

# Quality of Life

QUARTERLY

## IN THIS ISSUE...

- PAGE 1** President's Message
- PAGE 2** SAVE THE DATE!
- PAGE 3** From the Editor's Desk
- PAGE 4** Call for Nominations for the ISOQOL Board of Directors
- PAGE 5** Practical Approaches to Collecting, Managing, and Utilizing PRO and HRQL in Clinical Settings
- PAGE 6** ISOQOL Membership = Opportunities
- PAGE 6** ISOQOL responds to the European Medicines Agency
- PAGE 7** What Does Your Member Profile Look Like on the ISOQOL Website?
- PAGE 7** ISOQOL's QOL in Clinical Practice SIG - updates to ISOQOL User's Guide to Implementing PRO Assessments in Clinical Practice
- PAGE 8** SIG and Committee Leadership Keep ISOQOL Moving Forward!
- PAGE 8** ISOQOL Travel Scholarships – 2015 Annual Conference
- PAGE 11** Call for Volunteers: Abstract Reviewers
- PAGE 11** Submit Symposium and Workshop Proposals

VOLUME 21 ISSUE 1

Newsletter for  
ISOQOL Members

WINTER 2015



## PRESIDENT'S MESSAGE

*Galina Velikova, MD, PhD, FRCP; University of Leeds*



Dear Members,  
May I wish you a happy, healthy and successful New Year!

Looking back at 2014, I

would like to first thank you for your commitment to ISOQOL. It is our members and their work that strengthen our society and make working for ISOQOL not only professionally rewarding but fun too. For me the highlight of the year was the Annual Conference- it was my first conference as President, and despite being hectically busy, I thoroughly enjoyed every minute of it. It was one of the best attended ISOQOL conferences.

Here are a few of the current projects and accomplishments:

- ISOQOL Response to the EMA Draft Paper
- Expanded Scholarships to Patient Scholars for the 2014 Annual Conference

- Dictionary Project to be completed in 2015
- Companion Guide and revised User's Guide to be completed in 2015
- Webinars from the Ibero America, Health Preference, New Investigators SIG and the IAC Committee

We continue to advance and grow as a society. The start of a new year is a good opportunity to take stock and think of the times ahead, both on a personal and a professional level. We invite you to continue to expand your engagement and support of ISOQOL. When you renew your membership, make sure to look at the list of Special Interest Groups (SIGs) to join. The SIGs are active entities, developing webinars, guidelines, publications, educational programming and ongoing scientific discussions through their listservs. The SIGs are an excellent way to engage with like-minded researchers or to learn more about a new area of research.

*Continued on page 2.*



**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**

*President*

**Galina Velikova, MD,  
United Kingdom**

*Secretary-Treasurer*

**Cynthia Gross, PhD, USA**

*President Elect*

**Claire Snyder, PhD, USA**

*Executive Director*

**Colleen Pedersen, USA**

*Board Members*

**Melanie Calvert, PhD,  
United Kingdom**

**David T. Eton, PhD, USA**

**Lori Frank, PhD, USA**

**Sandra Nolte, PhD, Germany**

**Andrea Pusic, MD, MHS,  
FRCDC, USA**

**Rick Sawatzky, PhD, RN, Canada**

**Silke Schmidt, PhD, Germany**

**Jose (Chema) Valderas, MD, PhD,  
MPH, United Kingdom**

**Hwee-Lin Wee, PhD, Singapore**

#### **ADVERTISING INFORMATION**

Contact Executive Director,  
Colleen Pedersen:  
**cpedersen@isoqol.org**

#### **ISOQOL Executive Office**

555 E. Wells Street, Suite 1100  
Milwaukee, WI 53202, USA  
Telephone: +1 (414) 918-9797  
Fax: +1 (414) 276-3349  
**info@isoqol.org • www.isoqol.org**

#### *President's Message, Continued from page 1.*

The 2015 Annual Conference is another area of engagement. This year the theme is *"The Matrix: Quality of Life in Social Context"*. Please assist the planning committee by serving as abstract reviewers. This is an excellent way to impact the science presented at the conference and to provide a much needed service to your society. Please contact the ISOQOL office at **info@isoqol.org** for more information.

ISOQOL has issued a call for nominations to the Board of Directors. Please consider entering your name or another member of ISOQOL into the nomination process. More information about the nomination process is available on page 4. I ask you to strongly consider these opportunities for service on the Board of Directors. ISOQOL needs individu-

als who are interested in shaping the future of the society and the field of health-related quality of life research.

