

SIG/Committee Name: Australia & New Zealand SIG (ANZ SIG)
Date: 7 Mar. 2023
Co-Chairs: Liane Ioannou, Nadia Corsini, Melanie Hawkins, Rachel Campbell
Board Liaison: Tolulope Sajobi

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	Methods, Theory or Application project	Project Chair	Project Members	Timeline
Core outcome set of PROMs in Cancer survivorship	This project aims to develop a core set in cancer survivorship based on COSMIN's recommended approach for the selection of measures	Review of the literature and appraisal of 36 measures using the COSMIN criteria	Imogen Ramsay	Nadia Corsini Claudia Rutherford Ashika Maharaj Julie Campbell Jessica Roydhouse Natasha Roberts	In progress
Landscape of PROs in clinical practice in Australia	This project maps the centres that are implementing PROMs in routine clinical practice across Australia New Zealand	Online Survey	Ashika Maharaj	Natasha Roberts Claudia Rutherford Prof Bogda Koczwara Prof Michael Jefford Jerome Ng (NZ)	Final draft has been circulated to study authors
PROMs Downunder Conference scoping	Scope the feasibility of running a follow-up to the 2021 PROMs Downunder Conference hosted by The University of Sydney.	This will incorporate a range of applications	Nadia Corsini	Melanie Hawkins Rachel Campbell Nadia Corsini Liane Ioannou TBD	Not commenced

SIG/Committee Name: Canada PRO SIG
Date: 17 May. 23
Co-Chairs: Ana Maria Moga, Fatima AlSayah, Doris Howell
Board Liaison: Lotte Haverman

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. Networking Meeting of SIG held at the Annual Conference in October 2022.	Priority issues regarding how to build capacity for implementation of PROs and engage policy leaders/key stakeholders and key levers to use to accelerate progress in implementation of PROs in Canada.	Ana Maria Moga	Members of the PRO SIG	
2. Survey to Identify Use of PROMs and PREMs.	Survey circulated to 71 PRO SIG members with fifty-four responses.	Susan Bartlett and Sara Ahmed	Members of the PRO SIG	Completed and presented, October 2022.
3. Conduct an environmental scan reflecting the current state of PROMs/PREMs uptake in Canada.	Explore funding for the environmental scan. Engage a student to conduct the scan and in collaboration with CIHI, CADRH and other resources to lever. Conduct an online survey and interviews with key healthcare leaders in each province to assess current state of implementation of PROMs and their key success factors with an emphasis on levers i.e. capacity.	Doris Howell, Ana Moga	Engage members from each province in Canada/regions/population	Develop the protocol, identify the key stakeholders and knowledge end users in each province to be contacted. Initiate the review-August 2023.
4. Plan for a SIG Symposium for 2024 ISOQUAL Conference.	Present and publish the results of the Pan Canadian environmental scan.	Doris Howell	Members of the PRO Sig	October 2023 planning.

Issues for Board Attention:



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SIG/Committee Name: Chinese PRO SIG

Date: 17 May. 23

Co-Chairs: Daniel Fong and Qiuling Shi

Board Liaison: Tolulope T. Sajobi

Mission: The overall goal of the Chinese PRO SIG is to promote research and education of patient reported outcomes. 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	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
QoL Assessment and Interventions for Chinese: Challenges, Opportunities, and Implications	Organize an education symposium at the annual ISOQOL meeting in 2023		WJ Duan Daniel Fong	All	Proposal accepted in 2023
To develop linkage with international groups of researchers on Chinese quality of life research	Organize joint events with the World Association for Chinese Quality of Life		Daniel Fong Qiuling Shi	All	In one year

SIG/Committee Name: Child Health SIG
Date: 17 May. 23
Co-Chairs: Holger Muehlan, Zephanie F. Tyack, Sumedh Bele
Board Liaison: Roxanne Jensen

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	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Increase presence of CH-SIG and representation of methodological challenges/issues associated with child health assessment at ISOQOL Meetings	Prepared a joint SIG workshop with the Patient Engagement SIG (PE_SIG) for the 2022 ISOQOL Conference – Title: 'Engagement and Activation of Youth in Paediatric PROM/PREM research'. With contributions from SIG members in Australia, Canada & Sweden.	Theory & Application	John, Zephanie	John Chaplin, Zephanie Tyack, Sumedh Bele, Danielle Lavallee, Sandra Zelinsky, Natasha Roberts	Prepared October 2022 (canceled)
	Ongoing preparation of the 'Measuring what matters' workshop 2022. Title: Measuring What Matters in Child Health: Challenges, Developments and Opportunities	Methods & Application	Rob, Nalin	John, Holger, Nikki Ow et al.+ Adolescent and/or parent/caregiver representative	Completed July 2022
2. Expanding membership & networking	Conducted a SIG Pre-Conference Dinner at the annual conference in Prague.	Consolidation of membership	John	(25 attendees).	Completed Oct 2022
	Conducted a members meeting at the annual conference in Prague.	Consolidation of membership	Holger	(25 attendees).	Completed Oct 2022
	Preparing a special issue on Child QoL from the lense of ISOQOL in the journal Int. J. Env. Research & Public Health. The Child-SIG Chairs act as the editors.	Methods & Application	John, Holger, Zephanie	John, Holger, Zephanie	Preparation ongoing
3. Further Projects/Activities	Prepared a joint SIG session/symposium/webinar (instead of the workshop) with the Patient Engagement SIG (PE_SIG) – Title: 'Engagement and Activation in PROM/PREM research'.	Theory & Application	Zephanie, Sumedh	(tbd)	Preparation ongoing
	Conducting a virtual mid-term members meeting	Consolidation of membership	Holger, Zephanie, Sumedh	Holger, Zephanie, Sumedh	Preparation ongoing

SIG/Committee Name: Developing Countries SIG
Date: 17 May. 23
Co-Chairs: Adesola Odole, Liliane Lins-Kusterer, Vijaya K Gothwal
Board Liaison: Elizabeth Unni

