooms' windows, we enjoyed stimulating and thoughtful presentations and discussions of the methods and applications of HRQOL research. A big thank you to Sara Ahmed and Fabio Efficace (the conference co-chairs), the scientific program committee, and ISOQOL

staff (especially Rebecca Brandt and Heather Vitale) for putting together an outstanding program.

In 2012, we launched our new ISOQOL website that will provide excellent service to our ISOQOL members. In addition, the ISOQOL Newsletter (under Ana Popielnicki's excellent care) has been transformed into a wonderful briefing of key HRQOL and ISOQOL-related events and issues.

Credit for the successes and progress we achieved in 2012 is all due to the ISOQOL members, who include the experts and rising stars in the field of HRQOL research. I am so thankful and honored to work with you and to learn from you. I am also very excited about the energy and new ideas of the New Investigator SIG.

Our successes and recognition will continue to grow in 2013 as we expand our educational mission and outreach to key groups. Especially, I hope we may strengthen our bond with patient advocacy organizations, as 100% of our research and focus is on enhancing our knowledge of the impact of disease and treatment on patients' lives so that we may find more effective interventions to improve their care. We are also preparing for the celebration of our 20th ISOQOL Annual Conference in Miami, Florida!!! David Eton and Simon Pickard (conference co-chairs) are designing an excellent and stimulating program.

I wish all a very happy, healthy, and productive 2013!

Sincerely,

Bryce



FROM THE EDITOR'S DESK

By: Ana Popielnicki

Dear ISOQOL Family:

Welcome to our first issue of 2013, the Winter Edition! I am honored to continue for another year as your newsletter editor – the Executive and Marketing teams are the best, and they are still not sick of me, fortunately! We are starting the year with exciting news and announcements from our members and special interest groups; great initiatives, and important projects and publications.

In his President Message, Dr. Reeve reviews the tremendous growth our society experienced in the past year – with its active participation in guidance documents, webinars and workshops, as well as excellence in research publishing. ISOQOL's president sets the pace, as he has done since the beginning of his tenure, to continue ISOQOL's educational mission, as well as further our efforts on patient engagement and advocacy.

In keeping with ISOQOL's patient-centered approach, please check our featured article – Elizabeth Gargon, the COMET (Core Outcome Measures in Effectiveness Trials) Initiative Project Coordinator, brings us an article on the importance of including

patients in core outcome sets development. You can find out more about the COMET Initiative by contacting Liz directly or visiting their website (details can be found in the article).

Our members from the Corporate Translations team bring us an interesting article on *Assessing Readability and Translatability of Pediatric Patient Questionnaires*. The pediatric population requires special attention when developing measures – members of the Child Health SIG will find this article particularly pertinent.

Jean Wenzel and her team have gathered for you the first quarter Calendar of Events. Check out all the conferences, educational, and networking opportunities in the January – March Calendar. We welcome any suggestions for the upcoming quarters – please send us an email with your events for inclusion in future issues.

The awesome Executive team, Becky Brandt and Heather Vitale, have prepared for us a wealth of informational pieces and updates on activities and procedures. Please check out the Board of Directors nomination process, information on membership

renewal and profile updates, ISOQOL awards, and upcoming webinars. Do consider volunteering as a reviewer of abstracts/workshops/symposia – see details in Heather's Call for Reviewers article.

Also in this issue, please find an announcement from the New Investigators SIG about the launch of their new blog. Lastly, the amazing co-editors of our *Quality of Life Research* journal, Drs. Revicki and Schwartz, bring us information on how to respond to their Call for Quantitative Methods papers – check it out immediately (if not before), since the deadline for the letters of intent is this February 1st.

Your Communications Committee wants to hear from you! Please send your questions, suggestions, submissions, and comments to info@isoqol.org with "Newsletter" on your subject line. Enjoy your Winter issue!

My warmest wishes for a healthy, prosperous, and enriching New Year!

