

HEART VALVE DISEASE

Working together
to create a better
patient journey



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THE AUTHORS WOULD LIKE TO THANK THE FOLLOWING HEART VALVE PATIENTS FOR THEIR CONTRIBUTIONS:

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This report was commissioned by Heart Valve Voice Canada and written by The Health Policy Partnership, with co-authorship from an Advisory Council, which had full editorial control over content. The report was developed as an adaptation of the EU report by the same name, which was commissioned by the Global Heart Hub and published jointly by the Global Heart Hub and The Health Policy Partnership in 2020. The initiative was supported by a grant from Abbott, Edwards Lifesciences and Medtronic Canada.

Please cite this report as: Harding E, Budig K, Morris T, et al. 2022. *Heart valve disease: working together to create a better patient journey*. London: The Health Policy Partnership and Heart Valve Voice Canada.

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Foreword

Heart valve disease is a common, serious, but treatable condition. It affects more than one million Canadians but, until now, has maintained a low profile in the world of cardiovascular disease. Data on heart valve disease in Canada is sparse, and too many patients receive potentially life-saving treatments too late due to a combination of low awareness, deficiencies in detection, and delays in diagnosis and access to care.

It is in response to these major gaps in care that Heart Valve Voice Canada, a patient advocacy organization, developed this report. The report aims to raise stakeholder awareness of heart valve disease in Canada and describes an optimal care journey for people with heart valve disease.

This Canadian report builds on the European report published by the Global Heart Hub in 2020. It was developed under the guidance of a multidisciplinary advisory council, whose members included people with lived experience and healthcare professionals engaged in heart valve disease care in Canada. The patient perspective was the common thread throughout this report.

To our knowledge, this is the first report in Canada and North America that provides a comprehensive overview of the entire patient journey, from awareness and first detection to diagnosis, follow-up and treatment. Furthermore, the report provides a series of recommendations to improve the journey of people living with heart valve disease.

The report provides clear guidance and a road map for decision-makers and professional organizations on what they should do to reduce the burden of heart valve disease in the years to come. We hope it may also serve as an empowering tool for all people living with heart valve disease, to encourage them to seek optimal care for themselves and advocate for better care for others. Our next goal is to tailor this report and its call to action to meet the unique healthcare needs of each Canadian province and territory.

We would like to express our sincere thanks to all members of our advisory council for their continued support, enthusiasm and dedication throughout the development of this Canadian report. I am very proud of Heart Valve Voice Canada for bringing together this group of leading healthcare professionals and patients to describe the challenges that they face in managing heart valve disease, and for proposing actions to improve the patient journey.

Patient-driven and focused reports like this will help the collective ambition to achieve the best possible outcomes for patients, and will support national and provincial strategies related to heart valve disease in Canada.

Please join us in endorsing and disseminating this important, groundbreaking report and its call to action to stakeholders across Canada.

PHILIPPE PIBAROT

Board Member, Heart Valve Voice Canada
Canada Research Chair in Valvular Heart Disease

Executive summary

Heart valve disease has been described as ‘the next cardiac epidemic’.¹ It is a serious cardiovascular condition which can be fatal if left untreated.^{2,3} As Canada’s population is aging, heart valve disease is on the rise, contributing to increasing hospital admissions.^{4,5}

Unlike many other cardiovascular conditions, there are effective treatment options for heart valve disease that can slow disease progression, improve quality of life and reduce mortality.^{3,6,7} However, in too many cases the illness is undetected, untreated or treated too late. This results in avoidable deaths, high costs⁸⁻¹⁰ and significant compromises to people’s quality of life. Much of this burden could be alleviated by addressing existing gaps in care.

There are opportunities to improve heart valve care across the whole patient journey, from raising awareness through to ensuring timely and appropriate treatment and long-term follow-up. Investment in system-level improvements, such as building care around multidisciplinary heart valve teams and integrating remote technologies, can help ensure patients receive the appropriate monitoring, treatment and follow-up when and where they need it. There are also specific strategies that can be implemented at each stage of the patient journey to enable earlier detection of heart valve disease, improve access to specialist services and ensure all aspects of care align with the goals and priorities of the patient and their caregivers.

The growing prevalence of heart valve disease in our aging population makes improving care an urgent priority. If we want to ensure people living with heart valve disease can lead healthy, active and productive lives, we need to configure our health systems to deliver the highest quality of care to all.



Call to action

Addressing the gaps in the patient care journey is not only important for heart valve disease patients, it is also urgent if we want to protect the health and productivity of this growing population. Actions taken now will reduce the future burden of heart valve disease on our society in terms of impaired quality of life, avoidable deaths and costs to health systems.

To achieve this change, we call on decision-makers across Canada to work closely with healthcare professionals, patient organizations and the research community to ensure that all people with heart valve disease have access to appropriate diagnosis and treatment without delays.

OVERARCHING RECOMMENDATIONS ALONG THE ENTIRE CARE JOURNEY

Embed patient education and shared decision-making in all stages of care

Configure care around dedicated multidisciplinary heart valve clinics and teams

Facilitate integration of digital and remote technologies into care

Invest in data collection and research on heart valve patient-centred outcomes

Reduce inequalities in access to all components of heart valve care



SPECIFIC RECOMMENDATIONS AT KEY STAGES OF THE CARE JOURNEY



AWARENESS

- › **AWARENESS CAMPAIGNS:** Patient and professional cardiovascular organizations should develop national and regional campaigns to raise public awareness of the symptoms and impact of heart valve disease
- › **SUPPORT FOR PATIENT ORGANIZATIONS:** Public funding should be provided for patient organizations to ensure delivery of ongoing support and information to patients, families and caregivers



DETECTION IN PRIMARY CARE

- › **AWARENESS AND REFERRAL:** Patient and professional organizations should work in partnership to ensure primary care practitioners are aware of the red-flag signs and symptoms of heart valve disease, and of disease progression and contemporary treatment options
- › **SYSTEMATIC AUSCULTATION:** Every Canadian over 60, or with a pre-existing valve condition, should receive annual auscultation by stethoscope as part of routine check-ups by 2025
- › **ACCESS TO DIGITAL TOOLS:** Every provincial government should mandate and support the integration of digital tools, such as digital stethoscopes and handheld ultrasound, to aid in detection of heart valve disease in primary care settings



DIAGNOSIS VIA ECHOCARDIOGRAM

- › **RAPID REFERRAL:** Echocardiograms should be offered to symptomatic patients within two weeks of initial referral, and to asymptomatic patients within six weeks by 2025
- › **WORKFORCE PLANNING:** Provincial governments, in partnership with professional organizations, should increase the number of specialists able to perform quality echocardiograms, including in the community setting
- › **CONSISTENT QUALITY:** Professional and accrediting organizations should ensure that specialists performing and reporting echocardiograms receive adequate training, implement quality assurance programs, and develop standardized templates for echocardiography reports to referring physicians by 2030



REFERRAL, WORK-UP AND MONITORING

- › **REFERRAL TO ROUTINE REVIEW:** Every person diagnosed with heart valve disease should be promptly referred for regular scheduled follow-up, ideally within a dedicated service (i.e. heart valve clinic), including physical examination, echocardiogram and discussion about the care plan within four weeks
- › **CLEAR POINT OF CONTACT:** Patients should be provided with a clear and centralized point of contact to report any changes in their condition and receive their follow-up care



TREATMENT AND LONG-TERM FOLLOW-UP

- › **INDIVIDUALIZED TREATMENT CHOICES:** Healthcare institutions, in partnership with professional organizations, should implement shared decision-making between the patient and the multidisciplinary care team to select the most appropriate treatment for each individual by 2025
- › **TIMELY UPTAKE OF INNOVATIVE AND EVIDENCE-BASED TECHNOLOGIES:** Federal and provincial governments should ensure that every Canadian with heart valve disease has rapid access to innovative and evidence-based technologies
- › **CARDIAC REHABILITATION:** Healthcare institutions should provide cardiac rehabilitation, including physical and psychological support, to all people with heart valve disease by 2030
- › **ROUTINE FOLLOW-UP POST-TREATMENT:** Provincial governments, in partnership with professional organizations, should ensure that every patient has an echocardiogram annually as part of their long-term monitoring

The impact of heart valve disease

Heart valve disease is a debilitating condition with a significant impact on quality of life.¹¹⁻¹³ It occurs when there are structural or functional abnormalities in one or more of the four valves located in the heart (*Box 1*).^{14,15} Valves are vital to the heart's function, so any damage they sustain can cause debilitating symptoms.¹¹

Despite its rising prevalence, there is surprisingly little published information on the epidemiology of heart valve disease in Canada and its impact on patients' quality of life. What we do know is that increasing numbers of people are affected by heart valve disease, it causes avoidable deaths, and there is a high cost to not managing it effectively.



