

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

Number of SIG Members: 269

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

Issues Requiring Board Attention:

We would like to engage a patient partner to have a formal role on the SIG and would like to have Board advice and support to enable this in the form of a patient scholarship or remuneration of ISOQOL membership fees.