



# International Society for Quality of Life Research

Volume 16 Issue 1

Newsletter for ISOQOL Members

Spring 2011

## PRESIDENT'S MESSAGE

Carol M. Moinpour, PhD



So far, it has been a very busy year for ISOQOL due to our move to a new management company, Executive Director, Inc. (EDI). We appreciate everyone's patience while routines are set in place again. Rebecca Brandt, CAE (Certified Association Executive)

is ISOQOL's new Executive Director ([rbrandt@isoqol.org](mailto:rbrandt@isoqol.org)) and she is assisted by Heather Vitale ([hvitale@isoqol.org](mailto:hvitale@isoqol.org)). All ISOQOL members should have received an introductory e-mail from Becky on Jan. 21, 2011. When you call EDI [(414) 918-9797], located in Milwaukee, WI, the receptionist welcomes you to ISOQOL and you indicate whether you would like to speak with Becky or Heather (membership and meeting planning).

I have heard so many good comments about the London meeting, both for many good presentations and fun events. ISOQOL has always been for me this wonderful blend of excellent science and the opportunity to see many friends from all over the world. The plenary and symposia sessions were particularly interesting with the focus on psychometric methods/ issues and on health policy and patient-reported outcomes (PROs). We heard an excellent presentation by Richard Stephens, who presented a patient

advocate's perspective on the use of PROs in clinical care. [I personally had a lot of fun dancing at the Sat. evening dinner, mainly with my favorite dancing partner, Pam Hays. However, I also managed to get Rick Berzon on the dance floor. Finally, Carolyn Gotay, Claire Snyder, and I were true tourists and had a ride on the London Eye!] Many thanks to Jane Scott and Stefan Cano for the great meeting they organized for ISOQOL 2010!

We hope to see a large turnout for the meeting in Denver (Oct. 26<sup>th</sup>-29<sup>th</sup>, 2011). Cindy Gross and Karen Sousa are Chairing the Denver meeting and are working very hard to achieve the ISOQOL experience of top science and great collegial interchange. The theme is *"Pushing the Boundaries: Frontiers of Health-Related Quality of Life Research"*. The submission site for abstracts for oral and poster sessions as well as for symposia is currently

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## ISOQOL MEMBER'S SURVEY 2010

### Interim report to ISOQOL Board October 2010 from the Membership Committee

In August 2010, the membership committee, with the approval of the ISOQOL board, initiated a web based survey of members' views of the annual meeting and the website. A total of 251 questionnaires were completed (41% of the 614 initially sent).

### What factors influence attendance at annual meetings?

The first section of the questionnaire asked about what factors influence a member's decision to attend the annual meeting. In question one, respondents were asked to rate the extent to which fourteen different aspects of the ISOQOL conference influenced their decision to attend.

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

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**Deborah Miller, PhD, USA**

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### ***ISOQOL Member's Survey 2010, from Page 1***

The two most important aspects were that *'the content of the programme is of relevance to my work area'* (73%) and *'the content of the programme is of high quality'* (73%). Other important factors were *'my abstract is accepted for oral presentation'* (56%), *'the meeting is held in a location I can afford to travel to'* (53%), *'there are people attending the conference I would like to meet'* (48%) and *'my abstract is accepted as for a symposium presentation'* (48%). The second, follow up question asked respondents to rank order the top three reasons for attendance and the same themes emerged. Again, *'my abstract is accepted for oral presentation'* (50%), *'the content of the programme is of relevance to my work area'* (47%) and *'the content of the programme is of high quality'* (41%) were the frequently selected aspects. For both questions, of least importance were *'I wish to take part in the mentor/mentee programme'* (6% rating this as influencing their decision *'a lot'*) and *'I wish to participate in a special interest group activities'* (20% rating this as influencing their decision *'a lot'*).

Members were also asked whether there were any other factors that influenced their decision to attend the ISOQOL meetings in an open question. Seventy two (29%) provided an answer. The two issues that most commonly interfered with meeting

attendance were cost and timing. Many members' employers or academic departments were placing more limits on budgets, so members had to decide whether to attend ISOQOL or other conferences. Members decided on attending the meeting if they found it provided value for the cost which included travel, registration and housing.. Timing was an issue in terms of whether the conference clashed with or was too near to other meetings and the time that members needed to take out of their busy schedule to travel to and attend the conference.

An issue that we did not ask about in the survey were the workshops; three respondents mentioned their importance in response to the open question above. However, it is likely that more people would have rated the workshops as important if it we had specifically asked about them.

