

# Quality of Life

QUARTERLY

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VOLUME 20 ISSUE 4

Newsletter for  
ISOQOL Members  
FALL 2014



## PRESIDENT'S MESSAGE

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



Dear ISOQOL Members,

I am just now managing to pause and reflect on the recent ISOQOL annual confer-

ence. What a great time I had, with stimulating scientific sessions, talking to a lot of like-minded friends and enjoying the fascinating city of Berlin. I hope many of you had a similar exciting and stimulating time. The conference was a true demonstration of the strength and diversity within our society.

In Berlin we had five hundred and twenty-four delegates attend the conference, with an additional 10 delegates attending the German workshop. This makes 2014 one of the most well attended meetings of our society.

New this year was our Patient Engagement Scholarship Awards. The Patient Scholars joined us to incorporate a new dimension to

our Industry Advisory Committee Symposium panel and the World Café II. We thank both scholar winners and the patient research partners for the participation and insight.

I would like to congratulate Susan Bartlett, PhD and Jordi Alonso, MD PhD for putting together an outstanding conference program, celebrating the 21st Anniversary of ISOQOL. Thank you both and the other members of your committee for the time and dedication you invested in planning the stimulating plenary and oral sessions, the well-organized poster sessions, and lively interactions. I would also like to thank all the speakers, panelists, and attendees. It is their participation and support that made the conference a true success.

Nearly 214 of our conference attendees responded to the online survey evaluating the conference and providing some excellent suggestions for future conferences. Ninety-six percent of those responding rated the conference good to excellent!

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

Many thanks for taking the time to share your experiences and ideas. By providing your detailed feedback, we can advance the program for future conferences. This information will be forwarded to Ida Korfage and Carolyn Gotay, the 2015 conference co-chairs. Please SAVE THE DATE – 21-24 October 2015 for the next ISOQOL annual meeting in Vancouver, British Columbia, Canada.

On behalf of the Board of Directors, I would also like to thank our sponsors and exhibitors for their support of our society. Through your sponsorship, we are able to expand and enhance the conference and program. We thank you for the wonderful support in 2014 and look forward to an ongoing partnership with you.

As we move to 2015, I would like to invite our members to become more involved in the various committees and Special Interest Groups (SIG).

Both our committees and SIGs play an active role on the various tasks to advance our mission. As you renew your dues for 2015, 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.

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](mailto:g.velikova@leeds.ac.uk) or through our Executive Director, Colleen Pedersen, at [cpedersen@isoqol.org](mailto:cpedersen@isoqol.org). I look forward to the coming year and serving you as President.

Best Wishes,

Galina Velikova, MD PhD FRCP  
ISOQOL President



## **ISOQOL STAFF CHANGES**

Heather Vitale will be moving to another position within Executive Director, Inc. While we wish her the best in her new position, we will truly miss her guidance, dedication and enthusiasm over the past three years. Her hard work was very evident with the success of the ISOQOL Annual Conferences. We thank her for her diligence and support of ISOQOL.

We would like to announce that Michelle Holm has accepted the position of Meetings & Membership Manager. Michelle has worked with ISOQOL as the Administrative Coordinator for the past year and has been supporting Heather on all aspects of Membership and the Annual Conference initiatives. Please help me welcome Michelle in her new role.

Both Heather and Michelle will be working together to create a smooth transition. Michelle has already begun to transition into the position but will officially be managing membership and the 2015 conference as of November 15<sup>th</sup>.



## FROM THE EDITOR'S DESK

By: Ana Popielnicki



Dear ISOQOL Family:

I am pleased to welcome you to the last 2014 issue of our *Quality of Life Quarterly*! It

was fantastic to see so many of you at our Annual Conference in Berlin this past October – you will find in this issue a wealth of information about the conference and our Society's ongoing initiatives and projects.

I believe we can all agree that the conference, and consequently this issue, was in perfect tune with ISOQOL's patient-centered and patient engagement initiatives. Check out the pieces reporting on the various activities of our Patient Engagement SIG such as the World Café, Patient Engagement in Research, and our very first Patient Scholars, as mentioned by Dr. Velikova in her President's Message. In their conference wrap-up, Drs. Susan Bartlett and Jordi Alonso

bring us a comprehensive account of the conference workshops, plenary sessions, receptions, and activities. Many thanks to both of them for their excellent coordination of the meeting.

