

Quality of Life

QUARTERLY

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PRESIDENT'S MESSAGE

Galina Velikova, MD; University of Leeds



Dear ISOQOL Members,

This is my first opportunity as the new ISOQOL president to share with you, the society members, my thoughts. I wish to thank you all for trusting me to be your leader in the next 2 years. I am excited to take on this task and keen to serve the society to the best of my ability. I recognize the challenges ahead of us. Thanks to our prior president, Bryce Reeve, the EDI staff support and the hard work of the Board in 2013, we now have an ambitious, but exciting, strategic plan. My challenge is to inspire each and every member of the society to contribute to its implementation. I firmly believe that working together we can increase the impact and influence of our society.

Our recent annual conference was a true demonstration of the diversity within our society and its great potential. We have members who are

psychometricians, working to make statistics come alive for clinicians. We have clinicians who work to explain to the psychometricians what data is needed to allow them to improve patient care. We have patient advocates working on behalf of all patients, bringing a personal voice to healthcare. We have researchers working within the pharmaceutical industry, helping to bring new products to market in the hopes of improving patients' quality of life. We have academic researchers, and teachers who educate the future leaders in our field. And finally, we are proud to welcome each year many young PhD students who bring "new blood" and enthusiasm to the society.

Managing the unique needs of each of these groups can be challenging at times. We must identify ways to incorporate a variety of topics into our educational programs. In order to do this effectively, we provide our members with the opportunity for engagement through SIGs and committees. As you renew your dues for

Continued on page 2.

VOLUME 19 ISSUE 4

*Newsletter for
ISOQOL Members*
FALL 2013





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

Newsletter Editor

Ana Popielnicki, BA, USA

Send articles with subject line addressed "Newsletter Submission" to:
info@isoqol.org

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President's Message, Continued from page 1.

2014, you will find an opportunity to join a SIG on your dues renewal form. Please consider joining a SIG and becoming engaged with the society. The SIGs will play an active role in the work on the various tasks of our strategic plan and in the planning for the 2014 annual conference.

Four hundred and sixty delegates attended the conference in Miami, making it one of the most successful meetings of our society. I would like to congratulate David Eton and Simon Pickard for putting together an outstanding conference program, celebrating the 20th Anniversary of ISOQOL. Thank you both and the other members of your committee for the time and thoughtful process you undertook in planning the stimulating educational sessions and lively interactions. The memorable fun session with the past presidents will stay with us for long time.

Nearly 200 of our conference attendees responded to the online survey evaluating the conference, providing some excellent suggestions for future conferences. Ninety-two percent of the respondents were "satisfied" or "very satisfied" with the oral sessions

and 94% indicated that they are likely to attend future conferences. Many thanks for taking the time to share your experiences and ideas. We are providing your detailed feedback to the conference committee chairs for the next ISOQOL annual conference in Berlin.

On behalf of the Board of Directors, I would also like to thank our sponsors and exhibitors for their support of our society. We look forward to an ongoing partnership with you.

As I begin my term as President of ISOQOL, I welcome your comments and feedback on the direction of the society. Please feel free to reach out to me directly at g.velikova@leeds.ac.uk or through our Executive Director, Rebecca Brandt, at rbrandt@isoqol.org. I look forward to the next two years and serving you as President.

Best Wishes,

Galina Velikova, MD
President 2013-2015
ISOQOL



FROM THE EDITOR'S DESK

By: Ana Popielnicki



Dear ISOQOL Family:

I am pleased to welcome you to the last 2013 issue of our *Quality of Life Quarterly*. It has been

a rich, fulfilling year for our society, and I hope you have enjoyed our quarterly newsletter as much as we have enjoyed bringing it to you. This final issue of the year is full of interesting information, remembrances and plans for the future, and many ways to get involved.

Dr. Galina Velikova brings us her first President's Message, reflecting on ISOQOL's strong strategic plan and emphasizing how the ISOQOL family, with its rich diversity, individual member contributions, and strong sense of team efforts will ensure this plan comes to fruition.

It was a pleasure seeing so many friends and colleagues – and meeting new ones – at the Annual Conference in Miami last month! Those of you who were there will relive many great moments, and those who weren't will for sure enjoy learning about them in our Meetings and Membership Manager's recap of the 20th Anniversary meeting. In addition to all the usual fun activities, Heather Vitale provides key statistics about attendees and posters/presentations, and touches on standout sessions throughout the conference. Also listed are the winners of the Student and New Investigator Awards, the President's and Emerging Leader Awards, and the Outstanding Article of the Year Award.

