



International Society for Quality of Life Research

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Newsletter for ISOQOL Members

March 2010

PRESIDENT'S MESSAGE

Diane Fairclough, DrPH



It seems like the ISOQOL meeting in New Orleans is just over, but so much is happening. For me, the ISOQOL meeting was as always stimulating and enjoyable (see Claire and Michael's article for highlights). In my first message to the membership, I would like to update you about what is going on and then about plans for the future. I have thought about what I would like to accomplish during my presidency and have chosen education as a broad focus for a number of reasons that I discuss at the end of this message under Strategic Planning for Education. I hope that by the end of my term of one year, we can have a strong strategic plan

that identifies the gaps, the strengths and weaknesses of our current programs and where we want and need to go in the future.

Dictionary of HRQoL Terms: Nancy Mayo will be leading an initiative to develop a dictionary of terms frequently used in HRQoL research. The goals of the project are to a) fill a gap in available educational resources, b) raise additional income for ISOQOL and c) increase ISOQOL's visibility in the research community. ISOQOL members will be invited to suggest terms and submit definitions over the upcoming year. See pg. 9 for more details.

FDA Guidance: As many of you are aware, the final FDA guidance for the use PRO measures in labeling and promotion of drugs has been released. (<http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf>) My understanding is that the guidance is very similar to the original draft guidance with additional clarifications. We have already created a Discussion Board (<http://www.isoqol.org/bulletinboard/fdapro/frontend/index.cfm>) and you should have received an e-mail invitation. Other plans that are being considered are a Webinar as well as a series of papers if we have something new to contribute. Some of the potential questions that have been identified include:

1. How has the original draft guidance impacted the HRQoL research field since its release in 2006. How has it affected our work in academia and industry, in the US and abroad?
2. Has it changed the way we develop and use PRO measures? Please provide examples.
3. Are there scientific issues raised in the guidance (e.g., reference period,

single vs. multi-item scales, conceptual frameworks) that we feel we need more research to justify the claims made in the document?

4. Can we identify future research agendas on topics raised in the guidance to support or disprove them?

Your input will be shared among the ISOQOL members via this Discussion Board. It may also be used in a newsletter article or to develop themes for the ISOQOL sponsored manuscripts. Before using any details from your responses in a manuscript, you will be contacted for permission.

2009 Fall Board Meeting: The ISOQOL Board of Directors met on the Tuesday prior to the New Orleans meeting. Some of the highlights follow.

- The 2010 annual meeting will be in London, England and the 2011 meeting in Denver, Colorado.
- The Ibero-America chapter will be having the fifth Ibero-America meeting, in September 2010 in Santiago, Chile.
- Ongoing Board initiatives include clarifying and evaluating ISOQOL governance (Cindy Gross), refining our publication policy (Neil Aaronson), developing a professional education program (Juan Dapuerto), outreach to medical societies (Lena Ring & Carol Moinpour), finalizing the policy on SIGs (Claire Synder), enhancing the manual for the planning of our annual meeting (Dorcas Beaton), and fundraising (James Pierce & Rick Berzon).
- The responsibility for choosing the Outstanding Article of the Year will be transferred from the Nominations Committee to the editorial board of *Quality of Life Research*, with one member of the Nominating Committee assisting.

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QUALITY OF LIFE IN CLINICAL PRACTICE SPECIAL INTEREST GROUP NEWS

Maria Jose Santana, PhD

As part of the ISOQOL annual meeting in New Orleans, the QoL in Clinical Practice special interest group met. Galina Velikova and Michele Halyard decided to step down from their SIG responsibilities. The ISOQOL Board approved Susan Yount and Maria Santana as the new co-chairs. Susan and Maria are honored to lead and contribute to the future of the SIG

The objective of the meeting was to develop the agenda for next year with special emphasis on communication.

The first project is to create a bibliographic registry with publication on the use of PROs in clinical practice. The initiative takes advantage of the members of the SIG by using the listserv, to ask

The first project is to create a bibliographic registry with publication on the use of Patient Reported Outcomes in clinical practice.

them to notify the group when they publish or identify publications of possible interest. Claire Snyder very generously volunteered to work with the librarians at the John Hopkins University in creating, maintaining and updating the database.

Another project is a depository on the web site for slides from the ISOQOL presentations on the use of PROs in clinical practice. Once the functionality of the website is assessed, the slides will be

posted on the website.

The development of future symposia for other conferences in various clinical areas such as cardiology, neurology and oncology was considered. The strategy is to target national conferences, accumulate experience and later to expand to international meetings in the future.

