POLICY BRIEF:
Governments in the Dark on Patient Suffering

Colin Craig | April 2023

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Executive Summary

Patients often suffer while waiting long periods for surgery and other services in Canada's government-run health care system.

For instance, taking painkillers over long periods of time can lead to addiction problems and health complications, such as liver damage. Mental health problems, including depression and suicidal thoughts, are other consequences that patients have reported. In many cases, patients lose income as they wait for surgery and are unable to go to work or operate their businesses. These types of problems can even lead to family breakdowns due to strained relationships as treatable illnesses are turned into chronic illnesses purely due to long waiting periods.

Of course some patients pay an even greater price due to long waiting lists – death. Media have highlighted several such stories and data suggests it's happening more than we know.

The aforementioned consequences are serious and governments should of course seek to avoid suffering like this altogether. SecondStreet.org wanted to examine government analysis into patients suffering on long waiting lists. How often do these problems occur? What is being done to mitigate these situations?

SecondStreet.org filed freedom of information requests with provincial health departments across the country. The time period for the requests covered June 1, 2020 to August 1, 2022.

Highlights from our research include:

- No province in Canada had any documentation related to analyzing patient suffering due to long waiting periods. This does not appear to be something governments review.

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One option to help governments learn more about patient suffering would be to ask patients about any side effects they experienced, or are experiencing, while waiting for treatment. Existing patient surveys could be amended to ask about this problem. Data from this research could potentially help policymakers as they work to reduce wait times and mitigate patient suffering. For example, it might be the case that long wait times for knee surgeries often lead to patients requiring surgery on their second knee due to putting increased pressure on it. Thus, making it a priority to expedite knee surgeries might not only reduce patient suffering, but also save the health care system money by preventing second surgeries.

Copying the European Union's (EU) Cross Border Directive is a second option that could help patients. In short, instead of suffering for long periods of time, patients could be reimbursed for their health care expenses outside the province when the state can't provide care in a timely manner. For example, instead of struggling with chronic pain for, say, a year, a patient could pay for surgery immediately in another province or country. Like the EU, the government's reimbursement could cover up to the same amount the government would have spent to provide the care locally.

A third policy option discussed in this report would be to keep the public health care system, but allow private clinics to provide the same services on a fee for service basis or through private insurance. This would not only provide patients with more choices and ease suffering, it would also take pressure off of the public system.

Background

In 2009, Janet Walker, an adjunct professor at the University of British Columbia, released unique research into patient suffering while on long waiting lists in Canada. In her own words, "[I] documented the experiences, opinions and advice of Canadians who endured long waits for medically necessary care."

After interviewing 50 patients and concluding her research, Walker noted the following in Canadian Nurse magazine[1]:

> *"Participants also reported that they could not live normal lives. Much had to be put on hold. An electrician couldn't carry his tools. A bed and breakfast owner could not get up the stairs to clean guest rooms. A wilderness officer could no longer manage outdoor terrain. Parents couldn't play with their children…"*
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> *"When the diagnosis was life threatening, anxiety increased. One man, who had been diagnosed with borderline aggressive prostate cancer, was told that consults and treatment were still several weeks away: "They said that the wait time was 'acceptable.' Well, it wasn't acceptable to me. Those cancer cells were growing inside my body…"*
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> *"Ninety per cent of those who left the wait lines did so because of pain. Many used the phrase, "I couldn't wait." They reported severe and prolonged pain — the kind that had to be managed, often not successfully, with powerful narcotics like morphine. Pain drugs were found to be crude medicines, and no one liked taking them. Relief was variable, and many participants said that the drugs changed who they were. Several people stopped taking any pain medications, in spite of pain levels of 8 or 9 out of 10. The kind of pain reported arose from treatable conditions. That is, once the condition is treated, pain is no longer present…"*
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> *"Pain took away the appetite for life and ruined relationships. The link between pain and despair arose frequently in interviews. Several people described how at one point they could no longer continue to endure the pain and had contemplated ending their lives. Some implied intentions of suicide; others talked openly about it."*

Media have reported on numerous stories that highlight the side effects of long waiting periods.