Ana



THE COMET (CORE OUTCOME MEASURES IN EFFECTIVENESS TRIALS) INITIATIVE: THE IMPORTANCE OF INCLUDING PATIENTS IN CORE OUTCOME SET DEVELOPMENT



By: Elizabeth Gargon, COMET Initiative Project Coordinator

There is a growing recognition amongst clinical researchers and trialists that insufficient attention has been paid to the outcomes — e.g. survival, quality of life, cancer recurrence — to be measured in clinical trials. Difficulties caused by heterogeneity in outcome measurement and reporting often hinder or even prevent the comparison or synthesis of trial evidence. For example, the five most accessed and the top cited Cochrane Reviews in 2009 all reported problems related to outcomes in eligible trials¹. In addition, empirical research provides strong evidence that outcome reporting bias, defined as the results-based selection for publication of a subset of the original recorded outcome variables, is a significant problem in randomised controlled trials (RCTs) and reporting of items within patient reported outcomes (PROs). Furthermore, outcomes reported for RCTs assessing effectiveness may not necessarily reflect endpoints that are meaningful for health service users themselves. Similarly, the PRO selected may not be the most important to patients, resulting in a literature biased towards the views of health professionals.

Recent regulatory guidance requires documented evidence of patient input during the development of instruments to measure PROs². However, measurement of PROs in clinical trials is hampered by the multiplicity and heterogeneity of tools available. Many generic, disease-, and domain specific instruments have been developed and validated, each containing multiple scales and items. As a result, synthesis of PRO data from trials is difficult,

and reviews aiming to summarise treatment effect on PROs may fail. Indeed, a review of quality of life of rectal cancer surgery patients identified 26 trials, using 10 different PRO measures, including 367 different scales and items³. The authors concluded that synthesis of the evidence was impossible and agreement is needed about choice and reporting of PROs in trials. These issues could be addressed with the development and application of agreed standardised sets of outcomes, known as core outcome sets (COS).

Since the late 1970s, when the World Health Organisation published guidelines on the minimal requirements for reporting outcomes in cancer trials, initiatives in many areas have attempted to increase consistency by developing an agreed set of important outcomes that should be measured and reported by all studies of a specific condition. January 2010 saw the beginning of the COMET (Core Outcome Measures in Effectiveness Trials) Initiative (www.comet-initiative.org)—an innovative project to bring together people with an interest in standardising outcomes for clinical trials and systematic reviews, with the aim of facilitating the development and application of COS. These sets should represent the minimum that should be measured and reported in all clinical trials, audits of practice or other forms of research, for a specific condition. This would allow the results of trials and other studies to be compared, contrasted and combined as appropriate, as well as ensuring that all trials contribute usable information. They do not imply that outcomes in a particular

study should be restricted to those in the COS, and researchers would still continue to investigate other outcomes as well as those in the core set.

The development and application of COS would mean that research would be more likely to measure and report appropriate outcomes because it is desirable to involve multiple stakeholder groups to determine what should be core in a given condition. Bringing diverse stakeholders together to try to reach a consensus is increasingly well-accepted as the future of collaborative, influential research⁴. Stakeholders may include healthcare practitioners, regulators, industry representatives, trialists, researchers, patients, carers and the public. Examples exist where the involvement of patients in the development of COS identified an outcome important to them as a group that might not have been considered if the outcome set was developed by practitioners alone⁵. However, despite increasing recognition of the importance of incorporating health service user opinion in the development of COS, their involvement has been limited to date. Once a COS has been agreed, it is then important to determine how the outcomes should be defined and measured. Often a variety of instruments exist to measure a given outcome, and these may be measured, clinician reported or patient reported. Again, as patient views may differ from their clinician's, the use of patient reported outcome measures should be considered.

We need to work collaboratively with patient-interest organisations to promote the aims and principles of the COMET Initiative, work with COS developers to improve patient engage-

ment throughout the process, and work with groups such as ISOQOL to develop guidance on integrating patient reported outcomes into core outcome sets. COMET is holding its third meeting in Manchester (UK), on 20th-21st June 2013, where there will be workshops to explore how qualitative methods can be used to involve patients in core outcome set development. Further workshop details, as well of details of how to register, can be found at <http://www.cometinitiative.org/meeting>; or alternatively contact e.gargon@liv.ac.uk for more information.

