

Quality of Life

QUARTERLY

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VOLUME 18 ISSUE 2

Newsletter for
ISOQOL Members
SPRING 2012

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Jean Wenzel
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PRESIDENT'S MESSAGE

Bryce B. Reeve, PhD



Dear ISOQOL Family,

How can ISOQOL continue to carry out its mission to *advance the scientific study of health-re-*

lated quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations? This is the question the ISOQOL Board of Directors will be discussing at its upcoming meeting in April, 2012.

To address this question, the Board will draft a short and long term strategic plan including a broad range of ideas. One idea is more guidance documents like the article "Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations" published in *Quality of Life Research* (2011) by ISOQOL members, or the article "The use of patient-reported outcomes (PRO)

within comparative effectiveness research: implications for clinical practice and healthcare policy" that was accepted for publication in *Medical Care*.

Another idea to advance ISOQOL's mission is through education. In the past we have conducted methodological workshops at our annual meetings. These in-person workshops will continue. However, in the age of high-speed internet, we can offer distant learning opportunities. Also, we can consider mid-year meetings like the 2004 ISOQOL Symposium on "Advancing Outcomes Research Methodology and Clinical Applications" or the 2006 ISOQOL Symposium to discuss the FDA guidance.

ISOQOL will also look for opportunities to collaborate with other organizations and institutions. In the past, we planned back-to-back meetings with the Society for Decision Making and the Drug Information Association. However, ISOQOL can do much more than that by partner-

Continued on page 2.



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

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

ing with organizations to share our knowledge on HRQOL research.

Why have this strategic planning session? Well, this is not the first, as past Board meetings have launched some of the initiatives I list above and many I haven't. For ISOQOL to be recognized as leaders in the field, we must continue to update our strategic plan to respond to recent changes in the health research field.

For example, the Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created by the U.S. government to facilitate research that will help people make informed health care decisions and improve health care delivery. ISOQOL played a key role by making recommendations to PCORI for the minimum standards for the design and selection of patient-reported outcomes measures for use in patient-centered outcomes research. ISOQOL should continue to lead these types of initiatives.

ISOQOL's greatest resource is its members, which includes researchers and clinicians around the world who work in academics, industry, and government. The ability for ISOQOL to carry out its mission relies on our ability to leverage but not overburden these precious resources to advance the strategic initiatives. Thus, your feedback and participation is essential.

Following the Board meeting, we plan to seek your thoughts on the proposed plans and other opportunities. As always, the Board and I are open to your suggestions and to your help. I look forward to working with you to advance the HRQOL research field.

Sincerely,

Bryce



RENEW YOUR ISOQOL MEMBERSHIP FOR 2012

Membership renewal for 2012 is available online through the ISOQOL Membership Central page, <http://www.isoqol.org/membershipcentral.htm>.

RENEW YOUR ISOQOL DUES TODAY!

FROM THE EDITOR'S DESK

By: Ana Popielnicki

DEAR FELLOW ISOQOLERS:

Welcome to our Spring issue! That is, unless you are in the Southern Hemisphere like my good friend Dr. Juan Daputo, in which case – Happy Autumn! No matter where in Earth you are located, it is time for new beginnings, renewal, and growth. Our members are increasingly involved in new initiatives and a never-ending quest for understanding, and improving, quality of life.

This common mission is evident in the growing efforts that the Society, and many of our members individually, are investing in the Patient-Centered Outcomes Research approach. Look in this issue for an article from the Communications Committee on this topic, and make sure to read our President's exhortations to continue to collaborate in this and other initiatives in his President's Message.

We hear again from Sharon Chaplock, in "News from the Chalkboard", an interesting guide to conducting effective, productive virtual meetings. In this global society, we are more and more pressed to find ways to maximize our connections and optimize our time and resources management – all this is expertly addressed by Dr. Chaplock in her article.

As promised in our first issue earlier this year, we bring you our current Calendar of Events for the 2nd quarter – do feel free to send us your information on any future activities for inclusion in our next issue. And while we are on the events topic, please read the update on our 19th Annual Conference, from the conference organizers, Drs. Sara Ahmed and Fabio Efficace – many engaging sessions and activities are being planned so start your travel arrangements!