Speaking of articles, outstanding, and research, please check out the list

of all articles nominated for AOYA 2012 in QoL Research, as well as a list of the top ten downloaded journal articles, brought to you by your friendly journal editors, Drs. Carolyn Schwartz and Dennis Revicki.

My fellow Ibero-Americans, and ISOQOL Whole World Members: All the way from Argentina, Dr. Cristina Pecci has contributed with a description of the Parkinson's Disease Program being offered at the University of Buenos Aires' Hospital de Clínicas – an interesting and engaging project that showcases the many activities through which our members impact quality of life worldwide. We encourage other members to send us news about their community activities and initiatives for future dissemination!

We have our traditional Calendar of Events for the remaining of the year – since this issue was published later than usual, it is but a mini-calendar, but still very pertinent. Check it out to find many educational and networking opportunities in the November – December Calendar. We welcome any suggestions for 2014 first quarter (or any other quarter, really) – please send us an email with your events for inclusion in future issues.

In terms of announcements and news, please look for several "call for" pieces: The *Quality of Life Research* Journal is asking for papers on Patient Engagement, for a special series on methods of patient engagement in quality of life and patient-reported outcomes research. We are also calling for nominations for the Society's Board of Directors, President-Elect, and Secretary-Treasurer, for the terms beginning in 2014 – Look for details for both announcements in this issue.

Last but not least (I told you this was a full issue!!), we have two awesome articles about our SIGs: The New Investigator already traditional presentation during the Mentor-Mentee reception, Tricks of the Trade – great advice for not only new investigators and students, but for all our members. And our brand new Patient Engagement SIG, which started in a magnificent display with their Inaugural Symposium – I can attest to the incredible amount of fun we all had at their World Café, with the added value of a rich learning experience. Please consider joining this or any of our other special interest groups, and get involved in the excellent work our colleagues are doing all over the world.

Well, you've had enough of me already, and I'm sure you're eager to get to the actual articles. This is our last issue of the year, so to stay informed, please visit our website or contact us directly with questions, comments, or submissions for the 2014 Winter issue – please send your queries/comments to your Communications Committee at info@isoqol.org with "Newsletter" on your subject line.

It's getting colder in these parts of the world, so I will wish you all a great winter (or summer, should you happen to be in, say, New Zealand), and very happy and safe holidays – Enjoy your newsletter!

Ana Popielnicki
Editor



2013 ANNUAL CONFERENCE IN REVIEW

By Heather Vitale, ISOQOL Meetings & Membership Manager

ISOQOL members from around the world met in Miami, Florida for the ISOQOL 20th Annual Conference last month. The conference took place October 9 -12, 2013 at the InterContinental Miami Hotel. The hotel was in the center of vibrant downtown Miami overlooking Biscayne Bay and Bayfront Park.

Scientific Committee Co-Chairs, David Eton, PhD, Mayo Clinic and Simon Pickard, PhD, University of Illinois at Chicago coordinated an excellent program this year, with the theme *Energizing the Science of Quality of Life Research: Where Have We Been and Where Can We Go?*

The conference began in true Miami style with a salsa dance demonstration at the Welcome Reception on Wednesday. We also said, “Adios” to Miami with a live Cuban band and more salsa dancing at the Closing Dinner at Bubba Gump Shrimp, Co. on Saturday evening.

Some standout SIG activity in 2013 included the new Patient Engagement SIG and Quality of Life in Clinical Practice SIG presenting an interactive “World Café” symposium on *Patient and Public Engagement in Health Research*; and the New Investigator SIG joined the Mentor/Mentee Reception to present the “Tricks of the Trade” presentation series as an introduction to the Mentor/Mentee event.

Final conference attendance was **458**, with **148** first time ISOQOL attendees! In April, 412 abstracts were submitted for consideration as oral or poster presentations. These abstracts were carefully reviewed and assembled into the 24 Oral Sessions (114 individual presentations) and 151 Posters presented at the conference.

Among these presentations were several excellent ones from Students and New Investigators. There were four Student and New Investigator presentations that stood out to receive the ISOQOL Student and New Investigator Presentation Awards. Award finalists were determined based on abstract reviews, but the presentations were judged by a panel of volunteer judges to determine the winners.

