POLICY BRIEF:
Died on a Waiting List

Colin Craig | December 2023 Edition

Second Street.org
Real People. Real Stories.

For the past five years, SecondStreet.org has conducted research into the sad reality that many Canadian patients die before receiving the health care they need.

By filing *Freedom of Information* requests with government health care bodies nation-wide, SecondStreet.org has identified thousands of cases of patients dying while waiting for surgery and diagnostic scans. In some cases, patients died while waiting for care that could potentially have saved their lives (e.g. heart operations) while the majority appear to be cases where surgery could have improved the patient's quality of life (e.g. hip surgery).

SecondStreet.org's *Died on a Waiting List* reports were inspired by stories like Laura Hillier's – an 18-year-old Ontario patient who died in 2016 while fighting cancer. Hillier had a bone marrow donor lined up but passed away after waiting seven months for a bed and a surgeon to become available.[1] SecondStreet.org wanted to know – how often do stories like Laura Hillier's occur each year?

This report examines data SecondStreet.org gathered from health bodies across Canada covering the period from April 1, 2022 to March 31, 2023. Highlights from the research include:

- At least 17,032 patients died in Canada while waiting for surgery or a diagnostic scan. This figure does not include most of Quebec, Newfoundland and Labrador, and Manitoba. If we extrapolate from this figure and apply it across health regions that did not provide data, an estimated 31,397 patients died last year.

- Patients died after waiting anywhere from less than a week to nearly 11 years.

- 101 patients died while waiting for heart surgery in Ontario. Of those, 36 died after waiting longer than the maximum recommended wait time. Since 2013, there have been 931 cases where Ontario patients died while waiting for heart surgery (26% waited longer than the recommended time).

- SecondStreet.org has identified 58,652 cases where patients died while waiting for care since April 2018.

- Data from health care bodies that provided figures for each of the past five years shows there has been an increase in annual surgical waiting list deaths of 64%. Over the past year, surgical waiting list deaths are up 30% from those same health bodies.

Readers should note that over the last thirty years, government spending on health care has risen from $1,714 per person in 1992-93 to $5,607 per person in 2022-23.[2] Had spending merely kept pace with inflation it would be $3,127 per person.[3] Thus, spending has increased at nearly double the rate of inflation over the past three decades. Overall, the Canadian Institute for Health Information notes that Canada is "among the highest" spenders on health care among the 38 member countries of the Organization for Economic Co-operation and Development.[4]

More money will not solve Canada's health care crisis. However, health reform could improve results. For instance, the progressive Commonwealth Fund has repeatedly concluded that countries that outperform Canada offer patients a choice between using the public system or private options. Giving Canadians this same choice would take pressure off of the public system.

Second, Canada could follow the example of the European Union (EU) and allow patients to travel to other developed countries, pay for surgery themselves and then be reimbursed by their own government. In the EU, reimbursements cover up to the same cost the patient's home country would have spent to provide surgery locally. Thus, instead of Canadian patients waiting in pain for months or years, and potentially dying, they could receive care within weeks and get their lives back – potentially extending their lives.

Partnering with private health providers also has the potential to reduce wait times, and many provinces have already committed to this on a larger scale. Related to this strategy is the concept of activity-based funding – simply put, funding hospitals based on their output instead of annual block grants each year.

Finally, all health bodies would be wise not only to track data on how many patients die each year while waiting for health services, but also to assess whether or not long waiting periods contributed to their death. This would not only improve accountability in the health care system, but it would also help officials identify problematic areas and measure improvements as new policies are introduced.

Methodology and Interpreting the Results

In April 2023, SecondStreet.org filed multiple Freedom of Information requests with over 33 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, with the death of the patient, cancelled during the 2022-23 fiscal year (April 1, 2022 – March 31 2023). SecondStreet.org requested data on a fiscal year basis, maintaining the approach we used for our first *"Died on a Waiting List"* report.

For example, our request for data on 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 2022-23. 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:

First, the data contained in this report is underreported as it does not cover the entirety of Canada. Many health bodies informed SecondStreet.org in the past that they do not track information on cases where a patient dies while waiting for health services. However, SecondStreet.org was able to obtain at least partial data from 12 health bodies, altogether covering more than 73% of the population's health care.

Further, some health bodies informed SecondStreet.org that the cause for cancelling a procedure isn't always tracked for all procedures and may not be recorded by all staff. Alberta Health Services shared this caution when SecondStreet.org began working on this initiative back in 2019. In Manitoba, Shared Health services has only provided data for cases where patients died while waiting for heart surgery specifically.

This policy brief also 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.

