POLICY BRIEF: Died on a Waiting List

Colin Craig & Harrison Fleming | 2024 Edition





Executive Summary

For six years, SecondStreet.org has gathered government data nation-wide on cases where patients died while waiting for health services in Canada.

This research was inspired by many stories, including Laura Hillier's tragic experience with Ontario's health care system. The 18-year-old patient was fighting cancer and had a bone marrow donor lined up, but the system simply took too long to schedule her surgery. She passed away in 2016 – after her call for help went viral on social media.¹

SecondStreet.org set out to determine how often tragic stories like Laura's occur.

The data SecondStreet.org compiles is collected through filing Freedom of Information (FOI) requests with provincial health care bodies across Canada. It includes both cases where Canadian patients died while waiting for potentially lifesaving treatment (e.g. heart operations, cancer treatment) and surgeries, procedures and diagnostic scans which could help improve a patient's quality of life in their final years (e.g. hip operations, cataract surgeries). While many government health care bodies do not track this information, SecondStreet.org has been able to gather data documenting thousands of cases of patients dying on health care waiting lists since the 2018-19 fiscal year.

This report examines the data SecondStreet.org gathered from provincial governments and their health authorities, between April 1, 2023 and March 31, 2024. Highlights from the research include:

- At least 15,474 patients died in Canada while waiting for surgeries or diagnostic scans. This figure does not include Quebec, Alberta, Newfoundland and Labrador and most of Manitoba. Saskatchewan and Nova Scotia only provided data on patients who died while waiting for surgeries – not diagnostic scans.
- If one extrapolates the data provided across provinces and health regions that did not provide data, an estimated 28,077 patients died last year while waiting for health services from the government.
- While some response data is vague, SecondStreet.org observed cases where patients died after waiting anywhere from less than a week for treatment to more than 14 years.
- New data from Ontario Health suggests 378 patients died while waiting for cardiac surgery or a cardiac procedure.
- Since April 2018, SecondStreet.org has identified a staggering 74,677 cases where Canadians died while waiting for care.



Health spending in Canada remains at historically high levels across the country. In 1993-94, governments spent an average of \$1,688 per person on health care. Thirty years later, in 2023-24, it reached \$5,708 per person. Had spending merely kept pace with inflation it would be \$3,106 per person. Based on these figures, spending has increased at more than double the rate of inflation over the past three decades. The Canadian Institute for Health Information (CIHI) notes that Canada is "among the highest spenders" in the world on health care. It is clear money alone cannot solve this health care crisis.

SecondStreet.org recommends governments consider the following health reform options:

Improve Tracking and Disclosure: Similar to how government health inspectors report publicly if they find a mouldy soup can in a restaurant's fridge, governments should track and disclose serious flaws in hospital operations – particularly when it comes to the number of patients who died while waiting for life-saving treatment and the number of those patients who died after waiting longer than the recommended wait times.

Incentivize Output: Just as Quebec has done, governments should utilize activity-based funding to incentivize output. By paying hospitals based on their output, instead of through annual cheques (block funding), Quebec has increased productivity, while reducing costs for radiation oncology, MRI scans and colonoscopies to name a few.

Allow Choice in Health Care: It is unethical for governments to continue to fail to deliver services to patients in a timely manner while blocking patients from accessing nongovernment health services in their province. Allowing patients to pay for treatment at local private clinics would take pressure off the public system – just as better-performing European systems do. Partner with Non-Government Clinics: Governments should partner with anyone – public, private or non-profit clinics – if those partners can deliver health services safely, in a timely manner and for a competitive price. Canada is seeing more partnerships with non-government providers in recent years, but there is more work to do.

Cross Border Directive: In the European Union (EU), patients have the right to pay for surgeries and diagnostic scans in other EU countries, and then be reimbursed by their own governments. Reimbursements cover up to the same amount their home governments would have spent to provide treatment locally. A similar model could allow Canadian patients to access care more quickly, opening up thousands of health options around the world.

Methodology and Interpreting the Results

In May 2024, SecondStreet.org began filing FOI requests across Canada with over 30 government health care bodies – health departments, health authorities and health regions.

The requests were for cases where patients were removed from surgical and diagnostic waiting lists during the 2023-24 fiscal year as a result of the patient dying. This mirrors the approach SecondStreet.org has taken since launching its annual *"Died on a Waiting List"* research in 2019.

An example of the language used in FOIs related to diagnostic scans is as follows:

"Please provide data on the number of patients that died while on a waiting list for either a diagnostic scan or a consultation with a specialist in fiscal year 2023-24. Please break the data out by procedure and case info – date the patient went on the waiting list, date for the meeting with a specialist or date for diagnostic scan (if scheduled), and date of cancellation. Please also note the government's target time for providing the consultation or scan in question."



