

# State of the Nation

## **Heart Valve Disease in Scotland**

December 2021



the more we listen,  
the more lives we save



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## Foreword

Heart Valve Voice is the UK's dedicated heart valve disease charity. Formed in 2014, we are made up of both patients and those that treat the disease, including nurses, general practitioners, cardiologists and cardiac surgeons.

I consider myself extremely fortunate to work closely with patients who have been diagnosed with and effectively treated for heart valve disease. It is inspiring to see these individuals go on to live full and happy lives. However, it is an unfortunate fact, that far too many people in Scotland are not being diagnosed and treated quickly enough, despite the many advancements in the treatment of this disease. For those who do not receive timely attention for their condition, it can result in serious complications, reduced quality of life and, too often, premature death.<sup>1</sup> I am passionate about doing all that we can to ensure that all patients receive the right treatment at the right time.

Heart Valve Voice's mission, therefore, is to improve the diagnosis, treatment and management of heart valve disease by raising awareness of the need for timely detection and intervention. At a UK level, we have made great progress over the past few years. However, much more needs to be done to ensure that patients in Scotland receive the best possible care and support. I know and appreciate that the health service is experiencing one of the most difficult and unprecedented challenges it has ever faced, and I am so grateful for all of the hard work of all of those who have been at the frontline during the COVID-19 pandemic. As we move forward in the response to COVID-19, and as the Government set out in its NHS Recovery plan, we now have the opportunity to consider how we can best meet the ongoing needs of Scottish people and increase capacity as well as tackle the backlog in care. We now have the chance to do things differently and we need to seize this opportunity - as the 2021 Heart Disease Action Plan highlights "heart disease remains a major cause of death and disability in Scotland".

We believe that it is crucial that action is taken now to improve care and outcomes for patients with heart valve disease and in doing so, reduce the burden on the NHS. I truly believe that the recommendations in this report will help to achieve this aim and are aligned with the Scottish Government's ambitions to deliver an "NHS that is innovative, sustainable and stronger than ever before".

I would like to thank everyone who has contributed towards the production of this report and very much hope that it plays a role in driving real change in Scotland.

**Wil Woan**  
**Executive Director**  
**Heart Valve Voice**





## Executive Summary

This report takes into account evidence obtained through a process of gathering clinical, patient and stakeholder insight. On Thursday 10th June 2021, a group of clinicians, academics and representatives from the voluntary sector, chaired by Professor Huon Gray (former National Clinical Director for Heart Disease at NHS England), came together for a virtual roundtable meeting to help support the development of this report. The meeting focused on identifying the gaps in publicly available data and the current state of the nation with regards to heart valve disease diagnosis, management and treatment in Scotland. Data obtained through publicly available information and records have also been used in this report.

# Key Recommendations

## Heart Valve Disease in Scotland

- The exclusion of specific actions aimed at tackling heart valve disease in the Scottish Heart Disease Action Plan should be recognised, with a conscious effort from the Scottish Government and others to equally prioritise combating this disease along with other serious heart conditions.
- More standardised data needs to be collected on heart valve disease in Scotland to ensure there is a clearer picture of how the condition is currently being diagnosed, managed and treated. For example, statistics on heart valve disease referrals and echocardiograms should be included more specifically in the Scottish Heart Disease Statistics.
- The Scottish Government should build on the commitments in the new Women's Health Plan to improve information and public awareness of heart disease symptoms and risks for women, by ensuring there is a specific focus on heart valve disease.

## COVID-19 recovery

- As the National Heart Disease Task Force works to support Health Boards to implement the Heart Disease Action Plan, it should consider how effective recovery from the COVID-19 pandemic can be expedited.

## Detection

- The Scottish Government should urgently seek to review services in Scotland that offer heart valve disease services, to identify areas of expertise and construct an optimal patient pathway.
- Awareness of the signs and symptoms of heart valve disease amongst primary care healthcare professionals and the public must be improved through effective and targeted education and awareness-raising campaigns.
- All individuals over the age of 65 should have their hearts routinely checked with a stethoscope by a trained primary care healthcare professional.
- All patients with heart murmurs detected should be referred within appropriate timelines or echocardiography to assess the severity of the valve pathology. With the increased use of telemedicine and virtual appointments, there is a need to be mindful of the impact this may have in incidental or opportunistic detection / diagnosis.

## Diagnosis

- The target waiting time for echocardiography should be reduced to six weeks, in line with recommended European standards and in symptomatic patients, the target should be lowered to two to three weeks.
- The current variation in access to echocardiography across Scotland needs to be addressed as a matter of urgency.

## Treatment

- Heart valve disease patients must have access to appropriate and effective treatments. Specifically:
  - A multidisciplinary approach should be taken to ensure patients have a more informed choice of how best their disease can be managed.
  - There needs to be recognition of variation in access to treatment centres, particularly for those living in the Highlands.
- The Scottish Government should commit to filling the data gap created by the NICOR withdrawal and ensure heart valve disease data for TAVI procedures is collated.
- The Scottish Government should ensure that in consideration of any expansion of CVD waiting time targets, the needs of heart valve disease patients are also taken into account.

# What is Heart Valve Disease?

Heart valve disease is a condition caused by the malfunctioning or abnormality of one or more of the heart's four valves, which affects the flow of blood through the organ. If left untreated, the damage to the heart can lead to heart failure and ultimately, death.<sup>2</sup>

The heart, which is responsible for pumping blood through the blood vessels of the circulatory system, has four chambers, separated by four valves. When working properly, the valves maintain one-way blood flow through the heart and make sure there is no backward leakage. If the heart valves become diseased or defective the valves may not open or close properly, meaning the flow of blood may be obstructed or reversed. The most common heart valves affected are the mitral valve and aortic valve.

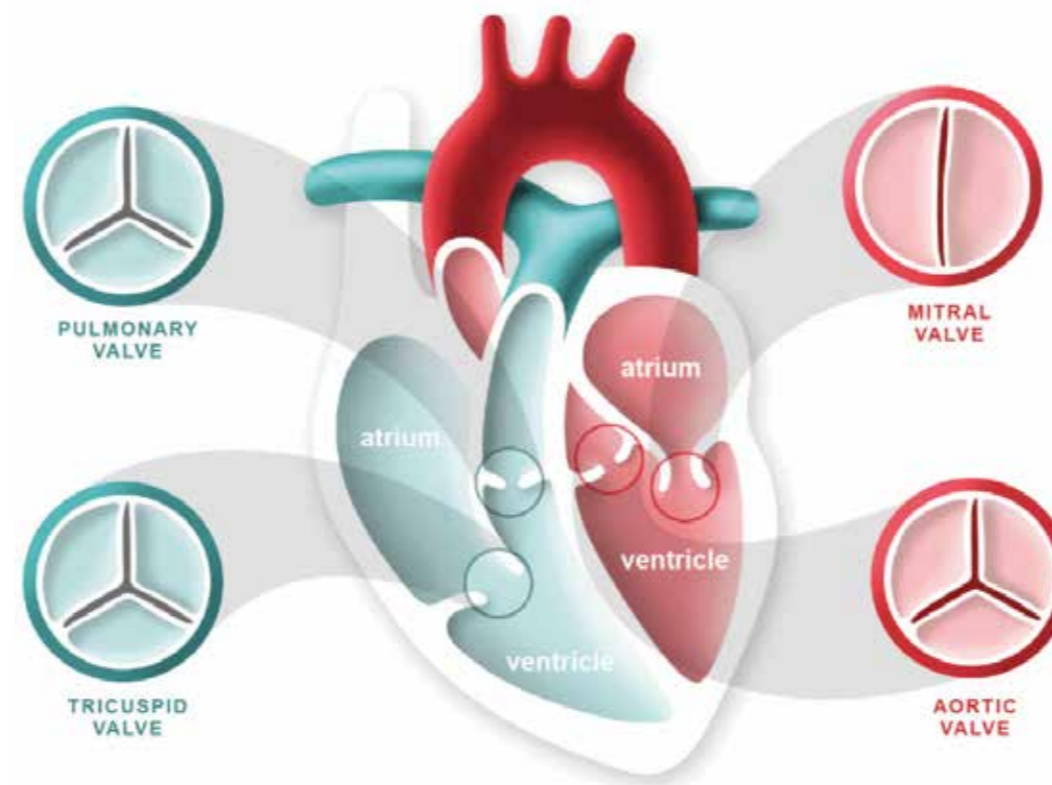
The primary types of heart valve disease are:

- **Valve stenosis or obstruction**

A valve can either become exceptionally narrow (stenosis) or have a blockage (obstruction). Either of these can limit the blood flow through the valve, which may result in a 'back up' of blood behind the valve. This can cause the heart to pump inefficiently, and for blood pressure to build up in the lungs.<sup>4</sup>

- **Valve regurgitation**

Also known as a 'leaking heart valve', this is when the valve's leaflets fail to close completely, allowing blood to flow back through the valve. This can cause the heart to work harder to pump the same amount of blood.



