

**SIG/Committee Name: Australia & New Zealand SIG (ANZ SIG)**

**Date: 29/02/2020**

**Co-Chairs: Rasa Ruseckaite, Rebecca Mercieca-Bebber, Askika Maharaj, Natasha Roberts**

**Board Liaison: Kim Cocks**

**Mission:** The Australia Special Interest Group brings together Australian-based researchers in the field of quality of life research. Given geographical remoteness of Australian quality of life researchers from colleagues in the northern hemisphere, the SIG aims to support local researchers by facilitating communication and opportunities for collaboration and exchange of ideas.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
Member engagement	<ul style="list-style-type: none"> <li>Member meetings held 3-4 times per year, encouraging contributions from members about achievements, upcoming meetings and ongoing research.</li> <li>Communication as needed (e.g. announcements, sharing relevant resources, conferences, updates from ISOQOL conference, etc) via teamwork</li> <li>Registry of member expertise</li> <li>Member share and brag – members encouraged to share any relevant news, publications, grants, etc. This is an agenda item for member meetings.</li> </ul>	SIG chair	All members encouraged to communicate with other members via teamwork and share relevant news and achievements.	On-going
Knowledge dissemination	<ul style="list-style-type: none"> <li>Member in the spotlight – a member invited to present results from their current work as a way of disseminating information to other members.</li> </ul>	SIG chair	Past 'spot light' members: Natasha Roberts Askika Maharaj x2 Melissa Rowthorn	On-going (4 times per year)
Collaboration	Members invited to submit ideas and/or proposals for collaborative projects at our quarterly meetings. Current proposals which may develop into collaborations include (1) PROs in haematological cancers, and (2) an audit of PRO measures used in clinical practices around Australia.	SIG chair	1. Natasha Roberts 2. TBC	On going
Regional meeting	<p>The PROMS2020 conference is planned for 22-24 July 2020, at the University of Sydney (pending adequate registrations to cover running costs). This unique event will bring together leading international experts, researchers, and clinicians to engage with the latest advances in the field of patient-reported outcomes (PROs) research and implementation.</p> <p>Dr Nancy Mayo is the confirmed international keynote speaker, and will also run the ISOQOL Introduction to PROs course on the first day of the event.</p> <p>The ISOQOL ANZSIG Chairs, and other ANZSIG members, will all be involved in running workshops at the meeting:            WS1: Trial design and conduct: An introduction to SPIRIT PRO and strategies for reducing missing data            WS2: Interpreting group differences and individual change: challenges and opportunities in PRO data            WS3: Implementation Science and Patient Reported Outcome Measures in Routine Care            WS4: PRO assessment in a multi-cultural context: Cross-cultural language translation and validation</p>	Claudia Rutherford (CR) and Madeleine King (MK)	CR is Chairing the meeting. SIG leaders will be involved in reviewing the program and chairing sessions. ANZSIG members have been invited to join the abstract review committee.	<p>Abstract registration closes at the end of January.</p> <p>Decision about feasibility of the conference will be made in early Feb 2020.</p>

	<p>WS5: Key considerations for selecting PROs and QOL measures for clinical research and health economics</p> <p>WS6: Inclusion of patient reported outcome measures (PROMs) within health systems or services.</p> <p>ISOQOL members and students are offered discounted registration. The conference is being broadly promoted around the Asia-Pacific region.</p>			
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## ANNUAL REPORT

**SIG/Committee Name:** Canada PRO SIG

**Date:** February 18<sup>th</sup>, 2020

**Co-Chairs:** Ayse Kuspinar, Nora Fayed, Ana Maria Moga

**Board Liaison:** Kevin Weinfurt

**Mission:** The Canada-PRO Special Interest Group members are a diverse group of researchers and clinicians with a common interest in promoting patient reported outcomes (PRO) research and use in Canada. Building on initial efforts of the co-leaders and informal meetings at ISOQOL, we will discuss methodological issues and PRO developments, and generate new ideas to move PRO forward in Canada. Initial goals are to identify priority issues for PRO applications in clinical practice, research, and population monitoring, facilitate networking for Canadian researchers and clinicians and provide support for students and fellows, new investigators and first time attendees at ISOQOL.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. National Survey of Canadian PROM Stakeholders	Survey sent across Canada with 54 complete responses to date, continue dissemination of the survey over the next 3 months. Draft a report to send to SIG members.	Ahmed, S	Ahmed, Fayed, Kuspinar, Bartlett, Moga	Report to be drafted, to be available for initial review by members July 2020
2. Draft a report of survey results with federal agencies in Canada	Connect with different federal agencies (e.g. CADTH, CIHR) and share report. Meet with ISOQOL Collaboration Committee to discuss these steps and potential for collaboration with these agencies.	Fayed/Kuspinar	Ahmed, Fayed, Kuspinar, Bartlett, Moga	November 2020
3. Canada-PRO SIG annual meeting in 2020	Hold annual Canada-PRO SIG meeting at ISOQOL, prepare a PowerPoint presentation to update members on survey results and connecting with agencies. Propose to plan a symposium for the ISOQOL conference in 2021.	Moga, A.	Ahmed, Fayed, Kuspinar, Bartlett, Moga	October 2020



