



# International Society for Quality of Life Research

Volume 15 Issue 2

Newsletter for ISOQOL Members

August 2010

## PRESIDENT'S MESSAGE

Diane Fairclough, DrPH



It is hard to believe that more than half of my term has passed. A lot has been happening as you will read in the rest of the newsletter which reports on the chapters, SIGs (Special Interest Groups), membership and a proposed monograph series. The London meeting this October promises to be one of our best meetings, with exciting plenary sessions and great workshops.

One of the major tasks of the ISOQOL board is strategic planning. This Spring's

two-day board meeting to do this was made more challenging by the volcano eruption in Iceland just as our European board members were about to depart for the United States. However, with some creative planning on both sides of the Atlantic, we were able to link the entire board and have a successful meeting.

The common theme that emerged from the strategic planning was the need and benefits of reaching outside of ISOQOL. One of the themes was the need to create strategic partnerships with groups who should be using patient reported outcomes (PROs). We need to communicate the benefits of their use for those groups who do not use PROs and the state-of-the-art for their use among those who do use them. Potential targets included comparative effectiveness researchers (CER), clinicians in practice, and decision makers about patient reimbursement. Another theme was reaching out through education.

Two initiatives were proposed, a monograph series (see article in this newsletter) and the other was e-Learning, where we plan to build on our existing educational activities such as the workshops.

These are challenging times for families, businesses and organizations. We all face the dilemma of whether to make bold but risky initiatives or to be conservative and look for smaller initiatives that preserve the unit but look for future growth. I believe that we have taken the later course.



## ISOQOL MEMBERS SURVEY: YOUR CHANCE TO TELL US WHAT YOU THINK

Joanne Greenhalgh, PhD, Chair, Membership Committee

Soon the Membership Committee, with the approval of the ISOQOL Board, will be asking ISOQOL members to complete a membership survey. The survey will be administered online and members will receive an e-mail with a link to the survey webpage. It should take no more than 5-10 minutes to complete. The purpose of the survey is twofold.

First is to ask members what they think about a central activity undertaken by ISOQOL: the annual meeting. Attendance at the annual meeting is a key driver in determining whether members renew their membership of ISOQOL. Member's views about what influences their decision to attend the annual meeting will help the board in their planning of future ISOQOL meetings to ensure that they meet members' needs.

Second is to ask members' views about the ISOQOL website. This is an important mechanism for keeping members up to date with what happens in the society and is a useful source of information about conceptualising and measuring HRQoL. ISOQOL is planning to update the website and to inform this process, we'd like your views about what works and what doesn't work on the website.

So, if you want an opportunity to influence how ISOQOL does things, we'd be really grateful if you could take a few min-

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Survey, from page 1

utes out of your day to complete the survey. It will make a difference. The previous members' survey conducted in August 2004, which focused on member's views of current ISOQOL benefits, led to the following changes:

- *Online access to Quality of Life Research as part of membership.* The 2004 survey asked if members would like to have the cost of the journal subscription included in their membership. The online journal is now included as a member benefit and the print subscription is available at a much reduced rate.
- *Arrangement with Quality Metric for ISOQOL to provide the Understanding Health Outcomes educational series on CDs to new and renewing members.* One of the most desired benefits from the 2004 survey was "Electronic access to teaching and learning resources relevant to QoL research".
- *Regional Chapters were formed, beginning in 2007.* 72% of members in

the 2004 survey indicated that they 'might' or 'definitely' wanted "Regional chapters of ISOQOL (to increase relevance to local issues and facilitate links between QoL researchers within a region or country)". We now have four regional ISOQOL chapters: the Ibero-American and Russian chapters, which were approved in 2007 and the Dutch and Asian Chinese chapters, which were approved in 2009.

- *Option to include membership dues with registration.* 72% of members in the 2004 survey indicated that they would like the option to pay their current and/or next year's dues with their conference registration. This has been available to members since 2005.

By completing this year's membership survey, your views will be instrumental in helping ISOQOL plan its annual meetings and update its website. It's coming to your inbox soon.



*ISOQOL 2010 Conference:*  
**"Translating Quality of Life Measurement into Decision Making"**

*October 27-30, 2010 ~ Hilton Metropole ~ London, England*

**Topics include:**

- Use and interpretation of Quality of Life and Patient Reported Outcome Measures (PROMs) in clinical research and practice
- Role of QoL and PROM data in health policy decision making
- Industry and clinical perspectives on QoL & PROMs used in clinical trials
- New approaches to developing and validating QoL and PROMs

**Invited Plenary Sessions:**

*Psychometric Methods for Developing and Evaluation Rating Scales: Why I do What I Do*

Speakers: David Andrich, PhD; Bryce Reeve, PhD; Geoff Norman, PhD

*The Routine Use of Patient-reported Outcome Measures in Health Service Decision Making: Challenges and Opportunities*

Speakers: Nick Black, MD; Nancy Devlin, PhD; Lewis E. Kazis, ScD; Richard Lilford, PhD