## Causes of Heart Valve Disease

Some people are born with heart valve disease (congenital), the causes of which are not known. For those that acquire it later on in life, the main causes are:<sup>5</sup>

- Degenerative reasons (ageing)
- Having had rheumatic fever
- Cardiomyopathy - a disease of the heart muscle
- Damage to the heart muscle from a heart attack
- A previous infection with endocarditis
- Previous trauma

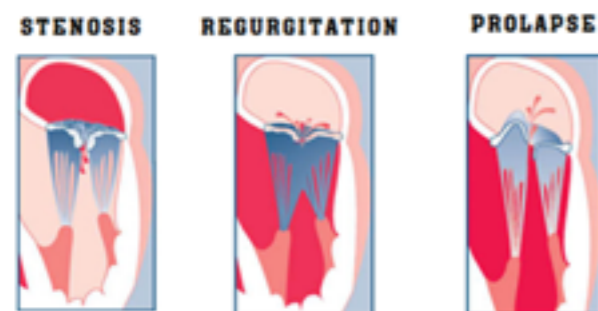


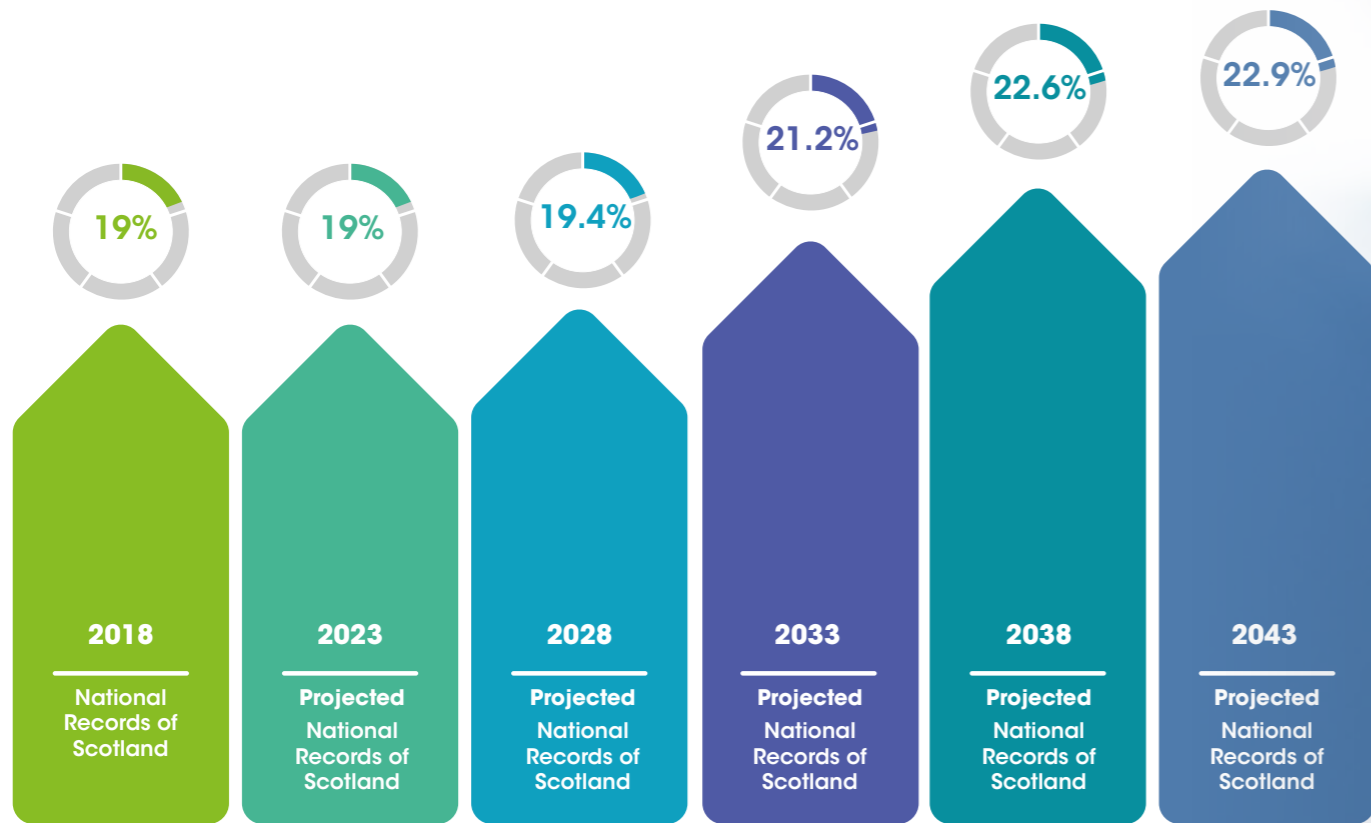
Image credit: RajNursing



# Scotland's Ageing Population

Ageing is a primary cause of heart valve disease and, as a result, the incidence of heart valve disease increases significantly with age <sup>6</sup>. Across the UK, an estimated 1.5 million people over the age of 65 are affected. With the number of people in this bracket expected to double by 2050 <sup>7</sup>, the prevalence of heart valve disease, which affects 13 per cent of those over 65 <sup>8</sup>, will increase concurrently.

For Scotland specifically, it is clear that the population is ageing according to national data. In mid-2018, 19 per cent of the population were of pensionable age, compared with 18 per cent in 1993. The proportion of the population who are of pensionable age is estimated by the Scottish Government to increase to 22.9 per cent by mid-2043.<sup>9</sup> Given that the prevalence of heart valve disease increases with age, affecting 13 per cent of those over 65 <sup>10</sup>, urgent action is required to ensure that Scotland is equipped to meet the expected increased patient demand for heart valve disease detection, management and treatment.



This table shows the projected acceleration of Scotland's ageing population from 2019 to 2043. With an aged population will come a higher prevalence of cardiovascular disease.

