



International Society for Quality of Life Research

Volume 17 Issue 2

Newsletter for ISOQOL Members

Fall 2011

PRESIDENT'S MESSAGE

Carol M. Moinpour, PhD



We have now had eight months of productive interaction with our new management company, EDI. We encourage you to contact Heather Vitale (HVitale@isoqol.org) for membership or annual meeting questions and Becky Brandt (RBrandt@isoqol.org) for questions about committee activities or other general questions about ISOQOL. The ISOQOL Board of Directors met on March 24th & 25th in Northern

Virginia. We discussed a publication policy for ISOQOL that addresses manuscripts written by individual members with no attribution to ISOQOL, manuscripts written by a task force or Special Interest Group (SIG), and papers where the authors want the content to reflect an ISOQOL policy. The third type of paper requires posting on the ISOQOL website and time for ISOQOL members to provide feedback. Authors then review and incorporate feedback, then submit to the Executive Committee of the Board of Directors prior to submission. An example of such a paper is "The Use of Patient-Reported Outcomes (PRO) within Comparative Effectiveness Research: Implications for Clinical Practice and Healthcare Policy" by Ahmed et al., which was posted on the ISOQOL website in July for member comment. Claire Snyder and colleagues have posted a "User's Guide to Implementing PROs in Clinical Practice" on the ISOQOL website; a summary of this guide may be submitted for publication. A report on another ongoing project ("QOL Reporting Standards in Clinical Trials", by Michael Brundage and colleagues) can be found in this issue of the newsletter.

We are looking forward to our annual meeting this year in Denver, Colorado, USA (Oct. 26th-29th, 2011). The meeting Co-Chairs, Cindy Gross and Karen Sousa, have done a wonderful job organizing it, and we encourage members to attend. There are many interesting workshops, plenary sessions, symposia, and oral/poster sessions; fun activities have not been

forgotten (e.g., the end of conference dinner on Oct. 29th at the Denver Art Gallery). We very much appreciate the Fundraising Committee's efforts led by its co-chairs, Rick Berzon and James Pierce. Many thanks to the meeting Co-Chairs, Drs. Gross and Sousa. In addition to all of their planning and organizing work, they were also successful in a meetings funding request to the NIH (R13 grant).

A new announcement is the location of our 2012 meeting, which will now be held in Budapest, Hungary (10/24-27/2012) instead of Athens, Greece. Sara Ahmed and Fabio Efficace are the 2012 Co-Chairs.

Once again, the ISOQOL Newsletter includes a comprehensive set of reports from chairs of committees and Special Interest Groups (SIGs). Please make sure that you read them to learn what is happening in ISOQOL and how you can get involved.

Many of you are aware of the sad news we have all had to deal with this year. Dr. Donna Lamping passed away June 8, 2011 from advanced stage colon cancer, which was diagnosed in August of 2010. Donna put up a very brave fight but succumbed to this disease at too young of an age. One of her many research areas addressed how patients adapt to the stresses associated with life-threatening disease. A Past President of ISOQOL, Donna was well known for her efforts in developing measures of quality of life and health status, and she was particularly appreciated for her mentoring of young investigators. We

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ISOQOL NAMES NEWSLETTER EDITOR



Ms. Ana A. Popielnicki, BA has accepted the role of Editor for the ISOQOL Newsletter beginning with this issue.

Ms. Popielnicki heads the Linguistic Validation Services Division (LVSD) at American Polygots Partners (APP) a division of Technical Language Services, Inc. that provides translation services customized for limited-English proficient (LEP) audiences living in the US. Born and educated in the Dominican Republic, Ana has over 20 years' experience in clinical psychology, public health and community education. She has worked exclusively in the translation industry for 7+ years.

Ana holds a Bachelor of Arts degree in Clinical Psychology and Psychometrics. She also has post-graduate studies in Higher Education Administration, Project Management and Research.

