



IN THIS ISSUE...

- PAGE 1** President's Message
PAGE 3 From the Editor's Desk
PAGE 4 25th Annual Conference—
Dublin 2018
PAGE 5 Call For Volunteers:
Annual Conference
Abstract Reviewers
PAGE 5 Thank You to Departing
ISOQOL Board Members
PAGE 6 Awards Presented at the
ISOQOL 2018 Annual
Conference
PAGE 8 Thank You for Making the
Inaugural #Movetheplane
Scholarship Fundraiser a
Success!
PAGE 8 ISOQOL Partners and
Sponsors Thank You
PAGE 9 ISOQOL Journals Seek
Volunteers
PAGE 9 Join a Special Interest
Group (SIG) Today!
PAGE 10 Don't Miss Out on
Benefits – Renew Your
ISOQOL Membership!
PAGE 11 New Investigators
Special Interest Group
Update From the 2018
Conference
PAGE 12 Members' Corner

VOLUME 24 ISSUE 4

Newsletter for
ISOQOL Members
DECEMBER 2018



PRESIDENT'S MESSAGE

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



Dear
Colleagues,

Happy
Holidays, ev-
eryone!
We are about
to conclude
2018. A lot
has happened

this year, and I would like to recount
some of ISOQOL's highlights.
Spring: ISOQOL member volun-
teers and staff were hard at work
implementing the beginning stages
of ISOQOL's 5-year Strategic Plan,
starting with the creation of two new
task forces: the Annual Conference
Integration Task Force and the
Communications Strategy Task Force.
Both groups have been hard at work
all year to accomplish their goals. You
will hear more about their work in
the coming year.

We also started off the year strong
with the first ISOQOL Webinar Series
called *Debating "Hot Topics" in HRQOL
Research*. In the first three webinars
we explored important research top-
ics from multiple perspectives, and

aimed at stimulating and facilitating
open discourse among participants.

- *Psychometric Versus Preference-
Based Health-Related Quality of
Life Summary Measures*
- *"The Times They are a Changing":
Exploring Meaningful Change in
Health Outcomes Measurement*
- *Different perspectives on mean-
ingful interpretation of change
in patient-reported outcomes:
Meaningful (Clinically) Important
Differences*

As you would expect and in order to
make sure many more can benefit
from the initiative, the recordings are
available in the Webinar Archives.
Special thanks to Rick Sawatzky and
Tom Willgoss for organizing the Hot
Topics Series.

Summer: This summer, things only
got busier for ISOQOL. The 2018
Measuring What Matters Symposium
brought together industry profes-
sionals, regulatory representatives,
patient research partners, clinical
staff and academic researchers for a
two-day meeting on measuring func-

Continued on page 2.



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President's Message, Continued from page 1.

tioning as a marker of clinical benefit in clinical trials. Work has progressed on a White Paper to further disseminate the discussions and move the science forward in this important area of measurement.

Shortly after the symposium, ISOQOL hosted a new education course aimed at fostering discussion of HRQOL among pharmaceutical and health-care industry representatives." The Introduction to Patient-Centered Outcomes Research (PCOR) for the Pharma/Biotech Industry pilot course was a success and prompted us to add the course as an additional offering at the Annual Conference. Special thanks to Betsy Tschosik and Josephine Norquist for taking the lead on building this new education course.

In addition, two Special Interest Groups organized additional webinars:

- *Introduction to Computerized Adaptive Testing*, organized by the Psychometrics SIG and sponsored by Vector Psychometrics Group
- *Using PROMs for Screening and Diagnostic Purposes*, organized by the QOL in Clinical Practice SIG

Autumn: Momentum continued to build with ISOQOL's Annual Conference this autumn. This year was the conference's 25th anniversary. To celebrate this historical achievement, Past President Claire Snyder led a toast during the Welcome Reception. I am sorry to have missed it because of my attending as ISOQOL President the WHO Primary Health Care Conference in Astana, Kazakhstan, but was back in time for one of the most successful conferences. You can read more about highlights from the conference on page 4.

A huge thank you to all who donated to our #MovethePlane Fundraiser. With your help, ISOQOL raised over

\$10,000 USD. This money will be used to increase the number of travel scholarships awarded to patients, individuals from developing countries, students and new investigators attending future Annual Conferences.