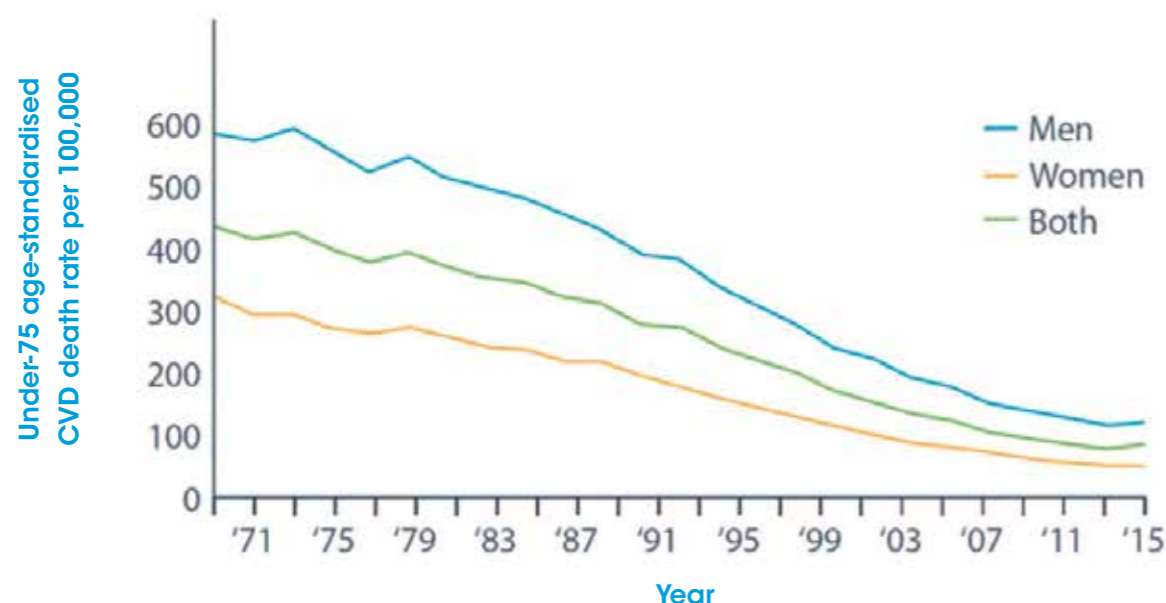
# Heart Valve Disease in Scotland

## Scotland's challenge

Heart disease remains a significant challenge in Scotland and is a major cause of death and disability. A 2018 study from the British Heart Foundation (BHF) found that 22 per cent of premature deaths in Scotland, accounting for 4,600 per year, were a result of CVD.<sup>11</sup> The Scottish Government's own National Records highlight that heart disease accounts for over 9,000 deaths each year<sup>12</sup> - approximately 15.6% of Scotland's total deaths in 2019.<sup>13</sup>

The incidence of conditions, such as heart valve disease, has been increasing, partly as a result of an ageing population, improved detection and increased survival from acute coronary events.<sup>14</sup> However, the BHF concluded in its 2018 report that "After 40 years of falling premature CVD deaths, progress has slowed".<sup>15</sup> Premature CVD death rates in Scotland had previously fallen by 78per cent over the last 40 years, largely thanks to research, advances in treating conditions like heart attack and stroke and the decline in smoking, as well as lifestyle changes.

After 40 years of falling premature CVD deaths, progress has slowed<sup>16</sup>



In addition, whilst there has been a steady rise in life expectancy over decades more broadly, this has also recently stalled, partly due to a slowdown in the progress in reducing mortality from heart disease, especially in people between the ages of 55 and 74.<sup>17</sup>

Heart Valve Voice, therefore, welcomed the publication of the Scottish Government's Heart Disease Action plan 2021,<sup>18</sup> which set out key priority areas by which to improve Scotland's heart health. These included:

- Prevention – tackling risk factors
- Timely and equitable access to diagnosis, treatment and care
- Workforce
- Effective use of data

The Plan outlines that, based on the global burden of disease estimates, 73,000 people currently suffer from heart valve disease<sup>19</sup> in Scotland. However, beyond this, no further specific mentions are made of heart valve disease within the document. We feel that this is a significant missed opportunity. There needs to be a conscious effort from the Scottish Government and others to equally prioritise combating this disease along with other serious heart conditions.

Lack of clear, accessible data presents a barrier to painting an accurate picture of heart valve disease in Scotland. Heart valve disease is not included in the annual Scottish Heart Disease Statistics.<sup>20</sup> This impacts our ability to accurately assess the exact number of patients living with heart valve disease in Scotland at any given time. It also impacts NHS Scotland's ability to forecast diagnosis and treatment levels, and therefore project gaps in the workforce. To take one example, this is why the Scottish Heart Disease Action Plan used global burden of disease estimates.<sup>21</sup> However, it is worth noting that Scotland's national records combined with Health Board population estimates give a different view – that an estimated 134,428 Scots experienced clinically significant heart valve disease in 2018/2019.<sup>22</sup> This discrepancy of data could be hiding a public health blind spot that is underestimating the severity of heart valve disease in Scotland.

Discussing the availability of heart valve disease data in Scotland at a Heart Valve Voice roundtable meeting, attendees explained that an application fee must first be made to access useful data – which can take weeks or months.<sup>23</sup> Heart Valve Voice believes this data must be readily available at request, free of charge, to assess Scotland's performance compared to other UK countries.

*“There is not a nationwide register of heart valve disease data”*

Scottish cardiologist specialist



## Gender inequalities created by cardiovascular diseases

Heart disease remains the leading cause of death for women in Scotland and is responsible for significant morbidity and reduced quality of life. The Scottish Government's Women's Health Plan highlights that there is a need to "expand the narrative of CVD in Scotland, raising awareness of the range of CVD as well as CVD risk in women".<sup>24</sup> This is required, it is argued in the plan, not only in the public domain but also among policymakers and healthcare professionals.

Women face several challenges in maintaining optimal heart health, with almost 1 in 10 deaths of women in Scotland resulting from Ischaemic Heart Disease.<sup>25</sup> The Women's Health Plan outlines a growing body of evidence that demonstrates that women presenting with symptoms of heart disease are under-investigated, less likely to access guideline-recommended treatments and often have worse outcomes following interventions.<sup>26</sup> Women are also less likely to have appropriate management of CVD risk factors, such as diabetes and high blood pressure. This is further compounded by unique risk factors for CVD in women, including adverse pregnancy outcomes, use of contraceptives that increase risk in CVD as well as endometriosis and menopause. In addition, there is often a failure to recognise CVD in younger women who present to healthcare services.<sup>27</sup>

The plan also states that CVD outcomes for women are also associated with social determinants of health, including access to healthcare services that meet the needs of women. Women are under-represented in health research related to CVD, which has implications for recommendations on optimal care for women at risk of or who have a diagnosis of CVD. There also remains an under-representation of female cardiologists and female clinicians in roles that design and develop guidelines and research in CVD.<sup>28</sup>

Heart Valve Voice welcomes the approach taken by the Scottish Government to address gender health inequalities created by CVD, including the Women's Health Action Plan. With Scotland's population expected to age further, heart valve disease will only become more prevalent in Scotland's female population.



## Recommendations

- The exclusion of specific actions aimed at tackling heart valve disease in the Scottish Heart Disease Action Plan should be recognised, with a conscious effort from the Scottish Government and others to equally prioritise combating this disease along with other serious heart conditions.
- More standardised data needs to be collected on heart valve disease in Scotland to ensure there is a clearer picture of how the condition is currently being diagnosed, managed and treated. For example, statistics on heart valve disease referrals and echocardiograms should be included more specifically in the Scottish Heart Disease Statistics.
- The Scottish Government should build on the commitments in the new Women's Health Plan to improve information and public awareness of heart disease symptoms and risks for women, by ensuring there is a specific focus on heart valve disease.



## The COVID-19 Recovery

The COVID-19 pandemic has had a detrimental impact on many areas of the heart valve disease pathway.

Patients with serious, life-long heart defects were told hospital appointments as far ahead as 2022 cannot go ahead due to COVID-19 “contingency planning” and backlogs.<sup>29</sup> The number of NHS patients presenting to cardiology services for serious heart problems more than halved while the number of heart attacks diagnosed fell by 40 per cent at one centre in Scotland during the lockdown.<sup>30</sup>

The coronary angiography services were also restructured with a focus on regional centralisation and reduction of inter-hospital patient transfer. The Golden Jubilee National Hospital (Glasgow) became the main regional centre for primary and urgent percutaneous coronary interventions (PCI) for patients presenting from Dumfries and Galloway and most of the West of Scotland.<sup>31</sup>

However, the pandemic also presented opportunities that transformed NHS ways of working in Scotland. Attendees at our roundtable noted that telemedicine, in particular, has been used much more frequently during the pandemic and that the expectation was that once restrictions are eased this would constitute approximately 50 per cent of appointments. One clinician, however, noted with concern the increase in the use of virtual appointments, outlining that it might lead to a tail-off in detection and an increase in undiagnosed valve disease in the community. It was noted that heart valve disease is probably the best example of a disease most commonly picked up as an incidental finding.

