System failure:

Healthcare inequities continue to leave women's heart and brain health behind

2023 Spotlight on Women's Heart and Brain Health

It is time to transform the system

Women make up just over half of Canada's population. But gaps in research, diagnosis and care threaten women's heart and brain health — and for many women these gaps are compounded by intersecting and overlapping factors that add to their risk.

Women remain under-represented in research. Medical school curricula and many guidelines for heart disease and stroke still fail to adequately address women's unique needs. Physicians are better at diagnosing and treating heart disease and stroke in men. This is partly because women-specific information is lacking and what is available has not been widely disseminated, but also because healthcare professionals are not aware that most best practices are based on evidence in men.

These shortcomings shape public awareness. According to the latest Heart & Stroke national polling data, nearly 40% of people in Canada do not realize that heart disease and stroke are the leading cause of premature death in women.

The results are heartbreaking:

- Half of women who experience a heart attack have their symptoms go unrecognized.
- Women who experience a heart attack are less likely than men to receive the treatments and medications they need or get them in a timely way.
- Women are still more likely than men to die in the year following a heart attack.
- Women who experience STEMI or NSTEMI — two of the three main types of heart attacks — are more likely than men to die or develop heart failure in the subsequent five years.
- Women who experience stroke are at higher risk of dying than men — and if they survive, their outcomes are worse.

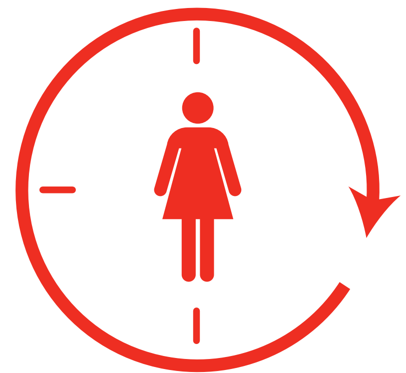
Women's bodies are not the same as men's — and neither are their lives. Biological differences mean that females face distinct risk factors — and at different points in their lives, and they are more likely to experience certain types of heart conditions and stroke.

There are also social differences that affect women's health. For example, the average woman earns less than a man. Women take on the majority of unpaid caregiving responsibilities and are more likely to experience negative health consequences as a result. Often, women put other people's needs before their own.

And while all women face inequities, there are **intersecting inequities** that put some women at greater risk than others. Every woman is an individual, with discrete overlapping factors that affect her heart and brain health including race, ethnicity, socioeconomic status, sexual orientation, geography, body size, ability and others.

There has been some progress but as we highlight in this report, much more needs to be done to ensure all women across Canada get the care they need when it comes to their heart and brain health — care that is sex- and gender-appropriate, equitable, culturally relevant and safe.

Heart & Stroke is committed to working with our partners in all sectors across the country to drive that change.



Heart disease and **stroke** claimed the lives of **32,271 women** in Canada in 2019. That's one woman's life every 16 minutes.

There has been a push to start closing some of these **sex and gender gaps in stroke and cardiovascular health.** But I think we still have a really long way to go.

— Dr. Kara Nerenberg, Heart & Stroke funded researcher

What's changed — and what hasn't — in women's heart and brain health

In 2018, Heart & Stroke drew attention to systemic inequities that compromise women's heart and brain health with two landmark reports: *Ms. Understood* and *Lives Disrupted*. Five years later, we've seen advances in research, care and education. However, many issues still need to be addressed.

Research: Women are playing catch up

From drug breakthroughs to clinical practices, advancements in heart and brain health begin with research. Both sex and gender matter in that research, as findings in men are not always applicable to women.

Two-thirds of participants in clinical trials on heart disease and stroke have been men and few studies account for the intersectional factors that further impact health such as ethnicity, socioeconomic status etc. When women are included, researchers don't always analyze the data by sex and gender. As a result, approaches to prevention, diagnosis, treatment and care often do not equally apply to women's bodies, gender identities and roles. Conditions that are more common or serious in women but rare in men typically get less attention. And there is a lot we don't know about how women's unique life stages affect heart and brain health.