For those of you interested in linguistic and cultural adaptations of PROs, see Barbara Brandt's article on successfully translating ePROs. We are also including several announcements, industry news, and committees/SIG reports – please read them and find out how you can get involved.

As usual, I would like to invite your comments, suggestions, and questions. Please send your e-mails directly to me at aap@tls-translations.com or to the office, at info@isoqol.org – do remember to write "ISOQOL Newsletter" in your subject line. I look forward to your contributions!

And now, let me get my coats out of the basement closet. I heard they are calling for snow this weekend... did I say Happy Spring??? Enjoy the newsletter!!

Warm regards,



Ana



Abstract Reviewers for the 19th Annual Conference

Volunteers are needed to serve as abstract reviewers for Oral & Poster Presentation abstract submissions. Abstract review will take place during the month of May.

Contact info@isoqol.org
for more information or to volunteer.

This volunteer opportunity is open to all current ISOQOL members.

ISOQOL 19TH ANNUAL CONFERENCE: BUDAPEST!

Another year has gone by and planning for ISOQOL's 19th Annual Conference is in high gear. We are fortunate to be hosting this year's conference in Budapest, Hungary, and to have the opportunity to experience the city's Old World grandeur and thriving cultural life. The meeting will be held 24-27 October and this year's theme is *"The Journey of Quality of Life Research: A Path Towards Personalized Medicine"*.

We, as co-chairs of the conference, found this theme highly relevant in light of the great progress that has been made over the last few years in several areas of medicine. As an example, the advent of targeted therapies has revolutionized how we think about clinical care and research in several ways. On one hand, this has led to tremendous potential for improvements in clinical outcomes,

and on the other, it has brought additional challenges into clinical practice that we face to ensure the highest possible quality of care.

We will be welcoming experts and an excellent array of keynote speakers from all over the world to participate in the conference's plenary sessions. Come take the journey with us as we address questions such as "What is personalized medicine?", and "What role do patient-reported outcomes play in personalized medicine including their role in diagnosing disease, tailoring interventions, and supporting individual adherence to recommended treatments?". The sessions will also present innovations in e-health, with presentations from *patientslikeme*. Other topics include the development of guidelines for incorporating PROs in research, clinical practice, and monitoring of PROs

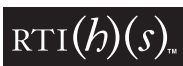
at a population level for supporting comparative effectiveness research. The speakers will be announced in the coming weeks.

In addition to excellent scientific content and exchanges, the annual conference is an opportunity for clinicians, early investigators, researchers, and members of the industry to network. Don't forget to keep an eye out for the conference's social events and the chance to explore Budapest in the company of colleagues and friends.

We look forward to seeing you in October!

Sara Ahmed, PhD
Co-Chair, 2012 ISOQOL
Annual Conference

Fabio Efficace, PhD
Co-Chair, 2012 ISOQOL
Annual Conference



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LEADING RESEARCH...
MEASURES THAT COUNT

NEWS FROM THE CHALKBOARD: TEN TIPS FOR HIGH TOUCH TELECONFERENCES THAT DELIVER RESULTS

By: Sharon Chaplock, PhD, Director of Education, Meetings & Publications, Society for Immunotherapy of Cancer (SITC)

More than likely, if you are an active committee member of ISOQOL or other professional membership groups, you have attended teleconferences to contribute to the work of the organization. The advantages are clear. Keeping meeting costs lean by working virtually is an obvious benefit. Engaging a diverse group of people on a project is now possible without the cost or time lost of travel. This inclusiveness is a major benefit that allows involvement of those who want to contribute but are not co-located.

In my previous article on Subject Matter Experts, I wrote about the value of participating in the development of professional growth opportunities. Teleconferencing allows experts in locations across the globe to collaborate in real time and accomplish what once was only possible at face-to-face meetings. With this in mind, it's useful to review some best practices for accomplishing a project using the virtual collaboration tool of the teleconference.

A good remote meeting incorporates the basics of a good in-person meeting: a clear goal, key participants, and an inclusive environment so all feel able to participate. The challenge with a teleconference comes with creating that all-important factor of "social presence" defined by Short, Williams and Christie (1976)¹ in their seminal work on telecommunications. Social presence theory claims that "communication is effective if the communication medium has the appropriate social presence required for the level of interpersonal involvement required for a task" (Wikipedia).

