

POLICY BRIEF: Died on a waiting list

Colin Craig | December 2021 Edition



For many years, media in Canada have brought to light stories of patients who died while waiting for the government to provide surgery and other medical services.

These stories inspired SecondStreet.org to gather government data on this problem to examine how often it occurs. Since 2019, SecondStreet.org has filed freedom of information requests with hospitals, health regions and provincial health bodies across Canada, seeking information on surgeries and procedures that were cancelled due to the patient having already passed away.

Unfortunately, many government bodies do not track the data. Despite this, SecondStreet.org has identified thousands of cases whereby patients died while waiting for health services that could have improved their quality of life in their final years (e.g. hip operations) or, in many cases, potentially even saved it (e.g. heart operations).

Highlights from this report include:

- At least 11,581 patients died while waiting for surgeries, procedures and diagnostic scans in 2020-21. Patients had waited between less than a month to nearly eight years for these services before passing away.
- Data from health bodies that provided surgical waiting list numbers over the past three years shows an 11.7% increase in deaths since 2018/19.
- Since April 2018, SecondStreet.org has now identified a total of 26,875 cases where patients died while waiting for surgery and health procedures from the government.
- Nova Scotia provided the most comprehensive data this year. During the 2020-21 period, 51 patients died while waiting for surgeries that could have potentially saved their lives. “Just over three quarters” of those patients had waited longer than the maximum wait time.



Due to some health bodies providing totals on how many patients died – rather than information on the surgeries and procedures the patients were waiting for – it is not possible to calculate how many of the 11,581 patients who died in 2020-21 were waiting for surgeries which could have potentially saved their lives. Evidence from health bodies that provided complete data suggests that most patients died while waiting for surgeries and procedures that would have improved their quality of life (e.g. hip operations) rather than saved it.

In terms of policy solutions, this policy brief discusses three options.

First, just as governments require businesses to report on workplace injuries and accidents, governments could regularly compile and disclose “waiting list incident reports.” Such reports could include anonymous information on cases where patients die while waiting for surgery, and situations where patients suffer as well (e.g. health complications due to excessive waiting periods, patients developing depression, substance abuse issues, etc.).

Second, governments could maintain our government health care system, but allow private clinics (for profit and non-profit) to provide the same services and charge the public on a fee-for-service basis. This could potentially save lives and provide patients with more choice instead of suffering on waiting lists during their final years. This option would also take pressure off the public system.

Third, governments could increase output in the health care system by implementing what is known as “activity-based funding”. In short, this would see hospitals funded based on services provided, rather than annual budgets. This approach incentivizes hospitals to complete more surgeries as they would receive more funding. Many countries around the world have adopted this model over the past 30 years.

Background

Canada is unique in the world when it comes to access to health care services. Our governments often give patients only two choices:

- Sit on a government waiting list for surgery, a procedure, diagnostic scan, etc.; or
- Leave the country

In many cases, private health care options are outlawed by the state. For instance, in Ontario, citizens cannot pay for something as simple as an MRI scan at a non-government clinic.¹

One key exception to this general rule is in British Columbia, where private clinics provide many diagnostic scans and elective surgical procedures. However, it should be noted that the B.C. government has been fighting in court for several years to prevent those clinics from offering patients a choice outside the public system. (See the *Cambie Surgeries Corporation v. British Columbia* case).

While governments in Canada often appreciate this monopolistic approach to health care when there’s an opportunity to receive credit for the system – holding a press conference to announce construction of a new hospital, hiring nurses, etc. – we see less enthusiasm from officials when it comes to disclosing information on shortfalls in the system.

Far too often, it is only the media or third parties who bring to light stories of tragic outcomes and patient suffering in Canada’s health care system.

Laura Hillier’s tragic case is a good example. The 18-year-old Ontario student was fighting cancer and had a bone marrow donor lined up, but passed away while waiting seven months for a bed and a surgeon to become available.² The government had only rationed enough funds for five transplants per month and Laura was forced to wait. This case became famous not because of proactive government disclosure, but because the young patient’s public cry for help went viral.

