Preliminary Program

Assessment, action, and accountability:
Achieving optimal patient-centered outcomes
through quality of life research

ISOQOL
26th Annual Conference

20-23 October 2019
San Diego, California, USA
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Telephone: +1 (619) 291-2900
Sheratonsandiego@sheraton.com
## Schedule at a Glance

### Sunday, 20 October (pre-conference day)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM - 7:00 PM</td>
<td>Registration desk open</td>
</tr>
<tr>
<td>9:00 AM - 4:00 PM</td>
<td>IPRO Course*</td>
</tr>
<tr>
<td>9:00 AM - 4:00 PM</td>
<td>IPCOR-Pharma Course*</td>
</tr>
<tr>
<td>9:00 AM - 12:00 PM</td>
<td>Morning Workshops*</td>
</tr>
<tr>
<td></td>
<td>WK1: Stated-preference methods – an alternative method to measure the patient perspective</td>
</tr>
<tr>
<td></td>
<td>WK2: Theoretical and methodological foundations of latent variable measurement invariance</td>
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<tr>
<td></td>
<td>WK3: Patient-focused endpoints: Defining, developing and analyzing PRO endpoints for optimal interpretability</td>
</tr>
<tr>
<td></td>
<td>WK4: Latent Dirichlet Allocation in Analyzing Free-Text Data in Quality Of Life Research</td>
</tr>
<tr>
<td>12:00 PM - 1:00 PM</td>
<td>Lunch on your own</td>
</tr>
<tr>
<td>1:00 PM - 4:00 PM</td>
<td>Afternoon Workshops*</td>
</tr>
<tr>
<td></td>
<td>WK5: How Rasch and Classical Test Theory Can Complement Each Other When Assessing the Reliability and Validity of Clinical Outcome Assessments: A Hands-on Workshop</td>
</tr>
<tr>
<td></td>
<td>WK6: Digital storytelling: Sharing healthcare experiences as meaningful expression of health-related quality of life</td>
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<td></td>
<td>WK7: Clinical outcome assessment in a multi-cultural context: Measurement challenges and solutions</td>
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<tr>
<td></td>
<td>WK8: What is Implementation Science and How Can It Help Us Integrate PROMs into Clinical Practice?</td>
</tr>
<tr>
<td>4:30 PM - 6:00 PM</td>
<td>Concurrent SIG Symposia</td>
</tr>
<tr>
<td></td>
<td>Patient preferences about health-related quality of life and healthcare: why and how to use them Presented by the Health Preference Research SIG</td>
</tr>
<tr>
<td></td>
<td>Integrating the patient perspective throughout the medical product lifecycle: Emerging opportunities Presented by the Industry SIG</td>
</tr>
<tr>
<td></td>
<td>How to Write a Competitive Grant Proposal Presented by New Investigator SIG</td>
</tr>
<tr>
<td></td>
<td>Patient engagement with PRO completion in clinical practice: Challenges and solutions Presented by the Patient Engagement SIG and Quality of Life in Clinical Practice SIG</td>
</tr>
<tr>
<td>6:00 PM - 7:30 PM</td>
<td>Welcome Reception</td>
</tr>
<tr>
<td>7:15 PM</td>
<td>Dine Arounds (advance sign-up required)</td>
</tr>
</tbody>
</table>

*Event requires pre-registration and the purchase of a ticket.*
# Schedule at a Glance