As mentioned above, many provinces have provided incomplete data. While this policy brief underscores the crisis in Canada's health care system, only 12 health bodies in seven provinces (representing 62% of the population) provide full or partial data. Alarming as the data is, the real numbers are likely much higher.

For example, when SecondStreet.org began this research in 2019, Alberta Health Services indicated its data was likely incomplete as staff were never trained to track this metric meticulously. Despite providing data for five years in a row, Alberta no longer tracks this data. Meanwhile in Ontario, a former senior health official indicated that the data, to his knowledge, was not tracked with purpose. It is SecondStreet.org's understanding that governments happen to track this data by chance through waiting list system software, rather than purposely tracking the problem to identify areas that require improvement.

Further, readers should note this report does not cover situations where a patient did receive surgery but died during the procedure or shortly after due to conditions worsened by a long waiting period.

The data SecondStreet.org obtained from health bodies can generally be classified into two groups:

1. This group includes cases whereby a patient may have died because of a long waiting period for treatment – for example, a patient dies from a heart attack after waiting too long for heart surgery or a diagnostic scan to identify a potentially fatal illness.

Historically, the Nova Scotia Health Authority has provided the most insightful data in the country when it comes to this category. Their response to our query in 2023 noted there were 532 total waiting list deaths in 2022-23, but only 50 were cases where patients were waiting for procedures that could have potentially saved their lives. The Nova Scotia government noted:

Fifty deaths on the waiting list involved procedures where delays in treatment might reasonably be implicated causally. Among these are bowel resections; cancer resections and coronary artery bypass surgery. Among these, 19 patients were waiting beyond the recommended wait times for the procedure in question.²

This analysis is important, as it helps the public, and policymakers, understand how many patients may have died because the government simply took too long to provide treatment. Additional analysis could have examined those 19 cases to determine if any of those patients died for other reasons or if the government bore responsibility.

Ideally, all government health bodies should be able to note definitively how many patients died each year due to long waiting periods. Doing so would allow governments to identify problem areas and to take action to prevent future deaths. Further, it would increase accountability.

Hamilton Health Sciences' response from 2020 provided some additional insight into cases where patients died while waiting for procedures that might have saved their lives.³ The health body noted that in some cases patients might not have been medically ready for treatment, which prolonged their waiting period. In other cases, the patient may have been waiting to receive another procedure first.

2. The second group included in the data involves patients dying while waiting for surgery or diagnostic scans that would appear to be non-life-saving services (e.g., a hip replacement, a cataract operation, an MRI to examine shoulder pain, etc.). Such cases should not be overlooked, however, as long waiting periods may have affected patients' quality of life before their passing. Indeed, people often value their eyesight and mobility as much as life itself.



The story of late British Columbia patient Erma Krahn helps illustrate how lengthy waiting periods can affect a patient's quality of life.⁴ At 75 years of age, Krahn developed knee pain and spent five months waiting to see a specialist. The specialist informed her that she required surgery but that she would have to wait "years" to receive it. Considering she was also battling lung cancer and did not want her quality of life to diminish during the time she had left, Krahn visited a private clinic in B.C. and paid for the surgery (note: B.C. patients were allowed to pay for surgery locally at the time).

While it seems unlikely that a patient would die due to not receiving something like a hip or knee operation in a timely manner, readers might consider that patients often lead inactive lives while waiting for such procedures. Inactivity can lead to other unrelated health problems and contribute to a patient's premature death.

It is also entirely possible that in both cases – that is, patients waiting for potentially life-saving treatment and those waiting for non-life-saving treatment – death occurred for reasons unrelated to the health care system or the patient's medical condition. For example, the system may have been timely about scheduling a procedure or appointment with a specialist, but, during the wait, the patient died in a motor vehicle accident.

All of the ambiguity surrounding waiting list deaths and suffering could of course be cleared up if governments took more care tracking, analyzing and reporting on these problems in the health care system.

One remedy would be for governments to hold themselves to the same standards they expect private businesses to meet.

For instance, the British Columbia government's WorkSafeBC program requires incident reports from employers whenever accidents occur. Even the most minor of incidents is reported publicly. For example, the government's website notes, for instance, that in September 2019, a young worker in the Lower Mainland who was "using stilts while applying drywall mud tripped and fell to the ground." This accident resulted in "bruising."⁵

In Manitoba, the government discloses names of restaurants and businesses that break public health rules. For instance, in 2019, the province noted the Wood Fired Pizza restaurant in Brandon was shut down for "extensively remodel[ing] a food handling establishment without first registering."⁶

Considering these requirements for businesses, one could reasonably expect a provincial government to carefully track and disclose how many patients die each year due to the state taking too long to provide treatment. Not only would this improve accountability in the health care system, but tracking this data would also allow health officials to measure improvements – especially after new policies are implemented.

