

# Quality of Life

QUARTERLY

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VOLUME 23 ISSUE 3  
Newsletter for  
ISOQOL Members  
SUMMER 2017



## PRESIDENT'S MESSAGE

*Claire Snyder, PhD, Johns Hopkins School of Medicine*



Dear Colleagues,

It is an exciting time for ISOQOL, with our organization playing an increasingly promi-

nent role in advancing the science of health-related quality of life and related patient-centered outcomes to identify effective interventions, enhance the quality of health care, and promote the health of populations. (If that sounds familiar, it's because it's paraphrased from our mission statement.) More and more, we are hearing from organizations and stakeholders interested in learning from, and collaborating with, ISOQOL.

Such partnerships are important. While not yet finalized, one proposed goal in our developing Strategic Plan is to position ISOQOL as the leader in integrating health-related quality of life and related patient-centered outcomes into health research, care, and policy. To accomplish this goal,

we aim to forge mutually beneficial collaborations with organizations to advance the field. In fact, with the increasing visibility of ISOQOL's expertise, we have already been approached by a number of groups interested in exploring opportunities to work together.

As you might have seen in a recent email announcement, the U.S. Food and Drug Administration has invited ISOQOL to participate in its Network of Experts, a vetted network of partner organizations and their members who provide the FDA Center for Devices and Radiological Health and Center for Drug Evaluation and Research rapid access to expertise. As a reminder, if you are interested in volunteering as a potential expert, log in to your ISOQOL member profile, and select the option under "Specialty" of "Yes - I am willing to be contacted as an expert to outside entities."

This FDA initiative is just one example of ISOQOL's contributions to important projects in the field. ISOQOL is a collaborating partner on

*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](mailto:info@isoqol.org)

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Colleen Pedersen:  
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**ISOQOL Office**

555 E. Wells Street, Suite 1100  
Milwaukee, WI 53202, USA  
Telephone: +1 (414) 918-9797  
Fax: +1 (414) 276-3349  
[info@isoqol.org](mailto:info@isoqol.org) • [www.isoqol.org](http://www.isoqol.org)

*President's Message, Continued from page 1.*

the recently released "Users' Guide for Integrating Patient-Reported Outcomes in Electronic Health Records." We are also collaborating on the SPIRIT-PRO Extension project – an effort to build on the SPIRIT Initiative (Standard Protocol Items: Recommendations for Interventional Trials) — to provide evidence-based guidance for the information to include in trial protocols specific to patient-reported outcomes. ISOQOL also has representatives contributing to the SISAQOL Consortium (Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data), convened by the European Organization for the Research and Treatment of Cancer. As another demonstration of the increasing interest in ISOQOL and its products, a Japanese translation of the "Users' Guide for Implementing Patient-Reported Outcomes Assessments in Clinical Practice" is nearing completion. These are just a few examples of ISOQOL's participation in, and leadership of, initiatives that are advancing the field.

Notably, all of ISOQOL's collaborations are governed by signed agreements with the partnering organizations. These agreements outline the terms of what each partner will contribute, how each partner will be recognized, and expectations for how the partnership will be conducted. To help

us pursue these collaborations, we have formed a Task Force to explore mutually beneficial opportunities for partnerships. As the Strategic Plan is finalized, the role of this Task Force will be further elucidated.

As noted in previous newsletter articles, these collaborations and partnerships are just one aspect of the Strategic Planning Committee's considerations. Sub-groups are also developing goals and objectives related to member engagement, development, and diversity; marketing and visibility; and sustainability of resources and funding. All of these goals will further increase ISOQOL's visibility in the field.

Once we have a complete Strategic Plan draft, it will be circulated to the membership for comment. Feedback received will inform the final plan, which will be presented at the Annual Conference in October in Philadelphia. I look forward to seeing you at the conference and invite you, as always, to send feedback to [ISOQOListsens](mailto:ISOQOListsens).

Sincerely,

Claire Snyder, PhD, ISOQOL President



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## FROM THE EDITOR'S DESK

By: Ana Popielnicki, BA



Dear ISOQOL family:

It is my pleasure to present to you our third issue of 2017. This is our last issue before the

Annual Conference, and plans are coming along nicely for a very enriching and innovative program.