# ANNUAL REPORT

**SIG/Committee Name:** Child Health SIG

**Date:** December 2019

**Co-Chairs:** Nalin Payakachat, Rob Arbuckle and John Chaplin

**Board Liaison:** Kirstie Haywood

**Mission:** Primary interests are to stimulate excellent child health-related quality of life research (C-HRQoL), to increase awareness among the general ISOQOL membership of the importance of early health and the potential of child health concepts and methodological practices to foster improvements in health across the lifespan. Such methods/practices include non-patient observer reports/studies; integration of data from multiple reporters: cognitive interviewing methods; adaptations of instruments for respondents with low literacy, attentional and other respondent challenges; and long term effects of health promotion interventions.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Increase presence of CH-SIG and representation of methodological challenges/issues associated with child health assessment at ISOQOL Annual Meetings	<p>Co-Chairs submitted 2 symposia abstracts for the 2019 conference – one for the pre-conference SIG education slot and the other for the general conference session. The symposium for the general conference session was accepted. It went well, was well attended (approximately 50 attendees), and generated a lot of questions and discussion.</p> <p>In 2020 we have again submitted a Child-Health focussed abstract for a symposium – for the general conference session rather than the educational slot.</p> <p>To achieve this the co-chairs created a survey to elicit symposia ideas from the CH-SIG members.</p>	Nalin, John, Rob	<p>Holger Mühlen-Rehmer, John Chaplin, Diane Turner-Bower</p> <p>TBC</p>	<p>Dec 2018-Oct 2019</p> <p>Nov 2019-Jan 2020 for abstract(s)</p>
2. Per member request provide an ongoing opportunity for early networking in the ISOQOL Annual Meetings to ensure time for ongoing conversations throughout the meeting	<p>Organized the 5<sup>th</sup> Annual pre-conference dinner at the San Diego Mtg. Attended by 24 members (increase from 16 the previous year) including some new members – provided good networking opportunity.</p> <p>Co-Chairs working on arrangements for the 6<sup>th</sup> pre-conference dinner for the Prague Mtg in 2020.</p>	<p>Nalin, Jeanne, John</p> <p>Nalin, Rob, John</p>	All members	<p>Jul-Oct 2019</p> <p>Jul-Oct 2020</p>
3. Increase CH-SIG presence within ISOQOL	<p>See #1</p> <ul style="list-style-type: none"> <li>Submit Abstract proposal for 2022 Measuring What Matters Workshop</li> </ul>	Nalin, Rob, John	All members	Concept proposal due in Sept 2020



## ANNUAL REPORT

**SIG/Committee Name: Chinese PRO SIG**

**Date: Feb 13, 2020**

**Co-Chairs: Daniel Fong and Ji-qian Fang**

**Board Liaison: Kevin Weinfurt**

**Mission:** The overall goal of the Chinese PRO SIG is to promote research and education of patient reported outcomes in the Chinese population. The ISOQOL Chinese PRO SIG will facilitate networking for Chinese researchers and offer support for students, fellows, new investigators and first time attendees at ISOQOL.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. To engage individuals with an interest in quality of life research in Chinese	Submit a proposal for an education symposium in an annual ISOQOL meeting	WJ Duan Daniel Fong	All	Proposal submitted on Jan 24, 2020
2. To translate the ISOQOL dictionary into Simplified Chinese	Expert review completed. Pending for editorial review.	JQ Fang Daniel Fong	All	End of 2020
3. To develop linkage with international groups of researchers on Chinese quality of life research	The World Association for Chinese Quality of Life welcome is willing to collaborate with ISOQOL.	JQ Fang Daniel Fong	All	Long-term



## ANNUAL REPORT

**SIG/Committee Name:** Health Preference Research SIG

**Date:** February 24, 2020

**Co-Chairs:** Manraj Kaur, Amy Cizik

**Board Liaison:** I-Chan Huang

**Mission:** The purpose of the Health Preference Research SIG is to perform and promote educational activities and scientific research with respect to health and health-related preferences and all that is related thereto in the broadest sense, is part thereof and/or may promote it; and to engage in organizational activities that support the growth and greater integration of preference research within ISOQOL and its membership.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Submit a HPR SIG-sponsored workshop	Preference elicitation methods for patient-centered outcomes using best-worst scaling and discrete choice experiments for quality of life research.	Amy Cizik	Gang Chen, PhD, MSc, BMed Heather Gelhorn, PhD I-Chan Huang, PhD Sam Li, PhD Donna Rowen, PhD	January 27, 2020
2. Submit a HPR SIG-sponsored symposium	Patient Preference Research: Whither Goest Thou?	Manraj Kaur	Julie Ratcliff (JR), Xiaoning He (XH), Philip Powell (PP), Richard Skolasky (RS), Johns Vishal Bhatnagar (VB),	January 27, 2020
3. Pre-review of HPR abstracts	HPR SIG members will be invited through Teamwork to submit their abstracts for review to select senior members of the SIG prior to the ISOQOL submission deadline. This exercise will not only ensure that high-quality HPR-relevant abstracts are submitted but also ongoing engagement of the senior and new investigator/junior members of the SIG	Amy Cizik	Manraj Kaur, Richard Skolasky	March 2020
4. Membership Survey	Write questions and conduct a membership survey	Amy Cizik	Amy Cizik, Manraj Kaur, Richard Skolasky	April 30, 2020
5. Quarterly Membership Meetings	Update the membership on what the SIG is doing and gain knowledge from the membership on goals for the SIG 1 <sup>st</sup> meeting held February 3, 2020 – only 4 in attendance	Manraj Kaur	Amy Cizik, Richard Skolasky,	Next Meeting: April 2020
6. Chair SIG Meetings	Bimonthly held 11/27/2019 and 1/8/2020. Communicate by email monthly	Manraj Kaur	Amy Cizik	Ongoing. Next Meeting to be determined



