

Falling short

**How Canada is failing people with heart failure
— and how we can change that**

2022 Spotlight on Heart Failure

Fighting heart failure on all fronts

Heart failure is a big problem. Each year, more than 100,000 people in Canada are diagnosed with this complex and incurable condition. And the problem is growing.



More than **100,000** Canadians are diagnosed with **heart failure** each year.

Heart failure places a serious strain on people living with the condition and their families and caregivers. As one of the top reasons why people in Canada end up in hospital, it also places considerable burden on the healthcare system, costing billions of dollars annually.

Each year, heart failure kills thousands of people across the country — and in many cases, these deaths are avoidable.

The good news is that lifestyle changes, better medications and devices, and advances in research are helping people with heart failure live longer, healthier lives. But many people in Canada still are not getting the care they need.

It's not easy to navigate Canada's siloed healthcare system, and there are big gaps in heart failure care across the country. For some, those gaps are bigger than for others. And that, in turn, can severely impact quality of life and health outcomes.

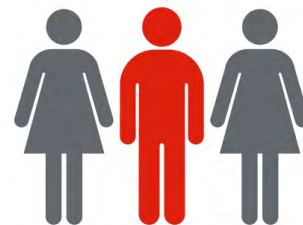
We need to fight heart failure on all fronts: advancing research, preventing the damage that reduces heart function, creating new treatments, and enhancing and improving diagnosis and early access to care and medications. People living with the condition and their caregivers deserve more support and resources to live their longest, healthiest lives.

Heart & Stroke, the Canadian Cardiovascular Society, the Canadian Heart Failure Society, HeartLife Foundation, the Canadian Institutes of Health Research — Institute of Circulatory and Respiratory Health, and the Institute for Clinical Evaluative Sciences are working together on an action plan to tackle heart failure at every level.

This report outlines the plan of action and describes some of the high-impact research funded by Heart & Stroke that is changing the trajectory of heart failure. For hundreds of thousands of people across Canada, we are working together to pave the way to a brighter future.

Heart failure is an epidemic. **It's one of the fastest growing cardiovascular conditions in the world.**

— **Dr. Anique Ducharme, President of the Canadian Heart Failure Society, Professor of Medicine at Université de Montréal and Cardiologist at the Montreal Heart Institute**



1 in 3 Canadians has been **touch**ed by **heart failure.**

Heart failure is a big problem in Canada — and it's growing

Today, 750,000 people across the country live with heart failure. According to a recent Heart & Stroke poll,* heart failure touches one in three Canadians, either because they have it themselves or because it affects a family member or close friend. And the problem is getting worse.



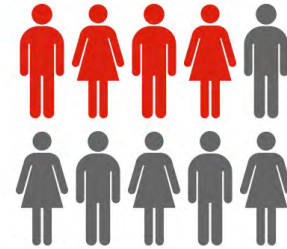
Anything that damages the heart affects how it functions, including heart attacks, high blood pressure, heart defects and other issues. For many people, these conditions will ultimately lead to heart failure. As more people survive heart attacks and as diabetes rates rise, heart failure rates will likewise increase. Yet not enough Canadians know what is coming; according to our poll, one in three Canadians does not know that heart failure is on the rise.

Although there is no cure for heart failure, early diagnosis and the right treatment plan can extend life expectancy and improve quality of life.

Some people with heart failure have severe symptoms, unpredictable downturns and much shorter life expectancy. Others have mild symptoms that can be managed effectively, especially if the problem is diagnosed early. Our poll revealed two in three Canadians do not know there is no cure for heart failure. There may not be a cure today, but we hope to change that.

Because heart failure is more common in the elderly, Canada's aging demographics will also contribute to the growing burden. But this isn't just a disease that strikes old people. Today more and more people in their 50s, 40s and younger are being diagnosed due to better tools for detection as well as an increase in some risk factors.

Meanwhile, because the COVID-19 virus can cause heart damage — even in mild cases — experts expect an extra jump in heart failure prevalence in the coming years. COVID-19 has also disrupted healthcare services. Hundreds of thousands



4 in 10 Canadians
**do not understand
heart failure.**

Understanding heart failure

According to our poll, four in 10 Canadians do not understand heart failure. Heart failure does not mean the heart stops beating.