In her President's Message, Dr. Snyder focuses on the tremendous growth and positioning of our Society as a leader in health-related quality of life research, and integrating patient centeredness into health research, care, and public policy. She also touches on our increasing strategic partnerships with other organizations and agencies, as our membership is recognized for their

expertise and knowledge in the industry at a global level.

In this issue we introduce the new members of our Board of Directors, and extend our heartfelt congratulations to Dr. Nancy Mayo, recipient of the 2017 President's Award. As well, we welcome our new members, who you will find in the Member's Corner section.

As we get ready to meet next month in Philadelphia, we include comprehensive information about the conference registration – please review the exciting educational opportunities during the conference, such as the IPRO course or the various half-day workshops, as well as many activities and opportunities to network and participate. Don't miss the wealth of information on the AC provided by our Executive Office in this issue!

Please check Dr. Benjamin Craig's piece on Health Preference Research – a very comprehensive look at answering the question "What is the Value of a Health Outcome?" In addition to the AC details, you can also find information about ISOQOL's year-round educational opportunities through the Webinar series – details in this issue.

Please send any questions, comments, or submissions for our next issue to [info@isoqol.org](mailto:info@isoqol.org) with "Newsletter" as your subject line. See you in Philly!



Ana Popielnicki  
Editor





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Dohme Corp.  
North Wales, PA  
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Modus Outcomes  
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Duke Clinical  
Research Institute  
Durham, NC  
United States

## CONGRATULATIONS!

### 2017 PRESIDENT'S AWARD RECIPIENT



Nancy Mayo, PhD  
Professor  
McGill University  
Health Centre  
Montreal, Quebec, Canada



24<sup>TH</sup> ANNUAL CONFERENCE

18–21 October 2017  
*Philadelphia, Pennsylvania*

UNITED STATES

**REGISTRATION NOW OPEN**



VISIT THE ANNUAL CONFERENCE WEBSITE TO  
REGISTER AND TO BOOK YOUR ROOM.

<http://www.isoqol.org/2017conference/registration>

<http://www.isoqol.org/2017conference/hotel--travel>



## 24<sup>th</sup> ANNUAL CONFERENCE REGISTRATION INFORMATION



Registration fees not only provide access to the Scientific Program of plenary sessions, oral and poster presentations, and symposia; but there are several exciting highlighted events that are included. These highlighted events can be attended at no additional fee, but pre-registration is requested.

### 24TH ANNUAL CONFERENCE HIGHLIGHTED EVENTS

Highlighted events can be attended free of charge for all registered conference attendees.

- **Industry SIG Symposium**  
Wednesday, 18 October, 4:30 PM - 6:00 PM  
*Real-world evidence to support product approval and reimbursement: new frontier?*
- **Welcome Reception**  
Wednesday, 18 October, 6:00 PM - 7:30 PM  
*Begin your time at the conference by visiting with old friends and networking with new friends and colleagues.*
- **Funders Meeting**  
Thursday, 19 October, 12:25 PM - 1:30 PM  
*Featuring Speakers from government and private funding organizations, learn about current and upcoming funding opportunities.*
- **Tricks of the Trade Presentation**  
Thursday, 19 October, 6:00 PM - 6:30 PM  
*Simplexity – How to transfer complex research into effective presentations*  
  
Speakers:
  - Karon F. Cook, PhD, Northwestern University, Houston, TX, United States
  - Christopher Gibbons, Cambridge University, Cambridge, United Kingdom

