



# Heart valve disease



Working together  
to create a better  
patient journey  
in Australia

# Contributing authors

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**Dr Heath Adams**, Interventional and Structural Cardiologist, Royal Hobart Hospital, Hobart Private Hospital and Calvary Lenah Valley, Menzies Research Institute, University of Tasmania, Hobart, TAS

**Dr Cara Barnes**, Interventional Cardiologist, Advara Heart Care, Perth, WA

**Professor Jayme Bennetts**, Director Cardiothoracic Surgery, Victorian Heart Hospital; Monash Health Professor, Cardiothoracic Surgery, Monash University; Professor, Cardiothoracic Surgery, Flinders University, VIC

**Tanya Hall**, CEO and Founder, Hearts4heart, Perth WA

**Rox Johnston**, Structural Heart Nurse Consultant, Alfred Hospital, Melbourne, VIC

**Jennifer Turner**, Nurse Practitioner, Valve Intervention Program, Fiona Stanley Hospital, Perth, WA

**Professor Jason Kovacic**, Director and CEO, Victor Chang Cardiac Research Institute; Chair of Medicine, University of NSW; Adjunct Professor, University of Western Australia, Perth, WA

**Dr Dale Murdoch**, Interventional Cardiologist, The Prince Charles Hospital, Brisbane, QLD

**Professor David Playford**, Professor of Cardiology, University of Notre Dame Fremantle, WA; Founder and Chief Investigator, National Echo Database Australia (NEDA); Specialist Cardiologist Hollywood Private Hospital, Nedlands, WA; Consultant Imaging and General Cardiologist, Advara Heart Care, Perth, WA

**Dr Nicola Straiton**, Senior Research Fellow, Nursing Research Institute, St Vincent's Health Network Sydney and the Australian Catholic University, Sydney, NSW

**Professor Dion Stub**, Co-Director, Centre of Cardiovascular Research and Education in Therapeutics (CCRET), Monash University, Coronary and Structural Interventional Cardiologist, The National Health and Medical Research Council (NHMRC) / National Heart Foundation; Fellow, Cardiology Medical Advisor Ambulance Victoria, Melbourne, VIC

**Dr Matias Yudi**, Interventional and Structural and Cardiologist, Epworth Richmond and Austin Health, VIC

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# Foreword

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Heart valve disease (HVD) affects millions of people globally but is not as well recognised as other cardiovascular issues, such as heart attack, stroke, heart failure and coronary artery disease. Data on the mortality and morbidity associated with HVD, and the benefits of surgical or transcatheter intervention are conclusive. However, local healthcare professional education and community awareness of HVD are limited, therefore many patients eligible for lifesaving treatment continue to experience significant delays in detection, diagnosis and access to life-saving treatments.<sup>1,2</sup>

This report aims to provide clear guidance to reduce the burden of HVD for people with this condition and enable them to seek optimal care for themselves. The report also provides information for decision-makers, patients' families and communities across Australia to advocate for better care for all.

**Tanya Hall,  
CEO and Founder,  
Hearts4heart,  
Perth WA**



# Executive summary

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HVD is a serious cardiovascular condition which can be fatal if left untreated.<sup>3,4</sup> It is estimated there are up to 600,000 people in Australia with HVD, and this number is projected to increase over the next thirty years as the population ages; globally it is expected to double by 2040 and triple by 2060.<sup>2,5</sup> In addition, another 254,000 people remain undiagnosed, and Australia's ageing population is expected to push this number to 336,000 by 2031 and to > 400,000 by 2051.<sup>2</sup>

HVD may be even more prevalent in Indigenous Australian populations where rates are not well defined. Rates of many chronic diseases such as diabetes, coronary heart disease and cancer are significantly higher in Indigenous than non-Indigenous Australian populations, and it is reasonable to expect this is also the case with HVD.<sup>6</sup> Indeed, Indigenous Australians suffer some of the highest rates of rheumatic heart disease in the world, which is strongly associated with the development of HVD.<sup>7</sup>

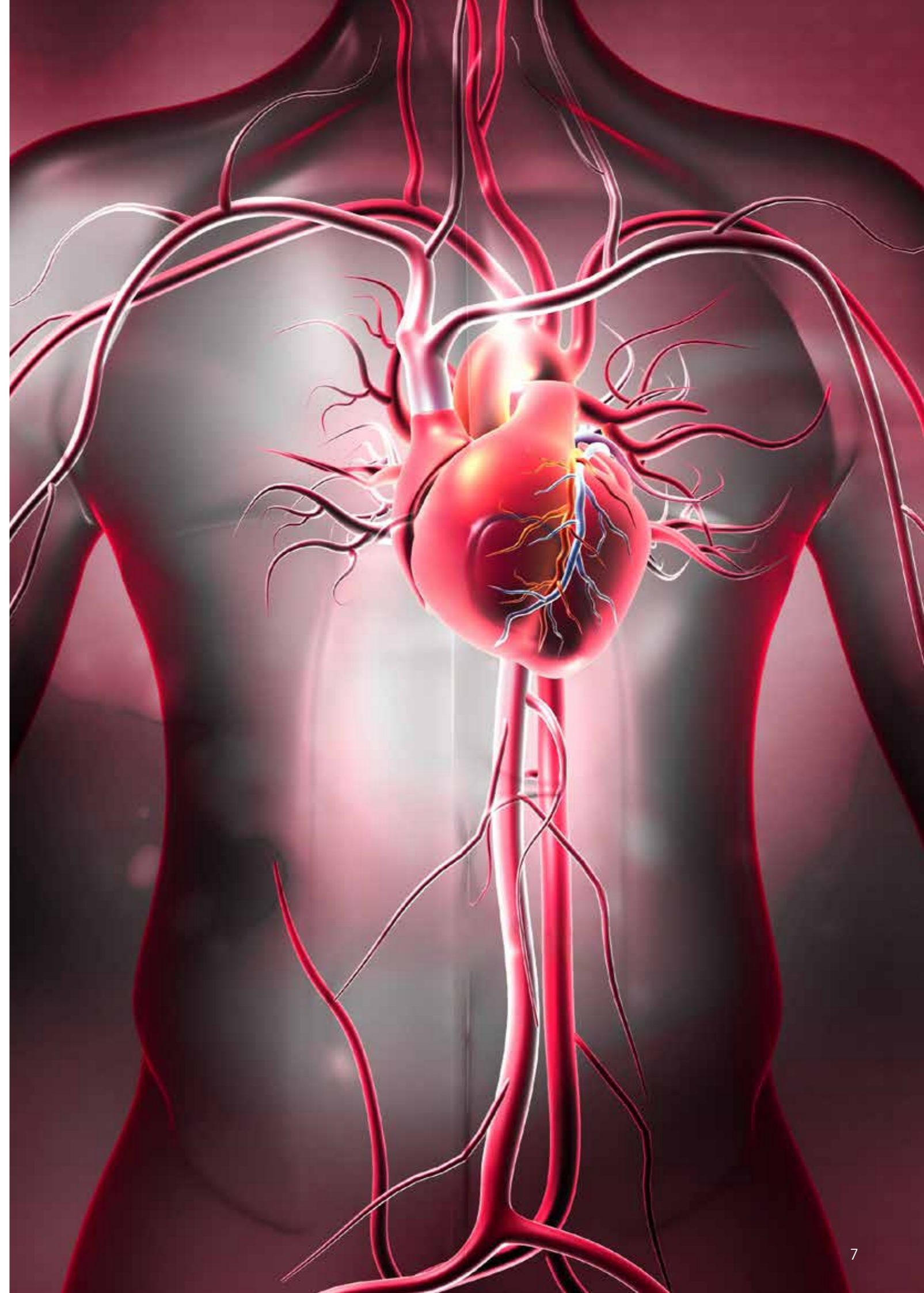
There are several interventions that can help alleviate the impact of HVD, including medication, transcatheter (minimally invasive) or surgical valve replacement/repair. In particular, definitive valve replacement/repair can either cure or significantly improve the severity of HVD thus improving quality of life and reducing morbidity and mortality.<sup>4,8,9,10</sup>

