

# Quality of Life

QUARTERLY

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VOLUME 23 ISSUE 1  
*Newsletter for*  
*ISOQOL Members*  
WINTER 2017



## PRESIDENT'S MESSAGE

*Claire Snyder, PhD, Johns Hopkins School of Medicine*



Dear Colleagues,  
I hope your new year is off to a good start. For ISOQOL, the first few months of

2017 have been very busy. In addition to our usual activities, as many of you know, ISOQOL is in the process of developing a new strategic plan to guide us for the next five years. Your input has been incredibly valuable to this process.

As mentioned in my previous column, our Strategic Planning Committee comprises the Board, a New Investigator representative, a Past President representative, and key staff. Informing our efforts are the results of a survey completed by the Committee, by 130 ISOQOL members, and by 14 key opinion leaders. The Committee has reviewed the feedback from these surveys and identified four key topics and questions:

1. **ISOQOL's Major Focus.** Given ISOQOL's strengths and assets, and diverse perspectives, what should be the major focus of ISOQOL for which we will be the trusted authority?
2. **Member Engagement, Development, and Diversity.** How do we build a diverse, well-resourced, networked, and engaged membership base that can also serve as a source of capable leadership for ISOQOL and the profession, now and in the future?
3. **Marketing and Visibility.** How can we best increase awareness, recognition, and support of ISOQOL as a leader in the field?
4. **Sustainable Resources and Funding.** How can we maintain, expand, and diversify a sustainable revenue base in a changing and increasingly competitive funding landscape to support ISOQOL and its members in advancing our mission?

Having identified these questions, the Strategic Planning Committee has  
*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](mailto:info@isoqol.org)

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

now formed work groups to develop issue briefing papers that will inform our discussions at April's in-person strategic planning meeting. Following the meeting and development of the draft plan, the ISOQOL membership will have an opportunity to comment.

In addition to the strategic planning effort, ISOQOL's normal activities are as busy as ever. Plans are developing for our 2017 Annual Meeting, which will be chaired by Roxanne Jensen and Kevin Weinfurt, with the theme "**Embracing Complexity: Using Patient-Reported Outcomes to Generate Real World Evidence.**" The workshop and symposia propos-

als are under review, and the oral/poster abstract opens 6 March with a deadline of 17 April. We're looking forward to a great meeting and to seeing you all in Philadelphia October 18<sup>th</sup>-21<sup>st</sup>.

As always, comments and feedback are welcome at [ISOQOListens](http://ISOQOListens).

Sincerely,

Claire Snyder, PhD, ISOQOL President



## **SUBMIT AN ARTICLE TO THE QUALITY OF LIFE QUARTERLY!**

*Quality of Life Quarterly* is an excellent opportunity to network, share ideas and disseminate information about important industry happenings, article reviews, keynotes, and special events. Although we cannot guarantee that all submissions will be published, we invite you to submit short articles and topic suggestions, achievement announcements, calendar of events, or comments.

Send your submission [info@isoqol.org](mailto:info@isoqol.org) with the subject line "Newsletter Submission". Please include a completed copy of the [copyright release form](#), both for original and reprinted material.

For more information on the QoL Quarterly, including submission deadlines, advertising opportunities, and more, visit: <http://www.isoqol.org/research-publications/quality-of-life-quarterly>



## FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA, TransPerfect



Dear ISOQOL friends:

It is my pleasure to bring you the first issue of the year for our *Quality of Life Quarterly* –

hope it finds you well, and ready for a new year of excellent initiatives and networking with our fellow members.

As our President informs in her traditional Message, ISOQOL has been very active in the first couple of months this year. Read all about the developing Strategic Plan, and the identified key topics being addressed by the Planning Committee, in Dr. Snyder's article.

In keeping with our Society's continued initiatives to offer educational opportunities, check out the IPRO Task Force overview of the Introduction to *Quality of Life and Patient-Reported Outcomes: Theory, Measurement, and Applications* (the IPRO Course). There is also information on travel scholarships, so remember to Save the Date for our 24<sup>th</sup> Annual Conference in Philadelphia – look for the abstract submission deadlines here. Speaking of – please consider volunteering as an abstract reviewer – instructions can be found in this issue.

You will also find the names and projects of the award recipients for last year, as well as a call for nominations for our Board of Directors. Being an engaged member of ISOQOL

is very rewarding and has many benefits – consider joining/renewing your membership, and participating actively in one or more of our wonderful Special Interest Groups. Please also join me in welcoming our newest members!