A more ambitious plan is to increase exposure of ISOQOL in other professional organizations. For instance, forging ties with the Society of Medical Decision Making (SMDM) and Society of Clinical Oncology (ASCO), with the future objective of offering joint sessions at ISOQOL and SMDM and ASCO.

The full year agenda requires more than the listserv to maintain communication among the members of the SIG. The ISOQOL Newsletter is a valuable tool to promote communication. The idea is to include a brief description of SIG activities in each issue of the Newsletter.

The SIG will identify a new focus for the 2010 ISOQOL symposium that could be considered for a presentation at the conference. Galina Velikova, Susan Yount and Maria Santana will coordinate the effort. Further details will be provided in the newsletter.

In summary, we (Susan and Maria) are delighted to work together with all the members of the SIG and wish to contribute to the development of the group and be active members of ISOQOL. In order to achieve our goals, we welcome comments and suggestions from our fellows 'ISOQOLERS'.



OUTSTANDING ARTICLE OF THE YEAR AWARD: *QUALITY OF LIFE RESEARCH 2008*

Donna L. Lamping, PhD

The Outstanding Article of the Year Award was established in 2003 to recognize and honor the single best article dedicated to health-related quality of life (HRQL) research that was published during the previous calendar year. In 2007, the award was modified to recognize the single best article dedicated to health-related quality of life (HRQL) research that was 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, the Nominations Committee identified the recipient of the Article of the Year Award.

The Nominations Committee is comprised of the Immediate Past-President and the two previous Past-Presidents, in this case Donna Lamping (Chair), Madeleine King and Peter Fayers. In response to the annual call for nominations, this year's Committee received 9 nominations from ISOQOL members and from Editor-in-Chief Ron Hays and his team of Associate Editors.

Nominations for 2008 ISOQOL Outstanding Article of the Year Award

Kudos to each of our colleagues below, whose papers were nominated for this year's award. Well done all, and many thanks for providing us all with such inspirational reading in 2008! To any new ISOQOL members, particularly those of you who are new to the field, and to students and others considering a research career in quality of life research, I can't think of a better place to start than with this "required reading list" of the best papers in the field:

Diane L. Fairclough, Herbert Thijs, I-Chan Huang, Henrik W. Finnern, Albert W. Wu. **Handling missing quality of life data in HIV clinical trials: what is practical?**

Qual Life Res (2008) 17:61–73.

Jolie J. Gutteling, Anne-Sophie E. Darlington, Harry L. A. Janssen, Hugo J. Duivenvoorden, Jan J. V. Busschbach, Robert A. de Man. **Effectiveness of health-related quality-of-life measurement in clinical practice: a prospective, randomized controlled trial in patients with chronic liver disease and their physicians.** *Qual Life Res* (2008) 17:195–205.

Nancy E. Mayo, Susan C. Scott, Nandini Dendukuri, Sara Ahmed, Sharon Wood-Dauphinee. **Identifying response shift statistically at the individual level.** *Qual Life Res* (2008) 17:627–639.

Michael B. Nichol, Joshua D. Epstein. **Separating gains and losses in health when calculating the minimum important difference for mapped utility measures.** *Qual Life Res* (2008) 17:955–961.

Dennis A. Revicki, Nancy Brandenburg, Louis Matza, Mark C. Hornbrook, David Feeny. **Health-related quality of life and utilities in primary-care patients with generalized anxiety disorder.** *Qual Life Res* (2008) 17:1285–1294.

Donald E. Stull. **Analyzing growth and change: latent variable growth curve modeling with an application to clinical trials.** *Qual Life Res* (2008) 17:47–59.

Lonneke V. van de Poll-Franse, Natalia Sadetsky, Lorna Kwan, Mark S. Litwin. **Severity of cardiovascular disease and health-related quality of life in men with prostate cancer: a longitudinal analysis from CaPSURE.** *Qual Life Res* (2008) 17:845–855.

J. M. Valderas, A. Kotzeva, M. Espallargues, G. Guyatt, C. E. Ferrans, M. Y. Halyard, D. A. Revicki, T. Symonds, A. Parada, J. Alonso. **The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature.** *Qual Life Res* (2008) 17:179–193.

Marjan J. Westerman, Tony Hak, Mirjam A. G. Sprangers, Harry J. M. Groen, Gerrit van der Wal, Anne-Mei The. **Listen to their answers! Response behaviour in the measurement of physical and role functioning.** *Qual Life Res* (2008) 17:549–558.