NEW INVESTIGATOR AWARDS

Oral Presentation: **Ester Villalonga, PhD**, Harvard School of Public Health, Cambridge, Massachusetts, United States

(201.3) Health-Related Quality of Life of Children with Immigrant Backgrounds: Towards a New Pattern in Europe

Poster Presentation: **Jiseon Kim**, University of Washington, Seattle, United States

(1029) Validation of CESD-20 and PHQ-9 Crosswalks to PROMIS Depression in Multiple Sclerosis

STUDENT AWARDS

Oral Presentation: **Kim Nicolaije**, Tilberg University, Tilburg, The Netherlands

(204.2) The Impact of an Automatically Generated Survivorship Care Plan on Patient Reported Outcomes: Results of a Pragmatic Cluster Randomized Controlled Trial (ROGY Care) among Endometrial Cancer Patients

Poster Presentation: **Amélie Anota**, Quality of Life in Oncology Platform, France

(2013) QoLR: An R Package for the Longitudinal Analysis of Health-Related Quality of Life in Oncology

These four outstanding young researchers each will receive a \$300 cash prize.

We also recognized additional outstanding achievements with the ISOQOL President’s Award, the Emerging Leader Award, and the Outstanding Article of the Year Award.

PRESIDENT’S AWARD

Peter Fayers, PhD, Emeritus Professor, University of Aberdeen, Aberdeen, United Kingdom

EMERGING LEADER AWARD

In Honor of Donna Lamping

Roxanne Jensen, PhD, Georgetown University, Washington, DC, United States

OUTSTANDING ARTICLE OF THE YEAR AWARD

Published in Quality of Life Research Journal

Richard C. Gershon and co-authors: Jin-Shei Lai, Rita Bode, Seung Choi, Claudia Moy, T. Bleck, Deborah Miller, Amy Peterman, David Cella

Neuro-QOL: Quality of Life Item Banks for Adults with Neurological Disorders: Item Development and Calibrations Based Upon Clinical and General Population Testing.

Quality of Life Research April 2012, Volume 21, Issue 3, pp 475-486

The final conference session on Saturday, Twenty Years of ISOQOL – A Celebration, was a relaxing plenary session to celebrate the last twenty years of ISOQOL – and to look to the next twenty years of health-related quality of life research. Several of ISOQOL’s past presidents shared

Continued on next page.

their views on the future – and some of their favorite memories and moments during their presidencies.

Conference attendees used social media to enhance their engagement in the conference. Whether it was using the conference Twitter hashtag, #isoqol13 or the ISOQOL Facebook and LinkedIn communities, discussion and photo sharing continued after the conference presentation ended.

Thank you to all who took the time to complete the post conference evaluation. Congratulations to Kim Nicolaije, the winner of the drawing for the Amazon.com gift Card.



2013 Annual Conference Chairs David Eton (left) and Simon Pickard (right) with Plenary Speaker Mihaly Csikzentmihalyi.

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ISOQOL 20TH ANNUAL CONFERENCE



October 9–12, 2013 **MIAMI, FLORIDA, USA**

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Contact Rebecca Brandt, Executive Director to learn how you can support ISOQOL.

OUR MEMBERS AROUND THE WORLD: PARKINSON'S PROGRAM AT UNIVERSITY OF BUENOS AIRES

Cristina Pecci PhD, ISOQOL Member

Today in healthcare we are challenged to incorporate more specific practices associated with the quality of life of our patients; to pay attention to patients' concerns and expectations, and to explore the different dimensions and limitations of Parkinson's disease.

Parkinson's disease (PD) is a degenerative neurological disorder characterized by cognitive, behavioral and mobility problems. The most common symptoms are slowness, rigidity, postural instability and resting tremors. The impact on quality of life is mainly observed in the impairment of physical mobility, emotional distress, social isolation, loss of autonomy and independence, and depression. In recent years, there has been significant progress in the development of HRQoL measures designed to evaluate and quantify the quality of life of patients and their families.

For the quality of life of our patients in the Parkinson's Program at the University of Buenos Aires' Hospital de Clínicas, we conduct a set of interconnected activities that are complementary to medical treatment. These activities are intended to offset some

of the negative impact that often results when medication is only partially effective. For example, we try to prevent the worsening of difficulties in writing (especially handwriting) in the Writing Workshop given by a team of graphologists; or, we try to offset the decline in vocal volume or the increase in the difficulty of articulating words in a Voice Workshop given by speech therapists. During these workshops, we are assessing HRQoL with a PD-specific questionnaire, and comparing the data with improvement indicators for writing and phonology.

Many patients do not know what PD is when they are diagnosed. For this reason, other important objectives of our work are: to accompany the patient in the early stages of the process after receiving the diagnosis (psychological support) and to facilitate access to reliable healthcare information on PD and its treatment. Since 1998, there have been informational meetings open to the community and made public by the Press and Institutional Communication department at the Hospital. These meetings help clarify general aspects

Continued on next page.