Mission: This Regional Network identifies the social and economic issues and concerns that impact health and health related quality of life in developing countries to inform future research, practice, and policy recommendations. It also serves as a link between the members of this SIG and other SIGs to bring these social and economic issues and concerns to audiences where they may not otherwise be represented. We invite you to join us in addressing the challenges of measuring the quality of life in developing countries, considering language, and cultural barriers, the ethics of research in situations of poverty, and reduced autonomy.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
Knowledge dissemination	Member in the spotlight – we will invite SIG members to present results from their current work to disseminate information to other members and stimulate cooperation among SIG members.	Use virtual platforms such as Zoom to share Powerpoint presentations, videos, and other media.	Liliane Lins-Kusterer, Adesola C Odole, and Vijaya K Gothwal	SIG members	Plan for 3 times a year
Collaboration	To create the opportunity of allowing SIG members to submit ideas and proposals for collaborative projects at our quarterly meetings.	Use virtual platforms such as Zoom to share Powerpoint presentations, videos, and other media.	Liliane Lins-Kusterer, Adesola C Odole, and Vijaya K Gothwal	SIG members	Plan for 3 times a year
Membership Drive	Hosting of SIG members virtual meetings - To increase awareness about qualitative research and ISOQOL in our different regions so as to increase the membership in this SIG	Use virtual platforms such as Zoom to share Powerpoint presentations, videos, and other media.	Lilliane Lins-Kusterer, Adesola C. Odole, and Vijaya K Gothwal	SIG members	To be coordinated as part of sessions mentioned above

Issues Requiring Board Attention:

The Developing Nations SIG encountered some difficulties in better interaction and planning between the co-chairs, given the time zone difference. In a meeting, we decided to carry out activities across continents according to their time zone, allowing for alternation of leadership in the organization of SIG meetings.

SIG/Committee Name: German-speaking Countries SIG
Date: 17 May. 23
Co-Chairs: Kathrin Fischer, Bernhard Holzner
Board Liaison: Lotte Haverman

Mission: This Regional Network promotes communication, interaction and collaboration between ISOQOL members from German-speaking countries. We create a platform that enables the exchange of information, promotes research and education of PROs and facilitates networking and collaboration between researchers of all career stages, including clinicians, patients, colleagues from industry, government, regulatory agencies, not-for-profit institutions and all interested in advancing the science of quality of life (QOL) and related patient-centered outcomes (PCO) in German-speaking countries.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Third SIG meeting during the annual conference 2022 in Prague	<ul style="list-style-type: none"> • Inform members about the upcoming F2F meeting • Prepare and host meeting • Sent meeting summary to members via Teamwork 		Kathrin Fischer		Completed October 2022
2. Set up LinkedIn group	<ul style="list-style-type: none"> • Reach out to ISOQOL staff to support set up of LinkedIn Group “ISOQOL German-Speaking Countries SIG “ • Inform members about new group and invite / add them to group 		Kathrin Fischer		Completed October 2022
3. Continue to build network within ISOQOL and increase membership of the SIG	<ul style="list-style-type: none"> • Reach out to members to share short bio-sketch with members via Teamwork • Plan for additional virtual meeting in Spring 2023 		Kathrin Fischer		Q1/2 2023



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SIG/Committee Name: Health Preference Research SIG

Date: March 1, 2023

Co-Chairs: Donna Rowen, Heather Gelhorn, Julie Campbell

Board Liaison: Kathryn Flynn

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.

Number of SIG Members: 95

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
PAST UPDATES					
1. Virtual SIG Meeting – Member Research Sharing Presentation(s) – May Meeting	Members volunteering to share their research with the group presenting to group (Donna Rowen, James Shaw) Additional meetings/sharing to be scheduled based on interest.	HPR Methods Application	Heather Gelhorn	Donna Rowen James Shaw	May 2022
2. Virtual SIG Meeting – Member Research Sharing Presentation(s) – September Meeting	Members were asked to volunteer to share their research with the group. However, due to lack of volunteers from the SIG membership, potentially due to the proximity of the annual ISOQOL conference, this did not go ahead.		Heather Gelhorn		September 2022
NEW UPDATES					
1) Annual SIG Meeting 2022	<ol style="list-style-type: none"> 1. Prepare for annual meeting 2. Create slide deck 3. Update membership on leadership role changes co-chairs to past, current, and chair-elect During the meeting we discussed HPR SIG priorities over the next year. This included raising the profile of HPR in ISOQOL, and for this reason it was decided to submit an organised session to the 2023 ISOQOL conference.		Donna Rowen	Heather Gelhorn Julie Campbell	October 2022

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2) Change/Communicate structure/roles responsibilities of SIG chairs	<p>We restructured our SIG chairs to the following roles:</p> <ul style="list-style-type: none"> • Past Chair (2021-2022) – Health Gelhorn • Current Chair (2022 – 2023) – Donna Rowen • Chair – Elect (2023 – 2024) – Julie Campbell <p>The current chair role will be responsible to set the SIGs agenda for the following year and submit the Annual Report. The current chair role will coach the chair-elect in the roles and co-lead where there are opportunities with the chair elect. They will lead the yearly activities of the SIG with the terms shifting from the Annual Meeting to the next Annual Meeting. The Past Chair can choose to remain engaged and be available to answer questions but will not be responsible to lead the SIG.</p>		Heather Gelhorn	Donna Rowen Julie Campbell	Began February 2021, finalized October 2022
3) Submitted a HPR SIG-sponsored workshop and/or symposium	<p>A group of SIG members, led by Donna Rowen, submitted a SIG pre-conference symposium. This was a truly collaborative effort with inclusion of members from several countries, members from academia and consultancy, and PhD students and early career researchers alongside established researchers.</p>		Donna Rowen	Health Gelhorn Julie Campbell	Submitted February 2023
4) HPR SIG Social Event at Annual Meeting in Prague	<p>HPR SIG members had indicated networking is an important part of what they would like from the SIG. Due to limited interest and availability in the evenings this was scheduled during the lunchtime after the SIG meeting, where SIG meeting attendees were able to informally chat over lunch.</p>		Heather Gelhorn	Donna Rowen	October 2022

Issues Requiring Board Attention:

In the annual 2022 ISOQOL conference there was no session on HPR, whereas in previous years there has been at least one session devoted to HPR. There was HPR work presented at the conference, but as this was split across multiple sessions it meant that the topic was diluted across sessions. This may lead to fewer HPR submissions to future ISOQOL conferences, since other conferences do have sessions solely on the HPR topic.

