



Alberta Medical Association PatientsFirst.ca Survey Findings

Issue 1: August 2022

Welcome

Thank you for your interest in this first report on data gathered from our website PatientsFirst.ca. Like all surveys, it is a snapshot in time. We will report again in the months ahead as more Albertans participate and the data evolves.

Thank you to everyone who has supported this important work by sharing their health care experience with the AMA.

Executive Summary

On May 16, 2022, the Alberta Medical Association launched a survey on PatientsFirst.ca to learn about the ways in which Albertans are waiting for health care. The goal was to offer Albertans an opportunity to voice their concerns and personal challenges regarding the health care system. We seek to understand how the health care deficit impacts Albertans so that the AMA can advocate for change where it is most needed and work with system partners to build a better health care system.

This report provides a high-level summary of quantitative data collected. It also provides interpretations of research findings from open-ended survey responses. Specifically, this study investigates observations from Alberta residents regarding medical wait times, access to care and personal experiences related to health care in the province.

As of release date for this report, we have collected over 8,000 responses from Albertans. While respondents live in all corners of the province and come from different backgrounds with distinct lived experiences, all participants are experiencing significant health care delays that severely impact their quality of life and well-being.

Themes that emerge from the collected data include *frustration over extended wait times, concerns related to personal and family well-being, health-related anxiety, lack of access to care in rural locales and a decidedly negative view toward the health care system in the province.*

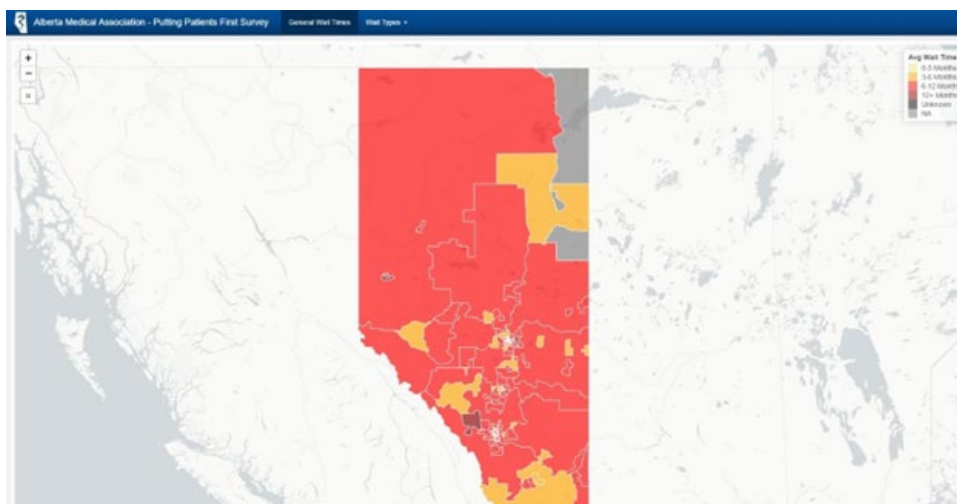
Physicians, government, Alberta Health Services and many other parties have a role in seeking solutions to what patients have described through this survey. We hope that bringing forward the voice of patients in this way will help guide the way forward, together.

By the Numbers

High level provincial statistics appear below. This is a self-selecting sample of people who chose to participate. We do not claim that results are statistically generalizable to the entire population, but they are important to understand since they are drawn from individuals who

came forward because they are waiting for care. Our intent is to compile experiences from a wide variety of Albertans in order to shine light on the challenges we all face. The results are persuasive and will become more so as they evolve with the participation of more Albertans in the months ahead.

For regional insights on patients waiting for care, [maps are available](#). We are displaying results based on the first three characters in an Alberta postal code, e.g., TOE. Some samples are very small, but it is interesting to note the distribution of issues across regions. Use the 'Wait Types' drop-down menu to view the different kinds of wait categories.