## ANNUAL REPORT

**SIG/Committee Name:** Ibero America SIG

**Date:** Feb 18, 2020

**Co-Chairs:** Pedro Ferreira, Noelle de Oliveira Freitas

**Board Liaison:** Kevin Weinfurt

**Mission:** The Ibero America SIG is open to any ISOQOL member residing in an Ibero American country. The SIG holds meetings on targeted issues pertaining to health-related quality of life research.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Annual meeting	Our meeting took place during 2019 San Diego ISOQOL Conference and new members expressed their interest in joining the SIG.			
2. IberoAmerican Meeting	The attendees on the annual meeting decided that next IberoAmerican meeting would take place in Coimbra, Portugal, perhaps during April or May (dates postponed due pandemic)			



## ANNUAL REPORT

**SIG/Committee Name: Industry SIG**

**Date: 02-14-2020**

**Co-Chairs: Linda Nelsen, Michelle White**

**Board Liaison: Josephine Norquist, MS**

**Mission:** The Industry Special Interest Group works to increase participation of the pharmaceutical and device industry in ISOQOL activities through spearheading scientific and methodological initiatives such as leading workshops, organizing symposia, supporting fundraising, authoring papers, and chairing meetings related to scientific and methodological topics of joint interest to industry and ISOQOL.

Project/Objective		Project Chair	Project Members	Timeline
I-SIG Symposium: Plan and deliver industry-focused symposium at the annual meeting		Linda Nelson	Linda Nelsen Emuella Flood Tom Wilgoss Elizabeth Bush Heather Gelhorn Jill Bell Paivi Miskala Michelle White Kathy Lasch William Lenderking	Speakers confirmed: 31 Mar  First TC with speakers: Apr - Sep  Draft Slides: 11 Sep  Final Slides: 9 Oct  Symposium: 20 Oct
TBD, webinar or other activity		Michelle White	Others TBD	TBD





## ANNUAL REPORT

**SIG/Committee Name:** Japan SIG

**Date:** 15 February 2020

**Co-Chairs:** Kojiro Shimozuma, Kikuko Miyazaki

**Board Liaison:** Kevin Weinfurt

**Secretary:** Yoshimi Suzukamo

**Mission:** This Regional Network aims to increase opportunities for Japanese professionals in HRQL to communicate and exchange valuable information. We facilitate collaborations on high-quality studies, create opportunities for information exchange, and disseminate the results with the Japanese research community as well as with wider Asian Pacific and global audiences.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. SIG meeting in San Diego	We held a start-up meeting of Japan SIG with 13 members. We discussed about future tasks and then 4 tasks were proposed. The minutes of meeting were circulated through Teamwork.	Shimozuma K Miyazaki K		Complete
2. Developing of Japanese version of ISOQOL Dictionary	We discussed with Colleen how to proceed with the translation work.	Suzukamo Y	Naito M Shimozuma K Miyazaki K Saito S And other members	under application
3. Regional meeting which holds under the auspices of Japan SIG	1) 7th Annual conference of Japanese Society for Quality of Life and Patient-Reported Outcomes 2) 14th QOL/PRO research seminar 3) 15th QOL/PRO research seminar 4) Pre-Seminar of the 30th Annual Scientific Meeting of the Japan Epidemiological Association 5) Clinical Research Methodology Seminar	1) Noto S 2) Naito M 3) Nishigori T 4) Miyazaki K 5) Miyaji T	Members of Japan SIG and collaborators.	1) Dec. 14, 2019 2) Feb. 29, 2020 3) June 27, 2020 4) Feb. 20, 2020 5) March 6, 2020

