

HEART VALVE DISEASE

# Working together to create a better patient journey

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TABLE OF CONTENTS

Authors	2
Foreword	5
Executive summary	6
Call to action	8
<hr/>	
Introduction	10
The impact of heart valve disease	12
The patient care pathway	14
Patient story	18
<hr/>	
Improving the patient care pathway: addressing the gaps	20
– Opportunities along the entire patient pathway	22
– Improvements at key stages along the patient pathway	26
<hr/>	
Call to action and recommendations	34
References	36

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# Foreword



Heart valve disease affects millions of Europeans but, until now, it has maintained a low profile in the world of cardiovascular disease. Across Europe, data on heart valve disease are sparse, and too many patients receive potentially life-saving treatments too late due to a combination of low awareness, missed detection opportunities, and delays in diagnosis and access to care.

In response, the Global Heart Hub established a Heart Valve Disease Patient Council in early 2020 to bring a patient advocacy focus to heart valve disease. We commissioned The Health Policy Partnership, an independent health policy research organisation, to develop a report aiming to raise stakeholder awareness of heart valve disease across Europe. This report is the result of this partnership.

**Heart valve disease: working together to create a better patient journey** was developed under the guidance of a multidisciplinary advisory group, whose members included patient representatives and different healthcare professionals engaged in heart valve disease care from around Europe. The report builds on other national efforts and takes a European perspective on what an optimal care pathway should look like for people with heart valve disease.

The patient perspective was the continuing thread throughout this report. To our knowledge, this is the first Europe-wide report that provides a comprehensive overview of the entire patient pathway, from awareness to follow-up care, looking at how it can be improved for people with heart valve disease.

The report provides clear guidance to decision-makers on what they can do to reduce the burden heart valve disease is predicted to pose on our families and communities in years to come. We hope that it may also serve as an empowering tool for all people living with this disease, to encourage them to seek optimal care for themselves and advocate for better care for others.

We would like to express our sincere thanks to all members of our advisory group for their continued support, enthusiasm and dedication throughout the development of this report. I'm proud of the Heart Valve Disease Patient Council for bringing together this group of leading clinicians and patients to describe the challenges faced by professionals and patients in managing heart valve disease and for suggesting ways in which services might be improved.

Patient-driven reports like this one will help the collective ambition to achieve optimal outcomes for patients, and will support national objectives related to heart valve disease across Europe.

Please join us in disseminating this report.

**Wil Woan**  
**Chair, Heart Valve Disease Patient Council**  
**The Global Heart Hub**



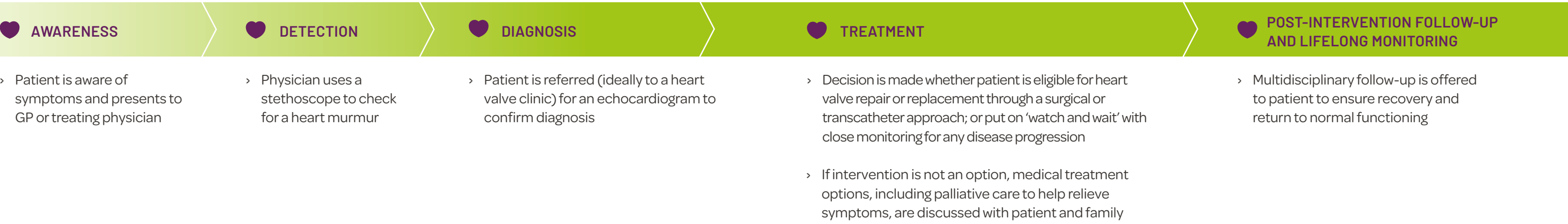
# Executive summary

**Heart valve disease is a serious cardiovascular condition which can be fatal if left untreated.**<sup>1-4</sup> In Europe, as the population is ageing, heart valve disease is on the rise.<sup>2,3,5</sup> The number of people affected by heart valve disease is expected to double by 2040 and triple by 2060.<sup>6</sup> Furthermore, the COVID-19 pandemic has compromised care for many people with heart valve disease, adding to existing deficits in early diagnosis and timely care.

**Unlike in many other cardiovascular diseases, there are effective treatment options for heart valve disease that can alleviate disease progression, improve quality of life and reduce mortality.**<sup>1,4,7-9</sup> However, in too many cases the illness is undetected, undiagnosed, untreated, or treated too late. This results in avoidable deaths, high costs<sup>10-12</sup> and significant compromises to people’s quality of life. Much of this burden could be alleviated by addressing the gaps that exist along the patient care pathway.



## THE IDEAL PATIENT PATHWAY FOR HEART VALVE DISEASE



# Call to action

Addressing the gaps in the patient care pathway 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 also reduce the future burden of heart valve disease on our society in terms of impaired quality of life, avoidable deaths and costs to healthcare systems.