Developing social presence on a teleconference is critical to creating effective communication in support of collaborative projects. But telecon-

ferences are limited by the absence of body language and eye contact so vital to establishing the full spectrum of communicating, especially if the participants have never met before in person. They are further threatened by multi-tasking and other distractions while on the call. Fortunately, much research is available on best practices that help create "high touch" teleconferences that encourage effective communication. I've synthesized them into Ten Top Teleconferencing Tips, five for the host and five for attendees.

HIGH TOUCH HOSTING

1. **Invite key participants.** Use a meeting scheduler tool like Doodle, ScheduleOnce or Tungle.me to find a time and date that works for your group. Keep in mind the various time zones of the participants. Follow up with dial-in and passcode information and a reminder at least 24 hours before the meeting.
2. **Assign roles.** Designate a facilitator who makes sure the agenda is followed and everyone is heard; a timekeeper who monitors the time for each item; and a note taker who takes and distributes minutes with action items.
3. **Set expectations.** Be explicit about the objective of the meeting at the beginning.
4. **Send handouts.** Include an agenda with time slots and responsibility assignments for each item and support materials as attachments. Consider linking to an online whiteboard, such as Basecamp, that serves as a repository and includes an instant message chat function that adds another channel for communication and aids complex decision making.

5. **Set rules that encourage participation.** These should include:
 - a. Identify yourself when speaking and wait your turn before speaking
 - b. Use the mute button when not speaking
 - c. If you must leave before the call is ended, let others know at the beginning of the call

HIGH TOUCH PARTICIPATION

1. **Be on time.** Dial in a minute or two ahead of time or let the organizer know you will be late so the meeting is not held up.
2. **Introduce yourself.** When connecting to the call, say "hello, this is...."
3. **Create a supportive environment.** Avoid cell phones and use a good land line if possible; arrange a quiet space; and beware that music on hold or call-waiting will be heard by all on the call if you use them.
4. **Follow the rules in number 5 listed in High Touch Hosting above.**
5. **Be fully present.** Avoid side conversations and, even though it's tempting, don't multi-task by viewing and responding to email or other distractions.

Following these basics can make the difference between an efficient and highly collaborative team, or one that never seems to achieve cohesion. If you have any tips to share, please send them here and I'll make sure they are shared.



¹ Short, J., Williams, E., & Christie, B. (1976). The social psychology of telecommunications. London, England: John Wiley.

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CALENDAR OF EVENTS—APRIL

- **April 12 – 13**
Medical Affairs Executive Forum
Morristown, NJ, USA
<http://www.exlpharma.com/events/2nd-medical-affairs-executive-forum>
- **April 16 -19**
Committee for Medicinal Products for Human Use (CHMP)
London, UK
<http://www.ema.europa.eu>
- **April 17 - 18**
Contract Manufacturing Summit
London UK
<http://www.pharmaphorum.com>
- **April 17**
FMCP Leadership Meeting: Improving Patient Care Through Research, Practice and Leadership
San Francisco, CA, USA
<http://www.regonline.com/builder/site/Default.aspx?EventID=1055186>
- **April 17 - 19**
PROficiency 2012 - PROs and Beyond
Naples, FL, USA
<http://www.invivodata.com/proficiency-2012/>
- **April 18**
Infection Control Risk Assessment (ICRA) for Healthcare Construction Activities Half-Day Workshop
ECRI Institute Headquarters, Plymouth Meeting, PA, USA
<https://www.ecri.org>
- **April 17 - 20**
World Drug Safety Congress Americas 2012
Boston, MA, USA
<http://www.healthnetworkcommunications.com/2012/world-drug-safety-congress/index.stm>
- **April 18 - 19**
5th Annual CEE & CIS Clinical Trials Forum
Vienna, Austria
<http://pharma.flemingeurope.com/ceecis-clinical-trials/>
- **April 18 - 20**
AMCP's 24th Annual Meeting & Expo
San Francisco, CA, USA
<http://69.0.204.76/conferences/2012/sf/>
- **April 23 - 24**
Reducing Legal Risks in the Sales and Marketing of Medical Devices
Chicago, IL, USA
<http://www.cbinet.com>
- **April 24 – 25**
2nd Annual Biopharma & VacTech China
Shanghai, China
<http://www.biopharma-china.com/>
- **April 24 - 25**
CBI's 7th Global Forum on Clinical Trial Registries and Results Databases
Philadelphia, PA, USA
<http://www.cbinet.com/conference/pc12135>
- **April 25 (2-5pm)**
The Donna Lamping Memorial Research Afternoon
Jerry Morris Room, London School of Hygiene & Tropical Medicine, London, UK
- **April 25 - 26**
2nd Annual Pharma Regulatory Affairs Asia
Singapore, Singapore
<http://www.croasia.net>