**SIG/Committee Name: Mixed Methods SIG**

**Date: 02/24/2020**

**Co-Chairs: Carla Dias-Barbosa, Motolani Ogunsanya**

**Board Liaison: Kirstie Haywood**

**Mission:** The purpose of the Mixed Methods SIG is to promote the use of mixed methods research in the field of QoL research by exploring the challenges and methodological solutions offered by this research paradigm, identifying opportunities for application of mixed methods research in the field, and defining good practice. Our ultimate aim is to share and learn best-practice methodologies that can be utilized to enhance the patient-centeredness of outcomes research.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Longitudinal Qualitative Research Systematic Literature review (LQR SLR)	<ul style="list-style-type: none"> <li>Development of a draft version of the literature review protocol with a core working team in April 2019</li> <li>Communication on the LQR SLR program to the SIG in April 2019</li> <li>Submission of the literature review protocol to the SIG for review and comments in April 2019</li> <li>Finalization of the literature review protocol based on MM SIG comments in July 2019</li> <li>Abstract screening process completed in September 2019</li> <li>Full-text review process ongoing – planned to be completed in February 2020/ manuscript) – Q3/Q4 2020</li> </ul>	Carla Dias Barbosa	Team of 20 members from the SIG	Q3/4 2020
2. Submission of a SIG educational symposium at ISOQOL	<ul style="list-style-type: none"> <li>The SIG symposium submission, <i>The Application of Mixed Methods to Measure Health Outcomes in Clinical Trials, Clinical Practice, and Health Policy</i>, has been accepted for presentation at the ISOQOL 27th Annual Conference in Prague, Czech Republic.</li> <li>Presentation Date: Wednesday, 21 October   4:30 pm - 6:00 pm</li> <li>Conference Location: Clarion Congress Hotel Prague</li> </ul>	Carla Dias Barbosa/ Motolani Ogunsanya	Skye Barbic Carla Dias Barbosa Motolani Ogunsanya Mona Martin Antoine Renaugt	Q4 2020
3. MMR Scoping review	<ul style="list-style-type: none"> <li>Complete draft of scoping review by September 1<sup>st</sup>, 2019, for review by SIG members and discussion at San Diego.</li> <li>Complete recommended revisions from San Diego by Nov 15<sup>th</sup>, 2019</li> <li>Submit to the ISOQOL Board for review by Dec 1<sup>st</sup>, 2019.</li> <li>Make revisions suggested by the board and submit for peer review by March 1<sup>st</sup>, 2020.</li> <li>Data extraction on progress</li> </ul>	Skye Barbic	Skye Barbic Elke Rammant Emma Lidington Antoine Renaugt	Q3/4 2020
4. Submission of written comments to the second FDA guidance ( <b>released in October 2019</b> ) on methods to identify what is important to patients; this	<ul style="list-style-type: none"> <li>Written comments submitted on behalf of the MM SIG members in December 2019.</li> </ul>	Carla Dias Barbosa/ Motolani Ogunsanya	MM SIG members	Dec 2019

guidance includes an overview of MM approaches and examples				
5. Newsletter	<ul style="list-style-type: none"> <li>Monthly profile of members of the month in a newsletter format to showcase our members. <ul style="list-style-type: none"> <li>Will also curate include hot topics, article links, methodology, or newspaper articles.</li> <li>Will also include announcement and updates on ongoing project.</li> </ul> </li> <li>The goal is to foster interrelationship and collaboration among members and to broaden knowledge of emerging topics and issues.</li> </ul>	Motolani Ogunsanya	MM SIG members who wish to participate	Ongoing through 2021



## ANNUAL REPORT

**SIG/Committee Name:** New Investigators SIG

**Date:** 1/30/2020

**Co-Chairs:** Laura Pinheiro, Niki Ow

**Board Liaison:** Nalin Payakachat

**Mission:** The New Investigators SIG is targeted at people new to QOL research. We welcome students, post docs, and anyone who has been working in QOL research for five years or less. We aim to create a network for investigators new to the field of QoL, facilitate discussions, both theoretical and practical and help solve common problems at early stages of one's career.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. New Investigators Special Interest Group 90-Minute Symposium	Laura submitted a symposium proposal, which was accepted for the 2019 annual conference. From April to October, Laura worked with the symposium panel to design a 90-minute symposium on how to write a competitive grant proposal. The panel was comprised of international experts. The symposium was well-attended and Laura received several email requests for the slides.	Laura Pinheiro	Bryce Reeve, Sandra Nolte, Antonia Bennett, Skye Barbic	January 2019- October 2019
2. New Investigators Special Interest Group Survey	Laura and Nikki developed and administered a survey to the membership in December 2019. The goal of this survey was to solicit feedback from the SIG members on ways to improve the SIG and what they would like to see in the upcoming year.	Laura and Nikki	NI SIG members	December 2019- January 2020
3. Educational Webinars	Based on the survey results, we plan to organize and hold at least 2 educational webinars before the annual ISOQOL conference in October 2020. We estimate one should take place in May and September 2020.	Laura and Nikki	NI SIG members	May and September 2020
4. ISOQOL Conference Happy Hour	We plan to organize an informal meet up for SIG members the first night of the annual conference. This will be an opportunity for members to meet and interact prior to the conference officially beginning. We hope this will increase attendance to our annual meeting which is scheduled to take place the first morning of the conference.	Laura and Nikki	NI SIG members	October 2020



## ANNUAL REPORT

**SIG/Committee Name:** Patient Engagement SIG

**Date:** Feb 14, 2020

**Co-Chairs:** Hilary Wilson, Elizabeth Unni and Danielle Lavallee

**Board Liaison:** Kirstie Haywood

**Mission:** The purpose of the Patient Engagement SIG is to place greater emphasis on patients' voice in relation to ISOQOL activities and work with patient advocacy organizations and partners. The Patient Engagement SIG will work closely with the QOL in Clinical Practice SIG to achieve these goals

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Webinar	Action Plans: Working with QOL SIG to Submit application to ISOQOL by Feb 20, 2020 Preplanning call in early April (Apr 8 and Apr 15)  Deliverable: Recorded webinar for members	E Unni	D Lavallee K Absolom N Roberts T Cole J Freel	April 22, 2020
2. Manuscript	Action Plans: Working with QOL SIG to Translate webinar content into manuscript. Target journal is JPRO as a special communication from 2019 ISOQOL conference.  Deliverable: Manuscript	D Lavallee	K Absolom N Roberts T Cole J Freel E Unni	June 2020
3. Survey of membership	To understand the interests of SIG members, identify the work setting of interested members, to engage members throughout the year  Deliverables: Collaboration projects for 2020	D Lavallee	E Unni	Throughout the year
4. Monthly teamwork Email	Recent Research publications on PE Member spotlight Collaborative ideas Discussion on recent readings on PE research	E Unni	D Lavallee	Throughout the year

