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VOLUME 24 ISSUE 2

Newsletter for
ISOQOL Members
JUNE 2018

PRESIDENT'S MESSAGE

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



Dear Colleagues,

I would like to give you a brief update on current developments at ISOQOL. It is

only fair to start by thanking all of you who contribute to the Special Interest Groups (SIG), committees, and task forces for making these initiatives possible.

The ISOQOL Board of Directors had its mid-year meeting last month. It was an intense two day meeting in which we made progress on a number of fronts including membership, SIGs, patient involvement, collaborations with other organizations and many others. You will be hearing about them in the coming months, as they materialize. I walked away from the meeting feeling incredibly honored to be a part of this society and energized seeing the huge commitment of all the board members.

The Measuring What Matters Symposium "*How should we be measuring functioning as a marker of clinical benefit in clinical trials?*" is fast approaching. We are excited to include a number of representatives from regulatory agencies in the speaker line-up in Washington, DC. Learn more about how regulators will address function measurement on page 8. If this is an area of interest, register today for the symposium on 23-24 July.

For those with an interest in the relationship between patient-centered outcomes research and product development in the pharmaceutical and biotechnology industries, there are still a few spots left at the pilot course* [Intro to PCOR for Pharma Education Course](#). It will be held in conjunction with the Measuring What Matters Symposium. If these dates are not suitable, don't worry, there will be another opportunity at the 25th Annual Conference in Dublin.

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.

Speaking of the 25th Annual Conference, *registration opens this month*. Visit <http://www.isoqol.org/2018annualconference> to learn more about the conference in Dublin this October.

The ISOQOL Clinical Practice SIG has prepared a webinar on Using PROMs for Screening and Diagnostic Purposes for 11 July 2018. If this topic interests you, hurry and sign up! Registration closes 8 July.

I am also delighted to announce the arrival of the new ISOQOL Chinese PRO SIG, which will promote research and education of patient reported outcomes in the Chinese population.

None of the opportunities listed throughout this newsletter would be possible without your continued hard work, passion and innovative thinking. Please, do join a SIG, and if we reach out to you for contributing to committees and taskforces, do consider contributing within your

possibilities. And whenever we hold elections, please find the time to read the statements of those who have been generous enough to put themselves forward to make further contributions to ISOQOL and take part in the ballot. Our membership is what makes ISOQOL a success!

Sincerely,

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

*Pilot education courses are offered at a 75% discount. Please note the Intro to PCOR for Pharma Education Course held at the 25th Annual Conference is only available at full-price.



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FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA



Dear
ISOQOLers:

Welcome to
our second
issue of the
year! Our
Society and
its members
are in a peak

of activity with numerous initiatives, educational opportunities, and Special Interest Groups' projects and outreach. Check all this information out in Dr. Valderas' President Message, where he informs about all this and updates us on the Board of Directors and the upcoming Annual Conference activities.

As it draws near, please find all details on the "Measuring What Matters" symposium, to be conducted July 23-24 in Washington, DC., with the added bonus of the

"Introduction to Patient-Centered Outcomes Research (PCOR) for the Pharmaceutical Industry: Using PCOR to Inform Decision Making for Regulators, Payers, Prescribers and Patients (IPCOR-Pharma Course)" – this is being offered this time as a pilot course at a discounted price; however, space is limited so hurry up and register! July also brings us the next in the ISOQOL Webinar series: "Using PROMs for Screening and Diagnostic Purposes", organized by the QOL in Clinical Practice SIG, and which will be held live on July 11th – registration is open this coming week and closes on July 8th.

This issue brings you an update and detailed news about our own Journal of Patient Reported Outcomes (JPRO) – please see Drs. Revicki and Feeny's article, as well as information on submission and call for reviewers.

We welcome the new SIG leaders, and the brand new Chinese PRO SIG! If you would like to get involved and participate in SIG activities, please check our website to become a member. You can find much more information and news about upcoming conferences and ISOQOL publications in this issue as well.

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. Enjoy!



Ana Popielnicki
Editor



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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



The International Society for Quality of Life Research is proud to announce the 2nd Measuring What Matters Symposium in Washington, D.C., United States on 23 and 24 July 2018.

Don't miss the chance to engage with speakers, exhibitors, and attendees from:

- QOL research
- The wearable and mobile health device industry
- The pharmaceutical industry
- US Food and Drug Administration

The aims of this symposium are to:

- Discuss definitions and concepts of functioning
- Identify fit-for-purpose approaches to measurement, including mobile devices and wearable technologies
- Identify evidence needs for different stakeholders, including regulators, payers, clinicians, and patients

BONUS EVENT

In addition the Measuring What Matters Symposium, ISOQOL also offers the opportunity to register for the first presentation of the IPCOR-Pharma Course as a pilot 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. This course is at a discount and will take place the day after the symposium. Registration is separate and limited to 25 attendees.