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SIG/Committee Name: Industry SIG

Date: 17 May. 23

Co-Chairs: Ana Maria Rodriguez-Leboeuf, Calvin Ho

Board Liaison: Jakob Bjorner

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	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
Symposium: 'Considerations for the use of Patient-Reported Outcomes data for RWE studies in Industry'	Annual meeting symposium	Methods and Application	Ana Maria Rodriguez-Leboeuf	Katarzyna Wac, Milena Anatchkova, Kathryn Lasch, Linda Nelsen, Kathleen Wyrich, Susan Vallow, Calvin Ho	October 2023
Webinar: Transitioning between industry and academia	Webinar	Methods and Application	Calvin Ho	Ahmed Osman, Mehmet Inceer, Ana Maria Rodriguez-Leboeuf, Kim Cocks, Tom Wilgoss, Claire Snyder	May or June 2023
Additional activities may be conducted but pending confirmation:	<ul style="list-style-type: none"> Conceptual models and measurement models in real world context: Potentially Kathy Wyrwich, Ana Maria Rodriguez, Michelle, Linda, Milena, and Sarah. Symposium on the use of technology for PRO reporting, e.g. digital bots, Digital health and eCOA, and related regulatory guidance, to be conducted in collaboration with the new digital health SIG, perhaps with Digital Health SIG <p>Use of COA data in regulatory and HTA reviews decision-making, including digital outcomes, to be done with Regulatory and Health Technology Assessment SIG to see if they are interested in driving this activity</p>		TBD	TBD	TBD

SIG/Committee Name: Japan
Date: February 21, 2023
Co-Chairs: Mariko Naito, Yoshimi Suzukamo
Secretary: Rika Hayashida
Board Liaison: Tolulope T. Sajobi

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 which can be utilized to enhance the patient centeredness of outcomes research.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. SIG meeting in Virtual	Six members attended this online meeting. We reported the annual activity and the public funded researches by members. We discussed about future tasks. We reported to change the Co-Chair and Secretary, too. The minutes of meeting were circulated through Teamwork.	Application Project	Miyazaki K Naito M		Complete
2. Online meeting for regional members	The regional meeting were held (Dec. 24, 2021). The participants in the ISOQOL Annual Conference reported on their presentations and impression of their participation.	Application Project	Miyazaki K Naito M		Complete
3. Developing of Japanese version of ISOQOL Dictionary	We are reviewing the translated ISOQOL Dictionary into Japanese.	Application Project	Suzukamo Y	Naito M, Shimozuma K, Miyazaki K, Saito S. Popielnicki A, and other members	In progress
4. Regional conference with held jointly with the JSQoIPro	1) 9th Annual Conference of JSQoIPro. Nov. 19, 2021 2) Let's talk about the ISOQOL 2021. Dec. 25, 2021 3) 16th JSQoIPro research seminar. March 12, 2022 4) 17th JSQoIPro research seminar. Sep. 10, 2022 5) 10th Annual Conference of JSQoIPro. Dec. 24, 2022 6) 18th JSQoIPro research seminar. March 11, 2023 7) 19th JSQoIPro research seminar. June undecided, 2023	Application Project	1) Tamura N 2) Naito M 3) Shirowa T 4) Taira N 5) Hayashida R 6) Murata T 7) Hikosaka M	Members of Japan SIG and collaborators.	1)-5): Complete 6),7) under application

SIG/Committee Name: Mixed Methods SIG

Date: February 21, 2023

Co-Chairs: Rachel Cusatis, PhD; Bridget Gaglio, PhD

Board Liaison: Kathryn Flynn, PhD

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 which can be utilized to enhance the patient centeredness of outcomes research.

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
3. Longitudinal Qualitative Research Systematic Literature review (LQR SLR)	<ul style="list-style-type: none"> Strategy meetings held with SIG members, and decision made to restructure project given some COVID-19-related roadblocks and delays Integrative review of methodological papers restarted – led by Amanda Drury: protocol successfully registered on PROSPERO (CRD42023387547); title/abstract screening completed; full text screening in progress Review of longitudinal qualitative research methods in the context of clinical trials is in development – led by Vanessa Merker and Carla Dias-Barbosa (protocol to be registered soon) Other topic-focused reviews are being considered but are on hold for now until more progress is made on the other reviews (members have expressed interest in oncology, musculoskeletal, and mental health topics) 	Brocha Stern	Team of 20 members from the SIG	Ongoing through 2023
4. Dissemination and SIG engagement	<ul style="list-style-type: none"> Successfully hosted a Mixed Methods SIG Meeting at ISOQOL Annual Conference in Prague SIG members interest survey was disseminated December 2022-February 2023 to learn of members interests and needs; Are planning newsletters, webinars, and mid-year meeting according to responses 	Motolani Ogunsanya/ Antoinette Davey/Rachel Cusatis/Bridget Gaglio	All SIG members who wish to take part	October 2022; Ongoing through 2023
5. Webinars and Mid-year Meeting	<ul style="list-style-type: none"> A survey was advertised to SIG members to complete highlighting interests for the SIG to focus on. Results of this survey identified themes and leads for these themes. Quarterly webinars are planned for the MM SIG members on themes suggested by members (e.g., rapid qualitative analysis) A mid-year meeting with the intention of providing opportunity for members to meet and identify opportunities for collaboration is planned for April 2023 	Rachel Cusatis/Bridget Gaglio	All SIG members who wish to take part	Ongoing through 2023
6. Newsletter	<ul style="list-style-type: none"> Quarterly profile of members in a newsletter format to showcase our members. <ul style="list-style-type: none"> Will also curate articles including hot topics, article links, methodology, or newspaper articles. Will also include announcement and updates on ongoing project. <p>The goal is to foster interrelationship and collaboration among members and to broaden knowledge of emerging topics and issues.</p>	Rachel Cusatis/Bridget Gaglio	MM SIG members who wish to take part	Ongoing through 2023