Heart failure is a chronic condition caused by the heart not functioning as it should, or by a problem with its structure. It can happen if the heart is too weak or too stiff, or both. This can lead to fatigue, swelling in the legs and abdomen and shortness of breath which can be from fluid in the lungs.

of surgeries, diagnostic and therapeutic procedures and specialist consultations across the country were postponed, resulting in people with heart conditions not accessing care and ending up sicker.

The heartbreaking result is more people in Canada developing heart failure.

Complex disease, serious consequences

Tens of thousands of people in Canada are diagnosed with heart failure each year and each year, 6,300 people die from the condition. Although across Canada, people with heart failure are surviving longer, nearly half of people with heart failure will die within five years.

Meanwhile, this condition often goes hand-in-hand with other serious health conditions, including diabetes, hypertension, atrial fibrillation, kidney problems, and chronic obstructive pulmonary disease (COPD). In fact, most people with heart failure have at least one other significant cardiovascular condition and many are managing up to six or seven.

This complicates treatment, driving up death rates even further into the tens of thousands and impacting quality of life.

Inequities in care

Where someone lives, the colour of their skin, their gender and their income can all affect the treatment they receive for heart failure. And that, in turn, severely impacts their quality of life and health outcomes. Smaller communities lack access to specialists. Without a national, universal pharmacare program, many families struggle to afford the cost of medications. Patients whose first language isn't French or English have a hard time accessing information.

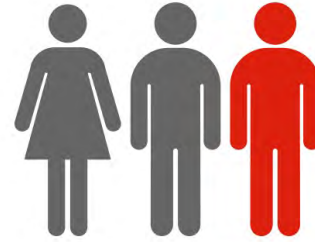
Indigenous communities are burdened with higher rates of cardiovascular disease than non-Indigenous communities, and obstacles in the healthcare system prevent them from having their needs met. Heart failure rates are higher among Indigenous people in Canada compared to the non-Indigenous population, and Indigenous people are more likely to die of heart failure.

As well, heart failure kills 20% more women than men in Canada.

Moving forward

Lifestyle changes, medication and medical devices like pacemakers, artificial heart valves or pumps can help improve heart function, allowing people to live longer, healthier lives.

Today, it's more urgent than ever to address the inequities, fill the gaps and create better outcomes for people with advancing heart failure.



2 in 3 Canadians do not know there is **no cure** for **heart failure**.

Know the symptoms

- increased shortness of breath, especially when lying flat — it's not normal to be short of breath, regardless of age
- unexpected weight gain
- bloating or feeling full all the time
- cough or cold symptoms that last for longer than a week
- tiredness, loss of energy or extreme fatigue
- loss of or change in appetite
- swelling of the ankles, feet, legs, lower back or abdomen
- increased urination at night.

When I see someone who has been in the hospital for a third time and there are new life-saving drugs available, but they cannot afford them, **I feel helpless with the limited options to increase access to these medications.**

— Dr. Sheri Koshman, Clinical Pharmacist, Mazankowski Alberta Heart Institute

The revolving door that costs thousands of lives — and billions of dollars

For many people, impaired heart function resulting from heart failure takes a big toll on their quality of life. Fatigue, shortness of breath and other symptoms can limit physical and social activities. Even popping out to the mailbox can become a breathless chore. People with heart failure are also likely to experience depression and anxiety, while more than 40% have cognitive impairments.

The disease also puts a significant load on the caregivers who help their loved ones manage a slew of appointments, medications, restrictive diets and frequent trips to the emergency department. “It is absolutely a full-time job,” says Heather Lannon, who cared for her husband, Jamie, for nine years after his heart failure diagnosis.

In fact, heart failure is one of the most common reasons why people in Canada end up in hospital. After they’re discharged, one in five will be readmitted within a month. This revolving

door puts significant strain on healthcare systems. In 2019, there were more than 71,000 hospitalizations for heart failure across the country and by 2030, the healthcare costs associated with heart failure in Canada are expected to reach \$2.8 billion per year.



Heart failure will soon cost Canada more than **\$2.8 billion** a year.



Kevin Lobo — Toronto

Kevin Lobo

“I thought I was invincible. Heart failure brought me to my knees.”

Kevin was walking his dog when his foot suddenly swelled up as big as a softball and he started sweating profusely. At the hospital, doctors diagnosed the athletic 38-year-old with heart failure. A life-saving stent and medications put him on the road to recovery. Today, despite a recent setback that required a triple bypass and valve replacement, Kevin remains upbeat and determined to live a full life.