**REGISTER TODAY**

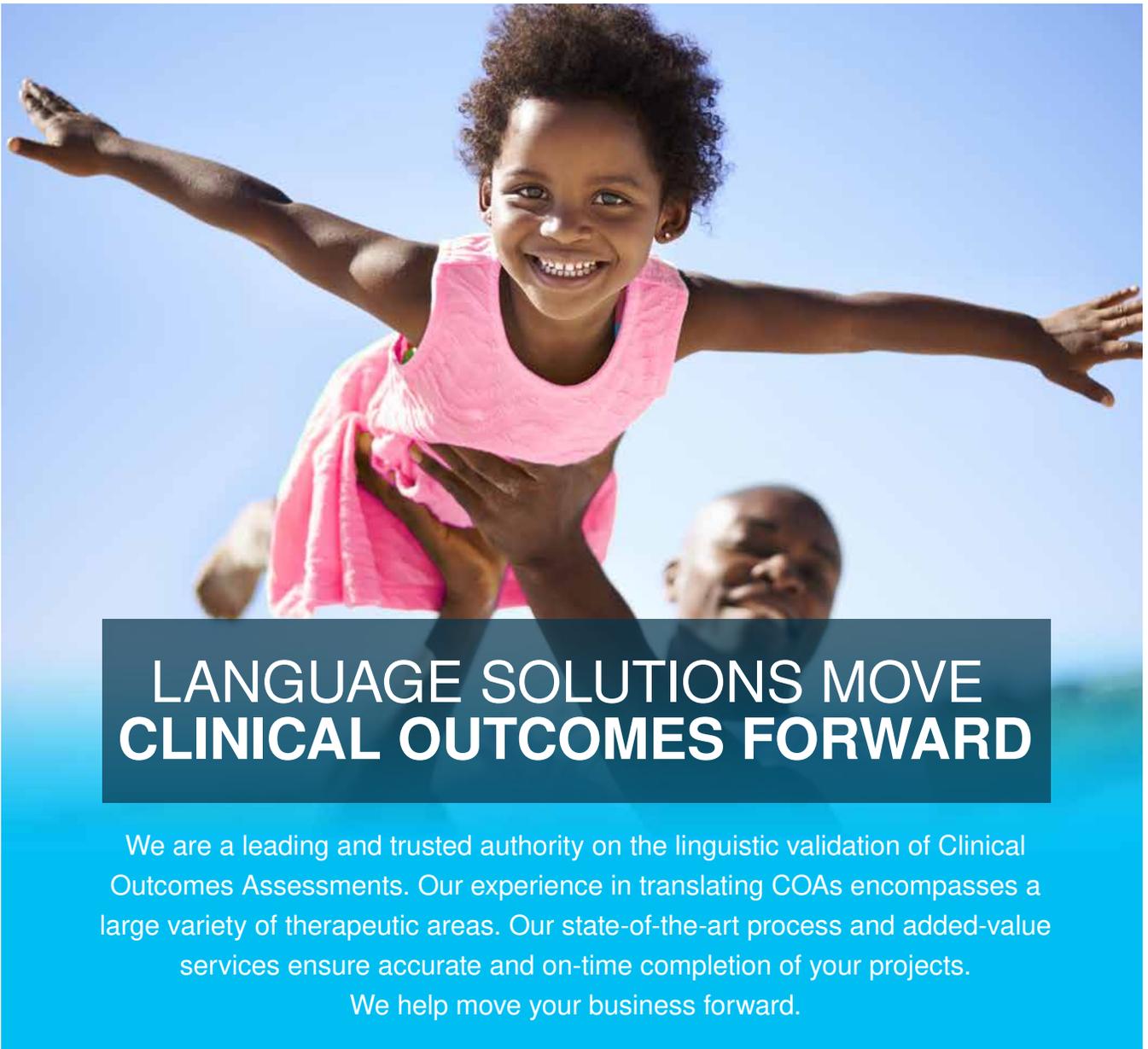


### CLOSING DINNER

Join us for the Closing Dinner on the last night of the Annual Conference. The Closing Dinner will be held at **Moshulu**. Moshulu is the world's oldest and largest square rigged sailing vessel still afloat. Built by William Hamilton and Company on the River Clyde in Glasgow, Scotland in 1904. The largest remaining original windjammer, she is currently the only restaurant venue on a Tall Ship today.

**The Closing Dinner will be held on Saturday, 21 October from 7:00 to 10:00 pm.** Tickets are required for this event and can be purchased through the [registration form](#). Space is limited, so be sure to register early for the Closing Dinner.





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## EDUCATIONAL SESSIONS AT THE 24<sup>TH</sup> ANNUAL CONFERENCE

Can't attend the entire Annual Conference? Looking for a shorter commitment? Attend one of our half-day workshops or the full-day IPRO course on Wednesday, October 18. *(Conference registration is not required for these events.)*

### IPRO COURSE

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

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.