To achieve this change, we call on decision-makers across Europe to work closely with healthcare professionals, patient organisations 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 PATHWAY

- Embed patient education and shared decision-making into all stages of care
- Configure care around multidisciplinary teams 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

## SPECIFIC RECOMMENDATIONS AT KEY STAGES OF THE CARE PATHWAY





# Introduction

**Heart valve disease has been described as ‘the next cardiac epidemic’.**<sup>5</sup> Prevalence is rising rapidly due to the ageing of the population<sup>3,12-14</sup> – it is estimated that the number of people living with heart valve disease will double by 2040 and triple by 2060.<sup>6</sup>

**If heart valve disease is detected and treated in a timely way, people can recover and enjoy good quality of life.**<sup>17-9</sup> Unfortunately, significant deficits exist in terms of detection, diagnosis and access to appropriate treatment. Many people live with their disease undetected for several years or receive treatment too late, which compromises their prognosis and can lead to premature death.<sup>12</sup>

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

**The growing prevalence of heart valve disease in our ageing population makes addressing the existing gaps in 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 healthcare systems to deliver the highest quality of care to all.



# The impact of heart valve disease

**Heart valve disease is a debilitating condition, with a significant impact on quality of life.**<sup>15-17</sup>

It occurs when there are structural or functional abnormalities in one or more of the four valves located in the heart (see Box 1).<sup>18,19</sup> Valves are vital to the heart's function, so any damage they sustain can cause debilitating symptoms.<sup>15</sup>

**Despite its rising prevalence, there is surprisingly little published information on the epidemiology of heart valve disease 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 significantly compromise patients' quality of life – yet it is somewhat forgotten within cardiovascular disease. It needs more attention at a political and clinical level. Otherwise, we're missing a real opportunity to save lives and reduce suffering in millions of people.

**Wil Woan,**

Heart Valve Voice UK and the Global Heart Hub  
Heart Valve Disease Patient Council

## PREVALENCE IS RISING

- Up to 2.5% of the general population and 13% of people over the age of 75 are thought to be living with heart valve disease.<sup>3</sup>
- In the UK alone, it is estimated that 1.5 million people aged 65 and over are living with moderate to severe heart valve disease.<sup>2</sup>

These numbers are likely to be underestimated due to underdiagnosis.

## MANY DEATHS COULD BE AVOIDED

- The rate of mortality in untreated, severe, symptomatic aortic stenosis (the most common type of heart valve disease) is between 25% and 50% per year.<sup>16,20</sup>
- 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.<sup>21</sup>

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

- Precise estimates of the cost of care in heart valve disease are not available. However, the care pathway is complex and resource intensive: individuals need multiple investigations to confirm diagnosis; follow-up and monitoring often continue for the rest of a person's life; and there may be associated comorbidities.<sup>12</sup>
- 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 due to prolonged hospital stays, admissions to intensive care units, rehospitalisation and rehabilitation,<sup>10,11</sup> not to mention avoidable ill health, poor quality of life and mortality.

## BOX 1

### 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 (see Figure 1).<sup>18,22</sup> When the leaflets or associated structures become damaged or the valve opening becomes compromised, blood flow is restricted or the valve becomes leaky. This causes strain on the heart as it attempts to compensate.<sup>22</sup>

**Causes of heart valve disease across Europe are mostly related to degenerative change due to ageing, and the illness primarily affects people over the age of 65.**<sup>3,6,12,14</sup> Other risk factors are common to cardiovascular diseases in general and include obesity, high cholesterol and high blood pressure. The presence of other conditions (e.g. congenital heart disease, coronary heart disease, cardiomyopathy, endocarditis infection or rheumatic fever) may also cause heart valve disease.<sup>18</sup>

**There are several types of heart valve disease.** These are defined based on which of the four heart valves 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.<sup>18,22</sup> The most common forms of heart valve disease typically encountered in Europe are mitral valve regurgitation and aortic stenosis,<sup>23</sup> but recent data suggest that tricuspid valve disease is also on the rise.<sup>7,24,25</sup>

