



# Ms.Understood

**Women's hearts are victims of a system that is ill-equipped to diagnose, treat and support them**

Heart & Stroke **2018** Heart Report



# It's time to break the glass ceiling on heart health

Too many women are unnecessarily suffering and dying from heart disease. They have been left behind because they are under-researched, under-diagnosed and under-treated, and under-supported during recovery. It is shocking we are only beginning to understand women's hearts, and gains in knowledge are so slow to reach the bedside. What we do know highlights a stark reality:

- Heart disease is the leading cause of premature death for women in Canada (dying before reaching their expected lifespan).
- Early heart attack signs were missed in 78% of women.
- Every 20 minutes a woman in Canada dies from heart disease.
- Five times as many women die from heart disease as breast cancer.
- Two-thirds of heart disease clinical research focuses on men.
- Women who have a heart attack are more likely to die or suffer a second heart attack compared to men.



"Women's hearts are still misunderstood. We are decades behind in our knowledge of the differences between men's and women's hearts," says Yves Savoie, CEO of Heart & Stroke.

The numbers are alarming. According to the most recent Statistics Canada annual data, close to 25,000 women die each year from heart disease.

Even more disturbing is that this is not new: For decades women have been dying before their time. More than 20 years ago, Health Canada issued new guidelines that, for the first time, recommended that women should be included as subjects in health research and clinical trials. The vision was to uncover evidence on the crucial impact that sex and gender have on health.

The need was urgent. Several important drugs commonly used to treat heart disease and other conditions had been pulled off the market when they caused harmful and even fatal side effects in women. In Canada and elsewhere this sparked a growing determination to improve and increase women-related heart research.

The goal was to correct inequities and usher in a new and better understanding of women's heart health. But today, when it comes to heart health, the glass ceiling is as thick as ever.

The Heart & Stroke 2018 Heart Report focuses on why we still struggle to untangle and apply new knowledge about women and heart disease, and why some women — Indigenous women, ethnically diverse women, women living in poverty, and women in remote and rural locations — often face even greater inequities.

For this report, we consulted leading experts in the fields of health research and research policy, clinical care and cardiac rehabilitation from coast to coast. We reviewed recent data and studies, and surveyed 2,000 women in Canada to better understand their perspectives.

And we spoke to many women with heart disease who shared their insights and experiences of being "Ms. Understood."

Sex and gender blinders have led to **too many women dying unnecessarily.**

**Dr. Karin Humphries**

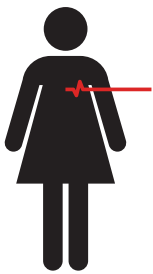
# How our system fails women

The discourse used to be that women needed to empower themselves, that their heart health was a matter of personal responsibility. Years of public education and campaigns from Heart & Stroke and other health organizations called on women to take charge of their hearts.

We now know that to make a difference, this responsibility must be applied much more broadly. Educating and empowering women is important, but it is only a part of the solution. Healthcare systems need to catch up with new evidence that women's hearts are different; they must incorporate new women-specific diagnostics and treatment. New knowledge must be gathered and translated into better and safer heart healthcare for women. We must accelerate the pace of change, and reach women in all communities across the country.

## Are women's hearts really that different?

"Yes and no," says Dr. Karin Humphries, scientific director of the B.C. Centre for Improved Cardiovascular Health. "While overall female hearts look the same as male hearts, there are important differences that are irrefutable and still poorly understood."



Heart attacks are more **deadly** for women.

Physiologically, women's hearts and coronary arteries are smaller; women tend to have lower blood pressure and faster resting heart rate than age-matched men. Importantly, there are differences in the way atherosclerotic plaque builds up in the blood vessels, causing coronary heart disease, and differences in the electrical patterns in women's hearts.

Women's hearts are impacted by pregnancy, menopause and hormonal changes throughout their lives. The types of heart disease that affect women can be quite different from those in

men, and require a different approach to diagnose and treat. Further, the way women experience and describe the signs of heart disease such as heart attack can be quite different. And there are previously unrecognized heart diseases and risks, predominantly seen in women, which we are just beginning to uncover:

- Women have more adverse reactions to certain heart medications and these reactions are more severe than men experience.
- Women are at greater risk of drug-induced heart rhythm disorders.
- Women have twice the risk of bleeding complications from common treatments such as angioplasty.
- Gender-based differences such as lower socio-economic status (and the resulting challenges in accessing healthy choices) and greater family responsibilities (and the stresses that go along with them) are interrelated and more prevalent among women than men.

## Sex and gender: What's the difference?

Sex and gender are different, and both affect women's health. Here's how the Canadian Institutes for Health Research explains the two terms:

- **Sex** refers to the biological attributes of humans and animals, including physical features, chromosomes, gene expression, hormones and anatomy.
- **Gender** refers to socially-constructed roles, behaviours, expressions and identities of girls, women, boys, men and gender diverse people.

"There is still so much we don't know, and we have an urgent need to better understand the differences between men and women," says Dr. Humphries.

"We are only beginning to break through, to understand the degree to which both sex and gender put women at risk."

# Women's reality is defined by "unders"

Today, when it comes to heart disease, women are under-researched, under-diagnosed and under-treated, under-supported and under-aware.