I am excited about the possibilities facing ISOQOL in 2015, and I hope you will consider joining us by engaging in new ways. I would also like to thank the leadership of our committees and SIGs for their ongoing dedication to the society. All of their names are listed here on page 8.

Best Wishes,

*G Velikova*

Galina Velikova, MD PhD FRCP  
ISOQOL President



## **SAVE THE DATE!**

The International Society for Quality of Life Research will hold their 23rd Annual Conference

**19 - 22 OCTOBER 2016 COPENHAGEN, DENMARK**

**PLEASE MARK YOUR CALENDARS!**



## FROM THE EDITOR'S DESK

By: Ana Popielnicki



Dear ISOQOL Family:

Happy New Year, and welcome to the first 2015 issue of our Quality of Life Quarterly!

While those of us in the Northeast of the United States are bracing ourselves for a major winter storm (stay safe!), it is my pleasure to bring to our worldwide membership an issue full of enthusiastic announcements, initiatives, and news from many of our groups.

Dr. Galina Velikova takes a look back to 2014 in her President's Message, reminding us of the many achievements reached as a Society during this past year. She also looks forward to this year's Annual Conference, and encourages everyone to get involved and collaborate through the various opportunities available to our mem-

bers. Speaking of opportunities for all, take a look at our membership coordinator's piece on the benefits of being a member, and how you can make the most of your membership profile and find ways to connect.

Our indefatigable New Investigators SIG, as is tradition, brings us an article about the use of PROs and HRQL measures in a clinical setting – take a look for their valuable tips regarding this approach.

Take time to read ISOQOL's response to the European Medicines "Draft reflection paper on the use of patient reported outcome (PRO) measures in oncology studies", and make sure to click on the provided link for the full document. Many thanks to our members, always engaged and contributing to the industry's thought leadership. And in mentioning leadership – check out our call for nominations to the Board of Directors! This is your chance to get more involved yourself, or nominate a deserving colleague.

Please look for information on dues renewal and Special Interest Group membership, our call for abstract reviewers, and for workshop and symposium submissions for the 2015 Annual Conference in Vancouver. And as always, do not hesitate to contact us directly with questions, comments, or submissions for the winter issue. Send your queries/comments to your Communications Committee at [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" on your subject line. Looking forward to wonderful things for this 2015 – Happy reading!

A handwritten signature in dark ink, appearing to read 'Ana Popielnicki'.

Ana Popielnicki  
Editor





## CALL FOR NOMINATIONS FOR THE ISOQOL BOARD OF DIRECTORS

The Nominations Committee welcomes recommendations from ISOQOL members for candidates to fill four (4) opening Board Member positions. Please consider nominating yourself or another ISOQOL member for one of these important positions. For self-nominations, please submit a C.V. and personal statement regarding your vision for ISOQOL. If you are nominating someone else, please provide a very brief statement supporting your nomination, and the ISOQOL office will follow-up with the nominee to obtain the C.V. and vision statement. The Nominations Committee will consider these recommendations in developing the slate of candidates. If you have any questions regarding the responsibilities of the positions, please contact Colleen Pedersen, ISOQOL Executive Director at [cpedersen@isoqol.org](mailto:cpedersen@isoqol.org) or Claire Snyder, PhD, Nominations Committee Chair at [csnyder@jhu.edu](mailto:csnyder@jhu.edu). Final nominations are due March 2015.

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.

### 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. Each board member shall participate and lead in the activities of ISOQOL. 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 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.



PROMIS  
HEALTH  
ORGANIZATION

### PHO Inaugural PROMIS Conference

**New Users Workshop, Thursday, May 14**

**All Day Conference Friday - May 15, 2015**

The goal of the PROMIS Health Organization (PHO) is to promote the use of **Patient-Reported Outcomes Measurement Information System (PROMIS®)** in research and clinical practice through education and service to the community. This conference is being planned to examine conceptual, methodological, clinical, and research aspects of assessing and using patient-reported outcomes (PROs).