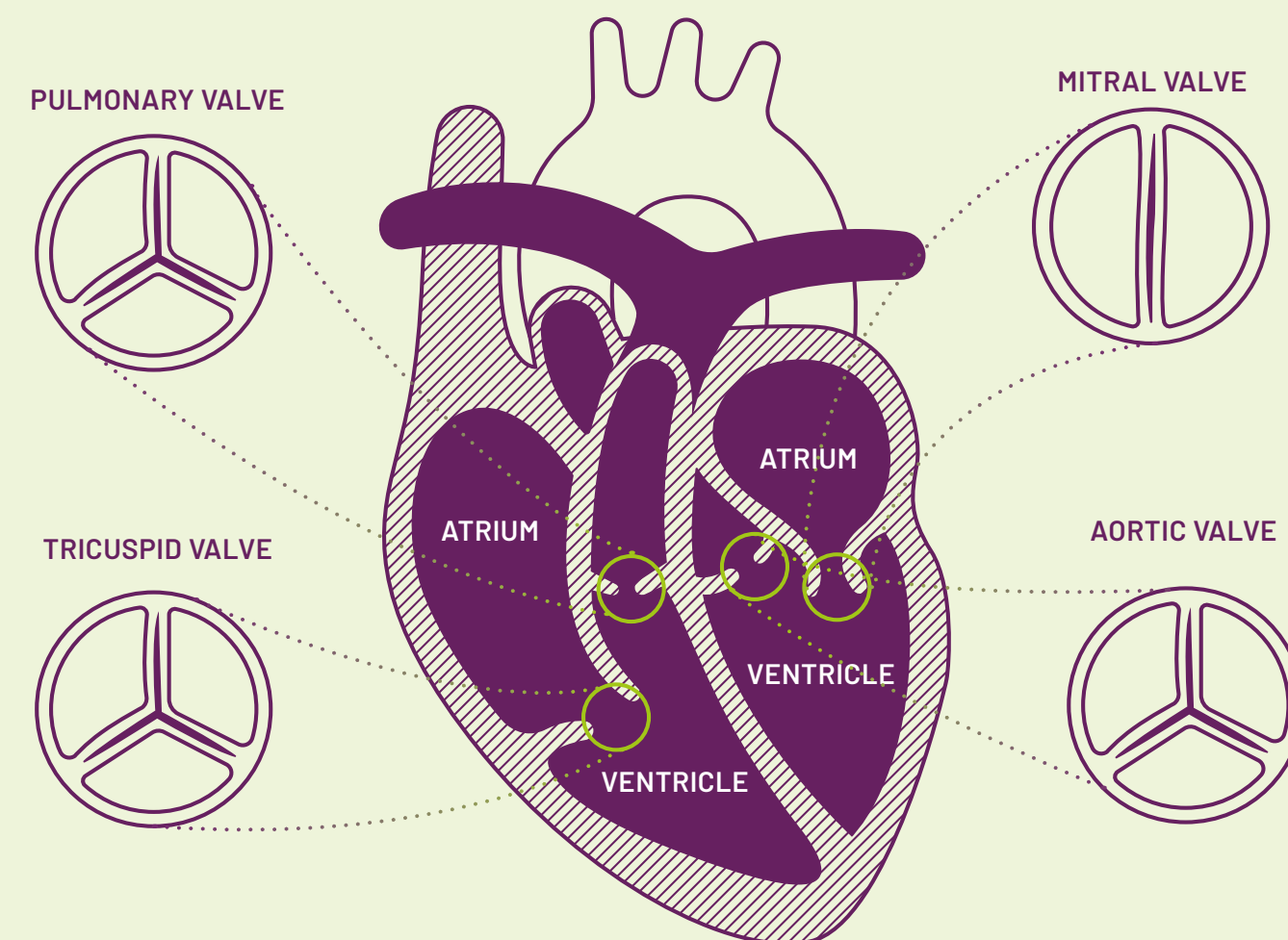


Figure 1: Heart valves

# The patient care pathway

Effective treatment for heart valve disease exists. It is therefore crucial for patients to enter appropriate care pathways as soon as possible to ensure they receive timely, best-practice care.

**The ideal patient care pathway for heart valve disease has been well defined in existing guidelines (see Figure 2).**<sup>26</sup> Actual care pathways, however, may vary between individuals: a younger person may experience a very different course of disease than someone who is older; the presence of comorbidities will affect how the disease progresses and its impact on the person; and intervention choices vary between the different types of heart valve disease.

**Taking a personalised approach to care through all phases of care is essential.** In addition to variability in their clinical situation, people with heart valve disease may have different personal preferences for treatment choices. They should always be consulted to ensure their personal goals and values are aligned with clinical decisions through all stages of their care.<sup>27</sup>

Key steps of the care pathway are described in more detail on the following pages (pp. 16 & 17).

## THE IDEAL PATIENT PATHWAY FOR HEART VALVE DISEASE

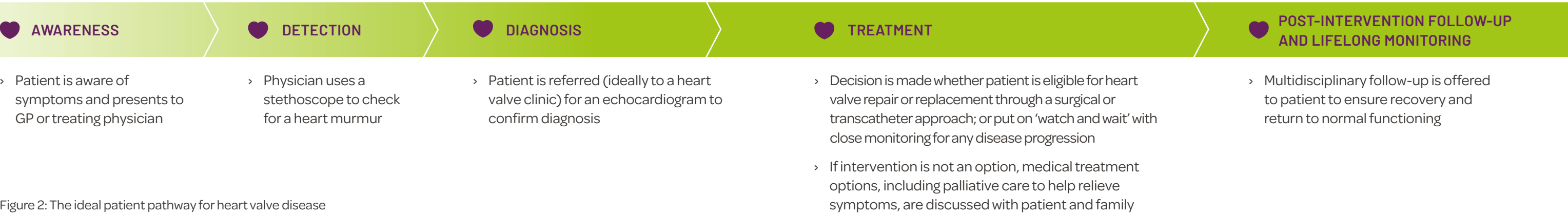


Figure 2: The ideal patient pathway for heart valve disease





## AWARENESS OF SYMPTOMS

**Awareness of symptoms is the first step in the patient pathway.** However, symptoms of heart valve disease may be difficult to recognise for patients, their loved ones and healthcare professionals, as they vary between individuals and often mimic general signs of ageing. As a result, people may live for a long time with symptoms without being aware that anything is wrong.