This complex mix of "unders" began in health research where, for decades, specific therapies were tested in controlled studies on primarily middle-aged, white male subjects. The assumption was that "one size fits all" and what was learned

formed the basis of clinical guidelines, diagnostic procedures and therapies that, even today, are widely used for both men and women.

Because for so many years research had limited women's representation as subjects, every aspect of heart health care for women was impacted and continues to be today.

## Women's heart health:



### Under-researched



Why were women excluded from clinical trials, and why were the results not analyzed by sex and gender initially? In large part, it began because of safety concerns involving women in drug development. Following the thalidomide disasters in the early 1960s, in which a drug used by pregnant women caused malformed limbs in a large number of newborns, it became common practice to assume all women between the onset of menstruation and menopause were "potentially pregnant" regardless of sexual orientation or activity. They were prohibited from participating as research subjects.

In 1997, Health Canada revised its guidelines, setting out conditions and recommendations for safe inclusion of women as research participants in all stages of drug development and clinical trials. Yet, partly because the hormonal shifts women



**2/3** of heart disease clinical research focuses on men.

experience add a layer of complication, and later in life, women diagnosed with heart disease tended to have other health conditions that make analysis more difficult to interpret, women's inclusion in research remained limited.

"The problem is, sex and gender do make a difference in safety and efficacy of therapies and diagnostic devices when they are used for women," says Dr. Louise Pilote, professor of medicine at McGill University and director of the division of internal medicine at the McGill University Health Centre. Some therapies have been shown to vastly increase a woman's risk while providing little benefit.

"The development of guidelines to ensure equal representation of women and men in clinical trials has been talked about for 25 years," explains Dr. Ed O'Brien, vice chair of the Canadian Institutes of Health Research (CIHR) Institute of Gender and Health Advisory Board and professor of cardiac sciences at the University of Calgary. "But there is still pushback, even today. Having balanced numbers of women in clinical trials can add to complexity and cost, but it is crucial."

Women comprise 51% of our population, he notes. "When you are translating your research into a therapy that will be given to half the population, there is a big problem if it hasn't been tested on that population or if your results have not been analyzed for that population."

Both Drs. Pilote and O'Brien note gender issues complicate balanced inclusion in trials: It is not just a matter of researchers not wanting to include women; it is more difficult to find women (especially women of diverse backgrounds and ages) willing to volunteer for these studies.

"We urgently need to better understand why the hesitation," says Dr. Pilote. The current thinking is women's multiple roles, family caregiving responsibilities and financial constraints may be at the heart of it. It is up to researchers to find different approaches that respect the realities of women's lives, so that more women are able to take part in research trials.

"There are some really exciting, promising new drugs being studied right now, but without balanced representation in the trials, we simply won't be able to say if they are safe or effective for women," she says.

#### **Some signs of positive change:**

- Increasingly, funding organizations, including Heart & Stroke, now require that sex and gender be defined and considered in research proposals. Other organizations in Canada such as CIHR also recommend this inclusion, and ask researchers for justification if it is not included.

- Among researchers themselves, an attitude shift is underway. They are becoming aware and are expecting that balanced inclusion and analysis needs to be part of their research.
- Evidence suggests that increasing the number of women scientists involved in heart research will improve our understanding of heart disease in women. A recent evaluation of 1.5 million research papers revealed a strong correlation between studies led by women and the chance that they include sex and gender analysis. In May 2017, Canada's science minister Dr. Kirsty Duncan, announced changes to the high-profile Canada Excellence Research Chairs program, which would require universities who host these chairs to develop, activate and publicize action plans to address equity and diversity objectives or risk losing the funding. At the time this change was announced, only one of the 28 chairholders was a woman.
- When it comes to research that looks specifically at women's heart conditions and risks, Canada is definitely punching above its weight, says Dr. Humphries. Dr. Jacqueline Saw's groundbreaking research looks into spontaneous coronary artery dissection (SCAD), a poorly understood heart condition that affects mostly women. And Dr. Margaret Davenport is studying how pregnancy complications lead to problems with the vascular system later in life.
- Canadian-led research has developed a gender scorecard to help healthcare workers understand and recognize the effect of sex and gender differences in their women patients with heart disease, and to equip them to provide personalised care, notes Dr. Pilote.

**Science has been slow to recognize sex and gender differences in heart disease, and equally slow to correct this misunderstanding.**

**Dr. Ed O'Brien**

## Women's heart health:

### Under-diagnosed & under-treated



In clinical practice — in emergency departments across the country — the textbook sign of a heart attack is chest pain. It is a “lights and sirens” emergency and patients are fast-tracked for angiography or other tests to confirm a blocked coronary artery and treat it quickly.

For women, however, the journey may not be the same. Women in Canada are less likely to receive care from a cardiologist, or to be referred for aggressive diagnostic tests or treatments. For Indigenous women who live on-reserve, there is a lack of cardiac care resources in remote or rural hospitals.

Less than one-third of women experiencing heart attack receive some standard types of care within times set out by guidelines:

- Only 29% of women receive an ECG (a standard test for heart electrical patterns) within the benchmark 10 minutes, compared to 38% of men.
- In cases where a patient requires clot-dissolving therapy, only 32% of women get this therapy within the benchmark 30 minutes, compared to 59% of men.