> **Great strides have been made** building capacity in women's heart and brain research thanks to the support and commitment of funders such as Heart & Stroke.
>
> **— Dr. Louise Pilote, Deputy Director, Research Institute of the McGill University Health Centre**

Progress over the past five years

- Heart & Stroke invested $5 million from the federal government and an additional $5.5 million from partners and donors in women's heart and brain health research and awareness efforts.
- Heart & Stroke launched the Women's Heart & Brain Health Research Network, connecting 200 researchers, clinicians, system leaders and women with lived experience, all committed to advancing sex- and gender-equitable research at hospitals and universities across the country.
- Heart & Stroke now requires all the research we fund to include sex and gender in its design, analysis and reporting. Canada's five major health agencies use sex- and gender-based analysis to develop, implement and evaluate research — including the Canadian Institutes of Health Research which has been doing so since 2010.

What else needs to be done

- Increase the number of funders investing in women's heart and brain health research.
- Ensure all research funders make considerations of sex, gender and other factors that impact care and health outcomes — like Indigeneity, race, ability, sexual orientation, education, income and geography — a key requirement for receiving funding. In addition, ensure enough funds are provided to allow researchers to examine these factors as part of the study.
- Routinely demand sex- and gender-based analysis and reporting for all research published in journals.

Diagnosis, treatment and support: Falling short

Today, many women in Canada are dying prematurely, and even more are suffering unnecessarily. They struggle to be heard or have their symptoms taken seriously, and they are less likely than men to be diagnosed accurately. In fact half of women who experience heart attacks have their symptoms go unrecognized. Women are less likely to receive CPR than men because bystanders worry about touching their chest.

Although we have seen some improvements in clinical best practices over the past five years, they typically don't extend beyond acute care. Women are still substantially less likely to be referred to cardiovascular rehabilitation and secondary prevention programs that reduce the impact of their heart condition through regular exams, exercise plans, daily medications, support and more. And when they are referred, they are less likely to participate because of financial challenges, family responsibilities and other social factors.

Doctors and other health professionals do not want to practise bad medicine. In most cases, they simply aren't aware that the care they provide women falls short. That lack of understanding stems from inequities that exist across society and have been ingrained in the healthcare system — and those need to be dismantled.

Progress over the past five years

- The Canadian Cardiovascular Society has started incorporating women-specific considerations into its clinical guidelines and standards of care for some conditions. To date, most of this work has focused on acute care.
- Heart & Stroke has been integrating women-specific evidence into our Canadian Stroke Best Practices guidelines and has held webinars and learning sessions at conferences.
- The Canadian Women's Heart Health Alliance has created a series of educational modules, accredited by the Canadian Cardiovascular Society, to help healthcare professionals reduce the systemic biases women face.
- *The Canadian Women's Heart Health Alliance Atlas* outlines the current state of women's heart health and provides direction on ensuring equitable care.
- Heart & Stroke has promoted a CPR curriculum that includes the use of female bodied mannequins and content on the importance of doing chest compressions on a person who has breasts.

What else needs to be done

- Continue to inform clinical practice guidelines with evidence that is sex- and gender-specific including for primary and secondary prevention, risk detection and rehabilitation.
- Develop guidelines for heart and brain conditions that predominantly affect women.
- Ensure that more women experiencing a heart attack receive the treatments and medications they need — and receive that care within recommended timeframes.
- Ensure more women who have experienced heart disease or stroke are referred to cardiovascular rehabilitation and secondary prevention programs — and get the support they need to participate.
- Educate women on how to talk to their healthcare providers, ask the right questions and advocate for themselves. Even more importantly, educate healthcare providers on how to listen to their female patients.
- Provide access to care or differentiated models of care to serve women from equity deserving communities.

Definitions

When we talk about **women** in this report, we mean cisgender and transgender women, and trans and non-binary people with shared health experiences but who may not identify as women.

According to the World Health Organization, **health equity** is the absence of unfair, avoidable or remediable differences in health status among population groups defined socially, economically, demographically or geographically.

Sex and gender are complementary concepts, but they are not interchangeable. Sex describes biology, such as hormones and chromosomes, while gender describes people's lived experience, socially constructed roles and self-identification. These differences impact women's health risks, the appropriateness of diagnostic procedures and interventions, how women seek knowledge and care, and so much more. In this report we usually defer to using the gender term women as it better refers to the relevant collection of experiences, however some literature specifies the term female (denoting sex).

I was **misdiagnosed so many times**; I was told I had anxiety, depression, menopause, a cold, flu, pneumonia, a prolapsed vagina, kidney stones.

—Michelle Logeot, living with heart disease

Michelle Logeot's story

Not taking no for an answer

Michelle Logeot with her husband, Dale

In 2017 Michelle Logeot was a busy educator in Thompson, Manitoba. But for several months she felt off, experiencing weakness and fatigue and sweating a lot. As she traveled across the province for work she was worried about her health and visited several hospitals, but her symptoms were dismissed.