THE PARKINSON'S PROGRAM IN THE HOSPITAL DE CLÍNICAS AT THE UNIVERSITY OF BUENOS AIRES



Tango classes for patients



Parkinson's Day –April 2013: Aula Magna Hospital de Clínicas



of PD, and there are health professionals available to answer questions about patient or family concerns in simple, everyday language. We also officially observe Parkinson's World Day on the date proposed by the World Health Organization, in efforts to raise social awareness about chronic debilitating diseases, and fight against discrimination.

There are other beneficial activities as well. To help with physical development we have a tango workshop, a body language workshop, an exercise group, and a Pilates room. For nutrition, we have a healthy eating workshop, and for better living: a workshop for family caregivers. We provide technology assistance for older PD patients in a "digital inclusion" workshop so they can stay in touch through our Communication Bulletin for People with PD, which we edit and publish electronically once a month. Finally, the contact between the patients and their peers in all these active groups is educational: They share experiences and different ways of coping with the disease and its limitations. We provide a place where our patients can find the courage not to isolate themselves from others due to this illness.

We believe that the systematic integration of HRQoL practices and measurements in health care promotes adherence to treatment and helps to improve doctor-patient-community-institution relationships.



Tango classes for patients



Writing workshop



Physical exercises



"Body language workshop"



"Digital inclusion" workshop



CALL FOR PATIENT ENGAGEMENT PAPERS

The Editors of *Quality of Life Research* are planning a special series on **methods of patient engagement** in quality of life and patient-reported outcomes research. We are seeking papers that exemplify excellent science on various methodologies or topics, including but not limited to:

- Cultural factors in patient engagement;
- Models for involving patients as agents as well as subjects in research;
- The use of health IT applications (including smartphones, text messaging, social networking, and email) in patient-reported outcomes research and the impact of such on outcomes related to health, provider-patient communication, adherence, etc.;
- Systems Science models of patient engagement in patient-reported outcomes research; and
- Patient engagement in clinical trials and other studies involving patient-reported outcomes.

Eligible papers must have a clear, well-thought out patient-reported outcomes component.

To participate in this call, please submit a **letter of intent** with draft title, contact information and institution for all co-authors, and abstract (250 word maximum). A subset of these letters of intent will be invited for full manuscript. We expect to publish 4-6 manuscripts.

Anticipated timeline:

Letter of Intent	January 31, 2014
Manuscripts invited based on screening of letters of intent	February 28, 2014
Manuscripts due	May 2, 2014
Anticipated publication of special section	Late Fall 2014

Please email to: Carolyn Schwartz (carolyn.schwartz@deltaquest.org) and Dennis Revicki (dennis.revicki@evidera.com).

Deadline for submission of Letter of Intent: January 31, 2014



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To apply, submit a letter of interest (referencing PVL 74845), CV and contact information for three references to F. Javier Nieto, Chair, Department of Population Health Sciences, 610 Walnut Street, 707 WARF, Madison, WI 53726 or by email to fjnio@wisc.edu. Review of applications will begin November 1, 2013 and will continue until the position is filled. For full consideration, complete applications must be received by December 1, 2013. For a complete description, please see: <http://www.ohr.wisc.edu/PVL74845>.

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CALENDAR OF EVENTS—NOVEMBER

- **Nov 25 - 27**
Practical Methods for Health Economic Evaluation
Melbourne, Australia
<http://blogs.unimelb.edu.au/sph-shortcourses/2013/08/14/practical-methods-for-health-economic-evaluation/>
- **Nov 27**
The Identification and Review of Evidence to Inform Cost Effectiveness
Sheffield, UK
http://www.sheffield.ac.uk/scharr/shortcourseunit/courses_new/modelling

