

Alberta Doctors' Digest

albertapathients.ca now has more than 11,000 members

Patients should have the most important voice in health care. However, patient voices often seem to be the last considered and hardest to hear when it comes to health care system evaluation and change. Patients are simply not positioned, organized or familiar enough with the numerous intricate processes, players and politics of the system to provide meaningful and timely input into health care decisions.

Patients can drift through the system with little ability to impact their own cases, let alone the broader system. [The tragic death of Greg Price](#) is just one example of how at the behest of the system patients can be.

Physicians have long recognized this imbalance and have strived to put patients first, not only in their places of work each day, but through advocacy and representation of the patient voice through the Alberta Medical Association. We care about this so much we have made Patients First® our registered trademark. And yet, noble as it is, this still puts physicians as the voice of patients, rather than patients themselves.

In 2014, the Alberta Medical Association sought to change that. The goal was to find a way to collect patient voices and effectively make them heard in the halls of health care decision making. To ensure this was more than lip service, the AMA decided to set up a panel where patients were in charge of the agenda.

The result, in 2015, was [albertapathients.ca](#), an online portal for patients to provide input and drive discussion about the health care system. Through patient-driven discussion boards, surveys and awareness of opportunities to impact health care decision making, [albertapathients.ca](#) allows Albertans to not only set and amplify the conversation but to learn more about how the system works. The hope was to create a positive feedback loop, where patients know where they can speak up and be heard, and the health care system knows where it can ask and consult on patient perspectives.



Why Join?

Alberta's doctors, through the Alberta Medical Association, have established [albertapathients.ca](#) - an online forum for Albertans to engage in dialogue about health care in our province. It's your health and your health care system and it needs to work for you and the people you care about. You have a voice and Alberta's doctors want to hear it.

Why join [albertapathients.ca](#)?

And it's working!

Today, albertapatients.ca has more than 11,000 members, making it the largest patient portal of its kind in Canada (and potentially anywhere in the world). The enthusiasm and insight of our members has been instrumental in its growth and the quality of the feedback we have received.

These are just a few examples of the many significant surveys we have conducted:

- [Mental health in Alberta – September 2015](#)
- Wait times – March and April 2016: [Part 1](#); [part 2](#)
- [Patient views on MAiD – June 2016](#)
- [Emergency department experiences and perceptions – November 2016](#)
- [Integrating patient medical records – October 2017](#)
- [Childhood vaccinations – January 2020](#)

Not only has there been value from the surveys and other activities our members regularly complete, but even more important and significant are the ongoing relationships that are developing, both among albertapatients.ca members and with the medical profession through the AMA. Decision-making bodies are increasingly aware of and asking to consult with our patient panel.

Responses to surveys typically have upwards of 3,000 responses, a validity and engagement that far surpasses traditional polling. Survey results have helped inform key decision makers and influenced the direction of changes. Not only that, but health care bodies are increasingly aware of and interested in consulting what Albertans have to say through the portal. As the portal continues to grow, important and significant relationships are developing.

Patients frequently bring their frustrations and challenges within the system to their physicians then are further frustrated to learn how little the physician can do. Now neither need be frustrated or feel at a dead end. If you have a patient who is concerned about health care, has ideas about the system, or is concerned about changes to health care, direct them to albertapatients.ca. We want to hear from more Albertans on more subjects.

As membership grows, so does the validity and impact of the portal. We want a more diverse panel that represents all Albertans and gives patients a proportional voice at the table, so Alberta patients can truly be heard.

11,000 patients is a great number, but it's only the beginning. We look forward to welcoming the next 11,000!