**Typical symptoms of heart valve disease** are shortness of breath, fatigue, chest pain, dizziness, fainting and swelling of ankles and feet, particularly in the morning. In many cases, people with heart valve disease do not present any symptoms at all.



## DIAGNOSIS

**People with a suspected heart murmur should be referred for an echocardiogram.** This should ideally be performed by a physician or a cardiac physiologist with specialist imaging expertise.<sup>128 29</sup> Additional tests, such as exercise stress tests, can also be helpful to confirm diagnosis in some cases.<sup>26 30</sup>



## DETECTION

**Detection of heart valve disease involves identifying a heart murmur through the use of a stethoscope (auscultation).**<sup>26</sup> This is usually done by a general practitioner (GP) in primary care, although it depends on who the person first contacts with their symptoms.



## TREATMENT

**The mainstay of heart valve disease management is valve repair or replacement.** This can be done through either surgery or catheter-based interventions, both of which have been shown to improve people's survival and quality of life.<sup>31 32</sup> Catheter-based approaches are becoming increasingly common.<sup>33</sup> They allow access to the heart valves through special catheters inserted through a blood vessel, typically in the leg. Surgical techniques are evolving towards minimally invasive procedures, which tend to be preferred by people with heart valve disease, although in some cases open-heart surgery is still needed.<sup>34</sup>

**The selection of which is the most appropriate intervention depends on the person's risk profile**<sup>4 26 35 36</sup> and should also take their preferences into account.<sup>27</sup> For example, clinical guidelines recommend transcatheter aortic valve implantation (TAVI) as an effective intervention for people who are otherwise not suitable for surgery<sup>20 26</sup> or are considered at high or intermediate risk.<sup>37-45</sup>

**If a person is not deemed ready or eligible for an intervention, they are put on active surveillance, and a 'watch and wait' approach is taken.**<sup>26</sup> They may be given medication to help alleviate their symptoms and comorbidities during this time. Medication does not, however, halt disease progression.<sup>4 26</sup> Therefore, individuals need to be reviewed on a regular basis, including periodic echocardiograms, to make sure their disease has not progressed to the point where they require valve repair or replacement.

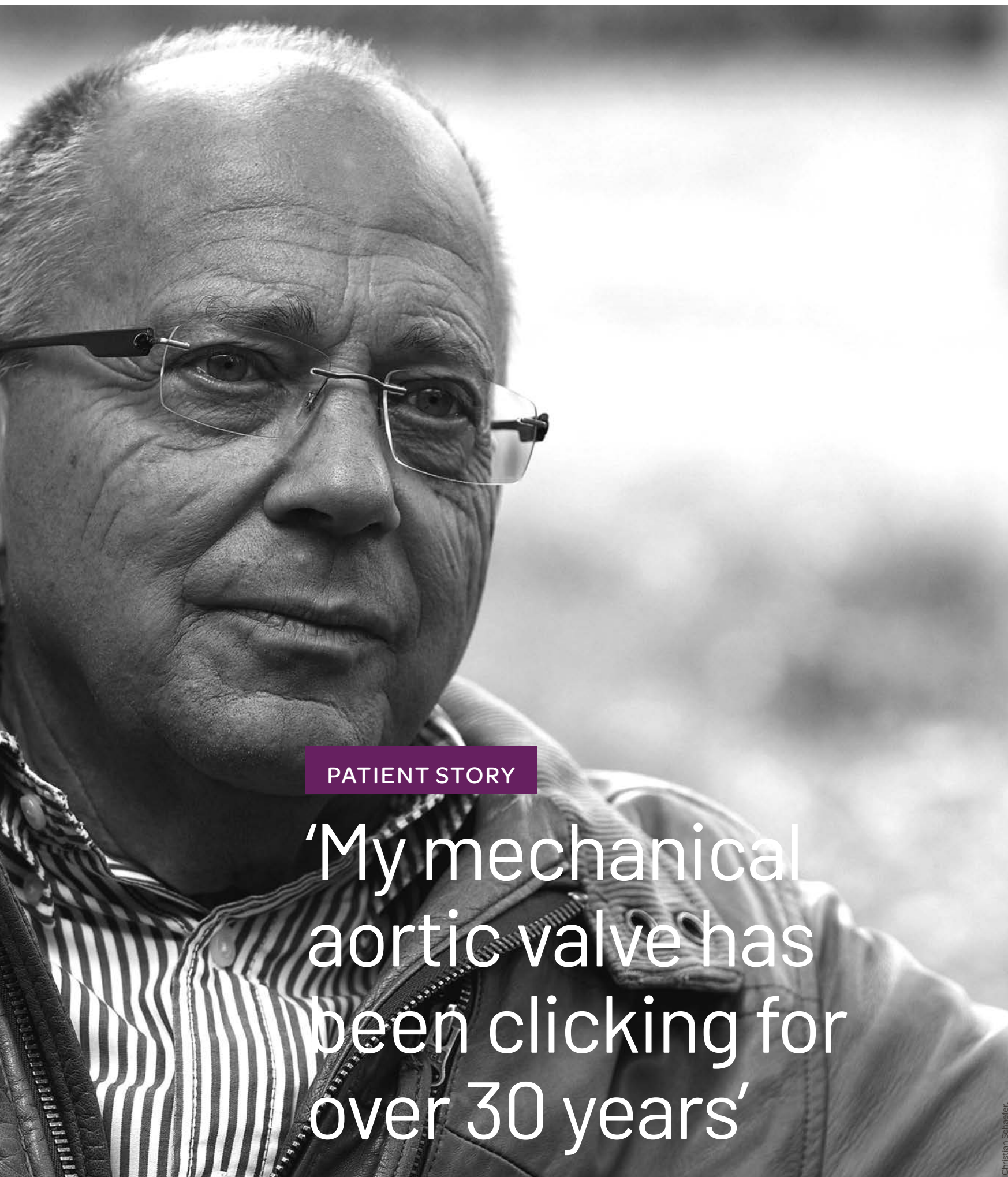
**In situations where the risks of intervention outweigh potential benefits for a person with heart valve disease, palliative options should be considered.** Choosing a palliative care approach must be a joint decision involving the multidisciplinary heart valve team,<sup>26</sup> the person and their family.<sup>46</sup> Respecting individual wishes is essential, as is involving palliative care clinicians in the multidisciplinary team.<sup>46</sup>