2008 ISOQOL Outstanding Article of the Year Award – The Winner!

Heartiest congratulations to Marjan Westerman and her colleagues from The Netherlands, who were awarded the 2008 Article of the Year Award for their paper:

Marjan J. Westerman,^{1,2} Tony Hak,³ Mirjam A. G. Sprangers,⁴ Harry J. M. Groen,⁵ Gerrit van der Wal,² Anne-Mei The.² Listen to their answers! Response behaviour in the measurement of physical and role functioning. *Qual Life Res* (2008) 17:549–558.

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I was delighted that Dr. Westerman was in New Orleans to accept the award, which was presented during the Awards Ceremony at the Conference Dinner. In a thought-provoking and intriguing study, Dr. Westerman and her colleagues raised questions about what quality of life measurement instruments actually assess. They investigated how patients interpret and respond to questions on the EORTC-QLQ-C30 over time, and sought to find explanations to account for counter-intuitive findings in QOL measurement.

OAY, continued on page 6

MEET THE NEW BOARD MEMBERS

ISOQOL is pleased to welcome the following new members of the Board of Directors:

Michael Brundage, Henrica de Vet, Joanne Greenhalgh and Kathy Wyrwich. Their terms began at the conclusion of the Annual Members' meeting at the conference last October, and will conclude at the conclusion of the same meeting in 2012. Please see below for details!

Michael Brundage

Michael Brundage, MD, MSc, is a Professor of Oncology and of Community Health and Epidemiology at Queen's University, Director of the Division of Cancer Care and Epidemiology research unit at the Queen's Cancer Research Institute, and a practicing radiation oncologist at the Cancer Centre of Southeastern Ontario. After completing radiation oncology training at Princess Margaret Hospital, he obtained his M.Sc. in epidemiology in 1991 from Queen's. Michael's research and teaching link epidemiological methods with clinical practice, including a major research focus on using health-related quality of life in clinical practice.



Michael has had the privilege of being involved with several ISOQOL activities since becoming a member. He serves on the coordinating committee that founded the special interest group exploring QOL in clinical practice. He also served on the planning committee for the 2007 ISOQOL special conference on Using Patient-Reported Outcomes in Clinical Practice. He also co-chaired the scientific program committee for the 2009 Annual Meeting, which was held in New Orleans, Louisiana. These experiences have provided Michael with the opportunity to work with many talented ISOQOL members who are willing to share their time, energy, and expertise in support of ISOQOL endeavors.

In addition to Michael's work with ISOQOL, he has served in various other capacities to support quality of life research. He currently chairs the Quality of Life Committee of the National Cancer Institute of Canada Clinical Trials Group, and is a member of the U.S. National Cancer Institute's Symptom Control and Quality of Life committee. He is a member of several academic boards, including the Advisory Council on Research of the Canadian Cancer Society Research Institute. The combination of his experiences both within ISOQOL and with these other organizations give Michael a unique perspective to bring to Board discussions. Michael looks forward to the opportunity to contribute to ISOQOL's growth and development by serving as a member of the Board.

Henrica de Vet

Henrica CW de Vet is professor in Clinimetrics and works in the Department of Epidemiology and Biostatistics, at the EMGO Institute for Health and Care Research, VU University Medical Center (VUmc), Amsterdam. She is clinical epidemiologist by background.



Education

She teaches courses in Clinimetrics for Master students of the Faculty of Medicine and Health Sciences, and for PhD students and clinical researchers.

She also teaches courses on the methodology of systematic reviews of RCTs, diagnostic and prognostic studies.

Research

She designed and supervised a large number of RCTs on low back and neck pain and other musculoskeletal disorders. In this field patient reported outcomes and quality of life are the most important outcomes. Lately she got involved in measurement of quality of life and quality of care in patients at the end of life. She is a consultant in many projects within the EMGO research programs on Musculoskeletal Health, Mental Health, Diabetes and Overweight, and Quality of Care.

Her main focus is on Clinimetrics, and especially on the evaluation of existing measurement instruments with regard to reproducibility, responsiveness and assessment of minimal important changes. She is involved in the development of new methodology to perform systematic reviews on measurement instruments. She supervises the COSMIN study (COnsensus-based Standards for the selection of health Measurement Instruments): an international Delphi study with the aim to achieve consensus on method guidelines for the evaluation of PRO instruments.

She is first author of a number of educational papers on Clinimetrics.