### **Summary and recommendations**

These findings suggest that our members focus on the quality and relevance of the annual meeting programme to their own work in addition to whether their abstract is accepted for presentation. It is likely that the quality and relevance of the programme influences their decision to submit an abstract – as one respondent wrote *"some issues are circular: you submit an abstract since you are*

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### ***President's Message, from Page 1***

open and will close on May 9. The ISOQOL website looks a bit different and we will be continuing to remodel the website over the next several years. **Please Note:** Members received an email (sent Feb. 7, 2011) requiring that you create a new login and password for the new ISOQOL website.

This issue of the Newsletter includes a comprehensive set of reports from chairs of committees and Special Interest Groups (SIGs). Please make

sure that you read them to learn what is happening in ISOQOL and how you can be more involved.

Please contact me with suggestions for how ISOQOL could be even better or if you run into issues when trying to get something done for the Society. I want to hear from you ([cmoinpou@fhrc.org](mailto:cmoinpou@fhrc.org) / (206) 667-4604). Please include "ISOQOL" in the subject of your e-mail.



## GET READY FOR ISOQOL 2011

*Cindy Gross, PhD*

“Pushing the Boundaries – Frontiers of Quality of Life Research” is our 2011 theme, and also a reference to our location, Denver, Colorado USA. Denver – a city on the high plains at the very edge of the Rocky Mountains - is synonymous with the American frontier and the lifestyle of the American west. Our meeting is **October 26-29 in at the Sheraton Downtown Denver.**

Expect crisp, cool autumn air (highs 20.0 °C /68.0 °F and lows 1.0 °C/ 33.0 °F) and spectacular scenery.

Volunteers are hard at work choosing plenary speakers who will highlight innovations in the use of quality of life measures. Proposed topics include eHealth, personalized health care, and new perspectives on qualitative methods. Expect updates on initiatives to improve or increase use of patient-reported outcome measures and to reduce health disparities.



A full array of pre-meetings workshops will be offered, and in conjunction with our call for abstracts (abstract submission deadline May 9) we are encouraging symposia organized by our SIGs and ISOQOL chapters. This year we are bringing back breakfast roundtables, and introducing a president-hosted welcome event especially for first time ISOQOL attendees. Look for calls to host a “meet the experts” event or lead a special topics breakfast discussion.



Take extra time to enjoy the Rocky Mountain scenery or ski after the meeting. Red Rocks Park and Amphitheater, just 15 miles outside of Denver, has wondrous, massive sandstone monoliths. [Denver ski resorts](#) begin opening in mid- to late October. Consider the following ski areas that are within a two-hour drive from Denver International Airport: Arapahoe Basin, Breckenridge, Copper Mountain, Keystone and Winter Park. For those with more time, a drive up to Aspen or Vail is breath-taking.

Recent prices for round trip air travel to Denver International Airport:

- Heathrow to Denver \$840
- Amsterdam to Denver \$980
- Montreal to Denver \$650
- Hong Kong to Denver \$1,400
- Washington, DC to Denver \$210
- Los Angeles, CA to Denver \$170
- New York, NY to Denver \$305



### CALL FOR WEBSITE REDESIGN TASK FORCE CO-CHAIR

ISOQOL is looking for an individual to Co-Chair the redesign of the website. The ideal Co-Chair will have previous exposure to website redesign, although expertise is not required. This position will require teleconference participation, online collaboration and one in-person meeting at the ISOQOL office between 2011 and 2012. If you are interested in playing a key role in an essential tool for your society, please consider this volunteer opportunity. Please contact the ISOQOL Executive Director, Rebecca Brandt, [rbrandt@isoqol.org](mailto:rbrandt@isoqol.org) with questions.

This is a non paid volunteer opportunity.

Dennis Revicki, Ph.D., & Carolyn Schwartz, Sc.D., USA

Co-Editors-in-Chief

ISOQOL's journal, *Quality of Life Research*, has been thriving over the past year. We have instituted several new features in the journal with the intent toward highlighting the cutting edges of our field, as well as bringing the patient's perspective into focus. In the past several months, the cutting edge work highlighted has a number of intriguing and novel contributions. In December 2010, we published a special section on the GENEQOL Consortium efforts, with a set of six articles addressing the genetics of health-related quality of life. We also have an ongoing series of peer-reviewed papers coming out from the NIH PROMIS project, and expect a special section on response shift analysis method to be published in the near future. Finally, we have invited leading scholars in the field to contribute articles on various theoretical and methodological issues, including an introduction to IRT methods, theoretical foundations of quality of life research, and responsiveness. To bring the patient's perspective into focus, we have initiated a Patient Voice section, composed of invited commentaries that reflect the patient's perspective on various topics, including health care reform, personality characteristics and HRQOL, and the experience of chronic pain.