*Dissemination and Integration of PRO Data into Clinical Care*

Speakers: Dale Vidal, MD, MS; Richard Stephens; Michael Brundage, MD, MSc

**Register now** at [www.isoqol.org](http://www.isoqol.org)

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## ISOQOL SIG REPORTS

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Deborah Miller, PhD on behalf of the SIG Chairs

### Introduction

ISOQOL supports several Special Interest Groups (SIGS) which are intended to facilitate collaboration among all members with a common theoretical or clinical focus who work together to address issues related to their field. The SIGS that ISOQOL sponsors include

- IRT/Psychometric Methods
- Kids: QoL Assessment in Children & Adolescents
- New Investigators
- QoL in Clinical Practice
- Response Shift
- Translation & Cultural Adaptation

Claire Snyder, PhD [csnyder@jhsp.edu](mailto:csnyder@jhsp.edu) is the SIG Liaison to the ISOQOL Board and oversees the general activities of the SIGS. Please feel free to contact Claire or the leadership of the individual SIGs, listed below, to learn more about or join the SIG of your choice.

The SIGs will be meeting at the ISOQOL Annual Meeting in London between the 27<sup>th</sup> and the 30<sup>th</sup> of October. The exact time, date and location of SIG will be announced closer to the meeting.

The leadership of each SIG is responsible for providing routine summaries of their on-going activities. Below are summaries of the SIG reports that will be reviewed at this year's annual meeting.

### *Child and Adolescent Special Interest Group (aka The Child SIG)*

#### Leadership:

Anne Riley, PhD  
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Michael Erhart, PhD  
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Hamburg, Germany  
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#### Date Organized: 2005

**Purpose:** The Child SIG is well and developing healthfully. Our primary interests are to stimulate excellent child health related quality of life research (C-HRQoL), to increase awareness among the general ISOQOL membership of the importance of early health and the potential of child health concepts and methodological practices to foster improvements in health across the lifespan. Such methods/practices include non-patient observer reports/studies; integration of data from multiple reporters: cognitive interviewing methods; adaptations of instruments for respondents with low literacy, attentional and other respondent problems; and long term effects of health promotion interventions. Some frustration was voiced about the too frequent adult-centric focus, such as sessions titled as though they involve a geographically based "population" when in fact only people over 18 are included.

**Recent Activities:** We meet annually at the ISOQOL meeting. In New Orleans, 21 members from 8 countries actively participated in setting goals for the coming year and sharing activities and opportunities in child HRQoL research and practice around the globe.

#### Upcoming Activities and Opportunities:

- The SIG will conduct a modified Delphi process this summer to obtain input on 2 or 3 models of health in order to foster advances in the conceptualization of health during childhood and across the lifespan. Contact us if you are interested in providing brief, short responses to 3 e-mails about your opinion of these models of health.
- Join the Child SIG and get on the mailing list. (If you did not get the summary of the SIG meeting in New Orleans it means that we do not have your correct email address.)
- Attend and participate in the ISOQOL meeting in London – October 2010:
  - o Assist in fostering excellent child focused sessions that have been accepted for presentation – We will pair senior researchers/experts with less senior investigators whose presentations have been accepted to

assist in preparing outstanding presentations or posters.

- o Help staff a Child Health SIG table at the Opening Reception – involves only a brief commitment and provides the opportunity to meet lots of interesting people.
- o Assist in preparing a summary of opportunities to work with datasets and researchers on child health related quality of life throughout the world. This will be circulated to the Child SIG via email and at the London Child SIG meeting.
- o Foster the development of researchers new to the field of child health research by offering your insights and expertise.

### *New Investigators Special Interest Group*

#### Leadership:

Roxanne Jensen, PhD  
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Sandra Nolte, PhD  
Arbeitsgemeinschaft Dermatologische Prävention e.V.  
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#### Date organized: 2007

**Purpose:** The New Investigators SIG is targeted at people new to QoL research. We welcome students, post-docs, and anyone working in QoL research for five years or less. We were founded after several senior ISOQOL researchers had approached us to be the support arm for the junior ISOQOL members. The founding co-chairs were Elsbeth Taminiau-Bloem and Sandra Nolte. After Elsbeth stepped down last year, came on board. The main aim of our SIG is to provide a forum for people who are as new to this area as are we.

**Recent Activities:** We organize meetings at every ISOQOL conference and send out e-mails throughout the year about useful topics for new investigators.

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*SIGs, continued on page 4*



### SIGs, from page 3

#### **Upcoming Activities and Opportunities:**

For the upcoming conference in London, we are very excited to have arranged a presentation regarding grant applications and funding opportunities by a senior researcher from the US. We will send out more information about the presentation in the coming months.

We are also about to launch a new listserv in cooperation with Bellinda Kallimanis-King at the University of Amsterdam. This listserv is targeted at both new investigators and others who need support in research methodology and statistics. It is meant to be a forum for you to ask questions of senior experts and your peers in a friendly environment. This listserv will also provide information on jobs and funding opportunities. If you are interested in joining the listserv but are not signed up with our SIG, please contact us! We would also appreciate hearing from senior QoL researchers who would be interested in answering questions from new investigators.

Last but not least: Sandra's term will be ending in October 2010, and we are soliciting nominations for her successor. It is a fun opportunity, so please consider running for this position in the fall!

