

Being a Patient Partner

- **Feel empowered:** you possess a unique form of expertise on your health condition and how the health care system is set up to address it. As a user of the health care system, you have seen it in a way that is unique to everyone else who sits within it. You understand what it is like to navigate the health system and can provide important insights on the needs, preferences and values that are important to users of the system.
- **Know the organization:** Become acquainted with the organization you are advising. What is their mandate? Where can they effect change? Who are their partners? Having a sense of what the organization is responsible for can help you become clear on how you can assist them in pushing for improvements in care.
- **What is your role?:** Patient partners are asked to share their ideas through numerous different ways. Ask for clarity before you engage to know how in-depth to participate and how the staff would like to partner with you to move work forward. Are they simply looking for some quick advice, or do they want to partner with you through a project from start to finish. Having a clear idea about this before you start can ensure you are on the same page with the same expectations.
- **Reflect on your experiences:** You have seen a lot of different parts of health care and had many experiences. To inform the work of an organization, you may have to think more broadly than your own individual experiences in the location you received care to consider what the underlying factors may be that contribute to an issue arising. For example, a medication error may be the result of many factors, such as poor discharge planning, lack of communication between health care providers, not including family members in discussions.
- **Be gently fierce:** Don't be shy to let staff know you want to lend your experiences to help make the health care system better for others. Indicate that you are keen to share your lived experience and that you believe this is a form of expertise that can offer value to help make policies, programs, and initiatives well thought out. If you have a question, ask it. If you have an idea, share it. Even if you may make people slightly uncomfortable, with the right tone, you can help push people's thinking to new places and find creative solutions!
- **Ask for support:** Build an ongoing relationship with staff so that if you have any special requests, such as needing to take extra breaks, needing to take phone calls during the meeting, or are not comfortable being put on the spot, please make these known to the Co-chairs so they can accommodate your needs.
- **Be inquisitive:** Ask staff to explain things another way if you aren't quite clear on what is being discussed. If you are not clear on some of the language used, such as acronyms, health care jargon, and overly academic, clinical terminology, do not be shy to ask for clarification. Sometimes this language can be a roadblock for thoughtful discussion.
- **Take care of yourself:** Sharing your own personal experience or hearing about other people's health journeys can be emotionally taxing. Sometimes taking a break for a personal moment is important, as is speaking to others about how you are feeling.