As usual, you can send any questions, comments, or submissions for our next issue to [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" as your subject line. Happy reading!



Ana Popielnicki  
Editor



## CALL FOR VOLUNTEERS: ORAL AND POSTER ABSTRACT REVIEWERS

Abstract reviewers serve a vital role in the scientific program planning process by ensuring the quality of the educational content presented at the annual conference. Serving as a reviewer provides an excellent way to support ISOQOL. Time commitment is low, but the impact is high!

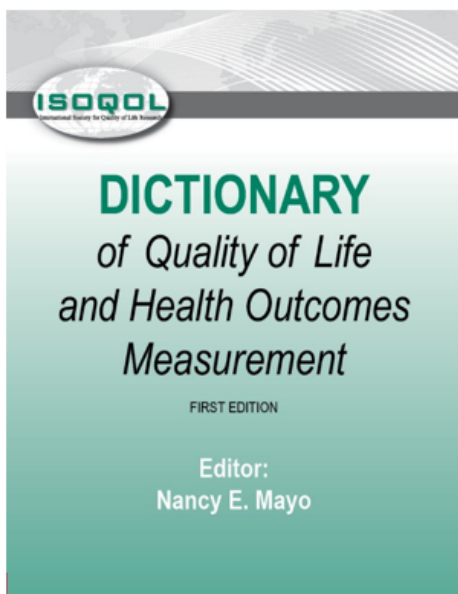
All abstracts reviewers will receive a certificate of participation, your name listed in the annual conference final program, and a ribbon for your badge if you attend the conference.

ISOQOL is seeking reviewers for Oral and Poster Abstracts:

**Review period runs 25 April - 22 May 2017**

Volunteers may choose which presentation types they would like to review - as many types as you would like. Abstract review is 100% electronic and all rankings will be submitted online.

To become a reviewer, please sign-up via the ISOQOL 2017 [Membership Dues Application](#) or email ISOQOL at [info@isoqol.org](mailto:info@isoqol.org) to participate. You will be contacted by the ISOQOL Office prior to the review period(s) listed above with further information and instructions.



### INTRODUCING:

*The First Edition*

ISOQOL Dictionary of Quality of Life  
and Health Outcomes Measurement

*Now available in print and E-book*

*To purchase a copy please visit the  
ISOQOL Website: [www.isoqol.org](http://www.isoqol.org)*



# INTRODUCTION TO QUALITY OF LIFE AND PATIENT-REPORTED OUTCOMES: THEORY, MEASUREMENT, AND APPLICATIONS (IPRO COURSE)

By: IPRO Course Task Force

Last summer, ISOQOL launched its first educational course for both members and non-members of ISOQOL at the University of Sheffield. The purpose of this article is to update everyone on this new innovative, comprehensive, and interactive course, its development process, and its current status.

## OVERVIEW OF THE NEW COURSE

Patient-reported outcomes (PROs) are outcomes that can only be reported on by the patients without any interpretation by any other person. Collecting and acting upon PROs is the cornerstone of patient-centered care. PROs include symptoms, some aspects of function, health perception, health-related quality of life and quality of life. Choosing the right set of PROs can be challenging, as there are many options, each with advantages and disadvantages. Sometimes there are no suitable measures for a specific need and a new one needs to be developed.

This one-day intensive and interactive educational course provides a basic level introduction to the why and how of using PROs in research with major emphasis on measuring quality of life. It also provides attendees with the opportunity to apply their learnings to real-life situations through examples and a case. This training is aimed at health professionals; medical scientists who are not experts in the use of PROs; consultants; pharmaceutical and medical device companies; new investigators and research students; policymakers; and other associations and other individuals who are interested in becoming more familiar with the terms

and methods of research on PROs. Each attendee receives copies of the presentation materials, a copy of the official ISOQOL Dictionary, an official course certificate, and lunch.

## BACKGROUND AND RATIONALE FOR THE DEVELOPMENT OF IPRO

One of the strategic initiatives of the ISOQOL Board is the development of an educational curriculum that provides a basic level introduction to patient reported outcomes (PROs) research. This is part of a broader initiative aimed at fulfilling the core mission of ISOQOL.

A Task Force Committee of the Education Committee was formed to develop the core curriculum consisting of Chema Valderas, Board Liaison; Joan Branin, Education Committee Chair; Ethan Basch; William Lenderking; and Nancy Mayo.