What issue is complete without the contribution of our New Investigator SIG? Our thanks to Marc Jacobs and Catherine Bottomley! Their piece on the value of making connections and participating in the various events geared towards new investigators (such as the Tricks of the Trade meeting and the Mentor/Mentee reception held at the Annual Conference) is an excellent guide to networking in the industry.

In this issue you can also find all the information on this year's Awards recipients, as well as a listing of our new Leadership, and news on changes to our staff — we want to extend our most sincere thanks to Heather Vitale, who will be transitioning to another position at EDI, while welcoming Michelle Holm in her new role as Meetings and Membership Manager. We will miss you, Heather!! Welcome, Michelle!!

Please look for information on dues renewal and Special Interest Group membership, as well as check out our call for abstract reviewers 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. Please receive our best wishes for a safe and happy holiday season!

Enjoy your reading!

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

Ana Popielnicki  
Editor





## AWARDS PRESENTED AT 2014 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 2014 ISOQOL President's Award was presented by President Galina Velikova to Mirjam Sprangers, PhD from the Academic Medical Center in Leiden, Netherlands. Professor Sprangers has made notable contributions to the field of health-related quality of life research and ISOQOL. She has had a profound impact on many professionals in the field and her elegant and caring leadership style is a model for all leadership in the society.

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

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

The 2014 recipient of the ISOQOL Emerging Leader Award in Honor of Donna Lamping is Antonia Bennett, PhD from the University of North Carolina at Chapel Hill. President

Galina Velikova presented the award to Dr. Antonia Bennett at the Awards Presentation during the Members Business Meeting. Dr. Bennett is a rising star in patient-reported outcomes methodology. She is highly dedicated to ISOQOL and has consistently contributed both scientifically and programmatically to the organization.

### ARTICLE OF THE YEAR 2013 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

Bentley JP, Brown CJ, McGwin G, Sawyer P, Allman RM, Roth DL. *Functional status, life-space mobility, and quality of life: a longitudinal mediation analysis*. Qual Life Res 2013;22:1621-1632.

#### Second Place

Ferreira MLP, Almeida RMVR, Luiz RR. *A new indicator for the measurement of change with ordinal scores*. Quality of Life Research 2013; 22:1999-2003.

#### Third Place

Boyce MB, Browne JP. *Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review*. Quality of Life Research 2013; 22: 2265-2278.

### NEW INVESTIGATOR & STUDENT PRESENTATION AWARDS

#### New Investigator Oral Presentation Award

Skye P. Barbic, PhD, OT Canada. Friday 17 October, 4:00 pm - 5:30 pm (207) *Advancing Mental Health Assessment. What can modern measurement methods tell clinicians about adaptive responses of depression?*

#### New Investigator Poster Presentation Award

Claudia Rutherford, PhD, Australia. Friday 17 October, 3:25 pm - 3:45 pm Poster Session 2 (2082) *Mode of administration of patient-reported outcomes (PROs): a systematic review*

#### Student Oral Presentation Award

Martine H.P. Crins, Netherlands. Friday 17 October, 4:00 pm - 5:30 pm (206) *PROMIS: New Measures, New Populations. The impact of Dutch-versus English-language calibrations on theta estimates of the Dutch-Flemish PROMIS Pain Behavior and Pain Interference Item Banks*

#### Student Poster Presentation Award

Alaa M. Arafah, MSc, Canada. Thursday 16 October, 10:25 am - 10:45 am Poster Session 1 (1043) *What Matters to Women Living with MS in Saudi Arabia*



# A huge Thank You

to our departing ISOQOL Board Members for their  
profound leadership and dedication.

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## ISOQOL 2014: WELCOMES THE FIRST PATIENT ENGAGEMENT SCHOLARS!