**SIG/Committee Name: Psychometrics SIG**

**Date: 11-02-2020**

**Co-Chairs: Henrik Eshoj, Frances Yang and Philip Griffiths**

**Board Liaison: Antoine Regnault**

**Mission:** The goals of the Psychometric SIG are to: 1) advance the science of HRQOL research through the application of psychometric methods; and 2) educate researchers and clinicians on the appropriate use of psychometric methods. The field of psychometrics plays a critical role in HRQOL research. Psychometrics plays a key role alongside qualitative methods to develop and evaluate HRQOL measures. Further, structural equation models provide an incredible methodology for looking at associations among HRQOL variables or to model change over time when there are multiple endpoints or mediating/moderating factors.

**Number of SIG Members: 340**

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
Psychometric SIG Survey Google Form to obtain information on what the Psyc SIG members would like this SIG to work with and how to do things in the years to come.	<p>Actions: Link to Survey send to all Psyc SIG members through Teamwork</p> <p>Deliverables: Presentation of Survey results for the Psyc SIG members at the yearly meeting at the ISOQOL conference in San Diego.</p>	Philip Griffiths, Henrik Eshoj	Philip Griffiths, Henrik Eshoj	Fall 2019 (ISOQOL Conference, San Diego)
<p>1. Educational Symposium on Longitudinal Item Response Theory</p> <p>1a. Turn the Educational symposium into a collection of tutorial papers/special issue.</p>	<p>Actions: Symposium proposal submitted January 24st on behalf of the 'Psychometrics' and 'Response Shifts' SIGs.</p> <p>Deliverables: Introduction to the "what, when and how" to use Item Response Theory for longitudinal health data.</p> <p>1a. Actions: Organize and write a letter of inquiry to the Editors of a relevant journal interested in publishing a series of methodological papers on how to use LIRT</p> <p>Deliverables: A collection of tutorial papers on longitudinal Item Response Theory analysis</p>	Henrik Eshoj, Philip Griffiths, Frances Yang	<p>Presenters include Frances Yang, Philip Griffiths, Andrew Trigg, Jacob Bjorner, Berend Terluin, Myriam Blanchin</p> <p>Moderator: Henrik Eshoj</p> <p>Discussant: Carrie Houts</p> <p>1.a) all presenters have agreed to work out a tutorial paper based on their symposium presentation</p>	<p>Fall 2020 (ISOQOL Conference, Prague)</p> <p>1.a: Fall 2020-2021</p>
2. QLR Special Issue on Meaningful Change	<p>Actions: 1) Letter of intent – to be submitted to QLR; 2) Splinter cells with various topics on "meaningful change" will be created. Psyc SIG members who have an interest in the same topic will be put together to explore each of the emerging methodologies and to highlight when</p>	Philip Griffiths	Philip Griffiths, Jan Boehnke, Claudia	2020-2021

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	<p>it should be used, its strengths and limitations.</p> <p>Deliverables: a series of publications on the various methodologies for calculating and evaluating meaningful change scores</p>		Guest Editors: to be decided/announced	
3. SIG Newsletter	Action: Newsletter posted for Psyc SIG members through Teamwork.	Henrik Eshoj, Philip Griffiths, Frances Yang	Henrik Eshoj, Philip Griffiths, Frances Yang	In progress for sending out by April 2020
4. SIG Video Series	<p>Action: Through the support of the ISOQOL Board and Staff video interviews related to the collection of Psychometrics SIG papers published in JPRO were completed at the annual conference in San Diego, CA. They are currently being edited into six separate videos. Three of the videos will be about career trajectories in psychometrics and the role of ISOQOL in furthering their careers in QOL research for each interviewee/author. Three other videos will be about methodology and references to the published papers in JPRO.</p>	Frances Yang	Frances Yang	In progress for review by July 2020.