## DEVELOPMENT PROCESS

The development of the IPRO Course was a multi-year process. The Task Force met frequently via teleconference calls. To assist with course design, an email was sent to a small group of experienced members of ISOQOL to elicit their views and provide a list of core PRO and QOL concepts that a basic education curriculum “must have” to meet the needs of people wishing to be involved in research involving Patient-Reported Outcomes and Quality of Life research.

These inputs were essential in developing the key learning objectives of this course, which are to:

1. Identify historical and conceptual foundations of PROs

2. Compare the main measurement approaches that apply to PROs
3. List criteria to judge whether existing PROs fit their purpose
4. Outline the steps needed to develop a new PRO
5. Identify optimal PRO strategies for different types of study designs and selected populations
6. Evaluate strengths and weakness of different PRO measures using real-life examples and cases

To ensure uniformity and consistent quality across different course delivery sites and by different faculty members, it was decided that all presentation materials such as PowerPoint slides and handouts would be developed by the Task Force and standardized for the course. Again, we enlisted the assistance of our experienced members who provided PowerPoint slides and other materials which were used in the development of the final IPRO PowerPoint slide deck and list of references.

## CURRENT STATUS OF THE COURSE

We are happy to report that the **IPRO Course** was piloted at the University of Sheffield in Sheffield, United Kingdom for the PROMs Conference in July 2016, subsequently revised, and taught at the 2016 ISOQOL Annual Conference in Copenhagen, Denmark where it received excellent evaluations. The IPRO Course will be available at the PROMs Conference again for 2017 at St. Anne's College in Oxford, United Kingdom.

The **IPRO Course** will be available as one of the pre-conference

*Continued on next page.*

workshops at the 2017 ISOQOL Annual Conference in Philadelphia, Pennsylvania to all conference attendees and members for an additional cost.

In September 2017, ISOQOL is scheduled to present this course to its first organizational client at Children's Hospital, Denver, Colorado. Thanks to the increasing awareness of this course from our pilot and pre-conference presentation and the efforts of our ISOQOL leadership, we have

identified several other presentation opportunities in Europe and Asia. Currently, we are developing our marketing plans to offer and sign-up other organizations. If you are aware of an organization that could benefit from this introductory course on patient-reported outcomes, please contact the ISOQOL Office at [info@isoqol.org](mailto:info@isoqol.org).



## PROMS RESEARCH CONFERENCE 2017

### **Advances in Patient Reported Outcomes Research Conference**

Thursday, 8 June 2017  
St. Anne's College  
Oxford, United Kingdom

The PROMs Research Conference includes a mixture of plenary sessions, oral presentations and posters by PROMs researchers from across the UK and Ireland. This unique event brings together researchers to engage with the latest PROMs advances.

To register and for more information on the conference visit: <https://www.kc-jones.co.uk/proms2017>



## AWARDS PRESENTED AT THE 2016 MEMBER BUSINESS MEETING

### PRESIDENT'S AWARD

The President's Award is presented to an individual who has advanced HRQOL research and has made outstanding contributions to the Society in one or more of the following areas: education of professionals, patients, or lay individuals about the value of HRQOL research; promotion or execution of HRQOL research or other scholarly activities; and facilitating or furthering policy initiatives that have an impact on HRQOL.

The 2016 ISOQOL President's Award was presented by President Claire Snyder to Carolyn E. Schwartz, ScD, United States. Dr. Schwartz has made notable contributions to the field of health-related quality of life research and ISOQOL.

### ARTICLE OF THE YEAR 2015 IN QUALITY OF LIFE RESEARCH

Since 2003, ISOQOL has awarded the "Article of the Year" Award to recognize and honor the single best article dedicated to health-related quality of life (HRQL) research published in Quality of Life Research journal during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that advance state-of-the-art science in HRQL theory, methods, clinical application, or policy.

#### First Place

Costa, D.S.J. Reflective, causal, and composite indicators of quality of life: A conceptual or an empirical distinction? Qual Life Res 2015; 24: 2057

#### Finalists:

Devine, J; Otto, C; Rose, M; Barthel, D; Fischer, F; et al. A new computerized adaptive test advancing the measurement of health-related quality of life

(HRQoL) in children: the Kids-CAT. Quality of Life Research 2015; 24 .4: 871-884.

Brundage MD, Smith KC, Little EA, Bantug ET, Snyder CF; PRO Data Presentation Stakeholder Advisory Board. Communicating patient-reported outcome scores using graphic formats: results from a mixed-methods evaluation. Qual Life Res. 2015;24(10):2457-72.