Winter: As the year ends, we prepare for another year of supporting QOL research. Workshop and Symposium submissions for the 2019 Annual Conference are now open. I am also excited to announce, my fellow board members and I voted to host the Measuring What Matters Symposium on an annual basis starting in 2020. We are now collecting topic proposals for future Symposia.

Please remember ISOQOL is here year-round to offer support to those working to improve quality of life for people everywhere. Our Special Interest Groups offer peer-to-peer support for members through Teamwork – an online space to collaborate and communicate with other SIG members. If you have not already, I encourage you to sign up and chime in on the e-introduce yourself message threads.

As always you, can reach out to the Board through ISOQOListens or contact staff via info@isoqol.org.

2019 is shaping up to be an equally busy year. I hope everyone has the chance to slow down, relax and enjoy time with their friends and families this holiday season.

Happy holidays everyone! See you after the New Year!

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



FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA



Dear ISOQOL Family:

Welcome to our last issue of the year, and please receive our best wishes for a safe and

happy Holiday Season!

Dr. Valderas brings us on a reflective journey through 2018 in his President's Message, a narrative of all projects, initiatives, and activities of the past year. He also hints of the ongoing plans for 2019, which will be a pretty exciting year for our Society!

We had a wonderful time at the Annual Conference in Dublin this past October! The Scientific Program Committee co-chairs Joanne Greenhalgh and Diana Rofail delivered an excellent program – check out their Conference review in this issue. Continuing with the conference theme, you do not want to miss the New Investigator's SIG article, and you can also find the announcements for all awards presented during the AC.

Please join me in thanking the departing members of the Board of Directors, as well as ISOQOL's sponsors and partners. It is my pleasure also to welcome our new members – please see a list in our Members' Corner section.

This issue brings you a treasure-trove of information on several educational opportunities, publications, ways to get involved, and resources that you can benefit from with ISOQOL's membership.

As we come close to the end of the year, I want to take the opportunity to wish all of you and your families a wealth of peace, love, and enrichment in the coming year and always. Enjoy your read!



Ana Popielnicki
Editor



25TH ANNUAL CONFERENCE—DUBLIN 2018

By: Diana Rofail, Roche and Joanne Greenhalgh, University of Leeds

“PROs in the digital age: New frontiers in research, policy and practice” – that was the theme of the 2018 Annual Conference held this October in Dublin, Ireland. 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.

A record-breaking 612 registrants from a variety of fields and career stages attended this year’s conference, and many of the events were filled to capacity. 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 2018 was ISOQOL’s Introduction to [Patient-Centered Outcomes Research \(PCOR\)](#) for the Pharma/Biotech Industry Course. The course offered superb insights into the reality of a role within the pharmaceutical industry and how to ensure that PCOR activities are embedded into business critical deliverables such as Target Product Profiles and Clinical Development Plans, and reference to how to enhance Probability of Technical Success. Attention to detail into differences between regulatory and patient access needs, and understanding stakeholders were also fundamental aspects.

The four plenary sessions this year provided opportunities to hear from top experts and researchers engaged in innovative work. The first plenary discussed increasing interest in the digital collection and use of PRO data by patients to support self-management of long term conditions.

Another session involved cutting-edge research submitted by ISOQOL members, while another session explored key questions on whether and how data can be brought together to improve health and the implications of data sharing for personal privacy and citizenship.

In Saturday’s plenary session we considered what the use of PROs in the digital age means for the concept of validity and how we apply PROs in drug development and trials.

ISOQOL’s Special Interest Groups (SIGs) were also very busy in Dublin. One highlight was the New Investigators SIG’s annual Tricks of the Trade Presentation: “Making the connections that work: academic social networking.” Another highlight included the Industry SIG Symposium during the preconference. The symposium focused on how to define and construct meaningful clinical trial endpoints specific to activities and events (passive outcomes) using mobile technology tools. 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 also had the chance to meet with more experienced members in quality of life research during the Mentor/Mentee reception.