While both men and women typically experience pain as their primary sign, the language women use to describe their pain may be different, and that can impact their diagnosis and treatment. Women may describe it as pressure or tightness, and they more often describe signs such as nausea, unusual fatigue or jaw pain — not always an elephant sitting on their chest.

Women and their doctors are slow to identify the early signs of an impending heart attack. According to a retrospective study published in *Circulation*, early heart attack signs were missed in 78% of women in the study group of women, even though these signs occurred repeatedly over a period of weeks or months. These early signs are subtle – shortness of breath, weakness, fatigue, dizziness – but are strong indicators of an impending heart attack. At the same time, they were often

missed (or dismissed) by women themselves or when they sought medical assistance.



**Early heart attack signs**  
were **missed** in 78% of  
women.

Today, physicians are far more aware of these differences, but still, women — particularly younger women — may have their signs attributed to anxiety or heartburn or other “female” issues. Physicians themselves, in a study published in the *American Journal of Cardiology*, indicated a desire for improved education in this area. Only 22% of primary care physicians and 42% of cardiologists felt well-prepared to assess heart disease in women.

“Gender bias still exists,” notes Dr. Tara Sedlak, director of the Leslie Diamond Women’s Heart Health Centre in Vancouver. “Physicians may look for other causes of a woman’s symptoms, without first doing appropriate tests to rule out cardiac issues. It may not be intentional, yet when there are differences in medical care for men and women across large numbers of patients, it is an indication there is still systemic bias.”

In my mind, the stereotypical heart attack was an old guy, clutching his chest on a golf course. **Women need to know that they can have a heart attack yet continue to walk, talk, work.** That was my experience.

**Carolyn Thomas, heart attack survivor**

Medical schools and continuing medical education need to adapt, to ensure healthcare providers have a strong basis of understanding these issues. In a step to address this, six medical schools in Ontario have collaborated to create online learning materials in gender and health that faculty can voluntarily incorporate into curriculums.

Every two years, Heart & Stroke and the University of Ottawa Heart Institute's Canadian Women's Heart Health Centre co-host the Canadian Women's Heart Health Summit to update clinicians, explore new research and advance women's heart health.

### **The problem with screening tests**

Many of the tests used to diagnose a heart attack were developed and tested on men, and may miss heart disease or a heart attack in a woman.

"Women tend to have disease in the small vessels of their heart, while men are more likely to have disease in their major coronary arteries," explains Dr. Sedlak. The angiogram — the standard diagnostic tool used to detect heart disease — images the major coronary arteries. It does not capture disease in the smaller coronary arteries (microvascular disease). A woman with this condition may go undiagnosed. Women with normal angiograms are four times more likely to be readmitted to hospital for chest pain within six months compared to men.

While no test is 100% accurate, some perform worse for women. The exercise treadmill (or stress) test for cardiac output is far less sensitive for women compared to men, and even worse for younger women compared to older women.

A misleading diagnosis delays early treatment. For heart attack, the key to effectively treating and minimizing irreversible damage is time: open up the arteries quickly, restore blood flow quickly.

## Learn the signs of heart attack



**Chest discomfort**  
Pressure, squeezing, fullness or pain, burning or heaviness



**Sweating**



**Upper body discomfort**  
Neck, jaw, shoulder, arms, back



**Nausea**



**Shortness of breath**



**Light-headedness**

**Call 9-1-1 right away.**

## **Signs for men, signs for women: Are they really different?**

Women generally recognize the "Hollywood heart attack:" Chest-clutching, crushing pain. If their pain is less severe, or if they have non-pain signs such as nausea, sudden fatigue or shortness of breath (signs more often reported by women) they are more likely to delay getting to emergency care, and once there, they are less likely to get fast, aggressive treatment.

“Treatment within one hour is far better than six hours,” notes Dr. Sedlak.

“Here in our hospital in Vancouver, we are developing new techniques in the angiography suite to detect small vessel disease or small tears or spasms in the arteries that are predominantly seen in women,” she explains.

At McGill University Health Centre, adds Dr. Pilote, “we are developing new magnetic resonance testing to understand why some women with heart attack do not have blocked coronaries on angiography.”

Meanwhile, an increasing number of research studies are evaluating the effectiveness of new cardiac imaging techniques and molecular tests to detect microvascular

## HERstory:

Nancy Bradley’s chest pain was so bad that she had trouble catching her breath. Given her family’s history of heart disease, she was sure that she was having a heart attack. But when she went to the hospital she was told that her symptoms were probably just a bad case of heartburn and sent home. Two weeks later, Nancy had a massive heart attack.

“I’ve had heartburn before. This wasn’t heartburn. I tried to explain that what I was feeling was different... when it happened the second time, the pain was exactly the same.”

disease, exploring technology such as cardiac MRI, positron emission tomography (PET) and other non-invasive imaging tools. They can’t come soon enough.

“These new techniques are not widely available, but they should be,” says Dr. Sedlak. “There is a real urgency, because outside of these larger institutions, women are regularly sent home because their arteries look normal, but in reality they go home with heart disease.”