This year's Article of the Year Award initiated a new process, whereby the journal's editorial board (Associate Editors and Co-Editors-in-Chief) nominated articles to be included among the special list of articles that would be Free Downloads. All editorial board members then provided a global rating for this grouping of articles, and the top-rated articles were selected for the annual ISOQOL Article of the Year Award, awarded at the banquet event of the conference. The top-rated article this year was by Ruth Barclay-Goddard, Joshua D. Epstein and Nancy E. Mayo, entitled

"Response shift: a brief overview and proposed research priorities" (QLR 18(3): 335-346). Two articles tied for second place. The first was by Ron Hays, Jakob B. Bjorner, Dennis A. Revicki, Karen L. Spritzer, and David Cella, entitled "Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items" (QLR 18(7):873-80). The other article that tied for second place was by Clare Robertson, Anne L. Langston, Sally Stapley, Elaine McColl, Marion K. Campbell, William D. Fraser, Graeme MacLennan, Peter L. Selby, Stuart H. Ralston, Peter M. Fayers, and The PRISM Trial Group, entitled "Meaning behind measurement: Self-comparisons alter responses to health-related QOL questionnaires" (QLR 18(2): 221-230). The top 20 rated articles to be offered as free downloads for 2010 can be found on the ISOQOL website.

On the horizon, we are excited to publish a special section on the use of mixed methods in quality of life research. This section will showcase high caliber research efforts that utilize qualitative and quantitative methods in a rigorous and innovative fashion to address research questions on a broad range of patient populations and research foci. Our call for papers yielded 19 letters of intent from researchers around the globe, including Australia, Brazil, Canada, Germany, The Netherlands, South America, Sweden, the UK, and the USA. Manuscripts were due April 1<sup>st</sup>, and the top rated manuscripts will be invited to present at ISOQOL 2011 in a special invited symposium on Best Practices in Mixed Methods in QOL research.

In addition to encouraging novel and innovative content, the journal is also growing in other measurable ways. We have experienced an increase of 13% in manuscript submissions compared to 2009, and have increased the number of published pages by 16% since 2008 (2010: 1550 journal pages; 2009:

1385 pages; 2008: 1331 pages). The journal's impact factor is also rising. In 2009, it was 2.376, as compared to 2.169 in 2008, 2.266 in 2007, and 2.037 in 2006. The 5-year impact factor for the journal is 2.985.

The average time between submission and initial decision for this time period was approximately 44 days (range in mean times 7 to 90 days). This is down approximately 6 days from data provided in the Spring 2010 journal report, and down approximately 38 days from Spring 2009. This reduction of almost 50% in the efficiency of the review process is due to the conscientiousness of our Associate Editors and our peer-reviewers for the journal.

We would like to take this opportunity to thank all of you have reviewed for the journal over the past year. The journal depends on timely and high quality reviews to function effectively. Our reviewer participation rate (agreement to review a manuscript when asked) among potential reviewers was 37% in 2010, which is comparable to the participation range of 33% to 39% in previous years. Based on current statistics to date, the average time for completion of manuscript reviews was 24.8 days in 2010.

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### CALL FOR ABSTRACT AND SYMPOSIUM REVIEWERS

The ISOQOL 18th Annual Conference Scientific Program Planning Committee is looking for reviewers for abstract and symposium submissions. Abstract and symposium review will take place in May and June. Please contact the ISOQOL Executive Office at [info@isoqol.org](mailto:info@isoqol.org) or by telephone at +1 (414) 918-9797 for additional information.

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## ADVISORY COUNCIL

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*David Feeny, Co-Chair, Advisory Council of Past Presidents on Behalf of the ACPP*

The ACPP was created by Donna Lamping to serve as an advisory group for the Board. Members of the ACPP also serve on committees and task forces such as Governance and Science Policy and Practice.

A major task for the ACPP in the last year was considering the extent to which ISOQOL should focus on activities that directly benefit members—such as the annual meeting, *Quality of Life Research*, and the Special Interest Groups—versus promoting the field by organizing commentaries on important public policy issues, or sponsoring sessions at other scientific meetings. Volunteer time and financial resources are limited and thus additional resources would be required for ISOQOL to invest in promoting the field. The ACPP has provided feedback on this issue. 

### WANTED: NEWSLETTER EDITOR

Would you like to have an opportunity to network with ISOQOL members? Does leading a new project for ISOQOL excite you? If the answer is “yes”, consider applying to serve as the Editor for ISOQOL’s new electronic newsletter. The newsletter will continue to be biannual and will be produced with assistance from ISOQOL staff. If you are interested in the position, please send an e-mail to [Rebecca Brandt Rbrandt@isoqol.org](mailto:Rbrandt@isoqol.org) by May 15.