SIG/Committee Name: New Investigators SIG
Date: 17 May. 23
Co-Chairs: Ahmed M.Y. Osman, Mehmet Inceer
Board Liaison: Elizabeth Unni

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	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. NI SIG "Ask Me Anything..." Series	Started in. 2021 with Nikki & Maryam, the podcast series are to be continued this year. We plan to organize and hold at least ONE interview before the annual ISOQOL conference in October 2022. These short interviews will feature the ISOQOL Awards winners	Methods & Application	Ahmed & Mehmet	NI SIG Members	March / April 2023
2. ISOQOL Conference Happy Hour	We plan to organize an informal meet up for SIG members the first night of the annual conference (pending conference schedule). This will be an opportunity for members to meet and interact prior to the conference officially beginning	Applications	Mehmet	NI SIG Members	October 2023
3. Tricks of the Trade	Still working on the suitable topic for the event and we are narrowing our options now.	Methods	Ahmed & Mehmet	NI SIG Members	October 2023
4. Webinar about Transitioning between the Industry and Academia	Invite a panel of experts who had an experience in transitioning between Academia and Industry in Health Economics & Quality of Life to share with us their experience in the process & highlight the pros and cons of each	Application	Ahmed , Mehmet, Calvin Ho & Ana María Rodríguez	NI & Industry SIG Members	17 th May 2023

SIG/Committee Name: Patient Engagement SIG
Date: 17 May. 23
Co-Chairs: Natasha Roberts, Sandra A. Zelinsky and Sadia Ahmed
Board Liaison: Roxanne Jensen

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 collaborate with other SIGs to progress this purpose

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Collaborative partnerships and patient led research	Manuscript development and submission to Quality of Life Research about patient adherence to patient reported outcome reporting in clinical practice	Case Study	PE SIG co-chairs	Natasha Roberts Danielle Lavallee Elizabeth Unni Kate Absolom Theresa Coles Jennifer Freel	Submitted awaiting peer review
2. Advancing the science of patient-centered measurement methods	Planned position statement manuscript on patient centred research methods in quality of life research	Theoretical evaluation	PE SIG co-chairs	Sandra Zelinsky Natasha Roberts Sadia Ahmed Danielle Lavallee	In discussion presently, aim for 12 months
3. Supporting patient involvement in the leadership of the PE SIG	Obtain support for and inclusion of an individual from the patient community to serve as a co-chair to the PE SIG. - Maintain active partnership in the PE SIG leadership Build activities specific to patients for ISOQOL annual meetings Conduct of ISOQOL meeting and dinner at the 2022 Annual Meeting	Application	Sandra Zelinsky	Danielle Lavallee Natasha Roberts Sadia Ahmed	Ongoing. Maintain active involvement of patient members in the PE SIG
4. Patient leadership in quality of life research	Formation of a working group with regional SIGs focused on international perspectives of patient-led quality of life research and clinical practice	Case Studies	PE-SIG co-chairs	Sandra Zelinsky Jessica Caron Leonie Young John Librett Natasha Roberts Sadia Ahmed Maria Santana Jessica Gentile	Abstract submitted for 2023 Meeting
5. Inclusivity of patient engagement in research and drug development	Formation of a working group in collaboration with the Child SIG to submit a workshop for ISOQOL 2023 focused on child/adolescent engagement in research	Case Studies	John Chaplin	Sandra Zelinsky Natasha Roberts Sadia Ahmed	Abstract submitted for 2023 Meeting

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6. Equitable patient engagement in research and drug development	Formation of a working group in collaboration with the TCA SIG to submit a symposium for ISOQOL 2023 focused on promoting equity in patient reported outcome measurement in clinical practice	Case Studies	Elizabeth Austin	Caroline Anfray Benjamin Arnold Emily Parks Anita Bradley-Gilbride Lauren Shapiro, Megan Turner Natasha Roberts	Abstract submitted for 2023 Meeting
7. Advancing patient engagement across ISOQOL	Development of a survey to SIG chairs to explore their understanding, needs and requirements with patient engagement within their SIGs	Cross sectional survey	PE SIG co-chairs	Sandra Zelinsky Natasha Roberts Sadia Ahmed	Ethical approvals obtained. Distribution and analysis planned completion within 6 months

Issues Requiring Board Attention:

Development of strategies that support greater inclusion of patient partners/consumer representatives within the ISOQOL community and facilitated attendance at the ISOQOL meetings