Research Findings

As previously noted, some health bodies in Canada do not track the reasons for surgical and diagnostic scan cancellations. This list includes most health regions in Quebec and Manitoba, Alberta and Newfoundland and Labrador. In other cases, some health regions only track surgical waiting list deaths.

Furthermore, SecondStreet.org has learned of several cases where a government health body does not learn that a patient has died until administrators call to schedule a surgery or diagnostic appointment. Thus, some waiting list deaths may not have been captured in the 2023-24 data.

With these reasons in mind, the findings in this brief are underreported, and the true numbers may be substantially higher. The following table summarizes the data that health bodies were able to provide to SecondStreet.org:



Table 1

Patient Deaths While Waiting for Surgeries and Diagnostic Scans (2023-24)

Province	Deaths (Surgery)	Deaths (Diagnostic)	Total
BC	988	3,528	4,516
 Interior Health Fraser Health Northern Health Island Health Vancouver CH 	212 230 73 217 256	1,232 1,343 105 360 488	
АВ	-	_	-
ѕк	385	-	385
MB*	31	-	43
Prairie Mountain HealthSouthern Health	31 12		
ON	1,935	7,947	9,882
QC	-	-	-
NB	51	-	51
NS	373	-	373
PE	17	207	224
NL	-	_	-
Total	3,792	11,682	15,474

^{*} Only two of the five health regions provided data

SecondStreet.org reiterates that the quality of data provided by health bodies varies greatly.

Ontario Health, Prince Edward Island and all five health regions in British Columbia were the only jurisdictions to provide data on patients passing away while waiting for both surgeries and diagnostic scans.

Ontario saw a year-over-year decline in both surgical and diagnostic waiting list deaths. In each area, however, there were instances where patients were waiting for long periods of time before they passed away. In one case, a patient required orthopedic surgery in July 2009 and had never received it when they passed away more than 14 years later in May 2023. In another instance, a patient required a CT scan in May 2010. The recommended wait time was 10 days. The patient died 4,917 days later, without ever receiving the scan.

There are hundreds of other instances just in Ontario alone where patients were waiting for more than 18 months for care before passing away untreated or undiagnosed.

Initially, Ontario Health indicated that 115 patients died in 2023-24 while waiting for cardiac surgery. More recent data, however, showed that when cardiac "procedures" are included, the total rises to 378 patient deaths.

Data from British Columbia's five health regions saw a slight increase in surgical waiting list deaths – rising from 935 in 2022-23 to 988 in 2023-24. A more detailed analysis of these deaths is not possible, however, as the health regions lump records by category or simply as "other." For diagnostic scans, a year-over-year comparison is not possible as only three health regions provided data for both years.

While Nova Scotia Health has, in the past, provided the most comprehensive data in the country, this year's response took a significant step backwards. As noted above, the health body would previously disclose not only the number of patient deaths each year waiting for surgery, but also the portion of those patients who were waiting for treatments that could have potentially saved their lives. The province would then break down that smaller figure by noting the number of those patients that died after waiting longer than the maximum recommended wait time.

Nova Scotia Health did not provide such analysis for its 2023-24 data. The province also no longer discloses waiting list death data on a case-by-case basis. Patients are grouped together by the type of surgery they were waiting for, and it is no longer clear how many days past the target each patient waited before dying.



In Manitoba, data on patients dying while waiting for treatment is rare. Only Prairie Mountain Health and Southern Health track the data (but only for surgical cases, not diagnostic cases). In the past, the Winnipeg Regional Health Authority (through Shared Health) has released data on patients dying while waiting for cardiac care. SecondStreet.org is optimistic such data will be released in the near future.

Prince Edward Island saw a slight increase in diagnostic scan waiting list deaths while its surgical waiting list deaths held steady at 17. Saskatchewan and New Brunswick both saw decreases in surgical waiting list deaths (down from 402 and 77 respectively). Neither province provided data on diagnostic scan waiting list deaths.