CALENDAR OF EVENTS—DECEMBER

- **Dec 3**
3:00 – 4:30 EST
Symptom Management Concept Design Webinar
Presented by the National Cancer Institute Symptom Management/Quality of Life Steering Committee and ISOQOL Online
Register Here: NCIWebinarQoLPROs@mail.nih.gov
- **Dec 3**
Patient Reported Outcome Measures (PROMs) research conference
London, UK
<http://www.kingsfund.org.uk/events/patient-reported-outcome-measures-proms-research-conference-0>
- **Dec 3 - 5**
A “How To” on Deriving Patient Utilities Webinar
Online
<http://www.evidera.com/expert-perspectives/webinars>
- **Dec 3 - 5**
Method Development and Validation
Philadelphia, PA, USA
http://www.cbnet.com/conference/pi13022a#.UkQ_xKwudhw
- **Dec 4 - Dec 5**
HTA World Europe 2013
London, UK
<http://www.healthnetworkcommunications.com/conference/health-technology-assessment/index.stm>
- **Dec 9 - 10**
5th Annual Diagnostic Coverage and Reimbursement Conference
Boston, MA, USA
http://www.q1productions.com/conferencepost/4th-annual-diagnostic-coverage-reimbursement-conference/?utm_source=mediapartner&utm_medium=socialmarketing&utm_campaign=2154#.UkQ-Zqwudhw
- **Dec 9 - 10**
Value Pricing for Market Access 2-day Course by Gary Johnson, Founder & CEO of Inpharmation.
Brussels, Belgium
<http://www.celforpharma.com/pharma-management/training/pharma-pricing-course.html>
- **Dec 10 - 12**
Medical Device Market Access Leaders Forum LEADERS FORUM 2013
Berlin, Germany
<http://medicaldevicemarketaccess2013.nextlevelpharma.com/request-agenda>
- **Dec 10**
PRO/HEOR Executive Summit
Philadelphia, PA, USA
<http://www.opalevents.org/p/97/pre-conference-workshop-healthcare-finance-101-for-the-clinical-team>
- **Dec 11 - 12**
Health Economics for Non-Health-Economists
Brussels, Belgium
http://www.celforpharma.com/pharma-management/training/pharma-health-economics-course.html?linkid=minimenu_dates#dates
- **Dec 12 - 13**
Medicare Advantage Strategic Business Symposium
Ft. Lauderdale, Florida, USA
<http://www.opalevents.org/p/76/medicare-advantage-strategic-business-symposium>

ARTICLES NOMINATED FOR ARTICLE OF THE YEAR AWARD 2012 IN QUALITY OF LIFE RESEARCH

FIRST PLACE

Gershon R et al. *Neuro-QOL: quality of life item banks for adults with neurological disorders: item development and calibrations based upon clinical and general population testing*. Quality of Life Research April 2012, Volume 21, Issue 3, pp 475-486

SECOND PLACE

Terwee C et al. *Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist*. Quality of Life Research May 2012, Volume 21, Issue 4, pp 651-657

THIRD PLACE

Garner RE, Feeny DH, Thompson A, Bernier J, McFarland BH, Huguet N, Kaplan MS, Orpana H, Ross NA, Blanchard C. *Bodyweight, gender, and quality of life: a population-based longitudinal study*. Quality of Life Research. 2012 Jun; 21(5):813-25. doi: 10.1007/s11136-011-9989-1. Epub 2011 Aug 13. Erratum in: Qual Life Res. 2012 Jun; 21(5):827.

Articles Nominated for Article of the Year 2012 in Quality of Life Research

Bauer M, Leavens A, Schwartzman K. *A systematic review and meta-analysis of the impact of tuberculosis on health-related quality of life*. Quality of Life Research 2012 Dec 12.

Colagiuri, B., King, M. T., Butow, P. N., McGrane, J. A., Luckett, T., Price, M. A., & Birney, D. P. (2012). *A comparison of the FACT-G and the Supportive Care Needs Survey (SCNS) in women with ovarian cancer: Unidimensionality of constructs*. Quality of Life Research, 21, pp. 887-897.

Gundy CM, Fayers PM, Groenvold M, Petersen MA, Scott NW, Sprangers MAG, Velikova G, Aaronson NK. *Comparing higher order models for the EORTC QLQ-C30*. Quality of Life Research 2012; 21:1607-17.

Lau, Agborsangaya, Sayah, Wu, Ohinmaa, Johnson. *Population-level response shift: novel implications for research*. Quality of Life Research 2012; 21:1495-1498.

Nolte, Elsworth, Sinclair, Osborne. *The inclusion of 'then-test' questions in post-test questionnaires alters post-test responses: a randomized study of bias in health program evaluation*. Quality of Life Research 2012; 21: 487-494.

Prior et al. *Influence of chronic disease on long-term changes in physical health*. Quality of Life Research 2012; 21:581-591.

Sajobi et al. *Measures of relative importance for HRQOL*. Quality of Life Research 2012; 21: 1-11.