*By: Sami McDonnell and Anne Lyddiatt*

The 21<sup>st</sup> ISOQOL conference in Berlin welcomed us as the 1st Patient Engagement Scholars to attend the scientific conference and share our perspectives as patient partners. Everyone from ISOQOL was very welcoming and inclusive from the moment we became Patient Engagement Scholars, with the result that we didn't feel like strangers upon our arrival – thank you. We experienced a fantastic level of engagement from many delegates at the conference and were able to share our experiences on individual and group levels. We thoroughly appreciated the opportunity to take part in some of the SIGs and the World Café on patient engagement. Sharing our experiences in health-care and research was a positive encounter that renewed our vigour for continuing involvement as patients. Collaborating with delegates at the conference has given value to the patient perspective and can only continue to flourish within the ISOQOL community and beyond. The conference program presented some very interesting symposia and sessions which we wished there had been more time to explore and learn



from. The poster exhibition across the days of the conference provided the opportunity to engage with individual delegates and explore some of the more intricate issues around patient engagement and the accessibility of research outputs for the general public on a global level.

The overarching feeling at the end of the conference is excitement for the future of patient and public engagement in research and healthcare. As the 1st Patient Engagement Scholars

we are enthused by the ISOQOL community's response to our presence and the future involvement of patients within the scientific community. The importance of the patient agenda has been recognised as integral to the work of academics and clinicians and we look forward to taking this forward to Vancouver next year!



ISOQOL MEMBERS AND LEADERSHIP WOULD LIKE TO THANK  
THE FOLLOWING ORGANIZATIONS FOR THEIR PARTICIPATION AND SUPPORT  
OF THE 21ST ANNUAL CONFERENCE.

Your support contributes to our mission and our education program!

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## WRAP UP FOR 2014 MEETING

The feedback has been tabulated, and by all accounts, attendees of the 21<sup>st</sup> Annual ISOQOL Conference entitled *Quality of Life (QOL): Advancing Measurement Science and Transforming Healthcare* found the meeting informative and worthwhile. A total of 524 attended the meeting with 169 first time attendees, making this one of the most highly attended meetings in recent memory. Most importantly, more than 96% of respondents rated the scientific program and networking opportunities good to excellent, with high marks as well to Berlin as our setting. Here we review some of the highlights of the 2014 meeting.

*Pre-Conference Workshops.* The workshops continue to be an important feature of Annual Meetings. This year 11 workshops were offered from basic through advanced levels, including a full day workshop in German hosted by Drs. **Matthias Rose**, **Sandra Nolte**, and **Felix Fisher**. In total, 225 people arrived early to participate in ISOQOL workshops.

*The Welcoming Reception* on Wednesday evening featured **Professor Monika Bullinger** of the University of Hamburg-Eppendorf with a Tribute to German Contributions to HRQL Research.



Beginning with a brief history of the city of Berlin, Professor Bullinger described the longstanding integration of QOL in research and medicine in Germany, along with current challenges. With Professor Donald Patrick, she proposed a toast to future directions and continuing collaborations among international QOL researchers to open the conference.

*2014 Plenary Sessions.* To increase awareness of ISOQOL as the leading scientific meeting on QOL/PRO research and of the critical role that our work plays around the globe, we invited a diverse group of thought leaders from outside and inside ISOQOL to share their expertise and innovative research. The four

plenary sessions were well attended and very highly rated. The opening plenary, *Contribution of PRO to Better Services and Better Societies*, with Drs. **Nick Black**, **Laurie Burke** and **Chris Forrest** provided rich examples of how PROs are used across nations to enhance medical outcomes and guide policy. Friday morning, Drs. **John Kirwan**, **Maarten de Wit** and **Lori Frank** presented their innovative efforts through professional organizations and funding opportunities to support the engagement of patients as full partners in research and measure development to improve decision-making by health-

*Continued on next page.*

And the winner of the 21<sup>st</sup> Annual Conference Evaluation Survey Amazon.com gift card is...

*Liv Marit Valen Schougaard*  
**Congratulations!**





care consumers and providers. Drs. **Thomas Willgoss**, **Jakob Bjorner** and **Claire Synder**, whose interesting abstracts received the top marks from reviewers, summarized their work for the *Cutting Edge Research* session. And the final plenary on Saturday featured Drs. **Carol Ryff**, **David Cella** and **John Brazier** who reflected on how careful evaluation of mental health and quality of life across populations has led to new opportunities to understand and enhance QOL and well-being globally. Many attendees commented specifically on quality of the speakers and the relevance of the topics addressed. It's clear that our plenary speakers set the tone for all other scientific communication activities, in particular the oral sessions, which were also well attended and very well rated.

