

My Journey – Shelly Kupsch

Becoming a Patient Researcher

Article written by Shelly Kupsch and Patrizia Ranieri, with the Patient and Community Engagement Research (PaCER) program

PaCERs are patient researchers who are creating a new collective research voice led by patients, with patients and for patients. These citizens, who have a variety of health conditions, are trained in qualitative health research. Shelly Kupsch is one of the first patient researchers to be receiving a PaCER professional development certificate through the University of Calgary's Continuing Education.

Patrizia Ranieri, the PaCER Communications Coordinator, had the pleasure of speaking with Shelly about her PaCER experience.



Shelly Kupsch. Photo courtesy of PaCER.

Please share your lived experience and how that brought you to PaCER.

I am a patient. I have survived a pulmonary embolism, a cancer diagnosis, emergency surgery, and if that wasn't enough, I endured a mid-foot amputation. You might say that I have been to "Hell & Back" and you would be right!

As a patient advisor with the Calgary Community Paramedics program, I attended the Alberta Health Services (AHS) Quality Summit in 2015. It was there that I was introduced to the PaCER program. This fueled my passion to learn more about how to bring the patient's voice to the healthcare experience. It took a couple of years, the tenacity of a pit bull and PaCER Director Dr. Nancy Marlett's words to me, "My goodness you are persistent!"

Simply put, it was my determination and a desire to learn more about patient-to-patient research that brought me to PaCER.



What did you learn from your PaCER Internship study?

Our internship study is “Understanding the Experience of Patients and their Companions with Managing a Cardiopulmonary Condition”. Working on this study reinforced that we, as patients, have a collective voice that we can empower to transform healthcare.

There are several key things from the internship that I consider crucial going forward for me as a patient researcher. Foremost is to always be mindful of the fact that the patient is the expert regarding their experience. Also important is to ensure that my peers, in particular the most vulnerable of the population, are protected, supported and respected. And finally, that all patients who participate in research have informed consent. Those who choose to participate need to be confident that the research is ethically responsible and they need to have a clear understanding of what the research entails.

What’s next for you after graduation?

First for me is a very long motorcycle ride, followed by an even longer fly-fishing trip! After that, my priority is to continue to volunteer with the AHS Critical Care Strategic Clinical Network™ and to be involved in other projects.

My goal will be to bring forward the skills I have developed as a PaCER to ensure that the patient voice is always front and center and to remove the power dynamic, whenever possible, while conducting patient-to-patient research.