Heart valve disease can substantially impact a patient's quality of life, but until now has maintained a low profile in the world of cardiovascular disease. More attention is needed at the political and clinical levels to ensure we don't miss the opportunity to save lives and reduce suffering for those living with heart valve disease in Canada.

Ellen Ross

Heart Valve Voice Canada

THE BURDEN IS INCREASING, BUT AWARENESS REMAINS LOW

- › Between 2007 and 2017, there was a 68% increase in the number of hospitalizations for heart valve disease in Canada.⁵
- › Only 3% of Canadians over 60 are aware of aortic stenosis, the most common type of heart valve disease.¹⁶
- › The latest available data from the United States suggest that 13% of people over the age of 75 are living with heart valve disease.¹⁷

MANY DEATHS COULD BE AVOIDED

- › The rate of mortality in untreated, severe, symptomatic aortic stenosis is between 25% and 50% per year.^{12,18}
- › Data suggest that 94% of patients who undergo valve replacement surgery (aortic valve replacement) still have a well-functioning valve 10 years after the intervention.¹⁹

THERE IS A HIGH COST TO NOT MANAGING HEART VALVE DISEASE EFFECTIVELY

- › Precise estimates of the total cost of care for all forms of heart valve disease are not available. However, the one-year costs associated with hospitalizations for aortic stenosis in Canada are estimated at \$393 million.²⁰
- › The cost of poor management of heart valve disease – and not providing patients with an effective intervention – is much higher than the cost of managing it appropriately. This is owing to prolonged hospital stays, admissions to intensive care units, rehospitalization and rehabilitation,^{8,9} not to mention avoidable ill health, poor quality of life and mortality.

WHAT IS HEART VALVE DISEASE?

Heart valve disease results from damage to the valves of the heart. Heart valves have tissue leaflets, which open and close with each heartbeat to control the direction and flow of blood through the heart (*Figure 1*).^{14,21} When the leaflets or associated structures become damaged, or the valve opening or closing becomes compromised, blood flow is restricted or the valve becomes leaky. This causes strain on the heart as it attempts to compensate.²¹

Causes of heart valve disease are mostly related to degenerative change due to aging, and the illness often affects people over the age of 65.^{17,22,23} Other risk factors are common to cardiovascular diseases in general and include obesity, high cholesterol and high blood pressure. Heart valve disease is sometimes congenital and the

presence of other conditions (e.g. coronary heart disease, cardiomyopathy or rheumatic fever) may also cause heart valve disease.¹⁴ Valves may also be severely damaged by an infection.^{10,14}

There are several types of heart valve disease. These are defined based on which of the four heart valves (aortic, mitral, pulmonary or tricuspid) is damaged or malfunctioning and whether it is a case of stenosis, which is a narrowing of the valve space, or regurgitation, which occurs because of improper closure of the leaflets and results in blood leaking backwards into the heart chamber.^{14,21} The most common forms of heart valve disease are aortic stenosis and mitral regurgitation,²⁴ but recent data suggest that tricuspid valve disease is also on the rise.^{6,25}

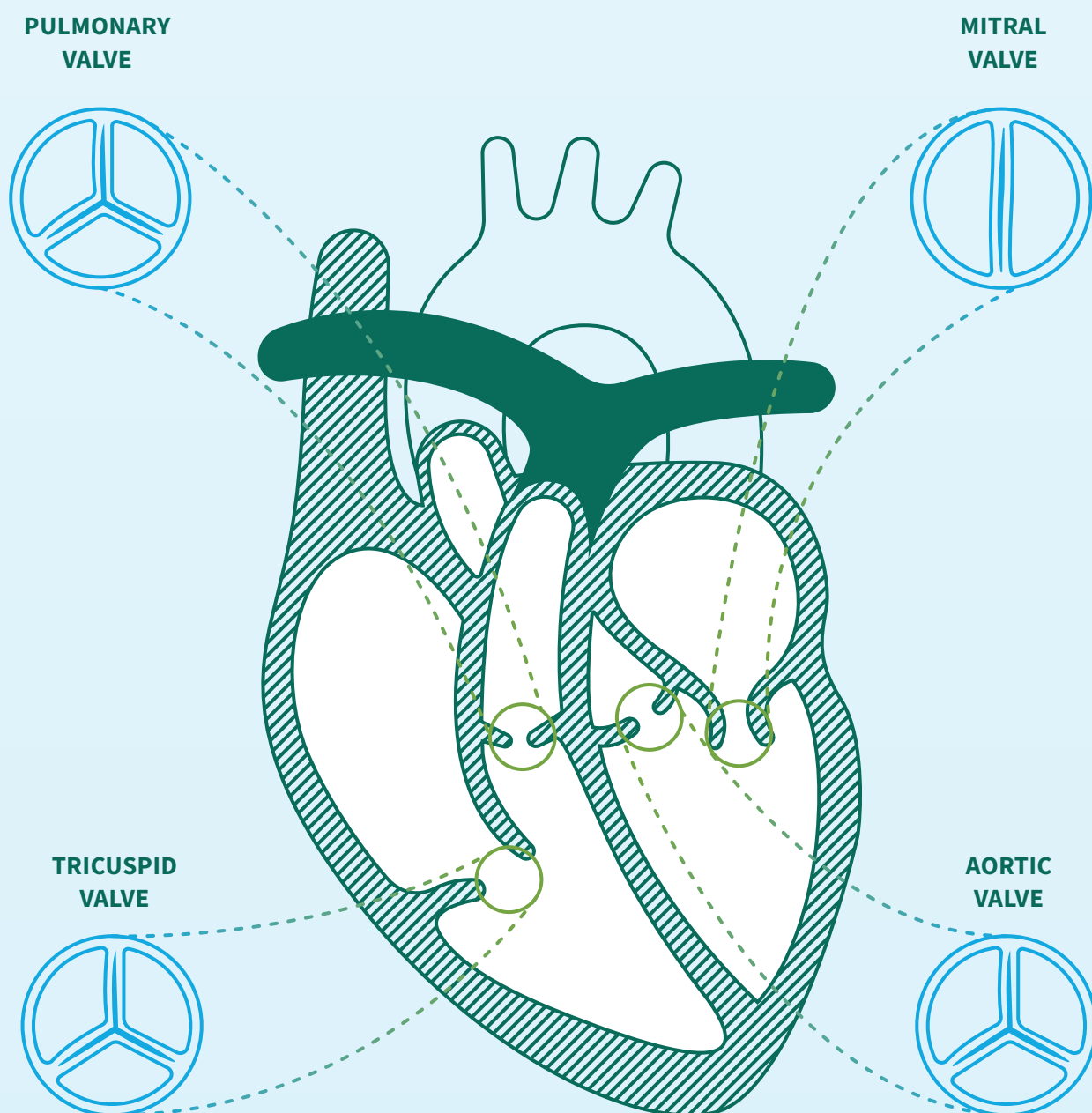


Figure 1: Heart valves

The patient care journey

We have effective, proven treatments for heart valve disease. It is therefore crucial that people with heart valve disease enter appropriate care pathways as soon as possible to ensure they receive timely, best-practice care (*Figure 2*).