**Monday, 21 October**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM</td>
<td>Registration desk open</td>
</tr>
<tr>
<td>7:15 AM</td>
<td>First Time Attendee - Coffee with Board of Directors</td>
</tr>
<tr>
<td>8:00 AM</td>
<td>Welcome from Scientific Program Co-Chairs</td>
</tr>
<tr>
<td>8:10 AM</td>
<td>President’s Address</td>
</tr>
<tr>
<td>8:30 AM</td>
<td>Plenary 1: Assessment: The art and science of selecting measures for patient-centered outcomes research.</td>
</tr>
<tr>
<td>10:00 AM</td>
<td>Refreshment break and exhibits open</td>
</tr>
<tr>
<td>10:05 AM</td>
<td>Monday Poster Session I</td>
</tr>
<tr>
<td>10:50 AM</td>
<td>Plenary 2: Cutting Edge Research</td>
</tr>
<tr>
<td>12:00 PM</td>
<td>Buffet lunch (included in conference registration)</td>
</tr>
<tr>
<td>12:05 PM</td>
<td>Committee/SIG Meetings</td>
</tr>
<tr>
<td>1:00 PM</td>
<td>Australia and New Zealand SIG</td>
</tr>
<tr>
<td>2:00 PM</td>
<td>New Investigator SIG</td>
</tr>
<tr>
<td>3:00 PM</td>
<td>QOL in Clinical Practice SIG</td>
</tr>
<tr>
<td>4:00 PM</td>
<td>Response Shift SIG</td>
</tr>
<tr>
<td>5:00 PM</td>
<td>Translation and Cultural Adaptation SIG</td>
</tr>
<tr>
<td>1:45 PM</td>
<td>Concurrent Oral Sessions (101-104)</td>
</tr>
<tr>
<td>3:15 PM</td>
<td>Refreshment break and exhibits open</td>
</tr>
<tr>
<td>3:20 PM</td>
<td>Monday Poster Session II</td>
</tr>
<tr>
<td>4:05 PM</td>
<td>Concurrent Oral Sessions (105-108)</td>
</tr>
<tr>
<td>5:40 PM</td>
<td>Tricks of the Trade Presentation</td>
</tr>
<tr>
<td>6:30 PM</td>
<td>Mentor/Mentee Reception (Ticket Required)</td>
</tr>
</tbody>
</table>
## Schedule at a Glance

### Tuesday, 22 October

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>7:00 AM - 5:00 PM</td>
<td>Registration desk open</td>
</tr>
<tr>
<td>7:30 AM - 8:30 AM</td>
<td>SIG Council Meeting (closed)</td>
</tr>
<tr>
<td>7:30 AM - 8:30 AM</td>
<td>Roundtables*</td>
</tr>
<tr>
<td></td>
<td>RT01: How to peer review a paper; David Feeny, PhD and Dennis Revicki, PhD</td>
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<tr>
<td></td>
<td>RT02: Measuring Mindfulness and Related Constructs: Lessons Learned from an NC-CIH-funded initiative, “COMMENCE”; David Victorson, PhD</td>
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<td></td>
<td>RT03: Health utility measures for QALY construction; Janel Hanmer, MD PhD</td>
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<td></td>
<td>RT04: Developing Clinical Outcome Assessments for Regulatory Purposes; William Lenderking, PhD</td>
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<td></td>
<td>RT05: Integrating patients as partners in clinical research: Perspectives from PCORI; Jason Gerson, PhD</td>
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<tr>
<td></td>
<td>RT06: Standardization of PROs and PROMs; Caroline B. Terwee, PhD</td>
</tr>
<tr>
<td>8:40 AM - 10:10 AM</td>
<td>Plenary 3: Theory, methods and application related to achieving optimal patient-centered outcomes - lessons from Implementation Science</td>
</tr>
<tr>
<td>10:10 AM - 11:00 AM</td>
<td>Refreshment break and exhibits open</td>
</tr>
<tr>
<td>10:15 AM - 10:55 AM</td>
<td>Tuesday Poster Session I</td>
</tr>
<tr>
<td>11:00 AM - 12:15 PM</td>
<td>Concurrent Symposium Sessions</td>
</tr>
<tr>
<td></td>
<td>Symposium 1: Unbiased Treatment Effect and Meaningful Change Detection in the Presence of PRO Missing Data: Updating historical practices to improve oncology outcomes</td>
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<td>Symposium 2: Value-Based Health Care and Outcomes Research; a Short Bridge to Close a Long Gap</td>
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<tr>
<td></td>
<td>Symposium 3: “Tell me more”: Qualitative and quantitative methods for eliciting supplementary data regarding patient experiences during clinical trials and observational studies</td>
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<td></td>
<td>Symposium 4: Novel approaches and solutions to the challenges of measuring health-related domains and concepts across children of a range of ages</td>
</tr>
<tr>
<td>12:15 PM - 2:00 PM</td>
<td>Buffet lunch (included in conference registration)</td>
</tr>
<tr>
<td>12:20 PM - 1:20 PM</td>
<td>Committee/SIG Meetings</td>
</tr>
<tr>
<td></td>
<td>Current Funding Opportunities in QOL Research</td>
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<td></td>
<td>Child Health SIG</td>
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<td></td>
<td>Health Preference Research SIG</td>
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<td>Industry SIG</td>
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<td></td>
<td>Mixed Methods SIG</td>
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<td>Patient Engagement SIG</td>
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<tr>
<td>2:00 PM - 3:30 PM</td>
<td>Concurrent Oral Sessions (201-204)</td>
</tr>
<tr>
<td>3:30 PM - 4:20 PM</td>
<td>Refreshment break and exhibits open</td>
</tr>
<tr>
<td>3:35 PM - 4:15 PM</td>
<td>Tuesday Poster Session II</td>
</tr>
<tr>
<td>4:20 PM - 5:50 PM</td>
<td>Concurrent Oral Sessions (205-208)</td>
</tr>
<tr>
<td>6:30 PM - 10:30 PM</td>
<td>Experience San Diego Social Event*</td>
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<tr>
<td></td>
<td>USS Midway Museum</td>
</tr>
</tbody>
</table>

