



Quality of Life

QUARTERLY

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PRESIDENT'S MESSAGE

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



Dear ISOQOL Friends,

It is very exciting to hear of the great plans for the 21st ISOQOL Annual Conference

in Berlin, Germany. You will not want to miss this exhilarating event. The scientific program committee (led by co-chairs Jordi Alonso, PhD and Susan Bartlett, MD) have brought together an incredible set of speakers that will cover a broad range of highly informative and cutting-edge topics in health-related quality of life (HRQOL) research.

On Wednesday, 15 October prior to the conference, you can expand your knowledge and skills by attending the highly acclaimed workshops offered. Please make sure to register early to ensure a spot at the various workshops.

Our conferences always end in a wonderful dinner and party to celebrate a successful conference. Join

us this year in the Mirror Hall of Spiegelsaal in Clarchens Ballhaus. The dance hall opened in 1913 and was the place for aristocrats to dance. Closed during WWII, it was reopened in 2005 and has been left largely untouched since the war. Please join us for dinner as we go back in time at the grand Mirror Hall. After dinner, stop downstairs in Clarchen's Ballhaus to dance the night away.

The Annual Conference is a wonderful opportunity to learn about fellow ISOQOL members' research findings during oral presentations and poster sessions, as well as to meet old friends and make new ones. Registration for the conference is open and may I ask that you serve as our ISOQOL ambassadors and *spread the word* to your colleagues about our conference. There are PDF documents available for download on our website: <http://www.isoqol.org/2014conference>

ISOQOL would also like to extend our deep appreciation to Rebecca Brandt

Continued on page 2.

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Newsletter for
ISOQOL Members
SUMMER 2014





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

Newsletter Editor

Ana Popielnicki, BA, USA

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

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President's Message, Continued from page 1.

for her guidance and dedication over the past three years. She will leave ISOQOL to work with another client at EDI. We thank her for her hard work in support of ISOQOL and our mission.

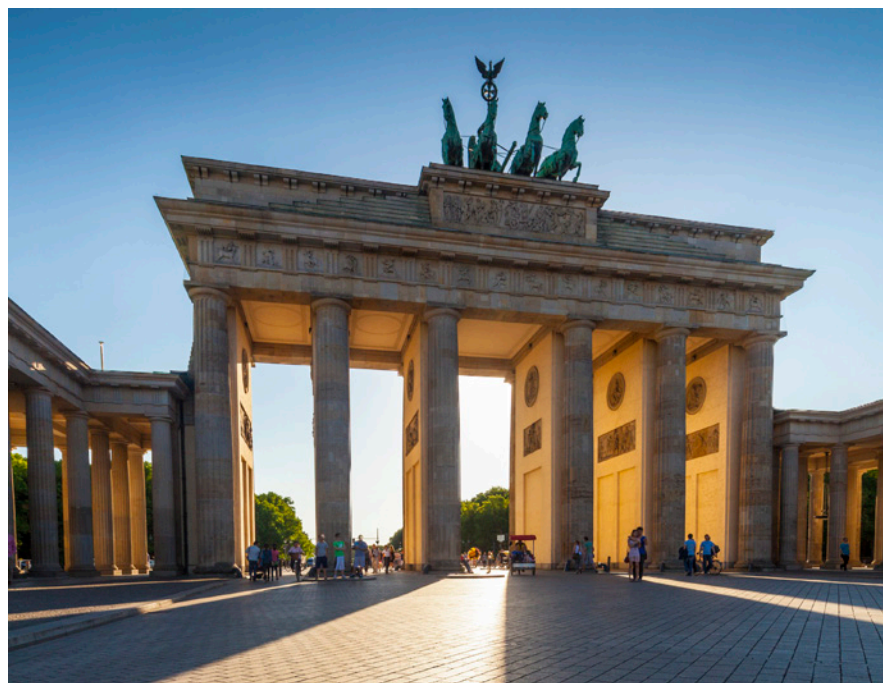
I would also like to introduce Colleen Pedersen as ISOQOL's new Executive Director. Colleen and Becky are working together to ensure a smooth and seamless transition. We welcome Colleen as part of our leadership team.

