



International Society for Quality of Life Research

Volume 13 Issue 2

Newsletter for ISOQOL Members

March 2009

PRESIDENT'S MESSAGE

Neil Aaronson, PhD
Amsterdam, The Netherlands



When informed by the chair of the Nominations Committee that I had been elected president of ISOQOL, the first thing that popped into my mind was the quip by William F. Buckley, Jr., the conservative US columnist, who, when asked what he would do if elected mayor of New York (in the 1965 election), responded, "Ask for a recount." Amusingly, this quip was also used by the anything but conservative singer, songwriter, novelist, and aspiring politician, Kinky Friedman during his (unsuccessful) 2006 bid for the governorship of Texas. Humor knows no political boundaries.

All kidding aside, it is a bit intimidating to follow in the footsteps of such skilled and creative leaders as Donna Lamping, Madeleine King, Peter Fayers, and David Feeny (to name but the most recent expres) who, during their respective terms at the helm of ISOQOL, prodded, cajoled, nurtured and inspired our Society to take on new challenges and to seek new opportunities. Fortunately, ISOQOL's leadership structure, with an Executive Committee formed by the current and Immediate-Past Presidents, and the President-elect, the Treasurer and the Executive Director, provided me with a 12 month grace period during which I could begin to learn the ropes. My thanks go to

Donna, Mad, Rick Berzon and Laura Degnon for their patience and support during my first year on the Executive Committee. Looking forward, I am delighted to have the opportunity to continue to work with Donna, and with Diane Fairclough as president-elect and Jeff Sloan as our new treasurer. Diane, with her quiet, down-to-earth, no-nonsense approach, and Jeff, with his get-to-the-heart-of-the-matter style (don't be fooled by his self-effacing humor) promise to keep the leadership of ISOQOL focused and alert.

ISOQOL's Mission

As ISOQOL grows and matures, it is useful to reflect on our overall mission as a society, and it is important to ensure that the mission is communicated in a way that is understandable and meaningful to the Society's membership and to the larger research and health care communities that we intend to serve. For many years, our mission statement read as follows:

"The scientific study of quality of life relevant to health and healthcare is the mission of the International Society for Quality of Life Research (ISOQOL). The Society promotes the rigorous investigation of health-related quality of life measurement from conceptualization to application and practice. ISOQOL fosters the worldwide exchange of information through scientific publications, international conferences, educational outreach, and collaborative support for HRQOL initiatives."

While all undoubtedly very true, all 63 words of it, the ISOQOL Board felt that it was time to revisit our mission statement, and come up with a more concise version that captures the essence of what we are all about. Nancy Mayo and Bryce Reeve, with input for various colleagues from

within and outside of the board, came to the October board meeting with a draft statement that, after some additional collective wordsmithing, emerged as follows:

"To advance the scientific study of health-related quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care, and promote the health of populations."

Concise (half the length of our previous statement), modern (expanding our scope to include PRO's other than HRQL), and oriented toward achieving tangible, real world results. The Board hopes that the membership of ISOQOL will embrace this mission.

Keeping the Ball Rolling

During the October Board meeting, committee chairs provided updates on important activities of the society, several of which I want to highlight here:

Membership:

Joanne Greenhalgh, chair of the Membership Committee, produced an in-depth report on trends in our membership. The key findings were that: (1) from 2000 through 2007, our membership increased

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The ISOQOL Newsletter is published two times a year by the International Society for Quality of Life Research with the cooperation of Degnon Associates.

Newsletter Editor
Deborah Miller, PhD, USA

Send articles and/or suggestions to:
info@isoqol.org

President
Neil Aaronson, PhD, The Netherlands

President-Elect
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ISOQOL Executive Office
6728 Old McLean Village Drive
McLean, VA 22101-3906 USA
PH: 703-556-9222
FAX: 703-556-8729
info@isoqol.org
www.isoqol.org

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2008 PRESIDENT'S AWARD

David Cella, PhD

President's Award acceptance remarks,
October 25, 2008

Madame President, ISOQOL Executive Committee, fellow members of the Society, I humbly and happily accept this prestigious award. Previous recipients of the award include people who have framed our field; people I have admired and emulated for many years. Donald Patrick, George Torrance, John Ware, Bob Kaplan, Neil Aaronson, David Osoba, and my good friend Dennis Revicki..... That is good company. As I look out into the room, attend our scientific sessions, and read our journal, I see many people more deserving of this award than me....but I am the lucky one, and I am grateful to the ISOQOL Executive Committee for this honor — Thank you.

ISOQOL is a small society, but a very special one. Those of us who come every year to these meetings know that ISOQOL is committed to every one of its words. The first word is "International", and you need look no further than our annual meeting venues than to see the Society's commitment. This year's meeting, here in Montevideo, enables us to forge new collaborations with Latin America. We are grateful to Laura Schwartzmann and Juan Dapuetto for putting together a splendid academic and social program. The social and cultural side to this meeting began with a splendid opening performance in Teatro Solis. which I unfortunately had to miss due to late arrival in Montevideo. I heard the singing and dancing were spectacular. I was particularly surprised to hear that two of the Tango dancers were familiar to us up in the Estados Unidos.