*Event requires pre-registration and the purchase of a ticket.*
### Schedule at a Glance

**Wednesday, 23 October**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 AM - 5:00 PM</td>
<td>Registration desk open</td>
</tr>
<tr>
<td>7:30 AM - 8:30 AM</td>
<td><strong>Japan SIG Meeting</strong></td>
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<tr>
<td>8:30 AM - 9:45 AM</td>
<td><strong>Concurrent Symposium Sessions</strong></td>
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<tr>
<td></td>
<td>Symposium 5: Incorporating quality of life into economic evaluation of cancer therapies: contributions of the Multi-Attribute Utility in Cancer (MAUCa) Consortium</td>
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<td></td>
<td>Symposium 6: Partnering with patients and caregivers in patient centered outcomes research: challenges and solutions</td>
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<tr>
<td></td>
<td>Symposium 7: Improving PROs in Clinical Trials: The PROTEUS Consortium (Patient-Reported Outcomes Tools: Engaging Users &amp; Stakeholders)</td>
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<td></td>
<td>Symposium 8: Moving the interpretation of PRO scores forward: MIDs et al!</td>
</tr>
<tr>
<td>9:45 AM - 10:35 AM</td>
<td>Refreshment break</td>
</tr>
<tr>
<td>9:50 AM - 10:30 AM</td>
<td><strong>Wednesday Poster Session I</strong></td>
</tr>
<tr>
<td>10:35 AM - 12:05 PM</td>
<td>ISQQL Awards and Member Business Meeting</td>
</tr>
<tr>
<td>12:05 PM - 1:50 PM</td>
<td>Buffet lunch (included in conference registration)</td>
</tr>
<tr>
<td>12:10 PM - 1:10 PM</td>
<td><strong>Committee/SIG Meetings</strong></td>
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<tr>
<td></td>
<td>Canada PRO SIG</td>
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<td></td>
<td>Chinese PRO SIG</td>
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<td>Ibero America SIG</td>
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<td>Psychometrics SIG</td>
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<td>United Kingdom and Ireland SIG</td>
</tr>
<tr>
<td>1:50 PM - 3:20 PM</td>
<td><strong>Plenary 4: Accountability: Counting What Counts</strong></td>
</tr>
<tr>
<td>3:20 PM - 4:10 PM</td>
<td>Refreshment break</td>
</tr>
<tr>
<td>3:25 PM - 4:05 PM</td>
<td><strong>Wednesday Poster Session II</strong></td>
</tr>
<tr>
<td>4:10 PM - 5:40 PM</td>
<td><strong>Concurrent Oral Sessions</strong> (301-304)</td>
</tr>
</tbody>
</table>
General Conference Information

Conference Theme
“Assessment, action and accountability: Achieving optimal patient-centered outcomes through quality of life research”

Target Audience
The 26th Annual Conference of the International Society for Quality of Life Research provides clinicians, outcomes researchers, surgeons, psychologists, psychometricians, nurses, new investigators, patient partners and other medical professionals with a multidisciplinary forum focused on advancing the science of quality of life and related patient-centered outcomes in health research, care and policy. ISOQOL provides the premier opportunity for those in HRQOL and outcomes research to connect and network.

Session types
The Annual Conference offers attendees educational opportunities in a variety of formats – many included in conference registration and some that require additional purchase to attend. The following descriptions can help attendees understand the features of each session type and select the type of instruction best suited to their educational needs.

General Scientific Program

Plenary Sessions
Plenary sessions are scheduled Monday, Tuesday and Wednesday. These sessions are the premier educational sessions of the Scientific Program. Invited speakers will present on topics of interest to the overall meeting audience in a didactic or panel debate format. Admission included with registration.

Symposium Sessions
Symposia are 90-minute didactic or panel presentations held Tuesday and Wednesday. Presenters will examine important issues from a variety of different perspectives. Presentations and debate among presenters will address alternative solutions, interpretations or point of view on an identified body of knowledge within the advertised topic area or theme. Symposia are selected based on peer-reviewed abstract submissions. Admission included with registration.

