



International Society for Quality of Life Research

Volume 11 Issue 3

Newsletter for ISOQOL Members

Winter 2006/2007

PRESIDENT'S MESSAGE

*Madeleine King, PhD
Sydney, Australia*

Life is full of surprises – little ones, big ones, delightful ones, frightful ones. Being voted President of ISOQOL was a big surprise for me; equal parts delight and fright. A great honour, to be sure, but I was also sure that there would be consequences, possibly even duties. The Presidential Welcome, for instance, which kicks off each annual conference – dreaded by all welcomers in the wings, each in turn wondering what to say that is suitably presidential. I have several months of ponderous dread left on that score, but no time left at all to dread my first President's Message. I'll start with something that's close to my heart, then move onto the more obvious – a look back on the past year and to the coming year, a first blinking glimpse through the eyes of a new president.

It's been in the wings for a while and is now about to burst onto centre stage – ISOQOL's policy for national and regional chapters. Being someone from the Outer Zones, I have some understanding of the geographical and financial barriers that can keep people away from ISOQOL's conferences, despite their interest and enthusiasm for QOL research. The vast majority of our membership comes from Western Europe and North America. No surprise then that the vast majority of registrants at our mid-year and annual meetings come from Western Europe and North America. These meetings offer so much – a chance to find out about cutting-edge research years before it makes it into press, to tell people about your own research while it's still fresh and exciting, to debate esoteric issues with like-minded people (i.e., the topics other

people roll their eyes at), to learn from the wise and to argue with the rest. All that lofty stuff, plus a bit of site-seeing and culture-sampling to boot! So how do we bring these benefits to people who live in those weird out of the way places where their day is your night, their summer your winter? Well, we can take the annual conference to them now and then. We did that very successfully with Hong Kong in 2004, and we'll do it again in Latin America in 2008. But that's really not much of a solution, because the world is just too big – someone somewhere always has to travel a very long way to get there, gets disgruntled, doesn't go, etc. Another solution is to hold more meetings more often in more places. So how do we do this? Setting up chapters of ISOQOL in other parts of the world is an idea that we're ready to try. You can read more about this later in this newsletter, and I'll keep you posted on progress in the next one.

I've always enjoyed ISOQOL's annual conferences, so much so that I've never minded traveling half way round the world to be there, with not a thought for the jetlag! Lisbon 2006 was yet another wonderful event, showcasing the remarkable range and depth of our membership's interests and activities. Special thanks go to the organizing committee, ably chaired by Andrew Bottomley from Belgium with help from local co-chairs Francisco Pimentel and Pedro Ferreira plus Henning Flechtner from Germany. You can read more about the conference in a report by Andrew and his co-chairs in this newsletter – prompting happy recollections for members who were able to attend and filling in the gaps for those who were not.

There are so many things to be done and so much organization behind each and every annual conference. So a big thanks

also to the forty (yes, 40!) members of the organizing committee for the many details they collectively attended to. ISOQOL depends on help from its membership to conduct all its activities, so I encourage members who have not yet been involved in organizing a conference to consider doing so in the future.

Looking back on 2006, the biggest event by far was the long-awaited release of the USA's Federal Drug and Food Administration (FDA) draft guidance for industry on the use of patient-reported outcome (PRO) measures in medical product development to support labeling claims. The release finally came on Friday 3rd of February 2006, ending much nail-biting and edge-of-chair sitting at the Mayo Clinic, where Jeff Sloan, despite an uncertain release date, had scheduled a big national pow-wow for 22-24 February. So the 2006 Award for Brinksmanship goes to the big guy with the curly hair, the audacious style and the winning smile. His

President, continued on page 9

IN THIS ISSUE . . .

President's Message	Page 1
National and Regional Chapters	Page 2
2006 Conference	Page 3
ISOQOL Website	Page 3
QOL Journal Report	Page 4
Third Ibero-American Meeting	Page 5
ISOQOL Publications	Page 5
2006 President's Award	Page 6
New Members	Page 7
2007 Annual Conference	Page 7
Article of the Year	Page 8
PROs Meeting	Page 10
Membership/Meetings	Page 12

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Kathleen Wyrwich, PhD, USA

Deadline for articles for our next issue is April 15, 2007

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

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NATIONAL AND REGIONAL CHAPTERS: CALLS FOR EXPRESSIONS OF INTEREST

Madeleine King, PhD
Sydney, Australia

ISOQOL is about to embark on an exciting new venture – the formation of chapters in nations and regions beyond ISOQOL's traditional base within North America and Western Europe. Guidelines about how to establish a chapter are now available at the ISOQOL website.

Why have chapters?

It is hoped that the development and growth of such chapters will foster a more truly international network of HRQL research and researchers and 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.

What do the new guidelines cover?

The new provisional guidelines cover the creation, approval and operation of national and regional chapters of ISOQOL. They outline: minimum requirements for a chapter; the relationship between ISOQOL and a chapter; the benefits and support provided by ISOQOL to a chapter; the operation of chapters, including financial arrangements under two possible models (franchise versus subsidiary); the process of application, approval, annual report and review; alternatives to forming a chapter; and the roles and responsibilities of the chapter leadership, of the Board Chapters Liaison Delegate (currently John Brazier), and of the ISOQOL Board.

Why are the guidelines “provisional”?

There are many issues to consider, and because this is ISOQOL's first experience with establishing and operating chapters, the optimal approach is not clear. It is therefore envisaged that these guidelines will be reviewed annually and revised in the light of experience both of the chap-

ters and the Board until such time as the guidelines match the needs and requirements of all concerned.