*A Special Focus on Patient Engagement* One goal of this year's meeting was to highlight the important contributions and new opportunities afforded through patient engagement in HRQL research. This year, ISOQOL sponsored attendance by patient representatives Anne Lyddiatt (Canada) and Samantha Brace McDonnell (UK) to help champion patient engagement within ISOQOL. These activities continue to build on critical patient engagement efforts over many years by Drs. Kirstie Haywood and Sam Salek, chairs of the Patient Engagement SIG. ISOQOL's 21st annual conference was an historic moment in the history of the organization – and will be remembered as the year that PE was firmly introduced into the proceedings.

*Our Setting – One of Europe's Most Vibrant and Beautiful Cities.* Our location in Berlin, one of Europe's most vibrant and beautiful cities, offered great opportunities to enjoy German culture and hospitality. Our location in the heart of Mitte made it a short walk to sites like Museum Island, Brandenburg Gate, Unter den Linden, the Reichstag and Tiergarten Park. Our closing dinner at **Spiegelsaal (The Mirror Hall)** provided an insider's view into one of few remaining original dancehalls to survive World War II that are still operating today.

*A Note of Appreciation.* We wish to thank all who helped plan and coordinate this meeting to ensure its success -- **Heather Vitale** and **Colleen Pedersen** at ISOQOL, and the 38 members of our **Scientific Advisory Committee**, the **Workshop Committee** led by Dr. Nancy Mayo, **Mentor/Mentee** led by Dr. Cynthia Gross, and the many abstract review-

ers. We're including a special shout-out to **Matthias Rose** and **Sandra Nolte** who scouted venues, local speakers, and coordinated on-site activities. Our sincere appreciation to the many speakers, moderators, and poster presenters for sharing their time, passion and commitment to QOL research and helping to make this meeting a resounding success.

We feel deeply honored to have had the opportunity to serve as your Chairs for the 2014 meeting. We wish you continued success in your effort to improve QOL and other patient-centered outcomes, to develop innovative interventions, enhance care and promote the health of populations. We look forward to seeing everyone in the beautiful coastal seaport of Vancouver, Canada next fall!

Susan Bartlett and Jordi Alonso





# 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

VANCOUVER



## NEW INVESTIGATORS: LET'S GET CONNECTED!

By: Catherine Bottomley & Marc Jacobs, NI SIG Co-chairs

As a New Investigator (NI), one of the biggest challenges in your early career can be making strong professional connections. As the old saying goes, 'it's not what you know, but who you know', and whether you work in academia, industry or a clinical setting, connecting with the right people can open doors for you now and in your future career. The theme of connections was strong throughout the NI activities at this year's conference in Berlin and will become a focus of the NI SIG over the coming years.

During the *Tricks of the Trade* panel session, Carolyn Schwartz and Galina Velikova explained how professional collaborations were key to advancing their careers and encouraged them to explore different areas of research, as well as to challenge their own thinking. The two panellists also reminded us of the importance of support from family and friends when the going gets tough!

The *Mentor-Mentee reception* is a long-standing tradition at ISOQOL, and it is a great way for new investigators or students to spend some one-on-one time with a person well established in the QoL Research field. These connections can encourage discussion around future career options and independent advice on current projects, and often result in the formation of long-term professional relationships.

Ways in which to connect with other likeminded researchers was a topic widely discussed in this year's NI SIG meeting. We learnt that NIs enjoy and value the opportunity to network at conferences such as ISOQOL, but that it can be difficult to maintain these connections between conferences, or identify others in the same area of work amongst the hundreds of conference attendees. Potential solutions to these concerns were identified by members of the NI SIG and will become the focus for the SIG over the coming years. These included holding a conference workshop specifically for NIs (a great success in Denver) covering topics such as networking skills, presentation skills and critical feedback and mock grant reviews. Suggestions for methods of making and maintaining professional connections ranged from the implementation of a 'networking board' at future conferences, to the use of Facebook and the development of a 'connections website' so researchers with common interests can find each other.