Oral Presentations
Oral sessions are 90 minutes long and are offered Monday, Tuesday and Wednesday. Each session is composed of five peer-reviewed abstracts clustered around common themes and presented via oral presentations. Each presentation is approximately 11 minutes in length, plus five minutes of questions and answers from the audience. Admission included with registration.

Oral Briefs
Individual abstracts selected as oral briefs are assigned to an oral brief session. An oral brief session includes up to 10 presenters. After a personal introduction by the moderator, each speaker has 5-7 minutes to present using four slides (maximum). While the rapid pace of oral briefs does not allow for audience Q&A within the session, presenters are encouraged to stay after the conclusion of the session to make themselves available for questions. Admission included with registration.

Poster Presentations
Poster sessions are 40 minutes long and offered Monday, Tuesday and Wednesday. They feature presentations of peer-reviewed abstracts in thematic groupings. Poster sessions allow abstract authors to discuss their research with interested colleagues in an informal setting. These sessions are a great way to see the latest research in the field while socializing with colleagues. Admission included with registration.

Poster Guidelines
Each poster is allocated a horizontal display board that is 48 inches (1.22 m) high by 70 inches (1.78 m) wide. Your printed poster must not exceed the allocated board space. Posters will be mounted on display boards with provided tacks.

Poster Numbers
All posters are assigned a poster number corresponding to the poster’s listing in the final program. Odd-numbered posters will be presented in the morning during the daily Session I, and even-numbered posters will be presented in the afternoon during the daily Session II. Posters should only be displayed on the board with their assigned number and during their assigned session (please refer to the “Poster set up and removal” chart).
**General Conference Information**

**Poster Set-Up and Removal**

Presenters are responsible for setting up and removing posters during the assigned set up and removal times. Posters will be mounted on display boards with provided tacks. All posters are assigned a presentation day and time. Posters should be displayed for the full duration in which they are assigned. A detailed schedule of set up and removal times is listed below.

Posters remaining in the hall will be discarded following the close of the conference on 23 October.

<table>
<thead>
<tr>
<th></th>
<th>Monday, 21 October</th>
<th>Tuesday, 22 October</th>
<th>Wednesday, 23 October</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1 Poster</td>
<td>7:00 am - 10:00 am</td>
<td>7:00 am - 10:00 am</td>
<td>7:30 am - 9:30 am</td>
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<tr>
<td>Set Up</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Session 1 Presentations</td>
<td>10:05 am - 10:45 am</td>
<td>10:15 am - 10:55 am</td>
<td>9:50 am - 10:30 am</td>
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<tr>
<td>Odd numbers</td>
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<td></td>
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</tr>
<tr>
<td>Session 1 Poster</td>
<td>11:00 am - 12:00 pm</td>
<td>11:00 am - 12:15 pm</td>
<td>10:30 am - 12:05 pm</td>
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<tr>
<td>Removal</td>
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</tr>
<tr>
<td>Session 2 Poster</td>
<td>1:00 pm - 3:00 pm</td>
<td>1:15 pm - 3:30 pm</td>
<td>1:05 pm - 3:00 pm</td>
</tr>
<tr>
<td>Set up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Session 2 Presentations</td>
<td>3:20 pm - 4:00 pm</td>
<td>3:35 pm - 4:15 pm</td>
<td>3:25 pm - 4:05 pm</td>
</tr>
<tr>
<td>Even numbers</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Session 2 Poster</td>
<td>4:00 pm - 6:30 pm</td>
<td>4:15 pm - 6:00 pm</td>
<td>4:05 pm - 5:00 pm</td>
</tr>
<tr>
<td>Removal</td>
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</table>

**Poster Hall Hours**

All poster presentations will take place in Grande Ballroom C. The Poster Hall will be open daily from 7:00 am - 5:00 pm from Monday, 21 October – Wednesday, 23 October.

**Roundtables**

Roundtables are held on Tuesday morning. Roundtables are informal meetings, with up to nine (9) participants, for networking and discussing mutual interests in a specific work or field. These are invited sessions and have not been peer reviewed.

**Pre-conference Sessions**

**Intro to PCOR for Pharma (IPCOR-Pharma)**

*Introduction to Patient-Centered Outcomes Research (PCOR) for the Pharma/Biotech Industry*

*Using PCOR to Inform Decision Making for Regulators, Payers, Prescribers and Patients*

PCOR is crucial to successful product development in the pharmaceutical/biotechnology industry. PCOR scientists seeking to pursue a career aligned with this industry should understand the product development process, the product lifecycle, the scientific communication process and interactions with key industry stakeholders – both internal and external (i.e., regulators and payers).