Heart Valve Voice’s virtual appointment guide was also mentioned at the roundtable as a positive step to help patients understand the telemedicine process, as well as the wider #JustGo campaign to encourage those with heart valve disease symptoms to access treatment and diagnosis during the pandemic.<sup>32</sup>

Heart Valve Voice welcomes efforts by the Scottish Government to strengthen and bolster NHS Scotland as the UK emerges from the pandemic. The recently published NHS Recovery Plan outlines extensive measures post-pandemic, committing more than £1 billion of targeted investment for the recovery and renewal of Scotland’s health service.<sup>33</sup> The plan outlines a range of reforms across primary and acute NHS services to help recover from the impact of the COVID-19 pandemic, and get everyone the treatment they need as quickly as possible.

*“It’s inevitable that fewer people are going to get picked up. I think that’s quite a concern. I don’t quite know what the solution is to it.”*

Scottish heart  
valve disease clinician

It is reassuring that the Scottish Government outlined the following priorities in the Recovery Plan:

- Primary and community care –the continuation of efforts to scale up the use of ‘NHS Near Me’ (video consultation service) with £3.4 million a year. Before the pandemic, usage of NHS Near Me was limited to around 1,200 consultations per month, but with the rapid scale-up due to the pandemic, this now stands at 12,000 per week.<sup>34</sup>
- Outpatient diagnostic procedures: Diagnostic imaging is also an important part of the patient pathway, and the Scottish Government will prioritise reducing waiting times for these important procedures. £29 million has been invested to increase diagnostic procedures by 78,000 this. Together with innovation in diagnostic procedures, the Government expects to increase capacity by at least 90,000 procedures by the end of the year.<sup>35</sup>
- Bolstering workforce numbers: increasing cardiac physiology training places by 30.<sup>36</sup>
- Additional inpatient and day-case activity: the creation of a network of National Treatment Centres (NTCs) for planned elective procedures and diagnostic care. The phased opening of the NTCs is being accelerated to support NHS recovery and help the increase in demand that is anticipated to arise from demographic changes.<sup>37</sup>

However, the Scottish Government must keep patients with heart valve disease in mind as it seeks to achieve these goals. It should ensure this cohort of patients are not overlooked by continuing ways of working developed and adapted throughout the COVID-19 pandemic that has been viewed by patients as successful, such as the use of innovative technologies, where clinically appropriate.

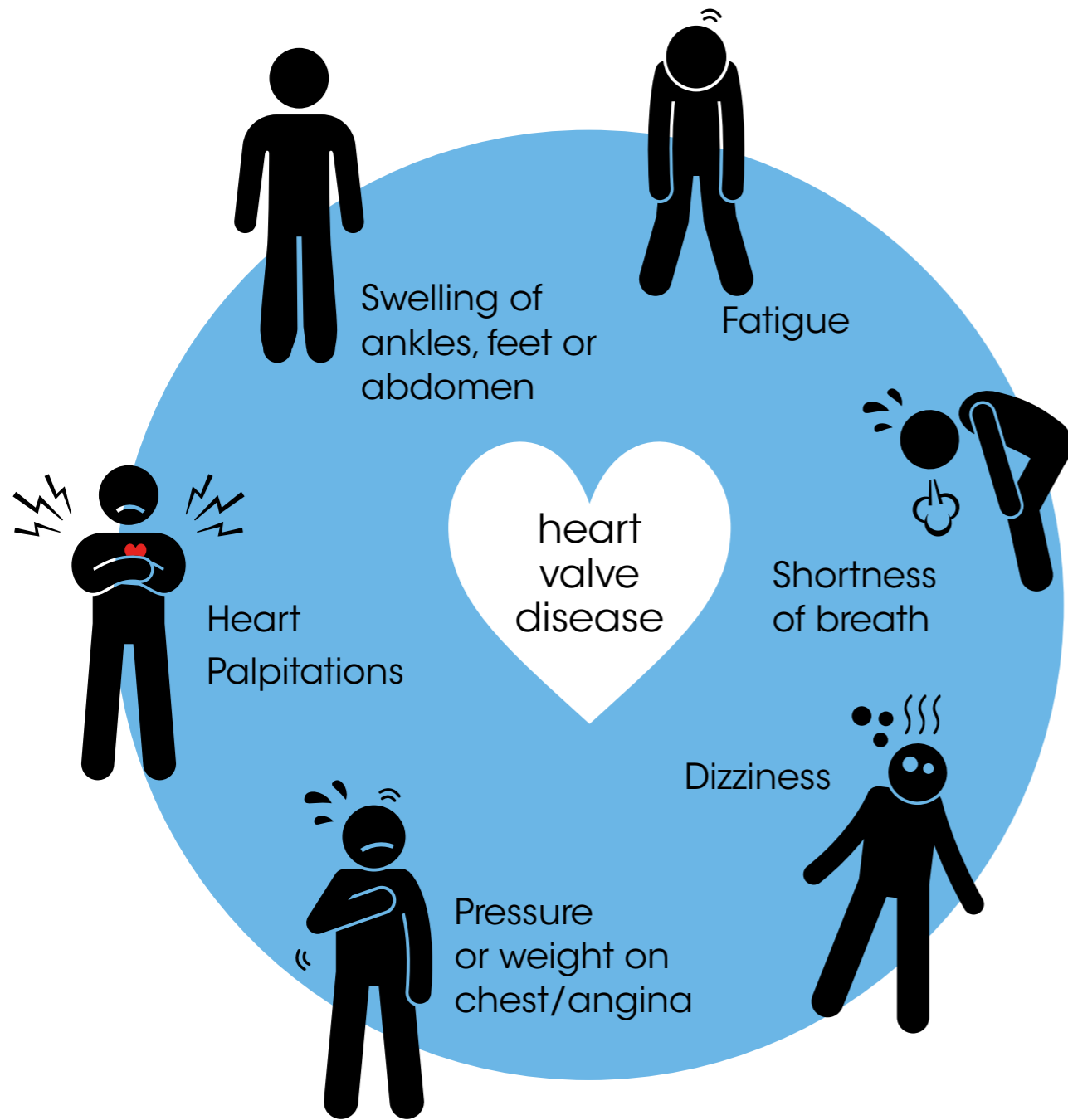
## Recommendation

- As the National Heart Disease Task Force works to support Health Boards to implement the Heart Disease Action Plan, it should consider how effective recovery from the COVID-19 pandemic can be expedited.