**However, in too many cases HVD remains undetected, undiagnosed, untreated or treated too late, resulting in significant symptom burden to patients, poor quality of life, avoidable deaths, and high healthcare and societal costs.<sup>11,12</sup> Much of this burden could be alleviated by addressing gaps along the patient care pathway.**



The new options for heart valve patients have been revolutionary. Despite this, too few patients can access these treatments in time, which leads to delays that significantly impact outcomes.

**Professor Dion Stub, Co-Director, CCRET, Monash University, VIC**



# RECOMMENDATIONS TO IMPROVE PATIENT OUTCOMES ACROSS THE PATIENT CARE PATHWAY

## For State Government/Local Health Services

- Introduce automated diagnosis for facilities providing echocardiographic services using Australian-built software specifically designed to help close the gap of missed diagnosis
- Encourage retrospective review of echocardiography studies to identify all patients at risk of HVD. This can be done automatically using Australian-built software
- Encourage early referral of at-risk patients to a specialist heart valve clinic
- Expand the specialist heart valve clinic model by drawing on the framework used by Australian clinics in major hospitals and incorporating best practices
- Ensure all patients indicated for valve replacement/repair have access to a specialist heart valve clinic and specialist Nurse Coordinators to support efficient treatment pathways, while facilitating communication and shared decision making. This requires adequate funding for enough valve specialist Nurse Coordinators across each state
- Increase transparency around waiting lists for valve replacement, including both surgical and transcatheter treatments
- Adopt key performance indicators (KPIs) to ensure patients receive appropriate referrals and treatment within recommended timeframes (i.e., within 30 - 90 days from presentation)
- Publish data on echocardiogram access and wait times
- Publish data on valve replacement or repair access and wait times

## For Federal Government

- Provide a Medicare Benefits Scheme (MBS) incentive for automated diagnosis and enhanced detection of HVD in echocardiographic service providers using Australian-built software specifically designed to help close the gap of missed diagnosis
- Expand the specialist heart valve clinic model by drawing on the framework used by Australian clinics in major hospitals and incorporating HVD best practices
- Make the MBS Heart Health Check a permanent item
- Include cardiac auscultation in the heart health assessment item descriptor to make the requirement more transparent and explicit for general practitioners (GPs)
- Ensure MBS reflects the complexity of ongoing management of HVD patients in primary and secondary care models including the need for Multidisciplinary Care Teams (MDTs) to optimise patient management
- Support greater understanding of HVD and treatment pathways in research priorities of the Medical Research Future Fund and National Health and Medical Research Council
- Support greater patient awareness of HVD diagnosis, treatment and management through awareness campaigns in conjunction with patient organisations
- Support the adoption and use of digital technologies by patients to support management and monitoring of disease progression at home

## For Clinical Societies

- Support development of clinical care pathways for HVD from clinical suspicion and auscultation through to detection, referral and therapy
- Support greater HVD awareness within primary care settings through additional healthcare professional (HCP) training and accreditation – especially education with murmur finding and utilisation of stethoscope
- Include HVD and auscultation in the Guidelines for preventive activities in general practice (Red Book)



I never got regular heart checks because I felt fit. Now I realise how important it is to get a heart check even if you feel well, because heart valve disease develops without you knowing and it can be fixed if you catch it early enough.

**Stephen Gallus, Patient, VIC**



# THE IDEAL PATIENT PATHWAY FOR HEART VALVE DISEASE

## AWARENESS

- Patient is aware of HVD and associated symptoms and presents to GP or specialist physician for screening

## DETECTION

- Physician routinely uses a stethoscope to check for a heart murmur in symptomatic young patients and screening at-risk populations, all individuals over 65 years of age
- Primary care clinicians are aware of referral pathways and treatment options for early HVD
- Specialist advanced practice nurses involved in early detection and monitoring and detection of changes in symptoms and condition

## DIAGNOSIS

- Patient is referred for an echocardiogram to confirm diagnosis and discuss treatment
- Echocardiogram is enhanced by clinical decision support software to improve detection of HVD
- Results of echocardiogram trigger early clinical review by physician with knowledge of HVD
- Patients provided with clear point of contact for timely coordination and integration of ongoing care and investigations