**SIG/Committee Name:** QOL in Clinical Practice SIG

**Date:** February 17<sup>th</sup> 2020

**Co-Chairs:** Kathryn Flynn, Kate Absolom and Angela Stover

**Board Liaison:** Antoine Regnault

**Mission:** The QOL in Clinical Practice Special Interest Group (CP-SIG) was formed by researchers and clinicians who are interested in health-related quality of life (QOL) assessment to improve clinical practice. Thus the CP-SIG is unique in that it is at the cusp between methodology and implementation. The ultimate objective of the CP-SIG is to bring together individuals who are interested in using QOL assessment to better involve, manage and treat individual patients as well as using QOL data for medical decision-making and improve clinical practice.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Webinar- <i>Patient engagement with PRO completion in clinical practice: Challenges and solutions</i>	Converting patient engagement in PRO completion in clinical practice symposium (delivered at ISOQOL 2019) to webinar (collaboration between QOL in Clinical Practice and Patient Engagement SIG)	Elizabeth Unni /Kate Absolom	Coles T, Wilson H, Lavallee D, Roberts N, Freel J	Webinar planned for April 22 <sup>nd</sup> 2020
2. Paper- <i>Patient engagement with PRO completion in clinical practice (Target journal JPRO)</i>	To complement the above webinar we are planning a complementary summary/commentary paper (ISOQOL concept proposal form to be completed)	Kate Absolom/ Danielle Lavallee	Coles T, Wilson H, Lavallee D, Roberts N, Freel J	May/June 2020
3. Paper series- <i>Using implementation science to implement and evaluate PROM initiatives in routine care settings</i>	Five interconnected papers were submitted to QOLR in November, 2019: <ul style="list-style-type: none"> <li>• “Using an Implementation Science Approach to Implement and Evaluate Patient Reported Outcome Measures (PROM) Initiatives in Routine Care Settings” by Angela Stover, Lotte Haverman, Hedy A. van Oers, Joanne Greenhalgh, Caroline M. Potter, on behalf of the ISOQOL PROMs/PREMs in Clinical Practice Implementation Science Work Group</li> <li>• “Prospective application of implementation science theories and frameworks to use PROMs in routine clinical care within an integrated pain network” by Sara Ahmed, Diana Zidarov, Owis Eilayyan, Regina Visca</li> <li>• “Implementation of the KLIK PROM portal using the Consolidated Framework for Implementation Research (CFIR) retrospectively” by Hedy A. van Oers, Lorynn Teela, Sasja A. Schepers, Martha A. Grootenhuys, Lotte Haverman</li> <li>• “Using Implementation Science to Inform Integration of Electronic Patient-Reported Experience Measures (ePREMs) into Healthcare Quality Improvement” by Kimberly Manalili and Maria Santana</li> <li>• “Using the Integrated Promoting Action Research in Health Services (iPARIHS) Framework to evaluate implementation of Patient Reported Outcome Measures (PROMs) into routine care in a medical oncology outpatient department “ by Natasha A. Roberts, Monika Janda, Angela M. Stover, Kim Alexander, David Wyld, Alison Mudge</li> </ul>	Angela Stover/ Lotte Haverman	Angela Stover, Lotte Haverman, Hedy van Oers, Joanne Greenhalgh, Caroline Potter, Sara Ahmed, Owis Eilayyan, Maria Santana, Kimberly Manalili, Natasha Roberts,	Two papers have received revise and resubmit invitations, and three are still under review. Anticipated to be published in special issue in summer 2020.
4. Symposium proposals submitted to ISOQOL 2020 conference	<b>Main meeting and SIG-specific symposia submissions</b> SYMPOSIUM DESCRIPTION: Patient-reported outcome and experience measures (PROMs/PREMs) are well established in research for many health conditions, but barriers persist for implementing them in routine care. Implementation science (IS) offers a potential	Angela Stover	Angela M. Stover, PhD University of North Carolina at Chapel Hill Chapel Hill, NC, USA	Proposals submitted in January for 2020



	<p>way forward, but its application has been limited for PROMs/PREMs. IS is the systematic study of methods to integrate evidence-based practices into care settings. Part of IS's appeal are the theories and frameworks guiding the translation process from research to practice. In this symposium, we will compare similarities and differences for five widely used IS frameworks and their applicability for implementing PROMs/PREMs in routine care through four case studies. Three case studies use theory to implement PROMs:</p> <p>1) pain clinics in Canada; 2) oncology clinics in Australia; and</p> <p>3) pediatric/adult clinics for chronic conditions in the Netherlands. One case study is using theory to plan PREMs implementation in primary care clinics in Canada. We compare case studies on theories, barriers, enablers, and implementation strategies.</p> <p>IS approaches are largely harmonious with PROMs/PREMs implementation in routine care, although no single framework or theory appears to fully capture the nuances for PROMs/PREMs across clinical contexts. Across case studies in different countries and health conditions, barriers were remarkably consistent, including technology limitations, uncertainty about benefits and concerns about negative impacts, and competing demands within established clinical workflows. A unique aspect of our study is case studies showed more variation for PROM/PREM enablers in clinics than barriers, indicating the potential for tailored solutions. A common enabling factor was designing a technology system with automated features (e.g., patient reminders) and rapid access to results. More unique enablers capitalized on local resources, such as peer champions, advertising campaigns, and providing clinics with implementation funding.</p> <p>Common implementation strategies included engaging stakeholders, changing infrastructure, providing interactive assistance, and training clinicians and staff. Evaluation in case studies was inconsistent, and thus we will present IS metrics specific to evaluating PROM/PREM implementation initiatives. Increasing the use of IS in PROM/PREM implementation studies will help advance our collective understanding of causal mechanisms to better understand how, why, and in what circumstances IS frameworks and implementation strategies produce successful PROM/PREM implementation (or not).</p>		<p>Caroline Potter, DPhil Oxford University UK</p> <p>Natasha Roberts, PhD Queensland University of Technology Brisbane, Australia</p> <p>Hedy van Oers, PhD Academisch Medisch Centrum Universiteit van Amsterdam Amsterdam, Netherlands</p>	conference- awaiting outcome
5. Workshop submitted to ISOQOL 2020 conference	<p><b>Workshop submission: Best practices and lessons learned on implementing PROMs in routine care settings</b></p> <p>WORKSHOP DESCRIPTION: This workshop will serve as a broad introduction to implementing patient reported outcome measures (PROMs) in routine care settings. Participants will learn the state of the field and best practices, common barriers and enablers in clinics, implementation support strategies, and how to evaluate PROM implementation initiatives. International case studies will cover diverse health conditions and populations such as cancer, pediatrics, surgery, and primary care. At the workshop's conclusion, participants will be able to navigate the PROM implementation literature through exposure to best practices, lessons learned, and evaluation methods. Attendees will be asked to bring their own implementation barrier questions to discuss in small groups.</p>	Angela Stover	<p>Angela M. Stover, PhD University of North Carolina at Chapel Hill Chapel Hill, NC, USA</p> <p>Angela Wolff, PhD, RN Trinity Western University Vancouver, Canada</p> <p>Natasha Roberts, PhD</p>	Proposals submitted in January for 2020 conference- awaiting outcome