Richard Gershon receiving the Article of the Year Award from Co-Editors-in-Chief of Quality of Life Research, Carolyn Schwartz and Dennis Revicki



CALL FOR NOMINATIONS FOR THE ISOQOL BOARD OF DIRECTORS

All ISOQOL members are encouraged to submit recommendations for the positions of President-elect, Secretary-Treasurer and Board Members (3). All nominees are required to submit a C.V. and personal statement regarding their vision for ISOQOL. Final nominations will not be due until March 2014. Please consider nominating yourself or another ISOQOL member for one of these important positions. If you have any questions regarding the responsibilities of the positions, please contact Rebecca Brandt, ISOQOL Executive Director rbrandt@isoqol.org or Bryce Reeve, PhD, Nominations Committee Chairperson bbreeve@email.unc.edu.

In addition to the duties listed below, all board members are expected to attend two face-to-face meetings; one just prior to the Annual Conference and a second mid-year meeting. Expenses to travel to the Board meeting not coinciding with the Annual Conference are covered by ISOQOL. Two conference calls are also required, along with any agreed-upon project work.

PRESIDENT-ELECT

The President-elect will assist the President as requested; shall chair meetings in the absence of the President and fulfill other duties as requested; and, will prepare for the duties and responsibilities of the President. The President-elect will chair the Nominations Committee in the year in which there is no Immediate Past-President on the Executive Committee. As a member of the Executive Committee, the President-elect is expected to participate in a monthly teleconference and be available for regular e-mail exchange.

The President-elect will serve a one-year term (2014-2015) beginning in October 2014. The President-elect will assume the Presidency at the 2015 Annual Conference and will serve a two-year term as President (2015-2017). Upon completion of the term as President, a one-year term as Past-President will be served (2017-2018) on the Board of Directors and as a member of the Executive Committee.

SECRETARY-TREASURER

To continue development and implementation of policies of fiscal responsibility that ensure ISOQOL's ability to implement its mission and strategic plan, and to participate as a member of the Executive committee with the same objectives. This is a three-year term (2014-2017), non renewable.

Prior to the mid-year Board meeting (typically held between April and May), the Secretary-Treasurer will carefully review the society's financial audit and identify any issues and/or trends that need the Board's attention. He/She will then submit the accountant's report and summary at the mid-year Board meeting. Prior to the annual conference, the Secretary-Treasurer will develop next year's budget with the Executive Director. He/She will present budget for approval by entire board.

The Secretary-Treasurer commits to reviewing the financial statements of the society on a regular basis and to be available to sign checks on behalf of the society in accordance with policy.

BOARD MEMBER

Actively promote the mission of ISOQOL and foster ISOQOL's development through strategic planning, policy making, development, and critical evaluation of ISOQOL's activities. Board members shall serve a term of three years and may not succeed themselves.

Duties of a Board member are:

1. To prepare for and attend Board meetings for the purpose of ensuring the good governance of ISOQOL.
2. To represent ISOQOL members, Special Interest Groups, local chapters or geographic clusters of members at Board meetings, including the raising of new business as required.
3. To undertake, between Board meetings, various administrative and research tasks determined by the Board.
4. To comment on and contribute to the discussion of documents provided at the Board meetings.
5. It is generally expected that Board members take an active role in the annual scientific meeting, for example by acting as peer reviewers of abstracts, chairs of plenary or parallel sessions, judges for new investigator awards, or participants in the mentor-mentee initiative.
6. To volunteer for task forces and special projects to promote ISOQOL.
7. To participate in activities to raise funds and resources for the Society's activities.





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TOP 10 ARTICLE DOWNLOADS IN 2012 FROM *QUALITY OF LIFE RESEARCH*

Title	Author	Volume	Issue	Year	Article Requests 2012
The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A Report from the WHOQOL Group	S.M. SKEVINGTON	13	2	2004	1,514
Qualitative Research And Content Validity: Developing Best Practices Based On Science And Experience	MERYL BROD	18	9	2009	879
The Impact Of Social Isolation On The Health Status And Health-Related Quality Of Life Of Older People	ANNIE HAWTON	20	1	2011	861
Pretesting Survey Instruments: An Overview Of Cognitive Methods	DEBBIE COLLINS	12	3	2003	766
Psychological Insulin Resistance: Patient Beliefs And Implications For Diabetes Management	MERYL BROD	18	1	2009	742
The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study	LIDWINE MOKKINK	19	4	2010	707
Self-report fatigue questionnaires in multiple sclerosis, Parkinson's disease and stroke: a systematic review of measurement properties	ROY ELBERS	21	6	2012	696
Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist	CAROLINE TERWEE	21	4	2012	681
Best Practices In Mixed Methods For Quality Of Life Research	ANN KLASSEN	21	3	2012	678
Post-Traumatic Stress Disorder, Depression, And Health-Related Quality Of Life In OEF/OIF Veterans	JAMES PITTMAN	21	1	2012	658
<i>(Source: SAP / Business Warehouse)</i>					