The second word in our name is "Society." We are most certainly a society. I will forever cherish my membership in this global society of friends and respected colleagues. I have learned much about culture and perspective and methodology from all of you and other ISOQOL mem-

bers who cannot be here today. Half of what I have learned, and loved, has come from off-line social events with people from around the world — in places around the world. It has been great fun.

The next few words are of course our key words: "Quality of Life." Well, that says a mouthful. Such an invitation for enjoying life! But can we really measure this holy grail? How do we possibly pretend to measure such a subjective and multifaceted thing that varies across cultures, across layers of society, and even across our own families!

And finally, the last word is "Research." Research is at the center of our identity. It is our fundamental common ground. With your indulgence, I'll spend the rest of my time talking about Research.

The theme of my remarks is **Coming of Age**. I chose this theme because virtually every culture in the world recognizes the physical transition from childhood into adulthood. The global human experience has a few common elements, and one of them is the inevitable progression from naïve, optimistic potential into a more informed ... more realistic ... livable action.

The **Quinceañera** or **Quince años** is, in some Spanish-speaking regions of the Americas (Mexico and El Salvador), a young woman's celebration of her fifteenth birthday, which is commemorated in a unique and different way from her other birthdays. The closest equivalents to the quinceañera in the English-speaking world are the sweet sixteen, the Bar Mitzvah and Bat Mitzvah for Jewish boys turning 13 and Jewish girls turning 12 respectively, the cotillion, or, in more affluent communities, the debutante ball for those who turn 18.

The field of quality of life research finds itself in that same transition from childhood to adulthood. We have come of age, and I suggest to you that it's time we recognize that quality of life research has matured to a science that can now be applied to influence clinical and health policy decisions. The background work of

President's Award, continued on page 5

QUALITY OF LIFE RESEARCH JOURNAL SUMMARY FOR FIRST 9 MONTHS OF 2008

Ron D. Hays, PhD, Editor-in-Chief

Manuscript Flow and Decisions. A total of 612 manuscripts were submitted between March 1, 2008 and February 28, 2009. The 612 manuscripts included 380 that were rejected, 61 accepted, 72 that are under revision, and 99 that are undergoing peer review. The estimated acceptance rate is approximately 21%.¹ The estimated acceptance rate was 24% in 2007, 27% in 2006, 32% in 2005, and 40% in 2004. Excluding the manuscripts rejected without review, the average time between submission and initial decision for this time period was 82 days (range: 20-267 days).

Publication of issues remains on schedule, with online publication of the 10 issues of 2008 (volume 17) and first two issues of 2009 (volume 18#1 and 18#2). We published approximately 1300 pages in 2007 compared to 1540 in 2006, 2358 in 2005, 1782 in 2004, and 1148 (plus a 94-page supplement) in 2003.

The impact factor (IF) for *Quality of Life Research* in 2007 was 2.466 (compared to IF of 2.037 in 2006, 1.915 in 2005 and 1.820 in 2004). The 5-year IF for the journal is 3.075.

Best Reviewers. 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 36% in 2006, 33% in 2007, and was 36% in the 12 months included in this report.

At the end of each year we identify the outstanding reviewers, defined as individuals who have reviewed at least 3 times and their reviews been rated highly by the handling editors. We recognize these reviewers in the ISOQOL newsletter and send them a letter of acknowledgement. In addition, Springer offers these reviewers a reward such as a choice of a one-year subscription to *Health Services & Outcomes Re-*

search Methodology or the 2007 Regional Zagat Guide.

Thirteen outstanding reviewers were identified: 1) Michael Erhart; 2) Marcel Adriaanse; 3) Cameron McIntosh 4) Eva Grill; 5) Diane Fairclough; 6) Mari Palta; 7) Fotios Anagnostopoulos; 8) Joseph Cappelleri; 9) Stacie Metz; 10) Jeff Dang; 11) A. Hirsch; 12) Meryl Brod; and 13) Per Wandell.

Best Article in Quality of Life Research. We submitted nominations for the best article published in 2007 in *Quality of Life Research* for acknowledgement at the 2008 ISOQOL Meeting in Montevideo. We will do the same for the best article published in 2008 in the journal for the upcoming ISOQOL meeting in New Orleans.

Statistician's Corner. We kicked off the brief paper series (small number of pages devoted to survey or methods/statistics issues such as power calculation, estimating responsiveness to change, reliability, etc.) this calendar year. Peter Fayers and Madeleine King have been doing a nice job authoring these briefs.

