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VOLUME 24 ISSUE 3

*Newsletter for
ISOQOL Members*
SEPTEMBER 2018



PRESIDENT'S MESSAGE

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



Dear Colleagues,

October will soon be here and with it our Annual Conference, ISOQOL's biggest event of the year. This year we will celebrate our 25th Annual Meeting, a historical achievement in ISOQOL history. Scientific Program Committee co-chairs Joanne Greenhalgh and Diana Rofail have dedicated countless hours to making this year's conference really memorable and I am sure this 25th Anniversary will give all of us something to remember. You can read all about the Annual Conference starting on page 9.

But the ISOQOL Annual Conference is not the only big event happening this fall. The World Health Organization will convene on Astana, Kazakhstan an ambitious Global Conference on Primary Health Care on October 25-26, aiming at reinvigorating Primary Health Care across the world with

an explicit commitment to achieving health and well-being for all. I have been asked to contribute to the preparation of core documents and to participate in the conference, both as an active Family Physician and Primary Health Care researcher, but also on behalf of ISOQOL, to provide a perspective on research relevant to Primary Health Care. Things are moving fast and I will be able to give you more details during the President's Address at the Annual Conference.

I am also delighted to introduce to you our new fundraising campaign to increase the number of travel scholarships. These awards recognize important contributions and are instrumental in securing attendance for patient research partners, students, new investigators and members from developing countries. You can learn more about this year's fundraiser on page 6.

Continued on page 2.



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

Newsletter Editor

Ana Popielnicki, BA, USA

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

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President's Message, Continued from page 1.

We do hope that you will join us for the whole conference in Dublin, but for those whose schedules may not make it feasible, select half-day and 1-day event tickets are available without conference registration, including ISOQOL's brand new and exciting course "Intro to PCOR for Pharma/Biotech", which follows on the steps of "Intro to Patient Reported Outcomes." More information on these select events can be found on page 12.

All in all, this fall is shaping up to be a busy one for ISOQOL members. I hope to see you soon at the Annual Conference in Dublin, Ireland. Safe travels!

Sincerely,

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



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FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA



Dear ISOQOLers:

It is my pleasure to bring you one of the most exciting issues of the year – it is

always so much fun to read all the pre-Annual Conference activities and learn about the fantastic program being prepared for us by the Scientific Program Committee co-chairs Joanne Greenhalgh and Diana Rofail!

In his President's Message, Dr. Valderas tells us about the conference, as well as highlights the historic significance of this being ISOQOL's 25th Annual Conference. Please also see his comments on the World Health Organization's Global Conference on Primary Health Care, and how our very own Chema has been invited to participate and contribute to the preparation of core materials for this event. This amaz-

ing opportunity he is doing not only as a primary care and family physician and researcher, but also as a representative of ISOQOL. We look forward to hearing more about this from our President during the AC!

Do check out all details on the "Measuring What Matters" symposium, conducted this past July in Washington, DC. The MWM Planning Committee, Tom Willgoss, Jenny Petersen, and Andrew Mulberg give us a full report and we can tell it was a resounding success.

In keeping with the spirit of globalization and inclusion that characterizes our Society, this year the ISOQOL Annual Conference is celebrating the past (25 years!), engaging the present, and preparing for the future. Read all details inside – but most important is the new fundraising campaign being launched to increase the number of travel scholarships awarded next year – get more information on the #MovethePlane fundraiser in this issue.

Please join me in welcoming the new members of the Board of Directors, new leaders and members of ISOQOL committees, as well as the new members of the Society. The dynamic and diverse membership of ISOQOL is what makes this global community special! I look forward to seeing old friends and meeting new ones next month as we get together once again and enjoy a few days of learning, fun, and enrichment.

As always, we would love to hear from you! Please send any questions, comments, or submissions for our next issue to info@isoqol.org with "Newsletter" as your subject line. See you in Dublin!



Ana Popielnicki
Editor



WELCOME!

Caitlin Willenbrink joined ISOQOL on August 6, 2018 as Membership and Programs Coordinator. A native of Louisville, Kentucky, Caitlin's most recent professional experience focused on training clinicians to recognize and respond to patients who are survivors of domestic violence. She is excited to support the mission and operations of ISOQOL!

2018 MEASURING WHAT MATTERS SYMPOSIUM IN REVIEW

“HOW SHOULD WE BE MEASURING FUNCTIONING AS A MARKER OF CLINICAL BENEFIT IN CLINICAL TRIALS?”