Prior to moving to the United States in 1997, Ana had her private practice as a therapist in the Dominican Republic. She was also in academia, holding the position of Assistant to the Rector, Administrator of the Faculty of Health Sciences, at her hometown university, Universidad Central del Este. During her 5 years at UCE, she also acted as Director of Mental Health for the Master in Public Health Department, ESL teacher for graduate students on the Health Sciences Faculty, and developed and taught the Industrial

Psychology program for Engineering students. It was also during this period that Ana collaborated with the PAHO/WHO country representatives, as well as the Dominican Ministry of Health, in developing and conducting health education and community involvement projects at a regional level in the Dominican Republic.

Ana has been involved in the LV industry since 2004, when she started working at Corporate Translations, Inc. in Connecticut, USA. She was that company's first trained cognitive debriefer and collaborated in its first publication of LV work, conducting the interviews with over 60 subjects in both English and Spanish (Linguistic Validation of the US Spanish Work Productivity and Activity Impairment Questionnaire, General Health Version).

Ana is actively involved in the quality of life, localization and outcomes research industries. She is a peer reviewer of abstracts for the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and for the International Society for Quality of Life Research (ISOQOL).

Ana is leading the expansion of APP to provide LV services for global clinical trials, as well as the company's efforts to collaborate with health organizations (such as PAHO) and government health authorities, in the assessment of quality of life and access to health care in Latin America.

She lives in Cape Cod, Massachusetts, USA, with her husband Ted and their sons Gabriel and Daniel. Ana is very excited to be working on the newsletter and welcomes suggestions for future issues. She can be reached at info@isoqol.org 

GET READY FOR DENVER! AN UPDATE ON ISOQOL 2011

Cynthia Gross, PhD & Karen Sousa, PhD, RN, ISOQOL 2011 Meeting Co-Chairs

ISOQOL is making its first trip to the Mile High City, Denver, Colorado. The ISOQOL 18th Annual Conference will be October 26-29 at the Sheraton Downtown Denver. The meeting promises to be an outstanding scientific forum for researchers, clinicians and policy makers interested in the use of health-related quality of life and patient-reported measures in clinical research and health care. An informative and interesting mix of invited plenary and contributed sessions will be interspersed with workshops, roundtables, special interest group meetings, mentoring programs and fun social events. The spirit of the American west and culture of our native people will infuse our opening reception and the beautiful Denver Art Museum and musical entertainment (dueling pianos!) will ensure that our annual dinner is a memorable celebration.

In keeping with our theme, “Pushing the Boundaries: Frontiers of QOL Research”, each day will include plenary speakers to highlight emerging issues and opportunities for quality of life researchers. We are pleased to have the following plenary sessions:

Enhancing Quality of Life Research with Qualitative Data

Pamela S. Hinds, PhD, RN, FAAN, Director, Dept. of Nursing Research and Quality Outcomes, Associate Director, Clinical and Community Research Center, Children’s National Medical Center, and Professor of Pediatrics, The George Washington University; **Kathy Lasch, PhD**, Director, Patient Reported Outcomes, Mapi Values; and **Sally Thorne, PhD, FCAHS, RN**, Professor, University of British Columbia School of Nursing

Innovative Approaches to Improve Health and Quality of Life Through e-Interventions

Alice Krueger, President, Virtual Ability, Inc.; **Fiona McTavish, M.S.**

Deputy Director, Center for Health Systems Studies, University of Wisconsin, Madison; and Marcia A. Testa, M.P.H., M.Phil., PhD, Harvard University, School of Public Health

Health Disparities: Measuring and Improving Outcomes and Patient Quality of Life

Paula Braveman, MD MPH, Professor, Family and Community Medicine, Director, Center on Social Disparities in Health, University of California, San Francisco; **Laura Camfield, PhD**, Young Lives, University of Oxford; and **Bruce Rapkin, PhD**, Albert Einstein College of Medicine, Albert Einstein Cancer Center

Genetics and QOL: How the Interface Can Impact Research and Practice

Meike Bartels, PhD, Associate Professor, Biological Psychology, Free University Amsterdam; and **Richard Goldberg, MD**, Richard M. Goldberg Distinguished Professor of Gastrointestinal Oncology, Chief of Hematology/Oncology, and Associate Director for Clinical Research, University of North Carolina, Lineberger Comprehensive Cancer Care Center