#### ***IRT/Psychometric Methods Special Interest Group***

##### **Leadership:**

Chih-Hung, Chang, PhD  
Northwestern University  
Chicago, IL, USA  
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Bryce Reeve, PhD  
National Cancer Institute  
Bethesda, MD, USA  
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##### **Date Organized:** 2002

**Purpose:** The field of psychometrics plays a critical role in HRQOL research. For the field of outcomes research to achieve its potential, it needs efficient, precise, and valid HRQOL measurement tools to identify the most efficacious treatment or to

identify meaningful changes in study populations. Psychometrics plays a key role alongside qualitative methods to develop and evaluate these HRQOL measures. Further, structural equation models provide an incredible methodology for looking at associations among HRQOL variables or to model change over time when there are multiple endpoints or mediating/moderating factors.

It is important for our group to highlight research that has shown effective use of psychometric methods and to find ways to make these tools and language more understandable for HRQOL researchers. What educational resources should we as a group come up with to guide both new and seasoned HRQOL researchers on the appropriate use of psychometric models? Where are there research gaps in the psychometrics field as it relates to HRQOL research? Can we identify short term and long term research goals and how do we prioritize them? How can we use ISOQOL to build a strong and connected network of researchers to collaborate on these ideas?

##### **Upcoming Activities and Opportunities:**

While the ISOQOL Psychometric SIG has not formally met over the past couple ISOQOL Conferences, Chih-Hung Chang and Bryce Reeve hope at the next ISOQOL Conference in London to invigorate and challenge the group to identify opportunities for us to lend our knowledge, skills, and ideas to advance HRQOL research. We see the core goals of this group as being to: 1) advance the science of HRQOL research through the application of psychometric methods; and 2) educate researchers on the appropriate use of psychometric methods.

However, at the upcoming ISOQOL Conference in London, we (the SIG) will revisit these goals and welcome your input regarding the direction and role this group should play for ISOQOL and the research field. So, put your thinking caps on and come prepared for an active discussion in late October.

It must be emphasized that this group should not work in isolation, but we must strive and push ourselves to keep con-

nected with the other ISOQOL SIGs (i.e., KIDS, New Investigators, Response Shift, and Translation and Cultural Adaptation). In fact, we should directly ask of their needs and questions and continue to maintain an open dialogue and support network among all the SIGs. We look forward to exploring this great area with you all.

#### ***Translation and Cultural Adaptation Special Interest Group (TCA-SIG)***

##### **Leadership:**

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Iliana Petkova  
administrative coordinator  
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##### **Date Organized:** 2003

**Purpose:** In response to increasing interest in cross-cultural issues, the International Society for Quality of Life Research (ISOQOL) created a special interest group in the field of translation and cultural adaptation (TCA-SIG) in 2004 during the ISOQOL annual meeting in Hong Kong. The aims of the group are (1) to identify and advance research in the fields of translation and cultural adaptation of PRO measures and (2) to provide an evidence database on translation and cultural adaptation of PROs.

The TCA-SIG counts 3 subgroups pursuing individual objectives to meet the overall aims:

- the Cross-Cultural Issues subgroup addresses issues related to the access of copyrighted instruments, the translation of PROs and their use in e-format,
- the Translation Methodology subgroup pursues a research agenda for the development of methodologies in the field of translation and cross-cultural research,
- the PRO Translation Certification subgroup aims at establishing an international certification program for PRO translations.

**Recent Activities:** Over the last 5 years, the first subgroup has put together a list of recommendations for developers and users of PRO measures based on the review of translation difficulties and copyright issues. Subgroup 2 has completed a first analysis to identify the crucial aspects in the standard PRO translation methodology based on the review of errors avoided during each translation step. Subgroup 3 is involved in establishing a rationale for the need for international certification of PRO translations. Results of findings have consecutively been presented during ISOQOL's annual meetings.

**Upcoming Activities and Opportunities:** This year's efforts will be focused on the publication of these. Manuscripts the TCA-SIG is currently working on include an article on translation certification and an article on copyright issues. Both articles and any other presented to and accepted by the steering committee of the TCA-SIG in the meantime will be discussed during the group's annual meeting during the ISOQOL conference in London later this year.

### **Response Shift Special Interest Group**

**Leadership:**

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Lena Ring, PhD  
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 Sodertalje, Sweden  
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**Date Organized:** 2005

**Purpose:** The purpose of the Response Shift SIG is to bring together investigators and clinicians who are interested in the influence of response shift (a change in an individual's values, internal standards, and conceptualization of QOL) on longitudinal evaluations of QOL and other patient-reported outcomes (PRO). The first series of articles on response shift in *Social Science and Medicine* in 1999 provided an initial glimpse into the theoretical, methodological, and applied implications of response shift (1). Since then, response shift research has seen a growth in the refinement of the theoretical framework and testing of methods across diseases.

The ultimate objective of the SIG is to, through active collaboration between our members, stimulate research and discussion to further advance work in this field. Some topics of discussion during our annual meetings and workshop activities have highlighted the evolving theoretical framework of response shift, the impact of response shift on the interpretation of PRO assessments, the status and use of various methodological approaches for evaluating response shift, and the role and feasibility of response shift assessments in clinical and research settings.