By: MWM Planning Committee

Tom Willgoss, Roche Products Ltd.; Jennifer Petersen, Genentech; Andrew Mulberg, Amicus Therapeutics

The second Measuring What Matters (MWM) Symposium took place on 23-24 July 2018, near Washington, D.C, in Arlington, Virginia, USA. It was largely attended by individuals from a variety of locations and backgrounds, including regulatory, industry, tech, and academia. The two-day meeting consisted of four panel sessions, two workshops, interactive coffee sessions and a welcome reception.

DAY 1

The aim of Day 1 was to come together as a community to discuss the common definitions, frameworks, and concepts used to describe “function” from the perspective of different stakeholders, as well as the considerations and pitfalls for incorporating measures of function in studies.

Session 1: What I talk about when I talk about functioning

Attendees heard what the concept of functioning meant to different stakeholders, including the viewpoints of Patty Spears (Research Patient Advocate, Komen, Alliance & UNC Lineberger), Bryce Reeve (academic researcher, Duke University), and Elektra Papadopoulos (FDA COA Staff).

A last-minute change in schedule meant that Planning Committee Co-Chair, Tom Willgoss, gave the introduction on definitions and models of functioning on behalf of Bryce Reeve, who was stuck at the airport. Patty then presented the patients’ perspective on the concept and measurement of functioning, which included some fantastic insights into what patients want to know and why it matters to

them. Elektra provided a regulatory perspective on measurement of function, including the roles of different types of clinical outcome assessment (COA) and the FDA’s emerging idea for the new label for digital measures, “Digital Monitoring COAs”.

Workshop 1: Conceptualizing functioning

Attendees were challenged to create their own conceptual model of functioning as part of the symposium’s first workshop. Small groups were led through an adapted Group Concept Mapping method to identify the most important functioning concepts associated with the common cold.

It was clear that perspectives on important functioning concepts varied greatly among participants. However, the final online group voting on dimensions of “bothersomeness” and “frequency” flagged work performance, poor concentration, and sleep as three key functioning concepts that were important to the majority of the attendees.

Session 2: Incorporating measurement of functioning in clinical trials: common pitfalls and lessons learned

Attendees learned about the practical elements of measuring functioning from experienced researchers. Thanks to a technological miracle (an iPhone plugged into the presentation laptop microphone!), Bryce Reeve was able to present to the group from North Carolina on some of his latest research exploring PROs

vs. Performance Based measures of functioning.

Sonya Eremenco (C-Path PRO Consortium) presented the consortium’s efforts on Qualification of Multiple Sclerosis (MS) and Cognitive Dependent functioning measures with the FDA.

Betsy Tschosik (Genentech, on behalf of Katie Zarzar of Genentech) presented on practical considerations for translations, study set-up, and planning activities to help ensure success with eCOA collection.

DAY 2

The core aims of Day 2 were to investigate the needs of stakeholders – namely regulators, payors and industry – and to touch on the new ways technology is being used to collect aspects of function.

Session 3: Generating meaningful evidence for key stakeholders

This insightful discussion focused on evidence needs for a range of external stakeholders including European payors/HTA agencies, US payors, FDA, and those working in industry.

Paul Kluetz (Oncology Center of Excellence, FDA) presented the US regulatory perspective on evidence needs for functioning measures, including some preliminary thoughts on the use of sensors and how they might compliment other COAs and the recent Hemlibra® example of patient-reported functioning claim in the USPI.

Francis Pang (Amicus Therapeutics) provided an overview of the European payor and HTA landscape,

and how functioning data could inform reimbursement decisions.

Raquel Cabo (Ovid Therapeutics) presented on the US payor landscape, with a focus on access for rare diseases, and support needs that payors have given the various ways function can be measured.

Session 4: Measuring functioning in the 21st century: state of the science

Kipp Bradford (engineer and former MIT Media Lab researcher working at the boundaries of emerging industries) led an overview of the use of sensors, spanning from Olympic cycling to the airline industry, he reiterated to be wary of signals in large data sets and the importance of clinical relevance. Study design and developing studies with a pre-specified measurement goal are still important in this era of technology. Depending on the study goal – asking the athlete, patient or caregiver about their experience is still often the best measure.

Antonia Bennett (University of North Carolina at Chapel Hill) presented preliminary findings from her work with breast cancer patients investigating patient-reported and pedometry data, including the use of pedometry as an indicator of symptom burden.



Finally, Matt Lashey (CEO of Treatment Technology Insights) shared his personal story of supporting a loved one through the diagnosis and treatment for lymphoma. Frustrated with the lack of support tools for patients and families, Matt developed a system to track symptoms, concomitant medication intake, and exercise, all of which were central aspects of medical appointments and treatment decisions. This development marked the start of chemoWave®. Paul Kluetz (Oncology Center of Excellence, FDA) joined the panel session to provide insights from the regulatory view. All panelists stressed that sensors would not replace PROs, and that there is need for patient-reported information to inform activity and pedometry data.

