

SIG/Committee Name: Australia & New Zealand SIG (ANZ SIG)
Date: 28 Mar 2022
Co-Chairs: Liane Ioannou, Nadia Corsini, Ashika Maharaj, 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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application project	Project Chair	Project Members	Timeline
1. 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	
2. Landscape of PROs in clinical practice in Australia	This project aims to map 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)	
3. PROMs Downunder Conference is planned for July 2023 (TBD)	Organise a follow-up to the PROMs Downunder Conference hosted by The University of Sydney in July 2023.	This will incorporate a range of applications	Liane Ioannou	Rachel Campbell Nadia Corsini Ashika Maharaj TBD	

Issues Requiring Board Attention:

Item 3 requires a concept proposal before the board can approve ISOQOL participation.

SIG/Committee Name: Child Health SIG
Date: 4th April 2022
Co-Chairs: Holger Muehlan, Zephania F. Tyack, 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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Time-line
1. Increase presence of CH-SIG and representation of methodological challenges/issues associated with child health assessment at ISOQOL Meetings	The SIG organised a full on-line symposia for the 2021 ISOQOL conference – which was well attended. Symposium Title: ' Young People in the Time of Covid '. With contributions from five SIG members in Canada, Germany, Netherlands and Sweden.	Methods & Application	John, Rob, Holger, Nalin	Malin Berghammer & Margaretha Jenholt Nolbris Christiane Otto Lotte Haverman Nancy L. Young Alisha Daya & Skye Barbic	Completed Oct. 2021
	Submitted a proposal for 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, Zephania	John Chaplin, Zephania Tyack, Sumedh Bele, Danielle Lavallee, Sandra Zelinsky, Natasha Roberts	Prepared Winter 2021
	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, Elizabeth Gibbons + Adolescent and/or parent/caregiver representative	Preparation ongoing; July 2022
2. Expanding membership & networking	Conducted a members meeting at the virtual conference.	Consolidation of membership	John, Holger, Zephania	(22 attendees).	Completed Nov 2021
	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.	Consolidation of membership	John, Holger, Zephania	John, Holger, Zephania	Completion Dec 2022
3. Further Projects/Activities	Initializing a review activity for a manuscript – Title: ' Non-publication of Paediatric PROM data from Registered Clinical Trials '	Methods & Application	John	(tbd)	Preparation ongoing

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SIG/Committee Name: Chinese PRO SIG

Date: April 2, 2022

Co-Chairs: Daniel Fong and Jiqian Fang

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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. To engage individuals with an interest in quality of life research in Chinese	A proposal for an education symposium in an annual ISOQOL meeting		WJ Duan Daniel Fong	All	Proposal accepted in 2020
2. 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 Jiqian Fang	All	In one year
3. To produce new criteria for PRO measures based on both theories of psychometrics and clinimetrics. References: 1. Brundage M et al. Patient-reported outcomes in randomized clinical trials: development of ISOQOL reporting standards. Qual Life Res (2013) 22:1161–1175 2. Patierno C et al., Carrozzino D, et al. Clinimetric Criteria for Patient-Reported Outcome Measures. Psychother Psychosom. 2021;90(4):222-232.	To run an international-wide Delphi survey mainly among ISOQOL members, provide some data of applications and finally publish the results	Reporting Criteria for PRO measures based on psychometrics and clinimetrics.	Fengbin Liu Jiqian Fang	All	In one year

Issues Requiring Board Attention:

Item 3 requires a concept proposal before the board can approve ISOQOL participation.

SIG/Committee Name: Developing Countries SIG
Date: April 2022
Co-Chairs: Adesola Odole, Liliane Lins-Kusterer, Vijava Gothwal
Board Liaison: Nalin Payakachat

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 Appl ication Project	Project Chair	Project Members	Timeline
1. Call for papers in a special edition for developing nations for publication in either of the two journals of ISOQOL (QLR and JPRO).	To write out a proposal on the need for this special edition.		X	X	2 years
2. To develop a theoretical framework of HRQoL for developing nations putting into consideration the cultural, language, spirituality, and political differences.	To review published instruments on HRQoL focused on developing nations. Links and files can be shared on the teamwork platform.	X	X	X	2 Years
3. To organize online webinar on an interesting topic that bothers on the peculiarity of health outcomes assessment in developing nations. The topic of interest can be arrived at in collaboration with the speaker. An open call for volunteer speakers can be made. Consideration for reduced rate to be given to attendees from developing nations.	To discuss the online and exchanges experience in HRQOL, considering DN.		X	X	Each Two or three months