The optimal patient journey for heart valve disease has been well defined in international guidelines.^{26 27} Actual care, however, may vary between individuals: a younger person may experience a very different course of disease than someone who is older, as might a man compared with a woman (*Box 2*); the presence of comorbidities will affect how the disease progresses and affects the person's life; and intervention options vary between the different types of heart valve disease.

It is essential to take a personalized approach through all phases of care. In addition to variability in their clinical situation, people with heart valve disease may have different personal preferences and goals for treatment. Patients are at the centre of the care process, therefore shared decision-making should be used to ensure their personal goals and values are aligned with clinical decisions through all stages of their care.²⁸ Key steps of the care journey are described in more detail on the following pages.

BOX 2

The patient care journey is often different for women

The causes, mechanisms and evolution of heart valve disease differ substantially in women and in men.²⁹⁻³¹ Women may develop different symptoms of valve disease. Because of these differences, valve diseases are underdetected, underdiagnosed, and thus undertreated to a greater extent in women.³²

Research conducted by the Canada Research Chair in Women's Cardiac Valvular Health showed that women with severe heart valve disease are referred less or referred later for intervention compared with men.^{32 33} This gap in care leads to increased risk of avoidable deaths and hospitalizations and lower quality of life in women with heart valve disease.

More research and clinical trials are required to determine the specific changes in the primary and specialized healthcare that need to be implemented to improve the longevity and quality of life of women living with heart valve disease.

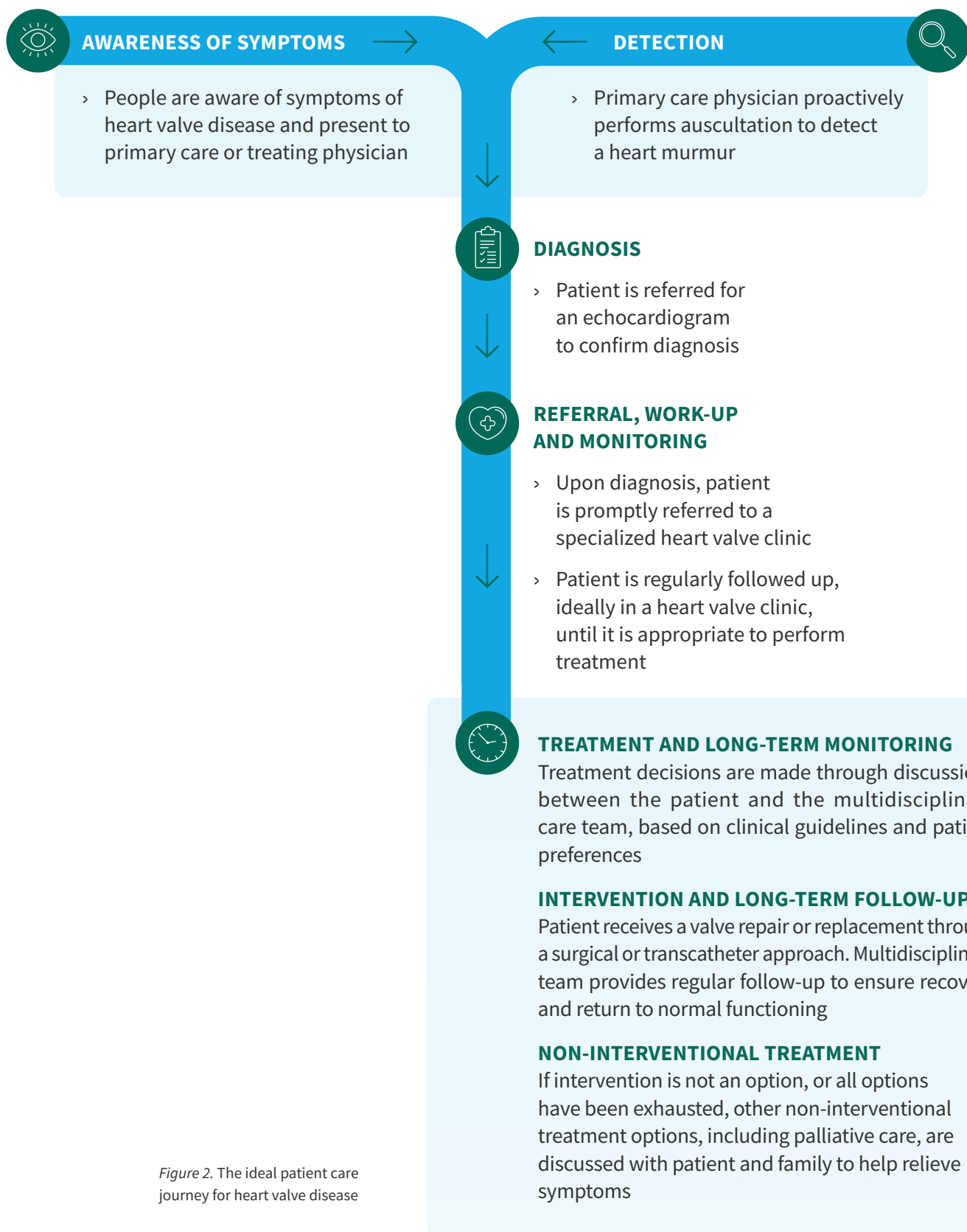


Figure 2. The ideal patient care journey for heart valve disease



AWARENESS OF HEART VALVE DISEASE AND ITS SYMPTOMS

Awareness of symptoms is the first step in the patient journey. The signs and symptoms of heart valve disease may be difficult for people to recognize as they vary between individuals and often mimic general signs of aging. People should be made aware of the main symptoms, which include: shortness of breath; fatigue; chest pain; heart palpitation; dizziness; fainting; swelling of ankles, feet or abdomen; and inability to sleep flat at night due to cough or congestion.³⁴ A person experiencing any of these symptoms should see their primary care physician. As a result of low awareness, people may live for a long time with heart valve disease without recognizing that anything is wrong.



TIMELY DETECTION

Timely detection of heart valve disease through identification of a heart murmur is essential to avoid irreversible heart damage and to improve patient outcomes.²⁶ Many patients in advanced stages of the disease are asymptomatic,³⁵ which is why regular screening is important. A heart murmur is typically identified in primary care through the use of a stethoscope (auscultation). Novel technologies, such as digital stethoscopes, computer-aided auscultation, electrocardiogram and point-of-care echocardiogram, have the potential to support detection and ensure timely diagnosis if widely adopted in the future.³⁶



DIAGNOSIS

People with a suspected heart murmur should be referred for specialist assessment and diagnosis, which should be done in a dedicated service (heart valve clinic) where available.^{37,38} An echocardiogram should be performed by a specialist with imaging expertise.³⁷ Additional tests, such as an exercise stress test, a transesophageal echocardiogram, computerized axial tomography (CAT scan), cardiac magnetic resonance imaging or cardiac catheterization, may also be helpful to confirm the diagnosis.^{26,39}