## MULTIDISCIPLINARY CARE TEAM ENGAGEMENT

- MDT engagement is offered to the patient to review and discuss treatment options

## TREATMENT

- Detection of HVD may occur in the absence of symptoms. Patient education needs to include the symptoms of HVD and the need to report symptoms to the medical team
- Comprehensive medical evaluation is completed, including any further specific investigations as indicated (e.g. CT imaging) to assist in identifying treatment options
- Treatment options are discussed with the patient, including regular close surveillance. Depending on their HVD progression, surgical and/or transcatheter valve intervention, clinical trials and palliative care may be recommended as appropriate. Shared decision-making processes are used to confirm treatment choice

## POST INTERVENTION FOLLOW-UP & LIFELONG MONITORING

- MDT follow-up is offered to the patient to ensure recovery and return to normal functioning
- Provide education and guidance on lifetime management of HVD and interventions



# The call to action

Improving the patient care pathway is an important first step towards protecting the health and productivity of our growing ageing population and to reduce the future burden of HVD in Australia. This would translate to an improvement in quality of life, a reduction in avoidable deaths, and a decrease in healthcare and societal costs.

To achieve this change, we encourage decision-makers across the country to work closely with

healthcare professionals, patient organisations and the research community to ensure those with HVD receive appropriate and timely diagnosis and treatment.

More specifically, there is a need for public health campaigns to raise awareness about HVD and encourage people to visit their GP for assessment. Consideration should also be given to the screening of asymptomatic individuals over the age of 65.<sup>13</sup>

**EMBED PATIENT EDUCATION AND SHARED DECISION-MAKING INTO ALL STAGES OF CARE<sup>14</sup>**

**CONFIGURE CARE AROUND MDTs CENTRED IN HEART VALVE CLINICS**

**FACILITATE INTEGRATION OF DIGITAL AND REMOTE TECHNOLOGIES INTO CARE**

**INVEST IN DATA COLLECTION AND RESEARCH ON QUALITY OF LIFE AND PATIENT OUTCOMES**



Heart valve disease can significantly impact a patient's quality of life, but until now it has only attracted a low level of awareness in the world of cardiovascular disease. Greater 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 Australia.

**Tanya Hall, CEO and Founder, Hearts4heart, Perth WA**



# RECOMMENDATIONS FOR THE PATIENT CARE PATHWAY



## AWARENESS

Raise **public awareness** of heart valve disease symptoms

Fund **patient organisations** who provide ongoing support and information to patients



## DETECTION

**Train primary care practitioners** on the red flag symptoms of HVD and signs of disease progression

Mandate **systematic auscultation** by stethoscope for those over the age of 65

Integrate **digital tools** in primary care to aid in the detection of HVD



## TREATMENT

**Improve access** to all components of HVD care, including in regional and remote areas

**Leverage clinical guidelines to drive investment** in evidence based technologies for the improved detection and diagnosis of HVD

**Engage a multidisciplinary care team**, along with the patient to individualise treatment plans

Provide patients with a **designated contact** within their multidisciplinary team for timely adaptations of the treatment plan

## DIAGNOSIS

Implement automated clinical decision support software to improve **early detection** and diagnosis of HVD

Conduct data-based **workforce planning** to increase patient access to echocardiograms

**Refer** symptomatic patients for an echocardiogram in a timely manner (two weeks for symptomatic patients and six weeks for asymptomatic patients)

Develop models of community-based echocardiography to **improve access**

Conduct regular audits (RACP CPD) to **enhance clinical practice**



## FOLLOW-UP AND MONITORING

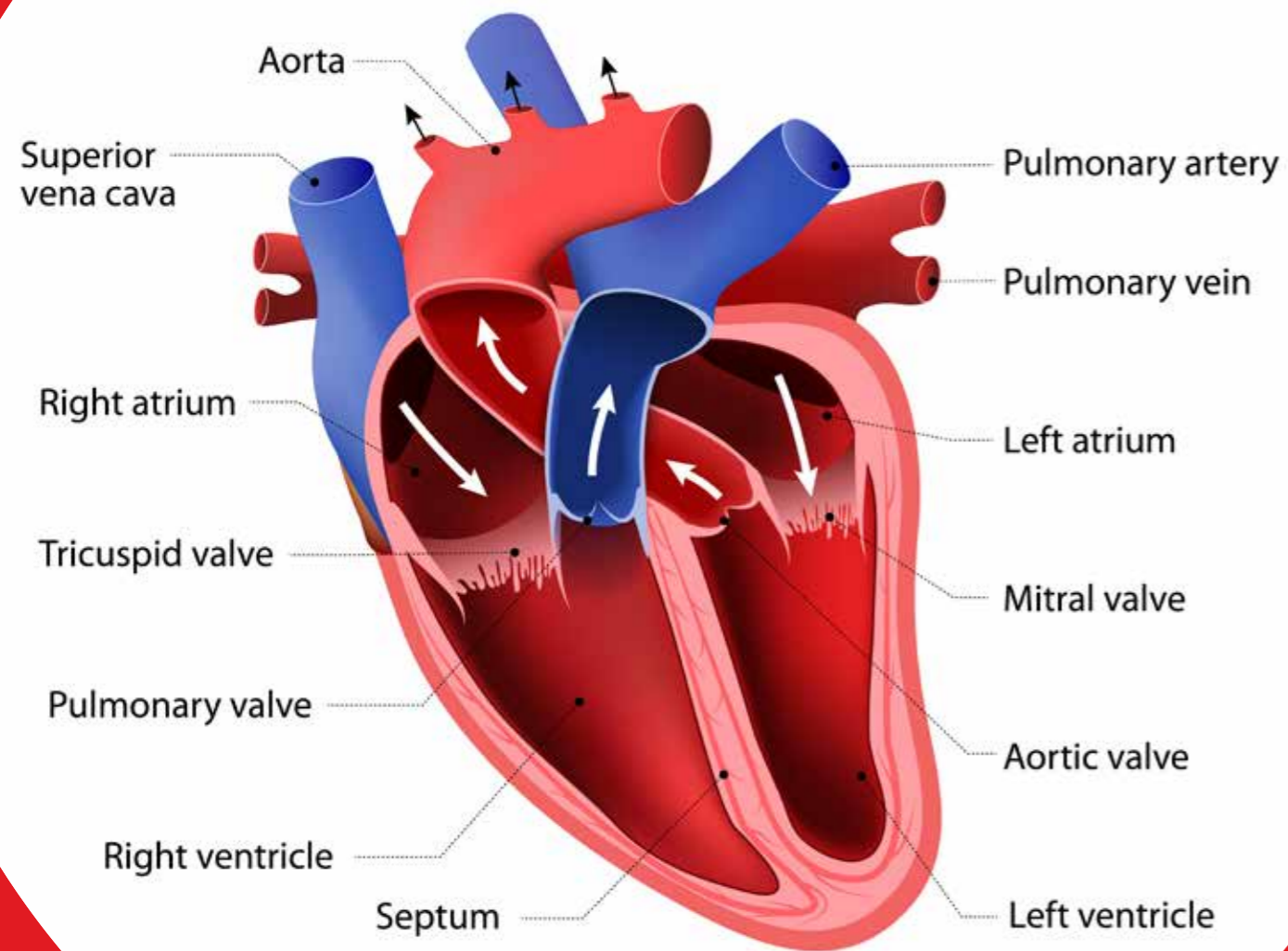
Offer **cardiac rehabilitation and psychological support** to HVD patients