SIG/Committee Name: Psychometrics SIG

Date: 17 May. 23

Co-Chairs: John Devin Peipert, Donald Bushnell and Jinxiang (Fran) Hu

Board Liaison: Jakob Bjorner

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 changeover time when there are multiple endpoints or mediating/moderating factors.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Psychometric Methods for Small Samples	Develop a set of recommendations for minimum sample size requirements for testing common psychometric properties <ul style="list-style-type: none"> • A scoping literature review is ongoing • We will perform simulation studies to fill-in gaps from literature as necessary • An abstract was presented for ISOQOL 2022 Annual Conference • Anticipate manuscript in 2023 	Methods	Devin Peipert	Ahmed Osman, Brandon Foster, Christina Zigler, Emily Henkle, Jimmy Martin Delgado, Nikki Ow, Cristian Gugiu, Jia Ma, Aaron Kaat, Fran Hu	Aim to generate our list of recommendations by the ISOQOL 2023 Annual Conference
2. Evaluating Correlations: Workgroup 1 - What is a correlation?	Conducted a literature search using a critical review methodology with the aim to identify and present the various correlation coefficient thresholds, labels for these thresholds, and the context in which they were used. Questions to answer: <ul style="list-style-type: none"> • What is a correlation and how we should use it? • What type of correlation to use depending on the data? • What are the thresholds that we should use to interpret the magnitude of the correlations? Abstract presented to ISOQOL 29th Annual Conference	Methods	Don Bushnell	Daskalopoulou (Leader), Ahmed Osman, Jimmy Martin Delgado, Kedar Mate, Milena Anatchkova, Valerie Williams	The effort will be to continue with more detail and work on a methods paper.

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	Title: Correlations: What Is With All Of These Different Thresholds?				
3. Evaluating Correlations: Workgroup 2 – Use in COA anchor-based analyses	<p>Group has been developed but has not met. Questions to answer:</p> <ul style="list-style-type: none"> - What are the thresholds that we should use when we judge the appropriateness of an anchor? - Should we have different thresholds depending on the nature of the anchor (i.e., self-reported, clinical)? - Synthesize current literature/recommendations? - Evaluate FDA recommendations? 	Methods	Don Bushnell	Christina Daskalopoulou, David Cella, Jakob Bjorner, Kedar Mate, Milena Anatchkova, Richard White, Valerie Williams	Aim to kick-off this workgroup in Q1 and share initial findings at the ISOQOL 2023 Annual Conference.
4. Psychometric methods for Intensive Longitudinal Data (ILD)	<p>Develop a set of methods for analysing ILD</p> <ul style="list-style-type: none"> • Presented at SIG Symposium on ILD at 2022 ISOQOL • Write 1-3 papers or a position statement on method use • Submit code for methods to be hosted on the Teamwork site 	Methods	Pip Griffiths	Fatoumata Fofana, Mathilde Verdam, James Shaw, Andre de Champlain, Joe Cappelleri, Veronique Seville, Dave Andrae, Shanshan Qin, Jinxiang Hu	Submit papers by ISOQOL 2023
5. Developing Useful Visualizations for Psychometric Results	<p>Develop set of standard visualizations for psychometric research</p> <ul style="list-style-type: none"> • Present a talk as part of an ISOQOL symposium • Develop standard code to be hosted on Teamwork site 	Methods	Pip Griffiths	Nikki Williams, Christina Cheng, Myriam Blanchin, Ava Mehdipour, Yangjun Liu, Frances Yang	Upload materials by end 2023

SIG/Committee Name: QOL in Clinical Practice SIG

Date: 17 May. 23

Co-Chairs: Liv Marit Valen Schougaard, Elizabeth J. Austin and Angela Wolff

Board Liaison: Richard Skolasky

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
Clinician training for PROMs	<ul style="list-style-type: none"> SIG symposium presented at 2021 conference Half-day workshop presented at 2022 conference Full-day workshop submitted to 2023 conference Manuscript in development (target submission: Summer 2023) 	Angela Wolff	Elizabeth Austin; Kate Absolom; Maria Santana; Sara Ahmed; Angela Stover; Susan Bartlett	Ongoing
PROs in Telehealth	<ul style="list-style-type: none"> Symposium presented at 2021 conference Delphi study launched in 2022; first round survey completed, results currently in analysis, manuscript in development Second round survey targeted for Spring 2023 	Elizabeth Unni	Lee Aiyegbusi; Natasha Roberts; Birgith E. Grove; Liv Schougaard; Elizabeth Austin; Holger Muehlan; Kedar Mate; Klara Greffin	Ongoing
Strategies to engage patients in PROM use <i>(Collaboration with PE SIG)</i>	<ul style="list-style-type: none"> Symposium submitted to 2023 conference Working group formed in late 2022, following CPSIG conference meeting 	Elizabeth Unni		Ongoing (new in 2022)
Address disparities in cultural adaptation of PROs in clinical practice <i>(Collaboration with TCA and PE SIGs)</i>	<ul style="list-style-type: none"> SIG Symposium submitted to 2023 conference Working group formed in late 2022, following CPSIG conference meeting 	Elizabeth Austin	Caroline Anfray; Benjamin Arnold; Emily Parks-Vernizzi; Anita Bradley-Gilbride; Lauren Shapiro; Megan Turner; Natasha Roberts	Ongoing (new in 2022)
Engaging clinicians in Clinical Decision-making / SDM with PROMs	<ul style="list-style-type: none"> Working group formed in late 2022, following CPSIG conference meeting 	Angela Wolff	Amy Cizik, Maud Van Muilekon, Liz Siembida, Lauren Shapiro, Anna Maria Rodriuez, Gida	Ongoing (new in 2022)

