

**SIG/Committee Name: Patient Engagement SIG**
**Date: February 27, 2024**
**Leadership: Sadia Ahmed, Christel McMullan, Leonie Young**
**Board Liaison: Roxanne E. Jensen**

**Mission:** This SIG aims to ensure the patient voice is represented in ISOQOL activities through the advancement of patient engagement in HRQL research. Not only do we discuss ways to incorporate the patient voice in HRQL research, but we also are here to support ISOQOL's current and prospective Patient Research Partners (PRP).

<b>Project/Working Group/ Initiative Title</b>	<b>Actions/Deliverables</b>	<b>Description</b>	<b>Project Chair(s)</b>	<b>Project Members</b>	<b>Date Executed/ Estimated Timeline</b>
1. Patient Engagement in Quality of Life Research: International Perspectives	Formation of a working group with regional SIGs  Workshop at the ISOQOL 2023 meeting  Meetup in 2023	international perspectives of patient engagement in quality-of-life research and clinical practice. Patients as partners in research	PE SIG Co-Chairs (2023 Co-chairs: Sandra, Natasha, Sadia)	Sandra Zelinsky Leonie Young John Librett Natasha Roberts Sadia Ahmed Maria Santana Jessica Gentile Sumedh Bele	October 2023
2. Exploring patient engagement across the International Society for Quality of Life (ISOQOL): A Quality Improvement Project	Distribution of Survey to all SIG Chairs  Reporting back at the ISOQOL 2023 Meeting  Preparation of Report	Surveying SIG chairs to explore their understanding, needs and requirements with patient engagement within their SIGs	Natasha Roberts	Sandra Zelinsky Natasha Roberts Sadia Ahmed Christel McMullan Leonie Young	October 2023  Report: in progress
3. Scoping Review	Scoping Review	To explore patient engagement in Quality of Life Research	Natasha Roberts	Sandra Zelinsky Natasha Roberts Sadia Ahmed Christel McMullan Leonie Young	In Progress
4. Position Statement	Position Statement	Summarizing the work done by the PE SIG, definitions associated with patient	Natasha Roberts	Sandra Zelinsky Natasha Roberts Sadia Ahmed	In Progress

		engagement, and measuring what matters to patients and families		Christel McMullan Leonie Young	
5. Collaborative Partnerships	<p>Manuscript- Patient Adherence to Patient Reported Outcome Reporting in Clinical Practice</p> <p>Manuscript writing working group- Patient Engagement in Pediatric Research</p> <p>Submission for ISOQOL Workshop with Child Health SIG</p>	Partnerships with Child Health SIG	PE SIG Co-Chairs & Child Health SIG Co-Chairs	Sandra Zelinsky Sadia Ahmed Christel McMullan Leonie Young Sumedh Bele Harpreet Chhina John Chaplin Zephania Tyack	In Progress
6. Patient Partner Involvement in Research and in ISOQOL	Patient Partner Meet up – in development for 2024	Meetups for Patient partners and researchers interested in engaging with patient partners	Leonie Young	Sadia Ahmed Leonie Young Christel McMullan	In Progress
7. Advancing the Science of Patient Engagement	Patient Engagement Webinar Series – in development for 2024	Highlighting presentations from PE SIG Members on their PE projects and group discussions	PE SIG Co-Chairs (Sadia, Leonie, Christel)	Sadia Ahmed Leonie Young Christel McMullan  PE SIG members	In Progress

**Concerns/Questions/Comments:**

Development of strategies that support greater inclusion of patient partners/consumer representatives within the ISOQOL community and facilitated attendance at the ISOQOL meetings