Are you interested in setting up a chapter?

Are you an ISOQOL member living in Asia, Latin America, Eastern Europe, Africa, Australia or New Zealand, or any other country outside North America and Western Europe? Would you like to help bring the benefits ISOQOL has to offer to your country or region? Then please consider getting together with other ISOQOL members from your country or region to establish a local ISOQOL chapter.

Deadline for EOI and draft applications – 16th April 2007

We are now calling for expressions of interest (EOI). EOI should take the form of a draft application, following the information in the guidelines. Please email EOI to info@isoqol.org by 16th April 2007. This will allow time for our feedback to you on how to complete your application in time for the 31st May final application deadline. Final applications will be considered at the June Board Meeting.

If you're interested in submitting an EOI but would like to discuss further, please email your query to info@isoqol.org.

CALL FOR NOMINATIONS

All ISOQOL members are encouraged to submit recommendations for the following leadership positions:

- * President-Elect
- * Board Members (2 positions)

Please send nominations to the ISOQOL Executive Office (info@isoqol.org). ISOQOL promotes the rigorous investigation of health-related quality of life measurement from conceptualization to application and practice, and is dedicated to ensuring a breadth of disciplines and geographic representation on the Board and Committees.

Please send your nominations by April 25, 2007.

THE ISOQOL CONFERENCE 2006

*Andrew Bottomley, Henning Flechtner,
Pedro Ferreira and Francisco Luis
Pimentel, ISOQOL Annual Conference
Chairs 2006*

In 2006, the ISOQOL held its Annual conference in Lisbon in the autumn. The theme for 2006 was *HRQOL Research: Making an Impact in the Real World*. Assessment of HRQOL is increasingly playing a role in settings such as oncology, and the conference objective was to review and evaluate the practical aspects of applying HRQOL in the real world. The President for this conference was Peter Fayers, medical statistician, who gave an insightful welcome speech setting the scene for the next few days. Representatives from the FDA and EMEA attended, and presented their latest thinking on applying HRQOL in the world of drug approval process. Donald Patrick's plenary presentation provided insight into the FDA's new PRO guidelines, while Mira Pavlovic gave a complementary talk about the EMEA experience in evaluating HRQOL in their activities.

Neil Aaronson played an important role in chairing a session with editors David McNamee from the Lancet and Ron Hays from QLR Journal, discussing how ISOQOL can obtain greater visibility for our work. Gordon Guyatt made an excellent plenary presentation that had us all thinking about how much progress we still need to make in getting our HRQOL results accepted and understood by clinicians, and Donald Patrick's plenary on the FDA's implementation of the new Patient-Reported Outcomes guidelines was very informative. Oncology abstracts were by far the largest submitted by the ISOQOL membership, and therefore played a major part in the conference. Topics on psychometrics were another key theme discussed, as were clinical practice, cultural issues and the vexing question regarding whether HRQOL is prognostic. There were also sessions and symposia on various topics around clinical use of HRQOL tools. Numerous presentations were made on

new HRQOL tools for many different disease sites, and workshops on fourteen topics on Wednesday were well attended and met the needs of the ISOQOL membership.

At this conference, as every year, we saw awards for impressive work done by our members, including new researchers. For example, students and new investigators were recognized for their outstanding posters and oral presentations including Janine Becker, Henrik Bergquist, Joan Branin, John Broderson, Olatz Garin, Peter Hagell, Murielle Mauer, Richard Sawatzky, Beate Bestmann, Elise Davis, Yeda Duarte, Sandra Nolte, Lisa Rubin, Claire Shenton, and Yaling Yang. Many of you will be pleased to know that the former President and long time contributor to ISOQOL, David Osoba, received the Presidents Award for Lifetime Achievements. This year the poster sessions were impressive and interactive. The standard of the studies presented during all the poster sessions was excellent, and the meet the author's sessions were well attended and highly interactive. Many Special Interest Groups met this year, for example, on QOL and clinical practice and translation and cultural adaptation.

If you missed the farewell dinner on Saturday night you missed some wonderful dining, dynamic Portuguese dancing and singing, the awards presentations and great speeches!

All in all, the conference was a big success; people made the most of the relaxed Portugal culture, the beautiful weather and had a fun time presenting work and socializing and networking with friends and colleagues. Madeleine King takes over as the ISOQOL President and I am sure she, along with all of us, expects to see everyone at the 2007 ISOQOL Annual conference to be held in Toronto in Autumn 2007!

IMPROVING OUR WEBSITE—PLEASE GIVE US YOUR IDEAS!

*Jordana Schmier, MA
Alexandria, VA, USA*

You already appreciate and use information on the ISOQOL web site to learn about upcoming conferences, member publications, and important announcements in the field. The site presents great information, but it's time for a makeover. We have set aside funds to make the site more user-friendly and easier to navigate. Don't worry - there will not be things flashing at you or multiple plug-ins to download. We want to keep the site simple so that everyone can use it, even if your internet connection is sometimes less reliable than you'd like.

Of course, the goal is to make the site more useful for members, so we'd like to hear your opinions. Are there features you'd like to see on the site that are not there? Are there categories you don't understand? Do you have problems with any part of the site rendering on your screen? Are there features or information that are available on the web sites of other organizations that you think the ISOQOL site should also have? Please let us know and we'd be glad to consider it for this web site upgrade. Please email any comments to: comments@isoqol.org.



