



## 2018 ANNUAL REPORT

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

**Date:** 4 April 2018

**Co-Chairs:** Sam Salek, Kirstie Haywood

**Board Liaison:** Josephine Norquist, MS

**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 all SIGs to achieve these goals

**Number of SIG Members:** 176

**Date of SIG Meeting:** 21<sup>st</sup> October 2017

**Number of attendees at meeting:** approx. 20

| Project/Objective  | Actions/Deliverables   | Project Chair                 | Project Members   | Timeline  |
|--|--|-------------------------------|---|---|
| 1. The projects outlined in the 2016/2017 annual report.                                 | All completed with deliverables including publications.  |                               |   |   |
| 2. Hosted Conference Workshop: Good Practice Guidance for Patient Engagement in Research | <p>A workshop co-hosted by the PE SIG chairs with presentations/ group discussions from ISOQOL members (Lori Frank) and PE Scholars (Jennifer Bostock and Philip Posner), plus invited patient research partners (Jen Horonjeff and Maarten de Wit).</p> <p>The workshop was co-developed in collaboration with Sophie Staniszewska (HTAi), Sally Crowe (PPI expert, UK).</p> <p>Following an ISOQOL press release, co-chair Kirstie Haywood participated in an as-live interview with a local US radio station (Generation Bold), providing the opportunity to promote both the work of ISOQOL and the PE SIG activities.</p> | Kirstie Haywood               | Kirstie Haywood<br>Sam Salek<br>Lori Frank<br>Maarten de Wit<br>Jennifer Bostock<br>Philip Posner<br>Sophie Staniszewska<br>Sally Crowe | <p>Abstract submitted January 2018</p> <p>Delivered October 2017.</p> |
| 3. Patient Scholar Activities  | Continuation of PE Scholar initiative  | Kirstie Haywood and Sam Salek |   | On-going  |
| 4. Developing a network of past PE Scholars  | Continuing discussions with the aim of establishing working group.   | Kirstie Haywood and Sam Salek | TBC   | On-going  |
| 5. Exploring links with international PPI groups and initiatives                         | <p>Developing links with an international network for public involvement and engagement in health and social care research</p> <p><a href="https://mailchi.mp/4c4c38c6f32f/an-international-network-for-public-involvement-and-engagement-in-health-and-social-care-research?e=bbb0a9a001">https://mailchi.mp/4c4c38c6f32f/an-international-network-for-public-involvement-and-engagement-in-health-and-social-care-research?e=bbb0a9a001</a></p>  | Kirstie Haywood               | Kirstie Haywood<br>Sam Salek<br>(Sophie Staniszewska;<br>COMET,<br>COCHRANE, NIHR,<br>INVOLVE, BMJ)                                     | On-going  |