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## ISOQOL FUNDRAISING & DEVELOPMENT COMMITTEE REPORT FOR 2010

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*Rick Berzon, PhD, Chair, USA*

The purpose of the Fundraising and Development Committee is to develop and implement innovative and successful fundraising and development strategies in support of ISOQOL’s mission. The committee roster this year included Sara Ahmed, Rick Berzon (Co-Chair), Andrew Bottomley, Somali Burgess, Dominique Dubois, Wenwel Huang, Barbara Marino, James Pierce (Co-Chair), Ana Rodriguez, Teresa Young. Additional support to the Committee was provided by Jeff Sloan (Treasurer); Bill Lenderking (IAC Chair); and Jane Scott (Annual Meeting Co-Chair).

The full Committee included three subcommittees: (1) Private Firms; (2) Government Grants; and (3) Foundations.

Results from the 2010 fundraising are as follows:

Fundraising Effort	2010	2009
Master List Email: Meeting Sponsorship*	\$30,750	\$39,450
Master List Email: Institutional Membership	\$36,500	\$38,000
Foundation Grant	\$25,000	None
NIH Grant	None	\$40,200
TOTAL	\$92,250	\$117,650

\*Meeting Sponsorship includes direct support for the meeting; exhibit booth at the meeting; and advertising at the meeting.

US Government grants were not solicited in 2010; however, with respect to the 2011 meeting in Denver, a grant application has been submitted to the NIH.

For their successful efforts in 2010, Rick and James thank all members of the Fundraising Committee; and they and the Board also express gratitude to Dennis Revicki and Bill Lenderking of UBC, and to Katrin Conway and Bernard Jambon of MAPI for assisting with outreach activities.

The Committee offers the following suggestions and recommendations for 2011:

- A strategy of how ISOQOL can best reach out to foundations and similar types of donors to build and advance long-term relationships should be developed.
- A meeting with all types of donors—perhaps combining public and private firms and foundations—to discuss how to build and strengthen relationships with ISOQOL should be a regular occurrence at our annual meetings
- To continue an effective working relationship between the Fundraising Committee and the IAC, the Fundraising Committee Chair and the IAC Chair—or designates—should regularly attend one another’s meetings.
- The ISOQOL Treasurer continues to play an active role on the Fundraising Committee and is an ex officio member of it. It is recommended that this relationship continue.
- It is recommended that ISOQOL donors—and meeting attendees from any firm that has made a donation—receive a ribbon at the annual meeting identifying these individuals as donors; and that all donors be recognized at the Annual Conference. 

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## A FOND FAREWELL TO LONDON

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*Jane Scott and Stefan Cano,  
2010 Program Co-Chairs*

Around the world patient reported outcome (PRO) and health-related quality of life (HRQoL) measures are becoming essential sources of information for understanding health, illness, and treatment outcomes. Last October, the London's Hilton Metropole Hotel was buzzing with the intellectual hum from hundreds of the world's leading scientists who came together to explore the best methods for "Translating Quality of Life Measurement into Decision Making" at the 17th Annual ISOQOL Conference. Hopefully all of them left with exciting new ideas, a renewed sense of the importance of their research, and new colleagues to aid their work.

For the 11 months leading up to the conference, dozens of ISOQOL members volunteered their time and expertise to bring together the rich and diverse 2010 program. The conference began on 26 October with 16 scientific workshops that offered outstanding learning opportunities for those interested in developing, validating, implementing, and using data from PRO and HRQoL studies. Eager attendees participated in workshops on topics ranging from training in qualitative methods for PRO development, classical and modern psychometrics (including IRT and Rasch methods), statistical analysis of HRQoL data from clinical trials, special challenges in PRO research in pediatric and geriatric populations, and methods for summarizing PRO for different audiences. The day was capped off with a fun networking reception where new and long-time members met to kick-off the conference.

Three scientific program tracks were organized by subcommittees who developed plenaries, invited symposia,

and posters and presentations that would keep the conference attendees challenged and engaged for three days. Starting on 27 October, the Methodology Track Subcommittee, led by Jeremy Hobart (Chair), kicked off the conference with the opening plenary, "Psychometric Methods for Developing and Evaluating Rating Scales: Why I Do What I Do" in which Geoff Norman, Bryce Reeve, David Andrich, and Ron Hays had a lively discussion about why they use the methods they use for PRO and HRQoL psychometrics.