It has been a busy year and I would like to take this opportunity to thank the leadership of our committees and SIGs for their ongoing dedication to

the society. Our special thanks to Jordi Alonso and Susan Bartlett for their relentless and yet imaginative hard work. I am excited about the possibilities facing ISOQOL in 2014 and I hope you will consider joining us by engaging in new ways to share your knowledge with your colleagues.

Sincerely,

Galina Velikova, MD PhD FRCP
ISOQOL President



Are you planning to explore Berlin before or after the annual conference? [Visit Berlin](#), has a great list of sites and attractions in Berlin.

FROM THE EDITOR'S DESK

By: Ana Popielnicki



Dear ISOQOLers:
Welcome to the Summer (or Winter, as the case may be in your particular country)

2014 issue of our *Quality of Life Quarterly*! We are busily getting ready for our Annual Conference, to be held as you know this October in Berlin, Germany. You will find important information about the conference in this issue.

In her President's Message, Dr. Galina Velikova gives us exciting details about the conference sessions and activities – many thanks to Jordi Alonso and Susan Bartlett, our Scientific Program Committee Chairs, for putting together a great program. Dr. Velikova also informs us of changes in our Executive Office: We join her in extending our deepest thanks and sincere appreciation to Becky Brandt, who will go on to another EDI client, while offering a warm welcome to our new Executive Director, Colleen Pedersen. Speaking of changes... the Board of Directors election results are in! Check out the power of your vote in this issue.

Many thanks to Katie Sommers, of the Plastic Surgery Foundation (PSF), for sending information on the Patient Reported Outcomes in Surgery (PROS) Conference. The event is being planned for January 2015 by the PSF, in collaboration with the American Society of Plastic Surgeons (ASPS), the American College of Surgeons (ACS), and our very own ISOQOL – please see details in this issue.

As we've all come to count on, of course we got the traditional contribution of our New Investigator SIG co-chairs, Marc Jacobs and Katerina Papageorgiou! Based on their own experience, they bring us handy tips for new investigators to ensure a productive and enjoyable conference stay – take note, these are truly golden ☺

Regarding information on our Annual Conference program, our Executive Office has provided details on registration, hotel reservations, workshops, the fabulous closing dinner, and SIG meetings. You will also find useful information on visiting Berlin – please look for the links included in the various informational pieces and ads.

As usual, please don't hesitate to contact us directly with questions, comments, or submissions for the autumn issue. Send your queries/comments to your Communications Committee at info@isoqol.org with "Newsletter" on your subject line. I look forward to seeing you all at the Annual Conference in Berlin!

Enjoy your reading!



Ana Popielnicki
Editor



PATIENT-REPORTED OUTCOMES IN SURGERY (PROS) CONFERENCE

The American Society of Plastic Surgeons (ASPS) and The Plastic Surgery Foundation (PSF), in conjunction with the American College of Surgeons (ACS) and the International Society of Quality of Life Research (ISOQOL), are convening the Patient-Reported Outcomes in Surgery (PROS) Conference, in Washington, DC, on January 29-30, 2015. The PSF was awarded an R13 Grant from the Agency for Healthcare Research and Quality to hold this conference.

The goal of the meeting is to stimulate discussion among stakeholders involved in the integration and interpretation of patient-reported outcomes in surgery. This will be one of the first opportunities for surgeons across all subspecialties to learn about how patient-reported outcomes are increasingly being in-

corporated into routine surgical care, quality metrics and comparative effectiveness research.

We anticipate engaging surgeons, quality of life researchers, psychometricians, information-technology experts, industry thought-leaders, and patient advocates in a multi-disciplinary exchange of ideas. The meeting will provide a unique opportunity for diverse stakeholders to interact and learn about each other's varied perspectives. Participants will consider challenges and opportunities and make recommendations for future research and collaboration to optimize and accelerate implementation of PRO measurement in surgery.

This one and a half day conference will include presentations by world-renowned quality-of-life researchers,

surgeons involved in PRO measurement, patient advocates, payers, device industry representatives, and regulators. Each panel will be followed by a discussion period that will engage stakeholders in thought-provoking dialogue. The meeting will conclude with a Mentoring Luncheon for faculty and trainees (surgical residents and junior quality of life researchers) to solidify the establishment of cross-disciplinary training relationships.