References:

1. Tovey D. Impact of Cochrane Reviews [editorial]. *Cochrane Database Syst Rev*. 2010;Jul 7;2011:ED0000007.
2. FDA. Patient-reported outcome measures: Use in medical product development to support labeling claims. 2009.
3. Pachler J, Wille-Jørgensen P. Quality of life after rectal resection for cancer, with or without permanent colostomy. *Cochrane Database Syst Rev* 2005;2(CD004323).
4. Williamson PR, Altman DG, Blazeby JM, Clarke M, Devane D, Gargon E, et al. Developing core outcome sets for clinical trials: issues to consider. *Trials*. 2012;13(1):132. Epub 2012/08/08.
5. Sinha IP, Gallagher R, Williamson PR, Smyth RL. Development of a core outcome set for clinical trials in childhood asthma: a survey of clinicians, parents, and young people. *Trials*. 2012;13:103. Epub 2012/07/04.
6. Kirwan J, Heiberg T, Hewlett S, Hughes R, Kvien T, Ahlmen M, et al. Outcomes from the Patient Perspective Workshop at OMERACT 6. *J Rheumatol*. 2003;30(4):868-72. Epub 2003/04/03.





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ASSESSING READABILITY AND TRANSLATABILITY OF PEDIATRIC PATIENT QUESTIONNAIRES

By: Mary C. Gawlicki; Barbara A. Brandt, M.A.; Matthew Talbert, M.A.; Corporate Translations, Inc.

Following development of patient questionnaires and Clinical Outcomes Assessments (COAs) intended for a pediatric population, it is recommended that developers work with their language service provider (LSP) to assess translatability, while also considering readability for a pediatric audience. The LSP can apply a face validity and translatability assessment of the text, making recommendations to improve readability and survey methodology, keeping in mind the target age group, and identifying potentially problematic terms for translation. Additionally, pilot testing of the translated questionnaire will evaluate the comprehensibility of the text for the target pediatric population. Though the source text may be age appropriate, more difficult terms may be introduced during translation. Pilot testing serves to identify any translated terms that may be difficult for the desired age range.

When evaluating a pediatric questionnaire, the LSP may initially conduct a "face validity analysis," during which the LSP will identify areas where survey methodology can be improved, as well as problematic concepts for translation. Examples are ambiguous concepts such as *bother or trouble*, which may result in different interpretations across cultures. Other items that may create

translation difficulty are idiomatic terms or phrases that are not readily available in the target language. Literal equivalents may be substituted for these items. The LSP will also make sure that the questionnaire instructions and response method are age appropriate, suggesting revisions, as necessary. Terminology may be further adapted for the desired grade level. For example, replacing the word "considering" with "thinking about" and "discomfort" with "hurting" will increase readability. The revised questionnaire can then be tested using a Flesh-Kincaid analysis, to ensure the correct grade level.

After the face validity analysis is complete and text revisions are made, a translatability assessment should be carried out to identify translatability concerns within and across languages, and to recommend revisions, as needed. Important outcomes of this assessment are to identify culturally-specific source items, ambiguous concepts, response sets containing conceptual overlap, and other areas with the potential for problematic translation. If a questionnaire uses pictorials, the LSP can recommend culturally appropriate modifications for the language and culture in which they will be used in order to be understood by a child and/or informant.

Following the translatability assessment, revisions and linguistic validation, pilot testing with subjects in the desired language and country should be completed to assess comprehension and confirm appropriateness for the local target population. Testing will involve subjects filling out the questionnaire or study diary as they would in a clinical trial, and responding to probe questions to identify concepts with which they had difficulty. Based upon subject feedback, revisions can be implemented, as agreed upon by the developer. In a recent project, pilot testing with a sample of five pediatric subjects was completed for a Spanish U.S. questionnaire. During testing, all subjects took issue with the word "gag" with regard to difficulty swallowing their study medication. The concept was replaced with an age-appropriate Spanish equivalent. While the source concept was appropriate for a pediatric population, during translation, a more difficult term was used by the linguist.