In addition to being a year of groundbreaking advances from QOL researchers around the globe, 2018 was the conference’s 25th anniversary. The program included several additions to celebrate this impressive milestone. To honor ISOQOL’s past, the ISOQOL Board of Directors presented past leaders who have made an extraordinary

contribution to ISOQOL and the field of quality of life research with honorary membership. They also added benefits for Retired Members, including to receive reduced rates for Annual Conference registration. To capture the present, a photographer was present for the Welcome Reception and Celebration. [Links to view photos are on the ISOQOL website.](#) Finally, to prepare for the future, ISOQOL Leadership launched their first-ever travel scholarship fundraiser to increase the number of travel scholarships awarded for future Annual Conferences. You helped us raise over \$10,000! (Learn more about the fundraiser on page 8.)

As usual, 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 Dublin has to offer. Thank you to the members and guests who toasted another successful Annual Conference with us at the closing dinner at Royal College of Physicians of Ireland.

Now that the 2018 meeting is wrapped up, plans are already being made for the 2019 Annual Conference in San Diego, California, USA. Keep an eye out for more details in the weeks and months ahead, and be sure to save the date for 20-23 October 2019.

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



CALL FOR VOLUNTEERS: ANNUAL CONFERENCE ABSTRACT REVIEWERS

Abstract reviewers serve a vital role in the scientific program planning process by ensuring the quality of educational content presented at the Annual Conference. Serving as a reviewer is an excellent way to build your resume, share your expertise, and support ISOQOL. The time commitment is low, but the impact is high!

All abstract 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 all 2019 Annual Conference abstracts. The review periods are as follows:

- Symposium and Workshop abstracts: 4 February – 22 February 2019
- Oral and Poster abstracts: 22 April – 20 May 2019

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 [2019 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.



THANK YOU TO DEPARTING ISOQOL BOARD MEMBERS

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We thank these ISOQOL members for their profound dedication and leadership!



AWARDS PRESENTED AT THE ISOQOL 2018 ANNUAL CONFERENCE

PRESIDENT'S AWARD

The President's Award is presented to an individual who has advanced health-related quality of life 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 2018 ISOQOL President's Award was presented by President Jose M. Valderas to **Andrew Bottomley, PhD**. Dr. Bottomley is Assistant Director of the Quality of Life Department at EORTC.*

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 in an ISOQOL activity by playing a key role in initiating and/or steering a specific task or project to successful completion.

*Congratulations to the 2018 Emerging Leader Award recipient, **Thomas Willgoss, PhD MSc**. Dr. Willgoss is Associate Director of Patient-Centered Outcomes Research at Roche Products, Ltd.*

ARTICLES OF THE YEAR 2017

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. Additionally, this year also marks the inaugural award for outstanding article in ISOQOL's official open-access journal, *Journal of Patient Reported Outcomes*, which published its first issue in 2017. These awards recognize the authors for significant intellectual contributions that promise to advance the state of the art science in HRQOL research methods or theory.

QUALITY OF LIFE RESEARCH JOURNAL ARTICLE OF THE YEAR

First Place

Ratcliffe, J., Lancsar, E., Flint, T., Kaambwa, B., Walker, R., Lewin, G., Luszcz, M., & Cameron, I. D. (2017). *Does one size fit all? Assessing the preferences of older and younger people for attributes of quality of life*. *Quality of Life Research*, 26(2), 299-309. <https://doi.org/10.1007/s11136-016-1391-6>

2017 Finalists

Moseholm, E., Rydahl-Hansen, S., Lindhardt, B. Ø, & Feters, M. D. (2017). *Health-related quality of life in patients with serious non-specific symptoms undergoing evaluation for possible cancer and their experience during the process: A mixed methods study*. *Quality of Life Research*, 26(4), 993-1006. <https://doi.org/10.1007/s11136-016-1423-2>

Emerson, S. D., Guhn, M., & Gadermann, A. M. (2017). *Measurement invariance of the Satisfaction with Life Scale: Reviewing three decades of research*. *Quality of Life Research*, 26(9), 2251-2264. <https://doi.org/10.1007/s11136-017-1552-2>

JOURNAL OF PATIENT-REPORTED OUTCOMES ARTICLE OF THE YEAR

First Place

Humphrey, L., Willgoss, T., Trigg, A., Meysner, S., Kane, M., Dickinson, S., & Kitchen, H. (2017). *A comparison of three methods to generate a conceptual understanding of a disease based on the patients' perspective*. *Journal of Patient-Reported Outcomes*, 1(9). <https://doi.org/10.1186/s41687-017-0013-6>