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Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
	<ul style="list-style-type: none"> • At the Oct 2022 meeting, it contained members also interested in Training Clinicians to incorporate PROMs in practice 		Mody, Anna (Andra) Beurkens, Juliea Lai-Kwon, Carolin Terwee, Istvan Mucsi, Christine Blome, Yoldana Pardo	
Using PROs for Screening	<ul style="list-style-type: none"> • Workshop presented at 2022 conference • Working group activities ongoing, including developing definitions for screening use in clinical practice (work subsided since Aug 2022 due to workload issues of project chairs) 	Kathleen Yost and Theresa Coles	Workshop leaders: Kathleen Yost, Theresa Coles, Minji Lee, Angela Wolff, Cindy Nowinski, Natasha Roberts	Ongoing
CPSIG Activities & SIG Engagement	<ul style="list-style-type: none"> • Continued efforts being made to use Teamwork to communicate with members and advertise relevant CP activities/opportunities. • We continued promoting and using the CPSIG Twitter hashtag (#ISOQOL_CP). <ul style="list-style-type: none"> ○ We continued to share papers/opportunities of interest with our hashtag. • We sent out a survey to CPSIG in September, 2022 (via RedCap) to solicit interest in potential working groups for 2023. 27 CP-SIG members responded to the survey. Feedback from survey results informed breakout group topics during our annual CPSIG meeting at the 2022 ISOQOL conference. • Our annual CPSIG meeting was held on Oct. 21, 2022, with 44 attendees. <ul style="list-style-type: none"> ○ We provided updates on CPSIG activities and new resources published in 2022 by CPSIG members ○ We held breakout groups (4) to allow members to brainstorm new topics for collaboration in 2023 • 3 new CPSIG working groups were formed following the 2022 conference. <ul style="list-style-type: none"> ○ Engaging patients in PROM use (led by Elizabeth Unni, collaboration with PE SIG) 	Elizabeth Austin, Angela Wolff	N/A	Ongoing

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Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
	<ul style="list-style-type: none"> ○ Engaging clinicians in SDM / PROM use for clinical decision-making (led by Angela Wolff) ○ Addressing disparities in cultural adaptation of PROMs in clinical practice (led by Elizabeth Austin, collaboration with TCA and PE SIGs) ● Three working groups submitted a workshop or symposium proposal for ISOQOL 2023: <ul style="list-style-type: none"> ○ Clinician training for PROMs (workshop led by Angela Wolff) ○ Addressing disparities in cultural adaptation of PROMs in clinical practice (symposium led by Elizabeth Austin, collaboration with TCA and PE SIGs) ○ Engaging patients in PROM use (symposium led by Elizabeth Unni, collaboration with PE SIG) ● Co-Chairs have led one interim meeting following the 2022 conference to bring CPSIG members together, and have another planned for Spring, 2023. ● Co-Chairs will launched outreach to engage new members in CPSIG in February, 2023, offering office hours and/or 1:1 consultation for members not previously active in CPSIG. 			

Issues Requiring Board Attention:

Overall use of Teamwork is sporadic and many members may not be utilizing it for this SIG. We are wondering how the platform is working for other SIGs.

SIG/Committee Name: Regulatory and Health Technology Assessment Engagement (R&HE) SIG
Date: 1 March 2023
Co-Chairs: Robyn von Maltzahn and Ashley F. Slagle
Board Liaison: Roxanne Jensen

Mission: This SIG routinely and actively engages with regulatory agencies and health technology assessment (HTA) bodies to address critical applied measurement issues raised by these entities or that emerge from their public communications (e.g., guidance documents, reflection papers, workshops). This collaboration embraces a broad measurement perspective and enables us to build scientifically-based patient-focused recommendations regarding the use of clinical outcome assessments (COAs) in the evaluation of therapeutic interventions aimed at advancing human health and well-being.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
7. Continue to provide comment on regulatory and HTA publications/draft guidances	Monitoring releases, drafting and providing comments to regulatory bodies or HTAs	Application	Ashley Slagle	Robyn von Maltzahn; Joy Whitsett; Cristina Ivanescu; Mayank Rehani; Calvin Ho; Bernice Gulek	<ul style="list-style-type: none"> Ongoing in real time as documents are released
8. To conduct and publish research to better understand HTA and regulatory approaches to the use of PROs and other PED	Interview study of HTA reps and pharma staff with experience: to identify HTA areas of interest and use of PED, including PROs <ul style="list-style-type: none"> Need to develop a concept protocol and then submit this to the board for approval 	Application	TBD	Ashley Slagle; Robyn von Maltzahn; Mayank Rehani; Bernice Gulek	<ul style="list-style-type: none"> Concept protocol submitted to board Q4 2023 Conduct research 2024
9. To provide a platform for education and knowledge sharing regarding FDA, EMA, HTA (other) activities. Anticipate partnering with other SIGs (e.g., Industry SIG)	<ul style="list-style-type: none"> Webinar / Symposium Online platform (e.g., Teamwork; group emails) Now working on finding a person/project members who is/are willing to lead this 	N/A	TBD	TBD	As relevant issues arise

Issues Requiring Board Attention:

SIG/Committee Name: Statistics SIG
Co-Chairs: Kim Cocks, Antoine Regnault

Date: 20 Mar. 2023
Board Liaison: Jakob Bjorner

Mission: This SIG connects statisticians working in the field of quality of life and provides a platform for communication, interaction and collaboration. Our aim is to identify and progress key areas for research and provide workshops and training for the wider ISOQOL membership.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
Time to event workstream	SIG symposium (Applying time to event analyses to PRO data from clinical trials: Current developments and future perspectives) accepted and delivered at the 2022 conference.	Methods, theory and application	Antoine Regnault	Amelie Anota Libby Floden Francesco Cottone Mallorie Fiero	Conference 2022
Missing data workstream	Full day workshop accepted and delivered at the 2022 conference. Feedback excellent. Prepared and submitted a workshop for ISOQOL 2023. (Not accepted for 2023 conference)	Methods, theory and application	Kim Cocks	Bellinda King-Kallimanis Gina Mazza Andrew Trigg	Conference 2022 and submission for 2023
Estimands workstream	Full day workshop accepted and delivered at the 2022 conference. "Patient-reported outcomes in clinical trials - what questions are we asking and how do we understand the results; how the estimand framework with sensitivity analyses can help". Workshop well received. Plan to further develop estimand training materials (focus outside oncology) to build on workshop presented at ISOQoL 2022 and looking to consider workshop/presentations at ISOQoL 2024	Methods, theory and application	Rachael Lawrance/Corneel Coens		Conference 2022 & 2024
Data visualisation workstream	Cross SIG initiative – in progress	Methods, theory and application	Bellinda King-Kallimanis		