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A Companion to the *User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice*

Podcast recorded by:

**Neil Aaronson, PhD
Michele Halyard, MD
Rachel Hess, MD**



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CALENDAR OF EVENTS—MAY

- **May 2 - 3**
RX Drug Pricing Boot Camp - West Coast Edition
San Francisco, CA, USA
<http://www.americanconference.com>
- **May 2 - 3**
Economic Evaluation in Clinical Trials
Morristown, NJ, USA
<http://www.healthconomics.org/conferences/2012/05/02/economic-evaluation-in.html>
- **May 7 - 8**
CBI's 9th Forum on Patient Reported Outcomes
Philadelphia, Pennsylvania, USA
<http://www.cbinet.com>
- **May 16**
CBI's 340B Contracting and Reconciliation
Lake Buena Vista, FL, USA
<http://www.cbinet.com>
- **May 17 - 18**
CBI's 14th Annual Medicaid Rebates Conference
Lake Buena Vista, FL, USA
<http://www.cbinet.com>
- **May 21-22**
Committee for Herbal Medicinal Products (HMPC)
London, UK
<http://www.ema.europa.eu>
- **May 21-24**
Committee for Medicinal Products for Human Use (CHMP): 21-24 May 2012
London, UK
<http://www.ema.europa.eu>
- **May 23**
Mental-Health-Forum 2012
London, UK
<http://www.mental-health-forum.co.uk/>

CALENDAR OF EVENTS—JUNE

- **June 2 - 6**
ISPOR 17th Annual International Meeting
Washington, DC, USA
<http://www.ispor.org>
- **June 7**
2012 PRO & ePRO Congress
Annecy, France
<http://www.phtcorp.com>
- **June 7 - 9**
Modeling Approaches for HTA: a Practical Hands-On Workshop
Oslo, Norway
<http://www.path-hta.ca>
- **June 12-13**
Committee for Orphan Medicinal Products
London, UK
<http://www.ema.europa.eu>
- **June 14-15**
Committee for Advanced Therapies
London, UK
<http://www.ema.europa.eu>
- **June 18-21**
Committee for Medicinal Products for Human Use
London, UK
<http://www.ema.europa.eu>
- **June 19 - 20**
CBI's 5th Bio/Pharmaceutical Summit on Managed Care Marketing
Philadelphia, PA, USA
<http://www.cbinet.com>
- **June 24 - 28**
DIA 2012: Collaborate to Innovate 48th Annual Meeting
Philadelphia, PA, USA
<http://www.diahome.org/DIAHome/Education/FindEducationalOffering.aspx?productId=27170&eventType=Annual%20Meeting>

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ISOQOL AWARDS

By: Rebecca Brandt, CAE, Executive Director, ISOQOL

NEW

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 in-

eligible. Self-nominations are accepted. Full information regarding the application process can be found on www.isoqol.org by clicking "awards" on the left of the homepage.

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.

Make sure to read the full description and criteria for the awards at www.isoqol.org by clicking on "awards" on the left side of the homepage.

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)



The Department of Public Health & Policy Invites You

The Donna Lamping Memorial Research Afternoon

Wednesday 25th April 2012, 2-5pm

Jerry Morris Room,
London School of Hygiene & Tropical Medicine,
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RSVP (for catering purposes) to Debby Stanley debby.stanley@lshtm.ac.uk

The afternoon will be followed by drinks and an opportunity
to catch up with colleagues & friends.

BUDAPEST

ISOQOL 19th ANNUAL CONFERENCE

October 24-27, 2012



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MEMBERSHIP COMMITTEE REPORT—ISOQOL: SO WHO ARE WE?