IN APPRECIATION . . .

ISOQOL would like to thank
Andrea Bezjak, MD,
Andrew Bottomley, PhD,
Kwok-fai Leung, PdipOT, and
Laura Schwartzmann, MD
for their service as Board
Members;
and **Peter Fayers, PhD**
for his service as immediate
Past-President.
Their hard work and dedication
have helped to further the
message of ISOQOL.

QUALITY OF LIFE RE-SEARCH JOURNAL SUMMARY FOR 2006

Ron D. Hays, PhD, Editor-in-Chief
Los Angeles, CA, USA

A total of 493 manuscripts were submitted between January 1, 2006 and December 31, 2006. The 493 manuscripts included 298 that were rejected, 59 accepted, 65 that are under revision, and 71 for which a decision has not been reached. The estimated acceptance rate is approximately 27%. The acceptance rate in 2005 was about 32% and in 2004 it was about 40%.

Excluding the manuscripts rejected without review, the average time between submission and initial decision in 2006 was 73 days (range: 19-231). Time between acceptance and publication is about 6 months.

Manuscripts in the hardcopy version of the journal are now published by subject category: Clinical and policy applications; Instrument development and evaluation; Value and preference assessment. Publication of the journal is on schedule, with all 10 issues of 2006 (volume 15) published online and in hardcopy.

The impact factor for *Quality of Life Research* in 2005 was 1.915 (compared to 1.820 in 2004), with a ranking of 12th out of 52 in the “health sciences and services” section.

Supplement

Chi-Hung Chang, Ron Hays, and Bryce Reeve are co-editing a special issue of the journal that includes 16 papers from June 2004 IRT meeting sponsored by the National Cancer Institute (NCI) and the Drug Information Association (DIA), “Advances in Health Outcomes Measurement: Exploring the Current State and the Future of Item Response Theory, Item Banks, and Computer-Adaptive Testing.” The special issue will be published in 2007.

Tenure of Associate Editors

Five associate editors recently retired

(Diane Fairclough, David Feeny, Jeanne Landgraf, Kathy Lohr, and Albert Wu), leaving 9 active: Elaine McColl, Henrica de Vet, Graeme Hawthorne, Luis Rajmil, Michael Ritsner, Carolyn Schwartz, John Brazier, Chih-Hung Chang, and Carol Moinpour. Marie-Louise Essink-Bot, MD, PhD is the newest addition to the associate editor team.

International Advisory Board

Our international advisory board is shown in Table 1. Each member has committed to reviewing at least 3 papers each year they serve on the board.

Best Reviewers in 2006

Twenty-three reviewers were identified as the best in 2006. These individuals each reviewed at least 3 manuscripts and their reviews were rated highly by the handling editor (Each review is rated as excellent, very good, good, fair or poor.) These outstanding reviewers are listed in Table 2.

Our acceptance rate (agreement to review a manuscript when asked) among potential reviewers was only 36% in 2006. We are hoping for a higher acceptance rate in 2007. We strongly encourage ISOQOL

Table 1: Constitution of International Advisory Board

Neil Aaronson	The Netherlands Cancer Institute
Jordi Alonso	Institut Munc. d'Investigacio Medica
Ivan Barofsky	The Quality of Life Institute
Rick Berzon	Global Hlth Bureau/Office of HIV-AIDS
D. Caetano	State University of Campinas
David Cella	Northwestern University
Barbara Cochrane	University of Washington
Mojca Dernovsek	University Psychiatric Hospital
Mona Eklund	Division of Occup. Therapy, Sweden
Peter Fayers	University of Aberdeen Medical School
David Feeny	University of Alberta
William P. Fisher	MetaMetrics, Inc.
Hans-Henning Fletcher	University of Cologne
Axel Hirsch	Retired, Spain
Janis R. Homewood	Royal Marsden Hospital
I-Chan Huang	University of Florida
Jeffrey Johnson	University of Alberta
Paul Krabbe	Radboud Univ. Nijmegen Medical Cen
Karoly Kulich	AztraZeneca R&D Molndal
Geraldine Padilla	UC San Francisco
A. S. Pickard	University of Illinois at Chicago
Alexander M. Ponizovsky	Ministry of Health
Dennis Revicki	MEDTAP International
Michael Sawyer	University of Adelaide
James Shaw	Thomas Jefferson University
Kevin Smith	RTI International
Alan Tennant	The University of Leeds
Caroline Terwee	VA University Medical Center

members to consider reviewing for the journal. If you are interested in helping, please contact drhays@ucla.edu to be added to the list of possible reviewers.

Future Plans. We will be identifying the best article published in 2006 in *Quality of Life Research* for acknowledgement at the 2007 ISOQOL Meeting in Toronto.

Table 2: Best Reviewers for Quality of Life Research Journal in 2006

I-Chan Huang
Michael Erhart
Marcel Post
Caroline Terwee
Joanne Cremeens
Michael Herdman
Peter Fayers
Carlo Marra
Stacie Metz
Deborah Miller
Carla Bann
Craig Becker
Dan Dumitrascu
William Cunningham
Rick Berzon
Axel Hirsch
Per Erik Wandell
Janis Homewood
Wen-Wei Huang
Wolfgang Linden
Karoly Kulich
Martin Dempster
Sharon Ives

THIRD IBERO-AMERICAN MEETING ON HRQOL

Laura Schwartzmann, MD
Montevideo, Uruguay

The 3rd Ibero-American meeting was held in 2006 in Buenos Aires on August 26 and 27 at the School of Medicine of the University of Buenos Aires. Prior to the meeting, there was very important participation in the 11th Congress of Internal Medicine of the Clinic Hospital, University of Buenos Aires, which took place from August 23 to 25, at the Retiro Sheraton Hotel in Buenos Aires. Donald Patrick and Claudette Varricchio, both from USA, delivered a workshop in Montevideo, on August 22, as a pre-meeting activity and celebration of the 20th Anniversary of the Department of Medical Psychology.