On the second day of the conference, the second plenary, "The Routine Use of Patient-reported Outcome Measures in Health Service Decision Making: Challenges and Opportunities" organized by the Policy Research Track Subcommittee (John Browne, Chair) invited Richard Liliford to lead a lively discussion between experts Professors Nick Black (UK NHS PROMs), Nancy Devlin (UK NHS Office of Health Economics), and Lewis Kazis (US VA) from the UK and USA about the role of PRO and HRQoL data in health policy decision making.

On the last day of the conference, the Clinical Practice Track Subcommittee led by Andrea Pusic (Chair) presented "Dissemination and Integration of PRO Data into Clinical Care" where experts answered the question "How can the quality of life research community best support clinicians and patients who

seek meaningful PRO data for shared medical decision-making and patient advocacy?" Invited speakers included Professor Dale Vidal, Dr. Michael Brundage, and Richard Stephens, a patient advocate and cancer survivor whose moving testimonial brought the entire audience to their feet in a standing ovation. In addition to the plenaries and invited symposia, 13 submitted symposia, 45 podium presentations, and more than 300 posters were organized into tracks over the 3 days of the conference.

The 2010 Program Committee also initiated a Best Poster Award for each of the three tracks. Congratulations to the following posters (and a special thanks to the poster reviewers Andrea Pusic, Claudia Gorecki, Rick Berzon, Nancy Mayo, Sharon Wood-Dauphane, Stefan Cano, Jeremy Hobart, and Jane Scott):

Best Methodology  
Poster: Norquist J, et al., Choice of Recall Period for PRO Measures: One Size Does not Fit All

Best Clinical Research  
Poster: Atkinson et al., Associations of Patient vs. Clinician Adverse Event Reports with Functional Status

Best Policy Research Poster: Shaw et al., Multinational Evaluation of Conditional Median Models of EQ-5D Health State Preferences

Beyond the track-based sessions, several special sessions were organized this year. After the opening reception, Geoff Norman presented a riveting workshop on Generalizability Theory that set the tone for the conference. Thursday evening, Jack Stenner gave a special workshop on the use of Rasch modeling to develop accurate measures for self-report. On Saturday, two special plenary sessions finished the program. Jane Scott led a discussion by experts Keith Tolley (SMC), Alan

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## 2010 ISOQOL SCHOLARSHIP COMMITTEE REPORT

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*Joan Branin, PhD, Committee Chair*

The ISOQOL Scholarship Committee's primary activity is to review scholarship applicants and make recommendations for the awarding of scholarships. The goal of the scholarship awards is to allow promising new investigators and those working in developing countries that might not otherwise be able to attend, the opportunity to participate in our annual conference. The committee's intent is to provide financial support to individuals who will interact and benefit from the experience of attending the Annual Conference. The annual budget is \$10,000.

The major criteria used in reviewing and evaluating applicants are: 1. **Acceptance of an abstract for a paper or poster presentation.** Strong consideration is given to those applicants that have an oral presentation accepted. 2.

**Geographic location.** The committee attempts to achieve geographic diversity in its selections. 3. **Prior funding.**

Although repeated funding has been done, given the number of applications and limited funds, repeated awards are discouraged. Other factors include the quality of the scholarship application and the amount of funding requested

The 2010 Developing Country Scholarship Award recipients were Yvonne Flores, PhD (Mexico), Gustavo Gomboski, MA (Brazil), Svetlana Kalyadina, PhD (Russia), Claudia C. A. Pereira, PhD (Brazil), and Lin Zhan, MS (China). The 2010 New Investigator Scholarship Award recipients were Nadine Aawar, BPHARM (UK), Camille L. Angus, MSc (Canada), Noemi Dahan-Oliel (Canada), and Ana Maria Rodriguez, MSc (Canada).

Recommendations for next year:

1. Expand the committee membership to include a broader representation of ISOQOL membership.
2. Consider increasing the dollar amount to provide support for more new investigators and those from developing countries. 

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## THE ISOQOL MENTORING PROGRAM AND RECEPTION, LONDON 2010

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New investigators and senior mentors again enjoyed a reception to meet and talk about mutual interests in London. Our goal was to promote career development and provide networking opportunities for new investigators within the Society. A total of 38 mentees from 12 countries were matched with 24 ISOQOL mentor volunteers. Matches were based on the best information and ties available (for example, a mentee might request cancer and epidemiology), but experiences from mentors suggests many conversations revolve around career advice more generally. Our mentor volunteers sometimes met with small groups of mentees. Looking around the reception in London, these small groups were as animated and interactive as the one-on-one pairs. We asked mentor volunteers to engage in the reception as a one-time commitment; however some mentees and mentors established on-going relationships. If you have an interest in the mentor program, please consider signing up when you register for the 2011 Denver meeting. 

