

## 2023 ANNUAL REPORT

**SIG/Committee Name: Patient Engagement SIG**

**Date: 17 Mar. 23**

**Co-Chairs: Natasha Roberts, Sandra A. Zelinsky and Sadia Ahmed**

**Board Liaison: Roxanne Jensen**

**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 collaborate with other SIGs to progress this purpose.

Project/Objective	Actions/Deliverables	Methods, Theory or Application Project	Project Chair	Project Members	Timeline
1. Collaborative partnerships and patient led research	Manuscript development and submission to Quality of Life Research about patient adherence to patient reported outcome reporting in clinical practice	Case Study	PE SIG co-chairs	Natasha Roberts Danielle Lavallee Elizabeth Unni Kate Absolom Theresa Coles Jennifer Freel	Submitted awaiting peer review
2. Advancing the science of patient-centred measurement methods	Planned position statement manuscript on patient centred research methods in quality of life research	Theoretical evaluation	PE SIG co-chairs	Sandra Zelinsky Natasha Roberts Sadia Ahmed Danielle Lavallee	In discussion presently, aim for 12 months
3. Supporting patient involvement in the leadership of the PE SIG	Build activities specific to patients for ISOQOL annual meetings  Conduct of ISOQOL meeting and dinner at the 2022 Annual Meeting	Application	Sandra Zelinsky	Danielle Lavallee Natasha Roberts Sadia Ahmed	Ongoing. Maintain active involvement of patient members in the PE SIG
4. Patient leadership in quality of life research	Formation of a working group with regional SIGs focused on international perspectives of patient-led quality of life research and clinical practice	Case Studies	PE-SIG co-chairs	Sandra Zelinsky Jessica Caron Leonie Young John Librett Natasha Roberts Sadia Ahmed Maria Santana Jessica Gentile	Abstract submitted for 2023 Meeting
5. Inclusivity of patient engagement in research and drug development	Formation of a working group in collaboration with the Child SIG to submit a workshop for ISOQOL 2023 focused on child/adolescent engagement in research	Case Studies	John Chaplin	Sandra Zelinsky Natasha Roberts Sadia Ahmed	Abstract submitted for 2023 Meeting
6. Equitable patient engagement in research and drug development	Formation of a working group in collaboration with the TCA SIG to submit a symposium for ISOQOL 2023 focused on promoting equity in patient reported outcome measurement in clinical practice	Case Studies	Elizabeth Austin	Caroline Anfray Benjamin Arnold Emily Parks Anita Bradley-Gilbride Lauren Shapiro, Megan Turner Natasha Roberts	Abstract submitted for 2023 Meeting



## 2023 ANNUAL REPORT

7. Advancing patient engagement across ISOQOL	Development of a survey to SIG chairs to explore their understanding, needs and requirements with patient engagement within their SIGs	Cross sectional survey	PE SIG co-chairs	Sandra Zelinsky Natasha Roberts Sadia Ahmed	Ethical approvals obtained. Distribution and analysis planned completion within 6 months
---	--	------------------------	------------------	---	---

### Issues Requiring Board Attention:

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