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SIG/Committee Name: German-speaking Countries SIG

Date: March 28, 2022

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. Second RGN meeting during the virtual annual conference 2021	<ul style="list-style-type: none"> inform the members about the meeting prepare meeting virtual meeting was hold on October 25, 2021 	N/A	Bernhard Holzner; Kathrin Fischer		Complete
2. Build a network within ISOQOL and increase membership of the RGN	<ul style="list-style-type: none"> Use of Teamwork to get an overview of current membership demographics and seek input to build and grow the network within ISOQOL 	N/A	Bernhard Holzner; Kathrin Fischer		ongoing
3. Third RGN meeting during the annual conference 2022	<ul style="list-style-type: none"> Inform members about the meeting via teamwork Plan (face-to-face meeting) 		Bernhard Holzner; Kathrin Fischer		Q3/4 2022



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SIG/Committee Name: Health Preference Research SIG

Date: April 15, 2022

Co-Chairs: Heather Gelhorn, Donna Rowen, Amy Cizik

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: 103

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
NEW UPDATES					
1) Annual SIG Meeting 2021	<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 		Heather Gelhorn	Amy Cizik Donna Rowen	October 2021
2) Virtual SIG Meeting – Member Research Sharing Presentation(s) – May Meeting	<ol style="list-style-type: none"> 1. Members volunteering to share their research with the group presenting to group (Donna Rowen, James Shaw) 2. Additional meetings/sharing to be scheduled based on interest. 	HPR Methods Application	Heather Gelhorn	Donna Rowen James Shaw	May 2022
3) Virtual SIG Meeting – Member Research Sharing Presentation(s) – September Meeting	<ol style="list-style-type: none"> 1. Members volunteering to share their research with the group presenting to group (TBD) 		Heather Gelhorn	TBD	September 2022
4) HPR SIG Social Event at Annual Meeting in Prague	<ol style="list-style-type: none"> 1. Planning an informal social gathering for members to network – HPR SIG members have indicated networking is a 		Heather Gelhorn	ISOQOL Attendees	October 2022



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SIG/Committee Name: Industry SIG

Date: May 1, 2022

Co-Chairs: Patricia Corey-Lisle, Ana Maria Rodriguez-Leboeuf

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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Methodological and Endpoint Considerations for Patient Reported Outcomes Derived Using Daily Diary Collection	Annual Meeting Symposium	Methods/Application	Stacie Hudgens	Michelle White Andre DeChamplain	October 2022
2. Decentralized Clinical Trials	Internal ISIG presentation on potential outcomes with decentralized clinical trials: based on simulations of on site and off site assessments	Methods/Theory	Patricia Corey-Lisle	N/A	2H 2022

Issues Requiring Board Attention:

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SIG/Committee Name: Japan SIG

Date: 26 March, 2022

Co-Chairs: Mariko Naito, Kikuko Miyazaki, Yoshimi Suzukamo

Board Liaison: Tolulope T. Sajobi

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.

Number of SIG Members: 23

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. SIG meeting in ISOQOL 28th Annual Conference	Eight members attended this online meeting. We reported the annual activity and the public funded researches by members. We discussed about future tasks. The minutes of meeting were circulated through Teamwork.	Application Project	Shimozuma K Miyazaki K		Complete
2. Online meeting for regional members	Two regional meetings were held (Oct. 26, 2020, May 29, 2021). We exchanged information about each member's activities in Japan and discussed using the Teamwork.	Application Project	Shimozuma K Miyazaki K		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 JSQolPro	1) 8th Annual conference of JSQolPro. Dec. 12, 2020 2) 14th JSQolPro research seminar. Feb. 6, 2021 3) 15th JSQolPro research seminar. July 17, 2021 4) 9th Annual Conference of JSQolPro. Nov. 20, 2021 5) Let's talk about the ISOQOL 2021. Dec. 25, 2021 6) 16th JSQolPro research seminar. March 5, 2022 7) 17th JSQolPro research seminar. June undecided, 2022	Application Project	1) Saito S 2) Naito M 3) Nishigori T 4) Tamura N 5) Naito M 6) Shiroiwa T 7) Taira N	Members of Japan SIG and collaborators.	1)-5): Complete 6),7) under application

* JSQolPro: Japanese Society for Quality of Life and Patient-Reported Outcomes Research