For instance, Nova Scotia cancer patient Robin McGee made headlines during the pandemic as she feared surgical delays could result in vision loss. McGee had a condition known as "nuclear cataracts" and was told by her doctor that if she didn't receive surgery right away, she would go blind within six months. McGee told Chatelaine:

> *"It had to be done before I could start chemotherapy; if not, my eyes wouldn't heal properly. I was desperate, so I posted about it on social media. Through lobbying efforts, I got a letter from the Nova Scotia Health Authority allowing me to go to a private clinic. I was able to get my eyesight corrected a few weeks before starting chemotherapy in May."*[2]

In Saskatchewan, patient Jolene Van Alstine spoke with media in late 2022 about her battle with parathyroid hyperplasia.[3] The condition causes her to suffer from vomiting, nausea, abdominal pain and frequent bone fractures. Long waiting lists in the health care system to see an endocrinologist have left Van Alstine hopeless – she has applied for medical assisted suicide (MAiD).

In British Columbia, patient Walid Waitkus was diagnosed in 2004 with a spinal-curvature condition called kyphosis. According to the CBC, in 2009, when the boy was 13 years old, "his doctor insisted the boy's condition required immediate attention." Despite the urgency with Walid's condition, the system took "27 months before he got a date for surgery". Before that date arrived, Khalfallah's family gave up on the system and sought help at the Shriners' Hospital in Washington.

Walid's mother, Debbie Waitkus, told CBC News, *"We had done so many things to try and expedite him being seen and nothing seemed to make a difference … Everywhere I went I was crying because I thought my son isn't going to survive this and nobody's listening to me."*

By the time Walid received surgery in the United States, the curvature in his back had more than doubled – from 53 to 127 degrees. Care did not come in time for Walid. Today, he is paralyzed from the waist down and has joined a legal challenge against the government's ban on private health care in British Columbia.

During an interview with Walker, she described to SecondStreet.org a troubling situation whereby a patient ended up requiring two knee surgeries instead of one. This was entirely due to the fact that the government forced the patient to wait nearly two years for surgery. During this time, the patient favoured their damaged knee and put additional pressure on their good knee. By the time the date for surgery arrived, the "good knee" wasn't good anymore. It too required surgery.[5]

But it's not just medical side effects that patients experience as they wait long periods for health services. Patients often lose income while languishing on waiting lists. One can easily see how requiring a knee replacement would leave a roofer unable to work. Or perhaps how an accountant might not be able to work if they're fighting depression. According to research by the Fraser Institute, Canadian patients lost $4.1 billion in wages and productivity in 2021 as they waited for health care services.[6] This represented an average of $2,848 per patient.

The most significant consequence from long waiting lists is, of course, death. This is something that SecondStreet.org began investigating in 2019.

To date, SecondStreet.org has released four *Died on a Waiting List* reports. These reports show more than 41,000 patients have died while waiting for various health services since April 1, 2018.[7] The waiting list deaths cover a wide array of health services – heart operations, hip operations, cataract surgery, CT and MRI scans, etc. Patients died after waiting anywhere from less than a month to more than eight years.[8]

The reports are, however, incomplete as many health bodies simply do not track the data – Vancouver Coastal, the Winnipeg Regional Health Authority (with the exception of cardiac data) and most health regions in Quebec to name a few. Indeed, many health bodies have to gather the data for SecondStreet.org, indicating that they're not examining the problem as a routine course of business.

Governments' lack of interest in tracking and reporting on patients dying on waiting lists stands in stark contrast to how governments often require businesses to track minor accidents in the workplace. For example, in 2022, WorkSafe B.C. reported on a situation where an employee fell down some stairs and was "bruised."

In 2022, SecondStreet.org sought to examine government data and analysis on patients suffering on waiting lists more closely by filing freedom of information requests for this material nation-wide.

Methodology

In August 2022, SecondStreet.org filed the following Freedom of Information request with provincial and territorial health departments across Canada:

> *"Please provide any memos, reports or analysis that examine patient suffering on health care waiting lists – patients going blind due to long waits for cardiac surgery, patients developing health problems while prescribed painkillers for long periods of time while they wait for surgery, patients developing depression, etc. The time frame for this request is June 1, 2020 to the present."*

While SecondStreet.org inadvertently included a typo in the freedom of information language (should have referred to "cataract surgery" not "cardiac surgery"), the intent was clear. What analysis did each government body have that examined how long waiting lists for surgeries were impacting patients?

Results

Responses were provided by all ten provincial governments.

No provincial government was able to provide any data or analysis on patient suffering due to long waiting lists in their respective health care systems.

If governments haven't assessed how patients may be suffering due to long wait times, how can they address the problem?