#### **Abstract Submission, Draft Agenda and Registration Information:**

<https://www.regonline.com/phoinauguralconference>

# PRACTICAL APPROACHES TO COLLECTING, MANAGING, AND UTILIZING PRO AND HRQL IN CLINICAL SETTINGS

*Tha'er G. Momani, Doctoral Research Assistant, St. Jude Children's Research Hospital – Memphis, TN, USA, New Investigators SIG*

Patient Reported Outcomes (PROs) and Health-Related Quality of Life (HRQL) are an important aspect of healthcare. During clinical appointments, PROs can effectively enhance the structure of communication between the patient and the clinician. However, PROs are hardly used in most areas of clinical practice. One possible reason for this lack of use is that there is no immediate feedback, and the lack of consistent and continuous collection of these measures in clinical settings. In addition, PRO instruments often contain multiple domains and require complex calculations to compute a score, which limits the utility of PRO scores on clinical decision making. As a result, PROs are not commonly used in settings where they matter the most, for instance during clinical decision making.

Recent developments in PRO measurement may help improve the use of PROs in clinical practice. One promising approach is the use of Mobile Health (mHealth) applications to collect data, monitor compliance, and measure vital indices in the field of PRO research. The collection of PROs using mHealth applications provides better access, rapid data collection, and remote data collection.

When researching PROs and HRQL in clinical settings, new investigators

should consider these recommendations for maximizing the utility of PROs in clinical decision making:

- Establish adequate support from the clinical staff. Researchers in a clinical setting have to rely heavily on clinic “gate-keepers”; clinicians who can identify new cases and facilitate the communication with patients and busy clinic staff.
- Demonstrate the relevance of the PRO to the clinical staff. This will encourage more support and enthusiasm among the staff.
- Get clinicians’ feedback on the ease and the length of the instruments used to collect PRO. This feedback can be vital in choosing an appropriate PRO instrument.
- Get feedback from clinicians on clinically significant time points for collecting PRO data. These time points can help detect the most significant changes in PRO.
- Longitudinal studies in clinical settings can help capture the most significant changes in PRO within a clinical setting.
- Opt for as short and limited number of PROs as possible to collect within a clinical setting.
- Use technology like mHealth apps to collect PRO; this gives

more time to the clinicians, better efficiency at collecting data, and allows rapid computation of PRO scores to clinicians’ benefit. In fact, clinician could have the PRO scores available for discussion at the clinic appointment.

- Involve clinicians throughout the study process from data collection to interpretation of results. They can help facilitate the process of data collection and draw better conclusions on the findings.

Getting clinicians on board, using advanced data collection methods, and consistent approaches to PRO collection and reporting can allow for improved utilization of PROs by clinicians, eventually leading to better response to the changing needs and demands of patients and an improved understanding of PROs in those patients.



## ISOQOL MEMBERSHIP = OPPORTUNITIES

Log in to your ISOQOL Member Profile to confirm your membership dues are paid through 2015. Member log in is available on the menu bar on the top left of the ISOQOL homepage: [www.isoqol.org](http://www.isoqol.org).

Renew today to maintain an active membership in the International Society for Quality of Life Research through the end of 2015. Visit the Membership page of the ISOQOL website for dues rates and a link to the online form. (<http://www.isoqol.org/membership>)

An active ISOQOL membership allows you to participate in the rapidly expanding science of health-related quality of life (HRQOL) research. ISOQOL is the best forum for you to present your work, to discuss your scientific work with like-minded colleagues, and to learn about the latest findings in our field.

ISOQOL membership is your ticket to quality education and collaboration. Members receive a free electronic subscription to the *Quality of Life Research* journal, and access to membership directory for establishing collaborations. ISOQOL members also receive discounts on ISOQOL publications, the ISOQOL Annual Conference, webinars and other educational offerings.

### JOIN A SPECIAL INTEREST GROUP (SIG) TODAY

Don't forget to update your SIG preferences when you renew your dues. Active participation in Special Interest Groups (SIGs) is open to all ISOQOL members. Update your SIG preferences on your member profile to make sure you are receiving information on special initiatives from the ISOQOL SIGs. You can update your

SIG preferences at any time, simply by logging into your account on the ISOQOL website.

### Current Special Interest Groups are:

Child Health  
Health Preference Research  
Ibero America  
New Investigators  
Patient Engagement  
Psychometrics  
Quality of Life in Clinical Practice  
Response Shift  
Translation and Cultural Adaptation (TCA)

For more information on ISOQOL SIGS, visit the Special Interest Groups page of the website at <http://www.isoqol.org/special-interest-groups> or contact the ISOQOL Office at [info@isoqol.org](mailto:info@isoqol.org).



## ISOQOL RESPONDS TO THE EUROPEAN MEDICINES AGENCY "DRAFT REFLECTION PAPER ON THE USE OF PATIENT REPORTED OUTCOME (PRO) MEASURES IN ONCOLOGY STUDIES".