SIG/Committee Name: Mixed Methods SIG

Date: March 21, 2022

Co-Chairs: Rachel Cusatis, Antoinette Davey

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

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Longitudinal Qualitative Research Systematic Literature review (LQR SLR)	<ul style="list-style-type: none"> Manuscript planned to be submitted to JPRO on the methodology used for this review Full text extraction planned to be completed by the end of February Review of methodological papers 		Brocha Stern	Team of 20 members from the SIG	Ongoing through 2022
2. Dissemination and SIG engagement	<ul style="list-style-type: none"> Speaker Series: Successfully hosted Dr. Olufikayo Bamidele for a webinar on Constructivist Grounded Theory Approach Successfully Hosted "Speed Dating" to share research interest and expertise to promote collaboration across the SIG Successfully Hosted Grant Writing Panel Discussion on Mixed Methods Research Opportunities 		Motolani Ogunsanya/ Antoinette Davey/Rachel Cusatis	All SIG members who wish to take part	Ongoing through 2022
3. Workgroups	<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. Meeting with the identified leads to be held to discuss the ideas for future projects in the specified areas. Workgroups will be created and ideas to be agreed 		Motolani Ogunsanya/ Antoinette Davey/ Rachel Cusatis	All SIG members who wish to take part	Ongoing through 2022
4. Newsletter	<ul style="list-style-type: none"> Monthly profile of members of the month in a newsletter format to showcase our members. <ul style="list-style-type: none"> Will also curate include hot topics, article links, methodology, or newspaper articles. Will also include announcement and updates on ongoing project. The goal is to foster interrelationship and collaboration among members and to broaden knowledge of emerging topics and issues. 		Motolani Ogunsanya/Rachel Cusatis	MM SIG members who wish to take part	Ongoing through 2022

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SIG/Committee Name: New Investigators SIG

Date: 2022/03/14

Co-Chairs: Maryam Mozafarinia, Ahmed M.Y. Osman

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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. NI SIG "Ask me anything..." series	Started last year with Nikki & Maryam, the podcast series are to be continued this year. We plan to organize and hold 2 or 3 interviews before the annual ISOQOL conference in October 2022. These short interviews will feature guests with various expertise areas.	Methods, theory & application	Maryam & Ahmed	NI SIG members	March to October 2022
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 (should the conference in 2022 be in person).	Application	Maryam & Ahmed	NI SIG members	October 2022
3. Tricks of the Trades	With collaboration of the Editors-in-Chief of the JPRO, the session would cover a discussion on "improving the quality of peer review of patient-reported outcome papers".	Methods & application	Maryam & Ahmed	NI SIG members	October 2022



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SIG/Committee Name: Patient Engagement SIG

Date: March 30, 2022

Co-Chairs: Natasha Roberts, Sandra A. Zelinsky 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

Number of SIG Members: 151

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Collaborative partnerships and patient led research	Conduct of ISOQOL Workshop at the 2021 Annual Meeting	Patient partnership and storytelling	Maria Santana	Danielle Lavallee Sandra Zelinsky Sadia Ahmed	Workshop planned and conducted during the 2021 Meeting
2. Advancing the science of patient-centered measurement methods	Submitted & conducted a symposium providing context for advancing the science of patient centred measurement through research initiatives where patient research partners served as research team collaborators.	Case studies	Rick Sawatzky	Danielle Lavallee	Submitted as part of the 2021 annual meeting
3. PE SIG Meet-ups on Patient Engagement in research	Conduct of 2 virtual PE SIG meet-ups over the summer of 2021 on PE SIG Community identified topics: - Pediatric engagement in research - Patient engagement 101	Case studies	PE SIG co-chairs	Maria Santana Zephania Tyack	February 2021 April 2021
4. 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	Application	Sandra Zelinsky	Danielle Lavallee Natasha Roberts	Ongoing. Maintain active involvement of patient members in the
5. Inclusivity of patient engagement in research and drug developmen	Formation of a working group in collaboration with the Child SIG to submit a symposium for ISOQOL 2022 focused on child/adolescent engagement in research	Case studies	John Chaplin	Natasha Roberts Danielle Lavallee Sandra Zelinsky	Planned for submission to the 2022 Annual meeting