So how can New Investigators get connected? Here are a few helpful hints:

- Get involved in the planning of meetings such as ISOQOL, whether this is volunteering to review abstracts or helping with the planning or hosting of webinars.
- Join a SIG; ISOQOL currently has nine SIGs and this is a great way to meet people with the same research interests as you and get involved in collaborations.
- Use opportunities at conferences to network. This could include talking to the authors of posters you find particularly interesting, asking the person next to you in the lunch queue about their favourite plenary session that day, or sitting with a group of people you don't know during a coffee break.
- Prepare a short 'elevator speech' describing your current activities and research interests in under one minute. This can help you feel more confident when introducing yourself to new people.
- Don't forget to swap details. Swap business cards or email addresses and make an effort to stay in touch after the conference. These connections have the potential to develop into long-term professional relationships and genuine friendships.

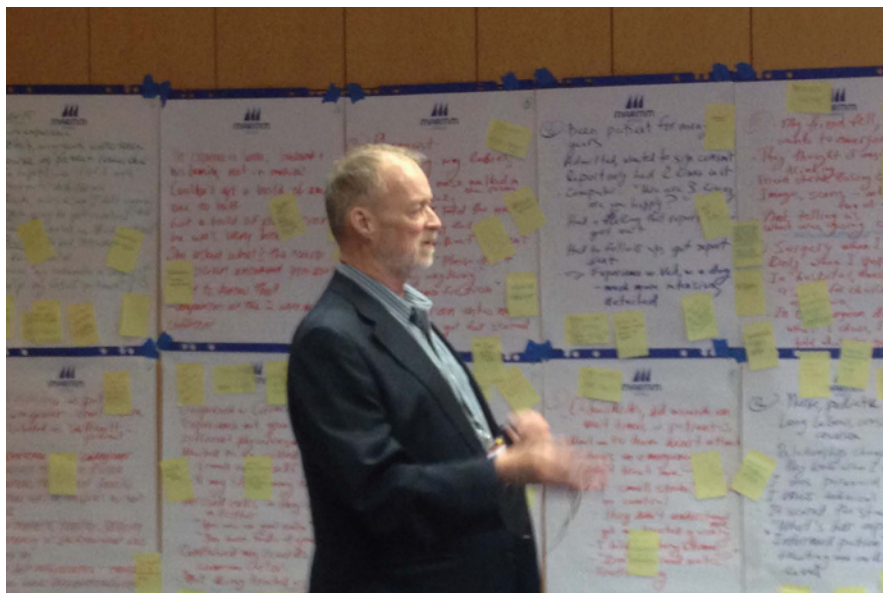


## A PATIENT-FACILITATED WORKSHOP INVITES CONFERENCE PARTICIPANTS TO EXPERIENCE PATIENT ENGAGEMENT METHODS

By Svetlana Shklarov, MD, PhD, ISOQOL Member and Patient Engagement SIG Member

A half-day workshop "How to Integrate Patient-Led Research in Your Health-Related Quality of Life Studies?" was delivered on October 15, 2014, for the ISOQOL 21st Annual Conference in Berlin.

Workshop facilitators and organizers (University of Calgary, Canada): Colin Penman & Sandra Zelinsky (PaCER facilitators), Nancy Marlett, Svetlana Shklarov and Maria Santana.



The international trend toward patients' active involvement in quality of life research was reflected in the activities of this year's ISOQOL 21st Annual Conference in Berlin. The Conference welcomed a number of patient collaborators, included a remarkable Plenary Session on integrating patients into PRO development and research, hosted a second Patient Engagement Café facilitated by the PE SIG, and set a precedent for patient partners presenting findings of their own, patient-led research.

In tune with these groundbreaking activities, patient engagement researchers from Calgary, Canada, invited workshop participants – health professionals, patient representatives, and quality of life researchers – to explore patient-led research methods first-hand. This workshop was delivered by patient members of the

Patient and Community Engagement Research Program (PaCER) at the University of Calgary: Colin Penman and Sandra Zelinsky, who organized this learning event together with their academic colleagues Nancy Marlett, Svetlana Shklarov and María Santana.

In the PaCER program ([www.pacer-innovates.ca](http://www.pacer-innovates.ca)) patients interested in health research and reform complete a one-year internship where they learn adapted qualitative methods and complete research projects in collaboration with sponsoring research teams. Many PaCER graduates are now employed by various research teams and conduct multiple patient-led research studies that are solicited and supported through academic and health care improvement initiatives.

All PaCER research studies begin with a "set" focus group, in which patient participants are asked to help

set the direction of a study by sharing their experiences, and by contributing to research planning. This "set" activity is a dynamic (usually full-day) group event that helps guide the content and process for the next stages of each particular study.