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. Case studies will engage participants and give them a chance to test their new knowledge.

This training is aimed at attendees pursuing a PCOR career or have recently started working in the pharma/biotech industry, looking to gain a better understanding of PCOR-related activities within the pharma/biotech industry (e.g., may currently be working in a Medical Affairs team), pursuing a career in an organization that works closely with the pharma/biotech industry (e.g., regulatory authorities, payer/health technology appraisal organizations, consulting companies) and mentors in academia who are mentoring students in choosing a career path.

*Additional purchase required to attend and seating is limited.*
The IPCOR-Pharma Course is held Sunday, the pre-conference day. Those that participate in the course will receive a certificate of attendance, upon completion of the course evaluation.

**Workshops***
Workshops are held Sunday, the pre-conference day, in the morning and afternoon. Each three-hour session features numerous presenters focused on a specific topic. Workshops are selected based on peer-reviewed proposal submissions.

**Special Interest Group (SIG) Symposia**
Four concurrent symposia hosted by ISOQOL Special Interest Groups (SIGs) are held Sunday, the pre-conference day. These symposia provide educational content related to the special interests and expertise of the groups hosting the session. SIGs have the opportunity to submit a proposal and groups presenting rotate annually to ensure parity and differentiation of content. Admission included with registration.

**Registration Desk**
ISOQOL accepts MasterCard, Visa, American Express and Discover credit cards. Cash transactions may be made in U.S. dollars. Payment by check is accepted so long as the check is in U.S. dollars and drawn on a U.S. bank account.

**Registration Desk Hours**
- Sunday, 20 October: 7:00 am - 7:00 pm
- Monday, 21 October: 7:00 am - 6:00 pm
- Tuesday, 22 October: 7:00 am - 5:00 pm
- Wednesday, 23 October: 7:30 am - 5:00 pm

**Coffee**
The conference registration fee includes two coffee breaks daily Monday, Tuesday and Wednesday. Coffee will be served in the Grande Foyer outside the Plenary Room and Poster Hall. The new extended morning coffee break replaces the breakfast offered from previous years.

<table>
<thead>
<tr>
<th>Day,</th>
<th>Morning Coffee Service</th>
<th>Afternoon Coffee Break</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday, 21 October</td>
<td>7:30 am - 10:50 am</td>
<td>3:15 pm - 4:05 pm</td>
</tr>
<tr>
<td>Tuesday, 22 October</td>
<td>8:15 am - 11:00 am</td>
<td>3:30 pm - 4:20 pm</td>
</tr>
<tr>
<td>Wednesday, 23 October</td>
<td>8:00 am - 10:35 am</td>
<td>3:20 pm - 4:10 pm</td>
</tr>
</tbody>
</table>

**Lunch**
The conference registration fee includes a buffet lunch Monday, Tuesday and Wednesday. Lunch will be served in the Grande Foyer on the lobby level with seating outside on the Bayview Lawn. *(In the case of inclement weather, lunch will be served in the Nautilus Foyer on the lower level with seating in Nautilus 4 & 5.)* Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. *Your conference name badge is required for entry to the buffet.*

**Ticketed Events and Name Badge Admission**
A paid “ticket” is required for the education courses, workshops, roundtables, and the Experience San Diego Social Event. **Tickets are printed on the back of attendee name badges** and can be added at the Registration Desk while supplies last.

**Cancellation Policy**
ISOQOL reserves the right to cancel any session or event due to lack of enrollment or other factors. In the event of a cancellation, registered participants will be notified by email and will have the option to exchange their ticket for an available alternative, or to receive a complete refund.

**Certificates of Attendance**
Certificates of Attendance will be emailed to all attendees the week following the conclusion of the conference.

**Certificates of Presentation**
Certificates of Presentation will be emailed to all presenting authors the week following the conclusion of the conference. Those who require a hard copy may request one at the registration desk following their presentation.

*Additional purchase required to attend and seating is limited.*
General Conference Information

Evaluations
Please take time to complete the Annual Conference evaluation distributed electronically immediately following the conclusion of the conference. Your input and comments are essential in planning future educational events.

Workshop attendees will receive an evaluation link during the course and are asked to respond before the session concludes.

Photography Disclaimer
By registering for the ISOQOL Annual Conference, you give consent to be photographed by ISOQOL staff for purposes of advertising and public display.