SIG/Committee Name: Psychometrics SIG

Date: 04/04/2022

Co-Chairs: John Devin Peipert, Donald Bushnell and Philip Griffiths

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 Intensive Longitudinal Data (ILD)	<ul style="list-style-type: none"> • Develop a set of methods for analysing ILD <ul style="list-style-type: none"> ○ Present SIG Symposium on ILD ○ 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 Sebillé, Dave Andrae, Shanshan Qin, Jinxiang Hu	Present ISOQOL 2022 Submit papers by ISOQOL 2023
2. Developing Useful Visualizations for Psychometric Results	<ul style="list-style-type: none"> • Develop set of standard visualizations for psychometric research <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	Present ISOQOL 2022 Upload materials by end 2022
3. Psychometric Methods for Small Samples	<ul style="list-style-type: none"> • 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 submitted for ISOQOL 2022 Annual Conference 	Methods	Devin Peipert	Ahmed Osman, Brandon Foster, Christina Zigler, Emily Henkle, Jimmy Martin Delgado, Nikki Ow, Cristian Gugiu, Jia Ma, Aaron Kaat	Aim to generate our list of recommendations by the ISOQOL 2023 Annual Conference
4. Evaluating Correlations: Workgroup 1 - What is a correlation?	<p>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.</p> <p>Questions to answer:</p> <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? <p>Abstract written and submitted to ISOQOL 29th Annual Conference Title: <i>Correlations: What Is With All Of These Different Thresholds?</i></p>	Methods	Don Bushnell	Christina Daskalopoulou (Leader), Ahmed Osman, Jimmy Martin Delgado, Kedar Mate, Milena Anatchkova, Valerie Williams	

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<p>5. Evaluating Correlations: Workgroup 2 – Use in COA anchor-based analyses</p>	<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? 	<p>Methods</p>	<p>Don Bushnell</p>	<p>Christina Daskalopoulou, David Cella, Jakob Bjorner, Kedar Mate, Milena Anatchkova, Richard White, Valerie Williams</p>	
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SIG/Committee Name: QOL in Clinical Practice SIG

Date: March 29, 2022

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

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.

Number of SIG Members: 270

Project/Objective	Actions/Deliverables	<u>Methods,</u> Theory or Application Project	Project Chair	Project Members	Timeline
<p>1. Symposium presented at ISOQOL 2021 virtual conferecne</p> <p>PROMs in telehealth</p> <p>CPSIG work group: PROMs in telehealth</p>	<p>Main meeting symposia presented</p> <p>SYMPOSIUM DESCRIPTION: The Covid-19 pandemic has accelerated the adoption of telehealth initiatives in the health care system. It has also emphasised the need and relevance of PROMs in routine clinical practice. PROMs in telehealth could be central to the COVID-19 response by facilitating the remote monitoring of symptoms and long-term effects. This symposium aims to provide insight into and discuss the use of PROMs in telehealth.</p>		Liv Schougaard and Elizabeth Unni	<p>Moderator: Elizabeth Unni</p> <p>Presenter Names: Lee Aiyegbusi, Natasha Roberts, Derek Kyte, Birgith E. Grove, Liv Schougaard</p> <p>New members 2022: Elizabeth Austin, Birgith E. Grove, Cindy Nowinski, Holger Muehlan, Jinxiang Hu, Kedar Mate</p>	<p>Complete</p> <p>The work group continues meetings in 2022 to discuss potential consensus study</p>
<p>2. Symposium presented at ISOQOL 2021 vidual meeting</p> <p>Putting the Horse before the Cart: Understanding the Needs and Individual Factors Influencing Clinicians' Behaviour to Integrate PROMs in Daily Practice</p> <p>CPSIG work group: Clinician training for for PROMs</p>	<p>SIG symposia presented</p> <p>SYMPOSIUM DESCRIPTION: To facilitate the use of PROMs in clinical practice, past research guided by implementation science theory primarily focuses on the characteristics of the intervention, organization and care setting, and implementation process. A gap is the examination of the needs of clinicians and inter-professional team. Understanding these needs and individual factors that influence clinicians' behavior is paramount for both initial and ongoing implementation of PROMs in clinical practice. The purpose of this symposium is three-fold, to: 1) Describe implementation science theory to inform clinicians' use of PROMs in daily practice (Theoretical Domains Framework [TDF]); 2) Share real-world examples from five research projects examining clinicians' needs for PROMs implementation in Canada, USA, Netherlands, and UK; 3) Learn about a newly created User's Guide that illustrates clinicians' needs and individual factors influencing PROMs implementation based on the CFIR and TDF.</p>		Angela Wolff	<p>Moderator: Angela Wolff</p> <p>Presenter Names 2021: Angela Wolff, Cecilia Pompili, Angela Stover, Lorynn Teela, Gita Mody</p> <p>Presenter Names 2022: Angela Wolff, Elizabeth Austin, Angela Stover, Maria Santana, Sara Ahmed</p>	<p>Complete</p> <p>Workshop proposal submitted in Jan. 2022 for ISOQOL 2022</p>