For more information, or to register for the meeting, please visit <http://www.the-psf.org/training/pros-conference.htm> or contact Katie Sommers (ksommers@plasticsurgery.org).



TIPS AND TRICKS TO ENSURE A PRODUCTIVE AND PLEASANT CONFERENCE STAY

By: Marc Jacobs & Katerina Papageorgiou, New Investigators SIG Co-Chairs

Some of you New Investigators have heard by now whether the Scientific Program committee has accepted your work as a poster, or perhaps, even as an oral. Meanwhile, the conference date comes closer and the ISOQOL website is updating conference information on a regular basis. For some, this will be their first ISOQOL experience. For others, the conference has by now become about catching up with colleagues and friends from abroad. In any case, regardless of experience, attending an ISOQOL conference can be daunting, especially since the number of conference attendees is getting higher each year. Hence, we want to use this issue of *Quality of Life Quarterly* to provide some tips and tricks that could help you have a fruitful and pleasant stay at beautiful Berlin, Germany.

- Prepare your conference schedule carefully – look up the symposia and presentations you would like to attend, people you wish to meet, and workshops you want to follow.
- Get to know other new investigators – not only will you learn more about their research, but you may also learn more about the conference, its attendees, and which bars you need to visit ☺
- Come to the Tricks of the Trade symposium – Galina Velikova, MD, PhD, FRCP (current president of ISOQOL) and Carolyn Schwartz, PhD will share with you their road to success and will make time to answer some of your questions.
- Get yourself a mentor during the Mentor/Mentee reception – it is by far the easiest and most straightforward way of asking a senior researcher about your research, doing research, being a researcher, and getting the most out of your conference stay.
- When presenting a poster – don't forget to bring handouts. In addition, make sure that everybody can clearly see who you are, where you are from, and how to contact you.
- Oral presentations are exciting. But they are never SO exciting that they need to become stressful to be successful. So enjoy it. And make sure those in the back can see and hear what you are talking about.
- Always wanted to meet that famed professor or that leading authority on your PhD subject? Go ahead and introduce yourself! Most of the time, these senior researchers are just as interested in you as you are in them.
- Make sure you get involved with a Special Interest Group (SIG) of your liking – chances are you will meet many new people, and these contacts often form long-lasting collaborations or even friendships.
- Don't be afraid to ask questions! It is a great way of getting involved during the conference.
- Remember – conference attendees are here to learn about new research and meet new people, so do not hesitate to approach people.
- Last but not least – have fun! Explore your surroundings and make sure there is enough room for leisure time.

For more tips and tricks, stay tuned with the New Investigators SIG!



Introducing the New Members of the ISOQOL Board of Directors

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ANNUAL CONFERENCE WORKSHOPS

All 21st Annual Conference attendees are invited to register for the workshops presented on Wednesday, 15 October. A ticket is required for each workshop, and can be purchased through the 21st Annual Conference registration form. Space in each workshop is limited, so please register early.

Workshops provide an in-depth, and often hands on approach to a wide range of focus areas in health-related quality of life and outcomes research.

New in 2014! All student conference registrations include one complimentary registration for the half

day workshop of your choice. Do not miss this excellent opportunity for a free workshop registration. Complimentary workshops must be redeemed on the registration form, prior to the advanced registration deadline.

If you have already registered for the Annual Conference and would like to add workshops to your registration, please contact the ISOQOL Executive Office.

Visit the Workshop page of the website for session descriptions and instructor information.