Ensure patients have an **echocardiogram at least annually**

Invest in **specialist nurses and cardiac physiologists** to provide ongoing support to patients



# Heart Anatomy



# Introduction

HVD has been described as ‘the next cardiac epidemic’.<sup>15</sup> The prevalence and incidence of aortic and mitral valve disease increases with age; thus, the burden of disease will continue to grow as the population ages.<sup>2,16,17</sup> It is estimated that the number of people with HVD will double by 2040 and triple by 2060.<sup>5</sup>

If HVD is detected and treated in a timely way, people will experience a significantly better quality of life.<sup>18</sup> Furthermore, significant delays in detection, diagnosis and access to appropriate treatment compromises a patient’s prognosis and can lead to premature death.<sup>4,11,19,20</sup>

The COVID-19 pandemic may have exacerbated existing disparities in care. Delays in diagnosis and interruptions in patient treatment may have led to compromised outcomes for patients. Ensuring patients have access to appropriate care without delays is imperative.

The growing prevalence of HVD in our ageing population makes addressing the existing gaps in care an urgent priority. To enable people with HVD to lead healthy, active and productive lives, we need to configure our healthcare systems to deliver the highest quality of care.<sup>11,17,21-28</sup>



# The impact of heart valve disease

HVD is a debilitating condition, with a significant impact on quality of life.<sup>18,29,30</sup> It causes avoidable deaths, as well as high healthcare and societal costs associated with ineffective screening, diagnosis and management.<sup>1</sup>

HVD occurs when there are structural or functional abnormalities in one or more of the four valves in the heart – aortic, mitral, tricuspid and pulmonary valves.<sup>2,31</sup> Valves are vital to the heart's function, so any damage leads to

debilitating symptoms of breathlessness, chest pain and fatigue.

The prevalence of HVD is increasing and according to several publications of Australian data there is a high mortality associated with HVD; however, there is limited data on the hidden burden and impact of HVD on the lives of those living with the condition and that of their families and communities.<sup>11,17,21-28</sup>



Now that I've had the procedure to repair my heart valve I can feel the difference it has made. Two days after the procedure I was able to walk out of the hospital and was back at home. Now I have no problem walking up hills. I'm the fittest I've been in years.

**Susanne Kalotas, Patient, VIC**

**Diagnosis:** Detecting HVD can be challenging due to several factors. Importantly, HVD may be asymptomatic, which means significant HVD may be present in the absence of symptoms and, when not diagnosed early, is associated with an increased risk of mortality. Traditionally, guidelines have recommended that a patient be investigated only when they show symptoms, but this may result in diagnosis only when advanced disease is present.

**Even more concerning, some patients will have died without having experienced any symptoms prior to their terminal event.**

When present, symptoms can be confusing as they may be subtle or mistaken for other conditions, leading to a delayed diagnosis. Symptoms, which may not always raise immediate concern, include exercise intolerance (often attributed to older age), fatigue, shortness of breath, chest tightness or pain, blackouts and heart palpitations. Some individuals with HVD remain asymptomatic for extended periods, making it harder to identify the problem early. Importantly, simple diagnostic tests like an electrocardiogram (ECG), echocardiography or a chest X-ray may not always be readily available due to cost or long waiting times for specialist appointments. Furthermore, disease progression can vary significantly among patients, complicating the timing of intervention and necessitating the role for surveillance in mild cases. Nevertheless, access to echocardiography is crucial to managing HVD, and the investment in and clinical application of artificial intelligence (AI)-supported clinical decision support technology is needed if we are to improve collection, measurement and analysis of ECG and echocardiogram results.<sup>2,27,32</sup>

Once initial diagnosis is made, preferably in a setting with clinical decision support technology to improve the consistency and accuracy of diagnosis, early referral of patients to physicians with expertise in HVD is essential. Overall, vigilance, screening and awareness are critical for timely detection and management of HVD. Providing patients with a clear point of contact is an important component for timely coordination of patient care. Dedicated HCPs,

such as advanced practice specialist HVD nurses, can help with the integration of care and management of changes in symptoms and condition.

**Optimising patient pathways:** Effective treatment pathways for HVD have been well defined and documented in evidence based international guidelines; however, there are significant barriers to delivering guideline directed care. Furthermore, diagnostic and treatment pathways for patients vary significantly, resulting in compromised quality of life and premature mortality.<sup>1,4,33,34,35</sup> The mainstay of effective treatments involves surgical or transcatheter valve replacement or repair, active watch and wait surveillance, and palliative heart failure management. Lifetime planning and informed shared decision making is essential in choosing a treatment pathway for patients.

It is crucial for patients to enter personalised and appropriate care pathways at the time of diagnosis to ensure they receive timely, best-practice care. For example, a younger person may experience a very different course of disease than someone who is older; the presence of comorbidities or frailty will affect disease progression and treatment options and intervention choices vary between the different types of HVD. Furthermore, individuals may have different personal preferences for treatment choices and should be consulted to ensure their personal goals and values align with clinical decisions through all stages of care.