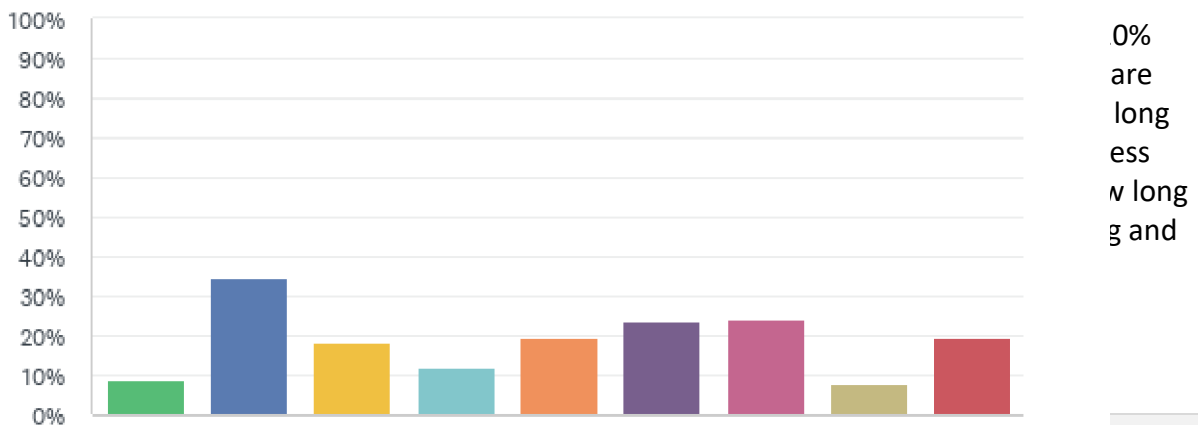
Provincial results

Over 97.2% of respondents indicated some form of deficit in their personal health care. Rural Albertans reported a higher rate of a health care deficit with longer wait times than urban areas for all types of services.

Noteworthy data include an overwhelming 40% who are waiting for a medical procedure or test; over 35% who are waiting for a health appointment; 34% who do not currently have a family doctor; and nearly 30% who are waiting for a referral to see a specialist or other health professional.

What are you waiting for?

Don't have a family doctor	34.5%
Waiting for a surgical procedure	24.2%
Waiting for a specialist appointment	23.9%
Waiting for a referral to see a specialist	19.7%
Waiting for diagnostic testing	18.3%
Waiting for a medical appointment	12.3%
Can't get in to see family doctor	9.2%
Waiting for a referral to see a psychiatrist or mental health professional	8.2%
Waiting for an unspecified type of care not mentioned above	19.6%



Wait Time	Can't get in to see a family doctor	Can't find a family doctor	Does not have a family doctor	Diagnostic testing	Medical appointment	Referral to a specialist	Specialist appointment	Surgical procedure	Referral to a psychiatrist or mental health professional	Other	Waiting for a referral to see a specialist
Over a year				12%			32%		22.1%		18.5%
Between 6-12 months				8.5%			16.7%		15.8%		13.3%
Between 3-6 months				7.6%			9.3%		13.2%		14.7%
Between 0-3 months				6.4%			3.1%		7.8%		7.2%
A few weeks				4.1%			1.3%		2.6%		3.5%
Up to a week				0.9%			0.22%		0%		0.6%
A few days				0.6%			0%		0%		0%
Unknown				52.2%			28.9%		28%		31.2%
Other				7.9%			8.6%		10.4%		11%

Wait Time	Waiting for diagnostic testing	Waiting for a medical appointment	Can't get in to see a family doctor	Waiting for a referral to see a psychiatrist or mental health program
Over a year	17.9%	10.9%	6.4%	22%

Between 6-12 months	9.8%	10.9%	5.3%	12.1%
Between 3-6 months	14.5%	12.6%	7.4%	9.9%
Between 0-3 months	14.7%	16.1%	22.3%	9.9%
A few weeks	11%	12.6%	24.4%	4.3%
Up to a week	1.7%	2.9%	5%	0%
A few days	1.5%	1.7%	2.1%	0%
Unknown	22.3%	22.4%	15.4%	34.7%
Other	6.7%	9.8%	11.7%	7.1%

In Their Own Words

Numbers tell a certain story. Equally powerful are the anecdotes that participants shared. This qualitative data, generated through open-ended survey questions, provided nuanced perspectives.