Tenure of Associate Editors. We appointed 5 new associate editors in February, bringing the total to 16 active associate editors: Carla Bann, John Brazier, Chih-Hung Chang, Jason Cole, Michael Erhart, Marie-Louise Essink-Bot, Cynthia Gross, Graeme Hawthorne, Youngmee Kim, Paul Krabbe, Elaine McColl, Carol Moinpour, Michael Ritsner, Caroline Terwee, Jose Valderas, and Eve Wittenberg. Luis Rajmil retired at the beginning of 2008. Marie-Louise Essink-Bot, Elaine McColl and Carol Moinpour will be rotating off at the beginning of the summer.

¹ If we assume that 50% of the manuscripts with a revise and resubmit decision will ultimately be accepted ($n = 36$), that 50% of those under review will receive a revise and resubmit decision ($n = 50$) and 50% of those will be accepted ($n = 25$), then the estimated acceptance rate is 20% ($n = 122/612$). If we assume that 75% of those with a revise and resubmit decision will be accepted ($n = 54$), that 50% of those under review will receive a revise and resubmit decision ($n = 50$) and 75% of those will be accepted ($n = 37$), then the estimated acceptance rate is 22% ($n = 134/612$).

Save these Dates!

**ISOQOL 16th
Annual
Conference
October 28 - 31,
2009**

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Health Care
Policy,
Research, and
Practice**

**New Orleans,
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REPORT FROM THE STUDENT / NEW INVESTIGATOR AWARDS SUBCOMMITTEE

Carolyn Gotay, PhD, Chair, Education Committee

The Annual Meeting provides a special opportunity to recognize the excellent achievements of the next generation of quality of life researchers. Both students - individuals enrolled in a full time educational program - and new investigators - those who have assumed their first independent research position in the past five years - are eligible for awards. Meeting attendees who submit top-scoring abstracts in both poster and oral presentation categories are selected as finalists for these awards. This year, the finalists were: Juliana Bredemeier, Lorena A. Hoffmeister, Sonia Rojas Farreras, Stephen M. Smith (student posters), Sofia F. Garcia, Eva Mautner, Elizabeth Medina-Castro (new investigator poster), Martin Duracinsky, Neusa S. Rocha, Brian D. Stucky, Ester Villalonga-Olives (student oral presentation), Milena D. Anatchkova, Richard Sawatzky, Claire F. Snyder, Bernard Van den Berg, and Inga Wahl (new investigator oral presentation). At the ISOQOL Annual Meeting, volunteer judges attend and evaluate all posters and presentations. Based on their ratings, the top contributions in each category are selected. This year's top winners were Sonia Rojas Farrera, Elizabeth Medina-Castro, Brian D. Stucky, and Richard Sawatzky. Based on my five years of having the privilege of leading this Subcommittee, this was one of the most competitive groups ever. All of the finalists and winners deserve our sincere kudos for their fine work. Their continued participation in ISOQOL portends wonderful accomplishments for the Society's future!



President, from page 1

from 435 to 730 members; (2) the number of members from academia has doubled over that period of time, the number of government-based members has increased six fold, while the number of industry-based members has declined significantly (about halved); and (3) while the majority of our members are from North America (55%) and Western Europe (26%), there is a substantial membership from Asia (9%), and a growing number of members from South America, Australia/New Zealand, and Eastern Europe (together, about 8%).

I find the drop in membership from industry (from 25% in 1999 to 7% in 2007) to be particularly telling. ISOQOL leadership has grappled for many years with the issue of how best to relate to and interact with industry. Sincere concerns with scientific integrity and academic freedom appear to have resulted, tacitly if not intentionally, in a policy of keeping industry involvement in check. While this is in some ways understandable, I see more advantages than disadvantages in partnering with industry where our interests converge (e.g., in standardizing measurement, in developing clinically meaningful interpretation of statistical evidence, etc.). While we may not want to share the same bed, a strategy that allows us to "kiss through a handkerchief" may prove to be both productive and mutually beneficial. Representation of industry (or more accurately, of "for profit" perspectives) on the ISOQOL board (Jane Scott) and the creation of the Industry Advisory Committee (chaired during the past year by Bill Lenderking) can facilitate the dialogue necessary to attract greater interest, participation and commitment from industry-based colleagues. The Special Symposium on PROs and Reimbursement Decision-Making organized by Bill at the 2008 Annual Conference in Montevideo is a good example of such constructive collaboration.

Lassoing the sages – The Advisory Council of Past Presidents (ACPP)

A one-year term as president of ISOQOL (or even a 3-year term as a member of the Executive Committee) provides office holders with only a limited opportunity

to develop new ideas and initiatives, let alone to see them through to fruition. The ACPP was created as a means of taking greater advantage of the creativity and wisdom of our past presidents. The current co-chairs of that council, David Feeny and Sharon Wood-Dauphinee, presented the outline of a bold plan to establish a non-profit Research and Development Institute (RDI), to be affiliated with ISOQOL. As currently envisioned, the RDI would combine elements of a think tank with those of a contract research organization, focusing on translating the basic science developed by ISOQOL into policy and practice. At this stage, the ideas are broad and the issues involved are complex. The board views this initiative favorably, and has asked the ACPP to move things forward with a set of concrete proposals. It was stressed that the RDI would need to be based on a business model that would self-supporting and preferably revenue-generating.