Michelle felt progressively worse. On her 51st birthday she was celebrating with family at their seasonal campsite. But she did not have the strength to enjoy the day. Not long after returning home to Thompson, Michelle went to lie down and fell unconscious. Her husband called an ambulance, and she was taken to the hospital where her heart stopped. She was revived and flown to Winnipeg where tests showed nine blockages in her coronary arteries. She had a procedure to open three of her arteries with stents.

During her recovery there were no rehabilitation services or supports in her area, but Michelle found a Facebook group for women with heart issues which helped her through. She now is able to support others and provides the following advice to women experiencing heart issues: "You have to advocate for yourself and if you have a doctor who dismisses you, then you have to find another one who will help."

Awareness: More work to do

Women can't receive timely diagnosis and care if they — or the people around them — don't recognize they need help. That's why it is crucial to increase public awareness about the prevalence of heart disease and stroke in women and the specific risks and symptoms they face, on top of the "traditional" risk factors.

Public campaigns have improved awareness. However, a large proportion of people in Canada remain unaware of the disease burden and the inequities faced by women when it comes to heart disease and stroke — or the signs and risk factors unique to women. Educating healthcare workers is just as crucial.

Progress over the past five years

- In 2018, Heart & Stroke launched a campaign to raise awareness around the inequities in women's heart and brain health. Other groups have delivered similar messages.
- Today, 75% of people in Canada think we should be more concerned about women's heart and brain health.

What else needs to be done?

- Increase efforts to raise awareness in all groups and sectors — including health professionals, health system leaders and decision makers, educators and the general public — around the inequities women face when it comes to heart disease and stroke.
- Increase targeted outreach to high-risk groups and communities with lower levels of awareness.
- Increase women's knowledge of their unique risk factors at different stages of their life, such as diabetes during pregnancy and atrial fibrillation in later life.
- Integrate check points or screening procedures for women's risk factors in various points of care across their life stages.

Dissecting the differences

There are a host of physiological differences between males and females, from the size of their heart and coronary arteries to hormone levels and how plaque builds up in their blood vessels. The result is often different risk factors and symptoms. It also means different treatments may be more appropriate.

Risk factors and conditions vary

"Traditional" risk factors like smoking, high blood pressure and diabetes increase the odds of heart disease or stroke for both men and women. But women also face a suite of unique risk factors, including hormonal changes over their life course, complications during pregnancy as well as use of some oral contraceptives and hormone replacement therapy.

Pregnancy

Pregnancy can lead to hypertension and gestational diabetes, both of which increase the lifetime risk of heart disease and stroke. In fact, cardiac disease is a leading cause of illness and death during pregnancy, and stroke during pregnancy is three times higher than in non-pregnant females of similar age. And polycystic ovary syndrome (PCOS) — a condition that affects one in five females of child-bearing age — increases the risk of obesity, insulin resistance and other metabolic risk factors that can lead to heart disease and stroke.

Most pregnant women get regular prenatal checkups to make sure mother and baby are doing well. Dr. Padma Kaul, the Heart & Stroke Chair in Cardiovascular Research at the University of Alberta's Department of Medicine, believes this presents a unique opportunity to identify pre-existing or pregnancy-related conditions that increase their risk of cardiovascular disease down the road.

For example, if a woman develops gestational diabetes, it doubles her risk of developing diabetes later in life. Ideally, she should get her blood sugar checked six weeks to six months after her baby is born. But according to Dr. Kaul's research, not enough women get this screening — in part because they tend to lose focus on their own health when they have young children. "Those are the things that we want to change," she says.

Women who experience hypertension during pregnancy are two to three times more likely to develop heart disease or stroke and two times more likely to die from cardiovascular disease before age 70.

Dr. Kara Nerenberg, Heart & Stroke Women's Heart and Brain Health Mid-Career Research Chair, University of Calgary, has spearheaded the development of national guidelines for preventing, screening and managing cardiovascular risk factors after pregnancy. She's also working with the Province of Alberta to send out automatic reminders to women with post-pregnancy risk factors to get follow-up testing.

Only **11% of women** in Canada can name one or more of **women's specific risk factors** for heart disease and stroke.

Through the Alberta Post-Pregnancy Longitudinal Evaluation System, Dr. Nerenberg been able to establish baseline figures. Now she plans to measure the impact of those reminders. "Is it changing the number of women being screened for diabetes, high blood pressure and cholesterol?" she asks. "And then is it impacting their treatment and long-term health as well?"