She is an active member of the Cochrane Collaboration contributing to various Cochrane Musculoskeletal Groups. But her main interest is in the methodology of systematic reviews, being member of various Cochrane Methods Groups: the PRO Methods group, the Methods group on Meta-analysis of Diagnostic and Screening Tests, the Economic Methods group, and convenor of the Prognosis Methods group.

She is member of the Dutch Health Council and was president of the Netherlands Epidemiological Society. She was Associate Editor of *Quality of Life Research* (2006-2007) and is member of the Consultant Board of the *Journal of Clinical Epidemiology*.

As Board member, she would like to initiate more regional ISOQOL societies in Europe, to improve the methodology of outcome measurements, and implement the knowledge about quality of measurements in the medical field. Furthermore, by discouraging the development of new measurement instruments for fields where many instruments are available and by motivating professional groups to choose their best measurement instruments, she wants to stimulate more uniform measurements of outcomes in a specific field, which makes results of research more comparable. A nice example of this is OMERACT, that made a core set of outcome measures to be used in the various types of rheumatologic disorders.

She would also like to help ISOQOL to promote high methodological standards, e.g. through educational papers, guidelines, and other activities, to maintain and improve the quality of QOL research.

Joanne Greenhalgh

Dr. Joanne Greenhalgh is a Senior Research Fellow at the School of Healthcare, University of Leeds. She has a background in psychology and public health and has worked in the area of patient reported outcomes (PROs) since 1995. Her research interests centre on the application of PROs in clinical practice, patient centred care and the use of qualitative research methods in the development, assessment and application of PROs. When she is not at work, Joanne is happily kept very busy looking after two young children. If she does get the time (!) she enjoys photography, singing and eating out.



Joanne started her career in PROs working for the UK Clearing House on Health Outcomes which aimed to assist clinicians and health commissioners to choose appropriate PROs to use within routine practice. Her doctoral work, funded by the Medical Research Council, involved the development and validation of a symptom diary for people with multiple sclerosis. She received an early career investigator award for her presentation on aspects of this work at the 2003 ISOQOL conference. Since gaining her PhD, Joanne has explored how clinicians actually use and make sense of PROs in clinical practice and has conducted a number of studies in this area. These have included a qualitative study of how neurorehabilitation teams use outcome measures within multidisciplinary meetings to inform patient care and secondary qualitative analysis of Velikova et. al's (2004) data to explore of how oncologists use HRQoL data in their consultations with patients. During her career she has published several papers in this area in both clinical and academic journals.

Joanne has been an active member of ISOQOL since 1999 and has contributed to the society in several ways; through presenting oral presentations and posters at numerous ISOQOL conferences, acting as a reviewer for *Quality of Life Research* and co-chairing the Abstracts Review Committee for the 2003 ISOQOL meeting in Prague. Most importantly, she has been chair of the Membership Committee for the last two years and has helped the Board to explore trends in membership and implemented a number of strategies to enable ISOQOL to attract new members and maintain existing ones.

During her time on the ISOQOL Board, Joanne will continue to address the issue of responsiveness to current and potential members' needs in order to ensure that ISOQOL continues to grow and remain at the forefront of this field. One of ISOQOL's great strengths is the diversity of its membership but we could do more to reach out to key stakeholders in clinical practice, policy, industry and patients themselves. Joanne would also like to promote a mixed methods approach to the development, assessment and application of PROs. Qualitative methods can shed light on the meaning of the measurements that PROs generate, as well as understanding how and why they might make a difference to clinical practice.

Kathy Wyrwich

Dr. Wyrwich is a Senior Research Scientist with the Center for Health Outcomes Research at United BioSource Corporation headquartered in Bethesda, MD. Kathy completed her graduate work in health services research at Saint Louis University in 1999. She holds adjunct faculty appointments in the Departments of Research Methodology and Health Services Research at Saint Louis University, and has many publications and book chapters on quality of life measurement and health status assessment.



Kathy has experience in designing and conducting studies involving health-re-

lated quality of life assessments, evaluation, health services research, psychometrics and clinical trials from a health outcomes perspective. A key research interest is the development and application of methodologies to study change in health outcomes and the determination of relevant thresholds that identify important changes over time.

A member of ISOQOL since 1998, she is currently Chair of ISOQOL's Education Committee. Kathy has served as Editor of the Society's Newsletter from 2005-2008. She has also headed the Mentor/Mentee Program in 2002 and 2003, as well as the Young Investigators portion of the Orlando and Prague Annual Meetings. She has served on the meeting planning committees for several Annual Meetings and ISOQOL's 2004 Scientific Symposium in Boston. She is also a member of the ISOQOL Industry Advisory Committee.