We thank our plenary committees and their conveners: Carolyn Gotay, Susan Parsons (eHealth), James Shaw (Health Disparities), Anne Klassen and Anita Molzahn (Qualitative Research) for organizing these sessions, and thank our marvelous local arrangements committee, Roxanne Jensen (convener), Ana Maria Rodriguez (convener), Susan Bartlett, Diane Fairclough, Elizabeth Gibbons, Bellinda King-Kallimanis, Anandi Law, Lauren Lee, Deborah Miller, Elizabeth Shenkman, and Jeannie Zuk, for planning our social events and for preparing guides to Denver for fitness, dining and touring.

New features at the meeting this year include a President’s Welcome for first time attendees. President Carol

Moinpour will host a special Meet the President/First Time Attendee Reception on Wednesday, October 26 from 6:30 pm – 7:00 pm for registrants attending their first ISOQOL meeting. The president and board will personally greet first-timers, and offer tips for getting the most out of the meeting. The President’s Welcome will directly precede the annual Opening Reception on Wednesday afternoon.

Denver will promote small group discussions and networking opportunities through hosted breakfast roundtables [separate fee] and guided poster tours [free]. For the poster tours, we have lined up experienced researchers to lead small groups as they engage in thought-provoking conversations with presenters. Denver is also continuing the well-received “track” system to aid attendees in selecting among competing sessions. Denver contributed sessions have been organized into four tracks: Methods and Theory, Population and Policy, Clinical Practice and Frontiers of Quality of Life Research.

A hallmark of ISOQOL meetings is our emphasis on education and mentoring. In Denver we will have a full-day of workshops on Wednesday before the official meeting starts. New educational offerings this year include an all-day PROMIS Assessment Center workshop [separate registration required]. There will also be a symposium sponsored by the Industry Advisory Committee (IAC), “To Quality or Not to Quality: Benefits and Challenges of PRO Instrument Qualification from Industry, Academic, and Regulatory Perspectives.” on Wednesday afternoon, that is open to all ISOQOL registrants at no extra cost. Several workshops and roundtables still have openings.

Keep up-to-date with the conference at <http://www.isoqol.org/2011conference/>

See you in Denver! 

Leadership: Donald Patrick, PhD, MSPH & Katrin Conway, MA

The TCA-SIG, established in 2004 during ISOQOL's annual meeting in Hong Kong, strives to identify and advance research in the fields of translation and cultural adaptation of Patient-Reported Outcomes (PRO) measures.

The SIG has divided its members into 3 subgroups, each pursuing individual objectives to meet the overall aim:

1. The **Cross-cultural Issues subgroup** is led by Sonya Eremenco, United BioSource Corporation, Bethesda, USA — Deals with issues related to the access of copyrighted instruments, the translation of PROs and their use in e-format.
2. The **Translation Methodology subgroup** is chaired by Mona Martin, Health Research Associates, Inc., Seattle, Washington, USA — Pursues a research agenda for the development of methodologies in the field of translation and cross-cultural research.
3. The **PRO Translation Certification subgroup** coordinated by Mona and Katrin — aims at establishing an international certification program for PRO translations.

After conducting exploratory work during the first 5 years of its existence, our group decided to focus its efforts on the publication of our findings. The following 5 topics were identified:

1. **Copyright of translations of PRO measures: rules and applications** — Senior author: Caroline Anfray, MAPI Institute, Lyon, France. Submission targeted 1 quarter 2012

2. **Translation of Patient Reported Measures: What type of certification should be offered?**

— Senior Author: Mona Martin, Health Research Associates, Inc., Seattle, Washington, USA. Submission targeted 1 quarter 2012

3. **The process of reconciliation in the translation of quality of life questionnaires. Evaluation of existing procedures, criteria and outcomes** — Senior author:

Michael Koller, Center for Clinical Studies, University Hospital Regensburg, Germany, *submitted*.

