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VOLUME 23 ISSUE 4

*Newsletter for
ISOQOL Members*

DECEMBER 2017



PRESIDENT'S MESSAGE

Jose M. Valderas, MD, MPH, PhD, University of Exeter



Dear
Colleagues,

I am really
honoured and
thrilled to be
your ISOQOL
President for
the next two
years. We

have so much ahead of us as we work
hard to find ways to improve quality
of life on a global scale.

ISOQOL Leadership feels energized
after an engaging and fulfilling
Annual Conference in Philadelphia
in October. I want to thank our
Scientific Program Co-Chairs
Roxanne Jensen and Kevin Weinfurt
for helping put together what
truly was both an educational and
thought-provoking conference. It
was wonderful to see those of you
who could attend in Philadelphia
as we shared research, ideas, and
thoughts about advancing quality of
life. I also want to say a special thank
you to Dr. Claire Snyder for her work
as President over the past year and

guiding us through an important
time for ISOQOL.

Now we are looking forward to our
2018 Annual Conference in Dublin,
but there is so much going on be-
fore we get together in Ireland next
October.

We start to implement our new
strategic plan which was approved
by the Board of Directors at our fall
meeting. You can find the plan posted
on the Members Only webpage for
your review. The first phase of the
plan is designed with several goals
in mind to increase awareness and
to position ISOQOL as the leader in
integrating health-related quality
of life in research, care, and policy.
In Philadelphia the Board also ap-
proved the new mission and vision
statements, which are displayed on
the [ISOQOL website](#).

In 2018, we are also delighted to
announce a change in the way the
conference registration is structured.
All attendees of the 2018 Annual
Conference will automatically receive
all membership benefits with their
registration. The registration fee for

Continued on page 2.



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

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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.

current members will include complimentary membership for 2019. For non-members, registration for the conference will include membership for the balance of 2018 and the full year of 2019.

I am also excited to let you know about the 2018 Measuring What Matters Symposium "How should we be measuring functioning as a marker of clinical benefit in clinical trials." The symposium will discuss definitions and concepts of functioning, to identify fit-for-purpose approaches to measurement (including novel technologies) and to identify evidence needs for different stakeholders, including regulators, payers, clinicians and patients. The symposium will be held in Arlington, Virginia, so be sure to save the date: 23-24 July 2018.

While there is much we are working on for the coming year, we need your input and ideas for the Annual Conference and anything else we do as a society. Feel free anytime to go to [ISOQOLListens](#) and submit your thoughts and questions.

I look forward to working with you over the coming years, and cheers until we meet again.

Sincerely,

Jose M. Valderas, MD, MPH, PhD,
ISOQOL President



JOIN THE CONVERSATION!

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And the winner of the 24th Annual Conference evaluation survey Amazon Gift Card is...

**Stacie Hudgens!
Congratulations!**

FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA



Dear ISOQOL family:

Welcome to our last issue of 2017! Another year of growth, challenges, and global

interaction for our society has passed, and while we take a look back at this year's achievements, our Leadership's eyes are focused on this coming year and the exciting new projects and initiatives projected for 2018.

Dr. José Valderas brings us his first President's Message, where he conveys his enthusiasm in serving our membership in the president role, comments on the excellent program put together by the Scientific co-chairs, and thanks Dr. Snyder for her hard work and guidance during her just-completed tenure. Dr. Valderas goes on to talk about the new Strategic Plan and Mission and

Vision Statements, which you can find on the ISOQOL website. Please see his thoughts on other educational opportunities, as well as the new conference registration/membership structure, in this issue.

Those of us who were present at the Annual Conference this past October in Philly will be able to relive our great experiences, with the co-chairs review of the AC in this issue. For our colleagues who couldn't attend, this is an excellent recap to get caught up! We have also a comprehensive overview of the Introduction to Patient Reported Outcomes (IPRO) course – check it out and consider benefitting from this exceptional educational opportunity.