2017 Finalists

Hays, R. D., Schalet, B. D., Spritzer, K. L., & Cella, D. (2017). *Two-item PROMIS® global physical and mental health scales*. *Journal of Patient-Reported Outcomes*, 1(2). doi:<https://doi.org/10.1186/s41687-017-0003-8>

Rodday, A. M., Graham, R. J., Weidner, R. A., Rothrock, N. E., Dewalt, D. A., & Parsons, S. K. (2017). *Leveraging pediatric PROMIS item banks to assess physical functioning in children at risk for severe functional loss*. *Journal of Patient-Reported Outcomes*, 1(10). <https://doi.org/10.1186/s41687-017-0011-8>

OUTSTANDING POSTER ABSTRACT WINNER

The top six (6) posters that scored the highest during the ISOQOL 25th 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. The Outstanding Poster Abstract Award Winner this year is:

Borghild Løyland, Associate Professor, Oslo Metropolitan University, Oslo, Norway

Down and out? Work and welfare trajectories among a cohort of Norwegian long-term social assistance recipients with complex health problems and low quality of life

NEW INVESTIGATOR AND STUDENT AWARDS

New Investigator Oral 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

New Investigator Poster Presentation Award (tie)

Philip Griffiths, PhD, Clinical Outcomes Solutions, Folkestone, United Kingdom

Psychometric Properties in the Face of Missing Data - A Simulation Study Assessing the Effect of Missing Data on Test-Retest Reliability in Diary Studies

John Peipert, PhD, Northwestern University, Chicago, Illinois, United States

Measurement Invariance between Black and White Dialysis Patients and Normative Scores for the General Dialysis Population in the United States on The Kidney Disease Quality of Life 36-item Short-form Survey (KDQOL-36)

Student Oral Presentation Award

Joshua Biber, MS, MBA, University of Utah Health, Salt Lake City, Utah, United States

Mapping PROMIS Physical Function Scores to Functional Ability

Student Poster Presentation Award

Loïs F. van de Water, MSc, Academic Medical Center Amsterdam, Amsterdam, Netherlands

Communicating treatment risks and benefits to cancer patients: a systematic review of different verbal and visual communication methods

Congratulations to all award winners!



**AND THE WINNER OF THE 2018 ANNUAL CONFERENCE EVALUATION
\$100 AMAZON GIFT CARD DRAWING IS...GRACE TURNER!**

Congratulations

THANK YOU FOR MAKING THE INAUGURAL #MOVETHEPLANE SCHOLARSHIP FUNDRAISER A SUCCESS!

ISOQOL supporters raised \$10,286 for ISOQOL's Travel Scholarship program through the first-ever #MoveThePlane fundraiser. Your donations moved the plane from Dublin, Ireland (2018 Annual Conference location) all the way to San Diego, California, USA (2019 Annual Conference location) and far beyond.

ISOQOL awards Travel Scholarships for the Annual Conference each year to Patient Research Partners, members from developing nations, and students and new investigators. All proceeds from #MoveThePlane will fund travel scholarships for these members to attend future Annual Conferences and contribute their voices and expertise to the diverse ISOQOL community.

Special thanks to our corporate sponsor, Optum, for their donation to #MovethePlane. Optum presented their donation to ISOQOL during the 2018 Annual Conference in Dublin.

We look forward to your support next year!

THANK YOU TO INDIVIDUAL DONORS:

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ISOQOL PARTNERS AND SPONSORS — THANK YOU



ISOQOL JOURNALS SEEK VOLUNTEERS

Quality of Life Research (QLR) is an 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 2017, the journal received 1447 manuscript submissions and accepted 277 manuscripts for publication.

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 new Co-Editor-in-Chief begins work on the journal in July of 2019.

Co-Editor-in-Chief applications are due 18 January 2019.

For full information about this position, the journal, and how to apply, visit the ISOQOL website.

BECOME A PEER REVIEWER!

Individuals with expertise in quality of life research and patient-reported outcomes are encouraged to become peer reviewers for ISOQOL's official journals: *Quality of Life Research* and *Journal of Patient-Reported Outcomes*. Use [this guide](#) for step-by-step instructions on how to register for Editorial Manager and become a reviewer.



JOIN A SPECIAL INTEREST GROUP (SIG) TODAY!

