

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 		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

	<ul style="list-style-type: none"> 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 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	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

<p>CPSIG work group: Clinician needs for PROM implementation</p>	<p>(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.</p>				
<p>6. Workshop submitted for ISOQOL 2021: 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 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.</p>		<p>Natasha Roberts</p>	<p>Workshop Organizers: Natasha Roberts, Elizabeth Austin, Liv Marit Valen Schougaard, Bernice Gulek, Angela Wolff</p>	<p>Submitted in Jan. 2021 for ISOQOL 2021</p>
<p>7. Workshop submitted for ISOQOL 2021: Using Patient-reported Outcome Measures for Screening</p> <p>CPSIG work group: PROM as screening tools for health conditions</p>	<p>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.</p> <p>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>Submitted in Jan. 2021 for ISOQOL 2021</p>
<p>8. Paper- PROs and Payers</p> <p>CPSIG work group: PRO performance measures being used in U.S.</p>	<p>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.</p>		<p>Kathryn Flynn, Amiy Cizik, Janel Hanmer</p>	<p>Flynn K, Yucel E, Cuzik A, Gulek-Bakirci, B.</p>	<p>Submission to journal in Feb or March 2021. Amy to present results at CPSIG 2021 meeting.</p>
<p>9. Communication with SIG members and formed 8 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 (#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). • 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: 		<p>Kate Absolom/ Angela Stover/ Liv Schougaard</p>	<p>N/A</p>	<p>Ongoing</p>

	<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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Issues Requiring Board Attention:

1) We would like to inquire about how to partner with ISOQOL for a Delphi panel so that PRO expertise can be highlighted in a grant proposal (Angela leading).