You can also find out our 2017 Awards Recipients (congratulations to all!), the amazing array of benefits of being an ISOQOL member, and a heartfelt Thank You to our departing Board members, while welcoming the incoming leadership. We are for-

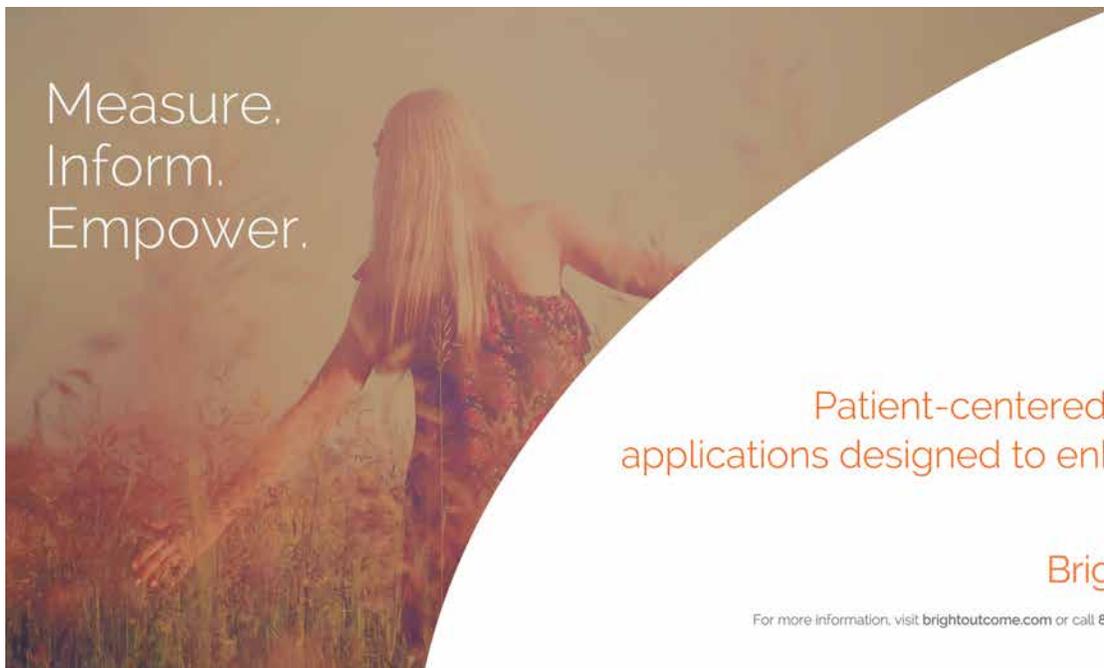
tunate to have such dedicated leaders serving the needs of our Society.

Lastly as usual please join me in welcoming our new society members in our Member's Corner, and don't forget to Save the Date for our 25th Annual Conference next year in Dublin, Ireland.

Please send any questions, comments, or submissions for our next issue to info@isoqol.org with "Newsletter" as your subject line. And wherever you are in this world, with no frontiers when united by our ISOQOL mission, I wish you and yours a happy and safe holiday, and an enriching and prosperous New Year!



Ana Popielnicki
Editor



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2017 IPRO COURSES IN REVIEW

2017 was a successful year for Introduction to Quality of Life and Patient Reported Outcomes courses. First established in 2016, the original pilot course was hosted by ISOQOL at the University of Sheffield in Sheffield, United Kingdom. Since then there have been a total of six IPRO courses within the United Kingdom and the United States, all receiving a consensus of positive reviews and constructive feedback.

The most recent course coincided with ISOQOL's 24th Annual Conference in Philadelphia, Pennsylvania, United States. Two other courses were held in conjunction with conferences hosted in European countries. However, in recent months, IPRO courses began moving to independent platforms.

Members of ISOQOL's IPRO Task Force created the IPRO course to be a living resource for the people of ISOQOL. With its immediate success, the task force quickly began promoting the IPRO course to outside organizations, including universities, hospitals, pharmaceutical companies and any others who might fall under the broad spectrum that is the field of Quality of Life Research.

