

Tips for Research Conversations with Patient Partners

January 25, 2019

Introduction and Purpose

These tips have been put together to help guide researchers' and/or trainees' preparation for research conversations with CPN patient partners. Rather than call these 'presentations' we are calling these 'conversations,' emphasizing that we anticipate the format to follow a dialogue/discussion approach instead of a lecture-style presentation.

The goals of these conversations include: providing researchers the opportunities to share their work and gain insights and feedback from people who have lived experience and providing people with lived experience the opportunities to learn about research in an informal environment and to share insights about their lived expertise with researchers. We're aiming to narrow the communication gaps between researchers and patient partners and to also increase the comfort levels of both with talking to each other about research and incorporating lived experience in to research. Patient partners have contributed to this document so that trainees and researchers can develop talking points that will be meaningful for both themselves and patient partners.

General Conversation Tips

- Remember your audience. Patient partners are often times very knowledgeable about their own experiences with pain. It will be helpful to use lay language, keep the overall approach simple with respect to discussing your research, and be prepared to listen and take questions and comments
- Avoid acronyms as much as you can. If you can't avoid acronyms, think about having a glossary to accompany your conversation (maybe it's a document you can send in advance)
- Avoid specific medical/scientific terms unless these are explained clearly early in the conversation
- Keep things informal. As much as possible, consider this a conversation rather than a presentation. Be prepared for comments, questions, and feedback throughout
- Pause to ask if people have general questions or need additional explanation – inviting people to comment is often more welcoming than simply assuming they will speak up
- Have a few key questions or points where you would specifically like to seek patient partner feedback on your work (e.g., methods design, knowledge translation, overcoming certain challenges, interpretation of results, and how it may lead to improved outcomes...etc.)

Suggested Conversation Template/Approach

Note that most of these conversations will take place virtually rather than in person (for example, on Zoom). While we are aiming to have conversations about pain research, we also know that slides or visuals are helpful for virtual meetings. With that in mind, below is a general approach to an outline that has worked well with previous conversations:

- Title slide
- Introduction to you and your general research interests (e.g. a bit about your education/training, why you are drawn to this research area)
- Goal of the conversation (e.g. to gain patient partner insights and feedback, to learn more about how to incorporate the patient voice and experience in your work, to get advice on how you can share your results more broadly beyond your scientific or medical colleagues, etc.)
- Background to your research topic (e.g. why this is important, how it may impact patient care or health policy, etc.)
- The research question you are setting out to answer and how it may ultimately relate to patients, their care, policy development, etc. (e.g. were patient partners involved in setting, informing or prioritizing the research question?)
- Research methods (e.g. questionnaires, intervention, how many participants, if you worked with patient partners to carry out the research, etc.)
- Research results and discussion (e.g. what did you find? Why is this potentially important? What do patient partners think about this? If you included patient partners in your work, how did that impact your research?)
- Conclusions from your work (e.g. how will you use this to move other research forward? How will you be communicating these results to others? Do patient partners have any questions/comments about this? Are patient partners surprised by any of the results – and if they are, why?)
- Consider having a dedicated slide that discusses how patient partners were involved in the work or could be involved in future work (e.g. maybe patient partners have also generated ideas during the conversation about how they or others could be involved as collaborators).