

# State of the Nation

## Heart Valve Disease in Wales



the more we listen,  
the more lives we save

September 2019



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## Foreword

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

As the Chief Executive of Heart Valve Voice, I am lucky enough to work on a daily basis with patients who have been diagnosed with, and effectively treated, for the condition. Unfortunately, many people with heart valve disease continue to go undiagnosed and are subject to a sub-optimal care pathway, resulting in complications and poor quality of life. As a condition predominantly affecting those over 65, this issue is particularly problematic in Wales, which has a far higher elderly population than the UK as a whole.

Heart Valve Voice's mission 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 Wales receive the best possible care and support.

In the last decade, the Ageing Well in Wales initiative, supported by the Welsh Government, has championed the need for focused work on ageing and ensuring people are able to age well. Meanwhile, various heart health strategies have been launched by NHS Wales to minimise the incidence of heart disease and ensure those affected have timely access to high quality care pathways. It is our hope that this report highlights the need for heart valve disease patients to also be considered in this work and associated policy making.

We believe it is critical that action is taken today to improve care and outcomes for patients with heart valve disease and in doing so, reduce the burden on the NHS. The recommendations shared in this report will help to achieve this aim.

I would like to thank everyone who has contributed towards the production of this report, including Dr Dave Smith and Dr Aprim Youhana.

**Wil Woan**  
**Chief Executive**  
**Heart Valve Voice**




# Executive Summary


To develop this report, Heart Valve Voice conducted a Freedom of Information request of every Health Board (HB) in Wales, as well as 23 NHS Trusts in England that lie on or near the border with Wales. In total we received 25 responses out of 30. These responses, alongside interviews with Welsh clinicians and comprehensive research, were used to draft the recommendations found within this report.

Across Wales, more than **118,000** people over the age of **65** are thought to suffer with moderate to severe heart valve disease.<sup>xiii, xiv</sup>


In the **over-75** population, it equates to nearly **1 in 5**.<sup>xiii, xiv</sup>

75 <sup>over</sup> 


Significant heart valve disease is linked to a worse prognosis for the patient, and is associated with a **35-75%** higher risk of death compared to those without significant valvular disease.<sup>xi</sup>




The elderly population in Wales will increase by at least **250,000** in the next 40 years: the prevalence of heart valve disease is expected to reflect this, rising by **37%**.<sup>xiii, xiv</sup>



Despite its prevalence, heart valve disease has been left out of all major cardiac strategies produced and implemented by the Welsh Assembly and/or NHS Wales.



In fact, the prognosis of patients with symptomatic aortic stenosis is worse than most cancers<sup>xii</sup>




**10,943**

Number of Welsh patients diagnosed with heart valve disease in one year.<sup>xxi</sup>

**Only one Health Board** (Swansea Bay) was able to indicate the total number of regular attendee episodes recorded for patients who suffer with heart valve disease (119)<sup>xxi</sup>



An echocardiogram is the gold standard of diagnosis for heart valve disease, and is the first step towards ensuring life-saving treatment.<sup>xix</sup>



Average wait for an echocardiogram:

Welsh Health Boards\* : **8 weeks**<sup>xxi</sup>

English Trusts: **2.6 weeks**<sup>xxii</sup>


Average number of patients awaiting an echocardiogram in Wales in July 2019\* : **754**<sup>xxi</sup>




English Trusts have treated over **600** Welsh patients for heart valve disease within the last year, with one charging NHS Wales **£1,780,627**<sup>xxi</sup>



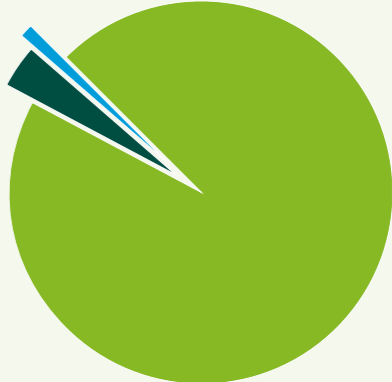
Only 1 responding Trust (Wye Valley) stated that they do not recharge Welsh Health Boards for treatment.<sup>xxi</sup>



Around **555** patients were transferred into NHS England care from Betsi Cadwaladr University Health Board.

Around **20** were transferred from Powys Teaching Health Board

Fewer than **5** were transferred from Swansea Bay University Health Board.<sup>xxi</sup>



Unless specified, all data refers to April 2018 – March 2019  
 \* Excluding Powys, where patients are transferred to an English Trust for an echocardiogram  
 \*\* Countess of Chester NHS Foundation Trust provided 2017/18 data

# Key Recommendations

## Detection and diagnosis

- 1 The omission of heart valve disease in the Heart Disease Delivery Plan should be recognised, with ongoing and future implementation activity to review the needs of heart valve disease patients.
- 2 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.
- 3 All individuals over the age of 65 should have their hearts routinely checked with a stethoscope by a trained primary care healthcare professional.
- 4 All patients subsequently diagnosed with heart murmurs should be referred for echocardiography to assess the severity of their valve pathology.
- 5 The target waiting time for echocardiography – the gold standard of diagnosis – should be reduced to six weeks, in line with recommended standards and English targets. Additionally, in symptomatic patients, targets should be lowered to 2-3 weeks.
- 6 GPs should have improved access to echocardiography for all patients with a heart murmur or suspected heart valve disease.