Michel Houle’s story in Quebec is also tragic. The 72-year-old patient required cardiac surgery within two to three months. Nine months after he was placed on a waiting list, the government phoned to schedule his surgery, but by then, he had passed away.³

More recently, SecondStreet.org brought to light Judy Anderson’s story. The retired nurse from Port Perry, Ontario has lost two daughters due to excessive waiting periods in the health care system.⁴

Even where governments have disclosed information on adverse patient cases, their reports often lack details. For example, a critical incident report from Manitoba in 2019-20 simply notes that a patient died and that there were “gaps in monitoring of results, communication to care providers, and treatment delays led to a significant decline in a patient’s medical condition.”⁵

What was the procedure that was delayed? How long was the delay? Was it longer than the maximum recommended wait time? Were hospital procedures changed as a result? The reports don't answer these questions, nor do they provide qualitative summaries indicating important information, such as: the number of patients that died while waiting for surgeries that could have saved their lives, or perhaps the number of patients that died while spending their final years in pain.

This lack of transparency stands in stark contrast to what governments require businesses to disclose. For example, the British Columbia government's WorkSafeBC program requires incident reports from employers when accidents occur. Even the most minor of incidents are reported publicly. 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."⁶

With this in mind, it is crucial for media and research-based organizations such as SecondStreet.org to examine the performance of Canada's government-run health care system.

In December 2020, SecondStreet.org released groundbreaking research into the sad reality that many patients in Canada die before receiving the surgery they require. During the 2018-19 fiscal year, government data showed at least 1,480 patients were removed from surgical waiting lists as the patient had passed away.⁷

SecondStreet.org's second *Died on a Waiting List* report was released in June 2021 and built on the first report. The second report identified 2,256 surgical waiting list deaths during 2019-20 and 6,202 deaths while patients waited for diagnostic scans.⁸

The surgeries in question in these two reports ranged from potentially life-saving operations (e.g. heart surgery) to surgeries that could have improved a patient's quality of life during their final years (e.g. hip operations). The data showed patients had waited anywhere from less than a month to more than eight years before passing away.

This policy brief builds upon the first two reports by providing new data for 2020-21.

Methodology and interpreting the results

SecondStreet.org filed multiple Freedom of Information requests with over 30 provincial health departments, health regions and hospitals across Canada.

We asked for data on the number of surgical procedures, diagnostic scans and appointments with specialists that were cancelled during the 2020-21 fiscal year (April 1, 2020 – March 31 2021) as the patient had passed away. SecondStreet.org requested data on a fiscal year basis as it was in keeping with the approach used for our first report.

For example, our request for surgical cancellations included the following language:

Please provide data on the number of patients that died while on a waiting list for a surgical procedure in fiscal year 2020-21. Please break the data out by procedure and case info - date the patient was referred to a specialist, decision date, date for the procedure and date of cancellation. Please also note the government's target time for providing the procedure in question. (Note: many hospitals/health regions were able to identify such cases as they track the reason for cancelled operations)

Readers should exercise caution when sharing content from this report and be mindful of the following:

The data contained in this report is incomplete as it does not cover the entirety of Canada. When SecondStreet.org conducted research for our first *Died on a Waiting List* report, we discovered that many government health bodies were often unable to, or refused to provide the information we requested. For that reason, we primarily directed Freedom of Information requests for this policy brief to health bodies that previously provided data.

Further, some health bodies, such as Alberta Health, informed us that the cause for cancelling a procedure isn't always tracked for all procedures, and may not be recorded by all staff.

For those reasons, readers should note the figures reported in this policy brief are likely underreported. This policy brief also does not cover cases where a patient did receive surgery but died during or shortly thereafter due to conditions worsened by the wait.

Data we obtained on patients' deaths while waiting for surgery, diagnostic scans and appointments with specialists can generally be classified into two groups:

First, cases whereby a patient died because of their long wait 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. This is obviously a very dreadful situation. The Nova Scotia Health Authority noted:

"Fifty-one (13.9%) of all 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, just over three quarters were waiting beyond the recommended wait times for the procedure in question."