“I still drive. I still go to the gym. I still play golf. I do everything.”



Paul Gee — Regina

Paul Gee

“It scared the heck out of me, and it still does. The mental, emotional part is the most difficult.”

As a fit, active person with no family history of cardiac problems, Paul was shocked when he learned he had heart failure. A cardiac rehabilitation program helps strengthen his heart, and a low sodium, low fluid diet and medications currently keep the condition under control. His latest echocardiogram results were very good. But Paul can't help dwelling on the fact that the average life expectancy of someone with his condition can be significantly shortened.



Heather Lannon
with her late husband Jamie — Toronto

Heather Lannon

“I don't think the medical community really recognizes all of the things we ask caregivers to do and all the roles they take on.”

When Heather's husband Jamie was diagnosed with heart failure at the age of 30, they couldn't get the care he needed in Newfoundland. Instead, they were forced to go to Toronto, 3,000 km away from family and friends, where Heather became his full-time caregiver. A challenge for her as a caregiver that is often not acknowledged was giving up her sense of identity. “I had all these hopes and dreams, and I felt like that was all just taken away from me,” she says.

Experiencing heart failure firsthand as Jamie's caregiver, made Heather realize that she could use the skills learned from her personal experience to help others living with heart failure and their families.

“After Jamie's passing, I returned to school and completed a PhD in social sciences exploring the experiences of those living with heart failure and their caregivers. I now work as a Care and Transitions Facilitator in the Department of Cardiac Surgery at St. Michael's Hospital, where I have the privilege of providing support to many other 'Jamies' on a daily basis.”

How current care falls short

Developing effective solutions starts with understanding the problem. That's why Heart & Stroke surveyed hospitals across the country in 2021 to develop a national Heart Failure Resources and Services Inventory.** We also led a national roundtable in June 2021, organized in collaboration with the country's top cardiac organizations: the Canadian Cardiovascular Society, the Canadian Heart Failure Society, HeartLife Foundation, the Canadian Institutes of Health Research — Institute of Circulatory and Respiratory Health, and the Institute for Clinical Evaluative Sciences. Specialists, care providers, researchers, health system leaders and people living with heart failure shared their insights and identified these five big areas requiring action.

1. Poorly integrated health systems

Improving heart failure care in this country requires action at all levels – national, provincial, regional, local. It is time for all levels of government to step up to improve funding, planning, delivery, support and research to provide better integrated and less siloed care. Health care is funded and organized at the provincial level, and not all regions can move forward at the same pace or with the same priority areas of focus, but some action can be taken in all jurisdictions.

Healthcare systems across the country are not set up in a patient-centred way. **And unfortunately, access to care is not consistent and can vary from province to province and even within provinces.**

— Dr. Sean Virani, Head, Division of Cardiology, Providence Health Care and Medical Director, HeartLife Foundation

2. Lack of evidence-based care

The right care at the right time leads to better outcomes. But in many cases, people living with heart failure aren't getting assessments, treatments and monitoring based on solid evidence and guidelines. This can be especially true in smaller communities and in community-based treatment settings. In part, that's because primary care practitioners are challenged to keep up with a daunting number of guidelines across conditions. They may be less attuned to early symptoms and recognition of heart failure, and less familiar with Canadian Cardiovascular Society guidelines for managing it.

Another reality is that the services and treatments recommended in the guidelines aren't available or affordable in many communities. According to the Heart Failure Resources and Services Inventory, at least 27% of hospitals don't have access to natriuretic peptide testing and at least 13% don't have access to trans thoracic echocardiography (TTE) — two procedures essential for diagnosing heart failure. And 16% of hospitals say they don't follow published heart failure care guidelines.

3. A scarcity of specialized care

Because heart failure is complicated, patients need access to advanced diagnostic testing and imaging. They need specialized medications and treatment. And they need a healthcare team with expertise in a range of fields to address the different pieces of the care puzzle, including mental health, cognition and rehabilitation. Specialized care makes a big difference: patients who are treated at specialized clinics are much less likely to end up back in hospital.

However, Canada has a limited number of advanced heart function clinics and highly trained specialists. The Heart & Stroke Heart Failure Resources and Services Inventory revealed that only 14% of hospitals have an interdisciplinary inpatient heart failure care team, while 28% have a dedicated, interdisciplinary outpatient clinic.