4. **Efficiency of Translation Methodology In Error-Reduction for new Language Versions of PRO Instruments**

— Senior author: Mona Martin, Health Research Associates, Inc., Seattle, Washington, USA. Submission targeted 2 quarter 2012

5. **Translation Difficulties** — Senior author: Catherine Acquadro, MAPI Research Trust, Lyon, France. Submission targeted 2 quarter 2012

6. **Pooling cross-cultural PRO data in global clinical trials: How much can a poor measure in a cultural subgroup affect the estimation in the overall population?** — Senior author:

Antoine Regnault, MAPI Values, Lyon, France. Submission targeted 1 quarter 2012

We are delighted to report the submission of the third topic in June 2011 to Expert Review of Pharmacoeconomics & Outcomes Research, and look forward to updating you on the progress of the remaining topics during our annual meeting at

the Denver conference. This year's meeting of the TCA-SIG will be on Thursday, 27 October between noon and 2 pm. The highlight of our annual meeting will be the following two presentations which, we are sure, will lead to a stimulating discussion:

- **“Linguistically Validating PRO measures with populations who are difficult to interview”** Darren Clayson of PharmaQuest Ltd, Banbury, Oxfordshire, UK
- **“The study of different Spanish versions of the DTSQ”** Annarita Felici, Health Psychology Research Ltd, University of London, UK.

We hope you will join us in Denver. Please contact Tatiana Gauchon tgauchon@mapigroup.com for more information prior to the meeting or consult the ISOQOL website about our activities. 

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will miss her terribly, and will be holding a memorial service for Donna on Oct. 29th from 4:30-5:30 as the last session of the Annual Meeting, prior to the conference dinner. We will describe Donna's contributions to ISOQOL and the field of quality of life research, discuss the plans to establish a Donna Lamping Memorial project in ISOQOL, and allow individuals to comment on their experiences with and memories of Donna. Please join us.

Please contact me with suggestions for how ISOQOL could be even better or if you run into issues when trying to get something done for the Society. I want to hear from you.

[cmoinpou@fhcrc.org / (206) 667-4604].



RESPONSE SHIFT SPECIAL INTEREST GROUP

Leadership: Sara Ahmed, PhD & Lena Ring, PhD

Over the past six years, since its creation, our group has grown and collaborated on numerous projects. The ultimate objective of the SIG is to stimulate research and discussion to further advance work in this field, through active collaboration between our members. During our annual meetings and workshop activities we have had the opportunity to exchange knowledge and research findings on the evolving theoretical framework of response shift, the impact of response shift on the interpretation of longitudinal changes in patient reported outcome assessments, the status and use of various methodological approaches for evaluating response shift, and the role and feasibility of response shift assessments in clinical and research settings.

The SIG has been active in supporting the work of its members and developing collaborative projects. To date, we have completed:

- A special issue of the Journal of Clinical Epidemiology which included 12 papers (1);
- SIG members were also involved in a Statistical and Applied Mathematical Sciences Institute (SAMSI)-sponsored working group on recent advances in interpreting longitudinal changes in health-related quality of life data (2);
- A publication by New Investigators on research priorities in the field (3);
- An application of methodological approaches for evaluating response shift among individuals with Multiple Sclerosis using the data from the NARCOMS National Registry of MS (4, 5, 6, 7).

The SIG remains active. In September 2010, we held a focused conference, **The Response Shift Think Tank 2010**, led by Carolyn Schwartz, ScD and Mirjam Sprangers, PhD. Held

in Cambridge, MA, at the Harvard Faculty Club, formal presentations and extensive group discussion focused on clinical, theoretical, and methodological advances in response shift. Participants included about 20 individuals from diverse disciplines, including social sciences, oncology, orthopedics, plastic surgery, and philosophy. The Think Tank aimed to critically consider the theoretical and methodological state of the field, and develop a clear agenda and mechanism for collaborative research projects among this interdisciplinary group. The first day of the session focused on theoretical discussions including clinical and philosophical insights to inform future directions for response shift research. The second day focused on recent methodological developments, with an emphasis on integrating the previous day's discussion into current methods. Working groups were formed to collaborate on papers that are currently underway to address emerging objectives that were defined during the Think Tank session. To date, one of these papers has recently been accepted for publication (8).