Developing a Translation Certification Program

The Translation and Cultural Adaptation Special Interest Group (TCA SIG), under the leadership of Katrin Conway and Donald Patrick, has put forward a proposal to develop and implement a certification program for translating and culturally adapting PRO instruments. They believe that there is a need, both perceived and real, for standardizing the process of questionnaire translation, and for certifying the quality of translations for regulatory and technology assessment agencies worldwide (e.g., the FDA, the EMEA, NICE, etc.). It is envisioned that such a certification program would be housed within ISOQOL. Several organizational and business models were discussed during the Board Meeting, and the Board has asked that a working group, including members of the TCA SIG, the Board, and ISOQOL management, develop a more detailed proposal to be presented at the next Board Meeting.

The Montevideo Conference

Prietitos del mismo arroz

Speaking of translations, the literal translation of this Spanish phrase into English is "The little black one's of the same rice,"



which, to put it mildly, doesn't make a whole lot of sense. The idiomatic equivalent, however, does: "It's all in a day's work." I want to take this opportunity to thank Laura Schwartzmann, Juan Dupueto, the members of the Program Committee and the Ibero-American Organizing Committee, as well as Laura Degnon, Sarah Shiffert, and Christine Lusk of Degnon Associates for organizing such a successful conference, both scientifically and socially. As anyone who has organized similar conferences knows, it's not all in a day's work; rather, it's a year of blood, sweat and tears.

Taking our Annual Conference to Montevideo was a calculated risk; one that I believe was, ultimately, worth taking. If we take the "International" in the name of our Society seriously, we are compelled to hold our Annual Conference, at least occasionally, farther afield than North America or Europe. The time was ripe to take our message to South America. Attendance was high, with 473 registered delegates. The plenary sessions were of a consistently high quality, as were the proffered paper sessions that I was able to attend. The availability of simultaneous translation for the plenary sessions encouraged active participation by the large contingent of South and Latin American attendees. For me personally, two highlights of the conference were Donald Patrick's opening plenary talk on quality of life and stigma, and David Cella's at turns touching, funny, brazen (who will ever forget his peacock cartoon?), and thought-provoking speech on the occasion of his receiving the President's Award.

El campo fértil no descansado, tórnase estéril

Literally, this phrase translates into English as "the unrested fertile field turns sterile." Idiomatically, the best translation would be: "All work and no play makes Jack a dull boy." Laura and Juan took steps to ensure that there were no dull Jacks or Jills at the conference. The opening of the conference in the Teatro Solis, Montevideo's glorious opera house, was delightful: the children's choir singing songs from around the world, and the

tango sextet, vocalists and dancers gave us a sense of the richness of the Uruguayan culture, and the warmth of its people. The conference dinner, held in the equally impressive Club Uruguay, with tango, salsa and candombe (a uniquely Uruguayan music and dance form), raised the bar for future ISOQOL social events. Those of us who had energy left over, joined in Juan Dupueto's and Bill Lenderking's songfest, held in the bowels of an Irish Pub.

The 2009 Annual Conference in New Orleans

Once the venue for the 2009 conference was set, there were two immediate questions at hand. The first was the correct pronunciation of the city's name: "New Orleeeees" or "NewOorlans." Claire Snyder, a native daughter, swiftly resolved that issue for us — the latter pronunciation wins hands down. She also proved to hold the answer to our second question: Who should be the Program chair? Claire, together with Michael Brundage from Toronto, will be Co-Chairing the 2009 Program Committee. Having worked with both of them in putting together our mid-year 2007 conference in Budapest, I know that we could not be in better hands. Claire and Michael have already reached out to the membership of the society for ideas for conference themes, and the response has been overwhelming. I believe that more than 70 members have volunteered to serve on the program committee.

I look forward to seeing y'all in the Queen of the Mississippi, The Crescent City, The Big Easy, the Birthplace of Jazz, Mardi Gras City, and the home of Creole and Cajun cookin'. In the meantime, rest assured that the ISOQOL Executive Committee and board will continue to work towards the realization of our Society's goals.



President's Award, from page 2

ISOQOL members and others over the past three decades has positioned us to have a major impact upon health care research in the next three decades. I also suggest to you that our biggest threat is internal. We could call it a collective tendency we have to doubt ourselves, or to implicitly choose inaction over risky action because we can't be 100% sure of our results. Funny thing is that our results are more reliable and relevant than most of the information used to inform clinical research or practice today. Medicine remains as much art as science, and our science will be a welcome informant if only we organize and present it in digestible form.

We certainly don't have all of the answers, and there is a huge agenda before us in a wide range of measurement and applications. This agenda should be pursued, but not at the expense of action. The optimistic QOL researcher sees the progress we have made and knowledge we have gained (the glass is half full); the pessimistic QOL researcher sees all of the blemishes and unresolved issues (the glass is half empty). Maybe it's time for the 21st century QOL researcher to realize that in today's healthcare policy and clinical setting, where we desperately need input from the patient to appreciate the value of interventions, the glass is twice as big as it needs to be! In other words, we have enough to work with. There is no shortage of tools. These tools are not only QOL instruments, they are interpretation guides, computerized assessments, online support, and a substantial base of research on minimally important differences, clinically important differences, and meaning of scores and changes on a host of QOL questionnaires.