Menopause

As estrogen levels drop during menopause, the risk of heart disease goes up. The question is why. Dr. Glen Pyle, a Heart & Stroke funded researcher at the University of Guelph, and his lab were the first in the world to identify the biological changes in heart muscle triggered by menopause, and how these reduce protective factors in women's hearts.

"For a long time, it was thought that the drop in estrogen at menopause explained the increased cardiovascular risk, so if you replaced estrogen, everything should be fine. But it wasn't that simple," says Dr. Pyle.

He also discovered that key protective pathways in women's hearts are altered very early in menopause, several years before other symptoms such as hot flashes appear. He is now examining how estrogen treatment after a heart attack can reduce damage.

Better screening, education and follow-up during and after pregnancy could help many women reduce their risk of heart disease later in life.

— Dr. Padma Kaul, Heart & Stroke funded researcher

Risk factors

Some "traditional" risk factors hit women harder. Smoking, high blood pressure, diabetes, obesity, physical inactivity and depression all have a greater impact in females. There is also strong evidence that females who have high blood pressure, especially in their 40s, have a high risk of developing dementia as they get older. This risk is not present among males. Additionally, as women age they acquire cardiovascular risk factors at a faster rate than men and physicians may be slow to treat them based on outcomes for younger women.

Certain diseases that are more common in women — like systemic inflammatory and autoimmune disorders such as rheumatoid arthritis and lupus — increase the risk of heart disease and stroke. Gender-affirming hormone therapy puts trans women at increased risk for stroke, blood clots and heart attacks.

Conditions that affect women

Women are also more likely to experience certain heart conditions than men. This includes Takotsubo cardiomyopathy, a transient heart condition triggered by severe stress. Myocardial infarction with non-obstructive coronary arteries (MINOCA) — a type of heart attack that occurs without blocked arteries — is at least twice as prevalent in women than men. The signs and symptoms of ischemic heart disease such as angina are more likely to be due to ischemia with non-obstructive coronary arteries (INOCA) in women than men.

"Women are more likely to get a report of normal coronary arteries with no obstruction seen, but what that doesn't diagnose is disease affecting the very small arteries and networks of arteries that we can't see on a conventional angiogram," says Dr. Sonia Anand, Heart and Stroke Foundation/Michael G. DeGroote Chair in Population Health Research at McMaster University in Hamilton. "A heart attack can occur even without a blockage in the large coronary arteries. We need to raise awareness of these conditions and we need to improve the diagnostic tests for them."

Spontaneous coronary artery dissection (SCAD), which also mostly affects women, is a common cause of heart attacks in younger women and during pregnancy or childbirth.

Females can experience different signs, symptoms and impacts

Heart disease and stroke can manifest differently in females. For example, females are less likely to experience the chest-clutching pain of a heart attack. Instead, they are more likely to experience discomfort in the neck, jaw, shoulder, upper back or upper belly; shortness of breath; nausea; or vomiting.

Most women experience more than one symptom, yet men are more likely to simply report chest pain. The symptoms of ischemic heart disease (caused by narrowing arteries) and arrythmia also differ between men and women.

"Our traditional teaching of how a heart attack presents is based on studies that looked at Caucasian males. However, we know that ethnic minorities and females can present with a heart attack very differently," says Dr. Inderveer Mahal, a family physician in Vancouver. "We need to emphasize in medical school that life-threatening presentations can vary based on the patient in front of you and our clinical judgment has to reflect that."

Traditional gender roles and expectations create barriers to care

Barriers to care go beyond physiological differences between men and women. Women tend to have more caregiving responsibilities and to prioritize the health needs of their family members over their own. That means a woman may prioritize caring for a child or taking an elderly parent to a medical appointment before seeking help for herself. Factors like low income and lack of access to child care can make it even more difficult to get the medical attention needed.

Women also face more challenges advocating for themselves. Men and women typically have different communication styles, and research shows that men's voices are considered more authoritative. As one woman with heart failure told us in a focus group, she always brings her son to appointments because her doctor pays more attention when he speaks.

When it comes to follow-up care, women are less likely to participate in cardiac rehabilitation programs than men and are less likely to stay in the program once enrolled. This puts them at a disadvantage for making the best recovery possible. Common barriers include lower incomes, family responsibilities and the lower likelihood of physician referrals.