Session Recording
Session content is copyright-protected by ISOQOL. Recording of any session without the consent of ISOQOL is prohibited. Any recording done with consent of ISOQOL is for personal use only and cannot be reproduced or distributed.
About ISOQOL

*Dedicated to the promotion of excellence in the science of health-related quality of life.*

The International Society for Quality of Life Research (ISOQOL), established in 1993, is a nonprofit society to advance the scientific study of health-related quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations. ISOQOL provides the premier opportunity for those in the quality of life research field to connect and network.

Quality of life has become a prominent subject in philosophy, social science, clinical medicine, health services and outcomes research. ISOQOL fosters the worldwide exchange of information through: scientific publications, international conferences, educational outreach, and collaborative support for health related quality of life initiatives. With over 820 members, ISOQOL is an international society with activities focused on promotion of high quality research in the science of health-related quality of life (HRQOL) measurement and patient-reported outcomes (PRO).

### Programs and Projects

#### Education Programs
- Annual Conference
- Measuring What Matters Symposium
- Intro to Patient-Reported Outcomes (IPRO Course)
  - Introduction to Quality of Life and Patient-Reported Outcomes: Theory, Measurement and Applications
- Intro to Patient-Centered Outcomes Research (PCOR) for the Pharma/Biotech Industry (IPCOR-Pharma Course)
- Mentor/Mentee Program
- Special Interest Groups (SIGs)

#### Publications
- *Journal of Patient-Reported Outcomes (JPRO)*
- *Quality of Life Research Journal (QLR)*
- *ISOQOL Dictionary of Quality of Life and Health Outcomes Measurement* (English & Portuguese)
- ISOQOL’s Comment on EMA Draft reflection paper on the use of patient reported outcome (PRO) measures in oncology studies
- ISOQOL Recommends Minimum Standards for Patient-Reported Outcome Measures Used in Patient-Centered Outcomes and Comparative Effectiveness Research (2013)
- Patient-Reported Outcomes in Randomized Clinical Trials (2012/2018)
- Using Patient-Reported Outcome Measures to Improve Clinical Practice (2012)
ISOQOL Membership

Benefits of Membership
ISOQOL continues to grow and now includes more than 820 international influential leaders, outcomes researchers, surgeons, physiologists, psychometricians, nurses, new investigators, students and other medical professionals. Membership in ISOQOL is a mark of professional distinction and denotes a dedication to understanding health-related quality of life measurement and patient-centered outcomes.

Tools and Resources
- Thirty-three percent submission discount for ISOQOL’s official open access journal, Journal of Patient-Reported Outcomes
- Free access to the online subscription of Quality of Life Research
- Discounted print subscription to Quality of Life Research
- Discounted access to the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID)

Grow
- Online education with reduced rates
- Discounted Annual Conference registration
- Discounted Measuring What Matters registration
- Reduced rate for ISOQOL Education Courses

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
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MPH PhD
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About ISOQOL

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Intro to PCOR for Pharma (IPCOR-Pharma) Course
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Betsy Tschosik, PhD, United Kingdom

Measuring What Matters
Lori Frank, PhD, United States
Jennifer Petersen, MPH, United States

Mentor/Mentee
Maria-Jose Santana, PhD, Canada
Yuelin Li, PhD, United States

Webinar
Claudia Rutherford, PhD, Australia
Xin Shelley Wang, MD MPH, United States

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Richard Sawatzky, PhD RN, Canada
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Judging Panels

Scholarship Panel
(New Investigator/Student, Developing Country and Patient Research Partner)
Kirstie Haywood, DPhil BSc (Hons), United Kingdom
Elizabeth Gibbons, PhD, United Kingdom
Marcelo Fleck, MD PhD, Brazil
Ana Maria Rodriguez, PhD, Spain
Laura Pinheiro, PhD, United States

Emerging Leader Award Panel
Madeleine King, PhD, Australia
Carol Moinpour, PhD, United States
Ida Korfage, PhD, Netherlands
Kevin Weinfurt, PhD, United States
Tom Willgoss, PhD MSc BA, United Kingdom
About ISOQOL

Special Interest Groups (SIGs)

Australia and New Zealand
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Rasa Ruseckaite, Australia - Chair
Rebecca Mercieca-Bebber, Australia - Chair Elect
Natasha Roberts, BN, Australia - Secretary

Canada PRO
Sara Ahmed, PhD, Canada - Past Chair
Ayse Kuspinar, PhD, Canada - Chair
Nora Fayed, PhD, Canada - Chair Elect