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## VALUES, TEAMS, AND CULTURE. REMARKS UPON RECEIVING THE 2010 ISOQOL PRESIDENT'S AWARD

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*David Feeny, The Center for Health Research, Kaiser Permanente Northwest; Health Utilities Incorporated, President's Award Recipient 2010*

It is a distinct honor to be added to the list of distinguished past awardees. I want to touch on three major themes: the importance of values in health-related quality of life research, the multi-disciplinary and multi-national nature of this field, and ISOQOL's special culture.

**Values.** The central importance of the value subjects place on health states is reflected in both the clinimetric and preference-based (utility) paradigms. In the clinimetric paradigm, an item is selected because subjects with that problem rate it as important. An example from the Pediatric Asthma Quality of Life Questionnaire: "In general, how often during the past week did you feel different or left out because of your asthma?" with seven response options ranging from "none of the time" to "all of the time".

The selection of attributes or domains in the Health Utilities Index Mark 2 (HUI2) was informed by previous work by David Cadman and colleagues, who in a random sample asked people to rate the importance of 15 aspects of health. The eight most important attributes formed the core of the HUI2 and HUI3 measures.

**Teams.** This field has been enriched by contributions from the fields of psychometrics, economics, management science, statistics, sociology, and anthropology and by a wide variety of clinical disciplines. Similarly, important contributions have been made by scientists worldwide. A quick review of the co-authors of my HRQL publications, for example, reveals at least 33 disciplines and 13 countries.

**Culture.** One of the precious assets of ISOQOL is its culture of mutual respect and engagement. ISOQOL provides a productive forum for exchange and learning across paradigms, disciplines, clinical professions and specialties, and degrees of seniority. I urge us all to nurture and preserve this very special culture. 

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## COMMUNICATIONS COMMITTEE

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Deborah Miller, PhD

The mission of the Communications Committee is to inform the membership about board activities, educational activities, ISOQOL and regional conferences and to devise an attractive, readable, and newsworthy Newsletter. Based on feedback provided by the Membership Survey and their own priorities, the Board had made a re-design of our website a major focus. Deborah Miller ([millerd@ccf.org](mailto:millerd@ccf.org)), committee chair, and Jordana Schmier, immediate past-chair, are eager to welcome new committee members.

In particular we are looking for a Newsletter Editor. Deborah will help the Editor to become oriented to the job which provides a great opportunity to network with ISOQOL leaders and members. 

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## EDUCATION COMMITTEE

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Kathy Wyrwich, PhD USA

The ISOQOL Education Committee is comprised of four active subcommittees: Workshops, headed by Elizabeth Merikle; Scholarships, led by Joan Branin; Student and New Investigator Awards, newly led by David Eton; and Mentor-Mentee Function, led by Elena Andresen. Over the past year, the number of members participating in the Workshop Subcommittee had waned, but a recent infusion of interest and energy from members of the New Investigators Special Interest Group has revived the Workshop Committee. Please also note that that workshop abstract submission process was moved to February this year in order to better facilitate the overall planning of the Denver Annual Conference. 

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## ISOQOL Member's Survey 2010, from Page 2

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*interested in attending. Also, we do not know the speakers enough in advance to make a difference”.*

This indicates that we need to put details of the plenary speakers and programme on the website as early as possible, so that people submit abstracts to the conference. In terms of location, cost of travel is more important than good transport links and the desirability of travelling there. Members also value the networking opportunities afforded by the meeting but do not necessarily value the more formal opportunities for networking such as the SIG meetings and the mentor mentee programme. This suggests we need to look at how these are organised – as many of the SIG and mentor mentee meetings are organised nearer to the conference and people may only be aware of them when they arrive.

### What do members think of the website?

The next questions in the survey asked about the website. Members were asked how often they had visited the website in the last month. Only 5% visited more than once per week, 12% had visited once per week, 30% had visited once every two weeks and 38% had visited once. 12% had not visited the website at all in the last month, 3% could not remember.

Members were then asked why they had visited the website. The two most common reasons were to access information about the annual meeting (84%) and to register for the annual meeting (51%). Other common reasons included to access the online version of Quality of Life Research (29%) and to renew their ISOQOL membership (20%). Fewer members had accessed the website to read the newsletter (11%), access the quality of life assessment guidelines (11%), access the bibliography of classic HRQoL articles (11%), search the membership directory (10%) or to access information about or contribute to a special interest group (9%). Only 2% of respondents had accessed the website to post on the ISOQOL list serv.