Currently, referrals can be more reliant on clinician relationships, resulting in fragmented and inconsistent care and duplication of investigations. Optimising referral pathways, preferably to heart valve clinics, promotes consistent and timely navigation of the complex diagnosis and investigation process reducing delays in care. Ensuring proper care will require specific actions at each stage, including further research into the impact and burden of HVD in Australia to guide future funding in healthcare delivery.



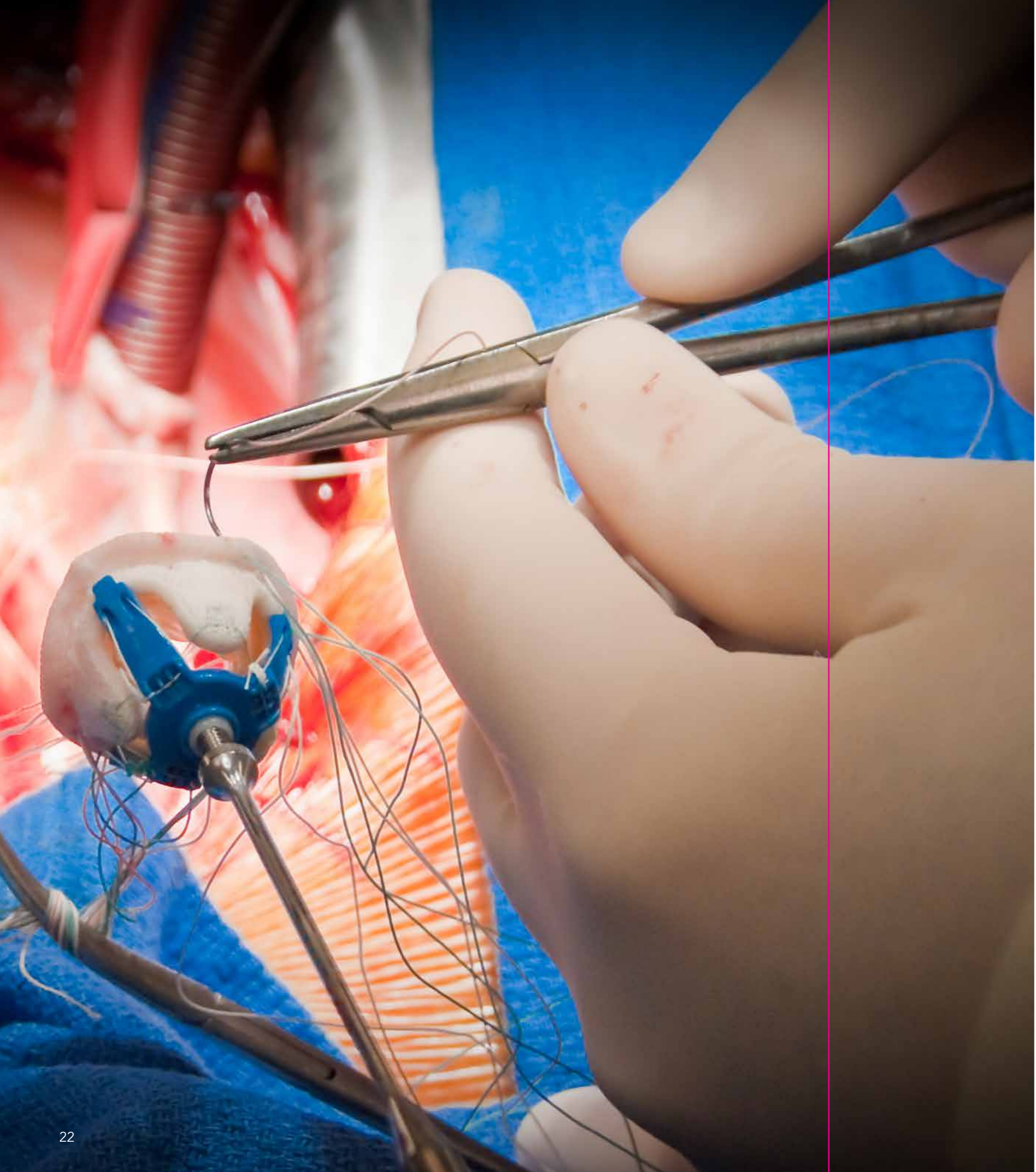
My experience as a patient with a previously unknown cardiovascular disease led me to becoming a cardiovascular physician. I wanted to understand what had happened to me. My experience and my knowledge allow me to resonate with my patients. While it's not an experience I'd wish upon anyone, I find the more people that are aware of the risk factors and their family history of heart disease, the better we can be at working together to manage and improve their health.

*Dr Geoffrey Lester, Patient, NSW*

**Clinical challenges:** A significant number of cases of HVD will go undetected, affecting prognosis and long-term survival. One of the key factors contributing to under detection is the limited awareness of HVD among GPs and primary healthcare providers, who are often the first port of call for people who experience symptoms. GPs are regularly performing 'heart checks' on their patients but often forget about HVD. Ideally, GPs should receive specific training; however, considering a GP's current workload this may be impractical. GPs may benefit from a public health and awareness campaign that reminds them of HVD and encourages them to look for potential symptoms, highlight the need for auscultation and encourage early referral and access to treatment pathways. The campaign should emphasise that HVD may be difficult to diagnose, particularly in older people, as it may be masked by the presence of comorbidities with similar presentation.<sup>26,36</sup>

As discussed, many cases of HVD present without obvious symptoms. GPs should be encouraged to auscultate all their patients over the age of 65 as part of routine annual care.<sup>24,37</sup> A recent survey across 11 European countries found that more than half of people over the age of 60 were not regularly checked with a stethoscope by their GP.<sup>38</sup> Rates of auscultation by GPs also vary considerably between countries.<sup>39</sup> One possible solution may be to encourage the use of electronic stethoscopes and, possibly, of handheld ultrasound devices in primary care which may complement the findings from auscultation. Pilot programs currently underway are training





health care workers to perform limited screening scans on asymptomatic individuals, with promising results. All people with an auscultated murmur suspicious of HVD should be referred for an echocardiogram to obtain a correct diagnosis and enter an appropriate care pathway.