Overall, government data shows at least 15,474 patients died in 2023-24 while waiting for surgery and diagnostic scans. If one extrapolates that finding across health regions that did not provide data, an estimated 28,077 patients died last year in Canada while waiting for health care services. Since SecondStreet.org began tracking this data in 2019, we have now identified 74,677 cases across Canada where patients have died waiting on waiting lists. In order to evaluate waiting list deaths in Canada over time, the data sources need to be held constant. While not every health region has provided data for both surgical and diagnostic scan waiting list deaths, there are seven bodies over the past five years that have consistently provided data on patients dying while waiting for surgery. These health bodies cover roughly half the nation's population.

Thankfully, these health bodies show a year-over-year decline in the number of patients dying while waiting for surgery. The total is, however, still higher than the previous three years and still paints a troubling picture about the state of health care access in Canada.

Note: Each health body's FOI response can be viewed at <u>www.secondstreet.org</u>.

Table 2

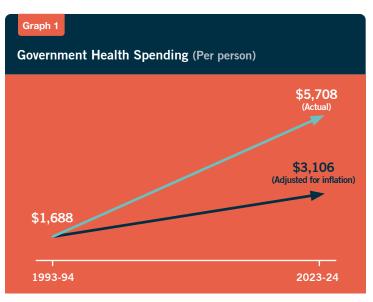
5-Year Surgical Waiting List Deaths (Health Bodies with 5 Years of Data)						
Jurisdiction	2023-24	2022-23	2021-22	2020-21	2019-20	
BC – Interior Health	212	217	224	206	149	
BC – Fraser Health	230	264	327	321	307	
ѕк	385	402	343	278	248	
MB – Prairie Mountain	31	43	48	24	33	
ON	1,935	2,096	1,417	1,096	986	
NS	373	532	352	367	424	
PEI	17	17	27	7	18	
Total	3,183	3,571	2,738	2,299	2,165	



Funding is Not the Problem

At \$231 billion, government spending on health care in Canada reached an all-time high in 2023-24 – a level that is on track to be surpassed by 2024-25 spending levels.⁷

On a per person basis, CIHI data shows that provincial governments spent an average of \$5,708 per person on health care in 2023-24 – up from \$1,688 in 1993-94.⁸ Spending, on a per person basis, has increased at double the rate of inflation over the last 30 years. Had spending increased merely at the rate of inflation, governments would only have spent \$3,106 per person in 2023-24.⁹



Sources: Canadian Institute for Health Information, Bank of Canada.

The CIHI has noted that Canada is "among the highest spenders in the OECD" when it comes to health care.¹⁰ Despite this, it is well-known that our system has fallen behind many other developed nations.

To be sure, some areas of the health system may require more funding to improve services for patients. Overall, however, it is clear that the system doesn't lack money. Health providers need to do a better job with the funds provided.

Policy Options

To address the large number of patients dying on waiting lists in Canada, governments should consider the following five policy options:

1) Better Tracking and Disclosure: Governments could, at the very least, track, analyze and disclose data on waiting list deaths each year. This could remove ambiguity around waiting list deaths while improving accountability. Such analysis could also help policymakers identify problem areas and work to improve shortcomings within the system.

A 2021 poll commissioned by SecondStreet.org found that 79% of Canadians think governments should carefully track and disclose data on how long patients wait for care, how that compares with maximum recommended waiting periods and the eventual patient outcome – including situations whereby patients die while waiting. A 2022 poll commissioned by SecondStreet.org found 66% of Canadians believe governments should have to go further – by not only tracking waiting list deaths, but also holding a press conference each year and announcing the number of patients that died due to long waiting lists.

It would be remarkable if governments disclosed more information on patient suffering and thereby held themselves to the same standard to which they hold private companies.

2) Activity-Based Funding: The Montreal Economic
Institute, Fraser Institute and many others have, for years, recommended reforming the way hospitals are funded in order to incentivize higher output and better results for patients.
"Activity-based funding" is a tool they have recommended as a possible solution.

This model sees hospitals funded based on services provided to patients instead of annual cheques to cover almost everything (global budgets). This means that patients are no longer thought of as people "to have to help" but rather as customers that should be welcomed as they represent additional funding for the hospital.



Thus, this approach incentivizes output as every patient that receives a surgery or other services, results in more funding for the hospital. Not only does activity-based funding incentivize output and customer service, but it also helps hospitals focus on patient care rather than on some of the distractions that hospitals sometimes pursue. For example, the Windsor Regional Hospital has owned and operated two money-losing Tim Hortons franchises for over a decade.¹¹

Under an activity-based funding model, the hospital would have more of an incentive to focus on providing surgery for patients rather than continuing to subsidize double doubles. A 2021 Fraser Institute report notes that "nearly all of the world's developed nations with universal-access health-care systems have moved away over the last three decades from global budgets towards at least partially having money follow patients for hospital care."¹²

Considering Canada would be a late adopter of activity-based funding, one benefit is that our country could learn from mistakes other nations made when they implemented this model decades ago.