By: Joanne Greenhalgh, Board member and Chair of ISOQOL Membership Committee and Heather Vitale, ISOQOL

If you're reading this newsletter, you're a member of ISOQOL. But who else is also reading it? Where do our members come from and what are their backgrounds? Well, luckily, this is the place to find out. This short article will give you a brief profile of ISOQOL members so that you have a better idea about who your colleagues are. If you want to find out more – come to the 2012 conference and meet them or get involved on the SIG discussion boards!

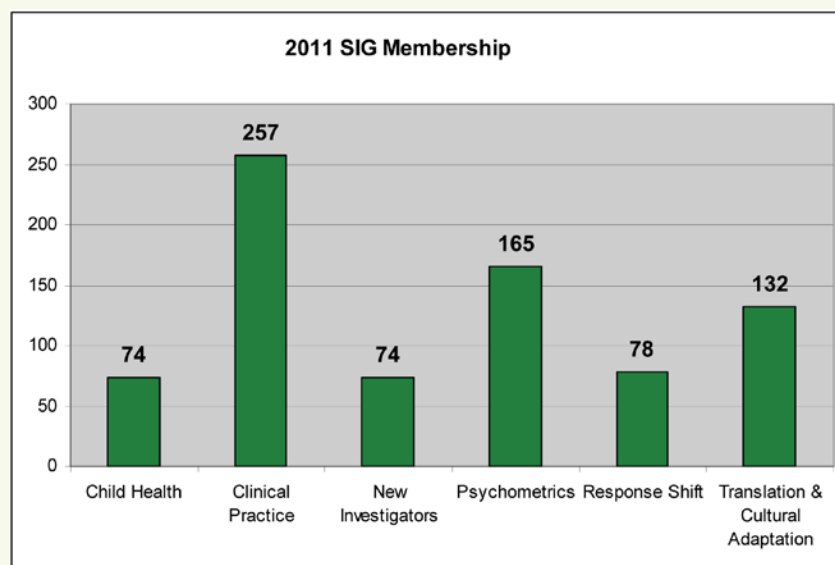
We are a truly international society, with just over 50% of our 2011 members coming from North America and the rest hailing from Europe (27%), Asia (12%), South America (5%) and Australasia (4%) (see Graph 1). Most of our members would describe themselves as either academics (69%) and/or clinicians (26%) but we're also very pleased to have a sizeable percentage of our members from industry (12%) and government (5%). We're also delighted that we have a growing number of student members.

Our members have a wide range of interests with psychology, medicine, epidemiology, statistics and health services research being the most commonly cited. This is also reflected in our range of Special Interest Groups (see Table 1) including Quality of Life in Clinical Practice, Child Health, Translation & Cultural Adaptation, Psychometrics, Response Shift, and New Investigators. All have a growing and active membership, and you can find out more and get involved in as many as you like through the SIG pages on our website -- or by attending their meetings at the annual conference.

Graph 1: Geography of our Membership



Table 1: Special Interest Groups Distribution



So, now you know more about who we are. ISOQOL depends heavily on its members' support to achieve its strategic plans and it would be great to see our membership grow even further, and include people from all corners of the globe as well as differ-

ent backgrounds and interests. If you want to help generate ideas for how to retain our existing members and attract new ones, join the membership committee! Drop me an e-mail on j.greenhalgh@leeds.ac.uk.



COMMUNICATIONS COMMITTEE REPORT: PATIENT-CENTERED OUTCOMES RESEARCH – HOW CAN WE GET INVOLVED?

By: Deborah Miller, PhD, Chair, and Ana Popielnicki, BA – Co-Chair

In our January 2012 issue, ISOQOL President Bryce Reeve, PhD talked about the increasing evolution of our industry towards patient-centered outcomes research (PCOR). As he mentioned in his President's message then, this focus on the patient as a whole and the successful integration of patient-reported outcomes and clinical data will give us safer and more effective tools to improve the quality of care and outcomes for patients of all ages.