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<p>3. Workshop presented at ISOQOL 2021 virtual meeting</p> <p>Why is it so complex? How to integrate PROs in routine care using Complexity Theory</p> <p>CPSIG work group: PROMs and complexity theory</p>	<p>Workshop presented WORKSHOP DESCRIPTION: The goal of this workshop is to explore the application of complexity theory to the use of PROs in routine clinical care. This workshop will: 1) Describe the fundamentals of complexity theory and complex interventions in relation to healthcare; 2) Describe PRO use in clinical practice as a complex intervention; 3) Apply understanding of complexity theory and complex intervention frameworks based on international case studies.</p>		<p>Natasha Roberts and Elizabeth Austin</p>	<p>Workshop Organizers: Natasha Roberts, Elizabeth Austin, Liv Schougaard, Bernice Gulek, Angela Wolff</p>	<p>Complete</p> <p>Workshop submitted in Jan. 2022 for ISOQOL 2022</p>
<p>4. Workshop presented at ISOQOL 2021 virtual meeting</p> <p>Using Patient-reported Outcome Measures for Screening</p> <p>CPSIG work group: PROM as screening tools</p>	<p>Workshop presented WORKSHOP DESCRIPTION: Our goal is to provide an overview of the development, evaluation, and implementation of PROMs for screening in clinical practice and research. We will emphasize key skills with workshop activities. Background: Patient-reported outcome measures (PROMs) used for screening purposes have score thresholds (cut-scores) that can be used to categorize patients into clinically-meaningful groups, which facilitates identifying patients who might benefit from additional intervention or supportive care. Score thresholds can also enhance the interpretability and actionability of PROMs in clinical practice and research.</p>		<p>Kathleen Yost and Theresa Coles</p>	<p>Workshop leaders: Kathleen Yost, Theresa Coles, Minji Lee, Angela Wolff, Cindy Nowinski, Natasha Roberts</p>	<p>Complete</p> <p>Workshop submitted in Jan. 2022 for ISOQOL 2022</p>
<p>5. Paper- PROs and Payers</p> <p>CPSIG work group: PRO performance measures being used in U.S</p>	<p>Scoping review completed and paper is accepted: <i>Hanmer J; Cizik AM; M Gulek BG; McCracken P; Swart ECS; Turner R; Kinsky SM. A scoping review of US insurers' patient reported outcomes use. AJMC. #AJMC-2021-02-0055.R1. (To be published in 2022)</i></p>		<p>Kathryn Flynn, Amiy Cizik, Janel Hanmer</p>	<p>Flynn K, Yucel E, Cuzik A, Gulek-Bakirci, B.</p>	<p>Complete</p>
<p>6. Paper series published in QOLR- <i>Using implementation science to implement and evaluate PROM initiatives in routine care settings</i></p> <p>CPSIG work group: ISOQOL PROMs/PREMs in clinical practice implementation</p>	<p>Five papers published online in QOLR in the summer and fall of 2020. Published in a 2021 special issue and available at the ISOQOL website: Resource Center ISOQOL</p>		<p>Angela Stover/ Lotte Haverman</p>	<p>Angela Stover, Lotte Haverman, Hedy van Oers, Joanne Greenhalgh, Caroline Potter, Sara Ahmed, Owis Eilayyan, Maria Santana, Kimberly Manalili, Natasha Roberts</p>	<p>Complete</p>
<p>7. Communication with SIG members and formed 3 new work groups</p>	<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. Our annual CPSIG meeting was held virtually on Oct. 27, 2021, with 45 attendees. <ul style="list-style-type: none"> We brainstormed new work groups for 2021-2022 based on group interests Then we sent out a survey to CPSIG in Nov. 2021 (via RedCap) with a list of 15 potential work groups people could join and/or lead. 49 CP-SIG members responded to the survey. The 15 work groups were generated by CPSIG members during our annual CPSIG meeting at the ISOQOL conference (virtual due to COVID-19). This survey led to 3 new CPSIG work groups forming. <ul style="list-style-type: none"> CPSIG new work group 1: PROMs in chronic care (led by Fran Hu) 		<p>Angela Stover/ Liv Schougaard/ Elizabeth Austin</p>	<p>N/A</p>	<p>Ongoing</p>