To analyze the flood of different experiences, we took counts of sentiment and word frequency derived from the full population of survey responses. Additionally, an in-depth thematic analysis was conducted on a random sample of 1,000 open-ended responses to assess the prevalence of high-level themes.

Sentiment Analysis

To assess broad attitudes toward health care and medical experiences across the province, our survey prompted respondents to voluntarily share their health care deficit stories. From the collected data, we performed sentiment analysis of the text-based data¹.

Results of this analysis in figure 1 illustrate the dominant trends. Here we find that negative sentiments outweigh positive sentiments, and language related to feelings such as “fear,” “sadness,” and “anticipation” are the most frequently used terms. In comparison, positive language related to “trust” and “joy” is used less frequently.

Figure 1. Health Care Deficit Story – Sentiment Analysis

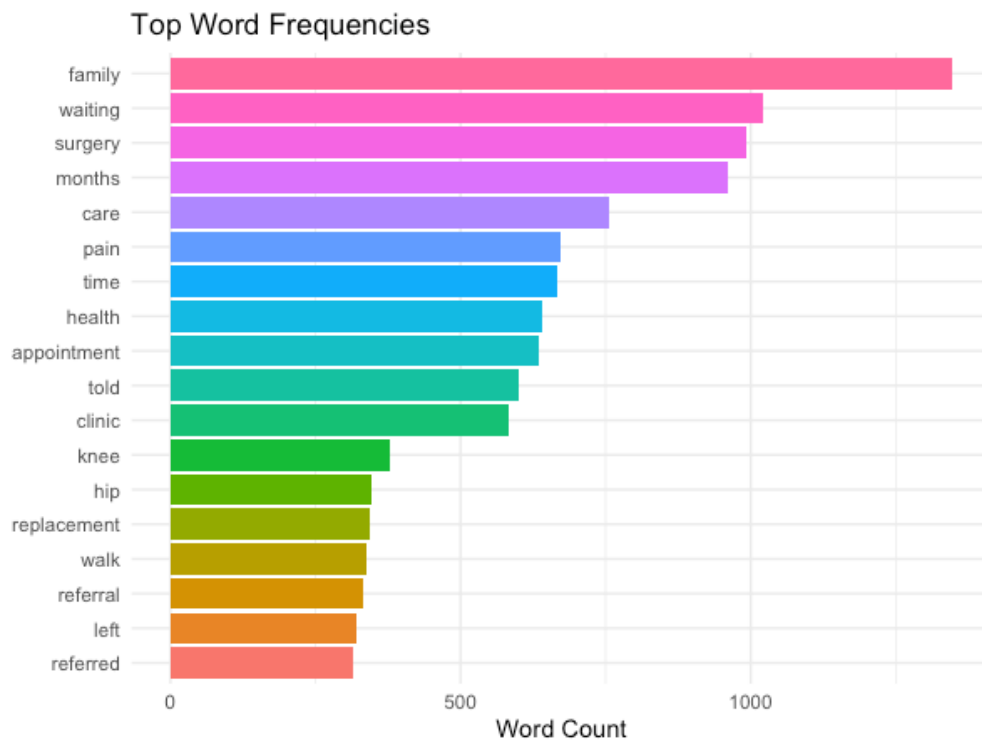


¹ This analysis was conducted using R open-source statistical software with National Research Council (NRC) Word-Emotion association sentiment dictionaries. Words were aggregated and compared based on underlying associated feelings.

Frequency Counts

Frequency counts of words contained within the open-ended response were used to rank certain concepts within overarching themes. For example, in figure 2, the word 'family' stands out as the most-used word in the body of responses, followed by concepts related to acute medical care. Prominent words and concepts reflect a keen focus of responses on the issues associated with waiting for a family physician, concerns about family members' access to care, and anxiety over receiving treatment for specific ailments (specialist care). Combined with the sentiment scoring metrics above, these frequency counts indicate the key overarching trends in the qualitative data.