(<http://www.isoqol.org/2014conference/workshops>)



MORNING WORKSHOPS

Wednesday, 15 October, 9:00 am - 12:00 pm

- (WK01) An Introduction to Health-Related Quality of Life Assessment
- (WK02) Discrete Choice Experiments: Enhancing Patient-Reported Outcomes Beyond QALYS
- (WK03) Best Practices for Qualitative Methods for Patient-Reported Outcomes Research
- (WK04) Analyzing Longitudinal Quality of Life Outcome Data
- (WK05) Standardized Evaluations of Patient-Reported Outcomes: The EMPRO Methodology

AFTERNOON WORKSHOPS

Wednesday, 15 October, 1:00 pm - 4:00 pm

- (WK06) Introducing the Concept of Response Shift - An Overview of Theory & Methods
- (WK07) Translation Methodology for Clinical Outcome Assessments in Global Trials
- (WK08) Improving the Design of Clinical Trials with Patient-Reported Outcomes: Tips for Protocol Design and Review
- (WK09) How to Integrate Patient-Led Research in Your Health-Related Quality of Life Studies
- (WK10) Whose Quality of Life Assessment Data Should You Use? A Bayesian Testlet IRT Model Perspective

FULL DAY WORKSHOP (PRESENTED IN GERMAN)

Wednesday, 15 October, 9:00 am - 4:00 pm

- (WK11) Basics You Need to Know About Methods Used in Quality of Life Research



SPECIAL INTEREST GROUPS: MEETINGS IN BERLIN

Special Interest Groups (SIGs) offer all ISOQOL members a unique network of researchers who share similar interests within the field of health-related quality of life and outcomes research.

CHILD HEALTH

Chair: Katherine Bevans, PhD, United States

Primary interests are to stimulate excellent child health-related quality of life research (C-HRQOL), to increase awareness among the general ISOQOL membership of the importance of early health and the potential of child health concepts and methodological practices to foster improvements in health across the lifespan. Such methods/practices include non-patient observer reports/studies; integration of data from multiple reporters; cognitive interviewing methods; adaptations of instruments for respondents with low literacy, attention and other respondent problems; and long-term effects of health promotion interventions.

Child Health SIG Meeting

Saturday, 18 October; 7:30 – 8:45 am

HEALTH PREFERENCE RESEARCH

Chairs: Benjamin Craig, PhD, United States
Axel Mühlbacher, PhD, Germany

The purpose of the Health Preference Research SIG is to perform and promote educational activities and scientific research with respect to health and health-related preferences, and the promotion of all that is related thereto. The SIG will engage in organizational activities that support the growth and greater integration of preference research within ISOQOL and its membership.

Health Preference Research SIG Meeting

Friday, 17 October; 7:30 – 8:45 am

IBERO AMERICA

Chairs: Pedro L. Ferreira, PhD, Portugal
Monica Avila, MPH, Spain

The Ibero America SIG is open to any ISOQOL member residing in an Ibero American country. The SIG holds meetings on targeted issues pertaining to health-related quality of life research.

Ibero America SIG Meeting

Friday, 17 October; 5:45 – 6:30 pm

NEW INVESTIGATORS

Chairs: Katerina Papageorgiou, MSc, Netherlands
Marc Jacobs, PhD Student, Netherlands

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

- Create a network for investigators new to the field of quality of life
- Facilitate discussions, both theoretical and practical
- Help solve common problems at early stages of one's career

New Investigator SIG Meeting

Friday, 17 October; 5:45 – 6:30 pm

PATIENT ENGAGEMENT

Chair: Sam Salek, BSc RPh PhD FFPM

The purpose of the Patient Engagement SIG is to place greater emphasis on patients' voice in relation to ISOQOL activities and work with patient advocacy organizations and partners. The Patient Engagement SIG will work closely with the QOL in Clinical Practice SIG to achieve these goals.

Patient Engagement SIG Meeting

Friday, 17 October; 7:30 – 8:45 am

PSYCHOMETRICS

Chairs: Stefan J. Cano, PhD, United Kingdom
Lori McLeod, PhD, United States

The goals of the Psychometric SIG are to: 1) advance the science of HRQOL research through the application of psychometric methods; and 2) educate researchers and clinicians on the appropriate use of psychometric methods. The field of psychometrics plays a critical role in HRQOL research. Psychometrics play a key role alongside qualitative methods to develop and evaluate HRQOL measures. Further, structural equation models provide an incredible methodology for looking at associations among HRQOL variables or to model change over time when there are multiple endpoints or mediating/moderating factors.

Psychometrics SIG Meeting

Friday, 17 October; 5:45 – 6:30 pm

Continued on the next page.