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	<ul style="list-style-type: none"> ○ CPSIG new work group 2: PROMs in rare disease (led by Kate Hayes) ○ CPSIG new work group 3: PROMs in pediatric care (led by John Chaplin, in collaboration with PESIG and Child Health SIG) • Three existing work groups submitted a workshop proposal for ISOQOL 2022: <ul style="list-style-type: none"> ○ CPSIG work group: Clinician training for for PROMs (led by Angela Wolff) ○ CPSIG work group: PROMs and complexity theory (led by Elizabeth Austin) ○ CPSIG work group: PROM as screening tools (led by Kathleen Yost and Theresa Coles) • The survey we sent to CPSIG members in Nov. 2021 also resulted in new collaborations between the following SIGs: <ul style="list-style-type: none"> ○ CPSIG, Child Health SIG, and PESIG, related to PROMs for pediatric care ○ CPSIG and Statistic SIG, related to use of PROMs for power calucations 				
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SIG/Committee Name: Regulatory and Health Technology Assessment Engagement (R&HE) SIG

Date: 1 April 2022

Co-Chairs: Robyn von Maltzahn and Ashley F. Slagle

Board Liaison: Jakob Bjorner

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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. To provide comment on regulatory and HTA publications/draft guidances	Monitoring releases, drafting providing comments to regulatory body or HTA <ul style="list-style-type: none"> - Have identified sources to track - Currently work on to implement a process for tracking and identifying documents 	Application	TBC	Ashley Slagle Robyn von Maltzahn; Joy Whitsett; Cristina Ivanescu; Mayank Rehani; Calvin Ho; Bernice Gulek	<ul style="list-style-type: none"> • Identified sources to track Q1 2022 • Process in place Q3 2022 • Ongoing in real time as documents are released
2. 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	TBC	Ashley Slagle; Robyn von Maltzahn; Mayank Rehani; Bernice Gulek	<ul style="list-style-type: none"> • Concept protocol submitted to board Q4 2022 • Conduct research 2023
3. To provide networking and discussion opportunities for SIG members	Virtual happy hours (informal but with topic of interest identified in advance) <ul style="list-style-type: none"> - Identified this as an interest at our first meeting - Now working on finding a person/project members who is/are willing to lead this 	Application	TBC	Open to all SIG members	Set up by end of 2022
4. To provide a platform for education and knowledge sharing regarding FDA, EMA, HTA (other) activities	<ul style="list-style-type: none"> • Webinars • Online platform (e.g., Teamwork; group emails) <ul style="list-style-type: none"> - Identified this as an interest at our first meeting - Now working on finding a person/project members who is/are willing to lead this 	N/A	TBD	Open to all SIG members	As relevant issues arise

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SIG/Committee Name: Response Shift SIG

Date: March, 30, 2022

Co-Chairs: Richard Skolasky, Gudrun Rohde

Board Liaison: Richard Skolasky

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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	<u>Methods,</u> Theory or Application Project	Project Chair	Project Members	Timeline
1. Serie of webinars	Title of the webinars: 1.Response Shift: Latent trajectory analysis 2.Response Shift: Structural equation modelling (SEM) and item response theory (IRT) 3. Response Shift: Individualized methods and Patient Generated Index (PGI)	Methods	Richard Skolasky and Gudrun Rohde	Rick Sawatzky (1). Mathilde Verdam (2) and Véronique Sebille (2), Nancy Mayo (3)	Three webinars during 2022
2. Discussion	ISOQOL Response Shift SIG Discussion Panel	Theory	Richard Skolasky and Gudrun Rohde	Several RS-SIG members are invited to take part	April – May 2022
3. RS - pharma	Listening to the elephant in the room: Response-shift effects in clinical trials research	Methods	Carolyn E Schwartz	Carolyn E. Schwartz, I-Chan Huang, Gudrun Rohde, and Richard L. Skolasky	The paper is submitted to Drug Safety
4. Qualitative Methods for Research in Response Shift: methodological guidelines	ISOQOL presentation, manuscript	Methods	Antoinette Davey	Nikki Ow, Stine Thestrup Hansen, Kathy Lasch, Kara Schick-Makaroff, Bernice Gulek	The project is put on hold due to maternity leave and sick leave, and is going to be re-vitalized during ISOQOL-meeting 2022

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5. Response-shift intervention curriculum	ISOQOL presentation, manuscript	Application	Ruth Barclay	Brittany Lapin, Bruce Rapkin, Kedar Mate, Nancy Mayo, Rick Sawatzky	The project is put on hold due to lack of time, and is going to be re-vitalized during ISOQOL-meeting 2022
6. Making cognitive-appraisal more accessible	ISOQOL presentation, manuscript	Methods and Application	Sujith Ramachandran	Bruce Rapkin, Joel Finkelstein, Ana Maria Moga	The project is put on hold, and is going to be re-vitalized during ISOQOL-meeting 2022

Issues Requiring Board Attention:

If item 3 includes the SIG or ISOQOL name on it, it needs to go to the Board for review and comment before being published.