Application of the aforementioned steps is recommended for creating patient questionnaires that are comprehensible by the target pediatric population, as well as for yielding sound and high-quality subsequent translations.



RENEW YOUR ISOQOL MEMBERSHIP FOR 2013

Membership renewal for 2013 is available online at, <http://www.isoqol.org>

RENEW YOUR ISOQOL DUES TODAY!

NEW INVESTIGATORS SPECIAL INTEREST GROUP – BLOG LAUNCH

By: NI SIG members

The New Investigator Special Interest Group (NI SIG) has created a blog to support investigators new to the field of QoL research, and to help each other solve problems at the early stages of one's research or career. Several authors have been contributing to the blog by posting articles and announcements about QoL research, career development, and the annual conference.

We would like to raise awareness of the blog's existence (it is easily accessible via the ISOQOL website under the menu tab "Special Interest Groups" or via the link: newinvestigators-isoqol.blogspot.com), and

welcome new investigators to not only visit and read the blog, but also to write and share experiences. We envision the blog to become an international and supportive platform for new investigators. In addition, we would like the blog to serve as a venue for discussing daily hassles of research, since many of us face similar challenges at similar times.

We welcome any contributions made by new investigators. Not only will the blog evolve better when more people contribute, but it will also provide a more stable and diverse network. Furthermore, we would sincerely welcome any contributions

made by our senior members. The high attendance at this year's "Tips and Tricks of the Trade" presentation at the ISOQOL conference has clearly shown how valuable such contributions are to new investigators.

If you have any ideas for the blog, or are interested in volunteering on NI SIG projects this year, please feel free to email the NI SIG Co-Chairs. Antonia Bennett, bennetta@mskcc.org, and Katerina Papageorgiou, a.papageorgiou@umcg.nl. We look forward to seeing you around!



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

ABSTRACT SUBMISSION DEADLINES

Friday, February 1

Workshop, Symposia Abstract Submission Deadline

Friday, April 12

Oral and Poster Abstract Submission Deadline

Monday, July 1

Speaker Confirmation Deadline

Workshop & Symposium Abstract Notifications will be sent in March 2013
Oral & Poster Abstract Notifications will be sent in June 2013

ISOQOL is now accepting abstracts for **Workshops** and **Symposium** presentations at the 2013 Annual Conference. Visit the **Abstract Submission Page** of the ISOQOL website for submission instructions and links to the online abstract submission system. (<http://www.isoqol.org/2013conference/abstract-submission>)

Workshop and Symposium abstracts will be accepted through Friday, February 1, 2013.

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CALENDAR OF EVENTS—JANUARY

- *Jan 16*
Biosimilars: Overview of Legislation, Policy and Current State of Implementation [Webcast]
Thousand Oaks, CA, US
http://www.ajmc.com/biosimilars1_recruit?goback=.gde_87445_member_189847719
- *Jan 21 - 22*
Advanced Modeling Methods for Health Economic Evaluation
New York, New York, US
<http://www.iconplc.com/news-events/events/workshops/advanced-modeling-methods/index.xml>
- *Jan 22 - Jan 23*
Medical Affairs Seminar - Launching a High-Value Medical & Scientific Affairs Team
Boston, MA, US
<http://www.exlpharma.com/medaffairs>
- *Jan 24 - Jan 25*
4th Annual Observational Sciences for Decision-Making
Philadelphia, PA, US
<http://www.isoqol.org/research/events/4th-annual-observational-sciences-for-decision-making>
- *Jan 28 - Feb 2*
Winter School in Clinical Epidemiology
Tyrol, Austria
http://www.umat.at/page.cfm?vpath=departments/public_health/htads_continuing_education_program_d/short_courses_d/winter_school_in_biostatistics_epidemiology_d
- *Jan 30 - Jan 31*
6th Annual Forum on Oncology Commercialization Strategies
Philadelphia, PA, US
<http://www.cbinet.com/conference/pc13108#.UMszklLwkxo>
- *Jan 30 - February 1*
1st Global Conference: Protoscience, Health and Well-Being
Sydney, Australia
<http://www.inter-disciplinary.net/critical-issues/ethos/protoscience-health-and-well-being/call-for-presentations/>

