



ANNUAL REPORT

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

Date: 11 Feb 2021

Co-Chairs: Ashika Maharaj, Liane Ioannou, Rebecca Mercieca-Bebber, Natasha Roberts

Board Liaison: Lotte Haverman

Mission: The Australia-New Zealand Special Interest Group brings together Australian and New Zealand-based researchers in the field of quality of life research. Given geographical remoteness of Australian and New Zealand 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 Chair	Project Members	Timeline
1. PROMs Downunder Conference is planned for July 2021	The program and workshops for this meeting are planned. Abstracts are being submitted and registrations are open	This will incorporate a range of applications	Claudia Rutherford		This meeting will take place July 2021
2. 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	Isobel Ramsay	Nadia Corsini Claudia Rutherford Ashika Maharaj Julie Campbell Jessica Roydhouse Natasha Roberts	Completion is anticipated for mid-2021
3. 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 (and potentially New Zealand)	Application	Ashika Maharaj	Natasha Roberts TBD	Currently in planning phase



ANNUAL REPORT

SIG/Committee Name: Canada PRO SIG

Date: February 27, 2020

Co-Chairs: Nora Fayed, Ana Maria Moga, Fatima AlSayah

Board Liaison: Kim Cocks

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

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. National Survey of Canadian PROMs Stakeholders and Users	Ethics approval and funding complete. Survey will be launched March 2021	Ahmed, S/Fayed	Ahmed, Fayed, Kuspinar, Bartlett, Moga	Informal interim report to be drafted, to be available for initial review with the collaboration committee July 2021
2. Draft a publication of survey results in collaboration with ISOQOL and disseminate to federal agencies and PROMs stakeholders in Canada	We received board approval to use the ISOQOL name in the dissemination of the survey and met with the collaboration committee to discuss the terms. Federal agencies (e.g. CADTH, CIHR) will be targeted as study recipients and knowledge end users.	Fayed/Kuspinar	Ahmed, Fayed, Kuspinar, Bartlett, Moga	November 2021

Comments:

We held our 2020 SIG Meeting in virtually and it was very well attended, with announcements about the next survey and the rationale for it being shared. The membership offered suggestions on additional survey dissemination networks to increase the numbers of people completing the survey and representation of non-academic stakeholders. We have received ethics approval to conduct the survey at Queen's and McGill, with the Ontario SPOR providing additional funding to complete the research and Sara Ahmed's lab also providing in-kind support. We are targeting high levels of engagement and representation from any and all PROM users in Canada and expect to report the final results at our 2021 meeting. Finally, in the 2021 meeting we expect to gage interest for a Canada-specific symposium.

SIG/Committee Name: Child Health SIG
Date: 10 Feb. 2021
Co-Chairs: Holger Muehlan, Robert Arbuckle, John Chaplin
Board Liaison: Kirstie Haywood

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

Project/Objective	Actions/Deliverables	Methods, Theory or Application	Project Chair	Project Members	Timeline
1. Increase presence of CH-SIG and representation of methodological challenges/issues associated with child health assessment at ISOQOL Annual Meetings	The SIG organised an on-line symposia for the 2020 conference –which was well attended Title: The future of electronic Patient-Reported Outcome Measurement for children and adolescents: the use of computer adapted testing.	Methods & Theory	John, Rob, Nalin, Holger,	Christiane Otto, Michiel Luijten, Kaveh Ardalan, Jin-Shei Lai, Kathrin Fischer.	Completed Oct. 2020
	Published a Letter to the Editor of QLR – Title: Registered reports and paediatric research – published Dec 2020. https://doi.org/10.1007/s11136-020-02702-3	Theory	John, Rob, Holger, Nalin	All members	Completed Dec 2020
	A submission for the ‘Measuring what matters’ workshop 2022 approved. Title: Measuring What Matters in Child Health: Challenges, Developments and Opportunities	Application	Rob, Nalin	John, Holger, Nikki Ow, Elizabeth Gibbons + Adolescent and/or parent/caregiver representative	Proposal accepted Deadline July 2022
	Submitted a proposal for a full symposium at the 2021 ISOQOL Conference– Symposium Title: ‘Young People in the Time of Covid’ . With contributions from five SIG members in Canada, Germany, Netherlands and Sweden.	Methods and Application	John, Rob, Holger, Nalin	Malin Berghammer & Margaretha Jenholt Nolbris Christiane Otto Lotte Haverman Nancy L. Young Alisha Daya & Skye Barbic	Submitted 19th Jan 2021

	Joined the joint working group on Pediatric Cognitive Interviews together with the TCA SIG.	Methods	Monika Vance from TCA SIG	John, Holger, Jeanne Landgraf	1 March 16:00 next meeting
2. Expanding membership and networking	Conducted a members meeting following the Conference. Created a survey to elicit symposia ideas from the CH-SIG members. Number of SIG Members: 130	Consolidation of membership	John, Rob, Nalin, Holger,	(approximately 50 attendees).	Completed Nov 2020
	Identified people interested in becoming a co-chair in 2021	Consolidation of membership	John, Rob, Holger, Nalin	Skye Barbic (Can) Zephania Tyack (Aus)	On going
	At the SIG members meeting we discussed plans to provide a # Newsletter for members ; # to establish further Working groups on Social Media in Child Health Research; and Disparities / Inequalities in Child Health. # Mentoring group of past chairpersons .	Consolidation of membership	Holger, John, Rob, Holger, Nalin John, Rob, Holger,	All members Nalin, Jeanne, Anne-Catherine, +	
3. Per member request provide an ongoing opportunity for early networking in the ISOQOL Annual Meetings to ensure time for ongoing conversations throughout the meeting	The Annual pre-conference dinner at the next ISOQOL mtg. in Calgary has been discussed with the membership and a member from Calgary and others from Canada have agreed to help with the organisation.	Consolidation of membership. Networking	John, Rob, Holger, Nalin	Sumedh Bele	Oct 2021