Dr. Cristina Pecci was the Argentinean chair of the International Organizing Committee integrated by Laura Schwartzmann, MD, Nora Taubenslag, MD, Juan



Jordi Alonso, MD, Spain, spoke at the 3rd Ibero-American Meeting on HRQOL in Buenos Aires

Dapueto, MD and Marcelo Fleck, MD.

A Scientific Committee chaired by Jordi Alonso, MD of Spain - with several representatives from Latin American countries: Julia González, MD (Chile), Cristina Lunic, MD (Argentina), Vera Santos, PhD (Brazil), Marcelo Fleck, MD (Brazil), Juan Dapueto MD (Uruguay)- was in charge of reviewing presented abstracts for posters and oral presentations and also judged the Young Investigator Award, given to Jacqueline S. Blair.

The 3rd Ibero-American Meeting, organized by the Clinic Hospital Foundation and sponsored by ISOQOL, had important local supporters. ISOQOL supported the meeting through partial funding. Several international experts also participated: WHO Chair of Commission on evidence-based decision making, Somnath Chatterji, MD and Claudette Varricchio, Donald Patrick and David Feeny.

With 280 attendees, the meeting was declared of national interest by Argentina's Presidency of the Nation. There was also a declaration of interest by the Deputies' Chamber of the Nation and the School of Medicine of the University of Buenos Aires, the Ministry of Health of the Province of Buenos Aires, the Argentinean Medical Association, the Ibero-American Scientific Information Society, the Argentinean Alzheimer Association, Biological Psychiatry Association and many more professional associations attended the meeting, as well as state and private universities' faculty from local provinces.

ISOQOL PUBLICATIONS

Kathy Wyrwich, PhD, St. Louis, MO and Peter Fayers, PhD, Aberdeen, UK

Books and Monographs

Over the years, ISOQOL has been involved in several publishing efforts whose revenues advance the mission of the Society. These books are:

Quality of Life Assessment in Clinical

Trials by Maurice J. Staquet, Ron D. Hayes, Peter M. Fayers (1998)

Assessing Quality of Life in Clinical Trials, 2nd Edition, edited by Peter Fayers & Ron Hays (2005)

Advancing Health Outcomes Research Methods and Clinical Applications, edited by William R. Lenderking & Dennis A. Revicki (2006)

Peer-Reviewed Papers

ISOQOL also encourages SIGS or other groups of members to publish, when appropriate, on behalf of or in recognition of ISOQOL. Manuscripts for such publications should be sent to the ISOQOL Executive Committee for approval, before they are submitted to a journal.



ISOQOL'S 2006 PRESIDENT AWARD'S ADDRESS

At the Closing Ceremonies of the 13th Annual Meeting in Lisbon, outgoing President Peter Fayers presented ISOQOL's President Award to David Osoba. Many ISOQOL members may know David first and foremost as the Society's President from 2001-2002.

Earlier that day, David gave the morning plenary presentation as part of his acceptance of the Award. We asked David to share his thoughts with all ISOQOL members in the article below.

HRQOL in Oncology: "Watching the Ripples"

David Osoba BSc, MD, FRCPC, QOL Consulting, and Professor (Retired), Department of Medicine, University of British Columbia, Vancouver, Canada



David Osoba (left) receives ISOQOL's President Award

I wish to convey my heartfelt thanks to the selection committee and the Board of ISOQOL for choosing me as the recipient of the President's Award. In my 25 years in this field I have seen a broad river of knowledge grow out of what were initially small intellectual streams of ideas. Throughout this I have felt myself to be largely a spectator, watching the ripples in the river in general and their impact in oncology in particular.

In oncology, performance status measures have existed for a long time. The Karnofsky Performance Status, proposed in 1949, and the Zubrod scale in 1960, (later known as the ECOG and the WHO scales) were initially entirely observer-rated. Their drawback is that they measure physical functioning and do not

measure the entire concept behind health-related quality of life (HRQOL). So, what were the origins of patient reported outcomes (PRO) and HRQOL measurement? The pioneers are many. They worked in: population health and health surveys (in 1966, DF Sullivan proposed a single index of mortality and morbidity and concepts on a health status index in 1971. Quality of American Life – A Campbell 1976); health insurance (NY State Health Planning Commission – Health Status Index - JW Bush, DL Patrick, S Fanshel, R Kaplan, MM Chen 1968-69); decision science and health economics (Weinberg MC – 1980); engineering (operations research and project appraisal – G. Torrance, 1979); measurement and psychometrics (D Campbell, J C Nunnally, many others). There were also others, working independently (e.g., M Bergner [initially with J Bush], J Ware [with R Hays and A Stewart at the Rand Corp.], and R Rosser [with P Kind]).

A very early study of "HRQOL" in cancer by E Carlens et al in 1970 (Scand J Resp Dis) proposed a 'Vitagram' to assess ability to work, symptoms and hospitalization in patients with lung cancer. T Priestman and M Baum were the first to study patients with metastatic breast cancer undergoing hormone and chemotherapy (1976, 1980). They used an unvalidated LASA scale. PH Sugarbaker, I Barofsky, et al compared surgery vs radiation for osteogenic sarcoma, using a battery of assessments, and obtained counter-intuitive results (1982). Patients who had surgery actually fared better than did those treated with radiation.