Workshop 2: Looking to the future

During the second workshop the attendees, working in small groups, selected one of nine “hot topics” that had emerged over the symposium regarding the measurement of functioning. Each group framed the challenge, the state of the science, and the evidence and guidance needed to inform future work on their selected topic. The group discussions will hopefully inform a series of white papers on behalf of ISOQOL and the meeting attendees.

Overall, the Measuring What Matters Symposium was highly collaborative and engaging. Attendees were highly engaged in meaningful discussions over the two days, and provided their feedback and experiences throughout, which further enriched the sessions. Feedback to date has been extremely positive, and there is great interest in future white papers to share thoughts from the meeting on how to move the science forward in this important area of measurement.



 DICTIONARY <i>of Quality of Life and Health Outcomes Measurement</i> FIRST EDITION Editor: Nancy E. Mayo	ISOQOL Dictionary of Quality of Life and Health Outcomes Measurement <i>Digital and print copies now available in English and Portuguese.</i> To purchase a copy, visit: www.isoqol.org	 DICIONÁRIO <i>de Qualidade de Vida e Medição de Resultados em Saúde</i> TRADUÇÃO EM PORTUGUÊS DA PRIMEIRA EDIÇÃO Editor: Nancy E. Mayo Editor de Tradução: Pedro L. Ferreira
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ISOQOL Travel Scholarship Fundraiser Donate Today



Help ISOQOL increase the number of Travel Scholarships awarded next year!

ISOQOL awards Travel Scholarships for the Annual Conference each year to:

- Patient Research Partners
- Members from Developing Countries
- Students and New Investigators

#MovethePlane

Every dollar donated moves the plane 1 kilometer.

Help move the plane 9,000 km from the 2018 Annual Conference location (Dublin) to the 2019 Annual Conference (San Diego) location by Giving Tuesday on 27 November 2018.

Corporate Scholarship Sponsor

Special thanks to Optum for pledging a donation to the #MovethePlane Travel Scholarship Fundraiser. Optum will present their donation to ISOQOL during the 2018 Annual Conference.



INTRODUCING NEW MEMBERS OF THE ISOQOL BOARD OF DIRECTORS

Please join us in welcoming new members of the ISOQOL Board of Directors:



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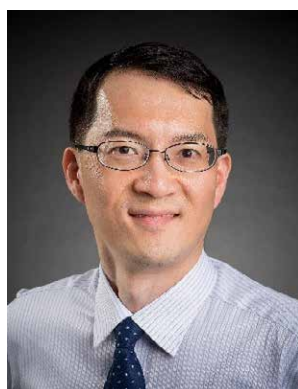
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Research Hospital
Memphis, Tennessee,
United States

The new board members will begin their term immediately following the 2018 Annual Conference.



INTRODUCING NEW LEADERS AND MEMBERS OF ISOQOL COMMITTEES

We are delighted to welcome new leaders and members of ISOQOL committees:

EDUCATION COMMITTEE

Co-Chair: Diana Rofail, PhD CPsychol
Roche Products Limited
Welwyn Garden City, United Kingdom

IPRO Course Sub-Committee

Nalin Payakachat, PhD MS BPharm
University of Arkansas for Medical Sciences
Little Rock, Arkansas, United States

Mentor/Mentee Sub-Committee

Yuelin Li, PhD
Memorial Sloan Kettering Cancer Center
New York, New York, United States

Webinar Sub-Committee

Xin Shelley Wang, MD MPH
The University of Texas MD Anderson Cancer Center
Houston, Texas, United States

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New York, New York, United States

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Salvador, Bahia, Brazil

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Ibadan, Nigeria

Member: Emre Yucel, PhD MS MIBS
AMGEN
Newbury Park, California, United States

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University of Nantes
Nantes, France

2019 ANNUAL CONFERENCE SCIENTIFIC PROGRAM COMMITTEE

Co-Chair: Deborah Miller, PhD
The Cleveland Clinic Foundation
Cleveland, Ohio, United States

Co-Chair: Kathleen Yost, PhD
Mayo Clinic
Rochester, Minnesota, United States

Please join us in thanking these members for their service!



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ISOQOL 2018 ANNUAL CONFERENCE: 25 YEARS OF NETWORKING, COLLABORATIONS AND RESEARCH

As you may already be aware, 2018 marks the 25th Anniversary of the ISOQOL Annual Conference.