ANNUAL REPORT

SIG/Committee Name: Chinese PRO SIG

Date: Feb 14, 2021

Co-Chairs: Daniel Fong and Ji-quan Fang

Board Liaison: Lotte Haverman

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

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 translate the ISOQOL dictionary into Simplified Chinese	Expert review completed. Pending for editorial review.		JQ Fang Daniel Fong	All	End of 2021
3. To comment on the new initiative of registered reports from the perspectives of researchers on Chinese PRO	Published a Letter to the Editor: "Registered Reports: response from the Chinese PRO SIG" Fong DYT, Osman AMY, Wang H, Yang CW Quality of Life Research volume 29, pages3185–3186(2020)		Daniel Fong	All	Delivered in 2020
4. To develop linkage with international groups of researchers on Chinese quality of life research	The World Association for Chinese Quality of Life is willing to collaborate with ISOQOL.		JQ Fang Daniel Fong	All	Long-term



ANNUAL REPORT

SIG/Committee Name: German-speaking Countries SIG

Date: 17.01.2021

Co-Chairs: Kathrin Fischer, Bernhard Holzner

Board Liaison: Kim Cocks

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. First RGN meeting during the virtual annual conference 2020	<ul style="list-style-type: none"> inform the members about the meeting prepare meeting virtual meeting was hold on October 12, 2020 	-	Bernhard Holzner; Kathrin Fischer		Complete
2. Build a network within ISOQOL and increase membership of the RGN	<ul style="list-style-type: none"> run a membership survey to get an overview of demographics of current members and seek input to build and grow the network 	-	Bernhard Holzner; Kathrin Fischer		Q1 2021
3. Second RGN meeting during the annual conference 2021	<ul style="list-style-type: none"> inform the members about the meeting call attention to the RGN meeting in the ISOQOL community prepare and hold meeting 	-	Bernhard Holzner; Kathrin Fischer		Q4 2021



ANNUAL REPORT

SIG/Committee Name: Health Preference Research SIG

Date: February 17, 2021

Co-Chairs: Amy Cizik, Heather Gelhorn, Manraj Kaur,

Board Liaison: I-Chan Huang

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

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
PAST UPDATES					
1. Submit a HPR SIG-sponsored workshop for 2020 meeting	Preference elicitation methods for patient-centered outcomes using best-worst scaling and discrete choice experiments for quality of life research	Methods and Application:	Amy Cizik,	Gang Chen, Heather Gelhorn, I-Chan Huang, Sam Li, Donna Rowen,	Completed, but not selected for the 2020 meeting.
2. Submit a HPR SIG-sponsored symposium	Patient Preference Research: Whither Goest Thou?	Theory and Application: Annual Meeting	Manraj Kaur	Julie Ratcliff (JR), Xiaoning He (XH), Philip Powell (PP), Richard Skolasky (RS), Vishal Bhatnagar (VB),	Completed, but not selected for 2020.
3. Membership Survey	Write questions and conduct a membership survey		Amy Cizik	Amy Cizik, Manraj Kaur, Richard Skolasky	Completed.
4. Quarterly Membership Meetings	Update the membership on what the SIG is doing and gain knowledge from the membership on goals for the SIG. 1 st meeting held February 3, 2020 – only 4 in attendance		Manraj Kaur	Amy Cizik, Richard Skolasky,	Discontinued due to lack of attendance
5. Chair SIG Meetings	Bimonthly held 11/27/2019 and 1/8/2020. Communicate by email monthly		Manraj Kaur	Amy Cizik	We continued to communicate by email.
NEW UPDATES					
6. Annual SIG Meeting 2020	<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 4. Present survey results to the membership 		Amy Cizik	Manraj Kaur Heath Gelhorn	October 2020
7. Change/Communicate structure/roles responsibilities of SIG chairs	We restructured our SIG chairs to the following roles: <ul style="list-style-type: none"> • Past Chair (2019-2020) – Manraj Kaur • Current Chair (2020 – 2021) – Amy M. Cizik • Chair – Elect (2021 – 2022) – Heather Gelhorn 		Amy Cizik	Manraj Kaur	Began February 2020, finalized October 2020