# Patient Impact

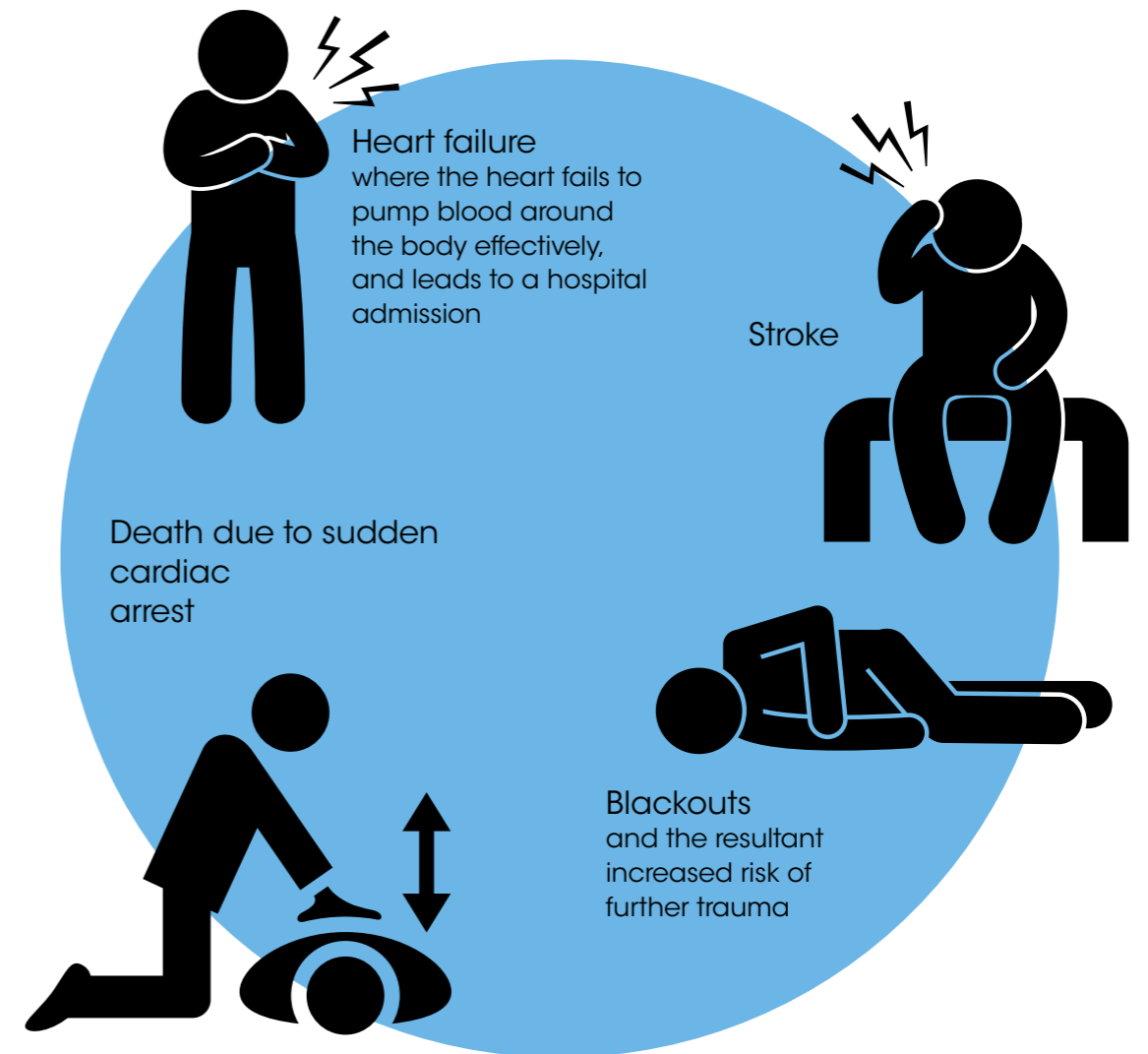
The impact of heart valve disease on a patient's life can be significant. The symptoms alone can restrict an individual's freedom to go about their daily activities, as they can include: <sup>38</sup>



In addition, untreated heart valve disease shortens their lives significantly. However, successful treatment will prolong their lives and can therefore enable patients to return to work, care for their families, travel, or take up a new hobby they have previously been unable to manage.

It should be noted that many people living with heart valve disease are asymptomatic – they don't show any symptoms and as a result, their condition is can be missed by health care professionals.

If not treated, heart valve disease can lead to:



# Diagnosis, Optimal Treatment and Heart Valve Disease Management

Outcomes for patients with heart valve disease whose condition is left untreated are poor. Studies show that people with serious aortic stenosis have around a 50per cent chance of living two years if they are not in receipt of effective treatment.<sup>39</sup> Therefore, people must be diagnosed at the earliest opportunity to ensure they can be appropriately treated as quickly as possible.

Because some patients are asymptomatic, Heart Valve Voice recommends that opportunistic case ascertainment is considered in high-risk populations, with outreach at events with a high proportion of over-75s in attendance.

At the Heart Valve Voice virtual roundtable meeting, it was noted that each heart valve centre across Scotland could be reviewed to identify areas of expertise and construct an optimal patient pathway. This section refers to Heart Valve Voice's own Gold Standard report recommendations, which focused on the entire treatment pathway from the initial onset of symptoms.

## Detecting heart valve disease

For the detection of heart valve disease, trained health care professionals can simply use a stethoscope (auscultation) to listen for the characteristic heart 'murmur'.

Heart Valve Voice recognises that there is an ever-increasing demand for primary care practitioners in Scotland, not just in terms of a heavy workload, but also in the intensity of work being carried out. Heart Valve Voice is therefore concerned that heart valve disease patients are not being effectively diagnosed and, as a result, are not being offered appropriate treatment.

Innovative technology, such as digital stethoscopes can also be employed to alleviate the workload of trained administrators while improving detection rates amongst populations. Heart Valve Voice notes that the charity has been involved in an intelligent stethoscope project with the University of Cambridge, which has demonstrated a 97per cent success<sup>40</sup> rate in detecting heart murmurs and can reduce the number of appointments that a patient needs to attend, which is particularly important in the COVID-19 era. One HCP at the roundtable meeting noted that there had not been an increase in the use of intelligent stethoscopes in Scotland<sup>41</sup>, and did not anticipate an increase soon. Although they noted that it would improve detection of the condition.

## Recommendations

- The Scottish Government should urgently seek to review services in Scotland that offer heart valve disease services, to identify areas of expertise and construct an optimal patient pathway.
- Awareness of the signs and symptoms of heart valve disease amongst primary care healthcare professionals and the public must be improved through effective and targeted education and awareness-raising campaigns.
- All individuals over the age of 65 should have their hearts routinely checked with a stethoscope by a trained primary care healthcare professional.
- All patients with heart murmurs detected should be referred within appropriate timelines or echocardiography to assess the severity of the valve pathology. With the increased use of telemedicine and virtual appointments, there is a need to be mindful of the impact this may have in incidental or opportunistic detection / diagnosis.



## Diagnosing heart valve disease

Once a heart murmur is detected, the gold standard is for patients to have their diagnosis and its severity confirmed via echocardiogram. This is the first step to effective treatment.

An echocardiogram (or 'echo') is a sonogram (ultrasound of the heart) and is one of the most widely used diagnostic tests in cardiology. During the test, images of the patient's heart valves are used to show whether they are working properly and, if not, how serious the problem is.

Digitalised innovations in detection have been welcomed, but must be rolled out more widely. Greater Glasgow and Clyde Health Board have adopted the 'Early Detection of Heart Failure' project. This project is for earlier detection of heart failure – before hospitalisation – using digital innovations and enhancing access to urban and rural community echocardiography. Funding has been achieved for the Artificial Intelligence (AI) heart failure risk identification with the BHF. A plan is underway to provide the implementation of part of the project on a simulation platform.

Heart Valve Voice's 2019 report: 'A Gold Standard in the Diagnosis, Treatment and Management of Heart Valve Disease in Adults' recommends that symptomatic patients must be referred to a specialist valve clinic within 2 weeks, while asymptomatic patients must be referred for an echocardiogram within 6 weeks.<sup>43</sup>