Kathy hopes to promote life-long learning opportunities as a continued and valued component of ISOQOL's organizational activities. She credits much of her own professional development to the continual encouragement, constructive scientific challenges and sincere collegiality provided by members of the Society, and as a Board member she hopes to instill and maintain these values as ISOQOL continues its organizational growth.

Communicating closely with research partners across the globe, Kathy conducts most of her research activities from her office in the 102 year old St. Louis, Missouri home that she and her husband John have been renovating for over 30 years. They have four grown children: Tom, a law student at the University of Washington in Seattle; Matt, an energy engineer in Milan, Italy; Luke, a herpetologist at Zoo Atlanta (Georgia); and Mary, a senior in management at the University of Missouri-Columbia.



OAY, from page 3

The Nominations Committee was of the unanimous view that the paper by Dr. Westerman and colleagues was a winner. It used excellent science to study an important, clinically meaningful question of clear relevance to people with a terminal illness, written in a style equally accessible to a non-scientific audience, and which lifted the lid on what actually happens when patients respond to questionnaires about their quality of life. Their findings also address the limitations of items in patient-reported questionnaires in capturing the actual experience of terminally ill patients, as well as the resilience of such folks in the face of adversity. And isn't the title something even your Mom could understand? So, forget the great debate in current journals about whether *declarative sentences as titles*, held by many to be the choice of "hard" scientists, is the true test of real science; give your titles the "Could my Mom understand this" test.

Again, our warmest congratulations to Dr. Westerman and her colleagues for a superb paper!

Previous Recipients of the Outstanding Article of the Year Award

Dr. Westerman and her colleagues join an illustrious group of researchers who have been past recipients of the Article of the Year Award. Previous recipients include:

2007: 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.

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 health related quality-of-life (HRQOL) domains during treatment.** *Qual Life Res.* March 2006; 15 (2): 273-283.

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** *JClinOncol.*, Volume 23, Number 28, October 1, 2005.

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.

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.

Thinking Ahead....

Just a reminder that as you are perusing the monthly issues of this year's *Quality of Life Research* journal, keep in mind possible nominations for the 2009 Article of the Year Award. The call for Nominations will be issued in early summer 2010, so there is plenty of time to consider your favourites for the 2009 award.

MEMBER NEWS

UMass Medical School Appoints John Ware Chief of Outcomes Measurement Science


John E. Ware, Jr., PhD, has been appointed Professor and Chief of the Outcomes Measurement Science Division in the newly-formed Department of Quantitative Health Sciences (QHS) chaired by Catarina Kiefe, MD, PhD, at the University of Massachusetts Medical School (UMMS) in Worcester, MA. QHS is collaborating with clinicians and basic scientists to shorten the time between advances in methodological research and their clinical applications. Dr. Ware's division, which is standardizing and improving patient-based measures of health status and outcomes, is recruiting to fill: tenure-track faculty positions at all levels from assistant professor to full professor as well as research assistant/associate positions and is also offering public/private research opportunities in affiliated organizations. Researchers interested in working with Dr. Ware and his team are encouraged to send a brief bio and current CV to the attention of Angela.Grubert@umassmed.edu.



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NEW INVESTIGATOR AND STUDENT AWARD WINNERS

Bryce Reeve, PhD

The future of health-related quality of life (HRQOL) research lies with our students and new investigators. The International Society for Quality of Life Research (ISOQOL) embraces their contributions each year by recognizing their outstanding work presented at the annual conference.

This year, ISOQOL was honored by hosting over 25 oral presentations and 50 poster presentations from students and new investigators. Their work expanded our knowledge and abilities in HRQOL research to inform decision making in healthcare practice and policy. Each year, ISOQOL awards the top student and new investigator in the categories of oral and poster presentations with a \$300 prize, an ISOQOL certificate and complimentary entrance to the Awards Banquet.

The list below shows the top candidates for each of the four awards. Each candidate was judged on the criteria of originality, scientific quality of study design, data analysis and interpretation of results, and quality of presentation.

At the final program dinner, ISOQOL announced the winners and handed out awards to **Caitlyn Wilke** (best student oral presentation), **Willi Horner-Johnson** (best new investigator oral presentation), **Francisco Lopez** (best student poster presentation), and **Phantipa Sakthong** (best new investigator poster presentation).