	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.				
8. HPR research in COVID/virtual era manuscript	At the annual meeting Manraj proposed an idea to do a group manuscript. She was an incredible leader and this went from idea in October 2020 to a submitted manuscript by January 2021	HPR methods & Application	Manraj Kaur	Manraj N. Kaur, Richard L. Skolasky, Philip A. Powell, Feng Xie, I-Chan Huang, Ayse Kuspinar, John L O'Dwyer, Amy M. Cizik, Donna Rowen,	Proposed October 2020 Completed January 2021
9. Submit a HPR SIG-sponsored workshop and/or symposium	<ol style="list-style-type: none"> 1. Encourage the membership to collaborate to submit HPR-related symposiums and/or workshops 2. The current chair and chair-elect deliberately chose to not lead these submissions this year: <ol style="list-style-type: none"> a) Balancing work/life responsibilities for two working mothers who were assisting children with remote learning and maintaining our paid responsibilities in our jobs. b) Hesitant to propose symposium/workshops that could very likely be "virtual" – which are more a lot of work c) Discouraged from not getting either accepted in the prior year, especially after a very successful and well-attended symposium the prior year. d) Feedback from the HPR survey results that membership preferred social engagement activities then project-based activities. e) There was an HPR-related symposium (Symposium 1) in 2020 that was preference-based but was not submitted or sponsored by the SIG 3. We did post an announcement in Teamwork (albeit with a late notice) if any of our membership was interested that we would support by coordinating people (see Teamwork announcement). 		Amy Cizik Heather Gelhorn	N/A	February 2021
4. Send a monthly email to the HPR membership via Teamwork to increase membership engagement	Send an email to the membership: offering opportunities for people to do a webinar on new methods, theory and application. Asking if people have news to share, papers published, etc.		Amy Cizik	Heather Gelhorn Manraj Kaur	January 2021
5. Engage membership socially	If we meet in-person plan an HPR-sponsored "Dine-Around" or Social Gathering for HPR members to meet one another.		Amy Cizik	Heather Gelhorn	October 2021



ANNUAL REPORT

SIG/Committee Name: Ibero America SIG

Date: Feb 09, 2021

Co-Chairs: Monica Avila, Noelle de Oliveira Freitas

Board Liaison: Kim Cocks

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

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Developing of Spanish version of ISOQOL Dictionary	The Spanish version is in the final review step by the collaborators and project chair. The final version will be available soon. We are trying to find more collaborators to finish the project as soon as possible if it is not finally possible; we will send the review in July.		Mónica Ávila	Members of the SIG or collaborators. (Spanish native) ISOQOL collaboration	Spanish version: July 2021
2. IberoAmerican Meeting - 2022	It was previously decided with the members of the SIG that the next IberoAmerican Meeting would take place in Coimbra, Portugal. Thus, we will propose to organize the conference in March or April 2022.		Noélie Freitas, Monica Avila and Members of the SIG or collaborator	Members of the SIG or collaborator	March or April 2022



ANNUAL REPORT

SIG/Committee Name: Industry SIG

Date: 2-17-2021

Co-Chairs: Patricia Corey-Lisle, Michelle White

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
1. I-SIG Symposium: Plan and deliver industry-focused symposium at the annual meeting	Will deliver symposium: Leveraging Social Media for Patient Centric Research in Medical Product Development	Methods and Application	Michelle White	Tom Willgoss, Louise Newton, Sarah Knight, Patricia Cory-Lisle, Helen Kitcen, Kathy Lasch, Calvin Ho, Bernice Gulek-Bakirci, Linda Nelsen, Paivi Miskala, Sarah Bentley	Finalize speakers: end of March Speaker meetings and slide development: April-July First draft slides: first week August Finalize slides: end of Sept
2. I-SIG has 4 proposals for consideration: 3 are webinars, 1 is position paper	As of 2/17, waiting on last 2 proposed ideas to put to I-SIG for vote on which to pursue. At this time, the 2 we have are: <ol style="list-style-type: none"> Position paper on core outcome sets (follow-up from Measuring What Matters) Webinar possibly : Patient-centric exposure-response analysis for medical product safety 	Methods and Application	If 1, Michelle White and Tom Willgoss. If 2, Paivi Miskala	TBD	TBD

SIG/Committee Name: Japan SIG

Date: 12 February 2021

Co-Chairs: Kojiro Shimozuma, Kikuko Miyazaki
Secretary: Yoshimi Suzukamo

Board Liaison: Lotte Haverman

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

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. SIG meeting in ISOQOL 27th Annual Conference and following online meeting	Fourteen members attended this online meeting. We reported the annual activity and the public funded researches by members. We discussed about future three tasks. The minutes of meeting were circulated through Teamwork.	Application Project	Shimozuma K Miyazaki K		Complete
2. 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 And other members	In progress
3. Regional meeting which holds under the auspices of Japan SIG	1) 7th Annual conference of JSQolPro Dec.14, 2019 2) 14th JSQolPro research seminar Feb. 29, 2020 3) 15th JSQolPro research seminar June 27, 2020 4) Pre-Seminar of the 30th Annual Scientific Meeting of the Japan Epidemiological Association Feb. 20, 2020 5) Clinical Research Methodology Seminar March 6, 2020 -> Nov. 27, 2020 6) 8th Annual conference of JSQolPro Dec. 12, 2020 7) 14th JSQolPro research seminar Feb. 6, 2021 8) 15th JSQolPro research seminar June undecided, 2021	Application Project	1) Noto S 2) Naito M 3) Nishigori T 4) Miyazaki K 5) Miyaji T 6) Saito S 7) Naito M 8) Nishigori T	Members of Japan SIG and collaborators.	1), 4): Complete 2), 3): Canceled due to Covid-19 5): Schedule change due to Covid-19 6)-8): under application
4.					