The workshop's presenters chose a "set" focus group as an illustration experience, inviting the attendees to participate in a short three-hour "imitation" group. To facilitate a true experience of engagement, workshop presenters suggested a discussion area that was expected to be familiar and important for the attendees: "Health professionals as patients: Do dual roles influence quality of life?" Participants were encouraged to bring their lived experience and use their research curiosity to explore this topic. In the second part of the session, participants discussed and analyzed general ideas gathered from the group's input, imagining what kind of research could come from this focus group session, and brainstorming how such an imaginary study could be set.

This simulation process exposed workshop attendees to a regular PaCER practice. The PaCER method is designed to facilitate a co-creation of knowledge by engaged peers – people who share an experience, commonly patients. Through peer-to-peer sharing, patient participants in PaCER research are encouraged to become co-researchers and together look at emerging ideas.



*A patient-facilitated workshop invites conference participants to experience patient engagement methods, Continued from previous page.*

The workshop focus group appeared to run almost exactly as it would in a standard PaCER setting. The level of engagement was remarkable. At the end of the workshop, the response of the group was overwhelmingly positive. The issue had piqued everyone's curiosity, skilled facilitation helped direct the discussion, and the

inquisitive minds of workshop participants – professional researchers and patient attendees – took up the challenge. Together the group came up with rich, productive ideas.

According to the final remarks by the attendees, one major outcome was their increased understanding of the effects that patients' peer-to-peer

engagement can have in producing important knowledge. There was also an agreement that competent facilitation by trained patient researchers helped achieve this outcome. This workshop experience illustrated the revolutionary new roles that patients can take in patient-led research.



## INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH SEEKS APPLICANTS FOR NEW CO-EDITOR-IN-CHIEF FOR *QUALITY OF LIFE RESEARCH*

Quality of Life Research (QLR) is the official journal of the International Society for Quality of Life Research (ISOQOL), and is one of the key international outlets for research in health-related quality of life and health outcomes. The journal is published 12 times a year by Springer, one of the largest publishers of scientific books and journals. In 2014, the journal received 1137 manuscript submissions and published 226 manuscripts. The journal editorial board is currently composed of two co-editor-in-chief (EiC), and 12 associate editors (AE's) representing a broad range of professional disciplines and research areas. The EiCs are responsible for overall editorial policy, planning and coordination. The day-to-day responsibilities of the EiC include: (1) initial screening of manuscript submissions for relevance and quality; (2) assignment of manuscripts to members of the editorial board (including him/herself) for further peer review; (3) maintaining close contact with the editorial office at Springer, which coordinates the logistics of the editorial management process; and (4) advising the editorial board and the editorial management team on matters arising both of a general policy nature, and regarding specific manuscripts. The term is for 3 years with the possibility of one successive 3 year term. The editorial management process – from initial manuscript submission to final editorial decision – is now fully automated, making use of Editorial Manager, a sophisticated, web-based system. The Springer team provides excellent logistical support to the EiC and the AE's.

The next EiC will work with the current EiC to continue to lead of an already outstanding and well functioning journal. At the same time, the incoming EiC will be expected to put his/her own imprint on the journal. There will be opportunities to expand or shift the editorial focus of the journal, and to create new journal features. Importantly, the responsibilities and tasks of the EiC are primarily scientific in nature; responsibility for the business and financial management of the journal rest with the publisher and the ISOQOL board and executive management team.

The journal is seeking a Co-Editor-in-Chief with a strong scientific background in the field of health-related quality of life and health outcomes research, with a keen interest in and commitment to a rigorous but equitable peer-review process, and preferably with previous editorial experience. The applicant should be in a position to commit a substantial and sustained amount of time (minimally, 10 hours per week) to the journal. The Co-Editor-in-Chief position receives an annual stipend.

The new Co-Editor-in-Chief begins work on the journal in June of 2015.

**Please email [info@isoqol.org](mailto:info@isoqol.org) for additional information regarding this position.**

**Applications for the Co-Editor-in-Chief position should be sent to the ISOQOL office at [info@isoqol.org](mailto:info@isoqol.org).**

**The application period is open until January 30, 2015.** The application should include a cover letter describing the applicants' interest in the position, outlining his/her ideas for the future of the journal, names of two references relevant to the position, and a curriculum vitae.