Early methodology focused on such issues as who should measure HRQOL (observer vs self-rating), instrument development, psychometric validation, and tended to favor a single-summed score. It was found that self-assessment differs from that of observers (e.g., CA Present 1983; ML Slevin et al 1988; S Wood-Dauphinee and JI Williams 1991; K Sneeuw et al 1998). Compared to patients, observers often overestimate symptoms like fatigue, insomnia and pain, but underestimate physical, social and role functioning. Thus, self-rating became the gold standard.

New instrument development led to a burst of studies in cancer between 1985 and 1990, e.g., chemotherapy for metastatic breast cancer and metastatic lung cancer, and adjuvant chemotherapy for stage II breast cancer. However, there were problems! These methodological difficulties reaffirmed that self-rating of HRQOL must be reliable, valid, reproducible and responsive to change over time (the "mantra" of investigators in this field). Instruments must be developed in the population for which they are intended and instrument development should include input from patients. Since a multidimensional approach is required domain scores are necessary whether or not the measure includes a single-summary score. There were also a number of procedural difficulties. In multi-institutional studies, not all institutions participated, there was too much missing data, and questionnaire administration times were often inappropriate. Formalization of procedures began with the development of policy, writing guidelines, procedures to be followed, e.g., D Osoba (NCIC CTG) 1992; P Fayers et al 1997. In addition to other issues, these dealt with timing and frequency of administration, and strategies for minimizing, and dealing with missing data.

Analysis and interpretation are major tools in HRQOL assessment. Initially, only mean scores were reported, but means are prone to "survivor effect". Later, "change from baseline" scores were added, but what does a small change mean, clinically? Social scientists use effect sizes (ES), but, what do these mean, to a medical clinician? More recently, it has been proposed that a determination of the minimally important difference (MID) or subjectively significant difference (SSD) is likely to be most useful. The MID is equal to ~ 7-8% of scale breadth, or a mean of ~ 0.5 of a standard deviation, as determined from health transition (global) questions (e.g., R Jaeschke et al; E Juniper et al; D Osoba et al), from anchor and distribution-based assessment (M King; D Cella et al), and SEM estimates (K Wyrwich et al). It has been cautioned that the MID may be lower for

President's Award, continued on page 9

ISOQOL WELCOMES NEW MEMBERS

Suzana Almeida
CEP, Brazil
Caroline Anfray
Lyon, France
Jan Barnsley
Toronto, ON Canada
Charles Barr, MD, MPH
Peapack, NJ USA
Signe Berit Bentsen
Haugesund, Norway
Richard Board
Rodeo, CA USA
Robert Brook
Santa Monica, CA USA
Julia Brown, MSc
Leeds, West Yorkshire, UK
Richard Chapman
Falls Church, VA USA
Scott L. Charland
Winter Park, CO USA
Marci Clark, PharmD
Ann Arbor, MI USA
Deborah Corring, PhD
Ontario, Canada
Carol Diener
Champaign, IL USA
Shirley Farlinger
Toronto, ON Canada
John T. Farrar, MD
Philadelphia, PA USA
Robert Gerber, MA, MBA
New London, CT USA
Claire Gilbert, MSc
Sandwich, Kent, UK
Dominik Golicki, MD, PhD
Warsaw, Poland
Claudia Gorecki
Leeds, UK
Martha Hartley, MSN
Roan Mountain, TN USA
MaryAnne Hope
Phoenix, AZ
Colin Johnson, Mchir
Southampton, Hants, UK
Arie Kapteyn
Santa Monica, CA USA
Sooyeen Kwon
Gainesville, FL USA
Carlota Las Hayas, MSc
Galdakao, Spain
Joseph Lipscomb, PhD
Atlanta, GA USA
James E. Littlefield
Blacksburg, VA USA
Victoria Loerzel, MSN
Orlando, FL USA
Maureen Logsdon
Mechanicsville, VA USA
Josefina Lugo
Havanne, Cuba
Joy MacDermid
Hamilton, ON Canada
Donna Malcolm
Saskatoon, SK, Canada
Sheila Mammen
Amherst, MA USA
Murielle Mauer, PhD
Brussels, Belgium

Eva Mautner
Graz, Styria, Austria
Carolyn McMillan, PhD
London, UK
Joseph Menzin, PhD
Waltham, MA USA
Elizabeth Molsen
Soleloury, PA USA
Clara Mukuria, MSc
Sheffield, South Yorkshire, UK
Deirdre Mylod
South Bend, IN USA
Fusako Nakamachi, PhD
Machida-shi, Japan
Hannah O'Gorman
Nottingham, UK
Jean O'Toole, OT, MPH
Melrose, MA USA
Nicole Pouliart
Brussels, Brussels
Paul Radensky
Miami, FL USA
Laurene Redding, MBA
Mississauga, ON, Canada
Javier Rejas, MD
Alcobendas, Madrid, Spain
Anna Maria Rodriguez, BSc
Montreal, QC Canada
Karen Saban
Naperville, IL USA
Assuntina Sacco, BS
Ann Arbor, MI USA
Bruce Schackman, PhD
New York, NY USA
Kevin Schulman
Durham, NC USA
Susan Shiff
New York, NY USA
Isabel Silva
Porto, Portugal
Kit Simpson
Charleston, SC USA
Kevin Stein, PhD
Atlanta, GA USA
Michelle Stewart, PhD
Waterford, CT USA
Pia Svedberg, PhD
Stockholm, Sweden
Laura Lee Symes
Portland, OR USA
Ian Tannock, MD, PhD
Toronto, ON Canada
Anne Taylor, MPH
Adelaide, South Australia, Australia
Miyako Tazaki, PhD
Toyko, Japan
Muzzafer Uysal
Blacksburg, VA USA
Karen P. Varcoe
Riverside, CA USA
James Vermilyea, PhD
Lincoln, RI USA
Gemma Vilagut, MD
Barcelona, Spain
Megumi Watanabe, MN
Shinjuku-k, Tokyo, Japan
Alex Wearing
Parkville, Victoria, Australia
John Weiler
Iowa City, IA USA
Richard White, PhD, MPH
Wilmington, DE USA