On 15 September, the IPRO course was hosted at a children's hospital in Colorado, United States. Later that month, a second independent IPRO course was hosted at a pharmaceutical company in Massachusetts, United States.

Moving forward into 2018, ISOQOL Industry Education Task Force members hope to introduce a second course more tailored to those who work in the Pharmaceutical Industry.

Members interested in taking the IPRO course should keep an eye on www.isoqol.org/education-events/ipro for future course updates.

Those interested in hosting future IPRO courses should contact ISOQOL headquarters at info@isoqol.org.

OVERVIEW OF THE IPRO 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.



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 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>



24TH ANNUAL CONFERENCE—PHILADELPHIA 2017

By: Roxanne Jensen, PhD and Kevin Weinfurt, PhD

“Embracing Complexity: Using Patient-Reported Outcomes to Generate Real World Evidence”

– that was the theme of the 2017 Annual Conference held this October in Philadelphia. It was a great time to re-connect, network, and learn new and exciting ways people around the world are contributing to a common goal: increasing the quality of life of patients everywhere.

There were an amazing number of participants in this year’s pre-conference workshops. ISOQOL’s Intro to Patient Reported Outcomes (IPRO) Course was offered as a pre-conference workshop again this year, giving attendees a detailed “first look” into some of the core concepts of PROs. New in 2017 was ISOQOL’s first “Meet the Funders” Panel. Speakers from multiple U.S. government agencies and private-funding organizations discussed current funding opportunities relevant to ISOQOL investigators.

The four plenary sessions this year provided opportunities to hear from some of the top researchers in our field on quality of life topics. The first plenary discussed the relevance and current barriers to collecting and using PROs in patient populations with multiple chronic conditions. Two other sessions involved cutting edge research submitted by ISOQOL members and examining the potential for PRO data to support complex decision making in clinical care settings. Then it was a trip back in time

to learn how past wisdom can be applied to present-day problems.

ISOQOL’s Special Interest Groups (SIGs) were also very busy in Philadelphia. One highlight was the New Investigators SIG’s annual Tricks of the Trade Presentation: “Simplicity - How to transfer complex research into effective presentations.” We want to thank all SIG Chairs for their time and hard work.

This year’s Roundtables included many hot topics in quality of life research. Newer members had the chance to meet with more experienced members in quality of life research during the Mentor/Mentee reception.

This year, ISOQOL had a strong media presence through targeted press releases and an enthusiastic social media following to promote work of ISOQOL members presented at the conference. Dr. Claire Snyder spoke with a reporter about her recent report: [“A Users’ Guide for Integrating Patient-Reported Outcomes in Electronic Health Records.”](#) Dr. Kirstie Haywood recorded a radio interview during the conference to discuss her symposium: [“Good Practice Guidance for Patient Engagement in Research.”](#)

Other business attended to in Philadelphia included the passing of the gavel to our new President, Dr. Jose Valderas. A big thank you to Dr. Snyder for all of her work as President, and we look forward to

her continued involvement with ISOQOL as Past President. A big thank you, as well, to Dr. Cynthia Gross, ISOQOL’s outgoing Secretary-Treasurer for her years of service in the position. Dr. Joan Branin will be the new Secretary-Treasurer, and she will be joined by three new Executive Board Members: Drs. Josephine Norquist, Antoine Regnault, and Kevin Weinfurt.

Of course, there were many great opportunities to meet colleagues old and new, and have a little fun. The “dine arounds” provided attendees a chance to network while experiencing some of the great food Philadelphia has to offer. Thank you to everyone who “set sail” for the closing dinner on board the Moshulu – the oldest and largest square-rigged vessel still afloat. The views from the Delaware River were outstanding, the food was delicious, and the dance floor got a workout!

Now that the 2017 meeting is wrapped up, plans are already being made for the 2018 Annual Conference in Dublin. This year will be the landmark 25th ISOQOL Annual Conference. Keep an eye out for more details in the weeks and months ahead, and be sure to save the date for 24-27 October 2018.

Thanks to those of you who joined us in Philly. We look forward to seeing you in Ireland!