### NEW INVESTIGATOR & STUDENT PRESENTATION AWARDS

#### New Investigator Oral Presentation Award

Chris Gibbons, PhD, University of Cambridge, United Kingdom  
*All CATS are grey in the dark: a novel approach to evaluating computer adaptive tests (CATs) in the real world*

#### New Investigator Poster Presentation Award

David Riedle, PhD, Medical University of Innsbruck, Austria  
*Cancer patients' understanding of their individual quality of life scores using graphical presentations*

#### Student Oral Presentation Award

Laura Pinheiro, MPH, University of North Carolina at Chapel Hill, United States  
*The Prognostic Value of Health-Related Quality of Life on Survival: A prospective cohort study of older Americans with lung cancer*

#### Student Poster Presentation Award

Elisavet Moschopoulou, PhD Student, Queen Mary University of London, United Kingdom  
*Post-Traumatic Stress in Head and Neck Cancer Survivors*

### OUTSTANDING POSTER ABSTRACT AWARDS

The top six (6) posters that scored the highest during the ISOQOL 23rd Annual Conference abstract review process were recognized with a ribbon posted on their poster board and were invited to display their poster throughout the entire conference and present in front of a panel of judges and the attendees at the Annual Conference.

#### Outstanding Poster Abstract Award Winner:

Dagmar Amtmann, PhD, University of Washington, United States  
*Development of an item bank to measure pain catastrophizing*





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MANAGEMENT**



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LICENSING**



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TRANSLATIONS**

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## 2017 ANNUAL CONFERENCE TRAVEL SCHOLARSHIP OPPORTUNITIES

### DEVELOPING COUNTRY & STUDENT AND NEW INVESTIGATOR SCHOLARSHIP

#### APPLY HERE

Eligible applicants for the Developing Country Scholarship must be current ISOQOL members, and hold their primary residence in one of the eligible emerging and developing countries. List of [Eligible Countries](#).

Eligible applicants for the New Investigator Scholarship must be current ISOQOL members, and either a current student or new investigator (within 5 years of completing terminal degree or medical residency).

### PATIENT ENGAGEMENT SCHOLARSHIP

#### APPLY HERE

In order to contribute to the advancement of patient engagement in outcomes research, ISOQOL has funding for selected patient partners with relevant experience to attend the ISOQOL 24th Annual Conference. The primary objectives for this participation are to:

- Collaborate with the Patient Engagement Special Interest Group (SIG) to develop educational programs and tools suitable for patient partners and researchers.
- Support the development and implementation of activities related to the active engagement of patient partners in research of relevance to the ISOQOL community.

Patient partners will be selected based upon their experience as active partners in research programs (particularly those of relevance to the ISOQOL community), and their potential to contribute to the development of the ISOQOL patient engagement initiative both during this conference and in the future. In this context, we are defining patient partners as patients who have actively contributed to the design, development, delivery and/or evaluation of research projects and not solely as patients who have participated as research participants.

This application is not complete without a letter of reference from an ISOQOL member who is nominating you & will accompany you to this meeting. Please address the letter to the Scholarship Committee and e-mail or mail it to the ISOQOL office. If sent via email, please use "Patient Engagement Scholarship Application – Surname" for the subject of the message and send to [info@isoqol.org](mailto:info@isoqol.org). If mailed, send to the office address is 555 East Wells Street, Suite 1100, Milwaukee, WI USA 53202.

#### **Scholarship Application Deadlines:**

Applications must be completed online by **Wednesday, 31 May 2017 at 11:59 pm CDT**. Applications will be reviewed by the ISOQOL Scholarship Committee. Decisions will be made in June. Scholarship funds will be provided following the conference. Advance funds will not be available.

Please direct any inquiries for the scholarship application process to [info@isoqol.org](mailto:info@isoqol.org).

Visit the [scholarship page](#) of the annual conference website for more information.