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

The second category includes cases whereby patients died while waiting for non-life-saving surgery (e.g. a hip replacement, cataract operation, MRI to examine shoulder pain, etc.) which may have affected their quality of life before passing. Indeed, patients often value eyesight and mobility as much as life itself.

The story of late British Columbia patient Erma Krahn helps illustrate this problem.

The first time Krahn required knee surgery, she was 75 years old and was told it would take a year before she could receive the procedure in the public system. As Krahn was fighting cancer, she didn't want to have limited mobility during her precious remaining years, so she went to a private clinic in Vancouver and paid out-of-pocket for the surgery.⁹

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 quick to schedule a procedure or appointment with a specialist, but, during the wait, the patient was involved in a motor vehicle accident and succumbed to their injuries.

Note: Each health body's response to SecondStreet.org can be viewed on the news release post for this policy brief at www.secondstreet.org.

Research findings

As noted, many health bodies in Canada previously informed SecondStreet.org that they do not track the reasons for surgical cancellations – almost all health regions in Quebec, Newfoundland and Labrador, two major health regions in British Columbia, the Winnipeg Regional Health Authority and several hospitals in Ontario.

Furthermore, we have learned of several anecdotal examples whereby a government health care body does not learn that a patient has died until administrators call to schedule a surgery or appointment. Considering the tremendous backlog in the health care system, it is likely that governments will not learn some patients died until 2021-22 – or whenever they finally call to schedule the medical appointments. For those reasons, the findings in this report are lowballed.

The following table outlines the data SecondStreet.org received from health bodies:

Table 1

Patient deaths while waiting for surgeries, procedures and diagnostic scans

Jurisdiction	Surgeries/ Procedures	Diagnostic Scan	Total
BC – Interior Health	206	668	874
BC – Fraser Health	321	1,098	1,419
AB – Alberta Health Services	64	57	121
SK – Ministry of Health	278	–	278
MB – Prairie Mountain Health	24	–	24
MB – Winnipeg RHA*	5	–	5
ON – Ontario Health	1,096	6,941	8,037
QC – Quebec City (Capital Nationale)	41	347	388
NB – Department of Health	61	–	61
NS – NS Health Authority	367	–	367
PEI – Health PEI	7	–	7
TOTAL	2,470	9,111	11,581

* Only covers cardiac deaths

The quality of data provided by health bodies varies greatly. For example, Nova Scotia continues to be a leader when it comes to tracking data related to patients dying while waiting for surgery. As noted earlier, the Nova Scotia Health Authority was even able to provide information on how many patients died while waiting for surgeries that could have potentially saved their lives:

“Fifty-one (13.9%) of all 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, just over three quarters were waiting beyond the recommended wait times for the procedure in question.”

But while the quality of Nova Scotia’s data was positive overall, many of the stories behind the numbers are likely tragic. As the quote above suggests, it is probable that dozens of patients died in Nova Scotia because the government took too long to provide surgery (while also preventing those patients from accessing the care they required by banning private pay-for-service providers in the province.)

Furthermore, the Nova Scotia data shows 30 patients died after waiting more than two years past the government’s target. In one case, a patient decided in 2012 to proceed with hand surgery, but died nearly eight years later while still waiting for the procedure. In another case, a patient decided to proceed with hip surgery in 2014, but died in 2020 – still waiting.

London Health Sciences Centre provided data showing 16 cases whereby patients died waiting for cardiac care. The health body only had information on the maximum recommended wait time for seven of those cases. Of the seven cases, five of the patients died after waiting longer than the government’s recommended time period.

In Alberta, the government’s data shows one patient decided to proceed with “heart valve surgery” in March 2017, but died in May 2020 – three years later.

B.C.’s Interior Health Authority provided little in the way of data. However, they did note that of the 206 patients who died on their surgical waiting list in 2020-21, approximately 58% were waiting longer than the benchmark time.

On the other end of the spectrum, the Winnipeg Regional Health Authority’s response (provided by Shared Health Manitoba) only included data on cardiac surgical cases. The Queensway Carleton Hospital in Ottawa refused to provide data beyond a simple total number of deaths, arguing that additional details would violate patients’ privacy rights.