TRICKS OF THE TRADE IN MIAMI 2013 – NEW INVESTIGATORS SIG EVENT

By Marc Jacobs, Lead Investigator SIG Co-Chair

Following its big success during the previous two annual conferences, the New Investigators event “Tricks of the Trade” was convened again this year, combined with the Mentor-Mentee reception. This year’s panel consisted of Prof. Donald Patrick, Prof. Karen Sousa, and the recipient of the 2012 Emerging Leader Award, Prof. Melanie Calvert, who were invited to talk about their own career development within QOL research; give advice to new investigators beginning to work in this field; and share their views about the future of QOL research.

Prof. Patrick told us that new investigators should start early on thinking about their career, and not be afraid to be flexible. It was often during times of change, and moving to a new place, that Prof. Patrick made his biggest advancements during his career. In addition, he urged new investigators to never stop writing and publish at least 4 manuscripts a year, of which at least two had to be good ones. A final remark was that to advance in this field, one should make sure to have a good spouse to get that much needed support.

Next up was Prof. Karen Sousa, who indicated that doing research is like a journey. New investigators should actively think about their career trajectory and research path, and compare their current status with

future goals. To help facilitate these future goals, new investigators need to be confident, and not be afraid to talk to people and ask for advice. Furthermore, Prof. Sousa urged new investigators to practice their “elevator speech”, which should contain no more than 10 words.

Last, but certainly not least, was the newly appointed professor of outcomes methodology, Melanie Calvert. Prof. Calvert told us that if constant meetings and different views hinder research progress, a new investigator should apply the *JFDI* method. In addition, new investigators need to make sure that they work with people they can learn from. New investigators should also learn to say ‘yes’ or ‘no’. Finally, when that hard work pays off, Prof. Calvert advises to make sure you actively celebrate that success with the team.

Some major tricks that stood out were the following:

First, all three professors agree that you have got to have a gimmick - you have to make sure that you are one of the very few that can do what you do. Second, find yourself a mentor who can help you with research and career issues.

Lastly, make sure you don’t forget you own quality of life - research should first and foremost be fun!



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THE NEW PATIENT ENGAGEMENT SIG STARTED WITH A BANG IN MIAMI: THE INAUGURAL SYMPOSIUM

By Maria-Jose Santana, PhD, SIG Liaison to the ISOQOL Board of Directors

During the Annual Conference in Budapest a group of ISOQOLers suggested the creation of a new special interest group with a focus on patients, a group where patients could be involved and engaged in research activities while collaborating in quality of life research with other ISOQOLers. This is how the patient engagement special group (PE-SIG) was born.

Over the course of last year and with the support of the clinical practice special interest group, CP-SIG, the PE SIG organized a symposium entitled “Patient and Public Engagement Café”. The purposes of the symposium were:

1. To create a space for exploration, for the exchange of international experiences, and for the generation of knowledge that will highlight the challenges and opportunities associated with patient engagement and promote and focus future efforts.
2. To inform the future direction of the new ISOQOL Patient Engagement SIG.
3. To inform the future direction of PE within the ISOQOL community.

The symposium was presented as a world café using the INVOLVE patient engagement approach, where participants were invited to participate in a learning conversation about patient engagement. The café setting provided a fun and enjoyable opportunity to explore together the challenges for patient engagement in quality of life research, describing international experiences. Participants provided their thoughts and suggestions written in sticky labels that were attached to a plain board to conform the “wall of engagement”.

The symposium was led by Drs. Kirstie Haywood and Joanne Brett, chaired by Prof. Sam Salek from the University of Warwick and Cardiff University, respectively. They were joined by the Canadian Team from University of Alberta, Dr. Colleen Norris and members of the University of Calgary, Drs. Nancy Marlett, Svetlana Shklarov, María Santana and Mr. Colin Penman, the patient engagement researcher.

The University of Calgary team invited symposium participants to explore a groundbreaking approach in which patients are rigorously trained and prepared to join collaborative research teams as full partners. The new approach is called Patient and Community Engagement Research (PACER). Patients participate in a one-year intense internship that prepares them to design and conduct health research, using specific adapted methods of qualitative inquiry to capture and analyze patient experiences. (Figure 1)

To date, PACER interns have produced five studies; examples are the exploration of the hidden pathways of chronic illness as experienced by patients with diverse diagnoses, a

case study of engagement through participation at a cancer support wellness centre, and an inquiry into the experience of waiting for help by patients with osteoarthritis. The PACER program is endorsed by the University of Calgary, Institute for Public Health, and actively collaborates with the Alberta Health Services’ (AHS) Strategic Clinical Networks.