Twenty-five years is an impressive milestone, so ISOQOL leadership and staff walked into the first stages of conference planning knowing this year's conference would have to be exceptional in some way. The 2018 Annual Conference Program would not only need innovative, engaging and high quality science, but would also need to celebrate the achievements of the Society while looking to the Society's future.

We think the science speaks for itself, and encourage you to visit www.isoqol.org/2018annualconference for an in-depth look at the scientific program.

But as any ISOQOL Annual Conference veteran can attest, ISOQOL is more than just exemplary science. ISOQOL is also about people who care about people. To celebrate the individuals dedicated to improving the quality of life for people around the world, ISOQOL has made some important additions to this year's conference.

LOOKING BACK

In honor of the 25th anniversary, the ISOQOL Board of Directors is pleased to honor past leaders who made an extraordinary contribution

to ISOQOL and the field of Quality of Life research by offering an honorary membership to select individuals. The Board may offer Honorary Membership to a member who has served as a past president, past editor-in-chief of an ISOQOL journal, received the President's Award, or has otherwise made an extraordinary contribution to ISOQOL and the field of Quality of Life research. Individuals receiving Honorary Membership will be honored during the Annual Conference Welcome Reception.

ISOQOL is also adding benefits for Retired Members. Retired Members now receive reduced rates for Annual Conference registration, as well as reduced registration rates for select ISOQOL education initiatives.

ENGAGING THE PRESENT

More important than simply honoring the past, ISOQOL leadership wants to improve their engagement with ISOQOL members. Look for current and former leadership participation in many of the Workshops and Roundtables at the Annual Conference.

To add to the celebration, ISOQOL is hiring a photographer for the Welcome Reception and Celebration to "capture the moments." Photos will be made available to attendees after the conference.

PREPARING FOR THE FUTURE

You cannot celebrate a society's past and present without also considering the needs of the future.

Around this time last year, leadership finalized the new 5-year Strategic Plan. Now, several of the Strategic Plan's initiatives are underway to position ISOQOL as the leader in health-related quality of life research. Some of these initiatives center on raising general awareness of ISOQOL as a trusted authority in fields relating to quality of life. Other initiatives focus on membership engagement and providing members with important resources.

Being an international society, the Annual Conference is held in locations all around the world, but not all can afford to pay the travel costs associated with attending the Annual Conference. To address this need, ISOQOL awards Travel Scholarships to patient research partners, students, new investigators and members from developing countries every year to help mitigate the cost of traveling to and attending the Annual Conference.

But ISOQOL leadership wants to do more, and is launching a fundraising campaign to increase the number of travel scholarships awarded in 2019. Please help leadership in its efforts by donating to the fundraiser. The

fundraiser will launch in October and run through Giving Tuesday on 27 November 2018. Keep an eye on your inbox for more details this fall.

Special thanks to Optum for pledging a donation to the fundraiser. Optum will present their donation to ISOQOL during the 2018 Annual Conference.

We hope you join us in Dublin to help celebrate 25 years of networking, collaborations and research in the field of Quality of Life. See you soon.



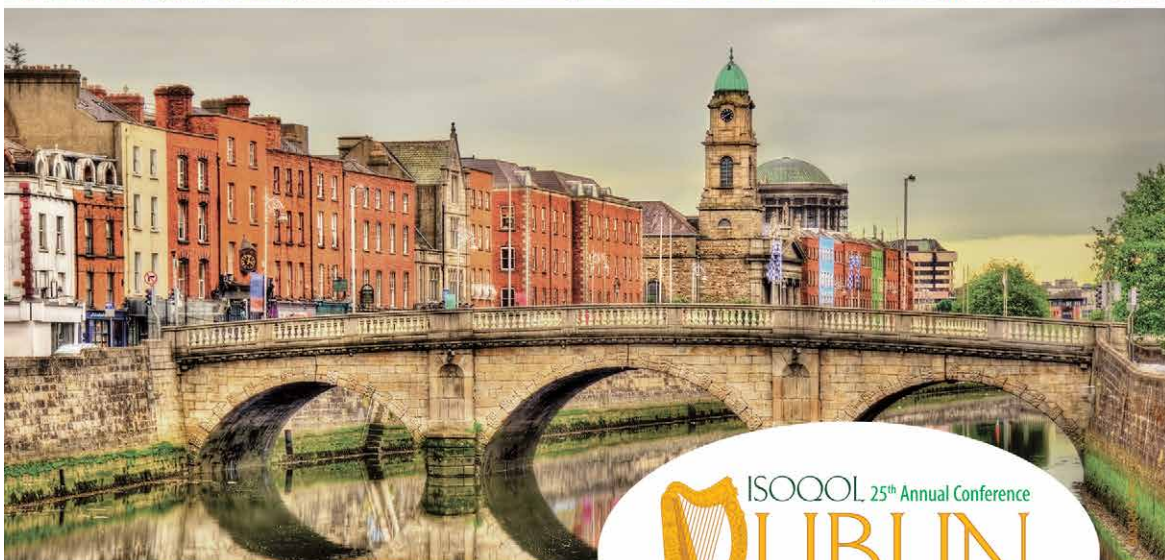
The efforts to improve health outcomes today are numerous and expansive. But these best intentions often miss the patient's perspective about his or her own care. As a health services and innovation company, we believe capturing reliable, practical and scientifically valid information on the patient's health and well-being is critical to evaluating outcomes and advancing health policy. We're doing more than logging data points. Our tools take us straight to the source — the patients themselves. When we amplify the patient's voice, we can better hear the answer to, "What does health care mean to you?"