The risk of stroke and its impact on recovery may vary across women's life stages. More importantly, stroke recovery is related not only to stroke severity, but to the psychological and social factors that are relevant to a woman's life stage at the time of her stroke. For example, an 80-year-old woman left with "mild" deficits following a stroke can often return to and enjoy much of her previous life if she is supported with appropriate help. But for a 45-year-old woman, those effects can be life-altering including her ability to return to work and care for her family.

Even compared to a 45-year-old man, the consequences can be more serious for women due to gendered roles. "If a man has a stroke and has a supportive partner at home, he

will achieve better functional and psychosocial recovery, but women often face different transitional needs," says Dr. Aleksandra Pikula, a stroke neurologist with expertise in women's brain health at the University Health Network. "Unfortunately, the psychosocial dynamics in a woman's life can dramatically change after stroke, and not uncommonly lead to a loss of professional and personal integrity. For some it may result in unfortunate events such as inability to return to work or even divorce."

Understanding these differences is crucial, Dr. Pikula argues. And so is recognizing the long-term impacts stroke can have and the need to provide ongoing support, so that women don't simply survive but enjoy a good quality of life. "It is important to accept that stroke is actually an acute event, but it's a chronic disease."

Bobbi-Jo Green's story

New test leads to new results

Bobbi-Jo Green was an active Edmonton school teacher and mother of two young children when she began experiencing symptoms such as a headache, chest pressure and tiredness. A year later, while on holiday, the 31-year-old felt serious chest pain and went to the hospital. Tests were inconclusive and she was sent home with muscle relaxants and told to manage her stress. The pain kept coming back and her other symptoms worsened, until she was no longer able to work.

Finally in 2020, after 10 years and dozens of doctor appointments and visits to the emergency room, Bobbi-Jo was given a new test that led to a diagnosis: ischemia with non-obstructive coronary arteries (INOCA). She was overwhelmed and relieved, but she was also angry. "I felt like I had wasted my 30s thinking I was crazy. For years I was having crushing chest pain and I knew it was my heart but I kept being told it wasn't," says Bobbi-Jo.

Much of that anger is gone. "Now I do a lot of advocacy work for both patients and physicians. Doctors are not being malicious, they just do not have the information or the training. But it is happening enough that they should know, especially in our emergency departments."

Bobbi-Jo Green and her family

Women are forced to navigate a healthcare system designed for men

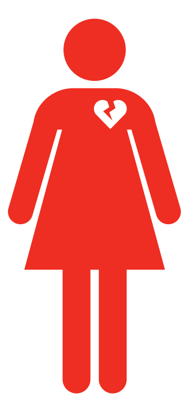
Many of the tests used to diagnose a heart attack were developed and tested on men. For example, conventional coronary angiograms don't always detect blockages and dysfunction in the very small arteries — which occur more frequently in women. That means doctors may miss heart disease or an impending heart attack.

Even when a woman is properly diagnosed, she may not receive appropriate treatment since most therapies have been developed in male-dominated research trials. In some cases, cardiovascular drugs at conventional doses are more likely to cause adverse reactions in women. Meanwhile, women are at greater risk of drug-induced heart rhythm disorders and have a 30% greater risk of bleeding complications from common treatments such as angioplasty.

To make matters worse, healthcare providers often lack expertise related to heart conditions that disproportionately impact women, like SCAD and angina without obstructive coronary disease. "We simply do not know how to treat forms of cardiovascular disease that are more common in women," says Dr. Husam Abdel-Qadir, Women's Heart and Brain Health Chair at Women's College Hospital in Toronto.

Dangerous differences

- In 2019, 20% more women in Canada died of heart failure than men, while 32% more women died of stroke than men.
- Elderly women are exceptionally touched by stroke: they are the most likely to have a stroke, their strokes are the most severe, their outcomes are the poorest, and stroke can put an end to their independence.
- Because they live longer, more women are living with the effects of stroke than men.



The **rates of many heart conditions and stroke are increasing among younger women in Canada**, and the number of women in Canada living with risk factors for heart disease and stroke, such as hypertension and diabetes, is increasing.

Our research will identify windows of opportunity during which estrogens protect against heart attacks, while at the same time testing the novel idea that short-term treatment is protective – which is especially impactful as chronic estrogen treatment has negative effects and is not feasible in men.