As a result, many people with heart failure cannot access the best available care, and those who do can face long wait times or long distances to travel.

4. Poor coordination of care and transitions from hospital to community

Most people with heart failure will be hospitalized several times over the course of their disease. But when they're discharged, the handoff to community-based healthcare providers often isn't smooth. People with heart failure don't know which specialist is handling their follow-up appointments. Pharmacists don't always know who to call to discuss prescriptions. A lack of integrated electronic health records complicates things further. And although patients are often dealing with other health issues as well, their different specialists work separately. That leads to challenges, frustrations and worse health outcomes.

5. Support and information in short supply

With the right knowledge and self-management skills, people living with heart failure and their caregivers can enjoy better quality of life and better outcomes. However, according to the Heart Failure Resources and Services Inventory, two-thirds of Canadian hospitals lack on-site or community-based support programs for people with heart failure. Outpatient care services and clinics are often overstretched, leaving less time for team members to provide education and skills training. Meanwhile, literacy, language and other social determinants of health create barriers for many people, and it can be difficult to find culturally sensitive, accessible and timely resources. As a result, patients and their families frequently feel overwhelmed and lost in the system, increasing burnout.

Heart failure brings so many mental, emotional and psychological issues, **and I don't think we really do a good job of treating that aspect of it.**

— Heather Lannon, caregiver

Prevention: The best medicine

Our action plan focuses on the best ways to care for people with heart failure. But it's important to note that many cases of heart failure can be prevented by managing existing conditions such as high blood pressure, high cholesterol and diabetes as well as establishing heart-healthy habits like being physically active, eating healthy, being smoke-free and moderating alcohol.

People with heart failure can disappear from my care and only return when there is a big issue. The flow of information (horizontal and vertical) can be a problem. If they are seen at a hospital and we don't get a copy of the report, we need to call medical records.

A report from a specialist's office can take a week or two. All of this delays care.

— Richard San Cartier, Nurse Practitioner, Maamwesying North Shore Community Health Services who works with N'Mninoeyaa Aboriginal Health Access Centre in partnership with 10 First Nations communities.

Virtual services can enhance care

Virtual care can't entirely replace in-person appointments; people with heart failure still need to have face-to-face visits for some assessments. But as the pandemic has proved, a lot can be done remotely — and that can create big benefits.

For someone with heart failure, seeing a health provider in person can feel like a marathon. Shifting some appointments online, where appropriate, can be an effective way to manage heart failure. It can also offer quicker access to care in some cases.

As well, for people in rural, remote and other underserved areas — including Indigenous communities — virtual care can provide access to specialists and ensure people with heart failure get the support they need when they leave hospital. Remote, at-home monitoring equipment can send information such as blood pressure and heart rate directly and securely to the healthcare team. Although they have potential, access to these types of technologies is still

limited to a small number of people with heart failure. And because many individuals and communities currently lack the devices or internet access required to take advantage of these possibilities, it's crucial to ensure equitable access.

The COVID-19 pandemic has accelerated virtual healthcare in Canada. According to the Heart Failure Resources and Services Inventory, most heart failure clinics are seeing more than half of the individuals they follow, virtually. "COVID has created an opportunity for us to transform our thinking and be more innovative about how we can deliver heart failure care," says Dr. Sean Virani.

Heart & Stroke developed a [framework](#) to help healthcare professionals decide when virtual care is the best option. And when virtual appointments are appropriate, our [checklist](#) for patients and [toolkits](#) for healthcare professionals helps make them as effective as possible.

A national action plan for better care

"There has been some progress to improve outcomes and quality of life for people living with heart failure, informed by important research. But much more could — and should — be done, especially as heart failure numbers continue to grow," says Dr. Patrice Lindsay, Director, Health Systems, Heart & Stroke. "That's why Heart & Stroke brought together leading cardiac organizations and others from across the country to drive an action plan, informed by nurses, cardiologists, pharmacists and people living with heart failure and their caregivers."

The action plan emphasizes an integrated approach to heart failure across Canada, to increase equity and ensure people living with heart failure have access to the right care at the right time and are fully supported to optimize their quality of life at every stage of the disease.

We need to work as a team and patients and caregivers are an integral part of the team.

It's the only way we are going to succeed.