CALENDAR OF EVENTS—FEBRUARY

- *Feb 11-12*
Genomics in Medicine Conference
San Francisco, CA, US
<http://www.triconference.com/genomics-personalized-medicine>
- *Feb 11 - Feb 13, 2013*
10th Annual Medicare Congress
Phoenix, AZ, US
<http://www.iirusa.com/themedicarecongress/home-page.xml>
- *Feb 11-14*
February International Conference on Bioinformatics Models, Methods and Algorithms (BIOINFORMATICS 2013)
Barcelona, Spain
<http://www.bioinformatics.biostec.org/>
- *Feb 26 - 27*
Health Economics for Non-Health-Economists
Brussels, Belgium
http://www.celforpharma.com/pharma-management/training/pharma-health-economics-course.html?linkid=minimenu_dates#dates
- *Feb 27-28*
8th Device and Diagnostic Coverage and Payer Strategies
San Diego, CA, US
<http://www.cbinet.com/conference/pc13192#.UMs0WYLwkxo>

CALENDAR OF EVENTS—MARCH

- **Mar 11 - Mar 13**
5th Annual Government Programs
Chicago, IL , US
<http://www.iirusa.com/gp/welcome.xml>
- **Mar 13-15**
18th Congress of the European Association of Hospital Pharmacists (EAHP) Seminar
Paris, France
<http://www.eahp.eu/congresses>
- **Mar 14 - Mar 15**
The World Congress Summit to Improve Adherence and Enhance Patient Engagement
Philadelphia, PA , US
<http://www.worldcongress.com/events/PB13001/>
- **Mar 14-15**
The 14th Annual IMI Conference on Intercultural Relations
Washington , D.C., US
<http://www.imi.american.edu/conference>
- **Mar 16-18**
3rd Global Conference: The Patient
Lisbon, Portugal
<http://www.inter-disciplinary.net/probing-the-boundaries/persons/the-patient/call-for-papers/>
- **Mar 18 - Mar 20**
Market Access: Overcoming the 4th Hurdle
Brussels, Belgium
http://pharmexpand.com/market-access.htm?goback=.gde_1995770_member_183768241
- **Mar 20 - Mar 23**
Pharma Pricing & Market Access Outlook 2013
London, UK
<http://www.healthnetworkcommunications.com/2013/pharma-pricing/index.stm>
- **Mar 21**
Health Professionals for a New Century: Transforming Education to Strengthen Health Systems In An Interdependent World
Brussels, Belgium
http://healthprofessionals21.org/index.php?option=com_content&view=article&id=164:brussels-belgium-21-march-2013&catid=11:events&Itemid=111
- **Mar 22 - Mar 24**
Mental Health Policy, Economics and Health Care Reforms
Venice, Italy
<http://www.icmpe.org/test1/events/veniceannounce.htm>

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ISOQOL AWARDS PROCESS

By: Rebecca Brandt, CAE, Executive Director, ISOQOL

EMERGING LEADER AWARD IN HONOR OF DONNA LAMPING, PHD

With the passing of Past President Donna Lamping, PhD in 2011, the Board of Directors agreed to establish an award for emerging leaders within ISOQOL and the field of health-related quality of life research. Donna spent much of her career mentoring young researchers and, by creating this award, ISOQOL hopes to honor her legacy. Special recognition goes to Neil Aaronson and Madeleine King for leading the process of designing this award.

The award nominee must be a current member of ISOQOL and have been active on an ISOQOL committee, SIG or working group for at least 2 years, having shown exceptional leadership skills and potential. Individuals must be within 10 years of completing a PhD (or equivalent), MD or Masters Degree. Current and past ISOQOL board members are

ineligible. Self-nominations are accepted. Full information regarding the application process can be found on www.isoqol.org.