Members were asked to rate the quality of several different aspects of the website from very poor (1), poor (2), average (3), good (4) and excellent (5). Almost all the mean ratings for the aspects were around the ‘average’ mark. The highest mean ratings were the accuracy of the information on the website (3.8), the reliability of the information on the website (3.7) and the usefulness of the information on the website (3.6). However, respondents were a little less enthusiastic about the extent to which the information on the website was up to date (3.4), the organisation of the website (3.4), the ease of navigation of the website (3.4) and the appearance of the website (3.2).

Members were also asked for suggestions as to how the ISOQOL website could be improved. Forty (16%) of respondents provided feedback. Two common themes were that the appearance of the ISOQOL website needed updating and its ease of navigation and layout needed to be improved. As one respondent succinctly put it “*this is ISOQOL’s public face and when funding bodies look at it, they think it’s a small operation and does not represent an international body*”. Another suggested that “*Revamping the website to have a more modern professional image would greatly increase ISOQOL’s profile in comparison with similar groups*”. Respondents made a number of different suggestions for how the content and appearance of the website could be improved, which could inform its redesign.

### Summary and recommendations

The majority of ISOQOL respondents had visited the website once or twice a month. The most important reason for visiting the website was to access information about the annual meeting; other reasons were more ‘functional’ such as registering for the conference, renewing ISOQOL membership or accessing the online version of

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HRQoL. Aside from information about the conference and the journal, it seems that few members access the ISOQOL website as a source of up to date information on HRQoL research; as one member put it *"The website is not a "go to" site for me even though I would like it to be. There is not enough going on the website to engage me and make me want to come there"*.

This may, in part, be explained by the appearance and layout of the website which were rated less highly by respondents and were the subject of many of the comments respondents made. These findings would strongly support the case for a redesign of the ISOQOL website to improve its appearance, layout and navigation.

#### **Demographic information**

Sixty three percent of respondents were female and 37% male. Most were from North America and Europe. Seventy three percent were regular members, 13% were student members and 9% were members with a reduced subscription rate. Seventy one percent of respondents were from academia, 12% worked in clinical

settings, 8% were from industry, 4% from government and 4% from business. When asked who pays for their ISOQOL **meeting registration**, 38% indicated their employer did, 29% depended on grant money and 33% paid registration themselves. When asked who pays for their ISOQOL **membership subscription**, 54% indicated they paid themselves, 30% indicated their employer paid and 16% indicated this was paid for by grant money. 90% of respondent indicated they were also a member of another professional organisation, with ISPOR being the most commonly mentioned. Members had also attended a range of other conferences, again with ISPOR being mentioned by many.

This membership survey provides important information to ISOQOL leadership about how this organization can provide added value for the membership and will be considered when planning our future activities. We recommend to the Board that particular emphasis should be placed on the redesign of the website. 

#### ***A Fond Farewell to London, from Page 6***

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Hickman (NICE), Stephen Clauser (NIH), Olivier Chassany (EMA), and Charles Petrie (Pharmaceutical industry) that challenged researchers to think about "Incorporating PRO in Health Policy Decisions: Where Should We Be Heading?" Then Stefan Cano led the discussion between experts Bryce Reeve, Ron Hays, Jack Stenner, and Donald Patrick on the "Roles of Classical and Modern Psychometrics in Developing and Validating PRO Measures for Clinical and Policy Research".

There was much more work going on to help make the conference a success than just the scientific program and the workshops. Three more subcommittees helped publicize the meeting (Publicity

Committee, Fabio Efficace, Chair), raise funds (Fundraising Committee, Rick Berzon, Chair), and organize social networking and fun ways for the members to get to know each other and make the most of their time together in London (Social Events Committee, Jennifer Petrillo, Chair).

The 2010 ISOQOL Annual Conference was the culmination of 11 months of work and creativity of dozens of ISOQOL member volunteers. As program committee co-chairs, we offer our heartfelt thanks to all those who helped make the 2010 annual conference a success, and to all those who participated in the London meeting.



In an effort to further improve the review process, we are gathering information to supplement the Editorial Manager characterization of our journal resources. We have implemented a web-based survey of our Associate Editors and International Advisory Board, and now have updated information on patient populations and methodological areas on which our editorial board has expertise. Please take a moment to check your information in the reviewer section of the journal and make any needed updates to your contact information, as well as your areas of expertise. We are currently exploring with the publisher whether we can supplement the Editorial Manager information to include more specific information about areas of expertise.