## POST-INTERVENTION FOLLOW-UP AND LIFELONG MONITORING

**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 intervention,<sup>47</sup> include cardiac rehabilitation<sup>48 49</sup> and psychological support,<sup>50</sup> and be provided by a multidisciplinary team.

**Regular monitoring after an intervention is important to check for potential deterioration of prosthetic valves and ensure early detection of any disease in another valve.**<sup>26</sup> Patients should have an echocardiogram at least every year, or as dictated by guidelines, to closely monitor the health of the valve. Ongoing monitoring of people's quality of life is also key to ensure they are adapting well post-intervention and are able to return to their normal levels of activity and functioning.<sup>47 50</sup>



## PATIENT STORY

'My mechanical aortic valve has been clicking for over 30 years'

Christian Schneider

During a holiday, I visited a country doctor, because I was worried not only about my cardiac arrhythmia but also about my shortness of breath when cycling. He advised me to see a cardiologist urgently after my return. I went to the outpatient department of a hospital and was immediately transferred to the intensive care unit. A few days later, I had ventricular fibrillation, so an emergency operation was unavoidable. The diagnosis: aortic vitium (in other words, an aortic valve insufficiency with a significantly changed valve apparatus, clinical severity III to IV).

The valve replacement was performed in October 1987. A while after the operation, the cardiac arrhythmia recurred. The irregular heartbeat made me nervous and I was worried that something was wrong with my heart. The following year, a pacemaker was implanted: reassurance for me. At first, I could hear the clicking of the mechanical heart valve clearly, but the more I accepted and became familiar with it, the quieter the clicking became for me. Now and then, I use my stethoscope to hear the click of my heart valve.

The mechanical heart valve does not restrict my everyday life and leisure time with sports and travel – regular walking keeps my heart fit. Additionally, we make sure that we eat a balanced diet at home. Of course, celebrating with family and friends as well as travelling – even to distant countries – is an important aspect of quality of life.

How do I protect my mechanical aortic valve? After the operation, I was treated with a vitamin K antagonist. In order to maintain the necessary therapeutic range, it is necessary to have the appropriate dosage of the anticoagulant and regular monitoring of the INR (international normalised ratio) value by my general practitioner.

During my rehabilitation in 1987, I learned how to use a coagulation monitor and blood thinners. After my return from rehabilitation, my health insurance company provided me with a coagulation monitor. At that time, I was one of the first anticoagulated patients to determine their coagulation values at home. As a self-employed person, this gave me and my family the freedom to organise our lives accordingly.

The weekly check of the coagulation value at home and the annual check-up with my cardiologist give me the additional assurance that the mechanical heart valve is working properly.

The most important thing is to accept your own situation and make the best of it in your own individual way. My personal motto: 'It keeps on clicking and I keep on ticking.'

**Christian, heart valve patient**



# Improving the patient care pathway: addressing the gaps

**Despite existing recommendations outlining best practice, adherence to guidelines at different stages in the patient care pathway varies considerably both between and within countries.**<sup>13 23 51-53</sup> Such gaps can result in compromised quality of life and premature mortality.<sup>54 55</sup> Addressing these gaps will require actions across the entire patient pathway, including further research to ensure we have appropriate data on the impact and burden of heart valve disease, to guide future investment in care. Specific actions are also required at each stage along the patient pathway.