**Recent Activities:** Over the past few years the SIG has been active in supporting the work of its members and developing SIG activities. The collaboration between our diverse membership has resulted in the successful completion of several projects. New Investigators in the SIG published a review on response shift with proposed research priorities (2). Response shift workshops were held at the 2007 and 2008 ISOQOL annual meetings. The response shift SIG also proposed and created a Special Issue on response shift in the *Journal of Clinical Epidemiology* (Volume 62, Issue 11, November 2009) on recent advances in interpretation of longitudinal changes in health-related quality of life data. The Special Issue included publications from several members of the SIG. The series of papers in the special issue were presented as a symposium at the 2009 annual ISOQOL conference in New Orleans, Louisiana, USA.

**Upcoming Activities and Opportunities:**

The SIG remains active and is currently conducting a head to head comparison of methodological approaches for evaluating response shift among individuals with Multiple Sclerosis using the NARCOMS data. Members of the SIG were invited to participate in one of four working sub-groups, and each sub-group will take the lead on one of the methodological approaches.

A think tank session on clinical, theoretical, and methodological advances in response shift that will bring together individuals from diverse disciplines is currently being organized for September 2010 in Boston. The first day will focus on theoretical discussions that attempt to bring clinical insights into the foreground as we think about future directions for response shift research. The second day will focus on discussions on recent methodological developments, with an emphasis on integrating the previous day's discussion into current methods. The main aim of the Think Tank is to develop a clear agenda for collaborative research projects between the disciplines.

1. Schwartz CE, Sprangers MAG. Introduction to symposium on The challenge of response shift in social science and medicine. *Social Science & Medicine* 1999; 48:1505-1506.
2. Ruth Barclay Goddard, Joshua Epstein, Nancy Mayo. Response shift: a brief overview and proposed research priorities. *Quality of Life Research*. 18(3):335-46, 2009



## THE ISOQOL PROGRAM OF GEOGRAPHICAL CHAPTERS

Montserrat Ferrer, MD, PhD  
Chapter Liaison

Since its foundation in 1999, ISOQOL has showed a clearly international vocation. The number of members from countries further than its original base in North America and Europe increased in absolute and relative terms during the last decade (from 10% to 20%, as depicted in figure 1). A main step in this progress of decentralization and bringing the society closer to these different geographical areas was the creation of the ISOQOL Chapters program in 2007. This allowed the creation of groups of members who wish to work on a national and geographical region scope, with specific objectives oriented to their local needs.

As stated in the guidelines on National and Regional Chapters of ISOQOL in 2007 ([www.isoqol.org/ISOQOLChaptersProvisionalGuidelines.pdf](http://www.isoqol.org/ISOQOLChaptersProvisionalGuidelines.pdf)), "ISOQOL supports the development of national and regional chapters as a means of fostering the field of health-related quality of life (HRQL) research in countries and regions beyond ISOQOL's traditional membership base [...] It is hoped that the development and growth of such chapters will not only increase ISOQOL's membership and foster a more truly international network of HRQL research and researchers, but also promote understanding and use of HRQL measures in a wider and more culturally and geographically diverse range of countries and regions. This in turn will promote more cultural and geographical balance in the field of HRQL research."

In only four years, this program has become a well-established initiative, with four current chapters: the *Ibero-American*, the *Russian* and the *Asian Chinese* chapters approved in 2007; and the *Netherlands* one approved in 2009. Figure 2 shows the large extent of countries where ISOQOL has members (colored areas), and those regions covered by specific chapters. In fact, preparations are in hand to establish another two chapters, the *Turkish* and the *Ghanaian* ones. The quick

development of this program in such different geographical areas indicates the good acceptance and vitality of this initiative. We will mention only some examples among the most relevant activities and planned events for each chapter.