— Dr. Glen Pyle, Heart & Stroke funded researcher

All women face inequities, but some face greater inequities than others

For women, the inequities discussed above are often exacerbated by layers of other intersecting social and cultural factors and power dynamics. Ethnicity can influence genetic predispositions to certain conditions and risk factors as well as access to health services and other supports. Socioeconomic status can affect everything from access to nutritious food to the ability to pay for medications. And challenges ranging from language barriers to institutional racism can make it more difficult to access care.

Racialized communities

Heart disease and stroke disproportionately impact some ethnically diverse communities in Canada. Heart & Stroke co-funded a birth cohort study to investigate the role of ethnicity and future risk of cardiovascular risk factors. Led by Dr. Sonia Anand, the research involved 1,000 pregnant South Asian women living in Ontario and revealed that gestational diabetes is at least two times more common in that population than in white women of European descent. This increases the mother's and her offspring's risk of future cardio-metabolic disorders.

Research also shows that South Asian, Afro-Caribbean, Hispanic and Chinese North American women have greater risk factors for cardiovascular disease. Despite these significant differences, there are currently no Canadian cardiovascular guidelines specific to ethnicity.

"If you don't know the system, if you don't speak English or don't have as strong a command of English — or French, depending on where you are in the country, if you can't advocate for yourself because it's not something that you culturally are used to doing, your outcomes tend to be worse," says Dr. Sherryn Rambihar, a cardiologist in Toronto.

A recent special issue of the *Canadian Medical Association Journal (CMAJ)* centres the health of Black people in Canada and explores anti-Black racism in Canadian healthcare spaces. One of the articles explores the perspectives of Black medical students and faculty and concludes: "Systemic anti-Black racism is deeply entrenched in health systems and all aspects of medical training – from admissions and assessment, to the everyday discrimination experienced by Black medical students and physicians."

"There can be mistrust of the system from Black people. They might be apprehensive of how they will be treated, and of how they might not get the care they need," says Dr. Alexandra Bastiany, an interventional cardiologist at Thunder Bay Regional Health Sciences Centre who has experienced and witnessed racism in healthcare. She is committed to calling it out and advocating for change. "I have seen Indigenous patients living up North not get their medication delivered to their community. Some will not get certain tests or treatments because they cannot afford to get to the city. That is not OK."

Indigenous people

Indigenous people in Canada are more likely to be at risk for or currently living with heart disease and stroke compared to the general population. For some Indigenous groups, the death rate from heart disease and stroke is also higher, particularly for women and younger age groups.

In part, that's because of elevated risk factors: the lifetime risk and prevalence of diabetes is higher in Indigenous people compared to the general population of Canada — particularly for women. And Indigenous women in Canada are more likely to experience diabetes during pregnancy than their non-Indigenous peers.

But accessing care is difficult. Some communities don't have emergency services, and people with complex needs may have to leave their communities to get specialized care. There are policy gaps that restrict the number of hours certain allied professionals — such as occupational therapists, physiotherapists and mental health specialists — can spend travelling, limiting services in the most remote communities.

Indigenous people also face extensive discrimination and mistreatment within the healthcare system. As a result, they're much less likely to seek care — and much more likely to get misdiagnosed if they do. Meanwhile, the intergenerational trauma caused by Canada's residential school system continues to affect their health in profound ways.

Socioeconomic status

Social and economic disadvantages are big factors that have always affected people's health status, risk of infections, health behaviours and access to health services. For example, women living with low socioeconomic status are more susceptible to heart disease and stroke than those with higher incomes. Low income also affects access to education, adequate housing, a nutritious diet and health care.

For Saskatchewan cardiologist Dr. Andrea Lavoie, it's a familiar challenge many of her patients face. "How are women supposed to pay for a $400 cardiac rehabilitation program, for example?" she asks. "They can't even afford to pay for the five medications that I've just put them on for their heart attack."

Dr. Inderveer Mahal also witnesses firsthand how the social determinants of health impact women living in poverty in Vancouver's Downtown Eastside. Here, she says, the odds are stacked against them. The rising costs of food, housing and other necessities limit their ability to access healthy choices, and for women who are precariously housed their priority is looking for housing and safety. Many cannot work because child care is difficult to find and expensive. Trauma and violence often exacerbate the situation, and if they are using drugs to cope, they're even more likely to encounter stigma within the healthcare system.

The stress related to living on or at the poverty line has a huge impact on women's health. As doctors we **need to be respectful, be proactive, give them the respect all patients deserve** and remember that often they have had multiple negative experiences with the healthcare system.