We have several planned sessions for the 2011 annual conference in Denver including a workshop on quantitative methods for detecting response shift (10/26, 9:30am-12:30pm), a symposium showcasing current efforts from the Think Tank collaborations (10/27, 4-5:30pm), and an oral presentation of current empirical research (10/28, 2-3:30pm). If you are interested in this area of work we encourage you to join the SIG and become an active member in our initiatives. We are always happy to include new members and hope to see you in Denver!

1. Volume 62, Issue 11, November 2009
2. Swartz RJ, Schwartz CE, Basch E, Cai L, Fairclough D, McLeod L, Mendoza T, Rapkin B, and the SAMSI Psychometric Program Longitudinal Assessment of Patient-Reported Outcomes

Working Group. The king's foot of patient-reported outcomes: Current practices and new developments for the measurement of change.

Quality of Life Research, 2011 in press. Epub February 19, 2011, DOI 10.1007/s11136-011-9863-1.

3. Ruth Barclay Goddard, Joshua Epstein, Nancy Mayo. Response shift: a brief overview and proposed research priorities. *Quality of Life Research*. 18(3):335-46, 2009
4. King-Kallimanis BL, Oort, FJ, Nolte S, Schwartz CE, Sprangers MAG. Using structural equation modeling to detect response shift in performance and quality of life scores of multiple sclerosis patients. *Quality of Life Research*, 2011 in press.
5. Ahmed S, Mayo N, Scott S, Kuspinar A, Hum S, Schwartz CE. Using Latent Trajectory Analysis to Detect Response Shift in General Health among Multiple Sclerosis Patients. *Quality of Life Research*, 2011 in press.
6. Li Y and Schwartz CE. Data mining for response shift patterns using recursive partitioning tree analysis. *Quality of Life Research*, 2011 in press.
7. Schwartz CE, Sprangers MAG, Ahmed S, Bode R, Li Y, Oort FJ, Vollmer T. Response Shift in Patients with Multiple Sclerosis: An Application of Three Statistical Techniques. (Revision under review.)
8. Barclay-Goddard R, King J, Dubouloz CJ, Schwartz CE. Building on transformative learning theory and response shift theory to investigate changes in health-related quality of life over time in individuals with chronic health conditions and disability. *Archives of Physical Medicine and Rehabilitation*, 2011 in press.



NEW INVESTIGATORS SIG

Leadership: Bellinda King-Kallimanis & Roxanne Jensen

The New Investigators SIG is targeted at people new to QoL research. We welcome students, post docs, and anyone who has been working in QoL research for five years or less.

We were founded in late 2007 to be the support arm for new ISOQOL members. The main aim of our SIG is to provide a forum for people who are as new to this area as we are. We organize meetings at every ISOQOL conference and send out e-mails throughout the year about useful topics and opportunities for new investigators to get involved in ISOQOL activities.

This year, our group has offered a variety of opportunities to new investigators. New investigators volunteered in record number to help out with the conference planning,

abstract reviews, and other ISOQOL committees. In addition to this, the group has worked closely with the editors of the *Quality of Life Research* journal to involve members in language editing, writing book reviews, and working with senior researchers to write methodological articles. We look forward to another great year providing more career-building activities for our members.

At the upcoming annual conference, we are very excited to have many SIG-sponsored activities on the schedule. The first is a career-focused workshop, titled "Career Development: Strategies for Landing a Great Job in Quality-of-Life Research." During this workshop we will have guests speak about different career paths and opportunities in QoL research, while providing useful information on how to get a job and important issues to consider

for individuals starting their careers. In addition to this workshop, we will host a symposium titled "Tricks of the Trade: Advice for Investigators in QoL Research," where a panel of leading QoL researchers from around the world will talk about the future of QoL research and highlight important skills that investigators will need to be successful in the future. Finally, we will be holding our annual SIG meeting, which will be aimed at having new investigators get better acquainted with each other, share experiences in QoL research, and discuss our plans for next year.