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SIG symposium – SISAQOL: Standardizing analysis of quality of life data in oncology	Prepared and submitted a SIG symposium for ISOQOL 2023 in collaboration with SISAQOL international consortium. (Not accepted for the conference)	Methods, theory and application	Kim Cocks	Antoine Regnault Corneel Coens Satrajit Roychoudhury Galina Velikova Madeline Pe	Conference 2023 (January 2023 symposium submission)
New workstreams	Discussed topics for 2023 focus at 2022 conference meeting Next steps to agree on workstream leads and priorities Aim for workstream leads to present ideas at 2023 conference	Methods, theory and application	TBA	TBA	Stats SIG meeting at 2023 conference for work plans 2023/2024

Issues Requiring Board Attention:

Nothing at this time

SIG/Committee Name: Translation & Cultural Adaptation SIG
Date: April 2023
Co-Chairs: Emily Parks-Vernizzi, Caroline Anfray and Anita Bradley-Gilbride (secretary)
Board Liaison: Richard Skolasky
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; and to promote visibility of cross-cultural issues in development and use of COAs in ISOQOL.

Project/Objective	Actions/Deliverables	Methods, Theory or Application	Project Chair	Project Members	Timeline
<p>10. Working group: Best practice guideline for global UX/UI practices of COAs destined for electronic based studies</p> <p>NOTE: Potential for this working group to be coordinated within the newly established Digital Health Special Interest Group chaired by Megan Turner.</p>	<p>Aim of this working group is to create a guideline of best practices for visual aspects of UI/UX for the instrument developers within digital based studies, for use in initial measure development and with an emphasis on the visual and functional capabilities.</p> <ul style="list-style-type: none"> - Literature reviews of existing guidelines/ practice - Survey on relevant areas following lit reviews - Evaluation of results - Identification specific aspects for guideline <p>Phase 1: Topics, keywords, roles, and timelines have been defined.</p> <p>Phase 2: Literature and full paper review complete.</p> <p>Submission as manuscript to JPRO [deliverable]</p>	<p>Application</p>	<p>Anna Richards</p>	<p>Megan Turner, David Churchman, Justin Raymer, Jeanne Landgraf, Vladimir Zah, Marlene Knupfer, John Chaplin, Yoshimi Suzukamo, Ay-Woan Pan</p>	<p>Current Status:</p> <p>Phase 3: Synthesis of research followed by first draft of manuscript- ongoing.</p> <p>We are in phase 3 at the moment.</p> <p>We have completed the last phase of full extraction with 56 papers identified for manuscript write up and another 70 papers to be additionally potentially included.</p> <p>Now we are in a research synthesis phase (preparatory manuscript phase), before embarking on manuscript draft phase (which is set to begin end of February /beginning of March 2023 and is anticipated to take 6-8 weeks).</p> <p>Submission: TBD</p>

<p>11. Working group: Concept Definition Standards</p>	<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 2023, a draft version of the manuscript is ready and review cycles will be starting (1. Working Group, 2. TCA-SIG Steering Committee, 3. ISOQOL Executive Committee).</p>	<p>Methods</p>	<p>Benjamin Arnold, Emily Parks-Vernizzi</p>	<p>Dana Weiss, Benjamin Arnold, Ana Popielnicki, Barbara Brandt, Sonya Eremenco, Emily Parks-Vernizzi, Jussi Repo, John Chaplin, Alexandra Crane, Mark Wade, Teresa Williams, Miguel Ruiz, Holger Muhlan-Rehmer, Clayton Hamilton, Adelina Lear, Beatrice Tedeschi, Katrin Conway</p>	<p>Submission to JPRO is anticipated in (late) Summer 2023.</p>
<p>12. Identify and advance research into cognitive debriefing (CD) methods in pediatric and adolescent populations during translation and adaptation processes</p>	<p>ISOQOL Oral Session 302: Qualitative methods in the development and application of PROs, "A Paediatric Case Study: Cognitive Debriefing with Trans-Adapted Neurocognitive Assessments."</p>	<p>Methods/ Application</p>	<p>Monika Vance, Jeanne Landgraf</p>	<p>John Chaplin, Holger Muehlan-Rehmer, Sonya Eremenco, Jeanne Landgraf, Monika Vance, Ligia Chavez, Ana Popielnicki, Beatrice Tedeschi, Rita A., Ahmed Osman</p>	<p>Project completed.</p> <p>Monika will consult with the group co-chair, Jeanne Landgraf about next steps. There is a possibility of generating posters on pediatric CD and transadaptation/usability of cognitive and maladaptive behaviour batteries.</p>
<p>13. Working group: Principles of Good Practice for</p>	<p>This work proposal was accepted in the summer of 2018 after the working group team submitted a conceptual proposal. This working group aims to:</p>	<p>Methods/ Application</p>	<p>Huda Shalhoub, Megan Turner</p>	<p>Anita Bradley-Gilbride, Ben Arnold,</p>	<p>Submission to JPRO expected by Fall 2023.</p>