THANK YOU TO OUR 24TH ANNUAL CONFERENCE SPONSORS



THANK YOU TO OUR DEPARTING BOARD MEMBERS

A HUGE THANK YOU TO OUR DEPARTING ISOQOL BOARD MEMBERS FOR THEIR PROFOUND LEADERSHIP AND DEDICATION.



Cynthia Gross, PhD
University of Minnesota,
Pharmacy & Nursing
Minneapolis, MN, United States



David Eton, PhD
Mayo Clinic, Department of
Health Sciences Research
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Lori Frank, PhD
Patient-Centered Outcomes
Research Institute
Washington, D.C., United States



Sandra Nolte, PhD
Charité – Universitätsmedizin
Berlin Medical Clinic,
Department of Psychosomatic
Medicine
Berlin, Germany

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 23 April - 21 May 2018

Volunteers may choose which presentation types they would like to review. Abstract review is completed through an online platform.

To become a reviewer, please sign-up via the [ISOQOL 2018 Membership Dues Application](#) or email ISOQOL at 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.

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ABOUT PROMS CONFERENCE

Following the success of last PROMs Research Conference held at St Anne's College, Oxford, UK we are delighted to announce the date of the forthcoming ISOQOL endorsed conference hosted by the Centre for Patient Reported Outcomes Research at the University of Birmingham, UK on 20th June 2018.

This one-day conference will include a mixture of plenary sessions, oral presentations and posters and will bring together leading international experts, clinicians, patient partners and early career researchers to engage with the latest advances in the field of PROMs research and implementation. We welcome oral and poster abstracts from clinicians, researchers, patient partners, industry, SMEs and others working in the field. Abstracts are due Wednesday 28th February.

Please save the date and join us on the Wednesday 20th June 2018.

PLENARY SPEAKERS

We are pleased to confirm the first Plenary Speaker, Daniel O'Connor, Medicines and Healthcare products Regulatory Agency (MHRA). More announcements to follow, keep checking the website for details.

REGISTRATION

Registration is open, £90.

FIND OUT MORE

Abstract submission and registration details can be found online, www.birmingham.ac.uk/proms2018 or email the Events Team: med-cpdbookings@contacts.bham.ac.uk

5 Reasons to renew your ISOQOL membership.

Reason #1 We make sure you are in the know of the latest and greatest in Quality of Life Research.

ISOQOL is proud to boast the publication of two internationally renowned journals, the first dictionary to standardize QOL research terminology, and more!

Check out ISOQOL's [Research & Publications page](#) to learn more.

Reason #2 Networking. Collaboration. Discussion.

ISOQOL keeps you connected with the best and brightest in QOL research. Don't pass up the opportunity to attend the 25th anniversary of ISOQOL's Annual Conference in Dublin, Ireland. Also back by popular demand is the second ever Measuring What Matters Symposium, to be held in Washington D.C., USA.

Updates for both events will be made available as they occur on ISOQOL's [Education & Events page](#).

Reason #3 Educational opportunities

The Intro to Patient-Reported Outcomes Course (IPRO) is aimed to help health professionals, medical scientists who are not experts in the use of PROs, consultants, pharmaceutical and medical device representatives, new investigators and research students, policymakers, and other associations or individuals who are interested in acquiring familiarity with the terms and methods of research on PROs.

Learn more on ISOQOL's [IPRO page](#).

Too busy to travel?

ISOQOL has a committee dedicated to hosting online webinars on a variety of topics.

Visit ISOQOL's [Online Education page](#) to see upcoming topics and our webinar archive!

Reason #4 We have 15 Special Interest Groups for you to choose from.

QOL research is a huge field and ISOQOL knows its members sometimes need targeted information. Some of our SIGs are discipline focused and some are geographically focused.

Learn more about the benefits of joining a SIG on ISOQOL's [Special Interest Groups page](#).

Reason #5 We save you money!