SPECIAL THANKS : MEASURING WHAT MATTERS SYMPOSIUM SPONSORS



LEARN MORE...

<http://www.isoqol.org/measuring-what-matters-symposium>

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

JOURNAL OF PATIENT-REPORTED OUTCOMES UPDATE

Journal of Patient-Reported Outcomes is a fully open access, online-only journal which published its first articles in September 2017. The open access model differs in several ways compared to traditional subscription-based journals.

First and perhaps most importantly, the published work is available to read online with no charge. This means that in addition to researchers, members of the public, patients, students and professionals can freely read the research. The potential audience for the published work is therefore quite large, and we have found that students and researchers from low and middle income countries particularly value this access.

Highly-accessed articles may go on to be cited; for example Springer Nature's open access title *Health and Quality of Life Outcomes* has an Impact Factor of 2.1, comparable to many subscription journals in the field. Indeed, ISOQOL's own *Quality of Life Research* publishes some of its content open access, for example [Herdman et al. \(2011\)](#), which has received nearly eight-hundred citations.

Another major difference with the open access model is that *JPRO* publishes its articles under the terms of the [Creative Commons Attribution 4.0 International License](#). This means that the author, rather than the

publisher, retains copyright of their article. In addition, others are free to reuse the article as they wish, provided full attribution is given.

For those who may be interested in citing articles from *JPRO*, you have the option to sign up for "[Article Alerts](#)." Once logged in, users can subscribe to email alerts for newly published articles daily, weekly or monthly.

Publishing open access articles is not without costs; as such the author or their institution must agree to pay an article-processing charge (APC). Agreeing to pay is done at the beginning of the submission process; however no payment is requested until the article has been editorially accepted.

This journal is an Open Access publication and an article-processing charge (APC) is levied on articles that are accepted for publication by the Editors.

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If your institution, society or other organization is a member, the APC amount may be wholly or partly covered by the membership arrangement. For an article to be eligible for APC coverage through institutional membership, the author submitting the article must be affiliated with the member institution.

APC waivers or discounts are granted on a case-by-case basis to authors with no or insufficient funds. Such waivers or discounts can be requested after you have clicked [View Publication Charges](#) and a decision will normally be made within two working days.

Submission of the article to the journal can be completed once the payment method has been agreed. Any applicable APC can be paid after editorial acceptance and must be paid prior to publication.

APCs for articles submitted from EU countries are subject to VAT (Value Added Tax). EU customers must supply their VAT number to be exempt from VAT. UK Customers are not exempt from VAT. If you choose to pay by a method other than by credit card, an administration surcharge will be applied.

For more information, see our [article processing charge FAQ](#).

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Many researchers will have accounted for potential article-processing charges in their grant applications. Those who have not may be able to access funds from their institution. Your institution's librarian may be a

good source of knowledge for this. In addition, ISOQOL members receive a 30% discount to all article-processing charges in *JPRO* if they select the institutional membership option and quote the ISOQOL membership code **EL-ISOQOL-JPRO-1016**.

APC Agreement

Title: test
Journal: [REDACTED]
Type: research
Author: @ ISO Journal Team

You, the submitting author, are required to arrange payment of a processing charge of [REDACTED] if your article is accepted for publication. Since you are based in United Kingdom, you will be charged the GBP price of [REDACTED]. This fee helps to cover the cost of managing peer review, data conversion, and permanent online hosting (see [more information](#) about SpringerOpen's processing charges).

If your manuscript is accepted, you will be given the option of paying by credit card or invoice. If you believe that payment for your article is covered by an institutional membership arrangement, please let us know using the form below. In the case of genuine inability to pay, you should request a waiver of the processing charge now, also using the form below.

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The Editors-in-Chief of the journal are entitled to waive the APC for a number of articles each year. If you have limited funds available, but have an idea for a manuscript you are excited about, please do reach out to the Editors-in-Chief to discuss the possibility of having an article commissioned.

If you do have any questions or concerns about any part of the submission or peer review process, you can find *JPRO*'s contact details at <https://jpro.springeropen.com/about/contact>.



JOURNAL OF PATIENT-REPORTED OUTCOMES: STATUS REPORT

By: Dennis Revicki & David Feeny, Co-Editors-in-Chief, *Journal of Patient-Reported Outcomes*

The *Journal of Patient-Reported Outcomes* is alive and well. We have been operational beginning in the Fall of 2016, and want to provide a brief status report on the journal to ISOQOL members. Since late 2016, the journal has received 143 manuscript submissions and has published 32 articles. The time to initial editorial decisions averaged approximately 75 days. Based on the last 12 months, we have a manuscript acceptance rate of 35%. Although most of the manuscript submissions are from researchers in the United States, we have good representation from the United Kingdom, Denmark, Australia and India, with a small number of

manuscripts submitted from Asia, other European countries, Canada, South America and Africa.