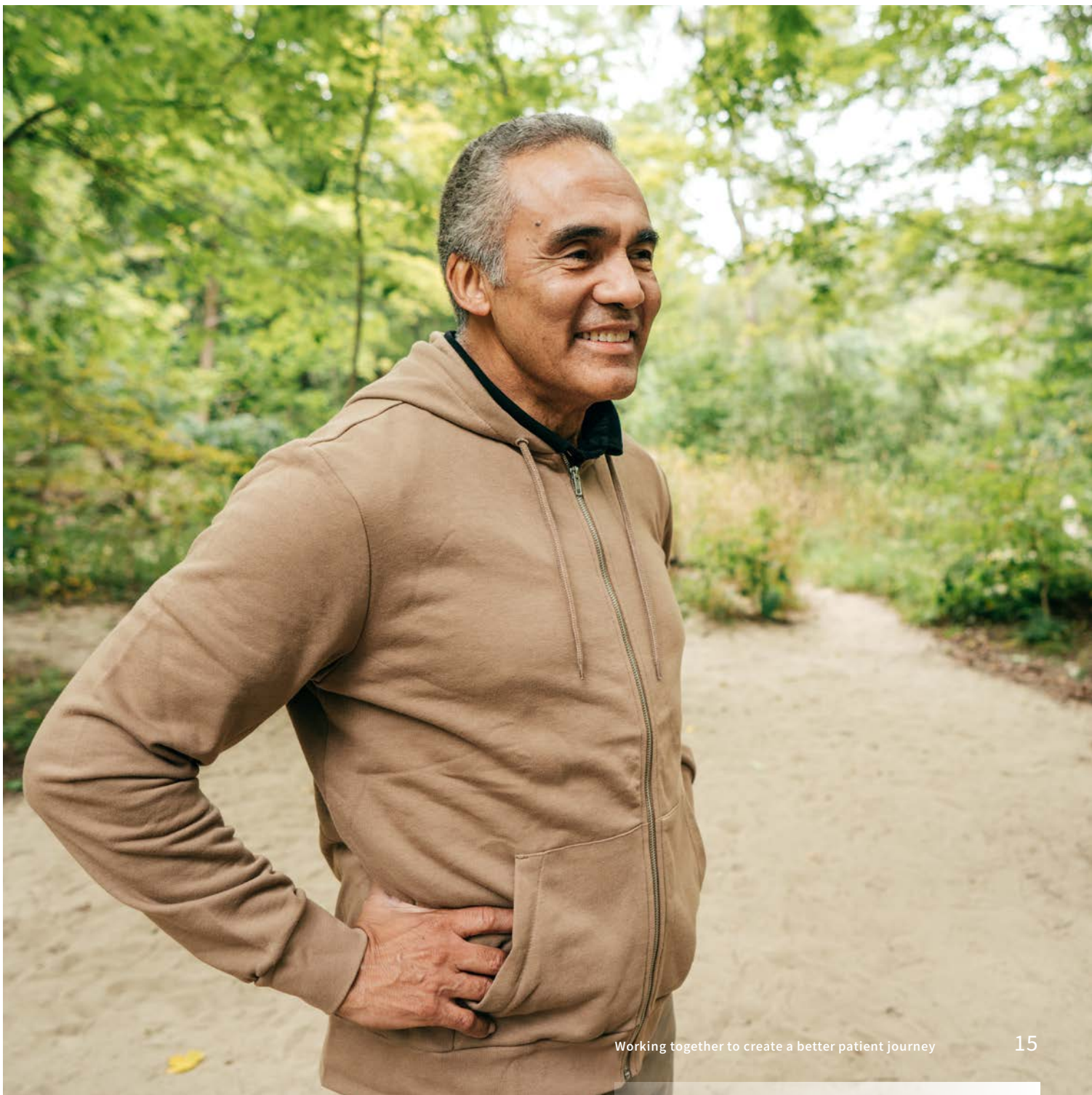
REFERRAL, WORK-UP AND MONITORING

Following diagnosis, people with heart valve disease must be promptly referred to a specialized program for work-up and monitoring before they require an intervention. The duration of this “watchful waiting” period varies from person to person. Ideally, they will be referred to a heart valve clinic or other dedicated service, where they are put on active surveillance and may be given medication to help alleviate their symptoms and comorbidities.^{3,26} Individuals who are being monitored need to be reviewed on a regular basis, including periodic echocardiograms and blood analyses, to monitor and identify signs of disease progression that may require valve repair or replacement. Any onset or increase of symptoms should trigger an immediate visit.



When experiencing valve-related symptoms of fatigue or shortness of breath, patients often self-attribute this to “old age” and down-regulate their physical activities to avoid any symptoms. Not only does this delay the time to appropriate medical evaluation and treatment, but it also initiates a vicious cycle of sedentariness leading to deconditioning and frailty.

JONATHAN AFILALO, cardiologist





TREATMENT AND LONG-TERM FOLLOW-UP

Treatment decisions must be made in consultation with a multidisciplinary team, informed by a range of clinical tests, and must aim to meet the goals and preferences of the patient and their caregivers.^{40 41}

In deciding how best to treat heart valve disease, a multidisciplinary care team (including specialists such as cardiologists, surgeons, nurses, psychologists, geriatricians, kinesiologists and others) needs to assess factors such as the appropriateness and feasibility of available options.²⁸ The team must review the results of diagnostic tests and consider the individual characteristics of each patient.⁴² A shared decision-making approach should always be taken, in which the patient and their caregivers are involved in care decisions and their preferences are understood and taken into account by the care team.²⁸

The mainstay of heart valve disease management is valve repair or replacement in conjunction with ongoing management and medical treatment. This can be achieved through either surgery or catheter-based interventions, both of which have been shown to improve people's survival and quality of life.^{43 44} Catheter-based approaches, such as transcatheter aortic valve implantation (TAVI) and transcatheter mitral or tricuspid valve repair, are becoming increasingly common.⁴⁵⁻⁴⁷ They allow access to the heart valves through special catheters inserted through a blood vessel, typically located in the groin. Valve repair and replacement strategies are evolving toward minimally invasive procedures, which may offer shorter recovery times⁴⁶ and tend to be preferred by people with heart valve disease, although in many cases open-heart surgery is still required.⁴⁸ Any intervention should be combined with long-term medical therapy for concurrent conditions and risk factors.²⁷

In situations where the risks of intervention outweigh potential benefits for a person with heart valve disease, more conservative treatment options should be considered.⁴⁶ Choosing to transition to supportive care that aims to maximize quality of life rather than longevity must be made by the patient and their caregivers, supported by the multidisciplinary heart valve team.^{26 46} Respecting individual wishes is essential, as is involving palliative care clinicians and psychological support services that are required to meet individual needs when invasive treatment is not an option or a patient's choice.⁴⁹

Once a person has had an intervention (either surgical or catheter-based), they enter a phase of recovery and follow-up care. This should start early after the intervention⁵⁰ and include cardiac rehabilitation^{51 52} and psychological support⁵³ provided by a multidisciplinary team. Regular, centralized, specialist-led monitoring, ideally in a heart valve clinic, is important to assess for potential deterioration of prosthetic valves and ensure early detection of any disease in another valve.²⁶ Canadian guidelines clarify that patients should have an echocardiogram 30 days after their valve intervention, and periodically thereafter, to closely monitor the health of the heart and identify any possible progression of disease severity.⁴⁶ Ongoing monitoring of people's quality of life is also vital to ensure they are adapting well post-intervention and are able to return to their normal levels of activity and functioning.^{50 53}

Ongoing management of cardiovascular risk factors and related conditions plays an important role in improving outcomes for patients. This includes, for example, fostering lifestyle change with regular exercise, optimal weight and cessation of smoking; using medication to reduce high blood pressure; and improving diabetes management²⁷ – all of which can help to prevent or delay related conditions, such as heart failure and coronary heart disease.⁵⁴





PATIENT STORY

David Smith

When my retirement began, I was enjoying an active lifestyle: golfing, boating and taking on big home improvement projects. I also started playing hockey again after years away from the sport, but was surprised at how breathless I was. I know now that the breathlessness I felt was a warning sign, but at the time I was unaware of heart valve disease. I assumed it was a normal part of aging, and told myself I was doing well to be so active in my 60s.

The following spring, I noticed that everyday activities like playing with my grandkids were tiring me out more quickly than they should. Thinking back to how fit I was just a few years before, I knew I should be able to do more, but I still wasn't worried enough to visit my family doctor. The COVID-19 pandemic meant I wasn't having regular check-ups either, so I missed out on a routine stethoscope check.

Fortunately, I have a friendly relationship with my family doctor, and that summer I mentioned the way I had been feeling in a casual conversation with his secretary. Thanks to that offhand remark, my doctor phoned me the next day and said I could be experiencing normal signs of aging, but that I should have an echocardiogram to be safe.