If you are interested in joining our group, or have any questions, please e-mail us at b.l.kallimanis-king@amc.uva.nl or rj222@georgetown.edu.

We look forward to seeing you in Denver! 



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We're passionate and rigorous about our science. For more than 30 years, Genentech has been at the forefront of the biotechnology industry, using innovative science to develop breakthrough medicines that improve the lives of people with serious or life-threatening diseases. We're also passionate about our people, our most important asset.

We are currently building out our Patient Reported Outcomes (PRO) organization, and are seeking experienced PRO Specialists to join our Global Outcomes organization, based in our South San Francisco, CA, headquarters. These individuals will lead PRO implementation activities for a molecule and provide support in developing global PRO strategies for molecules within a therapeutic area.

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careers.gene.com

In January 2011, Genentech was named to FORTUNE's list of the "100 Best Companies to Work For" for the 13th consecutive year.



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REPORTING STANDARDS FOR QUALITY OF LIFE OUTCOMES - WORKING GROUP

Leadership: Michael Brundage, MD

The group is making great progress. Our overall objective is to improve the quality of HRQL outcomes reporting in randomized clinical trials, given the existing evidence that many such publications report QoL results poorly. The main path for accomplishing this is to work with the CONSORT group, drafting an extension to the CONSORT Guidelines in Clinical Trials Reporting.

With the help of Dr. David Moher, member of the CONSORT Executive, we've planned a face-to-face meeting in January 2012 in London, England to draft this Extension Guideline. The attendees of the meeting will represent a broad group of stakeholders including members of the working group, editors, clinical trialists, statisticians, members of regulatory agencies and patient advocates.

As many are aware (thank you for participating!) ISOQOL conducted a survey of members' views with regard to standards of quality of life reporting. This survey is being repeated to elicit input from members of other organizations including ISPOR, the Cochrane PRO Methodology Group, clinical trials groups in other jurisdictions, and the general scientific audience through the *Lancet* and other venues.

We have embarked on a number of other knowledge translation activities in our goal to improve clinical trials HRQL reporting, which will complement the development of a CONSORT extension. These include an introductory workshop planned for the Denver ISOQOL meeting, a *Lancet* comment drawing attention to the CONSORT extension process, as well as other manuscripts in preparation.

At the Denver Annual Conference, Dr. Calvert will present the results of the ISOQOL Survey, and at the SIG on Quality of Life in Clinical Practice meeting, we will have a chance to discuss this project briefly.

We are very grateful for the support of the ISOQOL membership in moving this project forward. The project is funded by the MRC Network of Hubs for Trials Methodology Research (PIs Drs. Calvert and Blazeby) and by the Canadian Institutes of Health Research (PI Dr. Brundage). We are also grateful for the administrative assistance of Brenda Bass and welcome Helen Duffy, who is now the primary project coordinator. 

ANNOUNCEMENTS

Handbook: "Measurement in Medicine"

Authored by: Henrica C.W. de Vet
Caroline B. Terwee
Lidwine B. Mokkink
Dirk L. Knol
Issued by: Cambridge
University Press
Date of appearance: August 2011

It is a pleasure to announce a new book entitled "Measurement in Medicine". It is issued by Cambridge University Press in the series Practical Guides to Biostatistics and Epidemiology.

You might be interested in this book as a researcher or a teacher in the field of measurement instruments and the quality of measurements. The terminology and definitions in the book of the measurement properties

are based on the COSMIN study. The book provides a theoretical background combined with many examples. Moreover, there are assignments at the end of each chapter, with solutions and databases for practice at a special website. This is a perfect course book for students and a perfect companion for professionals/researchers in the medical and health sciences who care about the quality and meaning of the measurements they perform.

More information on the book can be found at the website of Cambridge University Press http://www.cambridge.org/gb/knowledge/isbn/item6439316/?site_locale=en_GB

If you have any questions, please let the authors know!