— Dr. Inderveer Mahal

Teaching the teachers

Margaret Hart, Ininew Scholar, Department of Occupational Therapy, Rady Faculty of Health Sciences at the University of Manitoba, has both lived experience of some of the challenges Northern Indigenous communities can face around heart disease as well as academic insight.

Margaret grew up in northern Manitoba, lived there for most of her life and recently moved to Winnipeg to be with her mother as she battled diabetes in her last years. "My mother lived with diabetes for 20 years until a heart attack took her life at 58. She died away from her family in Winnipeg, where she was forced to live due to the lack of services in the north. The access to services in the north when it comes to kidney, heart and brain health is zilch. Zero. The nearest hospital is seven hours away. This is a systemic barrier to care. No one in northern Manitoba can walk into a nursing station and request a heart, brain, or kidney check-up. The infrastructure isn't there."

Margaret has worked in First Nations education for 20 years. She is advocating for health literacy in high school curricula as basic health literacy will create an awareness of disease prevention, wellbeing, and sovereign healthcare structure. She is also currently developing an Indigenous curriculum for the department of occupational therapy at the University of Manitoba. When she looked at the existing university curriculum, she recognized gaps right away — there were no First Nation ways of knowing, being, and understanding. Two elements are driving her work: trauma-informed practice and sovereignty. "How do we begin to make change in healthcare to improve Indigenous health? I think where that begins is in the curriculum."

Sexual orientation and gender identity

There is mounting evidence that 2SLGBTQ+ people – a collection of communities with diverse, individual experiences – as a group face more health inequities than their cisgender, heterosexual peers. This is likely due to a mix of discrimination, risk factors, and lack of knowledge among healthcare providers. According to Dr. Andrea Daley, Professor, Renison University College at University of Waterloo, "One of the biggest barriers to care continues to be assumptions of heterosexuality and the gender binary (man/woman). It is important to know someone's sexual and gender identity to know which questions to ask in order to better understand their health services experiences and needs."

According to the Trans PULSE survey, many transgender people in Ontario report avoiding the emergency department or their family physicians due to negative experiences they've had or because they felt uncomfortable discussing health issues with doctors who receive very little training on serving transgender patients. The survey revealed that 44% reported an unmet healthcare need in the past year.

Dr. Jacqueline Gahagan, Associate Vice-President Research, Mount Saint Vincent University, explains how "minority stress" negatively impacts cardiovascular health in 2SLGBTQ+ communities. "It is not that your heart is a 'gay shape' and therefore pumps blood differently. It is the overarching notion that 2SLGBTQ+ people live with discrimination, harassment and the threat of violence at a much higher rate than cisgender, heterosexual folks do." They also cite lack of data as a key challenge. "We do not have a national 2SLGBTQ+ health strategy or survey. We need a more systematic assessment, a baseline on the health and wellness of 2SLGBTQ+ Canadians, and in particular we need to be much more inclusive and mindful of the needs of older 2SLGBTQ+ members of our communities, especially older lesbians who are often forgotten in health initiatives."

Geography

People living in northern, rural and remote areas are more likely to experience heart conditions and stroke — and more likely to die as a result. This is due in part to limited access to ambulances, emergency care, cellphone service and support services during recovery. In some regions, patients have to travel out of province to receive the care they need. Prevention and screening is another key factor. Residents in rural and remote areas typically see their family doctor less frequently and get less screening for blood lipid levels and diabetes. Even within big cities, there can be significant differences in life expectancy and access to care between neighbourhoods.

Getting care isn't easy if you live in a rural or remote community. "The number of rural physicians has declined significantly. We've seen a ton of rural emergency departments close," says Saskatchewan cardiologist Andrea Lavoie. "Now, they might be 45 minutes to two hours from even an emergency department." Add to that a lack of everything from laboratories and echocardiography equipment to services like stress testing and Holter monitoring. And COVID has amplified those problems.

The challenges are even greater in Indigenous communities, where systemic discrimination and the residential school legacy has left profound mistrust of institutions. "That's a huge barrier to care," says Dr. Lavoie. That's why she's involved in training people in the community to provide care, and providing portable echocardiogram machines so people can get screening right in the community.

A First Nations woman's story

A bumpy road to care

A First Nations woman from Saskatchewan we spoke with (who asked that her name not be used) recalls the struggles she faced when she was first diagnosed with heart failure. She had difficulty getting from her reserve to her appointments in the city to meet with specialists, get blood work done and other tasks. She does not drive and could not find anyone to drive her. Even once she became aware of the options available she continued to face challenges around communication, booking and coordinating rides. As a result, she had to cancel some appointments — sometimes at the last minute — and it could take up to a month to get a new time slot.

