



2019 ANNUAL REPORT

SIG/Committee Name: Patient Engagement SIG

Date: February 15, 2019

Co-Chairs: Hilary Wilson and Elizabeth Unni

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: 223

Project/Objective	Actions/Deliverables	Project Chair	Project Members	Timeline
1. Examine and share best practices and industry standards related to engaging with patients in the process of developing and communicating PRO results to patients	<ul style="list-style-type: none"> Working group meetings held monthly Topical review on methods, standards, and best practices for engaging with patients in the development of PRO communication materials Webinar Q4 2019 	Hilary Wilson Frances Yang Allison Martin Nguyen	Emmanuel Aiyenigba, Katy Benjamin, Jennifer Bostock, Eric Chan, Linda Deal, Amanda Drury, Joel Gagnier, Elizabeth Gibbons, Cynthia Grossman, Clayton Hamilton, Asha Hareendran, Trish Hoch, Danielle Lavallee, Marie McCarthy, Eve Namisango, Dorothee Oberdhan, Maria Jose Santana, Mel Tinsley, Elizabeth Unni, Galina Velikova, Carole White, Loretta Williams, Emre Yucel, Vladimir Zah	<ul style="list-style-type: none"> Topical review – completed Q3 2019 (results shared with PE Working Group) Webinar – Q4 2019 Manuscript may be developed in 2020 depending on the outcome
2. Identify the best practices/recommendations for engaging patients in the selection and implementation of PROs in clinical practice; and study how PROs increase the level of engagement patients have in their own care.	<ul style="list-style-type: none"> Working groups held monthly Collaborating with clinical SIG and submitting SIG symposium abstract for 2019 ISOQOL Developing projects for work groups to collaborate and work on 	Elizabeth Unni Anne-Marie Russell	Alexander Joeris, Carole White, Clayton Hamilton, Danielle Lavallee, Danny van Leeuwen, Dorothee Oberdhan, Elizabeth Gibbons, Emre Yucel, Frances Yang, Jennifer Bostock, Joel Gagnier, Loretta Williams, Maria Jose Santana, Marie McCarthy, Mel Tinsley, Patricia Holch, Samantha Noyek, Somali Misra Burgess, Willie Muehlhausen	<ul style="list-style-type: none"> SIG Symposium abstract submitted – Q2 2019 Projects identified – End of Q3 Projects completed – Q3 2020 Manuscripts submitted – Q4 2020