I went to the hospital for an echocardiogram the following day and the results showed that I had severe aortic stenosis. It was clear that I would need a valve replacement and I was told that I should go straight to the emergency department if I experienced any alarming symptoms, like chest pain or dizziness.

Soon after my diagnosis, I felt a pain in my chest while barbecuing and went to the hospital right away. Test results showed that I needed surgery more urgently than planned, so the necessary arrangements were made and I received my new valve a few weeks later.

Since my surgery, I have had virtual follow-ups with my surgeon and cardiologist. Unfortunately, post-operative rehabilitation services were closed because of COVID-19, so I have not seen any other specialists for physical or mental health. However, I did follow the exercise instructions I was given, making sure I went out for regular walks throughout the winter. After a year with my new valve, I am once again enjoying an active retirement. I can golf, swim and run around with my grandkids without exhaustion.

Following my experience, I have become an active advocate for raising awareness about heart valve disease, and encourage friends to get regular stethoscope checks. My best advice is to listen to your body and see your doctor if you think anything might be wrong. If I hadn't paid attention to the warning signs or made a casual comment about how I was feeling, it's frightening to think my heart valve disease might not have been spotted in time. Luckily, I had quick access to the necessary tests and treatment, and can now look forward to living a full life long into the future.



Following my experience, I have become an active advocate for raising awareness about heart valve disease, and encourage friends to get regular stethoscope checks.

PATIENT STORY

Mandy Irving



I was aware of my heart murmur for years as it runs in my family. My family doctor kept an eye on it with regular stethoscope checks and sent me for routine echocardiograms, but I never noticed any new symptoms like pain or breathlessness. To my surprise, the results of one of my routine echocardiograms showed that two of my heart valves were damaged and leaky.

My heart valve disease was caused by an autoimmune condition – a type of arthritis – that attacks healthy tissues, including my heart. This condition causes fatigue, which was masking the signs of heart valve disease. Because of this, it probably would not have been detected for a long time if my family doctor hadn't been following me so closely.

I was referred to a cardiologist, who decided that I should be monitored to see how my valve disease was progressing. I could tell that, as I was a young woman, he did not want to send me for heart surgery too soon, but after a year of monitoring and tests, he determined that I was ready for valve replacement surgery. I remember being quite surprised when he said that my heart was enlarged but not large enough to meet the guideline-based criteria for surgery. He explained that the guidelines are primarily based on men, and as a woman my heart would probably never reach the size specified in the guidelines, so he had to use his clinical judgement.

Once I had been referred for surgery, there were additional delays because of COVID-19, but I received two new valves in June 2020 – about two-and-a-half years after I was first diagnosed. I received great follow-up care and relished having a team of specialists supporting me as I worked



I can look back and see how badly affected I was by the heart valve disease without being aware of it. It's as though I've discovered new gears on my bike!

to recover. I have had virtual appointments with a cardiologist, a nurse practitioner, a physiotherapist, a nutritionist and a counsellor as part of my follow-up. I found the recommended outdoor walks to be especially beneficial and my biggest piece of advice to anyone recovering from heart valve surgery is to follow the walking plan. It was difficult at first, but I got so much out of it.

My experience of living with a chronic autoimmune condition definitely helped prepare me to deal with heart valve disease and surgery. I am familiar with doctors and our health system, and used to being involved in managing my own health. After years of being unwell before the autoimmune condition was diagnosed, it felt like a relief to have a clear, structured care plan following surgery and I was determined to make the most of it.

More than a year after my valve replacements, I can look back and see how badly affected I was by the heart valve disease without being aware of it. It's as though I've discovered new gears on my bike! I can do so much more exercise now and it no longer wears me out to run errands. I will always be managing a chronic condition alongside the long-term monitoring of my heart valves, but I am excited to see my stamina continuing to improve and feel hopeful about what I will be able to achieve in years to come.

Improving the patient care journey: addressing the gaps

Despite the availability of international guidelines outlining best practice, there are notable gaps in care at different stages in the patient journey, which can vary considerably both between and within provinces.^{16 55 56} Such gaps can result in missed diagnoses, compromised quality of life and premature mortality.^{57 58} Addressing them will require action along the entire patient care journey, including further research to ensure that appropriate data on the impact and burden of heart valve disease are available to guide future investment in care.



The new options for heart valve patients have truly been revolutionary over the past decade. Despite this, too few patients are diagnosed, and even when identified, too few are being offered options that align with their preferences. This is the challenge for the next chapter of heart valve therapy.

HARINDRA WIJEYSUNDERA, cardiologist





Opportunities along the entire patient care journey

PATIENT EDUCATION AND SHARED DECISION-MAKING

Patient education needs to be embedded across all stages of the care journey.

A person-centred approach is essential in heart valve disease and patient education is its key component. Patient education has been defined in international guidelines as a vital element of care.^{27 59} It should aim to help people with heart valve disease make informed decisions, understand why specific treatments are suggested to them, and prepare for and manage different aspects of their condition. Shared decision-making is a bidirectional process between patients and their healthcare providers that enables effective exchange of information and supports treatment decisions that complement patients' informed preferences.⁶⁰ Patient decision aids are evidence-based tools designed to support this process and help guide the conversation between patients and clinicians.^{61 62} The availability of decision aids for the treatment of heart valve disease, which reflect the Canadian context of care, would help to

facilitate the implementation of shared decision-making. Multidisciplinary teams, including specialist nurses, should receive dedicated training to encourage ongoing dialogue and empower patients to participate in their treatment decisions, and communicate their preferences, priorities and goals at every step of their care journey.^{28 39 50} The essential role that patient organizations often play in providing people with information and support to complement the work of the clinical team should also be recognized.



The goal of care is always to make a high-quality decision. This means using the best scientific evidence we have, but also asking patients what matters most to them. Shared decision-making is a way to have this conversation and give patients tools that empower them to be real partners in the treatment of their heart valve disease.

SANDRA LAUCK, cardiovascular nurse

GREATER INVESTMENT IN MULTIDISCIPLINARY TEAMS WITHIN DEDICATED HEART VALVE SERVICES

All people with heart valve disease should be treated by a multidisciplinary team.

Traditionally, it is recommended that cardiovascular conditions be managed by specialized teams. Such teams include cardiologists, cardiac surgeons, rehabilitation specialists and specialist nurses.^{37 63} However, depending on the complex needs of some people with heart valve disease, the involvement of other allied health professionals may be needed. This may include internists, neurologists, gerontologists, psychologists and palliative care specialists. Close communication and coordination between all these professionals, as well as with the person's primary care physician, is crucial at every stage of the care journey.²⁸

The heart valve clinic model allows people with heart valve disease to be cared for by a multidisciplinary team.^{26 63} This enables different professionals to engage in an interdisciplinary approach to inform treatment choices,⁶³ and provide comprehensive support and follow-up adapted to each individual.^{26 50 63 64} The heart valve clinic model ensures that decisions along the patient journey take account of the full spectrum of a person's needs over time, and provides them with optimal continuity of care while ensuring efficient use of specialist expertise when needed. It also ensures that a person's care can be rapidly adapted to changes in their condition both before and after heart valve intervention (Box 3).

BOX 3

The case for centralized management in heart valve clinics

Heart valve disease can be a complex and evolving condition. Centralization of care in a heart valve clinic provides opportunities for timely referral from diagnosis to intervention, regular follow-up and active surveillance, as well as patient education throughout all phases of care.^{63 64} However, recognizing the geographical diversity in Canada, with variable access to specialist clinics, delivery of care may depend on providers in the local community, such as primary care physicians and internists, in consultation with a centralized heart valve team.