GET READY FOR TORONTO AND THE 14TH ANNUAL CONFERENCE OCTOBER 10-13, 2007

*Nancy Mayo, PhD
Montreal, Canada*

The theme of the 2007 meeting is how our measures and our new methods for quality of life research can improve our understanding of quality of life at the individual, clinical and population level. Toronto, Ontario, Canada, will be hosting this meeting, and there are very few cities in the world where so many cultures co-exist - a perfect setting for a meeting where the celebration of diversity will lead to a greater understanding of quality of life.

Paper, poster and symposium abstracts are now being accepted! For details please visit www.isoqol.org.

THANK YOU!

ISOQOL would like to thank those who presented a Workshop at the 13th Annual Conference in Lisbon, Portugal. The meeting was a great success!

Sonya L. Eremenco
Ramona Lucas
David H. Feeny
George W. Torrance
Bryce B. Reeve
Chih-Hung Chang
Monika Bullinger
Corinna Petersen
Diane Fairclough
Richard H. Osborne
Ivan Barofsky
Desmond Curran
Herbert Thijs
Otto B. Walter
Dennis Revicki
Donald Stull
Kathleen W. Wyrwich
Stein Kaasa
SB Detmar
Paul F.M. Krabbe
Corneel Coens

ISOQOL OUTSTANDING ARTICLE OF THE YEAR AWARD FOR 2005

David Feeny, PhD
Portland, OR, USA

Nine articles on a wide-ranging set of topics and appearing in a diverse set of journals were nominated for the award this year. Each article was reviewed by the Nominations Committee consisting of David Feeny (Chair), Mirjam Sprangers, and Albert Wu. The Committee reports that reading this interesting set of papers was a pleasure.

Criteria for selecting the outstanding article include scientific excellence, innovativeness, promotion of the field of quality of life research, and diversity of topic in light of previous awards.

The articles nominated in the order of the receipt of the nomination are listed below.

Schwartz, Carolyn E., Sc.D., Melanie P. Merriman, Ph.D., M.B.A., George Reed, Ph.D., Ira Byock, M.D., "Evaluation of the Missoula-VITAS Quality of Life Index-Revised: Research Tool or Clinical Tool?" *Journal of Palliative Medicine*, Volume 8, Number 1, 2005.

Brundage, M., 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.

Fliege, Herbert, Janine Becker, Otto B. Walter, Jakob B. Bjorner, Burghard F. Klapp, and Matthias Rose, "Development of a computer-adaptive test for depression (D-CAT)" *Quality of Life Research* (2005) 14: 2277-2291.

Osoba, David, Andrea Bezjak, Michael Brundage, Benny Zee, Dongsheng Tu, Joseph Pater, for the Quality of Life Committee of the NCIC CTG, "Analysis and interpretation of health-related quality-of-

life data from clinical trials: basic approach of The National Cancer Institute of Canada Clinical Trials Group" *European Journal of Cancer* 41 (2005) 280-287.

Valderas, J. M., M. Rue, G. Guyatt & J. Alonso, for the Systematic Use of Quality of Life Measures in the Clinical Practice Working Group, "The impact of the VF-14 index, a perceived visual function measure, in the routine management of cataract patients" *Quality of Life Research* (2005) 14: 1743-1753.

Taphoorn, Martin JB, Roger Stupp, Corneel Coens, David Osoba, Rolf Kortmann, Martin J van den Bent, Warren Mason, Rene O Mirimanoff, Brigitta G Baumert, Elizabeth Eisenhauer, Peter Forsyth, Andrew Bottomley, for the European Organisation for research and Treatment of Cancer (EORTC) Brain Tumour Group, EORTC Radiotherapy Group, and the National Cancer Institute of Canada Clinical Trials Group (NCIC CTG), "Health-related quality of life in patients with glioblastoma: a randomised controlled trial" *Lancet Oncol* 2005; 6: 937-44.

Brunner, Robert L., PhD; Margery Gass, MD; Aaron Aragaki, MS; Jennifer Hays, PhD; Iris Granek, MD; Nancy Woods, PhD, RN; Ellen Mason, MD; Robert Bryzski, MD, PhD; Judith Ockene, PhD; Annlouise Assaf, PhD; Andrea LaCroix, MPH, PhD; Karen Matthews, PhD; Robert Wallace, MD; for the Women's Health Initiative Investigators, "Effects of Conjugated Equine Estrogen on Health-Related Quality of Life in Postmenopausal Women With Hysterectomy., Results From the Women's Health Initiative Randomized Clinical Trial" *Arch Intern Med.* 2005; 165: 1976-1986.