Congratulations to the awardees and to all the candidates for an outstanding showing at ISOQOL. We hope to see you and other student and new investigators at next year's ISOQOL meeting as you expand on your exemplary work.

Top Candidates for Student and New Investigator ISOQOL Awards

Student (Oral Presentation)

T.P. Elegance Lam, MA
University of Hong Kong
The effect of HRQOL on health service utilization and willingness to pay for treatment of Chinese with chronic hepatitis B infection

Veronika Ottova, MPH
University Medical Center Hamburg-Eppendorf
The impact of obesity on the HRQOL in children and adolescents – results from the European KIDSCREEN survey

Lixin Song, PhD
University of Michigan
Using multilevel modeling to analyze a longitudinal study of couples' QOL and related factors in prostate cancer

* Caitlyn Wilke, MS
University of Illinois at Chicago
Comparison of Patient and Proxy EQ5D Ratings Using Parametric and Nonparametric IRT Approaches

New Investigator (Oral Presentation)

* Willi Horner-Johnson, PhD
Oregon Health & Science University
Psychometric properties of a function-neutral measure of HRQOL

Francesca Martinelli, MSc
EORTC
A symptom index for cancer patients based on the EORTC QLQ-C30

Sandra Nolte, BBA, PhD
University of Melbourne
Tests of measurement invariance suggest weak psychometric performance of

"then-test" data
Lan Yu, PhD
University of Pittsburgh
Linking the PROMIS Depression Scale with the CES-D, BDI, & K-SADS

Student (Poster Presentation)

* Francisco Lopez, BA
University of Buffalo
Positive aspects of QOL in childhood cancer patients: a structural analysis

Denise Mercurio-Riley, MS
University of Buffalo
Resilience in caregivers of persons with chronic pain

Chinekwo Obidoo, MS
University of Connecticut
How does the SF-36 perform in healthy populations? A structured review of longitudinal studies

Shahnaz Shahrabian, MA
McGill University
Self-reported health and symptoms explains walking capacity in people with Multiple Sclerosis (MS)

New Investigator (Poster Presentation)

Thomas Atkinson, PhD
Memorial Sloan-Kettering Cancer Center
Confirmatory factor analysis to evaluate construct validity of the Brief Pain Inventory (BPI)

Martin Duracinsky, MD, MSc
Hospital Kremlin Bicetre
Differences in HRQOL across cultures measured by the PROQOL-HIV, a new specific instrument

* Phantipa Sakthong, PhD
Chulalongkorn University
Health-related quality of life and health utility in Thai patients with peritoneal dialysis

* received best presentation award

THE 2009 ANNUAL CONFERENCE: “WAY DOWN YONDER IN NEW ORLEANS”

Michael Brundage, MD, MSc & Claire Snyder, PhD

New Orleans musicians from Louis Armstrong to Harry Connick, Jr., have sung the classic “Way down yonder in New Orleans, In the land of the dreamy scenes, There’s a garden of Eden...you know what I mean.” The over 450 attendees who participated in this year’s annual meeting do indeed know what they mean.



The meeting kicked off with the Welcome Reception. Attendees snacked on gumbo, muffalattas, jambalaya, and more, while catching up with old friends and making new ones. With Mardi Gras beads for everyone and a live jazz trio playing in the background, the meeting got off to a festive start. But before the formal meeting could begin, it was necessary to orient everyone to the unique phrases common to New Orleans natives. Thursday morning, attendees learned how to greet each other with “Where y’at?” And respond with “Awrite!”

With that orientation complete, everyone turned to the academic program, focusing on the theme “Integrating HRQOL in Health Care Policy, Research, and Practice.” Each day we started with a plenary session addressing one aspect of the theme: *Patient-reported Outcomes for Adverse Symptom Reporting in Clinical Trials*, *Using Self-reported Measures to Assess Population Health*, and *Patient-reported Outcomes to Evaluate the Quality of Health Care Delivery*. With guid-

ance from ISOQOL planning committee members and moderators, our distinguished panel of plenary speakers raised important issues and generated significant discussion.

In addition to the plenary panels, attendees heard from then-President Neil Aaronson, who reminded us to find the right balance between scientific critique and a collective scientific mission. Ron Hays, this year’s recipient of the President’s Award, took us through a photo album of previous scientific meetings. This year’s business meeting featured remarkable performances by Rick Berzon and Dennis Revicki engaging in an ISOQOL sanctioned debate entitled

ISOQOL Parties on Halloween
in New Orleans.