***Urgency of referral will depend on a person's presentation, it is recommended that patients with symptomatic HVD be referred within two weeks of presenting to their GP or primary healthcare provider, and asymptomatic patients within six weeks.<sup>40</sup>***

There are many clinical challenges in the echocardiographic diagnosis of HVD. Notwithstanding recent evidence that milder forms of HVD may be associated with risk of future mortality, even those with guideline-directed severe HVD that should prompt referral for consideration of heart valve therapy, are often overlooked.<sup>41</sup> This problem is particularly evident in technically more challenging echocardiography studies (such as low-gradient severe aortic stenosis, which can lead to underdiagnosis, especially in women, see Box 1). There have been multiple calls by professional societies to improve physician reporting of HVD with the use of clinical decision support software.<sup>42</sup> An Australian company has recently received US Food and Drug Administration (FDA) approval for such software to improve the echocardiographic diagnosis of aortic stenosis.

**Box 1**

**Using AI to enhance detection of severe aortic stenosis**

A recent Australian study using artificial intelligence to aid human detection of severe aortic stenosis (AS) demonstrated evidence for an unconscious clinical bias in current standard echo reporting, particularly against females. Due to the smaller average body size of females, they do not reach the same aortic gradients as males despite a smaller valve area, potentially leading to the underdiagnosis of severe AS. This unintended bias results in delayed referrals for definitive valve interventions in women, as compared to men. An Australian artificial intelligence automated clinical decision support system which operates automatically and is impartial to gender, valve haemodynamics, symptoms, or clinical factors has the potential to reduce disparities and improve the detection and outcomes for those with severe AS who may otherwise remain undetected.<sup>65</sup>

Once the diagnosis has been made, decisions for referral to treatment or follow-up, in line with clinical practice guidelines, are crucial for improved outcomes and to ensure patients are offered life-saving treatment before their disease progresses.<sup>43</sup> Due to the burden of competing workloads, and lack of increased Medicare rebates, GPs often wait too long to refer their patients either for surgery or for catheter-based interventions, increasing the need for utilisation of healthcare services as their HVD

progresses. Patients who often present to emergency departments, require recurrent admissions for heart failure and frequent visits to GP and specialist clinics with progressive disease. As a result, patients are already considered high risk at the point of referral and have a higher likelihood of complications and mortality during the intervention and are less likely to enjoy the benefit of a new valve.<sup>34,35,43</sup>

Ideally, treatment time frames, and international guidelines on time from diagnosis of severe HVD to treatment, should be embedded in national standards and local care protocols, and regularly monitored through clinical audits. Currently, equity of access to appropriate testing services and long wait lists for specialist appointments contribute significantly to the delay in diagnosis and have a detrimental impact on long term health outcomes.

One notable study focusing on echocardiographic screening for rheumatic heart disease (RHD) in Indigenous Australian children found that screening could be cost effective, especially if it was able to detect the condition two years earlier.<sup>44</sup>

The incremental cost-effectiveness ratio was less than AU\$50,000 per disability-adjusted life-year (DALY) averted. Although sensitive to various assumptions, it did highlight the potential benefits of early detection and intervention. While this study specifically addressed RHD, the findings provide insights into the broader utility

of echocardiograms for diagnosing HVD in other populations as well.<sup>44</sup>

**The cost of effective intervention:** Precise estimates of the cost of care in HVD are not readily available. A recent Australian study in aortic stenosis demonstrated that any degree of disease is associated with premature mortality and loss of quality-adjusted life years (QALYs).

**The estimated Australian societal cost of premature mortality in aortic stenosis alone (not considering other HVDs) was recently reported to be \$6.29 billion.<sup>11</sup>**

This figure does not account for the increased hospitalisation and other increases in health care utilisation that result from untreated aortic stenosis. In addition, the care pathway for someone with HVD can be complex and resource intensive: depending on barriers to obtaining prompt diagnosis, individuals may need multiple investigations first before a definitive diagnosis is provided; follow-up and monitoring often continue for the rest of a person's life; and there may be associated comorbidities.<sup>45</sup> It is widely reported that the cost of healthcare, and patient outcomes, are worse with impaired heart function, which is the usual outcome for untreated valvular heart disease. Often these patients develop permanent heart dysfunction which creates quality of life, and functional impairment issues for patients, and is a resource and cost burden to the healthcare system.

Cost is often an important barrier to more widespread use of newer interventions for HVD, such as open-heart surgery or transcatheter heart valve procedures, or transcatheter aortic valve implantation (TAVI), which have been shown to reduce risk for appropriately selected patients – especially the elderly or those of higher surgical risk. However, it is crucial to emphasise that the cost of poor management of HVD – and not providing patients with an effective intervention – is overall much higher than the cost of guideline directed care. This is due to a combination of QALY, increased overall health care utilisation, frequent and recurrent hospitalisations with heart failure, potentially prolonged hospital stays, admissions to intensive care units, rehospitalisation and rehabilitation. Outside of these measurable items, additionally important costs of failure to provide early and appropriate valve therapy include, poor quality of life, and additional flow-on impact to caregivers and patient's families.<sup>12,46</sup> A recent Australian study demonstrated that increasing the proportion of lower risk patients with moderate aortic stenosis receiving TAVI results in greater benefits in terms of QALY, fewer life years lost and lower number of heart failure events. The incremental cost of \$10,000 per QALY gained was considered low from a healthcare system

perspective.<sup>2</sup> Increasingly, clinical trials show that early intervention leads to better outcomes and, therefore, reduced overall costs.<sup>47,48</sup>

Ideally, investment decisions for different types of interventions should take a long-term perspective on overall costs to the system, as well as risks and benefits to patients, as opposed to focusing solely on the immediate costs of performing the intervention. At a clinical level, appropriate evidence-based decisions should guide the use of catheter-based interventions (such as TAVI) over surgery and must be carefully assessed by the clinical team, considering the balance of risks and benefits for each person, the likelihood of further interventions and their individual preferences.<sup>49,50</sup>

A simpler, more streamlined approach to TAVI is now performed in many centres in Australia. This involves the use of local anaesthetic and sedation, early mobilisation and safe and effective discharge for suitable patients. This safe approach, used in a cohort of TAVI patients in Tasmania, conveyed significant reductions in bed day stay with up to three quarters of patients discharged one day post operatively, minimising the impact of HVD on an already stretched hospital system.<sup>51</sup>



Until recently we did not realise the size and scope of the problem, nor did we know the number of Australian lives lost due to heart valve disease. Thanks to advances in scientific discovery, we now have this information, and unfortunately many people will have poor quality of life and will die prematurely if we allow the status quo to remain unchallenged. It is now time for us to lead the way and help change the lives of countless Australians now and into the future.