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

Japan SIG Supplement

The speakers of three seminars hosted by the Japanese Society for Quality of Life and Patient-Reported Outcomes Research (JSQoIPro) are as follows.

*: Japanese SIG member

The JSQoIPro is a Japanese organization with many ISOQOL Japan SIG members. The chair of this society is Dr. Kikuko Miyazaki, who is also the co-chair of Japan SIG.

1) 8th Annual conference of JSQoIPro

- Date: Dec. 19, 2020 1:30 pm – 5:00 pm
- Host: JSQoIPro (Program Chair: Shinya Saito)
- Program
 - Educational lecture: What QOL beginners need to know by Kikuko Miyazaki* (Kyoto University)
Session chair: Shinya Saito*
 - Keynote speech: Ethical issues related to QOL by Shinya Saito* (Okayama University)
 - Symposium: Between measuring and valuing quality of life
Speaker 1: Naruto Taira* (Okayama University)
Speaker 2: Shinichi Noto (Nigata University of Health and Welfare)
Session chair: Kojiro Shimozuma*, Shinya Saito*
 - Oral session with 3 speakers
Session Chair: Shinya Saito*, Nobuichiro Tamura

2) 14th QOL/PRO research seminar

- Date: Feb. 6, 2021 1:30 pm – 3:30 pm
- Host: JSQoIPro (Program Chair: Mariko Naito*)
- Program
 - Lecture 1: Expansion of clinical epidemiological research utilizing IoT data
Speaker: Shingo Fukuma (Kyoto University)
 - Lecture 2: Trends in text analysis technology by deep learning and its application to sentiment analysis
Speaker: Mizuho Iwaihara (Waseda University)
 - Lecture 3: EPRO research collaborated with EORTC and prospects
Speaker: Yuichiro Kikawa*

3) 15th QOL/PRO research seminar

Date: June, 2021

Host: JSQoIPro (Program Chair: Tatsuto Nishigori)

Details of the program are undecided.

SIG/Committee Name: Mixed Methods SIG

Date: February 11, 2021

Co-Chairs: Antoinette Davey, Motolani Ogunsanya

Board Liaison: Kirstie Haywood

Mission: The purpose of the Mixed Methods SIG is to promote the use of mixed methods research in the field of QoL research by exploring the challenges and methodological solutions offered by this research paradigm, identifying opportunities for application of mixed methods research in the field, and defining good practice. Our ultimate aim is to share and learn best-practice methodologies 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 		Carla Dias Barbosa	Team of 20 members from the SIG	Q1-3 2021
2. Dissemination and SIG engagement	<ul style="list-style-type: none"> Create a LinkedIn for ISQOL_MM group and encourage members of the group to communicate the new advances in the research area Speed dating event for SIG members to get to know each other to be held in early part of 2021 Guest speakers to be invited to discuss methodological applications in this field. <ul style="list-style-type: none"> First speaker identified and has agreed. 		Motolani Ogunsanya/ Antoinette Davey	All SIG members who wish to take part	Ongoing through 2021
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	All SIG members who wish to take part	Ongoing through 2021
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. <p>The goal is to foster interrelationship and collaboration among members and to broaden knowledge of emerging topics and issues.</p>		Motolani Ogunsanya	MM SIG members who wish to take part	Ongoing through 2021



ANNUAL REPORT

SIG/Committee Name: New Investigators SIG

Date:

Co-Chairs: Maryam Mozafarinia, Niki Ow

Board Liaison: Nalin Payakachat

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

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	Based on our previous survey results and feedback from our members during the SIG meeting at the annual conference, we plan to organize and hold 3 interviews before the annual ISOQOL conference in October 2021. These short interviews will feature guests with various expertise areas.	Methods, theory & application	Nikki and Maryam	NI SIG members	February to October 2021
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. If there is not in person conference in 2021, we will do an online zoom happy hour.	Application	Nikki and Maryam	NI SIG members	October 2021
3. Educational Webinars	We plan to organize 1 educational webinar before the annual ISOQOL conference in October 2022. We estimate one should take place in September 2021. This webinar will focus on methods and application in outcomes research.	Methods	Nikki and Maryam	NI SIG members	September 2021
4. NI SIG Registered Reports Letter to the Editor of QLR	We submitted a response letter to the Co-Editors of QLR regarding the Registered Reports.	Application	Nikki and Maryam	Nikki and Maryam	November 2020



ANNUAL REPORT

SIG/Committee Name: Patient Engagement SIG

Date: 10 February 2021

Co-Chairs: Danielle Lavallee, Natasha Roberts

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 continue to work closely with the QOL in Clinical Practice SIG to achieve these goals.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Collaborative partnerships and patient led research	Workshop submission for ISOQOL Meeting	Patient partnership and storytelling	Maria Santana	Danielle Lavallee Sandra Zelinsky Sadia Ahmed	Workshop planned for the 2021 Meeting (Submitted as a proposal with intent to repurpose a synopsis for the SIG meeting)
2. Data visualisation to support patient engagement with PROMs	A working group has been formed: <ul style="list-style-type: none"> - A workshop submission abstract has been submitted for ISOQOL 2021 - A systematic review is underway - Collate resources on data visualisation 	Case studies	TBA	TBA	This is ongoing
3. Definitions of patient engagement in research to support QoL research	Formation of a working group to develop a manuscript for publication that will differentiate the roles of patient partner and patient participant in QoL research.	Systematic review of the literature	TBA	TBA	Goal: Draft review for the 2021 ISOQOL Conference
4. Inclusivity of patient engagement in clinics, research and drug development	Formation of a working group to develop a symposium for ISOQOL 2022	Rapid review of the literature and case studies	Natasha Roberts	TBA	Planned for submission January 2022