PRESIDENT'S AWARD

The goal of this award is to recognize outstanding contributions (by an individual or group) to the advancement of the quality of life field in one or more of the following areas: "education of professionals, patients or lay individuals about the value of quality of life assessment as related to health"; "promotion or execution of quality of life research or other scholarly activities"; and "facilitating or furthering policy initiatives that impact upon health-related quality of life." The winner may be given the opportunity to give a 20-minute plenary during the Annual Meeting.

Please submit your nomination package consisting of a letter from the

nominator specifying the nominee's contributions, the curriculum vitae of the nominee, and an external support letter.

The award will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. The award will consist of a plaque, a \$1,000 US honorarium and up to \$1,000 US in travel expenses if the recipient plans to attend the Annual Conference.

Nominations for both awards are due May 15, 2013

Please send your nomination package for either award to:

President's Award/Emerging Leader Award

ISOQOL Executive Office
555 E. Wells Street, Suite 1100
Milwaukee, WI 53202, USA
Fax: (414) 276-3349 (OR e-mail info@isoqol.org)



BOARD NOMINATIONS ANNOUNCEMENT

The ISOQOL Nominating Committee, chaired by President-elect Galina Velikova, is accepting nominations for the following ISOQOL leadership positions:

Member, Board of Directors 2013-2016 (Two open positions, three-year term)

Position begins at the 2013 Annual Conference and concludes at the 2016 Annual Conference.

Self-nominations are accepted and encouraged. The ISOQOL Nominating Committee is committed to encouraging a strong diversity on the Board of Directors regarding geographic representation as well as representation from all aspects of health-related quality of life research.

An e-mail with full position descriptions will be e-mailed to all members. If you are interested in learning more about being nominated for a position, please contact Becky Brandt, ISOQOL Executive Director at rbrandt@isoqol.org.





Refer to the experts in ePRO translations.

Developing instrument translations for use on ePRO devices requires early collaboration among the sponsor, ePRO vendor, and language service provider. This important step can eliminate many technical problems and instrument administration issues. Partnering with Corporate Translations ensures a thorough review and proper linguistic validation of the adapted instrument for use on an ePRO device when required. That's why Corporate Translations is the preferred supplier of ISO 9001:2008 translation and linguistic validation solutions to the world's leading life science companies.

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CALL FOR VOLUNTEERS: ABSTRACT REVIEWERS

Abstract reviewers serve a vital role in the scientific program planning by ensuring the quality of the educational content presented at the Annual Conference. Serving as an abstract reviewer provides an excellent way to support ISOQOL. Time commitment is low, but the impact is high! Abstract review is 100% electronic and all rankings will be submitted online.

Contact the ISOQOL Executive Office at info@isoqol.org for more information or to volunteer for any of the following roles:

- **Workshop Abstract Review:** February 4 - 15, 2013
- **Symposium Abstract Review:** February 4-15, 2013
- **Oral and Poster Presentation Abstract Review:** April 22 - May 17, 2013



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) and Dennis Revicki (dennis.revicki@unitedbiosource.com).

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



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Response Shift
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UPCOMING WEBINAR: LESSONS LEARNED FROM PROS IN FDA AND EMA LABEL CLAIMS

The Industry Advisory Committee is developing a webinar, which will include presentations from industry sponsors who have successfully interacted with either the FDA or EMA to support labeling of their products. This session will include a review of PRO measures and determination of how to move them forward and/or revise as appropriate to support labeling claims. Specifically, the webinar will address how to conduct a gap analysis, how to adapt or modify existing measures to assess and/or confirm the validity of the measure. The webinar will address both FDA and EMA considerations of PRO measures through the use of case studies.

The date of the webinar will be announced via e-mail, Facebook, Twitter and LinkedIn as soon as it is available. If you are interested in being notified directly when the date is announced, please send an e-mail to info@isoqol.org.