### The costs of bias

The Global Registry of Acute Coronary Events (GRACE) is a study conducted in 113 hospitals in 14 countries, including Canada. It found that women admitted to hospital for heart disease were less likely to receive beneficial medications or surgeries. The study cautions that more research is needed, as women who have heart disease also have higher rates of high blood pressure and diabetes, which impacts treatment choices.

GRACE points to the need for more research to better understand sex and gender differences in treatment, notes Dr. Humphries. There are social and psychological reasons for the under-treatment of women that require urgent attention, emphasizing there is bias that must be overcome.

Several drugs and devices (largely untested in women) have been withdrawn from the market because they resulted in adverse effects on women. For example, some medications for angina or hypertension actually increased the risk of heart rhythm or heart valve problems at a much higher rate in women. Several appetite suppressants were found to pose heart health risks for both men and women, but these risks impacted women disproportionately since they were prescribed and used far more often for women.

And finally, women are less likely to be on needed medications,

## Taking bias out of health care

Doctors at Johns Hopkins Hospital in Baltimore have adapted a simple concept to reduce gender bias in medical care, with potential application for cardiac care. Based on *The Checklist Manifesto* by Atul Gawande, they have introduced clearly-written checklists to help prevent human error and eliminate the often-subconscious bias that goes into medical decision-making.

Dr. Elliott Haut, a trauma surgeon, and his team at Johns Hopkins observed that female trauma patients were 50% more likely to miss out on blood clot prevention. After their checklist was implemented, the gender disparity disappeared, and the rate of preventable clots fell to zero. The checklist reminds people – even experts – that step-by-step guided analysis of a patient’s condition reduces human judgement that could be affected by a patient’s race, gender, occupation or other unrelated factor.



such as blood pressure or cholesterol lowering medication, after their heart attack. The reason why is unclear. Are physicians not prescribing them to women? Or are women not filling their prescriptions? Or are they filling but not taking? Again, the need for further investigation is urgent.

### The challenge of women's heart conditions

The "motherhood penalty" usually describes how women's career path may be disadvantaged by childbearing. It applies to heart health as well. Nearly a third of young women with premature acute heart attack have a history of pregnancy disorders. Gestational diabetes, hypertension or pre-eclampsia doubles a woman's lifetime risk for heart disease.

And unlike past generations, more women with congenital heart defects or other heart conditions are surviving to adulthood and having babies. Over the past 10 years, the number of pregnant women with pre-existing heart disease has increased by 24%. This is a new and complex problem that urgently needs study, so clinicians are prepared to provide specialized care for these women.

And we are only beginning to crack other predominantly women's heart conditions.

Spontaneous coronary artery dissection (SCAD) occurs when an unexpected tear develops in an artery. New Canadian research shows it is the underlying cause for roughly 25% of all heart attacks in women under age 60 (see one women's story, right). About 90% of SCAD patients are women, and almost all are young and otherwise healthy.

## HERstory:

When Patti Mersereau-Leblanc was rushed to Winnipeg's St. Boniface Hospital with heart attack symptoms, she was lucky to come under the care of Dr. Olga Toleva, who had trained under Canadian SCAD expert Dr. Jacqueline Saw. Dr. Toleva recognized the signs of SCAD and detected two tears in arteries supplying blood to Patti's heart. Many physicians are unfamiliar with this condition, which requires a trained eye and specialized imaging and equipment to detect.

Patti has recovered, but the thought of another episode haunts her. "I didn't know what I had. You're afraid to live. You're afraid to die. I couldn't lie on the couch forever. But if I went out for a jog, I might give myself another SCAD."



## Women's heart health:



## Under-supported

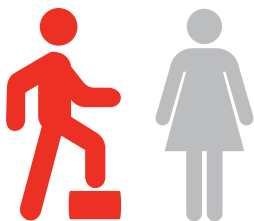


Cardiac rehabilitation programs are a combination of exercise, education, healthy lifestyle counselling and psychosocial support, intended to assist patients as they transition from hospital to home.

After a heart attack, heart surgery or a heart disease diagnosis, attendance at a typical 12 to 24 week rehab program can result in a 31% reduction in hospital readmissions and a 25% reduction in mortality. Patients who complete a program have better functional ability and quality of life, and experience less depression.

Despite this clear benefit, women are only half as likely as men to attend and adhere to the program.

Dr. Sherry Grace, a professor at York University and senior scientist at Toronto Rehabilitation Institute, [studies women in cardiac rehab](#). She has found women's under-use of rehab is due to a constellation of social and economic factors, beginning with low referrals from their physicians.



**Women are 50% less likely than men** to participate in cardiac rehabilitation.

"Through our research, we found that doctors do not perceive women will benefit from rehab as much as men," she says. "And one in three doctors was not even aware of their gender bias."

Dr. Tara Sedlak says it's time to put to rest the misperception that women do not need to attend rehab. It is clear that women derive a great benefit from attending. And it is a paradox that women who drop out of rehab, or who do not attend, tend to be the ones who would benefit most.

There are other gendered reasons why women are less likely to attend. Some are balancing work, child (or grandchild) responsibilities and caring for aging parents.