**Professor David Playford, Prof. of Cardiology,**  
University of Notre Dame, Fremantle, WA



# Importance of Multidisciplinary Care Teams

Treatment delivered by MDTs or structural heart teams of relevant professionals, ideally within a heart valve clinic, may help optimise the timing of treatment (e.g. delivering treatment at a less severe stage of disease increases the chances of improved clinical outcomes and enables various professionals to contribute to discussions about treatment options).<sup>49,52</sup> This approach also provides comprehensive, individualised support and follow-up.<sup>49,53,54</sup>

The Australian TAVI accreditation committee mandates that an MDT meets to discuss each patient prior to intervention and governs the minimum standards and essential requirements for valve centres with formalised competencies for all professionals within an MDT involved in heart valve care.<sup>55</sup>

The role of clinical audits, continuing medical education and reaccréditation ensure the adherence to recognised standards of care, thus improving patient outcomes. Some of these clinical audits can be performed automatically using clinical decision support software.

The heart valve clinic model ensures that decisions along the care pathway take account of the full spectrum of a person's needs over time and provide them with optimal continuity of care. Providing a clear point of contact to specialist nurses for management of symptoms and navigation of the healthcare system also ensures that a person's care can be rapidly adapted to changes in their condition (see Box 2 below).

## Box 2

### The case for centralised management in heart valve clinics

HVD diagnosis can be challenging. Overcoming the obstacles in the diagnosis of HVD has been addressed in the previous sections, which includes recommendations in primary care, in the reporting of echocardiography studies and in the diagnosis of HVD by a cardiologist. However, once the diagnosis of prognostically-important HVD has been made, timely early referral to an expert heart valve clinic is recommended. Since HVD can be a complex and evolving condition, centralisation of care in a heart valve clinic provides opportunities

for timely referral from diagnosis to intervention, enables regular follow-up and active surveillance, and improves patient education experience and outcomes.<sup>53,57</sup> However, it is acknowledged that there may be downsides to centralised care, including reduced access in regional and remote communities, first nations patients travelling off country for care, cost of transport and the need for intensive testing and follow up, to name a few.

Nevertheless, there is evidence that patient management within heart valve clinics leads to improved outcomes, including better long-term survival. Local and international experience shows that





patients who are offered individualised follow-up care in a heart valve clinic are less likely to be readmitted to hospital and have lower all-cause mortality than those who receive follow-up outside of a heart valve clinic.<sup>57,58,59</sup> In the UK, adherence to clinical guidelines tends to be better when care is managed in a heart valve clinic than in a general cardiology clinic.<sup>58,60</sup>

**Heart valve clinics are also likely to be more cost-effective than conventional models of care.<sup>61</sup>**

Processes across diagnosis, treatment and follow-up can be streamlined as they all take place at one site.<sup>53,56</sup> The centralised model of care allows for specialist expertise, quality control and monitoring of guideline adherence in practice in each centre.<sup>57,61</sup> Improvements in efficiency and reduction in cost are achieved by avoiding unnecessary echocardiograms, duplicative clinic visits (thus freeing consultant time) and prolonged hospitalisation.<sup>57,61</sup>

Multiple other cardiovascular conditions already have established guidelines on

management by 'heart teams' (such as complex congenital heart disease), which have memberships including cardiologists, cardiac physiologists, specialist nurses, interventional cardiologists and cardiac surgeons.<sup>53,58</sup> In selected cases, other allied professionals, such as physiotherapists, geriatricians, psychologists and palliative care services, are also required to meet the complex needs of heart valve patients. Close communication and coordination between all professionals in the MDT, including the GP, is key at every step of the care pathway.<sup>62</sup>

In addition, greater attention is required on strategies to provide better access to digital tools (i.e., to facilitate digital tools for patient management systems, integration of medical information and imaging transfer between facilities) and improved workforce planning, to foster the incorporation of advanced practice/specialist nurses (nurse practitioners, primary care practice nurses, clinical nurse consultants) for the detection and management of patient symptoms and navigation of the healthcare system.



For patients requiring a heart valve procedure, it is not just about the intervention, it is about the whole journey, from diagnosis and treatment to returning to daily life. To optimise care in valve programs, patients need timely access to dedicated specialist valve nurses and clinics. These clinics act as the primary contact point throughout the patient journey and facilitate referral, triage, and management of patients to ensure care is accessible and in line with the latest best practices.



**Rox Johnston,**  
**Structural Heart**  
**Nurse Consultant,**  
Alfred Hospital,  
Melbourne, VIC



**Jennifer Turner,**  
**Nurse Practitioner,**  
Fiona Stanley Hospital,  
Perth, WA



# The vital role of shared decision-making in heart valve disease

Shared decision-making between a person receiving care and healthcare professional(s) aims to ensure the patient feels fully supported to make treatment decisions that are right for them. Family members and caregivers may also be involved in this process, which involves an exchange between the healthcare professional(s) – who share information about the condition, treatment options, and the associated risks and benefits of each – and the patient (and sometimes family and caregivers), who share their preferences, values and goals. It involves working together to reach consensus on the most suitable path of treatment; therefore, it goes beyond just informing and educating a patient on their condition.<sup>5</sup> A quality decision is one that is informed and based on what is most important to the patient.

Shared decision-making has several benefits, such as improving patient outcomes and experiences due to increased knowledge, reduced uncertainty around choosing treatment options and greater satisfaction with care.<sup>63</sup> Shared decision-making and patient education also enable patient preferences around life expectancy and future procedures to be considered.