3) More Health Care Choices: A third policy option that governments could pursue – and one that would give more Canadians dignity during their final years – would be to increase the choices available to patients. Instead of forcing these patients to decide either to wait for the provincial government to provide a particular health procedure or to leave their province (or country) for care somewhere else, the government could keep the public health care system, but allow non-government clinics in Canada to provide the same procedures.

This approach would be similar to how parents across Canada can choose to put their children in public schools or pay outof-pocket and send their children to private schools. As the number of non-government health care clinics increases in Canada, they would not only increase patient choice but also take pressure off our public health care system. Most importantly, they would provide more patients with an alternative to spending their final days in pain and suffering. They might even allow some patients to avoid dying while waiting for medically necessary care. Countries with higher-performing universal health care systems than Canada allow patients a choice between public and private health care services. This is something the progressive Commonwealth Fund's international health care reports have routinely demonstrated. In fact, the aforementioned November 2022 poll commissioned by SecondStreet.org shows that a majority (62%) of Canadians support allowing such a choice while only 24% oppose it.

4) Copy the EU's Cross Border Directive: According to October 2024 public opinion research procured by SecondStreet.org, 73% of Canadians support copying a European Union (EU) policy called the "cross border directive."¹³ This policy gives EU patients the right to travel to other EU countries for health care, pay for the procedure, and then be reimbursed by their home government. Reimbursements cover up to the same amount their government would have spent to provide the surgery locally.

This policy could immediately help provincial governments in Canada reduce waiting list backlogs in Canada, as some patients would decide to travel outside the province for health care instead of depending on local health care. Not only would this benefit patients who decide to travel for health care, it would also benefit those who remain in Canada. This is due to the fact that patients remaining in Canada for health care would move up a spot on the waiting list each time someone ahead of them chose to travel for health care.

5) Partner With the Private Sector: Governments in Canada and around the world have found that they can often deliver better care for patients by hiring private clinics to provide treatment to patients in the public system. This relationship is similar to how family doctor's offices operate – a patient presents their health care card, receives surgery and the clinic then bills the government once the patient leaves.



Patients do not receive a bill for these services. The Saskatchewan government credits their decision to hire private clinics with helping to reduce wait times and their surgical backlog beginning in 2010. In fact, the government informed SecondStreet.org that hiring private clinics to provide care turned out to be a cost-effective decision: "...assessments showed that the difference between pre procedure costs in public hospitals and private surgical centres are roughly 35 per cent in plastic surgery and general surgery day procedures, and up to 45 per cent in orthopedic day procedures."¹⁴

The Fraser Institute concluded that private clinics hired by the Saskatchewan government only cost 26 per cent less per procedure, but either way it was a positive outcome considering these clinics had to meet the same standards as the public system.¹⁵

Saskatchewan was not the only province to find cost savings through private partnerships. Ontario's auditor noted in 2014: "The Ministry estimated that certain services—such as MRIs, dialysis and colonoscopies—were about 20% to 40% less expensive if delivered in community clinics, including independent health facilities, rather than in hospitals."¹⁶

In Sweden, the government has gone one step further and hired a private company to manage one of their hospitals in Stockholm: Saint Göran Hospital. During a conversation with the hospital's CEO, Gustaf Storm, SecondStreet.org was told that the privately-run hospital provides the same level of care for "30 per cent" less than nearby government-run hospitals.¹⁷

Ultimately, providing the same quality of services for a lower cost allows governments to use the savings to provide even more care to patients.

Conclusion

Each year in Canada, thousands of patients die while waiting for a variety of surgeries and diagnostic scans. In some cases, patients died simply because the government took too long to provide the care they require.

This is unacceptable.

Data shows that Canada is among the highest spenders in the world when it comes to health care. While there are many talented and hardworking staff working in health care, the system itself needs to be more efficient. Health officials need to be held accountable for the suffering endured by patients.

A first step would be for all health regions to not only track the number of patients dying while waiting for health care services each year, but also to examine how many of those patients died specifically because the government took too long to provide treatment. This would remove ambiguity over waiting list deaths and help officials identify problem areas and measure improvements once changes are made.

As this brief identifies, there are several other ways the system could improve to reduce patient suffering: giving patients more choice (both inside and outside of Canada), partnering with the private sector and funding output – not bureaucracies – to name a few. In closing, unless reform measures are implemented, Canadians should expect to see this problem continue for years to come.



About the Authors

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