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

Date: Apr 2022
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.

Number of SIG Members: 73

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Time to event workstream	<ul style="list-style-type: none"> Prepared and submitted a SIG symposium submission for ISOQOL 2022 that was accepted Next step for 2022: preparation of the symposium Next step: Identify any follow-on work e.g. collaborative paper 	Methods, theory and application	Antoine Regnault	Libby Floden, Francesco Cottone ; Mallorie Fiero (+ Amélie Anota – non-current ISOQOL member apparently)	Conference 2022
2. Missing data workstream	<ul style="list-style-type: none"> Prepared and submitted an abstract for a 2022 workshop submission that was accepted Next step for 2022: preparation of the workshop Next step: Identify any follow-on work e.g. collaborative paper 	Methods, theory and Application	Kim Cocks	Jan Boehnke, Bellinda King-Kallimanis, Gina Mazza, Andrew Trigg	Conference 2022
3. Data visualisation workstream	<ul style="list-style-type: none"> Contribution to a cross-SIG working group with psychometric, patient engagement and clinical practice SIGs Activities: prepared and submitted an abstract for a symposium at ISOQOL 2022 that was accepted. Next step for 2022: preparation of the symposium Next step: Identify opportunities and priorities for manuscripts resulting from the work of the cross-SIG group 	Methods, theory and application	Bellinda King-Kallimanis	39 ISOQOL members expressed interest and have engaged with the collaboration group that is co-lead with John Devin Peipert & Abi Williams	Ongoing into 2023
4. Estimands workstream	<ul style="list-style-type: none"> Continued discussion with EFSPi/PSI working group working on PRO estimands in oncology Identification of two possible themes related to estimands for which ISOQOL would be a good forum: PRO estimands in non-oncology studies and estimands for non-statisticians Next steps: identify possible initiatives for the two themes that were identified 	Methods, theory and application	Rachael Lawrence/ Corneel Coens	Currently being established	Ongoing into 2023

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SIG/Committee Name: Translation & Cultural Adaptation SIG

Date: April 1, 2022

Co-Chairs: Dagmara Kuliś, Emily Parks-Vernizzi and Dana Weiss (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.

Number of SIG Members: 126

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Working group: Best practice guideline for global UX/UI practices of COAs destined for electronic based studies	<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 (ongoing now) - Survey on relevant areas following lit reviews (TBD) - Evaluation of results - Identification specific aspects for guideline <p>Submission as manuscript to JPRO [deliverable]</p>	Application	Anna Richards	Megan Turner, David Churchman, Justin Raymer, Jeanne Landgraf, Vladimir Zah, Marlene Knupfer, John Chaplin, Yoshimi Suzukamo, Ay-Woan Pan	<p>Under progress but estimated:</p> <p>Literature review complete by April</p> <p>Surveys held in May-June</p> <p>Evaluation in July/Aug</p> <p>Identifying – Sept</p> <p>Write-up and reviews – Oct to Feb</p> <p>Submission: March 2023</p>
2. Working group: Concept Definition Standards	<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 March 2022, survey analysis is being concluded with manuscript authoring to follow.</p>	Methods	Dana Weiss	Dana Weiss, Ben Arnold, Ana Popielnicki, Barbara Brandt, Sonya Eremenco, Emily Parks-Vernizzi, Jussi Repo, Jie You, John Chaplin, Alexandra Crane, Elizabeth Yohe Moore, Mark Wade, Carter Cassedy, Teresa Williams,	Draft manuscript completion expected by December 31, 2022.