“Intellectual property considerations in developing and using HRQL measures: Fee or free?” The scientific content of the meeting was rounded out by a number of excellent poster and oral sessions, symposia and workshops. Finally, ISOQOL’s many active special interest groups and committees met during lunchtimes and breaks. Anyone who’s interested in getting involved in these ISOQOL activities is encouraged to visit the website and join (www.isoqol.org).

The social subcommittee made sure that the fun continued when the scientific sessions ended. Attendees received a locals’ guide to dining in New Orleans, as well as a list of top tourist attractions. The conference dinner at the Musée Conti Wax Museum gave ISOQOLers the opportunity to celebrate the conclusion of a successful meeting – and Halloween. To get into the spirit of the evening, folks wore masks and costumes and competed for prizes. The wide variety of costumes and masks proved that ISOQOL’s creativ-

ity doesn’t end with our science. The evening culminated with dining and dancing — Louisiana style.

Naturally, being hosted in New Orleans, we were reminded of Hurricane Katrina and those in the city and surrounding areas still trying to recover their quality of life. To help support the city, this year’s conference bag was a backpack, and attendees had the option of donating theirs to school children in need at the end of the meeting. Our “ISOQOL Gives

*“Thanks for helping
to rebuild public
education in New
Orleans!”*

--- New Orleans School Superintendent
Darryl Kilbert

Back(packs)” campaign donated several large boxes of backpacks. This philanthropy was complemented by Mapi Values, who donated boxes of school supplies to accompany the backpacks. Upon receipt of this generous donation, school superintendent Darryl Kilbert wrote “Thanks for helping to rebuild public education in New Orleans, Louisiana!”

On a personal note, we want to thank the over 70 planning committee members who worked so hard to make the conference a success. Special thanks to Sarah Shiffert, Christine Lusk, and Degnon Associates for their superb professional support. We look forward to seeing everyone again in 2010. As penned by the English Rock Band *The Clash* – “Now get this - London calling!”



President, from page 1

The most difficult issue that faced the board this year was to approve a deficit budget for 2010. When the budget is prepared we are generally very conservative, underestimating income and overestimating expenses, so hopefully the actual deficit will be small. There were three major contributors to projected deficit. The first will be a one time expense associated with the transition to a new management team at the end of 2010. The second is the increased compensation for the Editor-in-Chief of our journal, *Quality of Life Research*. After considerable research and discussion, we agreed that the proposed compensation was fair and in line with similar journals. Finally, we have what will probably be a one-time opportunity to have our annual meeting in London. We have negotiated a fantastic deal for the meeting, but it will still be more expensive than our past locations and the projected net income less.

Strategic Planning for Education: During the spring, the ISOQOL Board meets for two days. One of those days is typically reserved for strategic planning. In past years, we have considered a broad array of issues. This year I would like to focus our work specifically on education. I have made this choice because it is our strength and the benefits can spill over to other important areas such as fundraising, outreach and name recognition of ISOQOL. With a strategic plan, ISOQOL can be proactive rather than reactive. We have many educational initiatives, including annual meeting workshops, the HRQoL Dictionary and the continuing education program. One of our tasks will be to evaluate our ongoing projects to determine which are of value and where there are gaps. ISOQOL can then move forward to fill in the gaps and focus our energy and resources on projects that will benefit the HRQoL research community.



ISOQOL DICTIONARY PROJECT

Nancy Mayo, PhD

Following is information on a new ISOQOL project.

Working Title: Dictionary of Quality of Life and Health Outcomes Measurement

Overview: The goal of this project is to develop a *Dictionary of Quality of Life* (name not finalized). Currently, a single source does not exist that includes definitions of the terms that form our theory, science and use. This need is particularly important for individuals (clinicians) reading our research and new investigators to the field. We are aiming to publish a stand-alone book and have an ongoing interactive database of terms that ISOQOL members can access. We are targeting approximately 1000 to 1500 terms, some of which will have multiple definitions. The project will have multiple steps and we want as many people as possible to participate to enrich the content. This is an ISOQOL project designed to benefit the society; all proceeds will be donated to the society.

Generation of terms: The first step will be to generate the terms that will be included in the dictionary. A concept map will be developed to organize the terms and facilitate the matching of editors, definition contributors and terms. The next step will be to solicit candidate terms from multiple sources. The first source will be the ISOQOL membership. The second source will be an analysis of terms used in our journal, *Quality of Life Research*. The entire list of terms will be reviewed by the executive editors.