— Dr. Anique Ducharme

The Heart Failure Action Plan Advisory Committee established **five key goals** to improve heart failure care in Canada. Below are the goals and what needs to be done to achieve them.

Goal	Pathways to success
<p>Integrated systems of care that leverage collaboration at the national and provincial levels to optimize heart failure funding, planning, care and research</p>	<ul style="list-style-type: none"> • Educate the public across Canada on heart failure signs, symptoms and impact. • Advocate for increased access to heart failure services and for universal pharmacare as well as improvements to the Non-insured health benefits for First Nations and Inuit (NIHB) program. • Build economic models for effective and efficient heart failure care. • Develop comprehensive data monitoring systems that link to electronic medical records and drive quality improvement. • Increase research capacity and collaboration.
<p>Evidence-based care for all people living with heart failure, guided by the latest science and captured in published guidelines and standards of care</p>	<ul style="list-style-type: none"> • Develop and share educational resources for healthcare providers (including primary care) that increase the uptake of evidence-based guidelines as well as cultural competency training. • Create tools to help people with heart failure understand treatment options and make decisions about their care. • Increase access to testing and diagnostic services for rural and remote communities. • Address sex and gender differences in diagnosing and managing heart failure and provide gender-appropriate care. • As per The Truth and Reconciliation Commission Call to Action 19, support establishing measurable goals to identify and close the gaps in health outcomes for people with heart failure between Indigenous and non-Indigenous communities.
<p>Access to specialized care, including advanced diagnostics and treatment to address the different aspects of this complicated condition</p>	<ul style="list-style-type: none"> • Implement coordinated referral mechanisms to increase timely access to specialized assessments and management. • Increase capacity for virtual healthcare services and remote patient monitoring. • Embrace new models of care in smaller communities that leverage non-physician-led clinics.
<p>Coordinated and seamless transition of care between hospitals and community-based healthcare services</p>	<ul style="list-style-type: none"> • Ensure timely and comprehensive communication and information sharing between healthcare providers as people with heart failure transition from hospital and between community-based services. • Align and collaborate with other community services to support the broader needs of people living with heart failure. • Establish “care navigators” in underserved areas to guide people with heart failure through the various aspects of community-based care. • Optimize virtual care and expand use of electronic home monitoring systems. • Ensure patients have rapid access to care when symptoms change suddenly. • Work with Indigenous communities to understand and help build services to meet identified needs including discharge planning from acute and rehabilitation settings to Indigenous home communities.
<p>Support for people living with heart failure and for their families and caregivers</p>	<ul style="list-style-type: none"> • Taking a holistic approach, educate the public and healthcare professionals on the physical, emotional, mental and cognitive impact of heart failure and the needs of people at different stages of the illness and their caregivers. • Provide ongoing education and enhance self-management skills at every healthcare encounter and in community settings. • Advocate for a heart failure patient Bill of Rights. • Make community resources readily available and culturally appropriate and provide forums where people with heart failure and their family members can find peer support and share their experiences.

Research that changes the trajectory of heart failure

Forty years ago, heart failure was a death sentence – there were few treatment options. Since then, we've come a long way. That's especially true in the last 10 years, thanks to the introduction of two new drugs that have transformed treatments. And Canada has been a global leader in implementing new multi-drug protocols that dramatically improve patient outcomes.

Today, Heart & Stroke donors continue to empower researchers across the country who are pioneering new and exciting solutions to protect vulnerable hearts and translating that knowledge into better patient care.

Solution: A pacemaker innovation to prevent heart failure

Today, hundreds of thousands of Canadians rely on pacemakers to keep their hearts pumping properly. But in some of those patients, the different chambers of the heart slowly get out of rhythm, leading to heart failure. To address this issue, McGill's Dr. Jacqueline Joza is advancing new pacemaker technology that connects directly with the heart's electrical system, ensuring the heart keeps beating in a synchronized way. If a problem arises, it can also transmit an alert to the patient's cardiologist. Now, she's conducting a clinical trial with elderly participants to test the technology, paving the way for new standards of care that reduce hospitalizations and enhance quality of life.



One of the things that excites me is to really see patients thrive when we see them in follow-up.