**FOR MORE INFORMATION AND REGISTRATION ON IPRO COURSE**

### WORKSHOPS

Eight different half-day workshops on a variety of topics will be held Wednesday, October 18. This year's speakers come from across the globe and bring a wide range of experience from industry to academia. All workshop topics were selected based on peer-reviewed proposal submissions.

| <b>Morning Workshops<br/>9:00 AM – 12:00 PM</b>  | <b>Afternoon Workshops<br/>1:00 pm – 4:00 pm</b>   |
|--|--|
| WK01: An Introduction to Health-Related Quality of Life  | WK05: Improving the design of clinical trials with PROs: guidance for protocol writers   |
| WK02: Good Practice Guidance for Patient Engagement in Research  | WK06: Introduction to Latent Curve Modeling  |
| WK03: Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) – Qualitative Methodological Approaches for Data collection, Analyses and Reporting | WK07: Designing Quality of Life-driven Mobile Information Technologies   |
| WK04: Interpretation Guidelines to Define Clinical Relevance for Patient-Reported Outcome (PRO) Measures   | WK08: Patient Reported Outcome (PRO) Measurement in Pediatric Clinical Practice: Special Considerations from Patient and Family Engagement to Implementation |

**FOR MORE INFORMATION AND REGISTRATION ON WORKSHOPS**



## NETWORK & EXPLORE PHILADELPHIA

### JOIN THE ISOQOL DINE-AROUNDS

**Friday, 20 October 7:00 pm**  
**Various Locations Around Philadelphia**

Dine-Arounds are a great opportunity to visit with fellow members of the ISOQOL and Health Related Quality of Life Research community, as well as experience one of the wonderful restaurants Philadelphia has to offer!

If you choose to participate in the optional Dine-Around event, you will be placed in a group based on personal preference and availability. Tables will be reserved for all groups at unique restaurants around Philadelphia. On Friday evening, 20 October, after conference sessions conclude, you will meet with your designated group and walk or take a taxicab together to your specific dining location. All dine-around participants are responsible for paying for their own meal.

If you are interested in being a part of this year's Dine-Around event, please fill out the sign-up below! Space is limited and available on a first-come, first-served basis. Sign-up for a Dine-Around by adding your name next to the restaurant you would like to try via this link: <http://www.signupgenius.com/go/508084aafab2fa6f94-dinearound>



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# TOOLS MATTERS.



## WHAT IS THE VALUE OF A HEALTH OUTCOME?

*Benjamin M. Craig, PhD — University of South Florida, Tampa, Florida, USA*

One of the most difficult questions within quality of life research is “What is the value of a health outcome?” The response facilitates the design of instruments and studies and the interpretation of the outcome evidence. To answer this question, preference researchers rigorously design and conduct valuation studies that elicit the health preferences of a target population (i.e., choice defines value). The resulting value sets can be used to numerically summarize outcome evidence in terms of a common numéraire (e.g., losses in wealth, shorter lifespans) to inform health policy and decision making, particularly when faced with difficult trade-offs (e.g., benefits vs. risks).

In a paired comparison study, respondents are typically asked, “Which do you prefer?” given the attributes of an outcome and its alternative. Like prices on a restaurant menu, these attributes influence the respondents’ preferences. The law of demand states that as the “price” of an outcome increases, fewer consumers will choose the outcome over its alternative. This relationship between price and choice is commonly known as a demand curve. Regardless of attributes, numéraire and population, there are two prominent estimators of value that summarize the demand for health: the median (50<sup>th</sup> percentile) and the mean.

To most HPR researchers, the value of a health outcome is defined by the alternative such that exactly half of the respondents prefer the outcome over the alternative (i.e., the median at the center of the demand curve). For example, if exactly half of the respondents choose “Starting today, 10 years with severe anxiety and depression then die” over “Starting today, 5

years with no health problems then die,” the value of the loss in quality of life is equivalent to the shorter lifespan. In the United States, seven of the eight national valuation studies used this approach to produce value sets for PRO instruments on a quality-adjusted life year scale (i.e., SF-6D, PRO-CTCAE, PROMIS-29, EQ-5D-5L, EQ-5D-Y, BPI, NS-CSHCN).