Comments:

1) SIG is working on engaging a patient research partner to become an Patient Advisor Co-Chair to the SIG. This position is described as:

The Patient Engagement SIG governance will include a Patient Research Partner (PRP) for a one year term. This position will be an invited position by the SIG Co-Chairs and advise the patient perspective on the SIG initiatives. Each year in May the SIG co-chairs will send an invitation to either a current ISOQOL PRP member or to one of the patient scholarship awardees. The invite will describe the SIG's mission and initiatives and ask the person to participate as a co-chair for a one year term, May through May. When the PRP is selected, the co-chairs will advise the ISOQOL office of the new co-chair. This person will receive a full Patient Research Partner membership for that year.



ANNUAL REPORT

SIG/Committee Name: Psychometrics SIG

Date: 02/10/2021

Co-Chairs: John Devin Peipert, Henrick Eshoj 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.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. 2020 ISOQOL SIG Symposium: "Psychometrics and Response Shift SIGs: How to Assess and Interpret Measurement Properties and Change Over Time using Longitudinal Item Response Theory (LIRT)"	6 symposium presentations and 3 manuscripts	Methods	Pip Griffiths and Henrik Rode Eshoj, Frances Yang	Frances Yang, Andrew Trigg, Jakob Bjorner, Berend Terluin, Myriam Blanchin, Carrie Houts	Presentations given at virtual 2020 ISOQOL conference. Tutorial manuscripts based on the presentations are in progression and are scheduled for submission in 2021-2022.
2. <i>Quality of Life Research</i> Special Issue: "Methodologies and Considerations for Meaningful Change"	There was a need for a go-to resource for meaningful change methods in the field. Working with the psychometrics SIG, we worked to commission a special issue in QLR and compile a call for letters of intent. In addition, several SIG members submitted manuscripts in response to this call, organised through the Teamwork platform.	Methods	Pip Griffiths	Henrik Rode Eshoj, Frances Yang	Manuscript proposals are currently under review.
3. Cross-SIG Collaboration on Data Visualization	One element of this project is a collaboration with other SIGs to write a review paper on best practices around visualizing PRO data across settings (e.g., routine patient monitoring, clinical trials) and to identify opportunities for standardization. There is a second element of the project wherein a select group has submitted a workshop proposal around PRO data visualization for ISOQOL 2021.	Application	John Devin Peipert	Ethan Arenson	Review paper will be developed over 2021 and likely submitted in 2022.



ANNUAL REPORT

SIG/Committee Name: QOL in Clinical Practice SIG

Date: February 12th 2021

Co-Chairs: Kate Absolom (past), Angela Stover, Liv Schougaard

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	Methods, Theory or App Project	Project Chair	Project Members	Timeline
1. Paper- <i>Patient engagement with PRO completion in clinical practice (Target journal JPRO)</i>	Paper being drafted: Paper based on a previous webinar will be ready to submit to JPRO soon		Kate Absolom/ Elizabeth Unni	Coles T, Wilson H, Lavallee D, Roberts N, Freel J	Spring 2021 submission to JPRO
2. Paper series published in QLR- <i>Using implementation science to implement and evaluate PROM initiatives in routine care settings</i> CPSIG work group: ISOQOL PROMs/PREMs in clinical practice implementation work group for CPSIG	Five papers published online in QLR in the summer and fall of 2020: <ul style="list-style-type: none"> Stover AM, Haverman L, van Oers H, Greenhalgh J, Potter CM, on behalf of the ISOQOL PROMs/PREMs in clinical practice implementation science workgroup. Using an implementation science approach to implement and evaluate Patient-Reported Outcome Measures (PROM) initiatives in routine care settings. Qual Life Res. 2021. First published online 10 July 2020. DOI: 10.1007/s11136-020-02564-9. Open access link: https://link.springer.com/article/10.1007/s11136-020-02564-9 Ahmed S, Zidarov D, Eilayyan O, Visca R. Prospective application of implementation science theories and frameworks to use PROMs in routine clinical care within an integrated pain network. Qual. Life. Res. 2021. First published online 2 September 2020. doi: 10.1007/s11136-020-02600-8. https://link.springer.com/article/10.1007/s11136-020-02600-8 van Oers HA, Teela L, Schepers SA, Grootenhuis MA, Haverman L. Implementation of the KLIK PROM portal using the Consolidated Framework for Implementation Research (CFIR) retrospectively. Qual Life Res. 2021. First published online 15 August 2020. doi: 10.1007/s11136-020-02586-3. Open access link: https://link.springer.com/article/10.1007/s11136-020-02586-3 Manalili K, Santan M. Using Implementation Science to Inform Integration of Electronic Patient-Reported Experience Measures (ePREMs) into Healthcare Quality Improvement. Qual Life Res. 2021. First published online 26 July 2020. doi: 10.1007/s11136-020-02588-1. https://link.springer.com/article/10.1007/s11136-020-02588-1 Roberts NA, Janda M, Stover AM, Alexander K, Wyld D, Mudge A. The utility of the implementation science framework “Integrated Promoting Action on Research Implementation in Health Services” (i-PARIHS) and the facilitator role for introducing patient 		Angela Stover/ Lotte Haverman	Angela Stover, Lotte Haverman, Hedy van Oers, Joanne Greenhalgh, Caroline Potter, Sara Ahmed, Owis Eilayyan, Maria Santana, Kimberly Manalili, Natasha Roberts	March and April, 2020: ISOQOLboard reviewed and endorsed paper set Feb 2021: awaiting for papers to be published in a 2021 special issue so we can send to ISOQOL to post on their website