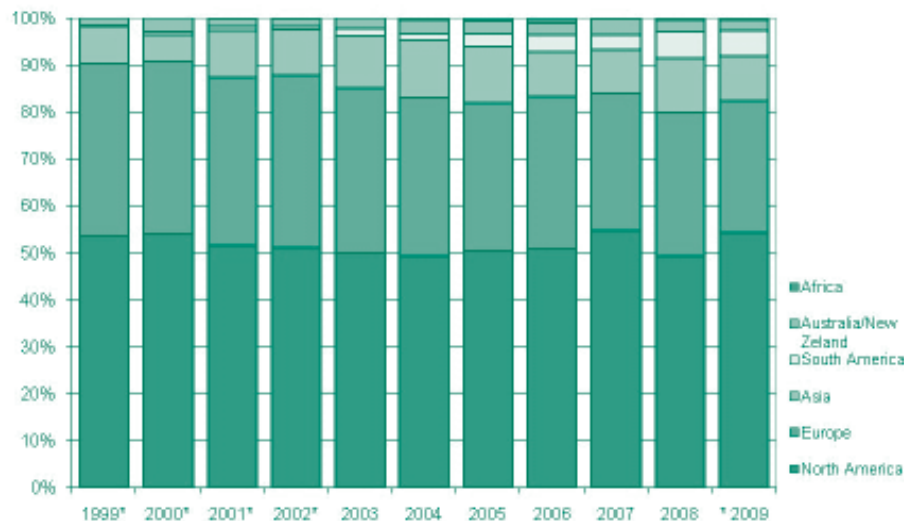
The *Ibero-American* chapter, co-led by Laura Schwartzmann and Cristina Pecci ([capituloiberoamericano.blogspot.com](http://capituloiberoamericano.blogspot.com)), submitted recently a proposal to develop a website for virtual education and collaboration among academic institutions of seven countries (Argentina, Brazil, Chile, Colombia, Mexico, Spain, and Uruguay). It is noteworthy that this year they will hold the 5th Ibero-American meeting in Chile (September 2010) despite the economic difficulties as well as the terrible earthquake occurred in Chile last February, which made them wonder about the opportunity of the event. However, the great effort carried out by the Chilean researchers managed to surpass these difficulties, and they have prepared an interesting program which includes a pre-meeting education course as well as a broad spectrum of conferences and symposiums. ISOQOL Ibero-American meeting has become a classic meeting point and well-known event among researchers of these countries. Previous editions have been placed in Uruguay, Argentina and Brasil.

The Russian chapter's chair is Prof.

Tatyana Ionova, director of the Multinational Center for Quality of Life Research, a scientific non-profit organization created in 1999 under the patronage of the Russian Federation's Minister of Health. Training and consulting on Patient Reported Outcomes for physicians and researchers from Russia, Ukraine, Belorussia, Kazakhstan, Turkmenistan, and Turkestan; as well as using an annual newsletter, regular issues of the "*Bulletin of the Multinational Center for QoL Research*", or specific tools (flyers, plastic bags...) for dissemination across these countries have been the main activities of the chapter.

The recently approved ISOQOL chapter for *The Netherlands* (ISOQOL-NL), led by Henk van Stel, was based on the previous Dutch study group on health status measurement, which already had a website ([www.gezondheidstoestand.nl/](http://www.gezondheidstoestand.nl/)) and a mailing list including around 300 email addresses. It also functions as a focus group of the *Netherlands Epidemiological Society* (NES) since early 2009. Last year's symposium "*Defining Quality of Life in Mental Health*" was organized as a pre-conference for the annual NES conference. Two further Symposia were planned during this year: '*Measuring participation*' (April 22<sup>nd</sup>) and '*Interpretation of patient-reported outcomes*' (September 24<sup>th</sup>) with Gordon Guyatt and Wieneke Mookink among other speakers.

Figure 1.





Finally, the *Asian Chinese* chapter was registered in Hong Kong under the Business Registration ordinance, and it covers Mainland China, Hong Kong, Macau, and Taiwan. The chair is Dr. Cindy L K Lam. An inauguration ceremony was held in May 2008 in the Asian Chinese QOL conference held in Guangzhou (China) and a 5-day workshop on Psychometric assessment of QOL scales was conducted in 2009. Now they are organizing the joint annual scientific seminar, together with the Hong Kong Society for Quality of Life (June 2010); and co-organizing the Asian Chinese conference (17-19 December 2010).

Yet, as you can imagine, establishing a chapter can be an exciting experience, but it requires a substantial commitment and effort. Therefore, it may be interesting in certain geographical clusters of ISOQOL members to try other ways of working within a region -either as a previous step, with the intention of becoming a chapter at a later date, or as an alternative to formally establishing a chapter when such an effort may not seem necessary or real-

Figure 2.



istic. So, ISOQOL members interested in proposing a new national or regional chapter are recommended to consider first two possibilities: One alternative is operating in the form of an ISOQOL Special Interest Group (SIG). This was the case for the Ibero-American chapter, which initiated its conception with the *Latino-American SIG*. A second approach would be to form an *ad hoc* project group, for instance with the purpose of organizing a one-off ISOQOL regional conference. In this sense, the *Turkish National HRQL Society* (SAYKAD) was devoted to organizing the regular National HRQOL meetings every 3 years since 2004 (2004, 2007 and 2010). A noticeable increase has been apparent in their last meeting, where in addition to the plenary sessions there were 18 parallel symposia on various medical specialties, with about 300 participants and 187 papers presented.

Figure 1. Percentage of ISOQOL members per region from 1999 to 2009.

Figure 2. Countries with ISOQOL presence, and regions covered by specific chapters.

## JOINT FORUM ON PATIENT REPORTED OUTCOMES ~ MAY 2010

William Lenderking, PhD

Montevideo. New Orleans. Budapest. Boston. The list of interesting locations where ISOQOL has had meetings now warrants a new entry: Philadelphia. Although perhaps not as exotic as some of these locales, the setting was well-suited for the recent conference on Patient-Reported Outcomes, which focused on the FDA Final Guidance, due to its reputation as the “City of Brotherly Love” and the cradle of American liberty. The release of the FDA Final PRO Guidance in December 2009 provided ISOQOL with an opportunity to partner with the Center for Business Intelligence (CBI) to provide education and training on it, as well as perhaps more importantly, a forum for discussion about the implications of the new guidance. Spearheaded by the Industry Advisory Committee (IAC) and the ISOQOL Board, with the goal of presenting a meeting that did not duplicate the webinars and educational sessions that sprouted up like mushrooms after a summer rain, and also to avoid excessive financial risk, the Board came up with an optimal solution: to partner with CBI to put on the conference. Since CBI was already planning a PRO conference, and had approached two ISOQOL members about chairing the conference, Jeff Sloan and William Lenderking, the arrangement had the potential to be a win-win situation for all.