So, it's time we focus on showing our stuff.

Don't oversell measurement, but also avoid apologizing for imperfection. You might be surprised to know how QOL scales stack up against common and trusted clinical measures in medicine.

President's Award, continued on page 8

OUTSTANDING ARTICLE OF THE YEAR AWARD: *QUALITY OF LIFE RESEARCH 2007*

Madeleine King, PhD
Camperdown, NSW, Australia

Each year since 2003, ISOQOL has awarded the Outstanding Article of the Year Award to recognize and honor articles of particular relevance and scientific excellence. The 2007 Award recognizes articles published in *Quality of Life Research* journal during the **previous calendar year**. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQL research methods or theory.

This year, like last year, the nominations were restricted to the Society's journal – after all, we should encourage home-grown achievements, right? So this year, like last year, Editor-in-Chief Ron Hays and his team of Associate Editors were asked to review the papers that they had handled and that were published during 2007 and nominate the best for consideration for the prize. **Thanks to Ron Hays and his team!** Members of the Society were also encouraged to nominate papers.

Just so you know the process ... Each year, the ISOQOL Nominations Committee serves as the review and selection committee for the Article of the Year Award. The committee is chaired by the Immediate Past President (this year, yours truly), and the previous two past presidents (Peter Fayers and David Feeny). But if a member of the committee is also an author of a nominated article, that member steps down to avoid any conflict of interest, and the Board of Directors appoints a substitute. This year, like last year, the prolific Peter Fayers was a co-author of two of the nominated papers, and Albert Wu graciously agreed to replace him. **Thanks to this year's Nomination Committee!**

When judging the nominations, the Committee considers: scientific excellence, innovativeness, promotion of the field of quality of life research, and diversity of

topic in light of previous awards. Given that last criterion, I thought you might be interested to see the past winners:

PREVIOUS WINNERS ...

2003: Jacob Bjorner, Mark Kosinski, John Ware. Calibration of an item pool for assessing the burden of headaches: an application of item response theory to the headache impact test (HIT). *Qual Life Res* 12 (8): 913-933, 2003.

2004: Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, Selby PJ. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*. 2004 Feb 15;22(4):714-24.

2005: Michael Brundage, D. Feldman-Stewart, A. Leis, A. Bezjak, L. Degner, K. Velji, L. Zetes- Zanatta, D. Tu, P. Ritvo, and J. Pater, "Communicating Quality of Life Information to Cancer Patients: A Study of Six Presentation Formats" *Journal of Clinical Oncology*, Volume 23, Number 28, October 1, 2005.

2006: Osoba D, Hsu M-A, Copley-Merriman C, Coombs J, Johnson FR, Hauber, B, Manjunath R, Pyles A. Stated preferences of patients with cancer for healthrelated quality-of-life (HRQOL) domains during treatment. *Qual Life Res*. March 2006; 15 (2): 273-283.

AND THIS YEAR'S NOMINATIONS ...

Bayram, N., D. Thorburn, H. Demirhan, and N. Bilgel 2007 Quality of life among Turkish immigrants in Sweden. *Qual Life Res*. 16(8):1319-1333.

Cella, D., R. Gershon, J. S. Lai, and S. Choi 2007 The future of outcomes measurement: item banking, tailored short-forms, and computerized adaptive assessment. *Qual Life Res*. 16 Suppl 1:133-41. Epub@2007 Mar 31.133-141.

de Vet HC, Ostelo RW, Terwee CB, van der Roer N, Knol DL, Beckerman H.

Boers M, Bouter LM. 2007 Minimally important change determined by a visual method integrating an anchor-based and a distribution-based approach. *Qual Life Res*. 16(1):131-142.

Edelen, M. O. and B. B. Reeve 2007 Applying item response theory (IRT) modeling to questionnaire development, evaluation, and refinement. *Qual Life Res*. 16 Suppl 1:5-18. Epub@2007 Mar 21.5-18.

Geyh S, Cieza A, Kollerits B, Grimby G, Stucki G. 2007 Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. *Qual Life Res*. 16(5):833-851.

Griffiths T, Giarchi G, Carr A, Jones P, Horsham S. 2007 Life mapping: a 'Therapeutic Document' approach to needs assessment. *Qual Life Res*. 16(3):467-481.

Guyatt, G. and H. Schunemann 2007 How can quality of life researchers make their work more useful to health workers and their patients? *Qual Life Res*. 16(7):1097-1105.

Hahn EA, Cella D, Dobrez DG, Weiss BD, Du H, Lai JS, Victorson D, Garcia SF. 2007 The impact of literacy on health-related quality of life measurement and outcomes in cancer outpatients. *Qual Life Res*. 16(3):495-507.