Skevington, Suzanne M., Rachel Day, Alison Chisholm and Paul Trueman, "How much do doctors use quality of life information in primary care? Testing the Trans-Theoretical Model of behaviour change" *Quality of Life Research* (2005) 14: 911-922.

Luo, Nan, PhD, Jeffrey A. Johnson, PhD, James W. Shaw, PhD, PharmD, MPH, David Feeny, PhD, and Stephen Joel

Coons, PhD, "Self-Reported Health Status of the General Adult U.S. Population as Assessed by the EQ-5D and Health Utilities Index" *Medical Care*, Vol. 43, Number 11, November 2005.

And the Winner Is!

The unanimous choice was 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.

The Brundage et al. paper reports on an innovative, well-designed, and well-executed study. The results have interesting implications both for the practice of medicine and evolution of the field of health-related quality of life. The authors report that they have "demonstrated that patients can accurately interpret graphical representations of HRQL data" (p 6954). The study represents an important step in understanding how to share HRQL information with patients effectively in order to improve decision making, care, and outcomes.

Congratulations to all of the authors of papers that were nominated!

Plans for the Outstanding Article of the Year Award for 2006

In June 2006 the Board of ISOQOL decided to change the award to the best paper published in the society's journal, *Quality of Life Research*, in the previous year.

Members are encouraged to scrutinize issues of *Quality of Life Research* in order to identify papers suitable for nomination -- the deadline for nominations is July 15, 2007.

Nominations Committee for the 2006 Award

The committee will consist of Peter Fayers (Chair), David Feeny, and Albert Wu. Papers in which any of these three individuals are authors will not be eligible for the award.



President's Award, from page 6

preference instruments (~0.3 (Farivar, Liu and Hays) and that studies should show the distribution and bounds of MID estimates. Knowing the MID allows a calculation of the proportions of patients who do, and do not, benefit from an intervention, e.g., using a predetermined cut-off, e.g., 10% of the scale breadth, patients can be classified into “responders” or “nonresponders” in terms of HRQOL scores. This is a meaningful result for clinicians since they can compare proportions between groups and can determine the number of patients that need to be treated (NNT) for one patient to benefit. Future directions in HRQOL research will include: more frequent use of PROs, not only in Phase III, but also in phase II and I clinical trials; more regulatory requirements for use of PROs in labeling claims, e.g., FDA Guidance for Industry; new technology and methodology e.g., IRT methods for computer adaptive testing; more precise interpretation of clinically meaningful effects; greater use and adaptation of utility measures to clinical situations; development of electronic medical records; better education of health care professionals, and incorporation of adaptation response (“response shift”). It is hoped that we will soon see the routine use of PRO in clinical practice with an integration of PRO data with classical “clinical” parameters. It is time for an acceptance of the equal status of PRO endpoints with classical “clinical” endpoints in clinical decision-making.

My personal view, strongly held and frequently enunciated since 1997, is that “The ultimate goal of health care is to restore or preserve health-related quality of life.”

(More information on the history of the development of HRQOL and PRO research can be found in the Oral History section of the ISOQOL website, www.isoqol.org.)



President, from page 1

timing was in fact impeccable – the Mayo meeting was a great success, as we read in ISOQOL's April and September 2006 newsletters. The FDA gave 60 days from release for written submissions, and Dennis Revicki took on the big job of compiling a collective response from ISOQOL – a big thanks to Dennis for taking on such an important job for ISOQOL and doing it so well. Dennis Revicki, Jeff Sloan and Bill Lenderking then organized another large meeting, this time in Washington DC, June 29, 2006. Presentations by FDA people were an opportunity for participants to get an update on the FDA's thinking, while presentations from a number of leading ISOQOL members provided useful overviews of the state-of-the-science as we see it, as reported in last September's newsletter.

So there's the potted history; now for the update. The June meeting was followed up in October with a one-day satellite meeting before our Lisbon conference. This time, the European EMEA was represented too, rounding out the international scope. And as a result of some very productive networking at the lunchtime “Meet the Editors” session at the Lisbon conference, a commentary on this issue is now in press in the Lancet. This is a great outcome from the conference, terrific exposure for ISOQOL, and a rewarding output for ISOQOL's Regulatory Issues and Patient-Reported Outcomes Task Force, lead by Dennis Revicki with members Neil Aaronson, Jakob Bjorner, David Cella, Diane Fairclough, Peter Fayers, Ron Hays, William Lenderking, and Jeff Sloan. We are yet to hear when the final guidance is to be released, but apparently the FDA is working on that now.

We are lucky that the Lancet's executive editor, David McNamee, is so receptive to ISOQOL's perspective on the importance of QOL and PRO and that he translated that into action so quickly on the FDA Guidance commentary. His support is ongoing, and we can hope to see more comments on QOL/PRO-related issues in future issues of the Lancet. But, as they say, you make your luck, and our journal

editor Ron Hays did a good job creating the necessary environment for this to happen – thanks, Ron.

The next big thing on the ISOQOL horizon is the mid-year conference on PROs in Clinical Practice, June 24-26, Budapest, Hungary. Its been interesting to watch the evolution of QOL methodology and spreading acceptance of QOL assessment over the years, to the point where we now have the confidence and momentum to take on one of the really big challenges in the field – how best to use self-reported health measures to improve the management of individual patients. This conference will bring together a critical mass of people working on various approaches to this important problem. And what a great chance to see Budapest!