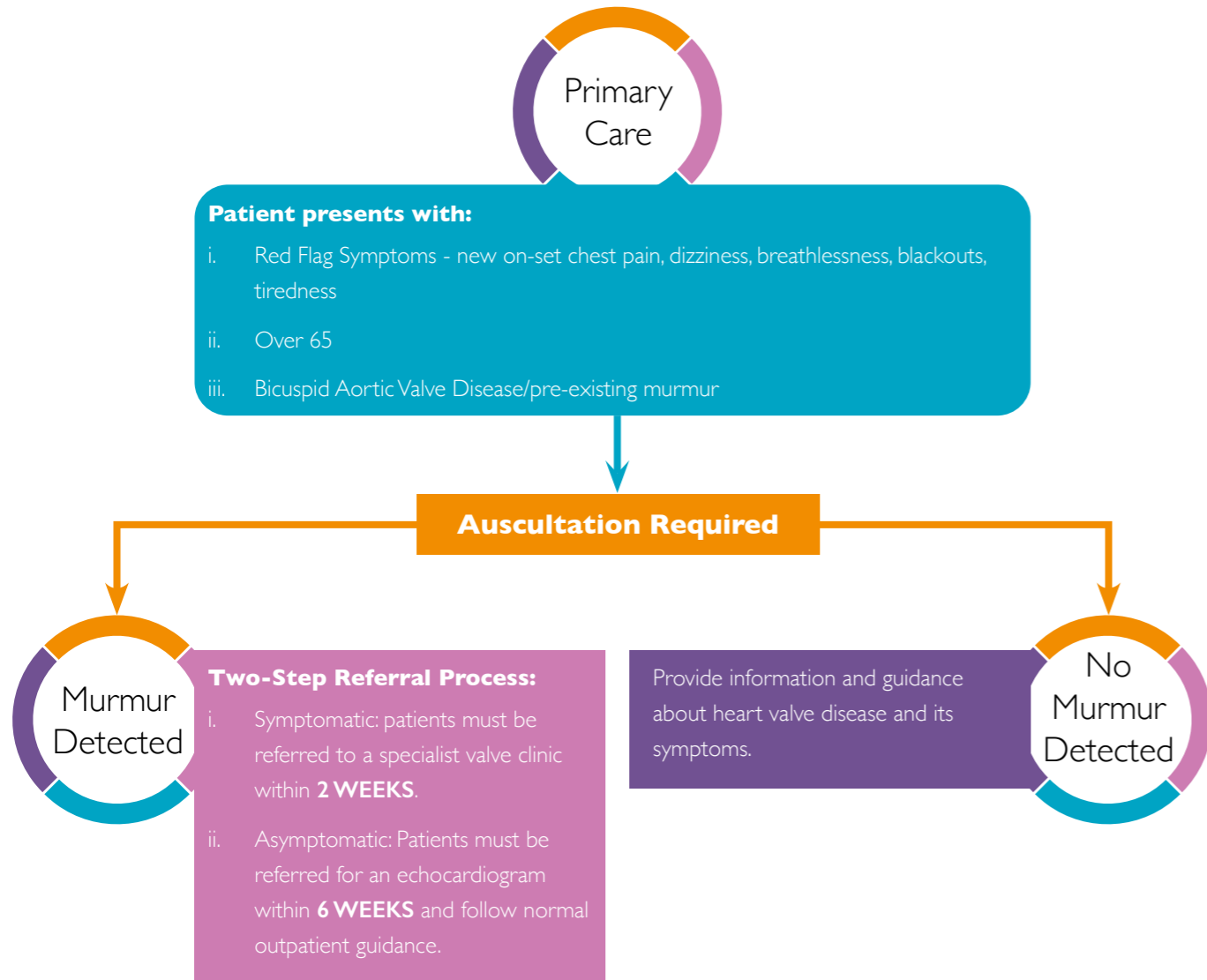


Image credit: Heart Valve Voice

In Scotland, SIGN guideline 147 (Management of Chronic Heart Failure) sets out an appropriate approach to echocardiography in people with suspected heart failure.<sup>44</sup> However, there is not something similar in place for heart valve disease. There is currently a lack of a structured approach to collating information on the diagnosis of heart valve disease at a national level to accurately identify unwarranted variation as recognised in Scotland's Heart Disease Action Plan 2021.<sup>45</sup>

In England, diagnostic waiting times are enshrined within the NHS Constitution, which pledges that patients should not be required to wait six weeks or longer for a diagnostic test.<sup>46</sup>

Data from a recent Freedom of Information (FOI) request to Scottish NHS regions, conducted by the BHF, found that from April 1 2019, through to October 31 2020, only 368 patients (28.07 per cent) received an echocardiogram test inside a month, with almost as many (305, or 23.26 per cent) only being seen after seven months at NHS Lanarkshire. This highlights the stark variation in the time taken to for patients to receive an echo, an issue certainly exacerbated by COVID. However, this has been a perennial issue, as shown in 2016, when NHS Fife's waiting time for a routine echocardiogram was 27 weeks.<sup>47</sup> Attendees at our virtual roundtable highlighted that variation in waiting times for echocardiography across Scotland is an area of particular concern and one where more data would be beneficial.<sup>48</sup>

Health Boards	1 month waiting	2 month waiting	3 month waiting	4 month waiting	5 month waiting	6 month waiting	7+ month waiting
Borders	Green	Red	Yellow	Orange	Yellow	Orange	Yellow
D&G	Green	Yellow	Yellow	Orange	Red	Red	Red
Lanarkshire	Yellow	Orange	Yellow	Yellow	Orange	Yellow	Green
Lothian	Green	Yellow	Red	Red	Red	Red	Red
Shetland	Yellow	Yellow	Yellow	Yellow	Yellow	Orange	Yellow

As such, the available evidence suggests that patients in Scotland are being unfairly penalised by late access to echocardiography, compared to their English counterparts. In England, diagnostic waiting times are enshrined within the NHS Constitution, which pledges that patients should not be required to wait six weeks or longer for a diagnostic test.<sup>49</sup> In 2017, waiting times for echocardiography in England was 2.6 weeks.<sup>50</sup> This is a stark contrast to the waiting times of some Health Boards in Scotland presented above, which illustrates the following percentages of patients waiting longer than a month for an echocardiogram:

- Borders 47.10%
- D&G 43.72%
- Lanarkshire 71.93%
- Lothian 22.13%
- Shetland 78.90%

## Recommendations

- The target waiting time for echocardiography should be reduced to six weeks, in line with recommended European standards and in symptomatic patients, the target should be lowered to two to three weeks.
- The current variation in access to echocardiography across Scotland needs to be addressed as a matter of urgency.





## Optimal treatment of heart valve disease

If diagnosed promptly, heart valve disease is an entirely treatable condition even in very high-risk patients, particularly as a result of recent innovations in treatment options (TAVI). Effective treatment can allow many patients to return to living normal, productive and active lifestyles. The appropriate treatment for each patient differs, depending on the severity of the disease and the patient's associated co-morbidities.

However, regardless of lifestyle changes, over time a valve problem can progress and become more severe.<sup>51</sup> In these cases, the only way to treat the condition is by repairing or replacing the damaged valve(s) with surgical treatment. Only 1,117 valve surgeries were performed on people in Scotland aged over 65 in 2018-19 — that is less than one per cent of heart valve disease patients<sup>52</sup> (although it should be noted that not all heart valve disease patients will need or be suitable for surgery).

**Valve repair** is often used for mitral valves that are leaking but are not seriously damaged, but it can also be used for leaking aortic valves. During the procedure, the damaged valve is repaired, whilst maintaining the patient's tissue.

Valve replacement is when the diseased valve is replaced with a new valve. The most common types of replacement valves are mechanical (artificial) valves or tissue (animal) valves.<sup>53</sup>

The traditional way to operate on either the mitral and aortic valves is via open-heart surgery - by cutting through the breastbone (sternum). Known as a sternotomy, the procedure leaves a 25cm scar on the front of the chest. This is a major operation and takes the patient on average two to three months to recover<sup>54</sup>, although many patients report that it takes much longer to feel 'back to normal.'

However, minimally invasive techniques can be used to reduce recovery times and the impact on the patient's quality of life:

**Minimally invasive heart valve surgery:** Also known as 'keyhole surgery', an incision of 5cm or less is made to reach the heart through the ribs, so no bones are broken. This has the advantage of a quicker recovery time, less discomfort for patients as well as less risk of infection.<sup>55</sup>

**Transcatheter aortic valve implantation (TAVI)** is a less invasive option to replacing the aortic valve, performed under local anaesthetic in most cases. It involves inserting a new valve through a catheter, usually by way of a blood vessel at the top of the leg, into the heart and inside the existing faulty valve. It is often used in adults who are considered to be at high risk for traditional heart surgery, but current evidence suggests it is at least as successful as traditional open-heart surgery in lower-risk groups.