“ Guidelines exist. Life-saving interventions exist. But we don't know to what extent guidelines are being followed, and too few patients are being offered potentially life-saving interventions in time to stop worsening of their condition.

**Marta Sitges**, cardiologist, Spain





# Opportunities along the entire patient pathway

## PATIENT EDUCATION AND SHARED DECISION-MAKING

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

**A person-centred approach is essential in heart valve disease, and patient education is a key part of this.** Patient education helps patients make informed decisions, understand why specific treatments are suggested to them, and prepare for and cope with different facets of their condition. Multidisciplinary teams, including specialist nurses, should receive dedicated training to encourage ongoing dialogue and shared decision-making with patients,<sup>27</sup> taking into account each person's quality of life, preferences and goals at every step of their care.<sup>30 46</sup> The essential role that patient organisations often play in providing people with information and support to complement the work of the clinical team should also be recognised.

## GREATER INVESTMENT IN TRAINED MULTIDISCIPLINARY TEAMS WITHIN HEART VALVE CLINICS

All patients with heart valve disease should be treated by a multidisciplinary care team, ideally within a heart valve clinic.

**The heart valve clinic model allows patients to be cared for by a multidisciplinary team.**<sup>26 28</sup> This enables different professionals to feed into discussions regarding treatment choices<sup>28</sup> and provide comprehensive support and follow-up adapted to each individual.<sup>26 28 46 56</sup> 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 people with optimal continuity of care. It also ensures that a person's care can be rapidly adapted to changes in their condition (see Box 2).

All relevant professionals need to be included in the wider multidisciplinary team.

**Traditionally, it is recommended that cardiovascular conditions be managed by 'heart teams'.** Such teams include cardiologists, cardiac physiologists, specialist nurses, interventional cardiologists and cardiac surgeons.<sup>28 29</sup> However, the involvement of other professionals is also required to meet the complex needs of heart valve patients. Allied health professionals such as physiotherapists, psychologists and palliative care specialists should be included in the wider multidisciplinary team. Close communication and coordination between all these professionals, as well as with the person's GP, is key at every step of the care pathway.<sup>27</sup>

Minimum standards and essential requirements for care should be applied to ensure consistent training of all members of the multidisciplinary team.

**There is currently a lack of formalised competencies for staff involved in heart valve care,** and inadequate systems to monitor the uptake of specialised learning.<sup>57</sup> All professionals working in a heart valve clinic, including nurses and cardiac physiologists, should undertake special training in heart valve disease within their scope of work to ensure they adhere to recognised standards of care.<sup>56-58</sup>

### BOX 2

## The case for centralised management in heart valve clinics

Heart valve disease can be a complex and evolving condition. Centralisation 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.<sup>28 56</sup>

There is evidence that management in heart valve clinics leads to improved outcomes for people with heart valve disease, including better long-term survival. Experience from Austria and Denmark 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>47 59 60</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>29 58</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>28 56</sup> The centralised model of care allows for specialist expertise, quality control and monitoring of guideline adherence in practice in each centre.<sup>29 56</sup> The overall cost of management can be reduced by avoiding unnecessary echocardiograms, duplicative clinic visits (thus freeing consultant time) and prolonged hospitalisations.<sup>47 61</sup>



## INTEGRATION OF DIGITAL AND REMOTE TECHNOLOGIES INTO CARE

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

**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 remain a permanent part of practice in heart valve care while maintaining high standards. Where possible, patient preferences should always be taken into account when offering remote or in-person consultations.

## INVESTMENT IN DATA AND RESEARCH

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

**An underlying issue in heart valve disease is lack of available data.** Existing epidemiological data on heart valve disease are often out of date. Specific incidence, prevalence and mortality data on heart valve disease do not feature in centralised databases such as the European Cardiovascular Disease Statistics. These data are needed if we are to present policymakers with accurate estimates of the number of people affected, and measure progress in patient outcomes over time.

**Studies are needed that look at patients’ quality of life across the entire care pathway,** including long after patients have recovered from surgery.<sup>15</sup> We also need more research on patient perspectives and values with regard to heart valve disease and care,<sup>27</sup> as current recommendations are too often formulated without appropriate input from patients.

**More research is needed to foster improvements in the entire patient care journey, not just interventions.**

The past few years have seen considerable research on different types of surgery and catheter-based approaches such as TAVI, but other important aspects of the patient journey – such as early detection and appropriate symptom management – are less well studied.<sup>54</sup> Important gaps include how best to identify and treat asymptomatic illness;<sup>13 62</sup> care pathways for younger patients;<sup>26 62 63</sup> standardised assessment tools to confirm diagnosis;<sup>54</sup> and quality control measures to track and monitor clinical performance and adherence to clinical guidelines.

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



# Improvements at key stages along the patient pathway



## AWARENESS

Greater efforts are needed to improve public awareness of heart valve disease, particularly among people over the age of 65.

