

## Roles for Patient Partners in Your Project

If you've never worked with patient partners or caregivers in your research before (or even if you have!), the CPN Patient Engagement Committee and Network patient partners have some ideas for you to consider. Below you will find the definition of Patient Engagement and some thoughts about the way you might work with us so that we may bring our lived experience to your research project as collaborators or partners.

We see Patient Engagement is an active collaboration with patient partners. Patient Oriented Research (POR) focuses on many areas, with researchers and patients working together on tasks such as priority setting, co-design of research, conducting research and knowledge translation.

We feel it is important for patient engagement in the Network to be an active collaboration with patient partners in the research process from the onset of a project. Patients act, not merely as research participants, but as co-researchers who can assist you and your team in:

- Co-designing, reviewing and commenting on informed consent forms or case report forms
- Co-building, reviewing and commenting on research protocols to identify potential hurdles or enablers for research participants
- Co-developing questionnaires or interview guides for participants in the research project
- Providing insights about living with chronic pain that may validate or change the direction of the research or concepts you wish to explore (for example, exploring outcomes that are important to patients)
- Participating in regular research team meetings to provide feedback or insight on the project
- Reviewing and participating in discussions about the analysis and findings of the project
- Providing patient perspective feedback and insight in to tools and resources that you are developing/wish to develop
- Talking to your trainees about the importance of being able to communicate their research to people from all backgrounds
- Assisting with knowledge translation planning and with sharing your research results to key audiences such as patients

Meaningful engagement can take many different forms but usually requires the involvement of multiple strategies and more than one patient partner. The CPN and SPOR Support Units have resources to support you in planning for, and implementing, patient engagement in your work. Please reach out for support!