## Validated translations of PRO instruments equal validated results.

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## VALUING PATIENT ENGAGEMENT

*Kirstie L Haywood, Sam Salek, Anne Lyddiatt, Samantha Brace-McDonnell, Sophie Staniszevska.*

Last year's ISOQOL conference in Miami hosted the first 'Patient and Public Engagement Café', providing an opportunity for conference delegates to explore and share international experiences of Patient Engagement (PE) in research and highlighting the challenges and opportunities associated with such activities. The findings from the Café have recently been published in *Quality of Life Research* [1], and have been key to informing the future direction of the new PE Special Interest Group as well as the direction of travel for PE within the ISOQOL community. The key messages were that members of the ISOQOL community are very keen to embrace PE, but good practice guidance does not exist, the evidence-based demonstrating the value of PE is limited, and that patients had not been involved in the process!

In response, the PE SIG embraced two key challenges during 2014:

- 1) Finding a way to ensure that we had patient partners at the next ISOQOL conference!
- 2) Working together with the ISOQOL community to create a framework for PE in health-related quality of life and PRO-related research. This framework would seek to provide guidance to embed PE within HRQL and PRO research, support rigorous evaluation, and include the patient's voice in the process.

### PATIENT ENGAGEMENT SCHOLARSHIP

Informed by examples of good PE within other organisations, we were inspired by the exemplary work of OMERACT (Outcome Measures in Rheumatology – [\[act.org/\]\(http://act.org/\)\), who have involved patient research partners as active members of their research community for the last 10 years. The first meeting to involve patients as partners had a core of 10 patient research partners \[2\] – this was our target for ISOQOL 2014! But how could we do it? The ISOQOL Executive Committee were wonderfully responsive to the active lobbying from the PE SIG, agreeing to the first PE Scholarship Award \(a total of \\$4,000\), advertised to the community in May 2014. The response was outstanding, resulting in nine truly inspirational applications – if only we could have awarded a scholarship to all applicants! Following a transparent assessment process undertaken by the PE Scholarship panel \(Sam Salek, Kirstie Haywood, Cindy Gross and Sandra Beurskens\), our first two PE Scholars were selected: Anne Lyddiatt \(Canada\) and Samantha Brace-McDonnell \(UK\).](http://www.omer-</a></p></div><div data-bbox=)

In addition to the PE Scholarship, members of the ISOQOL community were pro-active in finding alternative solutions to supporting the attendance of patient partners at the conference, with the result that we enjoyed a core of seven patient partners who were in attendance throughout the conference, with a maximum of 12 participating in the PE Café II!

We set our patient partners a task of fully engaging with the conference – to let us know how 'patient partner friendly' the conference is – and how we can improve! (Please see the article by Sami and Anne in this edition of the Newsletter). Whilst not wishing to detract from the scientific heart of the conference, if we are serious about patient engagement, then we need to understand how to improve engagement opportunities

for our patient partners. Again, we have a lot to learn from other 'scientific' conferences which have made great steps forward in engaging with patients. However, we also wish to understand more about the experiences of the wider ISOQOL community. Please do have your say and complete the PE Survey which will be landing in your email inbox any day! The results from the evaluations will be analysed and communicated to the ISOQOL Executive Committee, with the intent to further inform the way in which ISOQOL – the conference and the community – can enhance future PE activities. These are exciting times!

### A FRAMEWORK FOR PE

Patient Engagement (PE) is viewed by many as a social process in which we must seek to develop relationships and build trust between all partners [3]. Experience from the wider world of PE research would suggest that there are three essential stages in developing a framework for good PE:

1. Values: provide an explicit statement of the principles that should underpin good PE.
2. Standards: define the measurable standards against which practice will be assessed.
3. Methodological guidance: provide evidence-based road map for how to do it.

Step 1, exploring the values that should underpin good PE in research of relevance to the ISOQOL community, provided the focus for this year's PE Café, and was developed as a collaborative activity between members of the PE SIG (KH, SS, SSt) and the PE Scholars (AL, SBM). We sought to engage with delegates to explore why

we do PE, and to better understand the values associated with the doing and/or consequence of PE that are important to the ISOQOL community. Awareness of the wide range of values that exist is important – since differing values can influence the approaches to PE adopted and hence the potential impact [4]. Moreover, an explicit statement of values supports everyone in understanding their role in an activity [5,6]. It was recognised that the audience would be a mix of academics, health professionals, industry representatives and patients. Therefore, it was agreed that it would be of interest to separately explore, recognise and understand the values held by these different groups. The team felt that a good way of facilitating a full exploration of values was to invite the patient partners to form one group.