Generate of definitions: Within each content areas, a team will be formed to identify contributors for the candidate terms. We intend to ask the contributors to supply definitions for approximately 10 terms each. Where applicable, the source of the definition will also need to be identified.

Publication: We are currently exploring

publications outlets, including electronic digital publishing that would accommodate both an e-book version or print on demand as well as access through publishers such as Amazon. Any income generated from the sale of the book would accrue to ISOQOL.

Ongoing Wikipedia-like dictionary: We are also exploring ideas for developing an ongoing database of terms and definitions which could be continuously updated. This database would be available to members of the society.

Executive: Nancy Mayo, Sara Ahmed, Rob Arbuckle, Ruth Barclay-Goddard, Susan Bartlett, Cindy Gross, Diane Fairclough, Lena Ring, Rick Sawatzky, Jane Scott, and Sharon Wood-Dauphinee.



Translating Quality of Life Measurement into Decision Making

17th Annual Conference
October 27-30, 2010
*Hilton Metropole
London, England*

Call for Abstracts
available soon at
www.isoqol.org!

Deadline for workshops:
April 2
Deadline for regular abstracts:
May 12

LOOKING FORWARD TO LONDON: ISOQOL 2010

Stefan Cano, PhD & Jane Scott, PhD

With fond memories still fresh in our minds of the success that was ISOQOL 2009, we now look ahead to next October's conference to be held at London's Hilton Metropole Hotel. We were both delighted to be asked to take on the co-chair torches from Claire Snyder and Michael Brundage, who did such a fantastic job chairing the meeting in New Orleans. So, with some trepidation about 'keeping up the good work', but at the same time lots of excitement for the potential for the London conference, we wave farewell to the Saints of New Orleans and hello to Paddington Bear!

For those unaware of this mysterious little bear, he is an English children's literature icon. And as you arrive through Paddington's station, en route to the conference hotel, you will see him on the concourse. So, please take time to *doff your cap* to this little bear with his old bush hat and battered suitcase. And like many of the locals that we hope you will enjoy meeting, he is always polite, well-meaning (though he inflicts hard stares on those who incur his disapproval!) and likes marmalade sandwiches and cocoa!

We are excited that London was selected as the next year's city. Set along the banks of the Thames, the old Roman settlement has grown into Europe's largest city, with more than 7.5 million inhabitants. From humble beginnings has grown a cosmopolitan city that has witnessed numerous kings and queens, skirmishes and scrapes, and heroes and villains. Its colourful past makes London a wonderful and varied city of people, events,

and landmarks. It, therefore, has lots to offer everyone, and the only problem is going to be trying to fit in all the sightseeing and the science.



In terms of the scientific meeting, we are now under starter's orders and are starting to piece together the event details. From the scientific sessions you can expect to see talks and discussions on the key topics of the day, ranging from the recently finalised FDA guidance document, through a UK perspective on patient reported outcomes, government and industry opinion on quality of life measurement, and the new and exciting scientific progress in developing and testing quality of life measures. From a social perspective, we hope that you make the most of your time to visit the countless attractions and places of interest. In keeping with the Paddington Bear fictional character theme, you will be able to visit Sherlock

Holmes' digs on the way to Harry Potter's famous platform 9 ¾ before a quick trip down the Thames to see where Oliver Twist ducked and dived. Or you may instead be more interested in the creators of fiction and fancy visiting to William Shakespeare's Globe or Charles Dickens House. Whatever your interest, literary or otherwise, we will be putting together materials that will help you successfully navigate the metropolis.

So, that's it for now. Except to note that we are very much on the look-out for ISOQOL members who are willing to lend a hand (or two) to ensure next year's event is a good as this year's. If you would like to help out please contact Sarah Shiffert (Sarah@degnon.org) and let her know what you would be happy to do. We will be keeping members updated as we get closer to ISOQOL 2010.



Visit www.ISOQOL.org for more details and registration information.

ISOQOL MEMBERSHIP BENEFITS

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

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

ADVERTISING RATES

ISOQOL Members:

1st 10 lines - no charge
11 or more lines - \$10/line

Non-Members:

1st 10 lines - \$150.00
11 or more lines - \$10/line

Each line contains approximately 36 characters and spaces; this figure is an estimate only; advertisers will be charged based on the actual number of lines printed in the newsletter. If you have any questions, or if you wish to advertise a position opening, please contact the ISOQOL Executive Office.