The Communications Committee, in its recent report to the Executive Board (March 2012), is offering to facilitate the collaboration and sharing of experiences and perspectives of all ISOQOL members. We are seeking to maximize the advantages we share in the global context of our multi-disciplinary and international community. Some of the tools we have to utilize towards this movement are the following:

- A newly redesigned website (in progress): A more interactive and user-friendly website, as well as a list of resources and the ability to communicate in a safe platform is in the works. Several ISOQOL members are collaborating in this initiative, under the leadership of Dr. Miller, Communications Chair.
- Webinars and Long Distance Learning (LDL) modules will be offered, in coordination with Dr. Sharon Chaplock, Director of Education, Meetings and Publications for SITC – See her article on meeting virtually and the call for webinar submissions in this issue.
- Links with resources, websites, webcasts and presentations on PCOR will be published in the newsletter, as well as articles written by experts on PCOR and/or those currently involved in this

movement. We welcome your submissions of links or articles – please send to Ana Popielnicki at info@isoqol.org (Subject: Newsletter submission).

We are currently brainstorming on ideas and suggestions as to how the Society members can get involved and contribute to this important opportunity to improve quality of life and care. Please get in touch with any of us if you would like to participate in these initiatives (or any other that can help disseminate knowledge on PCOR and multi-disciplinary collaboration). We can be reached at the following addresses:

Deborah Miller, PhD – millerd@ccf.org
Ana Popielnicki, BA – aap@tls-translations.com
OR, you can reach the central office at info@isoqol.org.

We look forward to hearing from you!



SPECIAL INTEREST GROUPS

Do not miss the opportunity to connect with ISOQOL members from all around the world who share your research interests and goals.

How Do I Join?

- *Log into your account on the Members Only page of the ISOQOL website
- *Select "Edit my Profile"
- *Update your SIG membership

- *Child Health
- *New Investigators
- *Psychometrics
- *QoL in Clinical Practice
- *Response Shift
- *Translation and Cultural Adaptation

SIG membership is a membership benefit open to all current ISOQOL members.



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ePRO TRANSLATIONS: ACHIEVING A SUCCESSFUL END-PRODUCT

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

Developing translated instruments for use on ePRO devices requires early collaboration among the sponsor, ePRO vendor, and language service provider (LSP) in order to achieve a successful end-product. This important step can eliminate many technical problems and instrument administration issues. It is imperative for the LSP to communicate directly with the ePRO vendor at project start, establishing milestones within the confines of the delivery timeline to meet study requirements, and continuing a high level of communication throughout the endeavor.

When translating for ePRO, important considerations must be made to ensure a successful collaboration between the ePRO vendor and LSP, accurate translations, and timely delivery of the end-product. The LSP should confirm with the ePRO vendor any ePRO software font requirements and the format in which the translation should be provided. Font-testing should be performed to ensure that the required languages are compatible with the ePRO software platform. Many instruments place emphasis on certain terms, using underlining, boldface, italics, and capitalization. If the ePRO software does not support the mode of emphasis in the source, then the LSP and ePRO vendor should work to achieve a solution that maintains the source's intent. Anticipating ePRO-

specific translation modifications such as these saves time and unnecessary expense.

If electronic administration of a paper PRO is desired, adaptations are necessary for ePRO. Per the ISPOR ePRO Task Force recommendations, the extent of modification is an important consideration. When only minor changes are needed for paper PRO to ePRO migration, a large body of evidence suggests that the psychometric properties of the original measurement tool will be upheld (Coons, et. al., 2009). Major changes to the measure would warrant additional testing. The LSP should work with the instrument developer, sponsor and ePRO vendor to modify source instructions as necessary to accommodate the intuitive nature of electronic administration. For example, explicit skip pattern instructions may disappear in the electronic version. In paper administration, a respondent may be instructed "If YES, proceed to question 8," whereas ePRO eliminates the need for this direction. "Check a box" may become "touch a box." After ePRO adaptation has occurred, the ePRO vendor should furnish the LSP with a path or "road map" through the screens, showing their logical progression and contingencies based on responses to previous items. All localized screens must be checked against this source, to ensure ePRO accuracy.

Because ePRO creation may involve separating questions and response sets, all translations must be proof-read within the context of the questionnaire in its entirety, as well as per screen. Each screen should be checked for corrupted characters, and to ensure that the ePRO mirrors the paper version. Multiple quality assurance steps should be applied before and after cognitive debriefing, ensuring equivalency with the English source and a logical path through the questionnaire. If existing device instructional materials are available, they should be provided to the LSP in order to maintain consistency with terminology.