<p>Translation of Electronic Clinical Outcome Assessment (eCOA) Measures</p>	<p>(1) identify any existing translation approaches utilized in eCOA development; (2) review the currently used methodologies and summarize all steps, identifying similarities and differences between approaches, and lastly, (3) define and outline a minimal set of mandatory and optional steps as principles of good practice for eCOA translation. In order to prepare a manuscript, the team did a literature review and conducted a survey for eCOA and translation providers to be able to collect data. A second survey with copyright holders/developers was conducted during the autumn of 2021.</p> <p>Results of the 2nd survey were analysed; the results and the discussion sections were written. Second round of manuscript review by co-authors completed at end of January 2023.</p> <p>Next step: Review by writing team by end of March 2023.</p> <p>The ISOQOL Board and TCA-SIG reviews will take place prior to submission.</p>			<p>Caroline Anfray, Dagmara Kuliš, Emily Parks-Vernizzi, Holger Muehlan-Rehmer, Jason Bredle, John Chaplin, Mark Wade, Sonya Eremenco, Jussi Repo</p>	
<p>14. 'Getting Better Together Initiative (GBTI): "eCOA Translations and Licensing Management Project"</p>	<p>Project launched in Quarter 3 2022. Goal: to optimize eCOA implementation in clinical trials.</p> <p>Summary: This project intends to educate and inform the clinical trial community of the implications of the business practices/processes around obtaining licenses and translations for electronic formats of PRO measures as part of the clinical trial study start-up process. The purpose of the project is to identify specific pain points in the translations and licensing process and collaborate on development of educational materials to illustrate where all stakeholders can improve their respective processes to support on-time clinical trial initiation.</p>	<p>Methods/ Application</p>	<p>Scotti Kern, C-Path</p> <p>Project Liaison: Kate Zarzar (Genentech)</p> <p>Project Team Leaders: Piero Bindi (IQVIA) and Teresa Williams (Lilly)</p>	<p><u>TCA-SIG and C-PATH members:</u></p> <p>Caroline Anfray, Sonya Eremenco, Megan Turner</p> <p><u>TCA-SIG members:</u> Benjamin Arnold, Maria Arnott, Dipika Bansal, David Churchman, Marlene Knupfer,</p>	<p>Kick-off meeting held on September 28, 2022.</p> <p>October 25, 2022, a survey distributed to allow volunteers to indicate preferences for subtopic areas of interest and expertise.</p> <p>November 11, 2022, draft charter and project sub-topics distributed to all volunteers to review and provide feedback; responses were requested by November 18, 2022, for review by the Project Team</p>

			<p>TCA-SIG representatives</p> <p>Sonya Eremenco</p> <p>Caroline Anfray</p> <p>Emily Parks-Vernizzi</p>	<p>Dagmara Kuliś, Shawn McKown, Sandra Mitchell, Ahmed M.Y. Osman, Emily Parks-Vernizzi, Ana Popielnicki, Jussi Repo, Anna Richards, Ana María Rodríguez Leboeuf, Lillian Savic, Anita Bradley-Gilbride, Dana Weiss</p>	<p>Leadership. The Project Team Leadership made selections for sub-topic leaders and all volunteers have been notified of the group they are part of; all sub-topics teams will target launch in February.</p>
<p>15. CP-SIG/TCA-SIG Collaboration</p>	<p>Aim: develop guidance to support clinical practice settings in navigating PROM use when the availability of translations and/or cultural adaptation are limited.</p> <p>Clinical practice settings face unique challenges when selecting and implementing PROMs. For example, payers or other governing bodies may require specific PROMs to be used to support reimbursement, healthcare providers may have preferences for certain PROMs based on their clinical utility, or electronic health records systems may incentivize or deter use of a particular PROM. Furthermore, clinical practice settings often have limited knowledge and/or access to psychometric expertise and language support resources. These challenges limit the agency clinical practice settings have to prioritize PROMs based on the availability of the language and cultural translations, and may subsequently contribute to disparities in PROM use.</p>	<p>Methods/ Application</p>	<p>Elizabeth Austin, Co-Chair CP-SIG</p>	<p><u>TCA-SIG members:</u></p> <p>Megan Turner, Caroline Anfray, Benjamin Arnold, Emily Parks-Vernizzi, Anita Bradley-Gilbride</p> <p><u>CP-SIG members:</u></p> <p>TBA</p>	<p>SIG Symposium Abstract was submitted for consideration for the 2023 ISOQOL Annual Meeting.</p> <p>Awaiting decision – announcement of SIG symposium approval expected in March 2023.</p>

SIG/Committee Name: United Kingdom & Ireland SIG
Co-Chairs: Jonathan Evans, Timothy Pickles and Antoinette Davey

Date: 17 May. 23
Board Liaison: Lotte Haverman

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	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
6 th National PROMs Research Conference (Virtual Event). 14 th – 15 th June 2022 (Welsh Value in Health Centre)	The SIG chairs assisted in the promotion and organisation of this event. The Welsh Value in Health Centre organised this event and the SIG continued to support the organisation of this event.	Dissemination	Sarah Puntoni	Jonathan Evans, Timothy Pickles and Grace Turner	Complete
SIG meeting at the 6 th National PROMs Research Conference – 15 th June	Developing the network and discussing diversity research, which was led by Ameeta Retzer (CPROR, University of Birmingham).	Dissemination	Jonathan Evans	Jonathan Evans, Timothy Pickles and Grace Turner	Complete
SIG meeting at ISOQOL Conference 2022 (Prague)	Delivered the SIG meeting as part of the ISOQOL conference. We undertook a networking event and discussed the how members wish for the SIG to best serve them.	Networking	Tim Pickles and Antoinette Davey	Tim Pickles, Antoinette Davey and Jonathan Evans	Complete
7 th National PROMs Research Conference (Virtual Event). 22 nd June 2023 (University of Sheffield)	The SIG chairs have assisted in the ongoing promotion and organisation of this event. The University of Sheffield offered to organise this event, with the SIG continuing to support the organisation of this event.	Dissemination	Jill Carlton	Tim Pickles, Antoinette Davey and Jonathan Evans	June 2023
SIG meeting at ISOQOL Conference 2023 (Calgary)	The SIG chairs (along with the incoming chair elect) will deliver the SIG meeting as part of the ISOQOL conference.	Networking	Tim Pickles, Antoinette Davey, Jonathan Evans and incoming chair elect	Tim Pickles, Antoinette Davey, Jonathan Evans and incoming chair elect	October 2023
Collaboration with the National PROMs Network	Initial discussion have been started with the National PROMs Network and also ISOQOL about creating a collaboration between the SIG and the National PROMs Network. This is following from discussion at the SIG meeting at the ISOQOL Conference 2022.	Collaboration	Tim Pickles and Antoinette Davey	Tim Pickles, Antoinette Davey and Jonathan Evans	Ongoing