Now someone from her health centre picks her up and takes her to appointments. Her heart function has improved, thanks to changes to her medication, a healthier diet and better management of her blood pressure. Finally having access to reliable transportation has been important to her physical and mental health. "I was getting depressed before, I felt like no one cared about what was happening to me. But now that I have transportation I feel supported and more in control."

Other social factors

The list of social factors goes on. Women with disabilities have a higher risk of adverse cardiac events. Older patients are often excluded from clinical trials. And people with a high body mass index are significantly more likely to report discrimination in healthcare.

Naomi Lee's story

When the system works

Naomi Lee is a perfect example of everything that can go wrong with a woman's heart as well as everything that can go right. In June 2020 she was a fit, healthy 19-year-old in Coquitlam, BC, when she and others in her family contracted a non-COVID flu. They all got better — except Naomi.

In fact, she got worse. In addition to a fever and a cough, she started to have chest pains. Thinking she might be having a reaction to the antibiotics she had been prescribed, she and her mom went to the hospital. Much to her surprise she was diagnosed with viral myocarditis – inflammation of the heart muscle caused by infection. She was admitted to the hospital. The next day she went into cardiac arrest.

Naomi Lee (right) and her sisters

Soon after, Naomi was diagnosed with heart failure — difficult news to take in: "I was totally in denial. My brain couldn't comprehend it, how was it possible?" After a second cardiac arrest she had an LVAD implanted — a machine that does the work of the heart by circulating the blood around the body.

After several months, an echocardiogram showed that her heart had not healed despite the rest. "It was so damaged by the virus that it wasn't even muscle anymore, it had turned into scar tissue," says Naomi. "I learned that I needed a heart transplant. I was devastated."

After three months on the transplant list, and a little over one year after her initial diagnosis of heart failure her heart transplant surgery went smoothly with no complications, and she has made a remarkable recovery. "It was a fresh start, a new chapter for me but I was sad for my donor family because it was a tragedy for them."

Just over a year later Naomi is doing very well. She is pacing herself, but she is working part time and back at school, working on pre-requisites to get into nursing school — motivated by her experiences as a patient. "When I was in the hospital, having kind and empathetic nurses and doctors changed my experience. This made a huge difference during a really difficult time."

Heart & Stroke's vision to transform the health system together

Heart & Stroke's vision is to live in a world where all women receive the care they need when it comes to their heart and brain health.

Achieving this vision will be a massive collaborative effort. It will involve changing policies, systems, attitudes and behaviours — and it won't happen overnight. But we're committed to mobilizing partners from all sectors of society to collectively break down the barriers that create inequities.

To make a tangible and lasting difference, we have identified three strategic pillars to collectively tackle the core, systemic issues that underlie the problem; a cross-cutting focus on equity will be embedded in each pillar. Working with partners from all sectors we will drive change in each area.

Pillar 1: Research

We will expand the research conducted on women's heart and brain health. This means building capacity by investing in a community of champion researchers and driving new knowledge and innovation in women's heart and brain health. It means accelerating the translation of that knowledge into changes in clinical practice, policy, healthcare systems and health outcomes for women in Canada. And it means driving changes in research funding policies and practices in cardiovascular health research related to sex, gender and equity, diversity and inclusion.

Pillar 2: Public awareness and education

We will continue to empower and educate women about their unique signs, symptoms and risks. We will help them advocate for and access the care and support they need so that they can maximize their health potential. And we will engage all people in Canada to drive awareness and action on heart and brain health inequities faced by women.

Pillar 3: Healthcare journey

We will catalyze efforts to transform how heart and brain care is provided to women. We will partner with professional associations and healthcare stakeholders to equip healthcare professionals with emerging evidence and new guidelines for the prevention, diagnosis, treatment and ongoing management of women's heart and brain conditions across life stages and the continuum of care. We will work with health system leaders across the country to accelerate the adoption of new models and standards of care for women. And we will engage women as active partners in their healthcare journey and take into account their experiences and circumstances.

Health equity and Indigenous wellbeing

We will embed health equity and Indigenous health and reconciliation lenses into each of the three pillars to address systemic barriers faced by racialized and marginalized groups and ensure all women in Canada receive the care and support they need for optimal heart and brain health.

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Beat stroke.
Beat health inequity

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