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

The first 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. The Nova Scotia Health Authority provides the most insightful data in the country when it comes to this category. Their most recent response to our query noted there were 532 total waiting list deaths, but only 50 were cases where patients were waiting for procedures which could have potentially saved their lives.[5] 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.*

Despite providing the most insightful data in Canada, Nova Scotia did not clearly indicate how many patient deaths were due to long waiting periods. The government noted some patients may have been "inappropriately" left on the waiting list even though a patient decided not to proceed with surgery.

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 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.[6] 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.

The second type of situation 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 dismissed however, as long waiting periods may have affected patients' quality of life before their passing. Indeed, patients often value 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.[7]

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 should recall that patients often lead inactive lives while waiting for such procedures. Inactivity can contribute 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. 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."[8]

In Manitoba, the government discloses names of restaurants and businesses when they 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."[9]

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 some in British Columbia, Manitoba and Newfoundland and Labrador. In other cases, some health regions only track this occurrence for surgical cancellations.

Furthermore, SecondStreet.org has learned of several cases where a government health care body does not learn that a patient has died until administrators call to schedule a surgery or diagnostic appointment. With the tremendous backlog in the health care system, it is likely that governments will not learn that some patients have died until the 2023-24 fiscal year – or whenever they call to schedule the medical appointments.

For those reasons, our findings 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 (2022-23)

Jurisdiction	Surgery	Diagnostic Scan	Total
BC – Interior Health	217	1,274	1,491
BC – Fraser Health	264	1,253	1,517
BC – Northern Health	42	93	135
BC – Vancouver Coastal Health	222	N/A	222
AB – Alberta Health Services	61	179	240
SK – Ministry of Health	402	N/A	402
MB – Prairie Mountain Health	43	N/A	43
ON – Ontario Health	2,096	9,404	11,500
QC – Quebec City (Capital Nationale)*	4	656	660
NB – NB Health	77	N/A	77
NS – Nova Scotia Health Authority	532	N/A	532
PE – Health PEI	17	196	213
TOTAL	**3,977**	**13,055**	**17,032**

**Incomplete as the health region refused to provide comprehensive data on surgical waiting list deaths like they have done in the past.*

The quality of data provided by health bodies varies greatly.

Nova Scotia Health continues to be a leader when it comes to tracking and releasing data related to patients dying while waiting for surgery. However, the health body did not have data on cases where patients died while waiting for diagnostic scans.

One patient in Nova Scotia had spent 4,009 days (nearly 11 years) waiting for treatment before they passing away in 2022. The patient had been waiting for a septoplasty – a procedure which repositions the septum, helping to improve a patient's breathing and reduce the risk of sinus infections.

In Manitoba, data on patients dying while waiting for treatment is rare, as many health regions do not track cases. Prairie Mountain Health continues to track the data for surgical cases, but 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.

Ontario Health oversaw a significant increase over the past year in both surgical waiting list deaths (from 1,417 cases to 2,096) and diagnostic scan waiting list deaths (7,397 to 9,404). These figures represent increases of 49% and 27% respectively. In Thunder Bay, a patient passed away after waiting nearly four years for "benign prostate surgery" and in Hamilton a patient died after waiting nearly eight years for breast cancer reconstructive surgery.

Health PEI and Interior Health (B.C.) provided totals for various types of procedures but did not supply data for the cases as requested.

Finally, Quebec's Capitale-Nationale Health Region refused to provide complete data like they have in the past. While 569 patients died while waiting for surgery the previous year, this year's incomplete data only shows four cases.

Overall, government data shows 17,032 patients died last year while waiting for surgery and diagnostic scans. If we extrapolate from this figure and apply it across health regions that did not provide data, an estimated 31,397 patients died last year while sitting on health care waiting lists.

Table 2

Ontario Patient Deaths While Waiting for Cardiac Surgery

Fiscal Year	Deaths	Waited Longer Than Max. Recommended Time
2013-14	61	13
2014-15	84	23
2015-16	93	20
2016-17	85	18
2017-18	85	21
2018-19	108	18
2019-20	113	24
2020-21	118	40
2021-22	83	31
2022-23	101	36
TOTAL	**931**	**244 (26%)**

For the first time, SecondStreet.org was able to obtain data on the number of Ontario patients dying while waiting for cardiac surgery. Previously, the health body that collected such data, CorHealth Ontario, was not covered under Freedom of Information legislation and refused to provide the data to SecondStreet.org. The transfer of this entity into Ontario Health in December 2021 has helped with improving disclosure.[10]

As Table 2 shows, nearly 1,000 Ontario patients have died since 2013 while waiting for heart surgery. Approximately one in four of those patients died after waiting longer than the maximum recommended wait time.

Data provided by London Health Sciences Centre shows that of their 23 patients who died while waiting for cardiac surgery, 11 had waited longer than the recommended wait time.