To some HPR researchers, the value of a health outcome is defined by the mean of utilities. In economics, the term “utility” implies a latent function at the individual level that dictates a person’s choices. Utility cannot be observed without error (i.e., latent); however, some studies include adaptive preference tasks (e.g., time trade-off or standard gamble) that incrementally raise or lower the price of an outcome to identify a switching, matching or tipping point between the outcome and its alternative as a measure of a respondent’s utility. Such indifference statements are also known as “compensating variation.” The original U.S. valuation study of the EQ-5D-3L elicited preference evidence using a time trade-off task and estimated median and mean of utilities to produce value sets suitable for economic evaluations.

If utility is finite and symmetrically distributed within a population, the median and mean estimates should be the same. However, these conditions rarely hold. When asked to trade off lifespan, some respondents flatly refuse to choose a shorter lifespan, often citing religious convictions. For these respondents, life is priceless, implying that gains in lifespan have infinite utility and causing the mean estimator to become infinite for all outcomes. Likewise, the distribution of utility may be bimodal for some

outcomes, such that the mean may fail to represent the utility of any respondent. Although the median and mean estimators originate from the same demand curve, the median tends to be a more robust measure of central tendency than the mean.

Over the last ten years, the field of health preference research has matured greatly and moved toward more rigorous methods. It is no longer acceptable to drop those with specific religious convictions or manipulate the preference evidence to improve the face validity of value sets (i.e., worse-than-death transformations). Under majority rule, the median estimator has become the dominant approach to define value from the societal perspective; however, it is equally important to know whether subpopulations exist with distinctly different values. Novel techniques have been recently developed to enhance the analysis of such preference heterogeneity, particularly to estimate the prevalence of lexicographic preferences (e.g., non-traders in lifespan).

In summary, health preference research captures the preferences of stakeholders on health outcomes so that quality of life researchers can better understand the value of outcome evidence. Health valuation studies characterize the demand for health and enhance the relevance of quality of life research. This fall, I will step down as the founding co-chair of the Health Preference Research (HPR) Special Interest Group at ISOQOL. In this article, I hope to encourage more researchers to learn about preference research methods and expand the preference-based summary of PRO instruments to inform health policy and decision making.



## 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**

6 December 2017 at 10:00am CST

#### **'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 | Series |
|----------------|------------|--------|
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***Journal of Patient-Reported Outcomes***

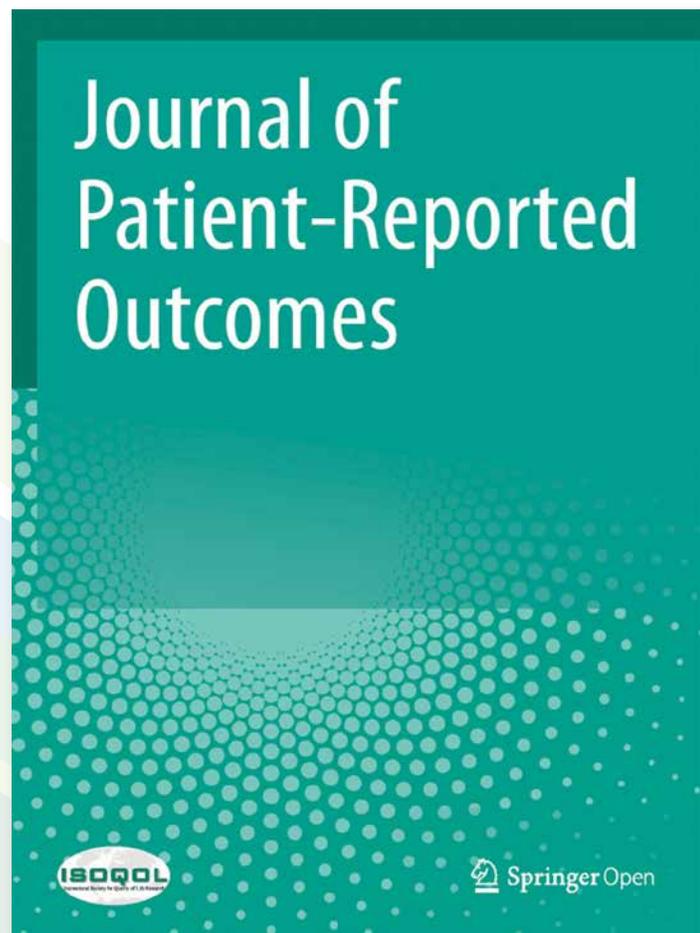
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