**There is generally low public awareness of the symptoms of heart valve disease, and this leads to underdetection.** Surveys have shown that most people do not know what heart valve disease is,<sup>64 65</sup> and that they would not usually think to consult a physician when experiencing some of the typical symptoms of heart valve disease; by contrast, if they had typical symptoms of a heart attack (e.g. chest pain), they would.<sup>66</sup> Greater efforts to improve awareness of heart valve disease and potential symptoms are therefore needed, particularly among people over the age of 65 (see Box 3).

### BOX 3

#### The Valve for Life initiative

The Valve for Life initiative was created by the European Association of Percutaneous Cardiovascular Interventions to address care gaps in heart valve disease across Europe.<sup>67</sup> It began in 2015 with the goals of improving access to catheter-based valve interventions, raise awareness of heart valve disease among the general public and address information gaps in heart valve care.

The initiative aimed to engage physicians, policymakers and healthcare authorities to increase the implementation of life-saving interventions. The aim was that it would improve treatment of severe heart valve disease by 20% by 2020.<sup>67</sup>

The programme was trialled in France, Poland and Portugal, where it led to measurable increases in life-saving interventions for patients.<sup>67</sup>



## DETECTION

**Underdetection is a considerable 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, the Ox-Valve study in the UK 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 over half of these cases had not been previously diagnosed.<sup>2</sup>

GPs require specific training to help them recognise signs of heart valve disease and enter patients into appropriate care pathways.

**One of the reasons for underdetection is limited awareness of heart valve disease among GPs, who are often the first port of call for people who experience symptoms.** GPs require specific training to help them recognise potential symptoms of heart valve disease. Training should emphasise that heart valve disease may be difficult to diagnose, particularly in older people, as it may be masked by the presence of comorbidities with similar presentation.<sup>30</sup>

GPs should regularly auscultate every patient over the age of 65 as part of routine care.

**Given that, in many cases, heart valve disease presents without obvious symptoms,** GPs should be encouraged to auscultate all their patients over the age of 65 as part of routine care.<sup>68 69</sup> A 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>65</sup> Rates of auscultation by GPs also vary considerably between countries.<sup>70 71</sup> One possible solution may be to encourage the use of handheld devices in primary care to complement findings from auscultation. This may help avoid missing possible cases of heart valve disease in people who are asymptomatic.<sup>72</sup> Patients could then be referred on for a comprehensive echocardiogram, if needed.





## DIAGNOSIS

### More rapid access to 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, which then delays treatment.** Although the urgency of referral will depend on a person's presentation, it is recommended that patients with symptomatic heart valve disease be referred for an echocardiogram within two weeks of presenting to their physician, and asymptomatic patients within six weeks.<sup>73</sup> These time frames should be embedded in national standards and local care protocols, and regularly monitored through clinical audits.

**Limited availability of echocardiograms is an issue in many countries.** People presenting to GPs with possible symptoms of heart valve disease need to be referred to a specialist cardiologist, who can perform an echocardiogram in a hospital. Often, however, there are many competing demands for the use of this equipment and waiting times may be considerable. At the height of the COVID-19 crisis, for example, redeployment of echocardiography machines and personnel towards the pandemic response meant that many patients with suspected heart valve disease were unable to have an echocardiogram to confirm their diagnosis. Such delays in diagnosis may result in compromised outcomes for many patients for years to come.<sup>74</sup>

### Ensuring consistent quality of echocardiograms regardless of where they are performed

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A high-quality echocardiogram has to be the starting point for any patient in whom heart valve disease is suspected. But of equal importance is the quality of the reports that go back to the primary care physician: these need to be of consistent quality and clearly worded to guide appropriate patient care.

**Paul Nolan**, cardiac physiologist, Ireland

Alternative models should be explored to improve access to echocardiography in community settings with clear integrated care pathways.

**In an effort to widen access to echocardiography, different models of care should be explored.** For example, open-access echocardiography allows GPs to refer patients directly for imaging without first referring them to a cardiologist.<sup>75-77</sup> These services have been implemented within hospitals, and variants of this model have also been developed in community settings. Community diagnostic hubs can be a valuable model as they avoid the need for patients to travel to a hospital.<sup>71</sup> Regardless of where they are offered, echocardiograms need to be built into integrated care pathways to ensure continuity of care.<sup>71,78</sup>

**Services that are run by a cardiac physiologist specialising in imaging offer the additional advantage of freeing up cardiologists' time.**<sup>128</sup> Availability of these specialist imaging personnel varies considerably by country. Careful workforce planning is thus needed to increase the number of cardiac physiologists who are trained to accurately perform echocardiograms and identify heart valve disease.

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 GPs and patients.

**It is important to ensure consistent quality of echocardiograms between settings and that quality be monitored by relevant quality assurance programmes.** Equally, reports communicated by the echocardiography team to the referring non-specialist physician need to be consistent and provide clear, actionable steps to guide patient care. Reports often tend to contain specific, technical information with which GPs or other non-specialists may not be familiar. Instead, they should be written in a language that the referring physician can readily understand and contain clear recommendations for next steps in the person's care. The physician can then share this information with the patient and discuss with them the most appropriate way forward.