There is evidence that dedicated, active monitoring leads to improved outcomes for people with heart valve disease. Following diagnosis, active surveillance can support earlier detection of disease progression and timely referral for valve intervention.^{65 66} After intervention, individualized follow-up can help prevent hospital readmission in the first six months following discharge.⁵⁰ Furthermore, adherence to clinical guidelines has been shown to be better when care is managed in a heart valve clinic than in a general cardiology clinic.^{37 67}

Heart valve clinics are also likely to be more cost-effective than conventional models of care.⁶⁸ Processes across diagnosis, treatment and follow-up can be streamlined when they all take place at one site.^{63 64} The centralized model of care allows for specialist expertise, quality control and monitoring of guideline adherence in each clinic.^{37 64} The overall cost of management can be reduced by avoiding unnecessary echocardiograms, duplicative clinic visits (thus freeing consultant time) and repeated or prolonged hospitalizations.^{50 68}

INTEGRATION OF DIGITAL AND REMOTE TECHNOLOGIES INTO CARE

Continued exploration of the appropriate use of remote technologies is needed.

Remote monitoring and other telehealth solutions could improve access to specialist care, especially for people living in rural parts of Canada. Distance to specialist clinics is a recognized barrier to accessing care for people living in rural areas, who make up approximately 19% of Canada's total population.⁶⁹ Coupled with the limited number and uneven distribution of heart valve clinics across the country, this means that many Canadians will be unable to easily access key services in person. Remote monitoring strategies and virtual appointments could facilitate access, and primary care practitioners could provide in-person care in close consultation with the heart valve team.

The COVID-19 pandemic has accelerated the use of telehealth and remote monitoring. As services settle into a “new normal”, it is important to understand to what degree telehealth services can be integrated and further expanded as a permanent part of practice in heart valve care, while maintaining high standards. Computer-aided auscultation, artificial intelligence-supported electrocardiography and handheld ultrasound devices have the potential to foster timely diagnosis and referral, and further support treatment planning.³⁶ It is equally important, however, to consider the value of physical examinations in detecting and monitoring heart valve disease. Where possible, patient preferences should be taken into account when offering remote or in-person consultations.

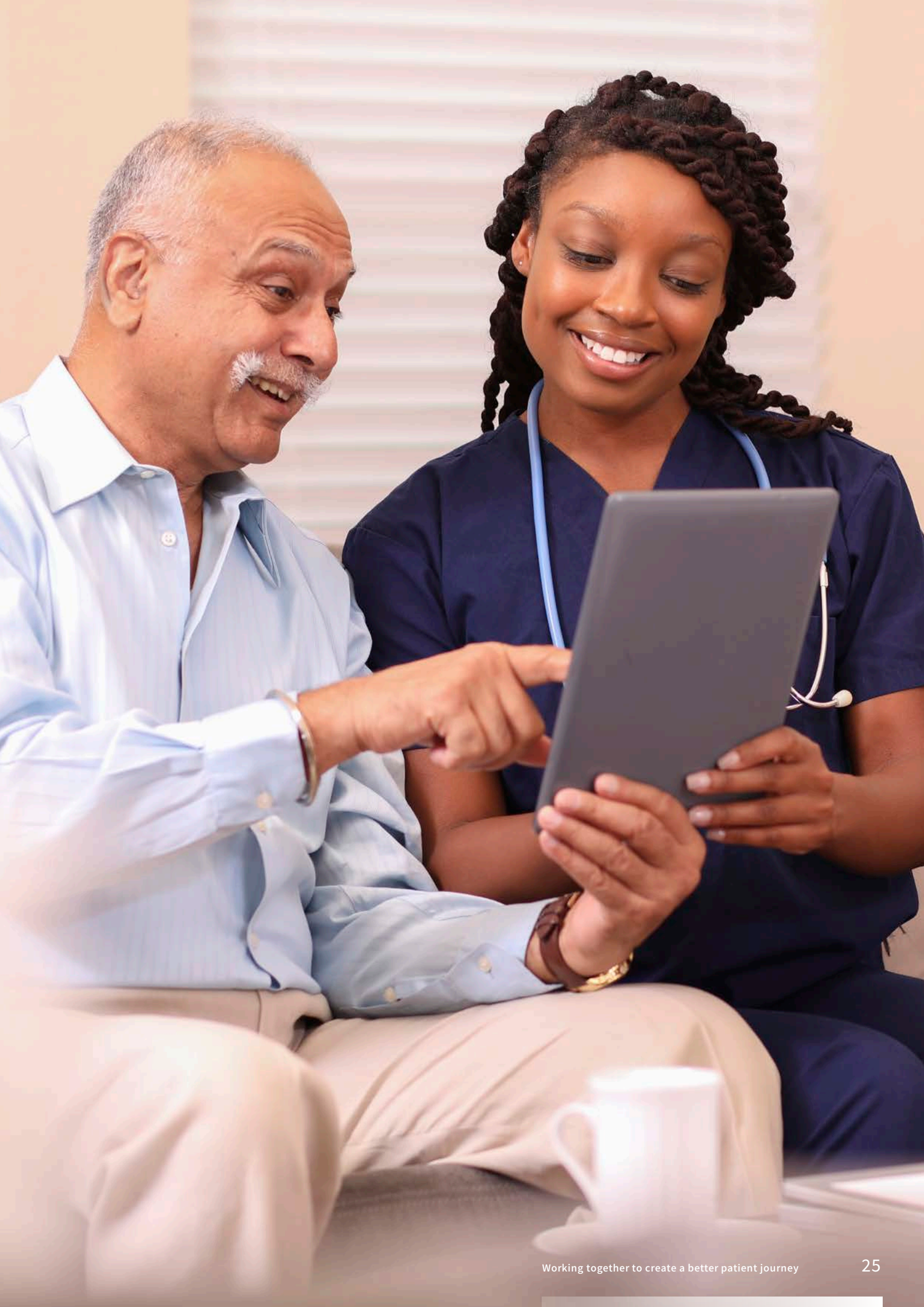
INVESTMENT IN DATA AND RESEARCH

Investment in data and research is needed to improve our understanding of the burden of heart valve disease and guide improvements in care delivery.

An underlying issue in heart valve disease is the lack of comprehensive and comparable real-world data. Some regional-level databases exist and the Canadian Institute for Health Information collects hospital discharge data and publishes cardiac care quality indicators. However, there is currently no centralized database collating data on incidence, prevalence, interventions and outcomes for heart valve disease across provinces.⁷⁰ These data are essential for presenting policymakers with accurate estimates of the number of people affected, as well as measuring progress in patient outcomes over time.

More research is needed to foster improvements along the entire patient journey, not just interventions. More research is needed on which outcomes and values are most meaningful to patients with regard to heart valve disease and care;²⁸ current recommendations are too often formulated without appropriate input from patients. The past few years have seen considerable research on different types of surgery and catheter-based approaches, but other important aspects of the patient journey – such as early detection, individualized risk assessment, improvement of quality of life and medical therapy for slowing the progression of heart valve disease – are less well studied.^{54 57} Important gaps include: how best to identify and treat asymptomatic illness;^{71 72} care pathways for younger patients or for women (Box 2);^{26 29 30 72 73} standardized assessment tools to confirm diagnosis;⁵⁷ and quality control measures to track and monitor clinical performance, adherence to clinical guidelines and patient-centred outcomes.

Finally, better economic data are needed to support the case for investment in heart valve disease. These data are important to gain an up-to-date understanding of the impact of the disease and care options on health system resources. They can then be combined with clinical and quality-of-life data to guide funders toward the most effective and cost-effective investments in care.



Improvements at key stages along the patient journey



PUBLIC AWARENESS

Greater efforts are needed to improve public awareness of heart valve disease, particularly in older adults.

Public awareness of the symptoms of heart valve disease is generally low, and this leads to underdetection. Surveys have shown that most people do not know what heart valve disease is and would not usually consult a physician when experiencing some of the typical symptoms;^{74 75} by contrast, if they had typical symptoms of a heart attack (e.g. chest pain), they would.⁷⁶ Greater efforts from patient and professional organizations are therefore needed to improve public awareness of heart valve disease and potential symptoms, particularly for older adults. This must be supported with public funding for key organizations.



