

Stories from the field: Inclusive Care Questions and Answers

Below are responses from our panelists to your questions from the chat.

Question One

How can we create spaces that allow for patients and families to speak up?

Farin Shore, Patient Partner, Médecins du Monde Canada:

Silence helps. Most people don't regularly deal with the heavy burden of protocol and procedure that exist within the health systems. The complexity of these elements of our work can be overwhelming and alienating for those who live simpler lives. Directives given in the interest of completing procedures can come across as dominating or intimidating. When the patient is in our physical space, taking the time to permit them to gather their thoughts, reflect before responding, and respond honestly without being judged allows them room to express themselves. It also allows us the space to use our active listening skills, to validate their concerns, and to encourage their engagement with health professionals.

Ghislaine Rouly, Co-director of the Canada Research Chair in Partnership with Patients and Communities and Patient Partner:

My work is at the clinic or through Zoom. We have the appointment set. I am not working in the street, so the context and situation are different from Farin.

Basically, we rely on trust – the chain of trust, transferred from one to the other. When a patient is referred to me, the trust that the patient has for their health professional is transferred to me almost immediately. This is somewhat worrisome to me since trust should be earned.

I make sure that I am worthy of their trust, and because of that I create a safe environment. If face to face, at the clinic for example, I would sit next to them, not across them behind the desk. I always make clear who I am, tell them again and again that I am not a health professional, I explain about bilateral confidentiality and ask how I can help. The majority need a safe place to be listened to – to be recognized in their entirety, physically and mentally. Giving them time. Time to speak, time to cry, time to keep silence, time to express whatever they need to express. This time is theirs.

It is all about relationship between two human beings. And suddenly the flow of conversation opens like water from a dam. Not being judgmental, accepting and welcoming their most intimate pain with humility and sincerity through validation, offering silence (as Farin noted) and recognition.

Question Two

On the issue of diversity of perspectives, patients from minority communities face a unique challenge of healthcare professionals' knowledge of variations in care and approach to illness, especially in end-of-life care. The speakers' awareness of both humility and variations in knowledge are inspiring but has there been any formal effort to integrate it in professional education of all stakeholders?

Farin Shore, Patient Partner, Médecins du Monde Canada:

As a member of a minority community myself, education has been something out of reach for me. Given this reality, I cannot speak to the standards of education. As an AIDS activist I have participated in many community-based initiatives to raise awareness about HIV and AIDS. I have done this work to educate the public over several decades. If I have learned anything, it is that the individual develops an attitude toward death within cultural frameworks, but not necessarily dictated by cultural standards. The end of life is a very intimate moment that is uniquely experienced by each individual. Much of my own experience indicates that answers to dealing with the end of life depend upon a respect for the grieving process and the sacred nature of the relationship between life and death.

Antoine Boivin, MD PhD, Co-director of the Canada Research Chair in Partnership with Patients and Communities:

There have been several initiatives to integrate patients and community members as educators in professional training. At Université de Montreal, we currently have over 250 patients training over 2,500 health professionals from 14 health disciplines every year about competencies in communication, collaboration and ethics. Other academic institutions in Canada, like University of British Columbia, also integrate patients and community members in medical education. One of the persistent challenges of those initiatives is the engagement of patients and communities who face major barriers to care.