Janssen, M.F., E. Birnie, and G. J. Bonsel 2007 Evaluating the discriminatory power of EQ-5D, HUI2 and HUI3 in a US general population survey using Shannon's indices *Qual Life Res* 16 (5): 895-904.

Masthoff ED, Trompenaars FJ, Van Heck GL, Michielsen HJ, Hodiament PP, De Vries J. 2007 Predictors of quality of life: a model based study. *Qual Life Res*. 16(2):309-320.

Norman, G. R., K. W. Wyrwich, and D. L. Patrick 2007 The mathematical relationship among different forms of responsiveness coefficients. *Qual Life Res.* 16(5):815-822.

O'Leary, T. E., L. Diller, and C. J. Recklitis 2007 The effects of response bias on self-reported quality of life among childhood cancer survivors. *Qual Life Res.* 16(7):1211-1220.

Protopopescu C. Marcellin F. Spire B. Preau M. Verdon R. Peyramond D. Raffi F. Chene G. Lepout C. Carrieri MP. 2007 Health-related quality of life in HIV-1-infected patients on HAART: a five-years longitudinal analysis accounting for dropout in the APROCO-COPILOTE cohort (ANRS CO-8). *Qual Life Res.* 16(4):577-591.

Scott NW. Fayers PM. Aaronson NK. Bottomley A. de Graeff A. Groenvold M. Koller M. Petersen MA. Sprangers MA. EORTC and the Quality of Life Cross-Cultural Meta-Analysis Group. 2007 The use of differential item functioning analyses to identify cultural differences in responses to the EORTC QLQ-C30. *Qual Life Res.* 16(1):115-129.

Simeoni MC. Schmidt S. Muehlan H. Debensason D. Bullinger M. Field testing of a European quality of life instrument for children and adolescents with chronic conditions: the 37-item DISABKIDS Chronic Generic Module. *Qual Life Res.* 16(5): 881-893.

van, Campen C. and J. Iedema 2007 Are persons with physical disabilities who participate in society healthier and happier? Structural equation modelling of objective participation and subjective well-being. *Qual Life Res.* 16(4):635-645.

As you can see, these sixteen papers cover a wide range of important topics, and each paper represented a significant intellectual contribution to the field of health-related quality of life.

Congratulations to all the authors for all the nominated articles!

So what happened next? The committee members ranked the papers independently, and perhaps not surprisingly, we did not agree unanimously on the 'best' article. (Turns out there is no absolute 'best'.) But after some discussion, we reached a very comfortable consensus, and agreed to recommend the following article ...

And the Winner Is....

The impact of literacy on health-related quality of life measurement and outcomes in cancer outpatients

Elizabeth A. Hahn^{1,2}, David Cella^{1,3}, Deborah G. Dobrez⁴, Barry D. Weiss⁵, Hongyan Du¹, Jin-Shei Lai^{1,6}, David Victorson^{1,3} & Sofia F. Garcia¹

1. Center on Outcomes, Research and Education (CORE), Evanston Northwestern Healthcare, 1001 University Place, Suite 100, Evanston, IL, 60201, USA (E-mail: eahn@northwestern.edu);
2. Department of Preventive Medicine, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA;
3. Department of Psychiatry and Behavioral Sciences, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA;
4. School of Public Health, University of Illinois at Chicago, Chicago, IL, USA;
5. Department of Family and Community Medicine, University of Arizona, Tucson, AZ, USA;
6. Institute for Healthcare Studies, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA

Why did we all feel good about this one?

Well, first, the authors identified an important need: measurement techniques for low literacy populations. Second, they developed an innovative technology: a Talking Touchscreen. Third, their study design and analyses were excellent: patients completed three questionnaires by TT (FACT-G, SF-36, and a standard gamble utility questionnaire); measurement bias was evaluated using item response theory (IRT); and effects of literacy on HRQL were evaluated using regression models. Their results were compelling: 97% patients rated the TT easy to use. In IRT

analysis, about half of the items demonstrated literacy bias, but mean literacy group differences were statistically and clinically non-significant for a little over half of the HRQL outcomes, and adjustment for bias and/or covariates eliminated most remaining differences. And finally, their conclusions demonstrate this thing has real application: the TT is valid and useful for HRQL assessment in low literacy populations, there appears to be no systematic literacy bias in reporting HRQL, and low literacy is not an independent risk factor for poorer HRQL. This is important stuff, not only for our Society (ISOQOL) but also, and perhaps more importantly, for those disadvantaged folks in our broader society.

Congratulations Elizabeth and colleagues!

I had the great privilege and pleasure of announcing the winner at this year's colorful conference dinner in Montevideo on Saturday, October 25. I would like now to reiterate my congratulations to all the authors and papers.

Here we go again! The deadline for nominations for next year's award is July 15, 2009. The ISOQOL website gives details for how to nominate an article for this award. Keep this in mind as you browse the 2008 issue of our society's fine journal, *Quality of Life Research*. So if you stumble across an article that you think is really special, really important and really good, ***why not nominate it for the 2008 award!?!***



Security update...