All ISOQOL members receive reduced rates for:

- Online Education and Archived Webinars
- Measuring What Matters Symposium Registration
- IPRO Course Registration
- PRO and QoL Instruments Database
- Submission to the Journal of Patient Reported Outcomes (JPRO)

All ISOQOL members receive complimentary access to:

- All ISOQOL Quality of Life Quarterly Newsletters
- An online subscription to the Quality of Life Research Journal
- The ISOQOL Membership Directory
- The ISOQOL Job Board
- Member-only webpages with various resources

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James Marcus

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Mariam Namasaba

Eman Nassr

Yoshita Paliwal, PhD

Tatjana Senin

Juliana Setyawan, PharmD

Kyra Sierakowski, MD

Mirko Sikirica, PharmD

Benjamin Steinberg, MD, MHS

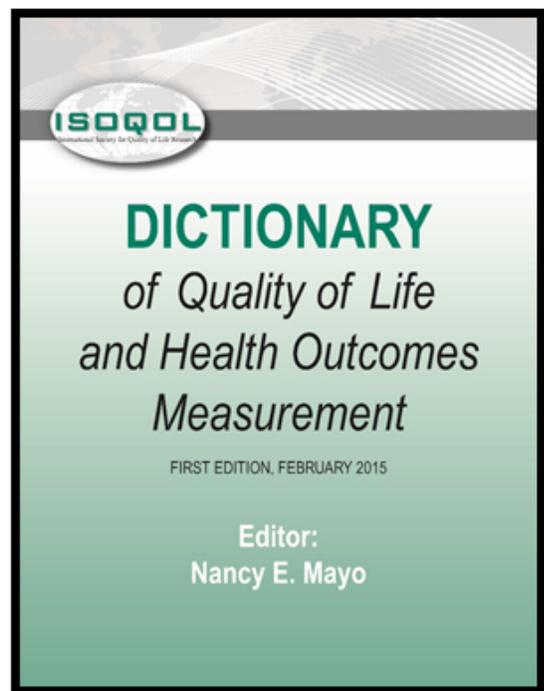
Callie E. Tyner, PhD

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Chengwu Yang, MD, MS, PhD

Diana Zidarov, PhD



**ISOQOL
Dictionary of Quality of Life and Health
Outcomes Measurement**

Over 600 definitions of terms related to quality of life and health outcomes measurement, study design, and analysis are covered, along with over 350 references. Look up a term, or read the Dictionary from A to Z to see the vast array of terms and concepts that apply to this important field.

Many thanks to Editor Nancy E. Mayo, PhD, for her dedication and hard work on this publication.

Purchase your e-version or print version now at www.isoqol.org. All profits go to support ISOQOL's activities to advance the scientific study of quality of life and other patient-centered outcomes.



MEASURING WHAT MATTERS SYMPOSIUM

How should we be measuring functioning as a marker of clinical benefit in clinical trials?

23-24 July 2018 • Washington, D.C., USA



Function is a multidimensional concept that is emerging as an important aspect of clinical benefit assessment across therapy areas, as well as a concept that matters greatly for patients (and families), regulators, HTA groups, clinicians and payers when making medical decisions.

This symposium aims to:

- discuss definitions and concepts of functioning,
- to identify fit-for-purpose approaches to measurement (including novel technologies) and
- identify evidence needs for different stakeholders, including regulators, payers, clinicians and patients.

Join us in Washington, D.C., USA 23-24 July 2018 for this inspiring symposium and prepare to further strategies to generate meaningful data on patients' functioning in clinical trials.



DEBATING 'HOT TOPICS' IN HRQOL RESEARCH

REGISTER TODAY FOR THE ISOQOL WEBINAR SERIES

The ISOQOL Webinar Committee presents a series of three webinars which will discuss important topics in HRQOL research. Each webinar will explore a topic from different perspectives to facilitate an open discourse among researchers. The aim of these webinars is to provide a forum where the ISOQOL community can learn about key issues and hear differing approaches and perspectives from experts in the field.