Cost can be a barrier for women, who are more likely than men to live in poverty, notes Dr. Sedlak. The cost is covered only in some Canadian provinces. In others, participants pay as much as \$100 per month.

A few clinics raise funds to cover the cost of cardiac rehabilitation for low-income patients and have social workers who evaluate ability to pay. Some clinics are looking at technology solutions, using telehealth and internet-based systems to offer hybrid at-home/group-session programs. Women-only and disease-specific rehab group models are being tested.

"In our clinic, women-only cardiac rehab programs have made a huge difference, particularly for younger women," says Dr. Sedlak. "In this type of setting, more stick through to completion. They feel they are better supported by others in the group who are age peers, and the information and education they receive is more relevant to them."

Pilot studies of virtual or online programs are underway, but may not be the perfect solution to address women's needs.

This innovation can help overcome some of the barriers, yet the social support benefit of an in-person group is missing.

This is especially important for women whose psychosocial need for support can equal or even outweigh their physical rehabilitation needs (see Beth's story, right). Women experience more depression after a cardiac event than men, so having peer support as well as access to social workers and psychiatrists makes a huge difference.

While women are still under-referred to cardiac rehab, Dr. Sedlak sees improvements in some larger institutions, many of which now include a standard tick-box on their discharge forms to ensure all women cardiac patients are referred to a program.

"In smaller, rural or remote communities, women might not get this same type of automatic referral," she says. "And without strong advice and support from physicians, it will be difficult to improve women's participation rates."

## HERstory:

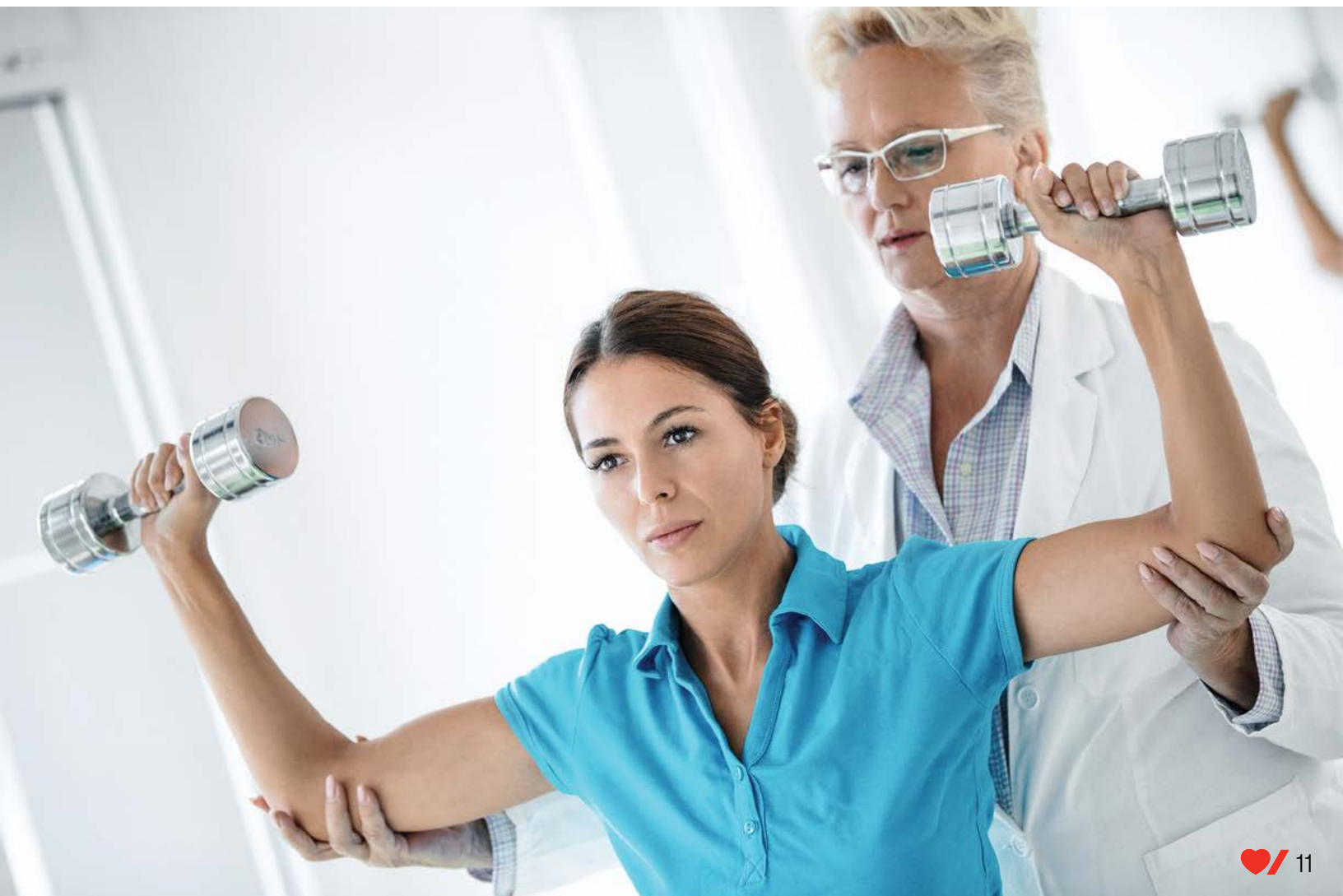
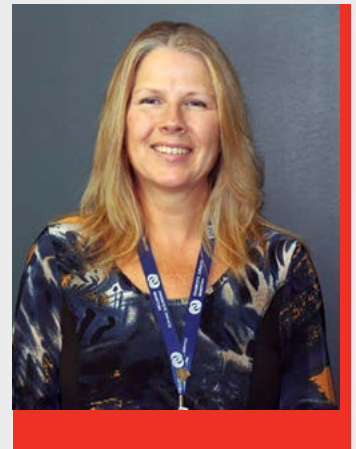
After a heart attack at age 51, Beth Luhowy was feeling isolated and anxious, as well as guilty over missing work.