...from the Montevideo meeting. The ISOQOL Executive Committee has been made aware of security issues at the 2008 Annual Meeting in Montevideo. Safety of our members is a primary concern that ISOQOL takes very seriously. The Board of Directors, working with the local organizers, has communicated the concerns and experiences to the host hotel and local police authorities.

President's Award, from page 5

A **yard** (or **yard glass**) is a very tall glass used for drinking beer; a **yard of ale** refers to a rather variable quantity of beer held by such a glass. The glass is historically 1 yard long (hence the name), shaped with a bulb at the bottom, and a widening shaft which constitutes most of the height. Drinking a yard glass full of beer is a traditional pub game. The object is to drink the entire glassful without pausing for breath, or to drink it as quickly as possible. The tradition is most often associated with drunkenness and excessive partying.

Because of the shape of the glass, once it is raised and the liquid starts to flow, it is hard to stop. When attempted by a novice, the liquid may rush out and soak the drinker. To counteract this, the glass is usually rotated as it is held.

The "Yard of Ale" is associated with Rugby team rituals, and has also had a significant effect on Australian drinking and popular culture. Former Australian Prime Minister Bob Hawke was at one time the world record holder for fastest sculling of a yard of beer.

In Australia and New Zealand, I am told, it is a popular tradition to receive a yard glass as a gift for coming of age celebrations on one's 21st birthday, and then consume the full glass during one's birthday party. A yard glass in New Zealand generally holds between 6 and 7 beers (just over two litres) substantially larger than the English version. Yet they are all called a Yard...now that's bad measurement.

Fortunately, we do a much better job in health status measurement. Beth Hahn led a paper written as one of the Mayo Clinic clinical significance series. In that paper, we showed that the accuracy of even simple QOL scales such as the SF-36, EORTC and FACT questionnaires, and others, equaled or exceeded common clinical measures used daily in clinical practice and clinical research. Not only do we have reliable QOL measures... We now have benchmarks, norms and interpretation guidelines for many generic and

disease-specific questionnaires. We even have an opportunity to standardize measurement of common symptoms and functional abilities across chronic disease and cultures. We have the ability to evaluate measurement precision and measurement equivalence and even to accept a common language for common problems. Let's do that. We can do it with collaboration; we can do it with conviction that a common shared language and metric is better than a relentless pursuit of perfection. We should always try to improve our measures, but can we stop rejecting the good because we wish for something better? And let's make sure that we really work to identify and agree upon critical tests of instrument superiority, so that science can replace personal preferences, bully pulpits and profit motives that currently cloud our view.

Parsimony is a cornerstone of science. We should be no different.

Let's take a page from old Doc Blue's book. Doc Blue was a doctor and a hardware store owner in a small town. He was famous for his miracle cures for arthritis, so always had a long line of patients outside his door. One little old lady, completely bent over, shuffled in slowly, leaning on her cane.

When her turn came, she went into Doc's back room. Amazingly, she came out in 10 minutes walking completely erect with her head held high.

Another woman waiting in line said: "It's a miracle! You walked in bent over in half and now you're walking straight. What did Doc do?"

She answered: "He gave me a longer cane"

Let's look for simple answers to common problems; for simple (but not necessarily short) measures of what we wish to know. If one dimension captures the vast majority of a concept, let's measure that without feeling compelled to capture every deviation from unidimensionality.

Three friends were killed in a car accident and met up in an orientation session at

Heaven's gates. The heavenly greeter asked each of them what they would most like to hear said about themselves as their friends and relatives viewed them in their funeral casket.

The first man says: "I hope people will say I was a wonderful doctor and a good family man."

The second man says: "I'd like to hear them say that as a schoolteacher I made a difference in the lives of kids."

The third man says: "I'd like to hear someone say: "Look, he's moving."

Perhaps the most important word in the term "Quality of Life" is "Life" itself. Indeed, we assume in most of our models that life is a prerequisite for quality. And people tend to think that way when they are asked to make decisions about therapy. Many cancer patients, for example, will accept inordinate toxicity in exchange for a small probability of success. This carries a lot of weight when it comes to valuing treatments and comparing treatment side effects to disease symptoms. Equal impact of side effects versus symptoms on functional ability will not carry the same weight to the patient, though they may to the economist. QOL differences between treatments in a clinical trial tend to mean more when there is no survival difference. Treatments that improve survival are usually adopted, unless the cost is outrageous for the magnitude of benefit.

The Cooper couple went into the dentist's office and Mr. Cooper made it clear he was in a big hurry. "No fancy stuff, doctor." He said. "No gas or needles or any of that stuff. Just pull the tooth and get it over with."

"I wish more of my patients were as stoic as you," said the dentist, admiringly. "Now which tooth is it?"

Mr. Cooper turned to his wife and said: "Open your mouth, honey."