We have recently expanded the Editorial Board to include Chih-Hung Chang, PhD, Northwestern University, as an Associate Editor and Dr. Chris Barker, Statistical Planning and Analytical Services, as the journal's Statistical Reviewer. They join existing Editorial Board members, David Feeny, PhD, McMaster University, Dennis Revicki, PhD, Evidera, and Maria Santana, PhD, University of Calgary. With new Editorial Board members we hope to decrease times from submission to editorial decisions significantly.

We need your assistance and participation as active reviewers of manuscripts for the *Journal of Patient-Reported Outcomes*. Identifying and recruiting good reviewers is a challenge for any journal, and is particularly challenging for new journals. If you are not registered as a reviewer for the journal, we urge you to register (go to Editorial Manager login for the JPRO, click on Register Now), and when called on to review a manuscript, please agree and complete the review as quickly as possible (or suggest a qualified alternative reviewer).



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ISOQOL PUBLICATIONS: NEW ADDITION

Implementing Patient-Reported Outcome Measures in Clinical Practice: A Companion Guide to the ISOQOL User's Guide

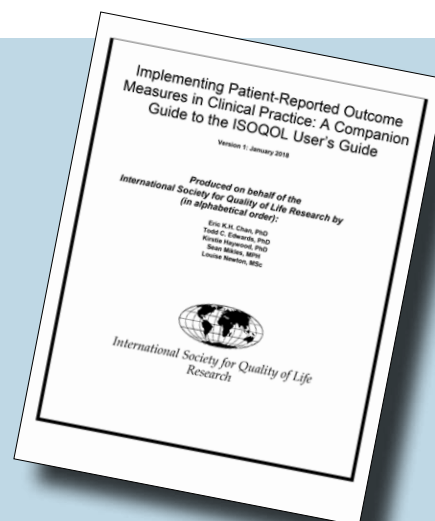
Special thanks to:

Eric K.H. Chan, PhD
Kirstie Haywood, PhD
Louise Newton, MSc

Todd C. Edwards, PhD
Sean Mikles, MPH

Download your free copy at

<http://www.isoqol.org/research-publications-landing-page/isoqol-publications>



NEW SIG LEADERS

ISOQOL is delighted to formally introduce you to the incoming Special Interest Group Leadership for the upcoming year. Please join us in welcoming the new leadership and wishing them well as they guide the SIGs in building upon an already long list of achievements.

Australia and New Zealand

Chair Elect: Rebecca Mercieca-Bebber
University of Sydney
Post-doctoral Research Fellow and Project Officer

Child Health

Chair Elect: Robert Arbuckle
Adelphi Values
Managing Director

Health Preference Research

Chair Elect: Manraj Kaur
McMaster University
PhD Candidate and EBS Program Coordinator

Ibero America

Chair Elect: Pedro Ferreira
University of Coimbra
Full Professor and Director of the Centre for Health Studies and Research

Industry

Chair Elect: Linda Nelsen
GlascoSmithKline plc
Senior Director and Head, Patient Centered Outcomes

Mixed Methods

Chair Elect: Carla Dias-Barbosa
Evidera
Research Scientist

New Investigators

Chair Elect: Laura Pinheiro

Patient Engagement

Chair: Hilary Wilson
Evidera
Director Patient Engagement and Research Scientists

Chair Elect: Elizabeth Unni
Roseman University of Health Sciences
Associate Professor

Psychometrics

Chair Elect: Henrick Eshøj
Odense University Hospital
Project Manager in Quality of Life Research Center

QOL in Clinical Practice

Chair Elect: Kate Absolom
University of Leeds
University Academic Fellow

Response Shift

Chair Elect: Lene Kongsgaard Nielsen
Odense University Hospital
PhD Candidate, MD

Translation and Cultural Adaption

Chair Elect: Huda Shalhoub
Evidera
Research Scientist

United Kingdom and Ireland

Chair Elect: Grace Turner
University of Birmingham
Research Fellow

To learn more about ISOQOL Special Interest Groups, visit <http://www.isoqol.org/special-interest-groups>.



WELCOME NEW CHINESE PRO SIG

ISOQOL is proud to announce the arrival of the Chinese PRO SIG, whose overall goal is to promote research and education of patient reported outcomes in the Chinese population.

Special Thanks to the Founding Co-Chairs Daniel Fong from the University of Hong Kong and Jiqian Fang from Sun Yat-sen University!

