



## 2022 ANNUAL REPORT

**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 Sadiah 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 development	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