	reported outcome measures (PROMs) in a medical oncology outpatient department. Qual Life Res. 2021. First published online 21 October 2020. DOI: 10.1007/s11136-020-02669-1. https://link.springer.com/article/10.1007%2Fs11136-020-02669-1				
3. Paper published in QLR	Paper published in QLR by CPSIG co-chairs: Stover AM, Schougaard LMV, Absolom K. Registered reports: Clarifications and opportunities from ISOQOL'S Special Interest Group for Clinical Practice. Qual Life Res. 2020;29(12):3183-3184. DOI: 10.1007/s11136-020-02695-z.		Angela Stover	Co-authors: Angela Stover, Liv Schougaard, Kate Absolom	Complete
4. Symposium presented at ISOQOL 2020 virtual conference CPSIG work group: ISOQOL PROMs/PREMs in clinical practice implementation work group for CPSIG	Main meeting symposia presented SYMPOSIUM DESCRIPTION: Patient-reported outcome and experience measures (PROMs/PREMs) are well established in research for many health conditions, but barriers persist for implementing them in routine care. Implementation science (IS) offers a potential way forward, but its application has been limited for PROMs/PREMs. In this symposium, we will compare similarities and differences for five widely used IS frameworks and their applicability for implementing PROMs/PREMs in routine care through four case studies. We compare case studies on theories, barriers, enablers, and implementation strategies.		Angela Stover	Angela Stover, Caroline Potter, Natasha Roberts, Hedy van Oers	Complete
Symposium (main meeting) submitted to ISOQOL 2021: PROMs in telehealth CPSIG work group: PROMs and telehealth	Symposium Proposal submitted for ISOQOL 2021: 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 patient-reported outcome measures (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. Members of the ISOQOL QOL in Clinical Practice Special Interest Group will share experiences with PROMs in telehealth initiatives and discuss challenges and opportunities.		Liv Schougaard and Elizabeth Unni	Moderator: Elizabeth Unni Presenters: Lee Aiyegbusi, Natasha Roberts, Derek Kyte, Birgith Engelst Grove, Liv Marit Valen Schougaard	Submitted in Jan. 2021 for ISOQOL 2021 Work group is meeting in Feb. 2021 to discuss potential consensus study
5. Symposium (main meeting) submitted to ISOQOL 2021: Putting the Horse before the Cart: Understanding the Needs and Individual Factors Influencing Clinicians' Behaviour to Integrate PROMs in Daily Practice CPSIG work group: Clinician needs for PROM implementation	Symposium Proposal submitted for ISOQOL 2021: To facilitate the use of patient-reported outcome measures (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. The five presentations are: (a) Clinicians' needs about how to "act on" PROM data (b) Surgeons' experience implementing PROMs in thoracic oncology		Angela Wolff	Moderator: Angela Wolff Presenters: Angela Wolff, Cecilia Pompili, Angela Stover, Lorynn Teela, Gita Mody	Symposium proposal submitted in Jan. 2021 for ISOQOL 2021

	(c) Clinicians' training needs for implementation of depression screening (d) Improvements to the KLIK PROM portal to meet clinicians' needs (e) Understanding the multilevel determinants of ePRO implementation for remote symptom management. We discuss these examples using the CFIR or TDF to illustrate individual factors and clinician characteristics.				
6. Workshop submitted for ISOQOL 2021: Why is it so complex? How to integrate PROs in routine care using Complexity Theory CPSIG work group: PROMs and complexity theory	Workshop Proposal submitted for ISOQOL 2021: The goal of this workshop is to explore the application of complexity theory to the use of PROs 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.		Natasha Roberts	Workshop Organizers: Natasha Roberts, Elizabeth Austin, Liv Marit Valen Schougaard, Bernice Gulek, Angela Wolff	Submitted in Jan. 2021 for ISOQOL 2021
7. Workshop submitted for ISOQOL 2021: Using Patient-reported Outcome Measures for Screening CPSIG work group: PROM as screening tools for health conditions	Workshop Proposal submitted for ISOQOL 2021: 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.		Kathleen Yost and Theresa Coles	Workshop leaders: Kathleen Yost, Theresa Coles, Minji Lee, Angela Wolff, Cindy Nowinski, Natasha Roberts	Submitted in Jan. 2021 for ISOQOL 2021
8. Paper- PROs and Payers CPSIG work group: PRO performance measures being used in U.S.	Scoping review completed and paper being drafted: Scoping review complete. Paper is drafted and has been circulated to co-authors. Target journal is American Journal of Managed Care.		Kathryn Flynn, Amiy Cizik, Janel Hanmer	Flynn K, Yucel E, Cuzik A, Gulek-Bakirci, B.	Submission to journal in Feb or March 2021. Amy to present results at CPSIG 2021 meeting.
9. Communication with SIG members and formed 8 new work groups	<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 (#CPSIG). <ul style="list-style-type: none"> We created a twitter "list" that >50 CPSIG members joined. We continued to share papers/opportunities of interest with our hashtag. Our annual CPSIG meeting was held virtually on Oct. 14, 2021. <ul style="list-style-type: none"> Really good attendance: 93 attendees We brainstormed new work groups for 2020-2021 based on group interests Then we sent out a survey to CPSIG in Nov. 2020 (via Qualtrics) with a list of 8 potential work groups people could join and/or lead. The 8 work groups were generated by CPSIG members during our annual CPSIG meeting at the ISOQOL conference (virtual due to COVID-19). 		Kate Absolom/ Angela Stover/ Liv Schougaard	N/A	Ongoing