Interested in joining the Chinese PRO SIG?

Visit <http://www.isoqol.org/special-interest-groups> or email info@isoqol.org.





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



MEASURING WHAT MATTERS – FACILITATING DISCUSSION WITH REGULATORS

This year's Measuring What Matters Symposium – to be held in Washington D.C. from 23-24 July 2018 – brings a dynamic look at how wearable and mobile devices play a role in clinical trials. Not only does the symposium bring together academic leaders, patient research partners, clinicians, the pharmaceutical industry, and representatives from the mobile health device industry, but it also opens discussion with regulators.

Regulators are the main gatekeepers for accessing new medicines and their perspectives on measuring function are critical. In addition, regulatory authorities set high standards for evidence generation, making it important to learn their views and expectations.

This summer, representatives from the FDA will contribute to several sessions regarding their views and concerns surrounding function measurement. Attendees will also have the opportunity to interact with regulatory representatives through a series of Q & A panels and interactive workshops. The symposium's closing event features a White Paper Workshop: Looking to the Future, led by FDA representative Bellinda King-Kallimanis.

Other FDA representatives include: Elektra Papadopoulos and Paul Kluetz.

To learn more about the symposium, we encourage you to visit www.isoqol.org/measuring-what-matters-symposium. linicians 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.



ISOQOL WEBINAR: USING PROMS FOR SCREENING AND DIAGNOSTIC PURPOSES

Registration Opens 2nd week of June • Registration Closes 8 July 2018
Live Webinar: 11 July 2018 • 10:00 AM CDT – 11:00 AM CDT

WHAT:

There is a growing body of evidence on the use of PROMs in clinical practice and its impact on processes and outcomes of care. However, evidence on the use of these tools for screening and diagnostic purposes is limited. In this webinar, we intend to provide an overview of the indications/ advantages of using PROMs for screening and diagnostic purposes, provide examples of using specific measures for these purposes, and discuss the implications and challenges of using PROMs for these purposes.

WHY:

At the conclusion of the webinar, participants would have an understanding of the current state of evidence on the use of PROMs for diagnostic and screening purposes, and gain insights into research gaps and potential challenges for using PROMs in this capacity. After watching this webinar, attendees will be able to:

Understand why and how PROMs could be used as screening or diagnostic tools.

Identify a research gap and potential research question to add to the body of evidence and further the discussion on the use of PROMs in this capacity.

WHO:

Theresa Coles, PhD
Director, Patient-Centered Outcomes Assessment
RTI Health Solutions

James H. Willig, MD, MSPH
Associate Professor
University of Alabama at Birmingham, School of Medicine

Amy M. Cizik, PhD, MPH
Research Assistant Professor
Department of Orthopaedics and Sports Medicine, University of Washington

ORGANIZED BY:

QOL in Clinical Practice SIG

COST:

ISOQOL Members: \$75
Student Members: \$25
Special Members: \$25
Non-Members: \$100

[Learn More](#)





NEW BENEFITS INCLUDED IN ANNUAL CONFERENCE REGISTRATION RATES

Starting in 2018, ISOQOL's Annual Conference Registration rates will include membership fees and three buffet lunches.

REGISTRATION BENEFITS OVERVIEW

- Access to scientific content from Thursday through Saturday - including all plenary sessions, oral and poster sessions, and symposia
- Access to the exhibit area and the Welcome Reception
- Two coffee breaks daily, Thursday, Friday and Saturday
- **NEW!** Buffet lunch daily on Thursday, Friday and Saturday
- **NEW!** ISOQOL member registration includes 2019 membership fees with continued access to full member benefits
- **NEW!** Nonmember registration includes prorated 2018 membership fees and 2019 membership fees with access to full member benefits

REGISTRATION RATES

Current members will pay the same amount in 2018 as they did in 2017 for their registration and membership. Non-members will pay less in 2018 than 2017.

	ADVANCED (through 10 September)	ONSITE (after 10 September)
ISOQOL Member	\$880	\$955
Student Member	\$397	\$472
Retired Member	\$397	\$472
Special Member*	\$382	\$457
Regular Patient Research Partner	\$490	\$565
Affiliate Patient Research Partner	\$397	\$472
Non-Member	\$955	\$1,030
Student Non-Member	\$428	\$503
Retired Non-Member	\$428	\$503
Special Non-Member*	\$405	\$480
Regular Patient Research Partner Non-Member	\$565	\$640
Affiliate Patient Research Partner Non-Member	\$428	\$503

**The Special Member and Nonmember Registration Rate is for current ISOQOL Members with an annual income of less than \$15,000 USD and/or members from developing countries. For a list of developing countries, visit www.isi-web.org/index.php/resources/developing-countries.*

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.

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.



 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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