I don't know how to fix the proxy problem. I do think we haven't studied it enough. Whether for cognitively impaired

patients or very young children, we are forced to get QOL information from proxies, and yet we know agreement is at best moderate. Proxies can't help but evaluate the patient from their vantage point. It's our job to help them minimize the bias they are bound to impose.

Take for example the guy who is afraid his wife is losing her hearing, so he consults a doctor. The doctor suggests that he try a simple at-home test on her: Stand behind her and ask a question, first from 20 feet away; then from 10 feet, and finally right behind her.

So the man goes home and sees his wife in the kitchen facing the stove. He says from the doorway, about 20 feet away: "What's for dinner?" ... no answer

Now 10 feet behind her he asks: "What's for dinner tonight?" ... again no answer

Finally, right behind her he asks: "What's for dinner tonight?"

His wife turns to him and says: "For the THIRD time — CHICKEN!"

It may sound trite, but the notion that patients have the answers we seek is very often true. In our work, we routinely triangulate patient input with expert input and clinical data. Each source is an important contributor to understanding QOL measurement and interpretation of results. And sometimes listening to the patient can be a matter of life and death.

A guy named Bill went to see his friend, Hatfield, who was dying in the hospital. As Bill stood by his friend's bed, Hatfield grew worse and gestured frantically for something to write on. Bill handed him a pen and piece of paper, and Hatfield used his last ounce of strength to scribble a note. Hatfield then died and Bill was too grief stricken to read the note so he put it in his pocket.

A few days later, as Bill was talking to Hatfield's family at the funeral, he realized that note was in the pocket of the jacket he was wearing. He announced to the family that Hatfield had written him a note on his deathbed and that Bill hadn't

yet read it. Sure that the note would be an expression of love or perhaps an inspiration, Bill decided to read the note aloud:

"You're standing on my oxygen tube!"

When Donna Lamping called me to tell me about the award, I was first elated and then worried...worried that I would not find the right way to say what I think might need to be said. Sometimes I get a little angry about where our field is going – and not going. I don't react well when a basically good questionnaire is criticized without data to support the criticism. I react even worse when I see people arguing (usually covertly) about whose questionnaire is better, or why a new one is needed, without providing a clear and meaningful basis for evaluating one versus another instrument. I hope I haven't come across as an old man yelling at a cloud.

In my remarks I have intentionally gone light on data. Those of you who know me know that isn't my usual way. Here today I confess to a bit of indulgence in the joy of this honor from the Society. But please know I don't take our field lightly at all. I am one of it's strongest supporters. We have very good measures. If anything, we have too many very good measures, and are continuing to proliferate them like an arsenal we're building up to measure each and every aspect of each and every condition in each and every language, culture and age group. This work alone is limitless. But while we're on that track, please be on the lookout for opportunities to come together, to measure on common ground, to merge scales with larger item banks rather than expand our Tower of Babel. The opportunities are out there....just look and ask.

Finally, let's close by reminding ourselves that we might actually accomplish more if we don't take ourselves too seriously. We have accomplished much, and there is more to do, but remember the story of the distinguished quality of life professor who was befriended by a wizard. The wizard granted the professor one of three wishes. The professor had to choose: wisdom, beauty, or one million dollars. Without giving it a second thought, the

professor chose wisdom. Suddenly there is a flash of lightning and the professor is transformed. He sits there, staring down in silent contemplation for what seemed like an eternity. Finally, one of his friends and colleagues whispers to the professor: "Say something!" The professor says: "I should have taken the money."



CALL FOR NOMINATIONS

Donna Lamping, PhD, Chair, Nominations Committee

All members of ISOQOL are encouraged to submit recommendations for the following ISOQOL leadership positions for next year (please see the job descriptions below):

- * President-elect
- * Board Members (4 positions)

Please send nominations to the ISOQOL Executive Office (info@isoqol.org). **Please send your nominations by April 15, 2009.**

ISOQOL's mission is to advance the scientific study of health-related quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations. We are dedicated to ensuring a breadth of disciplines and geographic representation on the Board and Committees.

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academics, industry, emerging and experienced researchers.*

Conference organizer:
Nancy Mayo, PhD, PT, Epidemiologist

Keynote Speakers:
Richard Osborne, PhD, Health Services Epidemiologist
Susan Bartlett, PhD, Clinical Psychologist

<p style="text-align: center;">Early Bird registration (before April 1, 2009)</p> <p style="text-align: center;">Students: \$65 Faculty: \$130</p>	<p style="text-align: center;">Late registration (after April 1, 2009)</p> <p style="text-align: center;">Students: \$75 Faculty: \$150</p>
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**Call for Abstracts:
Due April 1, 2009**



For more information www.clinepi.mcgill.ca

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- * Access to the "Members Only" section of the ISOQOL website – an invaluable resource tool!
- * Participation in a variety of committees
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ISOQOL, 6728 Old McLean Village Drive, McLean, VA 22101 USA 703-556-9222; fax: 703-556-8729; email: info@isoqol.org;
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