Decision-making in HVD is often complex as each treatment option is associated with risks and benefits. People diagnosed with HVD may be eligible for different treatment options, depending on their risk profiles, the severity of their condition and other potential chronic conditions they may have.<sup>16,64</sup> Treatment options involve medications, procedures and surgeries to repair or replace the diseased heart valve(s) using specialised devices and routine ongoing care and surveillance. This makes the decision around treatment options more significant, as valve repair or replacement cannot be reversed in the same way as starting new medications. Also, recovery periods and durability can vary by treatment option, impacting a person's return to physical function, quality of life and ability to regain independence.<sup>64</sup> As HVD requires lifetime management future treatment options must also be considered.

More investment in research to identify and scale-up best practices for shared decision-making in HVD is needed to ensure patients are involved and engaged in their care journey.





# Patient education

A patient-centred approach is essential in HVD. Patient education allows patients to make an informed decision about treatment options. MDTs, including specialist nurses, should receive dedicated training to encourage ongoing dialogue and shared decision-making with patients, by taking into account each individual's preferences and goals at every step of their care with a focus on quality-of-life following heart valve intervention.<sup>36,54,62</sup>

Furthermore, patient education is key for the MDT so that the patient can immediately inform them of any change to their condition that may affect their need for an intervention. If a person

is under active surveillance by their care team, it is important that they fully understand their treatment pathway and circumstance.<sup>40</sup> They also need to know what signs and symptoms could indicate their condition may have changed, so they can quickly consult their physician and have their treatment plan revised. Too often, patients wait too long, and their disease has progressed by their next scheduled appointment. Clinical teams need to provide clear guidance to patients to encourage them to present early.



Patient education is key to allow an understanding of the treatment options and ensure they can make an informed decision. This may require patients to meet with surgeons and cardiologists to explore the risks and benefits of all the treatment options. Often the best option focuses on planning for the long term, including 'lifetime management' procedures to manage valvular disease across the rest of their life.

**Professor Jayme Bennetts, Director, Cardiothoracic Surgery,**  
*Victorian Heart Hospital and Monash Health Professor, Cardiothoracic Surgery,  
Monash University Professor, Cardiothoracic Surgery, Flinders University, VIC*



# Preparing patients

Access to high-quality information about HVD is crucial to strengthen the integration of shared decision-making. A person who is equipped with knowledge about their disease and their treatment options is more likely to feel empowered when there is an opportunity to engage in shared decision-making with their healthcare providers. This is important for ensuring people with HVD feel prepared and are fully aware of the next steps in their care.

The development of educational materials should be a collaborative effort between people receiving care and clinicians and may leverage the information packs routinely provided to

patients by manufacturers of heart valves. Information needs to be inclusive and well informed around all available treatment options. Often patients are informed they are being referred for a specific management or procedure prior to expert speciality assessment (e.g. by a heart valve clinic), and this often limits patients' ability to consider all options presented after speciality assessment and MDT discussions. It is essential to prioritise the appropriate level and tone of content desired by people with heart disease while also ensuring any clinical information is communicated properly and accurately reflects the national HVD care pathway.



# Conclusion and specific recommendations

There is generally low public awareness of the symptoms of HVD and greater efforts are needed to raise awareness, and understanding, of these conditions, particularly among people over the age of 65. Surveys have shown that most people do not know what HVD is, and that they would not usually think to consult a physician when experiencing some of the typical symptoms of HVD thus leading to sub-optimal detection.<sup>24</sup>

Hearts4heart calls on decision-makers across the country to work closely with healthcare professionals, patient organisations and the research community to ensure all people with HVD have access to appropriate diagnosis and treatment without delays. Commitment is needed to the following key actions:

**EMBED PATIENT EDUCATION AND SHARED DECISION-MAKING INTO ALL STAGES OF CARE<sup>14</sup>**

**CONFIGURE CARE AROUND MDTs CENTRED IN HEART VALVE CLINICS**

**FACILITATE INTEGRATION OF DIGITAL AND REMOTE TECHNOLOGIES INTO CARE**

**INVEST IN DATA COLLECTION AND RESEARCH ON QUALITY OF LIFE AND PATIENT OUTCOMES**

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- **Dr Heath Adams**, Interventional and Structural Cardiologist Royal Hobart Hospital, Hobart Private Hospital and Calvary Lenah Valley, Menzies Research Institute, University of Tasmania, Hobart, TAS
- **Dr Cara Barnes**, Interventional Cardiologist, Advara Heart Care, Perth, WA
- **Professor Jayme Bennetts**, Director Cardiothoracic Surgery, Victorian Heart Hospital; Monash Health Professor, Cardiothoracic Surgery, Monash University; Professor, Cardiothoracic Surgery, Flinders University, VIC
- **Tanya Hall**, CEO and Founder, Hearts4heart, Perth WA
- **Rox Johnston**, Structural Heart Nurse Consultant, Alfred Hospital, Melbourne, VIC
- **Jennifer Turner**, Nurse Practitioner, Valve Intervention Program, Fiona Stanley Hospital, Perth, WA
- **Professor Jason Kovacic**, Director and CEO Victor Chang Cardia Research Institute, Chair of Medicine University of NSW; Adjunct Professor University of Western Australia, Perth, WA
- **Dr Dale Murdoch**, Interventional Cardiologist, The Prince Charles Hospital, Brisbane, QLD
- **Professor David Playford**, Professor of Cardiology, University of Notre Dame Fremantle; Founder and Chief Investigator, NEDA; Specialist Cardiologist Hollywood Private Hospital, Nedlands WA; Consultant Imaging and General Cardiologist Advara Heart Care, Perth, WA
- **Dr Nicola Straiton**, Nursing Research Institute, St Vincent's Health Network Sydney and the Australian Catholic University, Sydney, NSW
- **Professor Dion Stub**, Co-Director, CCRET, Monash University, Coronary and Structural Interventional Cardiologist, NHRMC / National Heart Foundation; Fellow, Cardiology Medical Advisor Ambulance Victoria, Melbourne, VIC
- **Dr Matias Yudi**, Interventional and Structural and Cardiologist, Epworth Richmond and Austin Health, VIC

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