	<ul style="list-style-type: none"> • This survey led to 5 new CPSIG work groups forming. Four out of the 5 new groups submitted a symposium or workshop proposal for ISOQOL 2021: <ul style="list-style-type: none"> ○ CPSIG new work group 1: PROMs and telehealth (led by Liv Schougaard and Elizabeth Unni) <ul style="list-style-type: none"> ▪ Submitted symposium proposal for ISOQOL 2021 ○ CPSIG new work group 2: Clinician needs for PROM implementation (led by Angela Wolff) <ul style="list-style-type: none"> ▪ Submitted symposium proposal for ISOQOL 2021 ○ CPSIG new work group 3: PROMs and complexity theory (led by Natasha Roberts) <ul style="list-style-type: none"> ▪ Submitted workshop proposal for ISOQOL 2021 ○ CPSIG new work group 4: PROM as screening tools for health conditions (led by Kathleen Yost and Theresa Coles) <ul style="list-style-type: none"> ▪ Submitted workshop proposal for ISOQOL 2021 ○ CPSIG new work group 5: Shared decision making and PROMs <ul style="list-style-type: none"> ▪ In the planning stage • The survey we sent to CPSIG members in Nov. 2020 also resulted in 3 new collaborative work groups forming with other SIGs: <ul style="list-style-type: none"> ○ New cross-SIG work group 1: TCA-SIG and CPSIG <ul style="list-style-type: none"> ▪ In the planning stage of work group ○ New cross-SIG work group 2: Psychometrics SIG and CPSIG <ul style="list-style-type: none"> ▪ Submitted a workshop proposal for ISOQOL 2021: ▪ “PROM data visualization in the clinical setting: what do clinicians need to see?” ▪ Workshop goals: Regardless of whether patient-reported outcome measure (PROM) data is collected via app or integrated into the electronic health record, the numeric results must be transformed into a format that is easy to read and interpret for busy clinicians and their patients. The workshop goals are to present and discuss examples and best practices for visualizing PROM data in the context of clinical care. ○ New cross-SIG work group 3: Data visualization and CPSIG (led by Bellinda King) <ul style="list-style-type: none"> ▪ Developed a work plan for next 12 months: ▪ Considering conducting a systematic review covering data visualisation across all areas represented by this collaboration (Clinical Practice, Clinical Trials, Psychometric work, Teaching/students). The review would be disease inclusive and assess how common PRO analyses have been reported in the literature with respect to data visualisation. ▪ Developing a shared list of resources on data viz ▪ Considering a workshop or symposium for ISOQOL 2022 on practical considerations for data viz (examples, etc.) 				
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ANNUAL REPORT

SIG/Committee Name: Response Shift SIG

Date: January 19, 2021

Co-Chairs: Richard Skolasky, Carolyn Schwartz

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.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. If it's information, it's not 'bias'	SIG symposium, manuscript	Theory	Carolyn Schwartz	Richard Skolasky, I-Chan Huang, Joseph Lipscomb, Gudrun Rohde	Symposium submission by January 2021; Manuscript submission by late summer 2021
2. 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	Abstract submission by April 2021; Manuscript submission by late summer 2021
3. Response-shift intervention curriculum	ISOQOL presentation, manuscript	Application	Ruth Barclay	Brittany Lapin, Bruce Rapkin, Kedar Mate , Nancy Mayo, Rick Sawatzky	Abstract submission by April 2021; Manuscript submission by late summer 2021
4. Making cognitive-appraisal more accessible	ISOQOL presentation, manuscript	Methods and Application	Sujith Ramachandran	Bruce Rapkin, Joel Finkelstein, Ana Maria Moga	Abstract submission by April 2021; Manuscript submission by late summer 2021
5. Discussing response shift with pharma	ISOQOL presentation, manuscript	Application	Ana Maria Rodriguez	Lene Kongsgaard Nielsen, Shirley Fung, Bellinda King-Kallimanis, Kristina Chen	Abstract submission by April 2021; Manuscript submission by late summer 2021