Visit optum.com/isoqol2018 to schedule a meeting with Optum® Patient Insights scientists while you're at the event.



INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH



ISOQOL 25th Annual Conference
DUBLIN
24 - 27 October 2018 IRELAND

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SCIENTIFIC PROGRAM HIGHLIGHTS:

- Wednesday Workshops*
- 2 Education Course Options*
- General Oral and Poster Sessions
- 10 Roundtable Topics to Choose From*
- 4 Plenary Sessions
- Plus Many More Networking Opportunities

Visit <http://www.isoqol.org/2018annualconference> for more information!

*Event requires additional cost and preregistration to attend.



SINGLE EVENT REGISTRATION

For those who do not have the time to attend the entire Annual Conference, tickets to select full-day and half-day educational events are available at a non-conference attendee rate for Wednesday, 24 October.

Because event times overlap, attendees are limited to either one education course ticket (a full-day event) or one morning workshop ticket and one afternoon workshop ticket (half-day events).

FULL-DAY EDUCATION COURSES

Intro to PCOR for Pharma/Biotech (IPCOR-Pharma Course)

This one-day, intensive and interactive educational course offers a curriculum that will provide an introduction to the application of PCOR research specific to the pharma/biotech industry. It will provide attendees with the opportunity to make informed decisions and advance their career with fundamental knowledge of the pharma/biotech industry.

Intro to Patient Reported Outcomes (IPRO Course)

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.

Full-Day Education Course Ticket Prices	
Non-Conference Attendee Category	Ticket Rate
Member	\$350
Member: Student/Retired/Special/RPRP/APRP	\$150
Nonmember	\$450
Nonmember: Student/Retired/Special/RPRP/APRP	\$200

HALF-DAY WORKSHOPS

Morning Workshops

Workshop 1: Interpretation guidelines to define clinical relevance for Patient-Reported Outcome (PRO) measures

Workshop 2: Multilevel Data: A Look at Psychometric Analyses

Workshop 3: What is Implementation Science and How Can It Help Us Integrate PROMs into Clinical Practice?

Workshop 4: Group Concept Mapping: Engaging Patients as Outcome Framework Co-Authors

Afternoon Workshops

Workshop 5: Clinical outcome assessment in a multi-cultural context: Measurement challenges and solutions

Workshop 6: Clinical outcome assessments embedded in mobile and wearable information technologies

Workshop 7: Back to the roots: the importance of applying theory to patient-reported outcomes measures (PROMs) validity testing

Workshop 8: Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) – Qualitative Approaches for Data collection, Analyses and Reporting

Half-Day Workshop Ticket Prices

Non-Conference Attendee Category	Ticket Rate
Member	\$225
Member: Student/Retired/Special/RPRP/APRP	\$50
Nonmember	\$275
Nonmember: Student/Retired/Special/RPRP/APRP	\$75

REGISTER TODAY

MEMBERS' CORNER

WELCOME TO OUR NEWEST ISOQOL MEMBERS

Abok I. Ishaya

Adrian Luca

Anna Kratz

Borghild Løyland

Carrie R. Houts

Courtney M. Mann, MA

Emmanuel Ayodeji Aiyenigba, MD

Florin Lazar, PhD

Gina L. Mazza

Jennifer Dine, PhD, RN

Laura Kelly

Linda Schumann Scheel, PhD, MBA

Luke Bamber, MSc

Maria Karabatzakis

Marie Isabelle Friedel, Pediatric Nurse

Michael Levas, MD

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jobs.isoqol.org



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



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



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