On the 17<sup>th</sup> of June the European Medicines Agency released a "Draft reflection paper on the use of patient reported outcome (PRO) measures in oncology studies" (EMA/CHMP/292464/2014) for consultation. ISOQOL reviewed the draft reflection paper and submitted a response in December 2014. The ISOQOL Response Paper is available for review on the website at <http://www.isoqol.org/research/isoqol-publications>.

We would like to thank all members who contributed to the development of a response to this paper. Your support and dedication help advance the scientific study of health-related quality of life and other patient-centered outcomes, leading to identify effective interventions, enhance the quality of health care, and promote the health of populations.



## WHAT DOES YOUR MEMBER PROFILE LOOK LIKE ON THE ISOQOL WEBSITE?

As part of your ISOQOL Membership Benefits, members can network together using the contact information on the ISOQOL website. You can find members via:

- Geographic area – who is in your city, state/province or country?
- Specialty – who is in your specialty or work environment
- Quick Search – you can search by name, company, etc.

Your contact information is displayed to all ISOQOL members on the ISOQOL Members Only page. Is your information updated?

### MAKE SURE YOUR MEMBER PROFILE IS UP TO DATE!

You are able to log-in to the Members Only page, select Member Profile and update your contact information at any time.

[Click here](#) to access your Member Profile through the ISOQOL Website.



## ISOQOL'S QUALITY OF LIFE IN CLINICAL PRACTICE SPECIAL INTEREST GROUP HAS UPDATED THE ISOQOL USER'S GUIDE TO IMPLEMENTING PATIENT-REPORTED OUTCOMES ASSESSMENT IN CLINICAL PRACTICE.

We are pleased to announce publication of an updated *User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice*. The original User's Guide was published in 2011, and Version 2, published in January, reflects developments in the field and an updated bibliography. The User's Guide's purpose is to help clinicians and researchers who are interested in using patient-reported outcome (PRO) measures in clinical practice as a tool in patient management. The Guide goes step-by-step through the considerations for implementing PROs in clinical practice – starting with determining the goals; continuing through identifying the patients, setting, and timing; addressing how PROs will be collected and reported; and finishing with evaluation approaches. Rather than providing one “right” answer, the User's Guide presents different options, as well as the resource requirements and relative advantages/disadvantages of each approach.

The User's Guide – Version 2 (2015) is available on the website at <http://www.isoqol.org/research/isoqol-publications>. We would like to thank all members who contributed to the development of the revised guide, including (in alphabetical order): Neil Aaronson, PhD; Thomas Elliott, MD; Joanne Greenhalgh, PhD; Michele Halyard, MD; Rachel Hess, MD; Deborah Miller, PhD; Bryce Reeve, PhD; Maria Santana, PhD; and Claire Snyder, PhD.

### COMING SOON – A COMPANION TO THE USER'S GUIDE, WHICH WILL INCLUDE CASE STUDIES OF APPLICATIONS OF PROS IN CLINICAL PRACTICE!



## ISOQOL TRAVEL SCHOLARSHIPS – 2015 ANNUAL CONFERENCE

Applications for the annual conference travel scholarships will be available online February 23, 2015. Travel scholarships funds have been created to increase the opportunity for ISOQOL members in the early stages of their careers and for members from developing countries to attend and present at the annual conference, by providing funds to help defray the expenses associated with travel to the annual conference.

Travel scholarships will be available for members that fall into one or more of the following classifications:

- Developing Country
- Student/New Investigator

Members can apply for both scholarships if both categories apply.

Scholarship applications will be available on the Scholarship page of the ISOQOL website. Applications must be submitted by **Friday, May 29, 2015**. Applications will be reviewed by the ISOQOL Scholarship Committee, led by Chair Gloria Juárez, PhD (United States). Decisions will be made in late June.



## SIG AND COMMITTEE LEADERSHIP KEEP ISOQOL MOVING FORWARD!

ISOQOL's SIGs and Committees keep ISOQOL's strategic plan progressing. The ISOQOL Board of Directors and membership is grateful to all members of the SIGs and Committees, and particularly to the 2015 leaders of these groups.