SPECIAL INTEREST GROUPS: MEETINGS IN BERLIN, CONTINUED.

QUALITY OF LIFE IN CLINICAL PRACTICE

Chairs: Kirstie Haywood, DPhil BSc, United Kingdom
Colleen Norris, PhD, Canada

The Quality of Life in Clinical Practice Interest Group was formed by researchers and clinicians who are interested in using health-related quality of life (QOL) assessment to improve clinical practice. This focus includes using QOL assessment to manage individual patients as well as using QOL data for medical decision-making.

QOL in Clinical Practice SIG Meeting

Saturday, 18 October; 7:30 – 8:45 am

RESPONSE SHIFT

Chairs: Leah McClimans, PhD, United States
Ruth Barclay, PhD MHSc BMR (PT), Canada

The purpose of the response shift interest group is to bring together investigators and clinicians who are interested in the influence of response shift (a change in an individual's values, internal standards, and conceptualization of QOL) on QOL assessments. The ultimate objective is to better understand when and why response shift occurs such that healthcare professionals and researchers using patient reported outcomes across various disciplines can recognize and account for response shift.

Response Shift SIG Meeting

Friday, 17 October; 7:30 – 8:45 am

TRANSLATION & CULTURAL ADAPTATION (TCA)

Chairs: Sonya Eremenco, MA, United States
Mona Martin, RN MPA, United States

The overall objectives of the TCA SIG are to identify and advance research into practices and outcomes of translation and cultural adaptation of patient-reported outcome instruments; to provide an evidence database on translation and cultural adaptation of PROs; and to promote visibility of cross cultural issues in development and use of PROs in ISOQOL.

TCA SIG Meeting

Saturday, 18 October; 7:30 – 8:45 am



2014 ANNUAL CONFERENCE – CLOSING DINNER

Join us for the Closing Dinner on the last night of the Annual Conference. The Closing Dinner will be held at **Spiegelsaal (Mirror Hall)** in the Clärchens Ballhaus. Clärchens Ballhaus is one of few remaining, original Weimar-era dance halls to survive World War II and to still be in operation to this day.

Learn more about Spiegelsaal's rich history here: <http://www.spiegelsaal-berlin.de/history.html>

The Closing Dinner will be held on Saturday, 18 October from 7:00 - 10:00 pm. Tickets are required for this event and can be purchased through the registration form. Space is limited, so be sure to register for the Closing Dinner before tickets are sold out.





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2014 ANNUAL CONFERENCE REGISTRATION INFORMATION

Register today for the 21st Annual Conference and receive the advance registration discount. Advance registration is available through **15 September**.

Visit the [Registration page](#) for details and to access the registration form.

New in 2014! Lunch will be provided to all registered conference attendees on Thursday, Friday, and Saturday. Daily lunch will be served in the Poster Hall.

New in 2014! All student conference registrations include one complimentary registration for the half day workshop of your choice. Do not miss this excellent opportunity for a free workshop registration. Complimentary workshops must be redeemed on the registration form, prior to the advanced registration deadline.

Registration fees not only provide access to the Scientific Program of plenary sessions, oral and poster

presentations, and symposia; but there are several exciting highlighted events that are included in registration fees. These highlighted events can be attended at no additional fee, but pre-registration is required.

21ST ANNUAL CONFERENCE HIGHLIGHTED EVENTS

Highlighted events can be attended free of charge for all registered conference attendees. Pre-registration is required.

INDUSTRY ADVISORY COMMITTEE (IAC) SYMPOSIUM

Wednesday, 15 October, 4:30 pm - 6:00 pm

Advancing Measurement Science Beyond Patient-Reported Outcomes: Patient-Centeredness and Validity Across All Clinical Outcome Assessments

Symposium organized by: Sarah Acaster, MSc, United Kingdom; Steven Blum, PhD, United States; Emuella Flood, United Kingdom; William Lenderking, PhD, United States; and Josephine Norquist, MSc, United States