In Scotland, this procedure is only available in selected hospitals, such as the Golden Jubilee, the Royal Infirmary of Edinburgh and Aberdeen Royal Infirmary, where access is capped at fewer than 400 procedures per year.

**Transcatheter mitral valve replacement (TMVR)** is currently being investigated as a less invasive alternative to open-heart mitral valve repair or replacement but is currently only routinely used to treat failed valves originally placed during open-heart surgery.<sup>56</sup> During the procedure, the replacement valve is usually inserted through the femoral artery in the thigh (transfemoral). In 15 per cent of cases, it is inserted via another route, for example, the aorta or subclavian arteries. All of these methods require general anaesthetic.<sup>57</sup>

## Benefits of treatment options

Because of the risks involved in the traditional treatment of open-heart surgery, a substantial number of patients are unsuitable due to their advanced age and/or multiple comorbidities. However, the availability of TAVI as a less invasive procedure offers a vital alternative for patients with a diseased aortic valve.

In addition to this, a report published in early 2019 found that TAVI offers an almost immediate cost saving for the treatment centre. Although the initial procedural costs of TAVI are higher than for SAVR, certain TAVI operations on a patient with intermediate surgical risk will have already delivered overall cost savings by the time the patient leaves the hospital.<sup>58</sup> This is because of a reduction in the length of stay with TAVI. In addition, follow-up costs were significantly lower with TAVI than SAVR. The paper concluded that TAVI is an 'economically dominant strategy, and provides both greater quality-adjusted life expectancy and lower short-term and long-term costs.'<sup>59</sup>

There is also an issue of geographic access – some Scottish patients living in the Highlands must travel hundreds of miles to gain access to valve treatment. Heart Valve Voice's virtual roundtable attendees agreed with this view.<sup>60</sup> They explained that this is a multi-faceted problem that is likely due to a lack of triaging, and concerns about workforce capacity.<sup>61</sup>



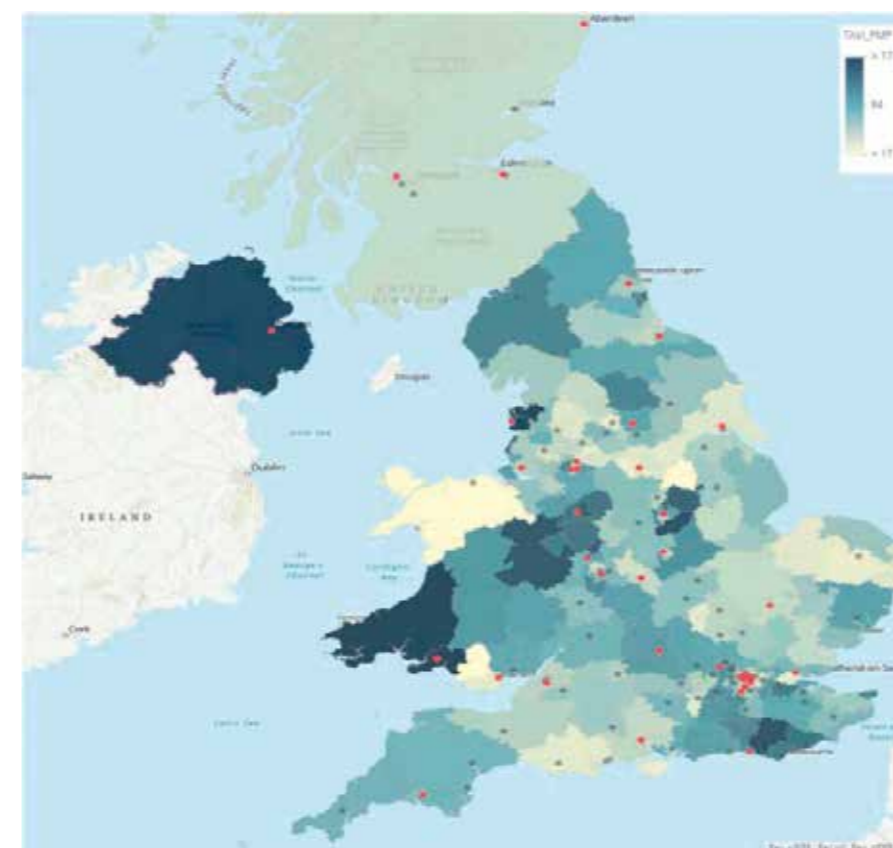


## Access to Optimal Treatment

### Treatment rates in Scotland need to be urgently improved

In Scotland, it is estimated that less than one per cent of the total number of heart valve disease patients in Scotland are treated every year. Only 1,117 surgeries were performed on people aged over 65 in 2018-19.<sup>62</sup> While we understand that not all heart valve disease patients will need or be suitable for surgery, this nonetheless is extremely concerning and needs to be addressed as a priority.

Evidence suggests that approximately one in three patients with severe aortic stenosis who presented with symptoms were left untreated in Scotland in 2019.<sup>63</sup> Decisions appear to be based on several factors, including a perceived high operative risk, patient choice or the condition not being deemed severe enough. This is significant because untreated symptomatic aortic stenosis has a **two-year survival of only 55 per cent.**



An illustrative representation of the geographical variation in TAVI procedures carried out in the UK in 2019. TAVI, transcatheter aortic valve implantation.

Additionally to lack of access to treatment available, geographic inequities also exist with TAVI procedures across the UK, particularly evidenced in Scotland. The graphic above illustrates how Scotland is lagging behind the rest of the UK in terms of TAVI procedures per million of the population.<sup>64</sup>

The number of procedures for valve surgery has increased since 2004. In 2018/19, there were only 34.9 procedures per 100,000 population for men and 23.8 procedures per 100,000 population for women.<sup>66</sup> These figures are likely to be worse in 2021 and 2022 as a result of the COVID-19 pandemic, which has led to significant backlogs across the entire health service.



## Waiting times

Anecdotal evidence gathered in summer 2021 indicated that waiting lists for TAVI were low owing to fewer patients presenting at primary care with symptoms. This could also be as a result of a bottleneck in referrals and fewer echocardiograms taking place. In addition, a personal assessment from a clinician at Heart Valve Voice's virtual roundtable outlined that TAVIs in summer 2021 were only being prioritised for 'high-risk' people.<sup>67</sup>

Scotland's waiting time policy requires that patients should receive surgery within 12 weeks of diagnosis.<sup>68</sup> Whilst waiting time data is collected for cancer, it was explained at the roundtable meeting that similar information is not kept for CVD because national targets do not exist specifically for this therapy area. While a commitment has been made to expand targets to CVD, no further detail has been given as to what these may be, or a timeframe for implementation.<sup>69</sup> The Scottish Government should therefore ensure that in consideration of any expansion of CVD waiting time targets, the needs of heart valve disease patients are also taken into account.