### COMMITTEES

#### Advisory Council of Past Presidents (ACPP)

Co-Chair: Neil Aaronson, PhD  
Co-Chair: Donald Patrick, PhD MSPH

#### Communications Committee

Chair: Deborah Miller, PhD  
Newsletter Editor: Ana Popielnicki, BA

#### Education Committee

Chair: Joan Branin, PhD  
Workshops Chair: Nancy Mayo, PhD  
Scholarship Chair: Gloria Juárez, PhD RN MSN  
Student/New Investigator Awards  
Chair: Roxanne Jensen, PhD  
Mentor/Mentee Chair: Cynthia Gross, PhD

#### Industry Advisory Committee (IAC)

Chair: Josephine Norquist, MS

#### Membership Committee

Chair: Andrea Pusic, MD MHS FRCSC

#### Nominations Committee

Chair: Claire Snyder, PhD

#### 2015 Scientific Planning Committee

Co-Chair: Carolyn Gotay, PhD  
Co-Chair: Ida Korfage, PhD

### SPECIAL INTEREST GROUPS (SIG)

#### Child Health SIG

Co-Chair: Jeanne Landgraf, MA  
Co-Chair: Nancy Young, PhD  
Co-Chair: Anne-Catherine Haller, Dipl.-Psych.

#### Health Preference Research

Co-Chair: Benjamin Craig, PhD  
Co-Chair: Axel Muehlbacher

#### Ibero America SIG

Co-Chair: Pedro L Ferriera, PhD  
Co-Chair: Monica Avila, BPharm

#### New Investigators SIG

Chair: Catherine Bottomley (née Golics), PhD  
Co-Chair: Marc Jacobs, PhD Student

#### Patient Engagement SIG

Chair: Sam Salek, PhD

#### Psychometrics SIG

Co-Chair: Stacie Hudgens, MA (AbD)  
Co-Chair: Wen-Hung Chen, PhD

#### Quality of Life in Clinical Practice SIG

Co-Chair: Sandra Beurskens, PhD  
Co-Chair: Louise Humphrey, MSc

#### Response Shift SIG

Co-Chair: Leah McClimans, PhD  
Co-Chair: Ruth Barclay, PhD MHS BMR (PT)

#### Translation and Cultural Adaptation (TCA) SIG

Co-Chair: Sonya Eremenco, MA  
Co-Chair: Mona Martin, RN MPA





# Validated translations of PRO instruments equal validated results.

Corporate Translations' state-of-the-art linguistic validation process is modeled after the FDA guidance document and the ISPOR Good Practice Guidelines for the translation and validation of PRO instruments. As pioneers in linguistic validation, we have developed an array of support services designed to help our clients utilize PRO instruments in their global clinical trials. Corporate Translations has completed over 10,000 PRO instrument translations in a wide range of languages and therapeutic areas. That's why we are the preferred supplier of ISO 9001:2008 translation and linguistic validation solutions to the world's leading life science companies.

[www.corptransinc.com](http://www.corptransinc.com)  
1-855-727-6003

Face Validation | Harmonization | Back Translation | Cognitive Debriefing | ePRO Consultation



ISOQOL  
22<sup>nd</sup> Annual Conference  
VANCOUVER  
British Columbia, Canada  
OCTOBER 21-24, 2015



**Abstract Submission Deadlines:**

Workshop & Symposium Abstract Submission—February 6, 2015

Oral & Poster Abstract Submission—April 24, 2015

## CALL FOR VOLUNTEERS: ABSTRACT REVIEWERS

Abstract Reviewers serve a vital role in the scientific program planning by ensuring the quality of the educational content presented at the Annual Conference. Serving as an Abstract Reviewer provides an excellent way to support ISOQOL. Time commitment is low, but the impact is high! Abstract review is 100% electronic and all rankings will be submitted online.

Contact the ISOQOL Office at [info@isoqol.org](mailto:info@isoqol.org) for more information or to volunteer for any of the following roles:

- Workshop Proposal Review: February 13 – February 27, 2015
- Symposium Review: February 13 – February 27, 2015
- Oral and Poster Presentation Abstract Review: May 5 – May 18, 2015



**ISOQOL**  
22<sup>nd</sup> Annual Conference  
**VANCOUVER**  
British Columbia, Canada  
OCTOBER 21-24, 2015

**Submit an Abstract**  
Workshop and  
Symposium abstract  
submissions due  
February 6.

## SUBMIT SYMPOSIUM AND WORKSHOP PROPOSALS

The 22nd Annual Conference Scientific Program Committee is now accepting abstracts for symposium and workshop presentations at the 2015 Annual Conference. Visit the **Abstract Submission Page** of the ISOQOL website for submission instructions and links to the online abstract submission system.

Symposium and Workshop submission is open through the first week of February. All abstracts and proposals must be received by 11:59 pm CST on **Friday, February 6, 2015**.