EXPERT PANEL DISCUSSION

Thursday, 16 October, 12:30 pm - 1:45 pm

Patient-Centered Outcome Measurement: Routes, Roadblocks and Roadmaps

Presenters: Laurie Burke, MPH, LORA Group, LLC, Royal Oak, MD, United States; Jeremy C. Hobart, PhD FRCP, Clinical Neurology Research, Plymouth University Peninsula Schools of Medicine and Dentistry, Plymouth, United Kingdom; and Stefan J Cano, PhD, Modus Outcomes, Newton, MA, United States

This Expert Panel Discussion will focus on the current state of play of patient-centered outcome measurement from the perspective of the three speakers. Speakers will first describe the significant progress that has been made during their working careers, and will then flag some concerning problems in the field, in particular, the ‘**routes**’ (i.e. competing methodologies) and ‘**roadblocks**’ (i.e., barriers preventing widespread take up of state of the art techniques). Speakers will introduce five key challenges: 1) which measurement paradigm to guide instrument development and evaluation; 2) how to recognize the limitations of psychometric “statistics”; 3) how best to measure change over time; 4) what sample sizes for scale development and evaluation studies; and 5) how to overcome the legacy of ‘legacy’ instruments. They will then go on to describe how the current best practice recommendations from the US Food and Drug Administration (the ‘**Roadmap**’) enables the development of clinically meaningful patient focused outcome measures.

Continued on the next page.

2014 ANNUAL CONFERENCE REGISTRATION INFORMATION, CONTINUED.

Mentor/Mentee Reception and Tricks of the Trade: Advice for New Investigators in Quality of Life

Thursday, 16 October, 6:00 pm - 7:30 pm

The ISOQOL mentoring program promotes career development and provides networking opportunities for students and new investigators within the society. Individuals interested in serving as a Mentor will pair up with students and new investigators that have signed up for the program. This reception provides a forum for the exchange of knowledge in a relaxed atmosphere. Refreshments will be provided.

Pre-registration is required for the mentoring program as participants will be matched prior to the conference. Sign up on the registration form or contact the ISOQOL Executive Office. **Registration for the mentoring program closes 15 August.**

The mentoring program will be immediately preceded by a presentation from the New Investigator SIG's *Tricks of the Trade: Advice for New Investigators in Quality of Life Research* series and segue into small group discussion with matched mentors and mentees.



RESERVE A ROOM AT THE ANNUAL CONFERENCE VENUE – MARITIM PROARTE BERLIN

The Scientific Program of the 21st Annual Conference will take place at the Maritim proArte Berlin Hotel. The hotel is located on the central shopping avenue, Friedrichstraße, just a few minutes off of the Spree River. This area offers a wide variety of restaurants and shopping ranging from designer fashion to souvenir shops. The U-Bahn (tube) stops a few steps outside the hotel, connecting you to all areas of the city. Several of the iconic Berlin attractions, such as the Museum Island, Alexanderplatz, Checkpoint Charlie, and the Brandenburg Gate can also be reached with a leisurely stroll.

Maritim proArte Berlin

Friedrichstraße 151, 10117 Berlin, Germany

Telephone: +49 (0) 30 2033-5

Reservations: +49 (0) 30 2033-4410

Website : http://www.maritim.com/en/hotels/germany/proarte-hotel-berlin/hotel-overview#hotel_content

The hotel is starting to sell out, so reserve a room as soon as possible to guarantee a sleeping room at the headquarters hotel.

Room Reservations

Conference attendees have been offered reduced sleeping room rates at the Maritim proArte Hotel. Use the reservation link below to reserve a room online.

Reservation Link

If you prefer to book by telephone, mention **ISOQOL** for the reduced room rate.

Room rates range from €149 - €169 for single occupancy. All guest rooms in the ISOQOL room block include the Maritim Breakfast Buffet, so there is a double occupancy fee of €38/room.

The discounted room rate will be available until the room block reaches capacity, or through **15 September 2014**. Reduced room rates cannot be guaranteed after this date.





ISOQOL
22nd Annual Conference
VANCOUVER
British Columbia, Canada
OCTOBER 21-24, 2015

VANCOUVER

Abstract Submission Deadlines:

Workshop & Symposium Abstract Submission—February 6, 2015

Oral & Poster Abstract Submission—April 24, 2015