

APPENDIX to OvCAN Priority 3 Guidelines

Potential Roles of Patient Partners on Research Teams

Introduction

Determining the specific role(s) that a patient partner will play on a research team will depend on the people on the team, the project, and a number of other factors. Some potential roles that patient partners may play on research teams are presented below, based on what stage the research is at in terms of a timeline, that is: not yet started, has started, and has finished. These potential roles are not exhaustive, rather are meant to provide a starting point to generate ideas about many potential ways that a patient partner may participate in research projects.

Research teams and patient partners are encouraged to have a discussion about the roles a patient partner may play on the team based on the: research project itself; interests, skills, and experiences of the patient partner; potential time commitment needed from both the research team and the patient partner to make the experience a meaningful one for the entire team; and the life and health circumstances of a patient partner that may affect their ability to contribute. Research teams are encouraged to get to know their patient partner and to have a discussion about the best way(s) to include a patient partner based on what will work for everyone on the team. There will be no one 'right role' for a patient partner on a research team – it will be unique for each project and team.

While potential patient partner roles may be outlined in a grant application or project plan, this may change if the patient partner was not part of the original application or project team, or once the patient partner gets to better know the team. The role(s) of patient partners is(are) likely to evolve over time as they become more comfortable with the team, their skills are more known, etc. The ebb and flow of patient partners' roles is natural.

Potential Roles of a Patient Partner in a Research Project

Before the research begins

- Sharing experiences related to living with, caring for, or knowing someone who lives with a disease or condition. Sharing these perspectives can help researchers understand areas and priorities that are important to patients and caregivers that they may have never considered before for research.
 - Helping shape the actual research question
 - Helping develop the plan for the research [for example, the characteristics of participants, the study protocol, reviewing the informed consent form and other recruitment materials, making suggestions for where and how to recruit potential participants, reviewing the Research Ethics Board submission, etc.]
 - Reviewing documents for the use of lay language
 - Participating in team meetings and sharing perspectives based on experiences of being a patient or a caregiver
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When the research is being done

- Helping recruit study participants (for example, through reviewing the language and information that is provided to potential participants and providing advice on how to approach potential participants about the study)
- Participating in collecting and/or analyzing the data and/or in discussions about the data
- Sharing information about patient experiences that might relate to the data collected and what it shows (e.g. identifying themes from the data, and making sense of those themes and results based on experiences)
- Being a member of the Data Safety and Monitoring Board. This is a group of people that reviews the data collected during the study to look at safety, study conduct, and scientific rigour during the study itself.
- Participating in team meetings and sharing perspectives based on experiences of being a patient
- Participating in preparing and presenting reports/updates on research in lay language

When the research is done

- Participating in team meetings and sharing perspectives based on experiences of being a patient or caregiver
- Reviewing materials that are written/shared about the research, its results, and what these results mean (for example, these might be manuscripts, presentations, or other materials)
- Helping develop summaries of results to provide to the study participants or that are aimed at other patients or the public (for example, it might mean making them easier to understand or providing suggestions about language and how things are written or presented as pictures/graphics, etc.)
- Participating in presentations for scientific or patient/public audiences about how patients were part of the research team (this might be in person or by webinar/videoconference)
- Developing ideas about what organizations and individuals could disseminate the research results as well as about how best to share those results (e.g. by social media, newsletters, webinars, in-person meetings, etc.)
- Remain involved with the team in some way if the research team decides to apply for new funding/develop a new project together to continue the research

References:

1. Patient Centered Outcomes Research Institute. Engagement Rubric for Applicants. 2016. <https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>
2. Chronic Pain Network. Roles for Patient Partners in Your Project. 2017. http://cpn-rdc.ca/docs/default-source/default-document-library/pe-in-projects-tip-sheet.pdf?sfvrsn=975963eb_2
3. Susan G. Komen. Guidelines for Advocate Involvement in Komen Funded Research. https://ww5.komen.org/uploadedFiles/Komen/Content/Get_Involved/Participate/Become_an_Advocate/Guide-Documents-for-Researchers-and-Advocates-0717.pdf