			Queensland University of Technology Brisbane, Australia  Hedy van Oers, PhD Academisch Medisch Centrum Universiteit van Amsterdam Amsterdam, Netherlands  Elizabeth Austin, PhD (c) University of Washington Seattle, WA, USA	
6. Paper- PROs and Payers	Scoping review underway, with 14248 abstracts identified, 13014 completed first level screening. Currently 1916 will need level 2 review (though some of the remaining in level 1 will also make it to level 2)	Janel Hanmer	Yucel E, Cizik A, Gulek-Bakirci B, McCracken P, Kinsky S, Swart E, Turner R.	Complete Level 2 screening by May 1, 2020. Then begin synthesis and writing
7. Webinar/2021 symposium proposal- Clinician engagement with PROs in clinical practice	Currently in early stages of planning activity around clinician engagement with PROs in clinical practice. Possible webinar towards second half of 2020 and subsequent symposium for 2021.	Angela Wolff/ Kate Absolom	TBC	Possible webinar later in 2020 and 2021 symposium proposal.
8. Communication with SIG members	<ul style="list-style-type: none"> <li>Continued efforts being made to use Teamwork to communicate with members and advertise relevant CP activity/opportunities. In the last few months we have used Teamwork to support SIG member (Jae-Yung Kwon) find clinician input in "<i>No one size fits all for measuring what matters: Supporting the use of PRO data in healthcare</i>" a project funded by the Michael Smith Foundation for Health Research.</li> <li>We recently started promoting the use of Twitter amongst CP SIG members- we suggest using the hashtag #CPSIG to help disseminate news and facilitate networking/discussions amongst our Twitter active members.</li> </ul>	Kate Absolom/ Angela Stover	N/A	Ongoing



## ANNUAL REPORT

**SIG/Committee Name:** Response Shift SIG

**Date:** February 10, 2020

**Co-Chairs:** Lene Kongsgaard Nielsen and Carolyn Schwartz

**Board Liaison:** Antoine Regnault

**Mission:** The purpose of the response shift interest group is to bring together investigators and clinicians who are interested in the influence of response shift (a change in an individual's values, internal standards, and conceptualization of QOL) on QOL assessments. The ultimate objective is to better understand when and why response shift occurs such that healthcare professionals and researchers using patient reported outcomes across various disciplines can recognize and account for response shift.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Special Interest Group Symposium for the ISOQOL conference 2020.	A symposium organized to extent the recurrent knowledge of longitudinal Item Response Theory (IRT) in collaboration with the Psychometrics Special Interest Group.	Pip Griffiths, Henrik Eshøj, Frances Yang, Carolyn Schwartz and Lene Kongsgaard Nielsen	Andrew Trigg, Jakob Bjorner, Berend Terluin and Myriam Blanchin	Submitted for January 27, 2020 deadline, with an aim to present at ISOQOL meeting in Prague October 2020.
2. Response Shift in Sync Symposium for the ISOQOL conference 2020	This symposium summarizes activities of several SIG members over the past two years.	Mirjam Sprangers and Veronique Sebille	Tolu Sajobi, Lisa Lix, Nancy Mayo, Rick Sawatzky	Submitted for January 27, 2020 deadline, with an aim to present at ISOQOL meeting in Prague October 2020.

