

How do Alberta's Cancer Patients Rate the Care they Get?

An ongoing province-wide survey aims to find out

During her 43-year career as a registered nurse, Sheila McKay saw the toll cancer took on her patients, both young and old. Then, in 2015, she got a diagnosis of her own.

"After some routine bloodwork, I learned I had non-Hodgkin's lymphoma," the Red Deer native recalls. "I underwent chemotherapy to treat it, and several months later a new - and different - cancer was discovered in my lung which was then removed with surgery."



Sheila McKay

In remission since 2016, McKay is thankful for the expert care she received through multiple courses of treatment. But she wonders if getting more advice about the emotional impact of cancer would have helped her endure it.

"I had fabulous nursing care. When I was going through chemotherapy, I got lots of tips about how to get over nausea, for example. But no one really asked how I was *feeling*. I didn't want to talk to my friends and family about my emotional state; I didn't want to burden them, or scare them. I really needed an experienced professional who could be dispassionate, and support me."

McKay's story is all too familiar to Dr. Linda Watson, Scientific Director of [Applied Research & Patient Experience](#) within [Cancer Research & Analytics](#) (Alberta Health Services).



Dr. Linda Watson

"We discuss all sorts of symptoms with our patients," Watson notes. "But because our primary business is treating cancer, we can treat it and not actually ask patients how anxious they are, or how sad they are. Are they having trouble coping? But if we don't know how they're doing, how will we support them? And there is lots of evidence that if emotional concerns are not managed well, patients don't do as well in treatment."

Wisdom and advice from patients

[Cancer Care Alberta](#) (CCA) is committed to ensuring that patients' perspectives, opinions and needs help drive the care they get. Through a large network of advisors active on committees and in research projects, these patients and family members provide highly valuable feedback on their interaction with clinicians, the support they receive, and more.

Watson's research team helps collect and implement this feedback. Every two years, with the help of [Cancer Surveillance & Reporting](#), they send a survey out to 4,000 Albertans who've been treated for cancer within the last 6 months. Called the Ambulatory Oncology Patient Satisfaction Survey (AOPSS), the anonymous questionnaire captures a broad range of impressions, with questions like 'Were you told of your diagnosis in a sensitive manner?', 'Were you involved in decisions about your care as much as you wanted?' and 'If you had worries or concerns during your treatment, did your care provider discuss them with you?'

"The people filling out the 2021 survey are doing it to benefit future patients," Watson explains. "It's designed to reveal how patients experience their care. The oncologist is the expert in the cancer treatment patients should get, but patients are the expert in how they perceive that care – their own *experience*. In order to shape our programs beyond the drug or other medical interventions, and develop the best cancer care system in Canada, clinical staff need to partner with patients to understand what excellence looks like.

"Our research mission within CCA is to measure the experience of patients through surveys like the AOPSS, identify gaps, help implement new practices, and subsequently measure again to see if there's been an improvement."

Past surveys have helped reduce regional disparities. For example, boosting Registered Dietitian capacity in areas of the province where patients reported they didn't get enough nutritional information during treatment, resulted in better dietary support scores in subsequent surveys.

Improving care for all Albertans

Watson emphasizes that polling patients will continue to drive more holistic cancer care.

"The whole strategy aims to understand what specific patients need, and build capacity to deliver it in the clinic. In past surveys for example, we've also heard that patients especially want more emotional support. CCA is building in ways to offer that in clinic visits, and more recent questionnaire results tell us that we're on the right track."

Sheila McKay applauds the effort to consult patients regularly, to learn what they need to better cope with the distress and uncertainty that often accompany cancer treatment.

"It really is about the patient! And broad data from surveys like the AOPSS confirm what many of us have experienced."

Thanks to the emotional support she did get from a professional counsellor – and expert care at the regional cancer centre – McKay says the future looks bright.

“It’s been almost 6 years since my cancer diagnoses,” she says. “Initially it was really scary, but I’ve reached a point where the prospect of cancer is not awful anymore. My life is normal, and I’m confident that if it comes back I can do something about it.”