**— Dr. Jacqueline Joza,
Cardiac
Electrophysiologist,
McGill University
Health Network**

Solution: Regenerative medicine that heals heart damage

A heart attack cuts off the blood supply to part of the heart, creating damage that can lead to heart failure. So Toronto researcher Dr. Ren-Ke Li started investigating how to use the body's own bone marrow stem cells to repair the damage. This approach worked beautifully in younger mice, preventing heart failure. But older mice (and older people) don't produce as many stem cells, and their body doesn't respond to them as effectively. Now he's looking at ways to generate healthy stem cells in older individuals. It's an approach that could not only prevent heart failure but also improve brain function and vision and strengthen muscles.



This is a rejuvenation project. It's not only focused on the heart. I believe it will be of benefit in so many other ways.

**— Dr. Ren-Ke Li,
Senior Scientist,
University Health
Network and Professor
of Medicine,
University of Toronto**

Solution: Virtual clinics that enhance access to care

Cardiologist Harriette Van Spall wants to break down the silos in Canada's current healthcare systems, give heart failure patients the multidisciplinary support they need and put them at the centre of care. One way to do that is through virtual heart function clinics that save patients the cost and stress of many in-person visits, make it possible to serve patients who live far away, and also reduce healthcare costs. Dr. Van Spall has been testing the effectiveness of an approach that combines video consultations, home monitoring systems that transmit health data and technology that lets doctors send prescriptions and test requisitions electronically to laboratories and pharmacies.



My research involves coming up with new ways to deliver care that expands access and makes care more convenient and equitable for people living with heart failure.

— Dr. Harriette Van Spall, Cardiologist, McMaster University

Solution: A national heart failure research network

Tackling something as complex as heart failure requires a coordinated effort. That's why Heart & Stroke is collaborating with the Canadian Institutes for Health Research, Mitacs, and the U.S. National Institutes of Health to launch the National Heart Failure Research Network. The \$5 million initiative will support a single, nationally coordinated structure that brings together researchers, patients, caregivers, Indigenous Knowledge Keepers, policymakers, healthcare providers, industry and more. The goal is to better understand the underlying causes and social determinants of heart failure — as well as the most effective ways to care for people living with this disease.



1 in 3 Canadians do not know that **heart failure** is **on the rise** in Canada.

Heart failure in Canada is **growing** due to:



Aging population



Younger people being diagnosed



Heart damage from COVID-19



Putting the focus on function, not failure

With the right management and support, people living with heart failure can continue doing the activities they love. Heart & Stroke is working with HeartLife, the Canadian Women with Medical Heart Issues group and other key partners to support people living with heart failure and their caregivers to live their best life.

Equipping patients and their families with the tools to thrive

People with impaired heart function can enjoy higher quality of life and better outcomes when they have the skills and knowledge to manage their disease effectively. Heart & Stroke's [website](#) provides heart failure resources in multiple languages to help, including *Living with Heart Failure*, an

80-page guide. HeartLife has produced a [patient journey map](#) and a [patient charter of rights](#) to help people with heart failure navigate the healthcare system as well as other [resources](#).

Creating community supports

Dealing with heart failure can feel very isolating, frustrating and all-consuming. That's why support groups can make a world of difference. Heart & Stroke's [Community of Survivors](#) and [Care Supporters' Community](#) are two separate members-only Facebook groups: one for survivors of heart disease or stroke and one for those who provide support or care to them. The groups offer social and emotional support in a safe, inclusive and respectful environment.

Shining a spotlight on heart failure: #HeartFailureWeekCan

A collaboration between Heart & Stroke, Canadian Heart Failure Society, Canadian Cardiovascular Society, HeartLife Foundation, Canadian Association of Cardiovascular Prevention and Rehabilitation, Canadian Council of Cardiovascular Nurses, and the Société Québécoise d'Insuffisance Cardiaque, Heart Failure Awareness Week takes place each May. The event raises awareness of heart failure through traditional and online media and includes a medical conference organized by the Canadian Heart Failure Society and webinars hosted by Heart & Stroke.

*The national, bilingual online poll was conducted by Environics Research Group, with 2,257 Canadian residents 18 years and older, Nov. 8-13 2021.

** The Heart & Stroke Heart Failure Resources and Services Inventory was conducted throughout 2021 and the interim data provided in this report includes responses from 405 of the 654 acute healthcare facilities in Canada completed as of Nov. 18, 2021. Some values may have minor changes once full data collection is complete.

 **Beat heart failure**

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