**SIG/Committee Name:** Translation & Cultural Adaptation SIG

**Date:** February 14, 2020

**Co-Chairs:** Huda Shalhoub, Shawn McKown  
**Secretary:** Dana Weiss

**Board Liaison:** Josephine Norquist

**Mission:** The overall objectives of the TCA-SIG are to identify and advance research into practices and outcomes of translation and cultural adaptation of patient-reported outcome instruments; to provide an evidence database on translation and cultural adaptation of PROs; and to promote visibility of cross cultural issues in development and use of PROs in ISOQOL.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Conduct SIG Annual Meeting	The 2019 Annual SIG meeting was held on 21 October 2019. The presentation by the team chairs included updates on work conducted by the TCA-SIG in the last year, the SIG structure and leadership model, and an interactive group activity. Shawn McKown was introduced as chair-elect, and Dana Weiss as Secretary. The group activity consisted of separating the attendees into groups of 3 or 4, with each group developing suggestions for working topics for the SIG to consider over the coming year. The meeting was very productive, with a number of strong topics suggested during a lively discussion.	Huda Shalhoub, Shawn McKown (chair-elect), Dana Weiss (secretary)	Entire SIG was invited	At the Dublin ISOQOL Annual Meeting – 27 October 2018
2. Non-PRO COA Translation Guidelines Working Group	The objectives of this working group are to address non-PRO COA translation challenges, and to prepare a good practices document suggesting additions/modifications to the generally accepted approaches for PRO translation.  As of February 2020, the manuscript draft has been completed and approved by the SIG.	Shawn McKown	Shawn McKown, Ben Arnold, Sonya Eremenco, Dana Weiss, Caroline Anfray, Catherina Acquadro, Christelle Giroudet, Adelina Lear, Mona Martin	Draft completed during 2019 and early 2020; to be submitted for publication in 2Q20
3. eCOA Translation Standards Working Group	The objective of this working group is to prepare a good practices document suggesting eCOA translation process standards.  As of February 2020, the draft Introduction, Methods, and Results sections have been completed. During 2020, proposed standards will be developed and the remainder of the manuscript will be completed and circulated for review. It is expected that this work will complete in 2020. A manuscript will be submitted.	Huda Shalhoub, Megan Turner	Megan Turner, Huda Shalhoub, Holger Muhlan-Rehmer, Dagmara Kulis, Ben Arnold, Sonya Eremenco, Caroline Anfray, Emily-Parks Venizzi, Jason Bredle, Mark Wade, John Chaplin, Clayon Hamilton, Anita Smarandache, Jussi Repo, Ligia Chavez, Alexandra Crane, Catherine Knoth	Manuscript draft expected completion by April 30, 2020; submission to steering committee by August 31, 2020

## ANNUAL REPORT

4. Concept Definition Standards Working Group	<p>The objective of this working group is to prepare a good practices document for the development of concept definitions as part of the translation and cultural adaptation of COAs.</p> <p>As of February 2020, a survey is prepared for distribution to industry group respondents to report on their concept definitions development practices.</p>	Dana Weiss	Dana Weiss, Ben Arnold, Ana Popielnicki, Barbara Brandt, Sonja Eremenco, Emily Parks Vernizzi, Jussi Repo, Jie You, John Chaplin, Alexandra Crane, Elizabeth Yohe Moore, Mark Wade, Carter Cassedy, Teresa Williams, Miguel Ruiz, Holger Muhlan-Rehmer, Clayon Hamilton, Adelina Lear, Zheng-kun Hou	Survey results analysis and draft manuscript initiated in 2020
5. Newsletter	The leadership team continues to regularly update the membership on the progress of various projects via a newsletter. Newsletters are prepared every 6-8 weeks and distributed through the Teamwork mailing list.	Huda Shalhoub, Shawn McKown, Dana Weiss	SIG membership	Every 6-8 weeks
6. Teamwork portal	Teamwork is in use by the full membership. Files are uploaded on a regular basis and it serves as a place to consult any SIG-related documents.	Dana Weiss	SIG membership and Working Group Chairs	Ongoing use

**SIG/Committee Name:** United Kingdom & Ireland SIG

**Date:** 17/02/2020

**Co-Chairs:** Trish Holch, Anju Keetharuth,

**Board Liaison:** Kim Cocks

**Mission:** The overall aim of the United Kingdom and Ireland SIG would be to promote research into use of PROMS in the UK and Ireland. We would hope to address important methodological issues, discuss UK PROM developments as they arise. This will be an opportunity to encourage and facilitate networking, and support engagement with users (policy, clinical and patients). Support could also be provided for research students and fellows, new UK investigators and first time attendees at ISOQOL.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. 4th PROMs research conference, endorsed by ISOQOL- June 13 <sup>th</sup> , 2019	The conference was held at Leeds Beckett University Centre for Psychological Research. This was as successful as the previous conferences with over 140 delegates and a large representation from ISOQOL members. The proceedings are to be published in the next edition of JPRO. For the first time the conference featured a well-attended workshop on clinical integration. The conference generated two publications 'Patient involvement in PROMS—individual opportunity and strategic challenge' (BMJ Opinion) Holch, Wilson & Bostock <a href="https://blogs.bmj.com/bmj/2019/07/23/patient-involvement-in-proms-individual-opportunity-and-strategic-challenge/">https://blogs.bmj.com/bmj/2019/07/23/patient-involvement-in-proms-individual-opportunity-and-strategic-challenge/</a> and an Interview in Pharmafocus 'The patient is always right: Extracting the full value of PROMs' featuring Trish Holch and Jose Valderas <a href="http://www.pharmafile.com/news/525309/patient-always-right-extracting-full-value-proms">http://www.pharmafile.com/news/525309/patient-always-right-extracting-full-value-proms</a>		Holch T., Absolon, K., Keetharuth A., Gibbons E.	Complete
2. 5th PROMs research conference, University of Sheffield 10 <sup>th</sup> June 2020	This is currently in full development and endorsement received from ISOQOL. Details of the conference registration have been circulated on Teamwork. Abstract submission will be open at the end of February 2020.		Holch T., Keetharuth A., Carlton J.	Ongoing
3. SIG meeting in San Diego	Introduction of Chair elect – Trish Holch from the Leeds Beckett University. The notes of meeting were circulated through teamwork.		Keetharuth, A & Holch, T.	Complete
4. Communication	TH and to liaise with Colleen Pedersen on the use of social media (ISOQOL team have been exploring options for different social media outlets and we will need to comply with the plans). In the meantime we suggest SIG Twitter users start using the hashtag #CPSIG in clinical practice relevant tweets so we can track and retweet them		Holch T., Keetharuth, A.	Ongoing