Participation in Special Interest Groups (SIGs) is open to all ISOQOL members. SIGs enable you to network and collaborate with other members in your region or who share your interests, and to learn about and take part in special initiatives and projects. You will be prompted to update your SIG preferences when you renew your membership dues. You can also update your SIG preferences at any time by logging into your member account on the ISOQOL website.

CURRENT SPECIAL INTEREST GROUPS INCLUDE:

Australia
Canada-PRO
Child Health
Chinese PRO
Health Preference Research

Ibero America
Industry
Mixed Methods
New Investigators
Patient Engagement

Psychometrics
QOL in Clinical Practice
Response Shift
Translation & Cultural Adaptation
United Kingdom & Ireland

For more information on ISOQOL SIGs, visit the Special Interest Groups web page or contact the ISOQOL Office at info@isoqol.org.



DON'T MISS OUT ON BENEFITS – RENEW YOUR ISOQOL MEMBERSHIP!

It's time to renew your ISOQOL membership – renewals are open now through 31 January, and can be completed at the ISOQOL website.*

As an ISOQOL member, you belong to a global community of researchers, clinicians, industry professionals, regulatory leaders, patients, and other professionals who share your passion for quality of life research. Members represent a diversity of nations, backgrounds, and career stages. Members benefit from a variety of registration discounts, tools, resources, and networking and leadership opportunities. Benefits include:

TOOLS AND RESOURCES

- Article submission discount for ISOQOL's official open access journal, Journal of Patient-Reported Outcomes
- Free online access and discounted print subscription to Quality of Life Research
- Discounted access to the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID)

OPPORTUNITIES TO GROW

- Online education at reduced rates
- Discounted Annual Conference registration
- Discounted Measuring What Matters registration
- Reduced rate for Intro to Patient-Reported Outcomes (IPRO) and Intro to Patient-Centered Outcomes Research for Pharma (IPCOR) courses

OPPORTUNITIES TO CONNECT

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

Additionally, dues are available at special rates for students, retired professionals, individuals who make less than \$15,000 USD annually, and individuals who come from developing nations.

We look forward to receiving your membership renewal soon. Don't hesitate to contact the ISOQOL office at info@isoqol.org if you need assistance.

****Note that if you attended the 2018 Annual Conference, 2019 dues were included in your registration – so your renewal is already complete, and you can take advantage of member benefits immediately.***



NEW INVESTIGATORS SPECIAL INTEREST GROUP UPDATE FROM THE 2018 CONFERENCE

Written by: Canhua Xiao and Manraj Kaur, New Investigators Special Interest Group Co-Chairs

What a wonderful time at ISOQOL's 25th Annual Conference in Dublin! The New Investigator Special Interest Group (SIG) meeting was held on October 27, 2018, welcoming new and returning members. Our lively discussion began with a fun activity where we introduced another SIG member (and hence, made a new colleague/friend at ISOQOL), and welcomed Dr. Laura Pinheiro, our incoming SIG co-chair (2018-20). Dr. Pinheiro is an Assistant Professor at Weill Cornell Medicine in New York City. She is a health services researcher with expertise in patient-reported outcomes, minority health disparities, and cancer outcomes.

Our meeting agenda highlighted the numerous ways in which new investigators can contribute to the society. For instance, SIG members can volunteer to organize webinars and SIG meetings or contribute to newsletters and SIG papers. There are several other opportunities to be involved with ISOQOL, and they are often posted on our communication platform, **Teamwork**. We highly encourage new investigators to ensure they select the New Investigator SIG when completing their ISOQOL profile and then log in into their Teamwork account routinely for opportunities and SIG updates.

One opportunity for SIG members to gain recognition for their involvement with the society and as a quality of life researcher is the **Emerging Leader Award**. The Emerging Leader Award is presented to an ISOQOL member who has been active on an ISOQOL committee, a SIG, or working group for at least two years and who has shown exceptional leadership skills and potential. The successful applicant is someone who has demonstrated leadership in an ISOQOL activity by playing a key role in initiating and/or steering a specific task or project to successful completion. For more information on the award, please visit: <http://www.isoqol.org/membership/awards> and follow our updates on Teamwork.