The symposium was led by Dr Kirstie Haywood (University of Warwick) and Anne Lyddiatt (PE Scholar, Canada), and chaired by Professor Sam Salek (Institute for Medicines Development, Cardiff). They were joined by a total of 12 patient research partners, including Samantha Brace-McDonnell (PE Scholar, UK), with further support from other members of the PE SIG, including Drs. Cindy Gross and Skye Barbic. The three plenary speakers for the PE session, Professor John Kirwan (OMERACT; Consultant Rheumatologist, UK), Dr Maarten de Wit (OMERACT; patient research partner) and Dr Lori Frank (PCORI) joined in with the event, together with 80 other ISOQOL Conference delegates.

To support this year's PE Café, reference was made to a recent synthesis of the values associated with PE in health and social care research produced as part of the UK-

funded Public Involvement Impact Assessment Framework (PiiAF) [4]. Participants were asked to consider three broad value systems associated with PE, and the relevance to the ISOQOL community: i. Process values – concerned with why we do PE; ii. Substantive values – concerned with the impact or consequence of doing good PE in research; and iii. Normative values – associated with the moral, ethical and/or political concerns of doing PE. The café setting provided a fun and enjoyable opportunity to explore these concepts; however, it was evident from the wide-ranging conversations that these were tricky issues to discuss and that more time was required to explore the issues raised in detail. Moreover, a clear illustration of 'values in action' was enacted following the 'first course' – when a spokesperson for the 'patient partners' made a clear plea that the patient partners should be integrated with other participants and not at a separate 'patient partners table'! The response was immediate and positive – a real illustration of the values of partnership, respect, openness and honesty in action! Professor John Kirwan (a founding figure for the OMERACT initiative) commented: 'It took OMERACT two-years to realise that patient partners should be integrated and not kept at a separate table – but it took ISOQOL just 20 minutes!'

The 'Wall of Engagement' made a welcome return – with all participants encouraged to write their thoughts and suggestions on sticky labels that were subsequently attached to the 'wall' (please see picture!). Participants clearly enjoyed the opportunity provided by the World Café format to meet with other delegates

– including the patient research partners - and to explore important issues of relevance to the community. The activity will result in a core set of values to underpin good PE which we hope will be endorsed by the ISOQOL community. The results will be presented to the community at next year's annual conference.

The 2014 Conference was a historic moment in the 21-year life of ISOQOL and will be remembered as the year that PE in PRO research was introduced with a Big Bang. All our patient partners, in particular our Scholars, were absolutely brilliant with their active participation, enthusiasm and passion which radiated throughout the Conference ensuring that this becomes a permanent feature of the future meetings of the ISOQOL and of its strategy.

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#### PICTURE:

ISOQOL 2014 PE Café and the Wall of Engagement: (from left to right) Sam Salek, Anne Lyddiatt (ISOQOL PE Scholar), Caroline Burdett (Patient Research Partner), Carolyn Morris (Patient Research Partner), Samantha Brace-McDonnell (ISOQOL PE Scholar), Kirstie Haywood.



## CALL FOR ASSOCIATE EDITORS

The journal *Quality of Life Research* is seeking to recruit two new Associate Editors to begin a three-year term in early 2015. Eligible persons will have published scientific works in *Quality of Life Research*, will have served as a reviewer in good standing for the journal, and will be committed to working on our editorial board team to improve the quality and efficiency of manuscript processing as well as the impact of the journal. If interested, please send to the Co-Editors-in-Chief at your earliest convenience, your updated curriculum vitae and a cover letter stating your background in quality of life research, your areas of expertise, and your reasons for seeking the role of Associate Editor for the journal. We are in particular seeking Associate Editors with generalist expertise (i.e., expertise in multiple domains/applications) as well as specialists with expertise in neurology, geriatrics, utilities, and rehabilitation.

Thank you.

Carolyn Schwartz, Sc.D., and Dennis Revicki, Ph.D.

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