The current set of Associate Editors include Elena Andresen, University of Florida, Carla Bann, RTI, Mimi Cohen, University of Haiti, Michael Erhart, University Medical Center, Cynthia Gross, University of Minnesota, Gertrudis Kempen, Maastricht University, Youngmee Kim, University of Miami, Leah Kleinman, United BioSource Corporation, Paul Krabbe, Radboud University, Deborah Miller, Cleveland Clinic, Caroline Terwee, VU University, and Jose Valderas, University of Manchester. The journal Associate Editors each handle a large number of manuscripts each year and we'd like to thank them for all of their hard work.

As always, if you have any ideas for improving the journal, please contact us ([dennis.revicki@unitedbiosource.com](mailto:dennis.revicki@unitedbiosource.com) and [carolyn.schwartz@deltaquest.org](mailto:carolyn.schwartz@deltaquest.org)), and we will see if it is possible to make changes. In particular, if you have an idea for a Patient Voice piece, please email us with a brief description of the topic and potential author(s) for the piece. We appreciate all of your support for Quality of Life Research and we look forward to increasing the quality of the manuscripts that get published in ISOQOL's journal. 

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## NEW SOCIETY CONTACT INFORMATION

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ISOQOL has transitioned to a new management company, Executive Director, Inc (EDI), based in Milwaukee, WI USA. With EDI's support, Rebecca Brandt, CAE will serve as the new Executive Director and she can be reached at [rbrandt@isoqol.org](mailto:rbrandt@isoqol.org). Heather Vitale, [hvitale@isoqol.org](mailto:hvitale@isoqol.org), is ISOQOL's Meetings & Membership Manager.

The ISOQOL Executive Committee met with the new EDI management team at the end of January to discuss this transition and related issues. If you would like us to discuss a topic of importance related to management of ISOQOL, please email your question or comment to Rebecca Brandt.

Please note the ISOQOL website and listservs are functioning as usual and you are still able to renew your 2011 dues through the website. New contact information for the society:

555 E. Wells Street, Suite 1100  
Milwaukee, WI 53202 USA  
Phone: (414) 918-9797  
Fax: (414) 276-3349  
[info@isoqol.org](mailto:info@isoqol.org)  
[www.isoqol.org](http://www.isoqol.org) 

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## EMPLOYMENT OPPORTUNITIES

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### Senior Research Associate, Clinical & Economic Evidence

As part of our global team, the evaluation of the relative clinical and economic value of treatments in their current or future market will be at the heart of your work. Our Clinical & Economic Evidence team provides strategic consultancy and scientific expertise to support our clients in clinical and economic positioning, Health Technology Assessment (HTA) and reimbursement. Our team is a global multidisciplinary group of Health Economists, Epidemiologists, Mathematicians, Statisticians and Clinical Scientists and we are looking to expand our team as demand for our services grows.

Mapi Values did not gain its current excellent reputation in evidence-based healthcare research by chance: it is thanks to the quality of our people and deliverables. As such we provide a dynamic, stimulating and rewarding working environment for ambitious and passionate individuals looking to join a global, world-class consultancy business.

**THE POSITION:** We wish to appoint a researcher to join our Clinical & Economic Evidence team based in our Global Headquarters in the cosmopolitan and friendly city of Boston. This is a great opportunity if you have a genuine interest in enhancing your knowledge and skills in health economics and outcomes research. We will provide you with all the necessary training and support for your professional development in this challenging and rapid-moving field. In return we expect you to quickly build on your existing knowledge and skills, acquiring the ability to work autonomously.

**RESPONSIBILITIES:** Your role will be exciting and varied, working in international projects supporting access to the market of our clients' products. You will be involved in a variety of tasks, including:

- Performing systematic reviews and meta-analysis support
- Developing and adapting health economic models for reimbursement and international marketing
- Preparing and writing documents to communicate health economic and other value messages

**REQUIREMENTS:** You are a highly motivated researcher, with experience in epidemiology, health services research, biostatistics or a related quantitative subject who enjoys teamwork and takes pride in the quality of your work. You will have a postgraduate qualification (MSc/PhD) or equivalent experience and will be able to demonstrate a track record in applied research. Skills in health economics research, statistics, epidemiology or quantitative analysis of biological/medical data are required. A demonstrated interest in cost-effectiveness evaluations would be an advantage. Excellent analytical skills as well as good communication skills are essential and you must enjoy working as part of a team. Strong writing skills are required.

**LOCATION:** US Office (Global Headquarters), Boston Massachusetts

**PACKAGE DETAILS:** Mapi Values offers competitive remuneration, generous paid vacation, tuition reimbursement, full health and dental benefits, and a 401K program in a friendly and informal office environment.