The negotiations that resulted ended with ISOQOL having considerable influence on the conference agenda, bearing none of the risk of organizing the meeting, receiving a guaranteed payment pegged to attendance, and winning a special steeply discounted rate for ISOQOL members who had never attended a CBI conference, in exchange for use of the ISOQOL mailing list for solicitations.

The meeting took place May 25 and 26, and was a success. There were 85 over-

*Joint Forum, continued on page 11*

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## ISOQOL'S 2010 CONFERENCE "TRANSLATING QUALITY OF LIFE FOR DECISION-MAKING": UPDATE FROM THE PROGRAM COMMITTEE

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Jane Scott, PhD and Stefan Cano, PhD,  
2010 Annual Conference Co-chairs

The 17th annual ISOQOL conference is scheduled for October 27-30. It promises to be an outstanding scientific forum for researchers and policy makers interested in the use of health-related quality of life (HRQL) and patient-reported outcome (PRO) measures in clinical research and health care. The program focuses on the increasingly important role PRO data plays in informing health policy and medical practice decision making. More than 500 scientific abstracts were reviewed by the program committee. Of these, 472 were accepted for presentation in one of the 12 symposia, 24 oral presentation sessions, and 3 poster presentation sessions. Sessions are organized in "Tracks" to ensure there is something relevant for the three primary interest groups within ISOQOL: *Methodology*, *Clinical Practice Applications*, and *Policy Research* (including epidemiology, clinical development trials, and health system research). Program sub-committees led by Jeremy Hobart, Andrea Pusic and John Browne (respectively) have developed exciting plenaries and symposia for each *Track* to ensure stimulating sessions that address key issues of the day for their respective research communities.

*The program focuses on the increasingly important role patient reported health data plays in informing health policy and medical practice decisions.*

A day of workshops will be offered prior to the official start of the conference. If you're a newcomer to PRO re-

search and want to learn about the basic principles and methods, or want to pick up some new knowledge about unfamiliar methods, there will be 10 basic level courses offered. And if you are a seasoned PRO researcher looking for new methods to enhance your research, 7 advanced-level workshops offer state of the art methods training. In addition to the full and half-day workshops, you may want to consider signing up for the special workshop, "Secrets for Outstanding Poster Presentation" offered by Nancy Mayo and Sharon Wood-Dauphinee at no charge for anyone registered for the conference (date and time to be confirmed). When the programming ends for the day, special interest groups and taskforces will meet to network and plan activities for the coming year.

*In addition to the full and half-day workshops, consider signing up for the special workshop, "Secrets for Outstanding Poster Presentation" offered by Nancy Mayo and Sharon Wood-Dauphinee at no charge for anyone registered for the conference (date and time to be confirmed).*

### **Wednesday, 27 October**

*Pre-Conference Workshops, 9:00am-4:00pm*

10 basic (B) and 7 advanced (A) level

workshops will help participants learn about application of HRQL and PRO research and reporting issues across a wide variety of topics. Workshop seating is limited so sessions fill up fast. Please register on-line early to be sure you get the sessions you need.

*If you are a new researcher interested in working with a more experienced research mentor, you can apply to participate in the ISOQOL Mentorship program through the Education Committee links on the ISOQOL website when you register for the conference.*

*Mentor Mentee Reception, 4:30-5:30pm*

After workshops end, mentors and mentees have a chance to meet at the Mentor-Mentee Reception. If you are a new researcher interested in working with a more experienced research mentor, you can apply to participate in the ISOQOL Mentorship program through the Education Committee links on the ISOQOL website when you register for the conference. Existing members interested in serving as mentors are invited to contact the Education Committee so they can be assigned a mentee to meet at the reception.

*Welcome Reception, 5:30-7:00pm*

To kickoff this year's meeting, the welcome reception is the place where you



can meet new faces and reconnect with old friends.

*Special Interest Groups (SIGs) and ISOQOL committees and task forces interested in meeting during the annual conference are encouraged to check with Sarah Shiffert ([sarah@isoqol.org](mailto:sarah@isoqol.org)) about meeting space availability after each day of programming ends.*

**Thursday, 28 October**

The scientific program for the 2010 meeting begins at 8:00am with a rich and lively discussion of psychometric methods for developing and validating PROM including HRQL measures in the plenary session organized by the Methodology subcommittee, “**Psychometric Methods for Developing and Evaluating Rating Scales: Why I Do What I Do**” Although classical test theory, generalizability theory and modern psychometrics (including Rasch analysis and IRT) are commonly discussed in ISOQOL meetings and publications in our journal, *Quality of Life Research*, the appropriate use of these different methods has not been discussed in a major forum within ISOQOL. To allow members to learn about the strengths and appropriate use of each of these models for psychometric analysis, session chairs Jeremy Hobart and Stefan Cano will lead what promises to be a lively session with some of the world’s experts in each of these methods answering the question “Why I Do What I Do”. Invited speakers (to be confirmed) include Geoff Norman

(guru in Generalizability Theory), Bryce Reeve (Item Response Theory) and David Andrich (Rasch Measurement). Don’t miss this once in a life-time session on what psychometric analysis approach to use when.