The 16-week cardiac rehabilitation program she attended at the Reh-Fit Centre in Winnipeg helped her adjust psychologically and regain her confidence.

It also set her on course to a physical activity routine that has her feeling energized and healthy.

Yet Beth understands why some women may hesitate to attend cardiac rehab.

"I felt very selfish doing something strictly for me. It was only going through the program that I realized I would be more selfish if I didn't do this. I'm not going to be good for anyone else if I'm not taking care of myself."



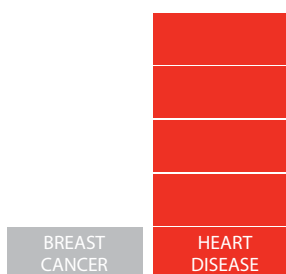
# Women's heart health:

## Under-aware



Despite years of information campaigns, women are still under-aware of the threat they face from heart disease. They don't know that heart disease claims five times as many women's lives as breast cancer. Or that it claims the life of one in five women. Or that some risk factors (high blood pressure, diabetes, alcohol intake and lack of physical activity) pose an even greater threat for them than for men.

To better understand why women themselves are not taking the risk seriously, Heart & Stroke conducted a survey of 2,000 women across Canada in June 2017, followed by in-depth interviews with a sample of respondents.



Women are **5X** more likely to die from **heart disease** than breast cancer.

The findings are striking. Low levels of health knowledge combine with high levels of unhealthy behaviours to put women at particular risk.

Risk factors reported by survey participants reflected high rates of overweight or obesity, high stress levels, unhealthy food choices and poor exercise habits. Yet only one in five said their doctor talked to them regularly about their heart health.

Knowledge about heart health was particularly low among young women, visible minorities and women in Quebec.

### Among women aged 19-29:

- **only 37%** believe heart disease can be different for women than men (compared to 67% of women age 50-69).
- **40%** eat unhealthy foods 5+ times per week (compared to 28% of women age 50-69).
- **58%** report stress most or every day (compared to 35% of women age 50-69).

### Among visible minorities:

- **only 48%** knew that nine out of 10 women have at least one risk factor.
- **only 28%** knew that heart disease and stroke are the leading cause of women's death worldwide.

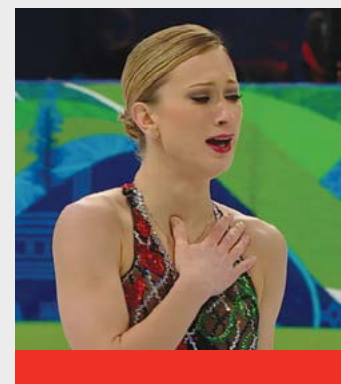
### And in Quebec:

- **39%** of women were able to correctly answer only four out of 12 basic heart health questions (compared to 44% nationally).



## HERstory:

Just two days before Joannie Rochette captured a bronze medal in figure skating at the Vancouver Olympics, her mother, Thérèse, died of a heart attack.



“She was 55. My mom wasn’t seeing a cardiologist or anything like that. It’s something that took me and my family totally by surprise; we didn’t see it coming.”

“Women often don’t put themselves first. My mom was definitely like that. After my mom passed away we found a piece of paper in her wallet that outlined some of the symptoms she was experiencing. She had never talked to us about them. She had pain in her left shoulder, numbness in her hands, blurry vision and she was tired all the time. When I saw that piece of paper, I felt guilty for not noticing it sooner. I was so busy training for the Olympics. The focus was on me at that time. I think that’s also part of the reason that she didn’t speak up.”

### How do we explain this perfect storm?

Diving deeper, some of the reasons became clear by looking at women’s perceptions of their roles.

For many women, the nurturing, caregiving role is deeply ingrained and connected to their identity. From birth to death, the act of caring for others – parents, spouse, children – shapes how women feel about themselves. The image of keeping it all together (and moving seamlessly between roles) reflects a source of pride and power for many women, and is enormously gratifying. It is learned in childhood, passed between generations and, for many women, becomes part of their DNA. Women’s roles within their cultures also play a role.

The flip side, however, is that for many women, keeping it all together means they don’t prioritize their own health. They may not voice their concerns about their heart health, and may downplay concerns in order to take care of other people’s needs.

This is who I am.  
I chose a partnership.  
I chose to have a family.  
These were my decisions  
so **I have chosen to care  
and I will give everything  
I can possibly give.**

Survey participant



Only **20% of women’s doctors** talk to them regularly about their heart health.