Figure 2. Top Word Frequencies



In-Depth Themes and Insights

Open-ended responses from the PatientsFirst.ca survey provide insights into the experiences of Albertans related to existing health care deficits. When prompted to share unique experiences with Alberta's health care system, over 50% of respondents shared their personal health care deficit stories. Below, we explore in more detail some of the frequent themes.

Frustration over extended wait times

All respondents indicate frustration and discouragement regarding extended wait times to access doctors, health care treatment, tests and surgery. Many reveal existing chronic and acute illnesses and conditions that have been left untreated for extended periods, leading to severe discomfort, pain and suffering. *“I’m waiting and waiting and getting sicker and sicker”* and *“Wait times mean there is constant pain”* are quotes from respondents that effectively describe how many feel about the consequences of lacking access to care.

Untreated health concerns that respondents repeatedly mention include, notably, hip replacements, knee surgeries and other mobility issues, for example: *“There’s been delay after delay for knee surgery, my mobility is getting worse, and I soon may need a walker”*; *“I live in constant pain waiting for hip replacement”*; *“It should not take 6-8 weeks to get an ultrasound... I experienced a great deal of pain and discomfort due to the long wait.”*

Of the 34% of all respondents who do not have a family doctor, many express the frustration they feel: *“I’m frustrated, depressed, beat down and so much more”*; *“My husband and I both are seniors, and we do not have access to a family doctor and have not had one in about ten years.”*

Respondents also indicate uncertainty and a lack of clarity about how long they will have to wait to find a doctor, access treatment, tests or surgeries. Some have said they simply do not know what the wait time will be.

Concerns related to personal and family well being

Many respondents express concern related to personal and family well-being. Some express worry about their elderly parents not having access to the health care they need to get by: *“My mom is in pain and shouldn’t have to wait so long for surgery. It’s so sad.”*

Many parents are worried about their children and about access to mental health services and programs for their children, for example: *“I waited over a year for a psychiatry referral to treat depression caused by my daughter’s illnesses”*; *“My daughter waits six months between psych appointments even though her meds aren’t stable, and her depression is disabling...there is no access to pain clinics or specialists”*; *“It is so disheartening for us and my son as we don’t know how to help him not get further behind in school and be able to stay with his peers.”*

Health-related anxiety

Respondents indicate feelings of anxiety around not having access to care for themselves and their families. One respondent described the impact of not having access to care as: *“agonizing, and the stress has certainly had a huge impact on MY health as a parent.”*

Several respondents indicate fear and anxiety around the retirement of their family doctors and their inability to find a new one. *“My family GP, who my family and I have had since 1992, retired in 2020. I cannot find a family doctor who will see me.”*

Some also noted the long distance needed to travel to access care and the challenge this presents for those who are vulnerable and elderly.

Lost confidence in the medical system

The [PatientsFirst.ca](#) survey reveals that Albertans have lost their confidence in the health care system. For many this includes the ability of doctors to get them the care they need or that they have previously received. Some comments point to lack of resources combined with higher volumes of patients and pervasive burnout, all of which are gripping health professionals across the country. Many patients express feeling like a number, not a person.

As one respondent noted succinctly: *“It’s a waiting game for so many tests, limited to what your doctor has time to talk to you about in an appointment, long waits in the ER, short staffing in hospitals and unvalued employees, high burn out of staff.”*

Many seniors express distress regarding their challenges in accessing the essential care they rely on to do everyday tasks, for example: *“I am 71 years old. My days are spent struggling to do the basics”; “In this day and age, a senior should not have to wait an extended period of time to get a few minutes with a doctor to get a prescription renewed.”*

A decidedly negative view toward health care in the province.

The [PatientsFirst.ca](#) survey suggests there are severe challenges facing Albertans regarding health care accessibility and delivery. A vast majority of respondents express a negative view toward health care in Alberta, calling it *“terrible,” “mismanaged,” “a complete failure,” “shattered,”* and *“broken long before COVID.”* Most indicate that health care in Alberta is not accessible and that they aren’t getting the tests, treatment or health services they need to reduce or relieve pain, get better and have a good quality of life.

Text Word Cloud