EORTC 2ND SYMPOSIUM ON QUALITY OF LIFE RESEARCH:

The lectures of the **2nd EORTC Symposium on Quality of Life Research** (September 7 - 9, 2011, European Parliament, Brussels) are now freely accessible at <http://www.informed-scientist.org/congress/2nd-eortc-symposium-on-quality-of-life-research> — Many thanks to Dr. Raimund Wieser from "The Informed Scientist" for forwarding the link.

ISOQOL IS NOW ON LINKEDIN!

In addition to our pages on Facebook and our Twitter presence, we are now also on LinkedIn. We will be posting activities and events there – feel free to link to us and send any questions you may have or announcements pertaining to events, publications or activities of interest to our members. During the meeting members can follow along on Twitter using #ISOQOL11 

ISOQOL DICTIONARY PROJECT - *WORKING TITLE: DICTIONARY OF QUALITY OF LIFE AND HEALTH OUTCOMES MEASUREMENT*

Leadership: Nancy Mayo, BSc (PT), MSc, PhD, Sara Ahmed, PhD, Ruth Barclay-Goddard, PhD MHS BMR (PT), Susan Bartlett, PhD, Cindy Gross, PhD, Diane Fairclough, DrPH, Lena Ring, PhD, Rick Sawatzky, PhD, RN, Jane Scott, PhD, and Sharon Wood-Dauphinee, PhD

The idea of creating a dictionary of terms used in our field arose out of the Uruguay meeting in 2008. It came from an encounter with a discouraged student who had just realized that, although seasoned members of our society distinguished between quality of life and health-related quality of life (health and health status, a patient-reported outcome and a directly measured outcome), novices and researchers from other fields did not. I well remember my years as a student in Epidemiology, another field replete with terms not well used by “outsiders”, having *Last’s Dictionary of Epidemiology* as an invaluable

resource. Why not have such a resource for those in the field of quality of life and health outcomes? This idea was enthusiastically received by the Board of Directors in 2009 and an initial call for contributors led us to the list of Executive Members seen above. In our initial enthusiasm, we developed a concept map to sketch the areas with a need for consistent and correct terminology. We added terms to the concepts. We had other grandiose ideas as well. However, the reality of undertaking such a project with no dedicated resources soon hit and progress did not outpace a snail, but all good ideas often just need time and some luck. In 2010, we had the opportunity to apply for some funding from the Quebec provincial government’s Public Health Network dedicated for scholarly works. Armed with \$5000 and a dedicated hound to keep us sending in definitions (C Moriello), the Dictionary project took on new life.

Another chance encounter also helped considerably when I discovered, in June 2011, the Dictionary Society of North America which has over 400 members worldwide, a huge amount of knowledge, and a t-shirt. Our group is now writing a glossary for a vertical audience, although it will be marketed as a “Dictionary”. This will not be just any dictionary and definitely not the Devil’s Dictionary.

Dictionary, n., A malevolent literary device for cramping the growth of a language and making it hard and inelastic. This dictionary, however, is a most useful work.

—Ambrose Bierce, *The Devil’s Dictionary*.

At the 2011 meeting in Colorado, our group will have a poster, so visit and join if you wish. All are welcome. Our poster will showcase what we have learned about collecting, modifying, writing, and referencing definitions. You will see our main concepts and how many terms now have working definitions — and how many we are aiming for. You will also be able to suggest words for defining (and win a prize for your efforts). Our next step — The T-Shirt. Hope to see you all in Colorado.

Nancy E. Mayo, BSc(PT), MSc, PhD
nancy.mayo@mcgill.ca 



CALL FOR WEBSITE REDESIGN TASK FORCE CO-CHAIR

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

This is a non paid volunteer opportunity.

ORAL HISTORY PROJECT

Leadership: Bill Lenderking, PhD & Ana Popielnicki, BA

The group’s aim is to document the history of Quality of Life Research through interviews with instrument developers and researchers in the field. Much work has been done already but the project was in a hiatus as leadership changed. We are now planning on resuming this work, after consolidating what has already been posted with our raw files. 