Jurisdiction	Response
BC	No data
AB	No data
SK	No data
MB	No data
ON	No data
QC	No data
NL*	No data
NB	No data
NS	No data
PE	No data

**Eastern Health Region responded for the government*

Second, it is an absolute double standard for any government to require a business to submit a report when an employee is "bruised" at work, yet the government does not track or report on more serious health consequences due to the state's long waiting periods for health services. Remember, governments enforce a monopoly in Canada when it comes to medically necessary procedures. They should be required to apply the same standard to themselves as they do those they govern.

Policy Solutions

Three policy solutions that governments could implement include:

The first option would be for governments to learn more about patient suffering by surveying patients about any side effects they experienced, or are experiencing, while waiting for treatment. Existing patient surveys could be amended to ask about this problem. Alternatively, if no surveys are being conducted, governments could periodically ask patients about this issue from time to time. Data from this research could potentially help policymakers as they work to reduce wait times and mitigate patient suffering.

For example, it might be the case that long wait times for knee surgeries often lead to patients requiring surgery on their second knee due to putting increased pressure on it. Thus, making it a priority to expedite knee surgeries might not only reduce patient suffering, it could potentially save the health care system money by eliminating the need for second surgeries.

Alternatively, governments might find that mental health issues arise more frequently for a particular procedure. This could allow health bodies to ensure patients are aware of mental health supports.

A second policy option for governments to consider would be to copy the European Union's "Cross Border Directive" policy. This policy could immediately help patients receive the care they need while reducing wait times.

In short, the Cross Border Directive allows a patient in one EU country to travel to another EU country for surgery, pay for it and then be reimbursed by their home country.[9] Reimbursements cover up to the amount the home country would have spent to provide the procedure locally.

If provincial governments implemented this policy, patients would have immediate remedy without worrying that they would be entirely out of pocket. This would be particularly beneficial for many low- and middle-income patients as they often lack the financial means to pay for surgery outside of their province.

It's important to note that in some cases, this option might even save the government money.

For instance, Manitoba patient Max Johnson told the CBC in 2021 that his successful knee surgery in Lithuania cost him $14,431 – far less than the $21,439 it would have cost the provincial government to provide the surgery in Manitoba. Johnson chose to travel abroad for health care as wait times for knee surgery in Manitoba were as long as two years.

A third option would be for governments to remove all barriers that currently prevent private and not-for-profit clinics from providing the same services as the public system. This would not only help increase the supply of health services in Canada, but more private clinics would also help take pressure off the public system as some patients choose to pay out-of-pocket rather than wait for the public system. This approach is standard in universal health systems that outperform Canada, such as Sweden, Australia, New Zealand and Norway to name a few.

Opponents often claim that more private providers would poach hospital staff from the public system. However, in the short term, this concern could be addressed by limiting the amount of time public sector staff work at private clinics. This is something that other nations, such as the United Kingdom, currently do.

Over the long-term, governments could increase the number of medical staff they train each year – enough to meet the needs of Canadian society. This could be coupled with efforts to reduce barriers for medical professionals from abroad to practice here.

Allowing patients to pay for more health services in Canada – instead of making them travel abroad for timely care – could support local jobs and businesses. Both of these groups would pay taxes in Canada – funds that could help fund the nation's universal health care system.

Conclusion

The consequences of long wait times in the health care system can be tragic.

From mental health problems and vision loss to joint deterioration, paralysis and even death, policy makers need to be mindful of the side effects caused by long waiting lists.

Surveying patients on long waiting lists could help policy makers identify areas which are particularly problematic. In some cases, once health bodies assess the side effects patients are experiencing, they might be able to provide additional support to patients.

The second option would be to replicate the European Union's "Cross Border Directive" policy. This option could help reduce wait times immediately. It puts patients in the driver's seat, empowering them to find health care options before their pain gets worse – including care that exists beyond borders of their government's local monopoly.

A third policy option discontinues Canada's monopolistic approach to health care by providing patients a choice when seeking care – use the public health care system or pay for private health care options. This would not only help patients receive relief faster, it would take pressure off the public system as some patients decide to pay out-of-pocket.

About the Author

Colin Craig is President of SecondStreet.org. He has an MBA and a BA (Economics) from the University of Manitoba and is the author of *The Government Wears Prada*, a book that examines how governments could be more cost-effective. Most recently, Colin authored several chapters for the eBook, *Life After COVID: What's next for Canada?* He has contributed to public policy changes at the federal, provincial and municipal levels in Canada and was awarded the Queen Elizabeth II's Platinum Jubilee medal in 2022 for his public policy work.

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