Ontario Health, which oversees millions of patients, also provided a single total and refused to provide additional details. Like Queensway Carleton Hospital, they too argued

that providing additional details (eg. information on how long patients waited and the procedures they waited for) could compromise their identities. However, this argument does not stand the test of reason as health bodies which cover far fewer patients were able to provide the information requested.

Not having adequate data on the types of procedures patients were waiting for when they died prevents a comprehensive examination into how long waiting times may have contributed to patients' demise. However, in cases where the data is available, it appears the majority of deaths occurred during waits for procedures that would have merely improved a patient's quality of life (e.g. hip operation).

Readers will note that responses from individual hospitals in Ontario were not included in Table 1. This is because Ontario Health maintains a centralized tracking system and could not confirm whether figures provided by individual Ontario hospitals to SecondStreet.org would also be included within their province-wide figures. To avoid duplication, SecondStreet.org did not include data provided by individual Ontario hospitals in the totals in Table 1. The details provided by individual hospitals are listed in Table 2 for information purposes.

Growth in waiting list deaths

Since SecondStreet.org began investigating waiting list deaths, the scope of this research and number of sources have grown. While SecondStreet.org's first report only examined data pertaining to patients dying while waiting for surgery, the second report included diagnostic scans and limited data on patients dying while waiting for appointments with specialists. The second report also includes information from Ontario Health, the largest source of medical data in Canada.

But if we strictly examine surgical waiting list data from sources which provided information for the past three fiscal years, we see an increase in the number of patients who died while waiting for care. According to data from 2018-19 to 2020-21, 12 of 19 health bodies saw an increase in patients who died while waiting for surgery.

Table 2

Patient deaths while waiting for surgeries, procedures and diagnostic scans

(Ontario Hospitals)

Jurisdiction	Surgeries/ Procedures	Diagnostic Scan	Total
Hospital for Sick Children	8	45	53
Guelph General Hospital	18	25	43
Trillium Health Partners	62	805	867
Queensway Carleton Hospital	3	67	70
Sinai Health	6	2	8
Southlake Regional Health Ctr	31	–	33
Mackenzie Health	19	76	95
Scarborough Health Network	31	76	107
London Health Sciences	41	52	93
Hamilton Health Sciences	48	461	509
The Ottawa Hospital	73	715	788
Thunder Bay Regional HSC	45	29	74
Lakeridge Health (Oshawa)	29	185	214
Markham-Stouffville Hospital	4	3	7
Hôpital Montfort	9	9	18
Halton Health Care	7	93	100
Niagara Health Systems	32	156	188
TOTAL	466	2,799	3,265

Table 3
Surgical waiting list deaths

(2018-19 to 2020-21)

Jurisdiction	2018/ 2019	2019/ 2020	2020/ 2021
BC – Interior Health	175	149	206
BC – Fraser Health	277	307	321
AB – Alberta Health Services	39	45	64
SK – Ministry of Health	242	248	278
MB – Prairie Mountain Health	27	33	24
ON – Hospital for Sick Children	7	10	8
ON – Guelph General Hospital	8	19	18
ON – Trillium Health Partners	33	28	62
ON – Queensway Carleton Hospital	6	5	3
ON – Sinai Health	5	3	6
ON – Southlake Regional Health Centre	60	41	31
ON – Mackenzie Health	12	5	19
ON – Scarborough Health Network	12	21	31
ON – London Health Sciences	9	51	41
ON – Hamilton Health Sciences	78	41	48
ON – The Ottawa Hospital	26	38	73
ON – Thunder Bay Regional HSC	49	27	45
NS – Nova Scotia Health Authority	398	424	367
PE – Health PEI	16	18	7
TOTAL	1,479	1,513	1,652

Overall, the 19 health bodies saw an 11.7% increase in waiting list deaths. COVID-19 has likely exacerbated the problem, but data suggests that waiting list deaths were on the rise prior to the arrival of the pandemic.

Data from Ontario Health shows a 390% increase in patients dying while waiting for CT scans between 2015-16 and 2020-21, and a 370% increase in patients who died while waiting for MRI scans. Surgical deaths increased year-over-year by 11% but are relatively in-line with the previous five years.