In addition to an informative SIG meeting, at this year's Annual Conference, the New Investigator SIG continued the tradition of organizing the **"Tricks of the Trade"** session. Dr. Skye Barbic, Assistant Professor in the Department of Occupational Science and Occupational Therapy at the University of British Columbia, shared insights and provided strategies for successful academic networking. During this hugely popular session, Dr. Barbic emphasized the significance of mentors who assist

in developing "laser-sharp" research focus and engaging with mentors without being afraid of their "stardom." One of the key takeaways from this session, in Dr. Barbic's words, is to "Find your mentor at the bar, not after the plenary." New Investigators, please take note!

Some of the **other opportunities** for new investigators at the Annual Conference included the Mentor-Mentee program, First Time Attendee Coffee with the Board of Directors, Dine-Around events, Roundtable sessions and Pre-conference workshops. Many of these events will occur again at the 2019 Annual Conference, so be sure to sign up for these events when registration opens in the spring.

With that, we are looking forward to keeping the momentum going on our wonderful discussion through Teamwork. We cannot wait to see you again at the 26th Annual ISOQOL conference in beautiful San Diego, California, USA!



WELCOME TO OUR NEWEST ISOQOL MEMBERS

Abdullah Alsoghier
Nina Balk-Moeller
Sarah M. Belcher, PhD RN
Audra Boscoe, PhD
Emily Boxell
David Brousseau, MD MS
Lei Chen, PhD
Desmond Curran, PhD
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Fernando Martins Carvalho
Tatsunori Murata

Elizabeth Straus, MN RN
Erinne Wasalski
Yanhong Zhang
Christina K. Zigler, PhD MEd





Webinar Archives

ISOQOL volunteers plan and host educational webinars throughout the year. These webinars are recorded, and then published in the ISOQOL Webinar Archives.

Recently Recorded Webinars

- Using PROMs for Screening and Diagnostic Purposes
- Introduction to Computerized Adaptive Testing
- Evaluating the Benefits of Mobile Health Devices in Clinical Trials

Interested in presenting a webinar?

If you are a member of ISOQOL and have an idea for a future webinar, fill out the Webinar Planning Form and send it to info@isoqol.org.

www.isoqol.org/education-events/online-education/archived-webinars

Save the Date

Abstract Submission Deadlines:

Workshop & Symposium Submission - 21 January 2019

Oral & Poster Abstract Submission - 8 April 2019



International Society for Quality of Life Research
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IPRO Course

Intro to Patient-Reported Outcomes



Introduction to Quality of Life and Patient-Reported Outcomes: Theory, Measurement, and Applications

<http://www.isoqol.org/education-events/education-courses/ipro-course>

Collecting and acting upon Patient-Reported Outcomes (PROs) is one of the cornerstones of patient-centered care. Choosing the right set of PROs can be challenging as there are many options, each with advantages and disadvantages. This one-day, intensive and interactive educational course offers a curriculum that will provide a basic level introduction to the why and how of using PROs in research.

Attendees will be given the opportunity to apply their learning throughout the course. This training is aimed at 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 and individuals who are interested in acquiring familiarity with the terms and methods of research on PROs.

Those that participate in the course will receive a certificate of attendance, upon completion of the course evaluation.

BRING THE COURSE TO YOUR ORGANIZATION!

ISOQOL will bring its LIVE one-day IPRO Course to interested organizations (Universities, Hospitals, Private Companies, etc.) or individuals (ISOQOL members, Professors, etc.) to the location of their choosing.

ISOQOL will provide:

- In-person training at the location of your choice
- IPRO Course curriculum for each attendee
- Official ISOQOL Dictionary for each attendee
- Certificates of attendance

The host is responsible for:

- Venue to accommodate attendees
- List of participants attending course
- Audio visual (minimum screen, projector and laptop)
- Food and beverage is optional

Exclusive Course

Attendee Rate = \$300.00 (Minimum of 25 Attendees)

If you would like to bring this intensive and interactive introductory course to your place of work or study, please contact the ISOQOL office at info@isoqol.org.

Course Agenda

- Introduction of Faculty and Overview of Course
- Conceptual and Historical Foundations of Patient-Reported Outcomes
- Main Measurement Approaches
- Development of a New PRO
- Evaluation of Patient-Reported Outcomes
- Cross-Cultural Translation & Adaptation of PRO Measures
- Adapting PRO Measures for Selected Populations – Youth Populations
- Adapting PRO Measures for Selected Populations – PRO Measure in Clinical Practice
- Strengths and Weaknesses of Different PRO Measures (Group Exercise)
- Introduction to ISOQOL