Table 3

Surgical Waiting List Deaths (2018-19 to 2022-23)

Jurisdiction	2022-23	2021-22	2020-21	2019-20	2018-19
BC – Interior Health	217	224	206	149	175
BC – Fraser Health	264	327	321	307	277
AB – Alberta Health Services	61	48	64	45	39
SK – Ministry of Health	402	343	278	248	242
MB – Prairie Mountain Health	43	48	24	33	27
ON – Ontario Health	2,096	1,417	1,096	986	1,039
NS – Nova Scotia Health Authority	532	352	367	424	398
PE – Health PEI	17	27	7	18	16
TOTAL	**3,632**	**2,786**	**2,363**	**2,210**	**2,213**

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 eight bodies over the past five years that have consistently provided data on patients dying while waiting for surgery. These health bodies represent more than half of Canada's population and are listed in Table 3.

During this period, surgical waiting list deaths at these eight health bodies increased by a combined 64%. Looking strictly at the past year reveals a 30% increase in surgical waiting list deaths. While some observers might be quick to conclude that COVID was responsible for the increase, data from Ontario Health tells a different story. The health body's figures show the number of patients dying while waiting for diagnostic scans rose each year between 2015-16 and 2022-23 – from 1,341 deaths to 9,404.[11] Ontario Health also saw an increase in surgical waiting list deaths over the past few years.

To be sure, the pandemic likely contributed to an increase in waiting list deaths. However, it is clear this was a growing problem before COVID emerged.

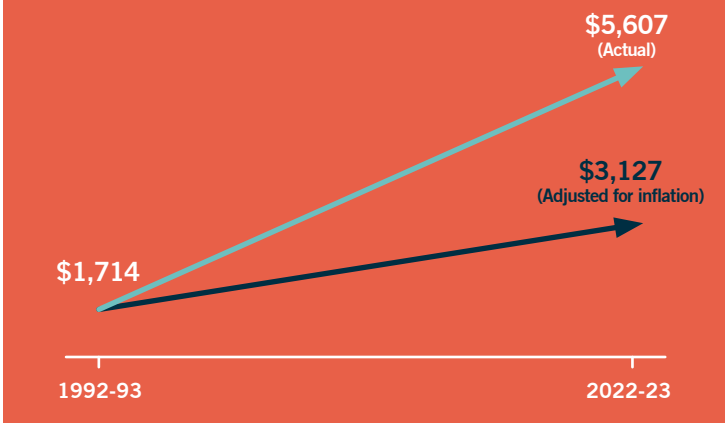
Note: Each health body's Freedom of Information response can be viewed at www.secondstreet.org.

Funding is Not the Problem

While critics of health reform often argue that "cuts" are responsible for Canada's health care crisis, the data suggests otherwise.

Graph 1

Government Health Spending (Per person)



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

As Graph 1 shows, per capita government spending on health care in Canada has increased at nearly double the rate of inflation over the last 30 years.

At the same time, the Canadian Institute for Health Information (CIHI), a government-created body, notes that Canada is "among the highest" in the world when it comes to health care spending.

Canada's health care system is not in crisis due to a lack of resources. The problem is that the funds are not spent cost-effectively within the system.

Policymakers would also be wise to examine the operational structure of the system itself – in particular, prohibitions on patients being allowed to spend their own funds on services outside of the public system.

Policy Options

To address the rising number of patients dying on waiting list deaths in Canada, governments could consider the following four policy options:

1) Better Tracking and Disclosure: Governments could, at the very least, track and disclose data on patients that die each year due to long waiting lists in the health care system. This would remove ambiguity around waiting list deaths while improving accountability. Such analysis could also help policymakers identify problem areas and address problems 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.[12] 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.[13]

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) More Health Care Choices: A second 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 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 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.[14] 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.[15]

3) Copy the EU's Cross Border Directive: According to October 2023 public opinion research procured by SecondStreet.org, 74% of Canadians support copying a European Union (EU) policy called the "cross border directive."[16] 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 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 in the waiting list each time someone ahead of them chose to travel for health care.

Provincial governments would need to determine which health facilities patients would be allowed to travel to for health care and receive reimbursements. A simple solution in the short term would be to approve all health facilities in OECD nations. A more thorough review could determine how to approve quality providers in other countries. (See SecondStreet.org's policy brief on this policy for more information.)

4) Activity-Based Funding: The Montreal Economic Institute, Fraser Institute and many other think tanks which research health care 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. 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 procedure, 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 operated a money-losing Tim Hortons franchise for over a decade. 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."[17]

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.

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 per-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."*[18]

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.[19]

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."*[20]

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.[21]

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 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.

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