A 2019 story from the CBC illustrates why it is important to not only track surgical waiting list deaths, but also deaths while waiting for diagnostic scans. The news outlet reported that wait times for echocardiograms in Manitoba soared to 70 weeks in 2018-19 – up from 21 weeks in 2016-17. It's easy to imagine how a patient could have passed away while waiting for the diagnostic scan, never reaching the stage where the patient met with a specialist to discuss a possible next step: surgery.

Table 4
Waiting list deaths – Ontario Health

(2018-19 to 2020-21)

	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21
Surgeries	940	1,045	1,138	1,039	986	1,096
CT Scan	944	2,838	3,346	3,991	3,924	4,624
MRI Scan	397	1,058	1,171	1,363	1,610	1,867
Total	2,281	4,941	5,655	6,393	6,520	7,587

Policy options

To address the issues discussed in this policy brief, governments could consider the following three policy options:

1) Waiting list incident reports: Governments could do a much better job of tracking and disclosing information on patient suffering in the health care system.

In fact, a recent poll commissioned by SecondStreet.org shows 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.¹¹

Anonymous “waiting list incident reports,” similar to how governments disclose even relatively minor workplace accidents in private businesses, could be an effective accountability measure while helping governments understand the shortcomings of their operations.

Death is of course the ultimate adverse event. Not only do many patients suffer while waiting, but some deteriorate to the point that the surgical outcome is negatively impacted or surgery is no longer possible.

Waiting list incident reports could include information on:

- The procedure a patient required;
- The recommended maximum wait time for that procedure;
- The date the decision was made to proceed with treatment;
- How long a patient waited to meet with a specialist for a consultation;
- How long a patient waited for diagnostic testing during their journey (MRI, CT, PET, etc.);
- How long a patient waited to receive surgery (or when their surgery was scheduled for when they passed away); and

- Consequences from waiting (e.g., death, health complications from relying on painkillers for too long, depression, mobility loss in other limbs, etc.).

One tool that could help with compiling such information would be coroner reports. When patients pass away, coroners could advise as to whether or not a long wait for treatment played a role in the patient’s demise.

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

2) More health care choices: A second policy option that governments could pursue – and one that would give more patients dignity during their final years – would be to increase the choices available to patients. Instead of patients having to decide between waiting for the government to provide a particular health procedure and leaving the country for care somewhere else, the government could allow non-government clinics in Canada to provide the same procedures as the public health care system.

This approach would be similar to how parents across Canada can choose to put their children in public schools or pay out-of-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 health care systems than Canada allow patients a choice between public and private health care services. The aforementioned 2021 poll commissioned by SecondStreet.org shows that a majority (62%) of Canadians “strongly support” or “somewhat support” this option. This finding shows an increase from March 2020 when 51% of Canadians supported the option.¹²

3) Activity-based funding: The Montreal Economic Institute, Fraser Institute and many other health care observers in Canada have, for years, recommended reforming the way hospitals are funded in order to incentivize better results for patients.

“Activity-based funding” is a tool they have recommended as a possible solution.

The model compensates hospitals based on services provided to patients. 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 procedure/surgery, 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 some of the distractions that hospitals sometimes pursue. For example, the Windsor Regional Hospital has operated a money-losing Tim Hortons franchise for over a decade.¹³ 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: “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.”¹⁴

Considering Canada would be a slow 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.

Conclusion

Governments do not like to discuss it – or even to report the details publicly – but Canadian patients continue to suffer on waiting lists each year; thousands even die while waiting for care.

The government data gathered for this policy brief suggests this is a growing problem, as well as one that predates COVID-19. However, the pandemic has likely exacerbated the problem and, without reform, the suffering of patients will be a major problem for years to come. Fortunately, many health reform options are available for policy makers to implement that could immediately improve health outcomes for patients without requiring significant government funding.

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 *Life After COVID: What’s next for Canada?* He has contributed to public policy changes at the federal, provincial and municipal levels in Canada.

Research contributor

Gage Haubrich is a SecondStreet.org research associate. He holds a bachelor’s degree in economics with a minor in political studies from the University of Saskatchewan.

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