				Miguel Ruiz, Holger Muehlan-Rehmer, Clayton Hamilton, Adelina Lear, Zhengkun Hou	
3. Identify and advance research into cognitive debriefing (CD) methods in pediatric and adolescent populations during translation and adaptation processes	Discussion with the leaders of the working group on the next steps, a proposal to be submitted for the Board's review	Methods/ Application	Monika Vance, Jeanne Landgraf	John Chaplin, Holger Muehlan-Rehmer, Sonya Eremenco, Jeanne Landgraf, Monika Vance, Ligia Chavez, Ana Popielnicki, Beatrice Tedeschi, Rita A., Ahmed Osman	On-going through 2023.
4. Working group: Principles of Good Practice for Translation of Electronic Clinical Outcome Assessment (eCOA) Measures	This work proposal was accepted in the summer of 2018 after the working group team submitted a proposal. This working group aims to create and outline a step-by-step descriptive approach of the methods to be used to translate non-instrument text needed for eCOA implementation; this need currently is not yet met in the field. 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 autumn 2021. Currently, the group is working on analysing the results of the 2 nd survey and writing the discussion section of the manuscript.	Methods/ Application	Huda Shalhoub, Megan Turner	Anita Smarandache, Ben Arnold, Caroline Anfray, Dagmara Kuliś, Emily Parks-Vernizzi, Holger Muehlan-Rehmer, Jason Bredle, John Chaplin, Mark Wade, Sonya Eremenco, Jussi Repo	Draft manuscript completion expected by December 2022.
5. Webinar: Good Practices for the Translation, Cultural Adaptation and Linguistic Validation of Clinician-Reported Outcome, Observer-Reported Outcome, and Performance Outcome Measures – February 16, 2022	Live presentation of research carried out by TCA-SIG members and led by Shawn McKown, which was published in JPRO in 2021.			Shawn McKown, Ben Arnold, Dana Weiss, Caroline Anfray	Completed February 16, 2022.

SIG/Committee Name: United Kingdom & Ireland SIG
Date: 28/03/2022
Co-Chairs: Jonathon Evans, Timothy Pickles and Grace Turner
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.

Number of SIG Members: 58

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. 6th National Patient Reported Outcome Measures (PROMs) Annual Research Conference (Virtual Event). 14 th – 15 th June 2022 (Welsh Value in Health Centre)	The ISOQOL Co-chairs have assisted in the ongoing promotion and organisation of this event. The Welsh Value in Health Centre were invited to organise this event by the UK SIG who have continued to support the organisation of this event.	To disseminate PROMs knowledge and expertise in the UK	Sarah Puntoni	The Welsh Value in Health Centre and UK SIG co-chairs	June 2022
2. SIG meeting at virtual ISOQOL Conference 2021	Delivered the UK SIG meeting as part of the ISOQOL conference. We discussed the previous years' survey, undertook a virtual networking event and discussed the theme of UK healthcare provider involvement in PROMs implementation.	Networking	Jonathon Evans	Jonathon Evans, Grace Turner and Trish Holch	Complete
3. UK SIG meeting at the National PROMs Annual Research Conference - Developing the network and discussing diversity research – 15 th June	As part of the 6 th National PROMs Annual Research Conference, we will be holding a UK SIG meeting to promote the work of ISOQOL, develop the UK PROMs network, discuss the hosts of the 7 th National PROMs Annual Research Conference and open the call for the next UK SIG chair-elect position	Networking	Jonathon Evans	Jonathon Evans, Timothy Pickles, Grace Turner and Trish Holch	June 2022
4. Training courses and resources relevant to PRO research collated and uploaded to Teamwork.	An update has been completed by SIG chair-elect Timothy Pickles list of training courses and resources relevant to PRO research. This has been added to Teamwork to share with all SIG members. We have encouraged members to add to this list which stands as the most comprehensive list of PROMs training courses in the UK	Dissemination of educational resources	Timothy Pickles		Complete
5. Compiled list of UK specific PROMs providers, research institutions and groups. Uploaded to Teamwork	Timothy Pickles and Jonathon Evans have compiled a list of PROMs interested groups, researchers and providers in the UK. We hope that the ISOQOL network finds this resource useful in developing collaborations. This list will be added to Teamwork and will be updated by all members.	Dissemination of networking contacts	Jonathon Evans and Timothy Pickles	Grace Turner and Trish Holch	Complete
6. UK specific PROMs introduction for clinicians – training offering or seminar	Following a discussion during the ISOQOL conference UK SIG meeting, an educational offering to UK clinicians and healthcare providers was discussed. This 'in progress' action will aim to collaborate with the QOL in Clinical Practice (CP) SIG and interested parties in the UK to deliver a training offering / seminar / webinar		Jonathon Evans	Timothy Pickles, Grace Turner and Trish Holch	June 2023