Child Health
Jeanie Landgraf, MA, United States - Past Chair
Nalin Payakachat, PhD, United States - Chair
Robert Arbuckle, United Kingdom - Chair Elect

Chinese PRO
Daniel Fong, PhD, Hong Kong - Chair
Ji-qian Fang, PhD, China - Chair

Health Preference Research
Richard L. Skolasky, ScD, United States - Chair
Manraj Kaur, PhD, Canada - Chair

Ibero America
Monica Avila, Bpharm PhD, Spain - Chair
Pedro Ferreira, PhD, Portugal - Chair

Industry
Paivi Miskala, MSPH PhD, United States - Chair
Linda Nelsen, MHS, United States - Chair

Japan
Kikuko Miyazaki, PhD, Japan - Chair
Yoshimi Suzukamo, PhD, Japan - Chair

Mixed Methods
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Carla Dias-Barbosa, MSc, United Kingdom - Chair

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Canhua Xiao, PhD, United States - Chair
Laura Pinheiro, PhD, United States - Chair

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Kirstie Haywood, DPhil, United Kingdom - Past Chair
Hilary Wilson, PhD, United States - Chair
Elizabeth Unni, PhD, United States - Chair-Elect

Psychometrics
R.J. Wirth, PhD, United States - Past Chair
Frances Yang, PhD, United States - Chair
Henrick Eshoj, PhD, Denmark - Chair-Elect

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Kathryn Flynn, PhD, United States - Chair
Kate Absolom, PhD, United Kingdom - Chair-Elect

Response Shift
Tolulope Sajobi, PhD, Canada - Chair
Lene Kongsgaard Nielsen, PhD, Denmark - Chair

Translation and Cultural Adaptation
Ana Popielnicki, BA, United States - Chair
Huda Shalhoub, PhD, United States - Chair
Dagmara Kulis, MA, Belgium - Secretary

United Kingdom and Ireland
Elizabeth Gibbons, MSc, United Kingdom - Past Chair
Anju Keetharuth, PhD, United Kingdom - Chair
Grace Turner, PhD, United Kingdom - Chair-Elect
Plenary Speakers

Plenary 1: Assessment: The art and science of selecting measures for patient-centered outcomes research.

Monday, 21 October | 8:30 am - 10:00 am
Sponsored By: EORTC

The goal for this plenary is to stimulate discussion regarding the choice of different types of outcome measures (PROMs, clinical outcome assessments, surrogate outcomes) in patient-centered outcomes research and the implications of those choices for policy and patient care.

Robert Kaplan, PhD, Stanford University, Los Angeles, CA, United States
Robert M. Kaplan served as Chief Science Officer at the US Agency for Health Care Research and Quality (AHRQ) and Associate Director for Behavioral and Social Sciences at the National Institutes of Health. He is Distinguished Research Professor at UCLA, and Adjunct Professor of Medicine at Stanford. Kaplan is a past President of five professional organizations including ISOQOL. He is a former Editor-in-Chief of Health Psychology and of the Annals of Behavioral Medicine and is a member of the National Academy of Medicine. His 20 books and over 550 articles or chapters have been cited over 50,000 times (H-index>100).

Paul Kluetz, MD, U.S. Food and Drug Administration, Silver Spring, MD, United States
Paul Kluetz is a medical oncologist and the Acting Associate Director of Patient Outcomes in the Oncology Center of Excellence at the U.S. FDA. His interests include defining clinical benefit in oncology trials, the use of expedited programs such as accelerated approval, and opportunities and challenges associated with patient reported outcomes (PRO) data, wearable technologies, and other methods to quantify the patient experience in the clinical trial and “real-world” settings. He is currently leading a team to develop regulatory science and policy initiatives to advance patient-focused drug development in cancer trials.

Plenary 2: Cutting Edge Research

Monday, 21 October | 10:50 am - 12:00 pm
Sponsored By: Vector Psychometric Group, LLC

This plenary session features some of the highest-ranked, most innovative research from ISOQOL abstract submissions. In particular, these abstracts span the research continuum and reflect research that truly “pushes the ISOQOL envelope” in providing new and different ways to look at quality of life.

Tuesday, 22 October | 8:40 am - 10:10 am

ISOQOL member and non-member conference attendees have made remarkable contributions to the field of patient-reported outcome (PRO) measurement. Increasingly more attention is being placed on implementing PROs in routine clinical practice. This plenary will provide a platform to discuss how patient-centered outcomes research and patient-centered care can be strengthened through Implementation Science.