DETECTION

Underdetection is a major issue in heart valve disease. Data suggest that a significant number of cases of heart valve disease may go undetected, affecting prognosis and long-term survival. For example, a major UK study found that, among a group of 2,500 people over the age of 65 who were registered in primary care centres, 11.3% had moderate to severe heart valve disease, but more than half of them had not been previously diagnosed.² In Canada, access to primary care is inadequate in many provinces and territories,⁷⁷ which undoubtedly creates a barrier to detection of heart valve disease (Box 4).⁷⁸



A routine stethoscope check in my 20s likely saved my life. It led to an early diagnosis of my congenital heart valve disease before I had any symptoms, so I was able to monitor and manage my condition from an early stage, and to seek care immediately when I noticed some chest pain decades later. Had I not known anything was wrong with my heart until the valve disease had become far more serious, it may have been too late.

NANCY BAGWORTH, heart valve patient

Inequalities in access to care

Canada's universal healthcare coverage means that every person with heart valve disease is entitled to free care at every stage of the care journey. However, inequalities in access persist, and are often driven by the country's geography and urban-rural divide. Access to healthcare, including specialist care, is also often deficient in Indigenous communities.^{79 80}

Primary care practitioners are key to detecting heart valve disease and should be involved in ongoing care following diagnosis. Unfortunately, many Canadians experience barriers to accessing primary care; fewer than half (43%) can get a same-day or next-day appointment when they are ill.⁸¹ Barriers to access vary significantly both between and within provinces, likely resulting in unequal detection, diagnosis and treatment of heart valve disease. The uneven distribution of healthcare providers is thought to be an important factor influencing healthcare access and usage: 92% of primary care practitioners work in urban locations,⁸² whereas 19% of the population live in rural areas.⁶⁹ Moreover, data from the Canadian Community Health Survey show that people living in the most urban and the most rural areas were the least likely to have a regular family doctor,⁸³ demonstrating the need to examine and address population needs at a local – rather than regional or provincial – level.

Specialist services, such as cardiologists and heart valve clinics, tend to be concentrated in larger cities. As a result, people in urban areas are more likely to consult specialists than those who live in rural areas.⁸³ People living in rural communities have reported that they would not be able to travel to specialist centres because of the financial cost of travelling, or because of the discomfort or unsafe conditions (particularly in winter) associated with travelling long distances.⁸⁴ For people with heart valve disease, the lack of access to specialist care in rural communities could prevent timely diagnosis and lead to inadequate monitoring and follow-up across the patient journey.

Primary care practitioners and community partners should be alerted to the signs and symptoms of heart valve disease and enter patients into appropriate care pathways.

As the first port of call for people experiencing signs and symptoms, primary care practitioners must be aware of the key signs of heart valve disease and the appropriate care pathways. Primary care staff may require specific training to help them recognize the signs and symptoms of heart valve disease, which can be difficult to diagnose. This is the case particularly in older adults, as it may be masked by the presence of comorbidities with similar presentation.³⁹ When heart valve disease is suspected, practitioners should be familiar with available resources and treatment options so that these can be discussed with the person, and to ensure the person is referred to the appropriate services. Additional providers of health information and care in the community, such as pharmacists and community nurses, could also be valuable partners in recognizing the signs of heart valve disease.

Primary care practitioners should perform regular stethoscope checks as part of routine care.

Given that heart valve disease often presents without obvious symptoms, primary care practitioners should be encouraged to systematically auscultate all patients over 60, as well as all those with pre-existing valvular disease, as part of annual routine health checks.^{85 86} International data repeatedly show that fewer than half of older adults receive a stethoscope check as part of primary care appointments, highlighting the need for training and improved awareness of this aspect of care.^{74 87 88} One way to improve detection of heart valve disease may be to facilitate the use of digital tools, including digital stethoscopes and handheld echocardiogram devices in primary care.⁸⁹ In addition, as the use of virtual healthcare has increased in the wake of COVID-19, physical examinations including auscultation may be in decline; a recent survey found that fewer than 40% of Canadian adults had had a stethoscope check in the preceding year.⁵⁶ While virtual healthcare offers a range of benefits, it is important that physicians and the public are also aware of its shortcomings, and that some consultations take place in person to allow for key physical examinations.



DIAGNOSIS

Rapid access to high-quality echocardiograms

All people with suspected heart valve disease should be referred for an echocardiogram within a set time frame, to ensure they can enter appropriate care pathways as quickly as possible.

People often experience delays in accessing an echocardiogram, leading to delays in diagnosis and treatment. Although the urgency of referral will depend on a person's presentation, it is recommended that those with symptomatic heart valve disease be referred for an echocardiogram within two weeks of presenting to their physician, and asymptomatic patients within six weeks.⁹⁰ In Canada, wait times for echocardiography vary both within and between provinces, ranging from as little as one week for some people to over a year for others.⁹¹ Recommended time frames should be embedded in provincial standards and local care protocols, and regularly monitored through clinical audits.

Ensuring the availability of a sufficient number of echocardiographers is important to increase access to diagnostic services.⁶³ Availability of these specialist imaging personnel varies considerably by province.⁷⁸ Careful workforce planning, including adequate training and funding for key roles, is needed to increase the number of echocardiographers and sonographers who are trained to accurately perform echocardiograms and, thus, identify heart valve disease.



Ensuring rapid access and consistent quality of echocardiograms regardless of where they are performed



In a patient suspected of having valvular heart disease, a cornerstone in the initial investigation is a high-quality echocardiogram. Ideally, this should be easily accessible in location and performed in a timely fashion. Of equal significance, however, is a concise and meaningful report that conveys the significant findings and potential recommendations to the referring family physician.

DAVID BEWICK, cardiologist

Consistent quality of echocardiograms should be ensured by requiring a high standard of accreditation for those performing the scan and clear communication of findings to primary care physicians and patients.

It is important to ensure consistent quality of echocardiograms between settings and that quality be monitored by relevant quality assurance programs. Equally, reports from the echocardiography team to the referring (non-specialist) physician need to be consistent and provide clear, concise and actionable steps to guide patient care. High-quality echocardiography can be guided and supported by the implementation of quality standards, such as those published in Ontario by CorHealth as part of the Echocardiography Quality Improvement Program.⁹² Since 2016, participation in the program is a requirement to be reimbursed for echocardiography services from the Ontario Health Insurance Plan.⁹²



REFERRAL, WORK-UP AND MONITORING

Provide a clear point of contact

During the monitoring phase of the patient journey, education is key to ensuring the clinical team is immediately made aware of any change to the person's condition that may affect their need for an intervention. If a person is placed on active surveillance by their care team, it is important that they fully understand why treatment is not yet appropriate.⁹⁰ They also need to know what signs and symptoms could indicate that their condition may have changed, so that they can quickly consult their care team and have their treatment plan revised as necessary. Patients often wait too long; by the time they present at their next scheduled appointment, their disease has worsened. Clinical teams need to provide clear guidance to patients to encourage them to present early.





TREATMENT AND LONG-TERM FOLLOW-UP

More timely and equitable access to interventions

Once a decision to treat has been made, the intervention should take place as quickly as possible. This will help ensure that patients are offered life-saving treatment before their disease progresses further.

Timely referral to the appropriate treatment is crucial to ensure good outcomes. For example, delaying TAVI in low- and intermediate-risk patients with symptomatic severe aortic stenosis by just three to six months decreases two-year survival.⁹³ International data have shown that people often experience delays in referral and do not receive effective interventions in time.^{71 94} Physicians may delay referral for either surgery or catheter-based interventions. As a result, patients are already considered high risk at the point of referral – and have a higher likelihood of complications, as well as risk of death, during the intervention.^{24 71 94}

Input from a multidisciplinary care team into treatment decisions may help optimize the timing of treatment. Specialist teams in heart valve clinics can help to determine the correct timing and type of intervention.³⁷ This ensures that treatment is delivered at a less severe stage of disease, thereby increasing the person's chances of full recovery.^{26 65}



The right procedure, done early enough to preserve a patient's enjoyment of life as well as heart function, is critical.