Psychometric versus preference-based health-related quality of life summary measures

Available in Webinar Archives 2 January 2018

'The Times They are a-Changing': Exploring Meaningful Change in Health Outcomes Measurement

10 January 2018 at 10:00am CST

Different perspectives on meaningful interpretation of change in patient-reported outcomes: Meaningful (Clinically) Important Differences

6 February 2018 at 9:00am CST

PRICING

Individual:

Member- \$75
Retired Member- \$25
Student Member- \$25
Special Member- \$25
Non-Member- \$100

AWARDS PRESENTED AT THE ISOQOL 2017 ANNUAL CONFERENCE

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 2017 ISOQOL President's Award was presented by President Claire Snyder to Nancy Mayo, PhD. Dr. Mayo has made notable contributions to the field of health-related quality of life research and ISOQOL.

EMERGING LEADER AWARD – IN HONOR OF DONNA LAMPING

The Emerging Leader Award was established in 2011 to honor and commemorate past-President Donna Lamping's contribution to the leadership of the Society. This is awarded to an ISOQOL member who has shown exceptional leadership skills and potential.

Congratulations to the 2017 Emerging Leader Award recipient, Skye Barbic, PhD OT

ARTICLE OF THE YEAR 2016 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 (HRQOL) 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 HRQOL theory, methods, clinical application, or policy.

First Place

Shoshani, A., Mifano, K., & Czamanski-Cohen, J. (2016). *The effects of the Make a Wish intervention on psychiatric symptoms and health-related quality of life of children with cancer: a randomised controlled trial. Quality of Life Research, 25(5), 1209-1218.*

2016 Finalists

Janse, M., Sprangers, M. A., Ranchor, A. V., & Fleer, J. (2016). *Long-term effects of goal disturbance and adjustment on well-being in cancer patients. Quality of Life Research, 25(4), 1017-1027.*

Greco, C. M., Yu, L., Johnston, K. L., Dodds, N. E., Morone, N. E., Glick, R. M., ... & Colditz, J. (2016). *Measuring nonspecific factors in treatment: item banks that assess the healthcare experience and attitudes from the patient's perspective. Quality of Life Research, 25(7), 1625-1634.*

NEW INVESTIGATOR & STUDENT PRESENTATION AWARDS

New Investigator Oral Presentation Award

Antoine Vanier, MD PhD, INSERM - University of Nantes - University of Tours, Nantes, France
What are all the proposed methods to estimate the Minimal Clinically Important Difference of a Patient-Reported Outcomes Measure? A systematic review.

New Investigator Poster Presentation Award

Derek Kyte, PhD, University of Birmingham, Birmingham, United Kingdom
Systematic Evaluation of Patient-Reported Outcome (PRO) Protocol Content and Reporting in Cancer Clinical Trials: The EPiC Study.

continued on next page.

AWARDS PRESENTED AT THE ISOQOL 2017 ANNUAL CONFERENCE, CONTINTUED.

Student Oral Presentation Award

Josh Biber, MBA, University of Utah, Salt Lake City, Utah, United States

Comparing automated mental health screening to manual processes in a health care system.

Student Poster Presentation Award

Lene Kongsgaard Nielsen, Quality of Life Research Center, Odense University Hospital, Odense, Denmark

Health-related quality of life in non-transplant eligible newly diagnosed multiple myeloma patients treated with melphalan/prednisolone plus either thalidomide or lenalidomide; results of the HOVON87/NMSG18 study.

OUTSTANDING POSTER ABSTRACT AWARDS

The top six (6) posters that scored the highest during the ISOQOL 24th 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:

Francesco Cottone, PhD, GIMEMA (Italian Group for Adult Hematologic Diseases), Rome Italy

The FA-IPSS(h): A New Index Combining Clinical Data and Patient-Reported Outcomes to Improve Prognostication for Myelodysplastic Syndromes.

JOB OPENING: PRINCIPAL OUTCOMES RESEARCH SCIENTIST

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Contact: Chloe Reed chloe.reed@roche.com

Roche are advertising a uniquely rare opportunity to join the Patient-Centered Outcomes Research team at either of our sites in; Welwyn Garden City (UK). This role will report directly into the Global Head of Patient-Centered Outcomes Research for Neuroscience.

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[See this job advertisement in full.](#)