Before signing off, I'd like to thank the outgoing board members, Andrea Bezjak, Andrew Bottomley, Kwok-fai Leung and Laura Schwartzmann for their wonderful help and support over the years, and to welcome the new board members, Nancy Mayo, Carol Moinpour, Bryce Reeve and Lena Ring.

So, is that all there is? The New President's First Message, done? Not that painful, after all. Another of life's little surprises!



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ISOQOL Conference on Patient Reported Outcomes in Clinical Practice

June 24-26, 2007
Budapest, Hungary

Routine clinical practice is a relatively new setting in which PROs are being applied. The primary goals of PRO assessment in clinical practice are to provide information important for monitoring and improving patients' physical and psychosocial functioning, to facilitate effective symptom management during and following treatment, to inform decision-making and, more generally, to improve communication. ISOQOL has planned a special conference on PROs in Clinical Practice to summarize the state-of-the science, identify gaps in our knowledge base, and develop a research agenda for improving the science and practicality of PRO assessment in clinical practice. For details and to register, please visit www.isoqol.org.

SUNDAY, JUNE 24:

1:00-5:00 Workshops
Coordinator: Albert Wu, MD, MPH

1 **Introduction to Patient Decision Aids** ~ Deborah Feldman-Stewart, PhD

2 **Incorporating Health-Related Quality of Life Measurement in Oncology Outpatient Consultations - Physician Attitude, Patient-Physician Communication and Decision-Making** ~ Galina Velikova, MD

3 **Interpreting PRO Scores for Individual Patients** ~ Jeff Sloan, PhD

4 **Basic Methods for Measurement of Patient Reported Outcome Measures** ~ Ron Hays, PhD

5 **Methods for Cross-Cultural Development, Translation/Adaptation, and Evaluation of Health Outcomes Measures** ~ Sonya Eremenco, MA

Evening Welcome Reception

MONDAY, JUNE 25:

posters up for the three Monday topics 9:00-5:30

9:00-9:15 **Welcome**
Conference Chairs: Neil Aaronson, PhD, and Claire Snyder, PhD

9:15-10:00 **Opening Session**
Chairs: Neil Aaronson, PhD, and Claire Snyder, PhD
Speakers:
* Kathleen Lohr, PhD, RTI International and University of North Carolina at Chapel Hill School of Public Health, Research Triangle Park, NC, USA
* Brad Zebrack, PhD, MSW, MPH, University of Southern California School of Social Work and 21-year survivor of Hodgkin's disease, Los Angeles, CA, USA

10:00-11:30 **Theoretical Underpinnings for Using PROs in Clinical Practice**
Chair: Michael Brundage, MD, MSc
Speakers:
* Deb Feldman-Stewart, PhD, Queens University, Kingston, Ontario, Canada
* Gary Donaldson, PhD, University of Utah, Salt Lake City, UT, USA

11:30-12:45 **Lunch/Poster Session 1** (box lunch)

Monday, June 25 continued

12:45-2:15 **Applications of PROs in Clinical Practice**
Chair: Susan Yount, PhD
Speakers:
* Joanne Greenhalgh, PhD, School of Healthcare, University of Leeds, Leeds, United Kingdom
* John Wasson, MD, Dartmouth Medical School, Hanover, NH, USA

2:15-3:00 **Break/Poster Session 1** (continued)

3:00-4:30 **Content of PROs in Clinical Practice**
Chair: Claire Snyder, PhD
Speakers:
* Ted Ganiats, MD, University of California-San Diego, La Jolla, CA, USA
* Ron D. Hays, PhD, University of California-Los Angeles, Los Angeles, CA, USA

4:30-5:15 **Day 1 Panel Session**

Evening Optional Outing

TUESDAY, JUNE 26:

posters up for the three Tuesday topics 8:00-4:00

8:00-9:30 **Logistics of Collecting PROs in Clinical Practice**
Chair: Neil Aaronson, PhD
Speakers:
* Andrea Beznak, MD, MSc, Princess Margaret Hospital/University Health Network, University of Toronto, Toronto, Ontario, Canada
* Matthias Rose, MD, PhD, Health Assessment Lab & QualityMetric, Boston, MA, USA

9:30-10:15 **Break/Poster Session 2**

10:15-11:45 **Training Health Care Professionals to Use and Interpret Data from PROs in Clinical Practice**
Chair: Galina Velikova, MD, PhD
Speakers:
* Molla Donaldson, DrPH, MS, George Washington University School of Medicine & Health Sciences and MSD Health Care Consulting, Washington, DC, USA
* Lesley Fallowfield, BSc, DPhil, Brighton & Sussex Medical School, University of Sussex, Sussex, England

11:45-1:00 **Lunch/Poster Session 2** (box lunch)

1:00-2:30 **Evaluating the Effectiveness of Using PROs in Clinical Practice**
Chair: Albert Wu, MD, MPH
Speakers:
* Sherrie Kaplan, PhD, MPH, University of California-Irvine, Irvine, CA, USA
* Emmett Keeler, PhD, Pardee RAND Graduate School, Santa Monica, CA, USA

2:30-3:15 **Day 2 Panel Session**

3:15-4:00 **Closing Session**
Chair: David Osoba, MD
Speakers:
* Peter Selby, CBE, MA, MD, FRCP, FRCR, FMedSci, Cancer Research United Kingdom, Leeds, United Kingdom
* Ian Tannock, MD, PhD, Princess Margaret Hospital and University of Toronto, Toronto, Ontario, Canada

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