The plenary will be followed by two 90-minute oral presentation sessions. After lunch on your own, the invited symposia from the Methodology Program Sub-Committee will present issues in rating scale validity, while updates on response shift, genetics of HRQL, and preference measurement will be presented in concurrent symposia. After these, another great set of oral presentations will cover methods issues including scale selection and validation, and application of PRO to study of geriatrics and fatigue. The final session of the day allows everyone to meet the authors of the posters as they enjoy refreshments at the Meet the Poster Presenter Reception.

Special Interest Groups (SIGs) and ISOQOL committees and task forces interested in meeting during the annual conference are encouraged to check with Sarah Shiffert ([sarah@isoqol.org](mailto:sarah@isoqol.org)) about meeting space availability after each day of programming ends.

**Friday, 29 October**

Friday morning’s plenary is “**The Routine Use of Patient-reported Outcome Measures in Health Service Decision Making: Challenges and Opportunities.**” This plenary developed by the Policy Research SubCommittee looks at the role patient reported health information is playing in medical service delivery decisions today and asks “Where should we head in the future?” Presentations by speakers will address the use of PRO in evaluation of service provided by the US Veteran’s Administration health service system (Lewis Kazis), UK PROMs initiative (Nick Black), and in the UK’s National Institute for Clinical Excellence (NICE) decisions (Nancy Devlin). Professor Richard Lilford will serve as moderator.

The Friday plenary also will be followed by two 90-minute oral presentation ses-

sions organized by interest tracks. Four 90-minute symposia will be presented after lunch. The invited symposia from the Policy Research Program SubCommittee will explore approaches to utility assessment, with a comparison of generic and disease-specific assessments and their merits for valuing health states for policy decision-making. Three other concurrent symposia will present issues in symptom assessments in gastrointestinal disorders, methods for translating PRO in oncology clinical practice and research, and an update on the WHOQOL. From 3:45-5:15pm, another great set of oral presentations will cover methods and policy issues which will be followed up with the Friday Poster Reception where you can meet the authors of the posters to discuss their research.

*After the plenary, the winner of the ISOQOL President’s Award, Professor David Feeny, will open a special panel discussion session in which luminaries of health policy and research from the US, UK, and EU will address questions about the future of PRO in national and international health policy decision-making.*

**Saturday, 30 October**

The final day of the conference starts with concurrent symposia, including

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*Annual Meeting, continued on page 11*

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## ISOQOL MONOGRAPH SERIES – EDITORS NEEDED

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*Diane Fairclough, DrPH, 2010 ISOQOL President*

During the April 2010 ISOQOL Board of Directors' meeting, an initiative to develop a monograph series has approved. The monograph series is intended to provide a resource for health care practitioners and researchers on topics relevant to assessment and interpretation of measures of health-related quality of life (HRQOL), patient-reported health statistics and health preferences. The monograph series will be available as e-books print-on-demand or through the usual options (Amazon, etc.) at prices ranging from \$12-\$20 USD. It is expected that the monograph series will initially focus on topics fundamental to the assessment and interpretation of HRQoL presented at an introductory and conceptual level. The series may then progress to technological issues at the discretion of the editorial board, which is described below.

We envision a series that is accessible to clinicians, students and researchers, and similar to the SAGE series of green books in terms of technical level and appeal to a broad audience. With this goal in mind, it is anticipated that the length of monographs will be the equivalent of 3-4 book chapters. These monographs will differ from journal articles submitted to QOLR in terms of intent (tutorial) and length.

The first step for initiating this endeavor will be the formation of an editorial board with 4-6 individuals (with staggered terms of 3 years) who will be responsible for the monograph series. This editorial board will be responsible for soliciting proposals for monographs, reviewing the proposals/concepts, and editorial oversight of the monographs. It is anticipated that proposals will be both author initiated and solicited by the editorial board.

The anticipated process (contingent on modifications by the editorial board) is that:

- The proposals will consist of:
  - o An outline of the monograph
  - o 2-4 potential reviewers (with consent)
  - o A brief biographical sketch supporting the expertise of the author(s)
  - o Examples of writing (e.g., chapters, books) [Optional]
- The editorial board will review the proposals and notify authors of decision. The editorial board can also obtain feedback from outside reviewers or those proposed by authors after the review of a proposal
- The editorial board will review the draft monograph. Upon receipt of the monograph, the editors will forward the draft to 2-3 reviewers (who may be solicited from the proposed reviewers as well as externally). At least one reviewer should be selected from the target audience for the monograph (e.g., clinician, researcher, student). The review process is intended to be friendly

with the goal of improving the quality of the monograph series.