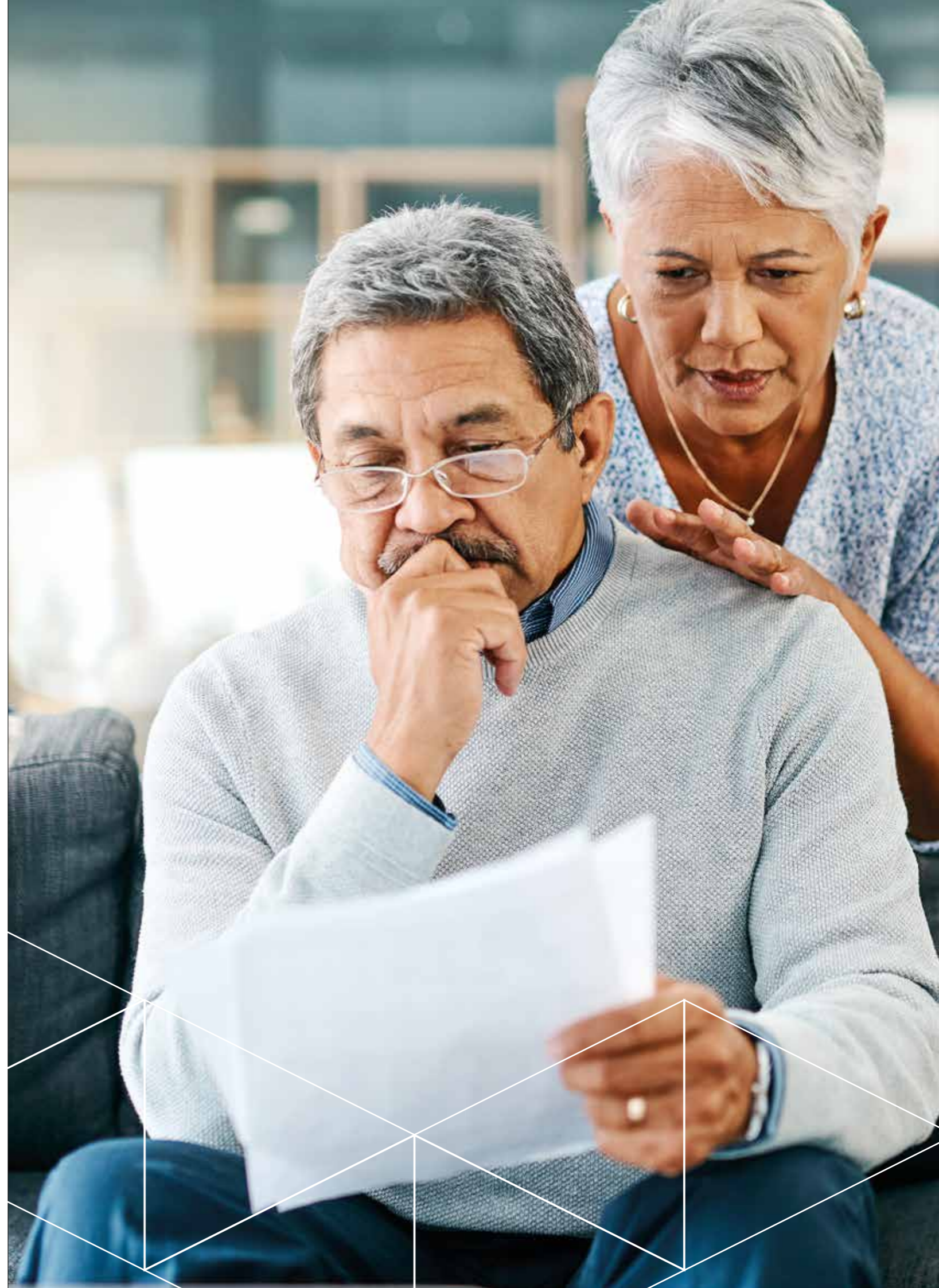
## TAVI Infrastructure in Scotland

TAVI procedures occur across three sites in Scotland (Edinburgh, Glasgow and Aberdeen). The procedure is not commissioned by the National Services Division (NSD) and instead falls under the remit of individual Health Boards. The Health Boards of other patients who are transferred to these sites, compensate on a per-patient basis for TAVI, the cost of which is approximately £22,000.<sup>70</sup>

Data relating to TAVI procedures, such as the rate per million, is kept by the National Institute for Cardiovascular Outcomes Research (NICOR). This data indicates that Scotland has mostly caught up with England in terms of treatment rates and that the variation between the regions of England is now more substantial than the variation between England as a whole and Scotland.<sup>71</sup> Despite this, Heart Valve Voice's virtual clinician roundtable attendees concluded that the data available is mostly "top-level", and that more in-depth data would be useful to dig into these trends in greater detail to identify patient-level outcomes.

An issue also exists with sharing of heart valve disease patient data with colleagues in England. Attendees at the same roundtable discussed as of April 2021 Scotland has pulled out of the NICOR and does not submit information to a TAVI registry as per Scottish Government policy. A replacement to NICOR is set to be introduced in due course<sup>72</sup>, but additional information or timelines are not known at this stage. If the Scottish Government does pursue such a route, it should work with patient groups to ensure heart valve patient data is prioritised.

Research has demonstrated that there is higher mortality from four weeks on the waiting list than from actually having the procedure itself.





# Burden

A recent analysis of a sub-optimal and optimal pathway in England revealed that the latter, with timely diagnosis and TAVI treatment, led to a **34% cost saving for the local Trust.**

The below outline of the sub-optimal and optimal pathways considers the emotional, physical and financial cost to the patient.

Sub-optimal and optimal pathways for an 80-year old father of two with mild chronic obstructive pulmonary disease (COPD) and undiagnosed heart valve disease:

## Suboptimal

**Misdiagnosis:** GP mis-diagnoses heart valve disease as COPD complications and a chest infection, prescribing a second inhaler and antibiotics.

**999 response:** Emergency ambulance called after patient collapses while walking.

**A&E:** A&E attendance where a heart murmur is detected.

**Detection:** Overnight stay in hospital for monitoring, followed by an echocardiogram and referral to cardiology.

**Diagnosis:** Aortic stenosis diagnosed, patient referred to surgeon and 5-week wait for angiogram.

**Treatment:** Patient deemed too high risk for open heart surgery; TAVI not considered as an option.

**Care package of support:** Exacerbated COPD, nursing and social services support. Patient becomes frailer and frequently visits GP and A&E due to falls and soft-tissue damage; the decision is made that the patient should enter a nursing home, where they received long-term oxygen therapy and was subject to further A&E and GP visits before their death 2 years after their diagnosis.

## Optimal

**Diagnosis:** GP listens to patient's heart with a stethoscope, heard a heart murmur and referred them directly to hospital for an echocardiogram

**Valve clinic:** Patient referred to a heart valve clinic and meets their TAVI nurse co-ordinator

**Valve clinic:** Six weeks later, patient sees a surgeon and TAVI specialist. They are immediately referred for an angiogram and CT scan

**MDT:** A multidisciplinary team meeting decides patient is a suitable candidate for TAVI as they are a high surgical risk for open heart surgery

**Treatment:** TAVI procedure conducted under local anaesthetic. Patient is home within 48 hours of the procedure

**Care package of support:** Follow up appointment and repeat echocardiogram at TAVI clinic revealed no untowards issues.

**Ongoing support:** Ongoing COPD appointments and yearly TAVI check-ups before their death 6 years after their diagnosis.

# Recommendations

- Heart valve disease patients must have access to appropriate and effective treatments. Specifically:
  - A multidisciplinary approach should be taken to ensure patients have a more informed choice of how best their disease can be managed.
  - There needs to be recognition of variation in access to treatment centres, particularly for those living in the Highlands.
- The Scottish Government should commit to filling the data gap created by the NICOR withdrawal and ensure heart valve disease data for TAVI procedures is collated.
- The Scottish Government should ensure that in consideration of any expansion of CVD waiting time targets, the needs of heart valve disease patients are also taken into account.



## Conclusion

Significant progress has been made to address the high levels of cardiovascular disease mortality in Scotland over the last three decades, particularly with the launch of the Heart Disease Action Plan 2021. However, evidence suggests that this improvement was already slowing and has now been made worse by the global COVID-19 pandemic. As the NHS in Scotland starts its recovery, now is the time to take action and transform services to accommodate rising demand due to the ageing population.

Heart valve disease is still sadly under-recognised and under-prioritised in comparison to other CVD conditions, evidenced by the fact it is only afforded a few mentions within the Scottish Government's Plan. This is an oversight that could negatively affect the health of a large number of patients in Scotland, both now and in the future, as well as place an unnecessary burden on an already stretched NHS.

This report highlights clear steps that can be taken to improve the detection, management and treatment of heart valve disease for patients across Scotland. We look forward to working closely with partners across the heart valve disease community to ensure their implementation so that all patients receive the very best care possible.



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