SIG/Committee Name: Statistics SIG

Date: Feb 2021

Co-Chairs: Kim Cocks, Antoine Regnault

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
1. Time to deterioration workstream	<ul style="list-style-type: none"> Establish a team of interested members Prepare a 2022 SIG symposium submission Identify any follow-on work e.g. collaborative paper 	Methods, theory and application	Antoine Regnault	Currently being established	Conference 2022
2. Missing data workstream	<ul style="list-style-type: none"> Establish a team of interested members Prepare a 2022 workshop submission Identify any follow-on work e.g. collaborative paper 	Methods, theory and Application	Kim Cocks	Currently being established	Conference 2022
3. Data visualisation workstream	<ul style="list-style-type: none"> Join with other interested SIGs (psychometric, patient engagement and clinical practice) to set up a cross-SIG working group Activities: <ul style="list-style-type: none"> Systematic review, covering data visualisation across all areas represented by this collaboration (peer review paper 2022) Create data visualisation resources for ISOQOL webpage from ISOQOL members (work with ISOQOL to have available end of 2021) ISOQOL 2021: focus on clinical practice and implementation of data visualisation ISOQOL 2022: workshop potentially relating to practical considerations for data visualisation (working on examples, etc.). 	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 2022
4. Estimands workstream	<ul style="list-style-type: none"> Attend a kick off meeting with EFSPI/PSI working group to establish key initiatives going forward (Jan 2021) Identify a workstream from this to be led within ISOQOL 	Methods, theory and application	Rachael Lawrance/ Corneel Coens	Currently being established	Ongoing into 2022



ANNUAL REPORT

SIG/Committee Name: Translation & Cultural Adaptation SIG

Date: 12 February 2021

Co-Chairs: Dagmara Kulis, Shawn McKown and Dana Weis

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; to provide an evidence database on translation and cultural adaptation of PROs; and to promote visibility of cross cultural issues in development and use of PROs in ISOQOL.

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. 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"> - Timeline planning - Literature reviews of existing guidelines/ practice - 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	Sujyotee Kretz, Dagmara Kulis, Beatrice Tedeschi, Alisa Heinzman, Monika Vance, Ana Sofia Correia, Megan Turner, David Churchman, Justin Raymer, Jeanne Landgraf, Vladimir Zah, Ligia Chavez	<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 2022</p>
2. Concept Definition Standards Working Group	<p>The objective of this working group is to prepare a good practices document for the development of concept definitions as part of the translation and cultural adaptation of COAs.</p> <p>As of February 2021, survey analysis is being concluded with manuscript authoring to follow.</p>	Methods	Dana Weiss	Dana Weiss, Ben Arnold, Ana Popielnicki, Barbara Brandt, Sonja Eremenco, Emily Parks Vernizzi, Jussi Repo, Jie You, John Chaplin, Alexandra Crane,	Draft manuscript completion expected by December 31, 2021.

				Elizabeth Yohe Moore, Mark Wade, Carter Cassidy, Teresa Williams, Miguel Ruiz, Holger Muhlan-Rehmer, Clayton Hamilton, Adelina Lear, Zheng- kun Hou	
3. Identify and advance research into cognitive debriefing (CD) methods in pediatric and adolescent populations during translation and adaptation processes	Create a guidance for practical methods to conduct cognitive debriefs with children and adolescents ages 8-18 yrs.	Methods	Monika Vance, Jeanne Landgraf	John C Holger MR Sonya E Jeanne L Monika V Ligia C Ana P Beatrice T Rita A Ahmed O	Q4 2021
4. 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 vendors to be able to collect data. Currently, the group is working on analysing the results and writing the discussion section of the manuscript.	Methods/ Application	Huda Shalhoub, Megan Turner	Anita Smarandache Ben Arnold Caroline Anfray Clayton Hamilton Dagmara Kulis Emily Parks- Vernizzi Holger Muehlan- Rehmer Jason Bredle John Chaplin Mark Wade Sonya Eremenco Alexandra Crane Jussi Repo Adelina Lear	Q2 2021



ANNUAL REPORT

SIG/Committee Name: United Kingdom & Ireland SIG

Date: 11th Feb 2021

Co-Chairs: Anju Keetharuth, Trish Holch and Grace Turner

Board Liaison: Kim Cocks

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

Number of SIG Members:

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. 5th National Patient Reported Outcome Measures (PROMs) Research Conference (Virtual Event). 16th - 17th June 2021 at The University of Sheffield	Work in progress: Abstract submission deadline closed 8 th Feb 2021 64 Abstracts submitted		Tracey Young John Brazier	Jill Carleton, Trish Holch, Grace Turner, Amanda Lane, Phillip Powell, Kathryn McKellar, Alexis Foster, Laura Flight, Lizzie Taylor Buck	June 2021
2. SIG meeting at virtual ISOQOL Conference 2020	Successful meeting- high attendance. Launched survey to capture data on the impact of COVID on PRO research/ clinical practice.		Trish Holch	Holch, Turner and Keetharuth	Complete
3. Survey: Exploring the impact of COVID-19 on patient reported outcomes (PROM/PRO) collection, utilisation and development in clinical practice and research in the UK & Ireland.	Survey launched in November 2020. Continue to disseminate via Teamwork, Twitter and email. Results of the survey will be disseminated at a virtual SIG meeting.		Trish Holch	Holch, Turner and Keetharuth	Spring 2021
4. Training courses and resources relevant to PRO research collated and uploaded to Teamwork.	SIG member Timothy Pickles collated a list of training courses and resources relevant to PRO research. This has been added to Teamwork to share with all SIG members. We will encourage members to add to this list.		Timothy Pickles	Holch and Turner	Complete.