## TREATMENT

### More timely and equitable access to interventions

Decisions for referral to treatment or follow-up should be made as quickly as possible and in line with clinical guidelines. This will help ensure that patients are offered life-saving treatment before their disease has progressed.

**Timely referral to treatment is crucial to ensure good outcomes.** However, people often experience delays in referral and do not receive effective interventions on time.<sup>13 79</sup> Physicians often wait too long to refer their patients either for surgery or for 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 (see Box 4).<sup>13 23 79</sup>

**Input from a multidisciplinary care team into treatment decisions may help optimise the timing of treatment.** It helps ensure that treatment is delivered at a less severe stage of disease, thereby increasing the person's chances of full recovery.<sup>26 59</sup>



Choosing the right intervention for patients is so important – it has to be done early enough to allow lasting repair of the valve, but also the type of intervention should be chosen with each patient's preferences in mind.

**Ruggero De Paulis**, cardiothoracic surgeon, Italy

#### BOX 4

### Late referral to interventions: what can go wrong

A Europe-wide registry (the IMPULSE study) looked at data collected from patients with previously undiagnosed aortic stenosis across nine countries. The study found that patients with aortic stenosis experiencing severe symptoms were often referred for surgery too late for it to be safely and effectively performed. Many patients were denied the intervention despite clear guideline recommendations and availability of appropriate treatment.<sup>80</sup> The registry also showed differences between countries in the proportion of interventions performed within three months of diagnosis, with timely surgery occurring more often in Germany than in the UK.<sup>81</sup>

**Patient 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 put on active surveillance by their care team, it is important that they fully understand why treatment has been deferred.<sup>73</sup> They also need to know what signs and symptoms could indicate that their condition may have changed, so that they can quickly consult their physician and have their treatment plan revised as appropriate. Too often, patients 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.



Patients often think they have to wait until their six-monthly visit to see the cardiologist – potentially missing the opportunity to receive a life-saving intervention when their disease progresses. Patient education is key to avoid this happening.

**Keith Pearce**, consultant cardiac scientist, UK

### Use of interventions based on clinical need rather than cost considerations

Selection of the right intervention needs to be driven by best-practice recommendations, not just costs.

**In addition to the factors already discussed, limited availability of surgical and catheter-based interventions is an issue in many countries.** Data across Europe show widespread variation in access to TAVI, for example;<sup>82</sup> data for other types of surgical interventions are limited.

**Cost is often an important barrier to more widespread use of interventions for heart valve disease.** This is particularly true for TAVI: the costs associated with the procedure and the infrastructure required to undertake high numbers of procedures have been cited as potential impediments to widespread use.<sup>35 83</sup> Yet data suggest that the higher initial cost of TAVI compared with surgery is offset by a reduction in hospital readmissions, medication usage and length of stay in hospital.<sup>84</sup> TAVI has also been associated with improvements in quality of life reported by patients within two weeks post-procedure.<sup>31</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, the use of catheter-based interventions such as TAVI over surgery must be carefully assessed by the clinical team, considering the balance of risks and benefits for each person as well as their individual preferences.<sup>26 35</sup>





## FOLLOW-UP AND MONITORING

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

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Clinical teams tend to think of surgery as the end-point in the patient's care – but the road to recovery for patients after surgery is still long and needs more attention from medical professionals to understand the whole picture of what it means to return to 'normal life'.

**Britt Borregaard**, post-doctoral fellow, nurse, Denmark

**Comprehensive, long-term support is of vital importance to people with heart valve disease – but it may be overlooked by clinical teams.** 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.<sup>50</sup> Each person's recovery path and time required to be able to return to their normal functioning, work or usual activities, will be different.

**Individualised follow-up care by a multi-disciplinary team 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 each person over time.<sup>28 47 56</sup> This may require investment in key roles, such as dedicated specialist nurses and cardiac physiologists with enhanced scope of practice. Specialist nurses

can provide patients with ongoing support post-intervention and throughout their rehabilitation, whereas cardiac physiologists can manage imaging in surveillance and follow-up care. It is also important to involve GPs at this stage, given their ongoing role in patients' 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 pathway should not be underestimated – patients 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 sad mood after heart valve surgery, many were also unclear on what the follow-up procedures were.<sup>50</sup>

“

The mental aspects of heart valve disease are significant for patients. They have to adapt to each stage in their pathway: the shock of diagnosis, waiting and uncertainty about whether they'll have an intervention, then recovery from the intervention and trying to adapt to returning to normal life.

**Jens Näumann**, heart valve patient, Germany





# Call to action and recommendations

The ageing of the population will double the number of people living with heart valve disease in the next 20 years. 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 pathway, in addition to cross-cutting changes to the organisation of heart valve care and investment in data and research.

We call on decision-makers across Europe to work closely with healthcare professionals, patient organisations and the research community to ensure 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 PATHWAY

- Embed patient education and shared decision-making into all stages of care
- Configure care around multidisciplinary teams 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

## SPECIFIC RECOMMENDATIONS AT KEY STAGES OF THE CARE PATHWAY



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