CHARLES PENISTON, cardiovascular surgeon

Timely adoption of guideline-based interventions

Adoption of innovative interventions should be timely to ensure the best treatment options are rapidly available for people with heart valve disease.

In addition to the factors already discussed, limited availability of surgical and catheter-based interventions is an issue in many provinces. Recent data have exposed significant inequity in access to TAVI: there is more than a threefold difference in capacity between provinces,⁵⁵ and national rates of TAVI are up to 50% lower than in other Western countries, such as Germany.⁹⁵ Wait times have been increasing in recent years, with wide disparities between Canadian provinces.⁵⁵

Availability of funding is sometimes viewed as a barrier to more widespread use of interventions for heart valve disease. This is particularly true for catheter-based approaches such as TAVI or transcatheter mitral valve repair. The costs associated with these interventions and the infrastructure required to undertake a high number of procedures have been cited as potential impediments to widespread use.^{95 96} However, national and international data suggest that the higher acquisition cost of the TAVI prosthesis or transcatheter mitral valve repair device compared with surgical valves or repair rings is offset by a reduction in hospital readmissions, medication usage and length of stay in hospital.^{97 98} In addition, transcatheter interventions have been associated with improvements in quality of life reported by patients within two weeks of the procedure.^{43 98} Costs vary significantly across Canadian hospitals, but recent research has shown that reducing inefficiencies across the treatment process could reduce the costs associated with TAVI.⁹⁶ Recent data from Ontario and Quebec have shown that the costs of transcatheter valve interventions, including TAVI and transcatheter mitral repair, are in fact lower than costs of surgery during the procedural phase.^{99 100} Ideally, adoption decisions for different types of intervention should be timely and recognize the rapid iterative improvements in device technology, which translate into improvements for the person receiving treatment and efficiencies for the health system.



Multidisciplinary cardiovascular rehabilitation has been shown to improve quality of life, fitness and functionality, and reduce morbidity and mortality. Rehab is vital for full physical and psychological recovery from major interventions, so that people can return fully to their social and family roles.

PAUL OH, physician



Maintaining support for good mental health is critical after heart valve surgery, and because it is often underappreciated, patients and caregivers need to be aware of what psychological support is available and how to access it. Psychological support should always be part of post-treatment follow-up.

JOHN STOTT, heart valve patient

There should be greater recognition of the support that patients and their caregivers need before and after valve replacement or repair, clinically as well as psychologically.

Comprehensive, long-term support is vital for people with heart valve disease, yet clear guidance for clinical teams is often lacking. Heart valve repair or replacement can improve a person's physical functioning and symptoms, but their journey to recovery does not end after a successful intervention.^{28 53} Each person's recovery path, treatment plan and time required to be able to return to their normal functioning, work or usual activities will be different, and it is important to ensure long-term support and continuity of care between the different phases of that journey. More research into post-intervention management and support is needed to provide effective guidance for clinicians.²⁸

Individualized follow-up care from a multidisciplinary team, ideally in a heart valve clinic, may offer the best outcomes for patients. Such care allows for a comprehensive assessment of a person's evolving needs and tailoring of services to individuals over time.^{50 63 64} This may require investment in key roles, such as dedicated specialist nurses and cardiologists with enhanced scope of practice. Specialist nurses can provide patients with ongoing support post-intervention and throughout their rehabilitation, whereas cardiologists can manage surveillance and follow-up care. It is also important to involve primary care practitioners at this stage, given their ongoing role in the person's care.

Appropriate psychological support should be a cornerstone of comprehensive follow-up and rehabilitation. The psychological toll on patients as they move through different phases of the care journey should not be underestimated – they may feel anxiety and uncertainty, and have difficulty coping with the evolution of their condition and its impact on their daily life. A qualitative study of patient experiences in Denmark, for example, found that not only were individuals still feeling fragile and experiencing sadness after heart valve surgery, many were also unclear on what the follow-up procedures were.⁵³

Call to action and recommendations

The burden of heart valve disease is increasing as the population ages. Although life-saving treatment is available, too many cases of heart valve disease continue to go undetected and be treated too late. The resulting human and economic cost is considerable.

Actions must be taken now to address the gaps in care. Specific improvements can be made at different stages of the patient care journey, in addition to cross-cutting changes to the organization of heart valve care and investment in data and research.

We call on decision-makers across Canada to work closely with healthcare professionals, patient organizations and the research community to ensure that all people with heart valve disease have access to appropriate diagnosis and treatment without delays. Commitment is needed to the following key actions.

OVERARCHING RECOMMENDATIONS ALONG THE ENTIRE CARE JOURNEY

- Embed patient education and shared decision-making in all stages of care
- Configure care around dedicated multidisciplinary heart valve clinics and teams
- Facilitate integration of digital and remote technologies into care
- Invest in data collection and research on heart valve patient-centred outcomes
- Reduce inequalities in access to all components of heart valve care

SPECIFIC RECOMMENDATIONS AT KEY STAGES OF THE CARE JOURNEY



AWARENESS

- › **AWARENESS CAMPAIGNS:** Patient and professional cardiovascular organizations should develop national and regional campaigns to raise public awareness of the symptoms and impact of heart valve disease
- › **SUPPORT FOR PATIENT ORGANIZATIONS:** Public funding should be provided for patient organizations to ensure delivery of ongoing support and information to patients, families and caregivers



DETECTION IN PRIMARY CARE

- › **AWARENESS AND REFERRAL:** Patient and professional organizations should work in partnership to ensure primary care practitioners are aware of the red-flag signs and symptoms of heart valve disease, and of disease progression and contemporary treatment options
- › **SYSTEMATIC AUSCULTATION:** Every Canadian over 60, or with a pre-existing valve condition, should receive annual auscultation by stethoscope as part of routine check-ups by 2025
- › **ACCESS TO DIGITAL TOOLS:** Every provincial government should mandate and support the integration of digital tools, such as digital stethoscopes and handheld ultrasound, to aid in detection of heart valve disease in primary care settings



DIAGNOSIS VIA ECHOCARDIOGRAM

- › **RAPID REFERRAL:** Echocardiograms should be offered to symptomatic patients within two weeks of initial referral, and to asymptomatic patients within six weeks by 2025
- › **WORKFORCE PLANNING:** Provincial governments, in partnership with professional organizations, should increase the number of specialists able to perform quality echocardiograms, including in the community setting
- › **CONSISTENT QUALITY:** Professional and accrediting organizations should ensure that specialists performing and reporting echocardiograms receive adequate training, implement quality assurance programs, and develop standardized templates for echocardiography reports to referring physicians by 2030



REFERRAL, WORK-UP AND MONITORING

- › **REFERRAL TO ROUTINE REVIEW:** Every person diagnosed with heart valve disease should be promptly referred for regular scheduled follow-up, ideally within a dedicated service (i.e. heart valve clinic), including physical examination, echocardiogram and discussion about the care plan within four weeks
- › **CLEAR POINT OF CONTACT:** Patients should be provided with a clear and centralized point of contact to report any changes in their condition and receive their follow-up care



TREATMENT AND LONG-TERM FOLLOW-UP

- › **INDIVIDUALIZED TREATMENT CHOICES:** Healthcare institutions, in partnership with professional organizations, should implement shared decision-making between the patient and the multidisciplinary care team to select the most appropriate treatment for each individual by 2025
- › **TIMELY UPTAKE OF INNOVATIVE AND EVIDENCE-BASED TECHNOLOGIES:** Federal and provincial governments should ensure that every Canadian with heart valve disease has rapid access to innovative and evidence-based technologies
- › **CARDIAC REHABILITATION:** Healthcare institutions should provide cardiac rehabilitation, including physical and psychological support, to all people with heart valve disease by 2030
- › **ROUTINE FOLLOW-UP POST-TREATMENT:** Provincial governments, in partnership with professional organizations, should ensure that every patient has an echocardiogram annually as part of their long-term monitoring

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