Achieving a successful ePRO end-product requires a flexible, innovative LSP, a dynamic relationship between both vendors, and careful planning during project inception. These pieces are essential in yielding a high-quality, error-free ePRO translation.

REFERENCES

Coons SJ, Gwaltney CJ, Hays RD, et al. Recommendations On Evidence Needed To Support Measurement Equivalence Between Electronic And Paper-Based Patient Reported Outcome (PRO) Measures: ISPOR ePRO Good Research Practices Task Force Report. *Value in Health* 2009;12(4):419-429.





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Call for Webinar Presentations

ISOQOL is seeking proposals for its 2012 Webinar series aimed at researchers, practitioners, clinicians, healthcare providers and other health care providers concerned with patient quality of life issues. The scope of webinars includes but is not limited to, the following major topics:

- HRQL Research Basics
- Conducting Qualitative Research
- ePRO System Selection
- QOL Assessment
- QOL Basics

Webinars are 45 to 60 minutes in length followed by a 15 – 30 minute Q & A Session. The live broadcasts will also be recorded and archived on the ISOQOL website for on-demand viewing.

Submissions should be sent to info@isoqol.org with the subject line, "Webinar Topic."

The Webinar Review policy requires that each proposal is peer-reviewed by the ISOQOL Webinar Review Taskforce. Early deadline for submissions is **Monday, April 30, 2012.**

CHILD HEALTH INTEREST GROUP REPORT— IDENTIFYING RESEARCH NEEDS

Co-Chair: Anne W. Riley, B.S.N., M.S. Ph.D., Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

The Child Health Interest Group meeting in Denver, Colorado was productive and enjoyable. With 21 members from eight countries in attendance, we discussed the initial results of our Delphi process to develop a research agenda for Child and Adolescent HRQOL. We have now heard from over 60 researchers, the results have been summarized, and the 2nd round of the Delphi is being emailed to the sample - which includes CHIG members and others. We encourage broad participation.

Although not yet prioritized, the most commonly suggested areas for advancing the science of child health assessment were focused on the need for research that:

- Tests and validates criteria to guide the use of child and adolescent HRQOL instruments in clinical care
- Empirically demonstrates the contribution to clinical outcomes of child and adolescent reports of HRQOL
- Characterizes how HRQOL changes with the age and development over childhood and adolescence

- Shows how to link reports of children in longitudinal studies
- Develops and validates methods for assessing children under 8 years of age
- Demonstrates the validity and utility of combining reports from multiple observers - parents, children, teachers, and clinicians and/or determines which reporter to use for what outcomes

Of course, the most commonly submitted topics may not turn out to be the ones selected as most important for future research. The Delphi results of the prioritized areas of research for child and adolescent HRQOL will be posted on the ISOQOL website, reported in the next Newsletter and at the meeting in Budapest. See you there!

We sincerely welcome your input. Contact one of us if you would like to get the Delphi results directly and/or join the CHIG.



Two CHIG leadership issues: 1) Drs. Katherine Bevans and Christopher Forrest, both of Children's Hospital of Philadelphia and University of Pennsylvania would like to be more prominent in the leadership of the CHIG. I value their contributions and have taken the liberty of including them as co-chairs with me. 2) An additional co-chair, someone from outside the U.S., is needed. If you are interested in becoming a Co-Chair and working to promote the visibility of children's health in ISOQOL, please contact me.

PHT

Science Advisor Positions in ePRO Consulting Services

As a member of a team of accomplished clinicians and technologists, the Scientific Advisor provides scientific guidance and analysis to the Sales, Marketing & Client Services functions in a software company that creates electronic data collection systems for clinical trials. The Science Advisor combines expertise in measurement theory with knowledge of regulations related to patient & clinician reported outcomes to guide decisions in protocol development & in the software designed for that protocol. On a day-to-day basis, you may be advising a clinical trial manager responsible for a multinational trial with 3000 subjects on the best instrument to measure the concept of interest, or advising a team of researchers on the meaning of the latest FDA guidance related to electronic data collection. You will learn the capabilities of electronic data collection systems, advise PHT's developers on best practices for software design, analyze operational data to answer questions for clinical teams and for PHT's internal customers and participate at the national level through meetings and organizations committed to excellence in electronic collection of patient and clinician data.

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