The engagement café highlighted that patient and public engagement can occur at various levels of clinical and quality of life care research, from a general patient participation in particular research activities to the full collaboration between patients and health researchers at multiple levels of research design and decision making, in which trained patients conduct research studies and analyze the findings.

The symposium presented, as a world café was a success – data were collected and will be presented as a manuscript. The PE-SIG is ready and willing to collaborate with other SIGs and welcome the participation of patients including having patients presenting at the next Annual conference.



Figure 1.



Symposium organizers and members of the PE-SIG guarding the “wall of engagement”

Left to right: Kirstie Haywood, Joanne Brett, Colleen Norris, Svetlana Shklarov, Colin Penman, Sam Salek, María Santana and the two kneeling are Nancy Marlett and Sandra Beurskens

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ERRATUM — QUALITY OF LIFE RESEARCH JOURNAL ABSTRACT SUPPLEMENT

The following authors were unfortunately omitted from the *Quality of Life Research Journal Abstract Supplement for the 2013 Annual Conference*:

Michael Brundage, MD, Division of Cancer Care and Epidemiology; Dept. of Public Health Sciences, Queen's Cancer Research Institute, Kingston, ON, Canada; **Julie Rouette**, Division of Cancer Care and Epidemiology; Dept. of Public Health Sciences, Queen's Cancer Research Institute, Kingston, ON, Canada; **Melanie Walker**, Dept. of Public Health Sciences, Queen's University; NCIC Clinical Trials Group, Kingston, ON, Canada; **Jane Blazeby, MD**, MRC ConDuCT Hub for Trials Methodology Research, School of Social and Community Medicine, University of Bristol, Bristol, United Kingdom; **Melanie Calvert, PhD**, School of Health and Population Sciences, University of Birmingham, Birmingham, United Kingdom; **Madeleine T. King, PhD**, School of Psychology, University of Sydney, Sydney, Australia; **Paul Peng**, Division of Cancer Care and Epidemiology; Dept. of Public Health Sciences, Queen's Cancer Research Institute, Kingston, ON, Canada; **Jolie Ringash, MD**, Dept. of Radiation Oncology, Princess Margaret Cancer Centre and the University of Toronto, ON, Canada; **Ralph Meyer**, Juravinski Hospital and Cancer Centre, Hamilton, ON, Canada; Presentation (2007) *Oncologists' preferences for presentation of PRO data in randomized clinical trial (RCT) publications: A quantitative assessment* presented in Poster Session 2

Arijit Ganguli, PhD MBA, Senior Manager, AbbVie, Inc., North Waukegan, IL United States; Presentation (209.3) *Responsiveness*

and Minimal Important Difference of the Rheumatoid Arthritis-Work Instability Scale (RA-WIS), presented in Oral Session 209

Michiko Kobayashi, MD PhD, Japanese Society of Quality of Life Research, Kobe, Hyogo, Japan; and **Takashi Mandai, MD PhD**, Japanese Society of Quality of Life Research, Kobe, Hyogo, Japan; Presentation (1046) *Quality Of Life (QOL) Questionnaire For Children And Mothers*, presented in Poster Session 1

Takashi Mandai, MD PhD, Japanese Society of Quality of Life Research, Kobe, Hyogo, Japan, and **Rika Hayashida, MS**, University of Nagasaki, Siebold, Nishisonogigun, Nagasaki, Japan; Presentation (305.2) *Is there any difference on quality of life between hospital doctor and practitioner?* presented in Oral Session 305

Neusa Sica da Rocha, MD, Professor, Hospital de Clinicas de Porto Alegre, Porto Alegre, Brazil Presentation (1060) *Psychotic and Non-psychotic Depression: are there differences in symptom intensity and quality of life among hospitalized patients?* presented in Poster Session 1

Correction:

Presentations (103.3) *Use of PRO data from clinical trials to inform cancer care: an international perspective* and (3018) *Evaluation of the CONSORT extension recommendations for PRO reporting in clinical trials: An international survey of oncologists* incorrectly listed Julie Rouette's affiliation. The corrected affiliation: **Julie Rouette**, Division of Cancer Care and Epidemiology; Dept. of Public Health Sciences, Queen's Cancer Research Institute, Kingston, ON, Canada



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