For ISOQOL, the goal of this monograph series are three fold; the primary goal is education, and the monograph series will provide educational resources for researchers, clinicians, healthcare professionals and students. The organizational second goal is outreach; the series will enhance the recognition of ISOQOL as the leader in HRQoL education and potentially increase membership and annual meeting attendance. Finally, this initiative also has a fundraising goal, and sales should provide a very modest income source for ISOQOL.

Call for applications for ISOQOL Monograph Series Editors:

If you are interested in participating in this project as a series editor, please

1. Send a brief e-mail letter of intent to [diane.fairclough@ucdenver.edu](mailto:diane.fairclough@ucdenver.edu) by August 30, 2010.
2. Send a full application by September 21, 2010 containing
  - a. A cover letter containing a summary of your editorial and writing experience and your vision for the monograph series
  - b. A brief biosketch (3-5 pages) with experience that is relevant to a role as a monograph series editor.



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## ISOQOL MEMBERSHIP BENEFITS

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Know someone who might benefit from ISOQOL membership? Share these benefits with them and encourage them to join today!

- \* Online Membership Directory
- \* Access to *Quality of Life Research* Journal online at no additional charge!
- \* Reduced subscription rate for paper copy of the *Quality of Life Research* Journal
- \* Participation in a variety of Special Interest Groups
- \* Reduced conference registration rates
- \* Opportunity to present and hear cutting edge research presentations and posters
- \* Opportunity to have special interest group meetings at the annual meeting
- \* Access to the "Members Only" section of the ISOQOL website – an invaluable resource tool!
- \* Participation in a variety of committees
- \* Participation in the ISOQOL listservs - email communication with other QOL experts
- \* Exposure to and participation with other professionals involved in quality of life research
- \* Discount on annual subscriptions to the Quality of Life Instruments Database, offered by MAPI Research Institute
- \* Complimentary receipt of newsletters

Annual Meeting, from page 8

the invited symposia from the Clinical Practice Program Subcommittee, "Information Systems for Collection and Use of PRO in Clinical Practice," and three other symposia addressing pediatric PRO assessment, methods for testing effectiveness of using PRO in clinical practice, and research on adapting PRO to be administered using American Sign Language.

The Clinical Practice Subcommittee's plenary session, "**Dissemination and Integration of PRO Data into Clinical Care**" follows, with a discussion of PRO information needed and how to improve information to patients and clinicians to aid in more effective health care decisions. Andrea Pusic will serve as moderator of the panel discussion following presentations about shared decision-making and evidence-based practice (Dale Collins), improving clinician and patient understanding of clinical trial report results, and what information patients need and want (Richard Stephens).

*The meeting opens and ends with networking and fun at the Welcome reception (Wednesday evening) and the Annual dinner (Saturday evening).*

After the plenary, the winner of the ISOQOL President's Award, Professor David Feeny, will open a special panel discussion session in which luminaries of health policy and research from the US, UK, and EU will address questions about the future of PRO in national and international health policy decision-making. This is a chance to hear some of the leading health policy decision makers share how they are using PRO and what they need from

ISOQOL to improve health policy in the future.

A reception follows the panel session in the poster viewing area where you can meet the Saturday the luminaries and poster presenters for Saturday's poster session. This will be followed by the annual ISOQOL Member's Meeting where the outgoing president (Professor Diane Fairclough) welcomes the 2011 president (Dr. Carol Moinpour), and the society's committee chair people and special interest group leaders are recognized for their contribution to ISOQOL's 17<sup>th</sup> year.

The meeting opens and ends with networking and fun at the Welcome reception (Wednesday evening) and the Annual dinner (Saturday evening). But if you can come a day or two early or stay a few days longer, the Hilton Metropole hotel where the ISOQOL meeting will be held this year is in the heart of London. From there you can hop on London's "Tube" (Underground train) or a famous double-decker bus and head to all the museums, art galleries, theaters, shops, and other attractions of one of the world's most exciting cities.

Register soon if you can. An early registration discount is available until August 17 online at <http://www.isoqol.org/registration>, with a slightly higher rate for online registration August 18 through September 14. Otherwise, on-site registration will be available at standard rates.



Joint Forum, from page 7

all delegates, of whom 12 registered with the ISOQOL rate, although a show of hands at the beginning of the meeting indicated that about 30 ISOQOL members were in attendance. There were 20 speakers and a number of exhibitors, and ISOQOL qualified for the minimum payment. Several of the speakers who participated said that their willingness to join the forum was directly related to the ISOQOL sponsorship.

After a number of months digesting the guidance, and consistent with the content of the meeting, the FDA Final Guidance seems to primarily represent a clarification of a number of the positions originally staked out in the draft guidance. The meeting featured sessions on content validity, interpretation, ePRO, moving beyond PROs to patient relevant outcomes, developing PRO strategy with the guidance in mind, and conjoint analysis, and opened with a workshop on the guidance itself. In the end, fierce debate did not materialize, and the conference concluded in the spirit of its setting.



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