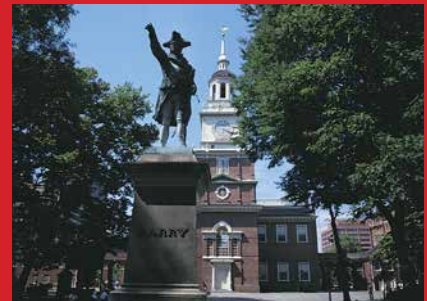
# EXPLORE PHILLY



Snap a photo in front of the  
Liberty Bell



Enjoy a  
Philly cheesesteak



Tour Independence Hall

Dine on food at the  
Reading Terminal Market

Visit the museums on  
Benjamin Franklin Parkway

Visit the LOVE sculpture  
in Dilworth Park



## MEMBERS' CORNER

### WELCOME TO OUR NEWEST ISOQOL MEMBERS

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Corinne Eldridge

Joel A. Finkelstein, MD

Poorna Kushalnagar, PhD

Adelina MA Lear, BA (Joint Hons)

Linda McBride, R.Ph. RAC

Maruschka P. Merkus, PhD

Christel Naujoks, MSc, MPH,  
MHlthEcon,

Peter Newcombe

Evalill Nilsson

Kjersti Oterhals, RN, ICN, Msc, PhD

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## THE VALUE OF BEING AN ISOQOL MEMBER

As a member you belong to a global community of researchers, clinicians, industry professionals, government leaders, patients, and other professionals who share your passion for quality of life research.

ISOQOL membership provides access to a collection of tools, resources, content, development opportunities, and a vibrant community of peers.

### BENEFITS OF MEMBERSHIP:



#### Tools and Resources

Free Access to the online subscription to the Quality of Life Research Journal  
Discounted print subscription to Quality of Life Research  
Access to ISOQOL's official open access journal, Journal of Patient-Reported Outcomes  
Updates from ISOQOL's newsletter – Quality of Life Quarterly  
Discounted access to PRO and QoL Instruments Database



#### Grow

Online Education with reduced rates  
Discounted Annual Conference registration  
Discounted Measuring What Matters registration  
Reduced rate for Introductory to Patient-Reported Outcomes Course (IPRO)



#### Connect

Serve in leadership roles and sit on ISOQOL Committees and Initiatives  
Participation in Special Interest Groups (SIGs) with access to Teamwork  
Access to ISOQOL membership directory and listserv



[Renew your Membership Today](#)

## 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 include:

Australia  
Canada-PRO  
Child Health  
Health Preference Research  
Ibero America  
Industry  
Mixed Methods

New Investigators  
Patient Engagement  
Psychometrics  
QOL in Clinical Practice  
Response Shift  
Translation & Cultural Adaptation  
United Kingdom & Ireland

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 AWARD NOMINATIONS 2017

### *ISOQOL IS NOW ACCEPTING NOMINATIONS FOR THE FOLLOWING AWARDS:*

#### **EMERGING LEADER AWARD IN HONOR OF DONNA LAMPING**

##### **Nominations due**

**Wednesday, 31 May**

The Emerging Leader Award recognizes ISOQOL members who have been active in an ISOQOL committee, special interest group (SIG), task force or working group for at least 2 years and who have shown exceptional leadership skills and potential.

**Nominations:** Both peer and self-nominations will be accepted. In addition to a nomination letter, a two-page curriculum vitae (CV) is required.

**Note:** Current and previous ISOQOL Board members are not eligible for the award.

##### **Eligibility Criteria:**

A person will be eligible for the Emerging Leader Award if s/he:

- is a current ISOQOL member
- has been active in an ISOQOL committee, special interest group, task force or working group for at least 2 years (but has not been a member of the ISOQOL Board)
- has completed his/her PhD (or equivalent), MD, or Master's degree within 10 years of application
- has demonstrated leadership in an ISOQOL activity by playing a key role in initiating and/or steering a specific task or project to successful completion

#### **ISOQOL PRESIDENT'S AWARD**

##### **Nominations due**

**Wednesday, 31 May**

The ISOQOL President's Award honors outstanding contributions to the advancement of the quality of life field in one or more of the following areas:

- Education about the value of quality of life assessment as related to health
- Promotion or execution of quality of life research or other scholarly activities
- Facilitating or furthering policy initiatives that impact health-related quality of life

**Nominations:** President's Award nominations should include a letter specifying the nominee's contribution, the CV of the nominee and an external letter of support.

For more information and nomination package requirements, visit the ISOQOL Awards Page.

Questions should be directed to the ISOQOL Office at [info@isoqol.org](mailto:info@isoqol.org) or by telephone at +1 (414) 918-9797.



24<sup>TH</sup> ANNUAL CONFERENCE

18–21 October 2017  
*Philadelphia, Pennsylvania*

UNITED STATES

# SAVE THE DATE



## *Abstract Submission Deadlines:*

WORKSHOP & SYMPOSIUM SUBMISSION — 30 JANUARY  
ORAL & POSTER ABSTRACT SUBMISSION — 17 APRIL