**Carl May, PhD**, London School of Hygiene and Tropical Medicine, London, United Kingdom

Professor Carl May is a medical sociologist and health systems scientist with a wide range of research interests across the sociology of health technologies and of human relations in the healthcare systems of the advanced economies. This work has ranged from very applied evaluation studies in health services research (especially in qualitative studies nested within randomised controlled trials) through studies of the social construction of professional-patient relations and different disease entities, to fundamental social science research on the dynamics of human agency under conditions of constraint in implementation science.

**Karen Emmons, PhD**, Harvard T.H. Chan School of Public Health, Boston, MA, United States

Karen Emmons, Ph.D., is a Professor of Social and Behavioral Science at the Harvard-Chan School of Public Health. Her work focuses on community-based approaches to cancer prevention for disadvantaged populations. These efforts target a range of cancer risk factors, including nutrition, physical activity, sun exposure, tobacco and second-hand smoke exposure, and cancer screening. With a passion for community-based implementation science, Dr. Emmons has been actively involved in national efforts to develop implementation research and training programs. As the Faculty Director of the Community Engagement Program for Harvard’s Clinical Translational Science Award, she brings this focus to advance evidence-based strategies to improve community health.

**Amy M. Kilbourne, PhD, MPH**, U.S. Department of Veterans Affairs, Washington, DC, United States

Amy Kilbourne, PhD, MPH is the Director of the Quality Enhancement Research Initiative (QUERI) for the Veterans Affairs and Professor of Psychiatry at the University of Michigan. Dr. Kilbourne is a national expert in implementation science, partnered-oriented research, and translation of clinical quality improvement intervention findings into actionable policy and practice. She has been widely recognized for her research in multisite implementation intervention trials, development and application of large outcomes databases to improve person-centered care, and integrated physical and mental health care strategies.
Plenary Speakers

Plenary 4: Accountability: Counting What Counts

Wednesday, 23 October | 1:50 pm - 3:20 pm
The goal of this plenary is to consider how we can expand the use of PROMs and promote them as endpoints for assessing healthcare quality, clinical decision making, and delivery of patient-centered care.

Mona Khalid, BSc (Hons), MSc, PhD, International Consortium for Health Outcomes Measurement (ICHOM), London, United Kingdom

Mona Khalid joined ICHOM as the VP of Outcomes Research and Development. Prior to joining ICHOM, Mona spent 10 years in the life sciences industry, leading teams to demonstrate the value of medical interventions. She has joined from Takeda Pharmaceuticals, where she was Global Head of Evidence and Value Generation. Before her tenure in the life sciences industry, she held academic roles at the Institute of Child Health, UCL and at the University of Toronto. She holds a BSc. (Hons) in biology, a MSc. in biomedical science and initiated her PhD in epidemiology.

Rachel Hess, MD, MS, University of Utah, Salt Lake City, UT, United States

Rachel Hess, MD, MS is a Professor of Population Health Sciences and Internal Medicine, Chief of the Division of Health System Innovation and Research (HSIR) and co-Director of the Utah Center for Clinical and Translational Science at the University of Utah. As a General Internist and Health Services Researcher, Dr. Hess brings a unique perspective of translating research into clinical and policy practice. Dr. Hess’s research aims to improve patient-centered outcomes in clinical care. In service of this mission, she seeks to understand determinants of quality of life and how health-related quality of life affects health and cost outcomes.

Dominick L. Frosch, PhD, Palo Alto Medical Foundation Research Institute, Palo Alto, CA, United States

Dominick L. Frosch, Ph.D. is Director and Senior Scientist at the Palo Alto Medical Foundation Research Institute. Dr. Frosch’s research has focused on advancing patient engagement and patient-centered care for over 20 years. He has published over 120 articles, editorials and chapters in the scholarly literature (h-index=44) and serves as Deputy Editor for the Journal of General Internal Medicine. Dr. Frosch received his Ph.D. in clinical psychology with an emphasis on behavioral medicine from the University of California San Diego and completed a fellowship as Robert Wood Johnson Foundation Health & Society Scholar at the University of Pennsylvania.
MEASURING WHAT MATTERS SYMPOSIUM

Development and stakeholder perspectives of core outcomes sets

27-28 JULY 2020
WASHINGTON, D.C., USA

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Abstract Submission Deadlines:
Workshop & Symposium Submission - 20 January 2020
Oral, Oral Brief & Poster Abstract Submission - 6 April 2020