# At high risk: Indigenous women

Indigenous people in Canada — First Nations, Métis and Inuit — are up to two times more likely to develop heart disease. Coronary heart disease, which can lead to heart attack, is responsible for a 53% higher death rate in Indigenous women compared to non-Indigenous women. And Indigenous women die from heart disease at a younger age compared to non-Indigenous women.

Indigenous leaders say their communities are in a state of health crisis. Access to diagnosis, treatment and supports is a major issue. Poverty, education, access to affordable food and water and unsafe living conditions have created a widening health gap. Currently there is a research gap, indicating an urgent need for further study and a better understanding of how these factors impact Indigenous women.

Generational trauma and high-stress environments created by the impacts of historical policies have resulted in a disparate burden of risk factors and heart disease and stroke in Indigenous women. They are further affected by the high rate of inequities and by systemic racism.



## HERstory:

Looking back at her own health crisis, Esther Sanderson, a Cree woman from Opaskwayak Cree Nation, sees a connection to the decline in Indigenous traditional ways. As a result of significant damage from a heart attack in 2004, Esther underwent emergency heart transplant surgery. Five months later she returned to her home community in northern Manitoba, deeply appreciative of the care she received in a large centre, but she knew she had to return home to heal her spirit. She compares the differences between medical care in a large city and the type of care available to Indigenous women in First Nations communities:



*“Access to health care on-reserve carries equal barriers for both men and women but women are additionally disadvantaged.*

*Women especially face racism and marginalization in their encounters with the healthcare system. Indigenous women’s health is also impacted by family responsibilities, especially since many are single parents.*

*Since my heart transplant, I have met other women living with heart disease and learned that many don’t have the same success with their treatments.*

*Most First Nations communities do not have a doctor and there are no specialists. On-reserve, there are language problems — not only dialect, but also “doctor jargon.” Many people who have been through the residential school experience are hesitant to ask questions of people in authority, so may not understand their condition or medication. The health care and treatment at the very beginning of these people’s medical journey is crucial. If that doesn’t work well, they are reluctant to return.*

*I believe that the healthcare system can learn from the experience of Indigenous people. We all need the biomedical model to determine a diagnosis, but it is up to us to figure out what will restore our health — within ourselves, our family and our community. We must understand that spiritual, cultural and traditional healing are all important.”*

See Esther’s video here.

[https://www.ccnsa-nccah.ca/495/Video\\_mite\\_achimowin - Heart Talk by Esther Sanderson. nccah?id=211](https://www.ccnsa-nccah.ca/495/Video_mite_achimowin_-_Heart_Talk_by_Esther_Sanderson_nccah?id=211)

# At high risk: Women of South Asian, Chinese, and Afro-Caribbean descent

Women of South Asian, Chinese, and Afro-Caribbean descent experience higher rates of heart disease and poorer outcomes compared to Caucasian Canadians. They are also at a higher risk.

“Women of these ethnicities are more vulnerable to heart disease,” says Dr. Humphries. “They are also less likely to have optimal awareness, prevention, assessment and treatment.”

## What’s behind this reality?

- Increased risk factors include higher levels of physical inactivity, high blood pressure and diabetes.
- These women can be affected by income inequalities and consequences of racism.
- Many women face social and health inequities including additional systemic barriers to treatment and cardiac rehabilitation.
- Poorer outcomes are shaped in part by a lack of awareness for risk factors and symptoms, a lack of diverse

representation in clinical trials, as well as cultural and gender expectations.

Dr. Sonia Anand, Canada Research Chair in Ethnic Diversity and Cardiovascular Disease, notes that addressing the heart health challenges of women from these higher-risk ethnicities is complex. “There is a spectrum of vulnerabilities, based on the interaction between ethnicity, sex and socio-economic status,” she says. “How they intersect in each individual creates vulnerabilities which are unique to that person.” If a woman from a non-Caucasian ethnic group is at a low economic status, for example, she is at a greater risk than a woman from the same ethnicity who is at a higher economic status.

Adding to the challenge is that, while risk factors are the same between ethnic groups, the prevalence of the risk factors varies between ethnic groups, thus making the impact (or population attributable risk) of a given risk factor different in each ethnic community. The intersection between ethnicity, socioeconomic status and gender must be considered when developing strategies to lower the burden of heart disease in certain ethnic groups.



# Heart & Stroke's vision for women's heart health

"Heart & Stroke is committed to closing these gaps, so we better understand why heart disease affects women so profoundly," says Mr. Savoie. "We will advocate for healthcare systems changes so that women can know their symptoms will be investigated and their risks evaluated equitably through expanded knowledge of women's hearts. We will advocate for changes that will remove bias. We will champion support

systems so that once a woman is discharged from hospital, her recovery will continue with affordable access to cardiac rehabilitation and we will facilitate peer-to-peer connections. And we want women to know that if they choose to become advocates, speaking out and taking action for women's heart health, we will be there shoulder to shoulder with them."





# What is Heart & Stroke doing?

To improve women's heart and brain health, Heart & Stroke will:

## 1 Encourage and invest in research for and about women.

- Leverage Health Canada's \$5 million investment in women's heart health research to grow this pool of funding and maximize impact.
- Require research to address sex and gender as appropriate, including clinical trial enrollment.
- Translate knowledge to enable the development of better diagnosis, treatment, recovery and support for women.
- Increase support for the current and future generations of women and Indigenous scientists in research.
- Bring together the best researchers and clinicians in women's heart and brain health, as well as individuals with lived experience and community leaders to accelerate best-in-class research collaboration across Canada through:
  - the Heart & Stroke Women's Heart and Brain Health Research Network.
  - the Canadian Women's Heart Health Summit (co-hosted by Heart & Stroke and University of Ottawa Heart Institute's Canadian Women's Heart Health Centre).

## 2 Partner with system leaders, healthcare providers and people with lived experience to improve women's diagnosis and treatment.

- Develop and disseminate women-specific heart health clinical guidelines and standards of care.
- Advocate for training and continuing education of health care professionals to reduce the systemic bias women face in health care.

## 3 Facilitate connections for people with lived experiences, caregivers and families.

- Nurture and build a community of peer-to-peer support, so that women living with heart disease can connect, share resources and offer mutual support regardless of geography and income.

## 4 Build awareness and understanding of women's heart health.

- Educate people in Canada about the differences in women-specific risk factors, symptoms and prevention associated with heart disease, respecting diversity and inclusion.

## 5 Mobilize people in Canada to take action in support of better women's heart health.

- Inspire women to be self-advocates, ask questions of their healthcare provider, learn about their personal risk, share their stories, talk with other women and support collective action for improvements in women's heart health.
- Engage people with a passion for women's heart health, including women living with heart disease, to influence our research, programming and advocacy efforts.

## 6 Prioritize health reconciliation in our organization to build internal capacity and positively influence external networks and partners to help close the gap in Indigenous and ethnically diverse women's health.

- Work with Indigenous organizations to support and advocate for critical priorities for Indigenous women as identified by Indigenous people.
- Continue to develop the Heart & Stroke Partners Roundtable on Reconciliation to facilitate collaboration of health and Indigenous partners to build on joint strengths to address the Truth and Reconciliation Commission of Canada Calls to Action.

# The pursuit of heart health equity

## What can Canadians do?

It will take comprehensive commitment and action to correct the factors that have left women under-researched, under-diagnosed and under-treated, under-supported and under-aware.

### Under-researched

- **All funders of health research including provincial/territorial and federal governments** should invest in women's heart health research, and in building capacity across all pillars including basic biomedical, clinical, health systems and population health.
- **All funders of health research** should adopt policies which require that researchers collect, analyze and report data by sex, gender and race.
- **Funders and academic institutions** should develop strategies to understand and overcome women's hesitancy to participate in clinical trials.
- **All health research funders** should work with academic institutions to remove barriers to the advancement and leadership of women and Indigenous scientists in research.
- **Indigenous researchers and Indigenous communities** should identify unique issues facing Indigenous women and have the opportunity to work with non-Indigenous health researchers and others.

### Under-diagnosed and under-treated

- **Provincial/territorial governments and healthcare systems** should deliver personalized medicine (tailored to the individual patient based on their predicted response or risk of disease) and patient-oriented services, across the continuum of care, and should recognize Indigenous traditional medicine practices.
- **Healthcare systems, provincial/territorial and federal governments** should generate linked health and social surveillance data and use it to drive quality improvement through better understanding of the health and social issues facing women in Canada.

- **Universities, including medical schools and continuing medical education**, should deliver, as a prerequisite, training on sex and gender.
- **Healthcare institutions and systems** should accelerate knowledge into treatment, so that newest technology is available to all women, across the country (e.g., new diagnostic imaging technology to diagnose small-vessel disease).
- **Healthcare systems** should adopt/apply gender-neutral screening and risk assessment methodologies.

### Under-supported

- **Healthcare providers** should deliver patient-centred and clearly communicated risk factor and chronic disease management that meets the physical, social and emotional needs of women along the life course.
- **Hospitals and clinical settings** should provide systematic referrals to rehabilitation for all cardiac patients, as part of discharge checklists.
- **Provincial governments and healthcare facilities** should put programs into place to fund or subsidize cardiac rehabilitation so that cost is not a barrier for women.
- **All governments and health institutions** should implement the recommendations from the Truth and Reconciliation Commission report.

### Under-aware

- **Healthcare providers** should create positive environments and encourage open dialogue with women, contributing to increasing health literacy regarding heart and brain health.
- **Women and men** should strengthen their heart health literacy, becoming familiar with their risks, similarities and differences.

Together, we will transform the future of women's heart health!

See more real women's stories and learn more about women's heart health at **[heartandstroke.ca/heartreport](http://heartandstroke.ca/heartreport)**.

**Data sources and acknowledgements**

The survey and qualitative research with women in Canada was conducted by Intensions Consulting between June 23 -29, 2017. A total of 2,000 female respondents, age 19 or over took part in a 14-minute online survey. The results were stratified to reflect the distribution of the Canadian population by age and province as determined by 2016 Census data. The results are considered accurate to within plus or minus 2.2 percentage points, 19 times out of 20.

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Together, we're committed to saving women's lives by advancing women's heart and brain health in Canada.

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