## Treatment and management

- 7 Heart valve disease patients must have access to appropriate and effective treatments. This specifically includes the following:
  - a A multidisciplinary approach should be taken to ensure that patients have a more informed choice of how best their disease can be managed.
  - b Recognition of the unique situation of North Wales and its patients who are often transferred into NHS England care, and the facilitation and enhancement of links between diagnostic centres in Wales and treatment centres in England.
- 8 The recommendations from the Royal College of Physicians review into waiting list management at all parts of the pathway should be implemented as soon as possible, to allow patients of Wales the timely service they deserve.



# 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>i</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.<sup>i</sup>

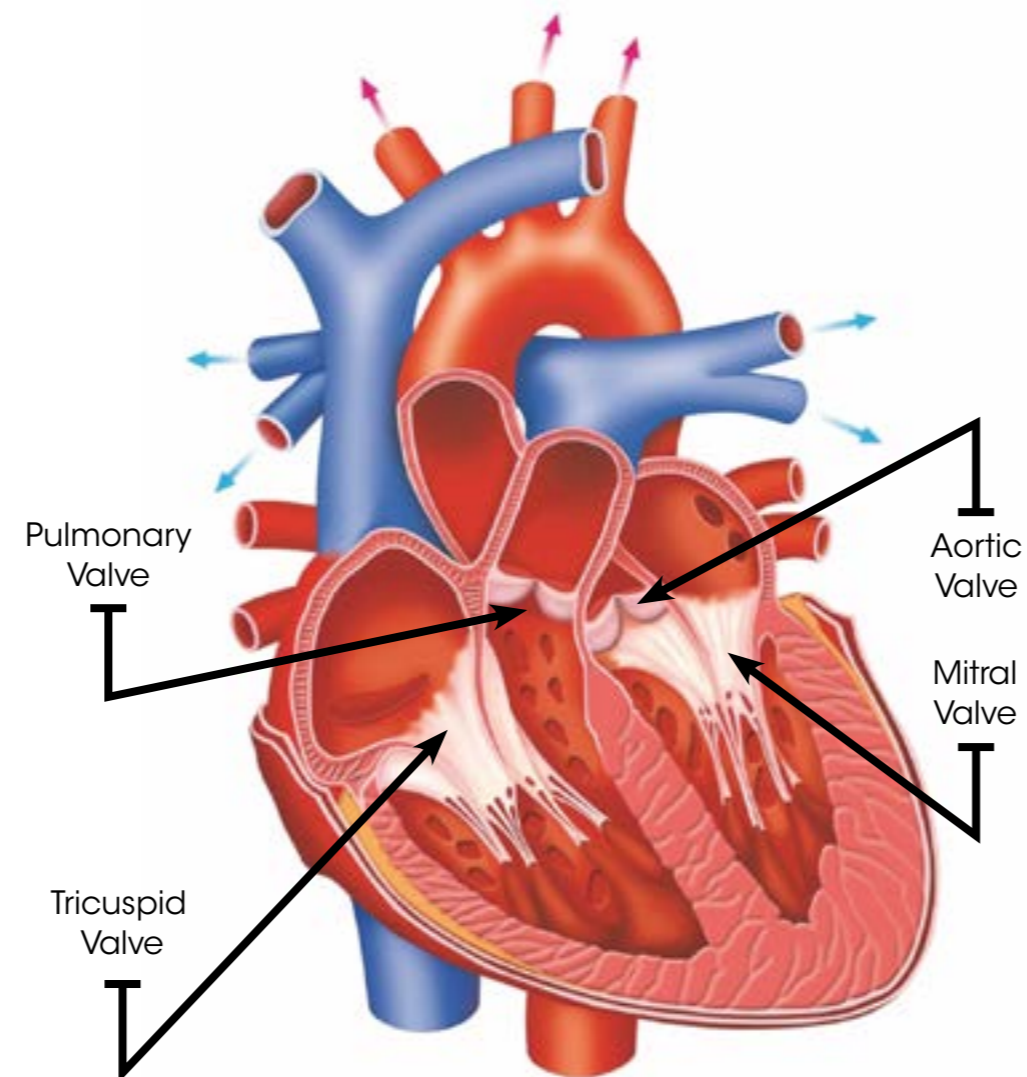
The primary types of heart valve disease are:

- **Valve stenosis or obstruction**

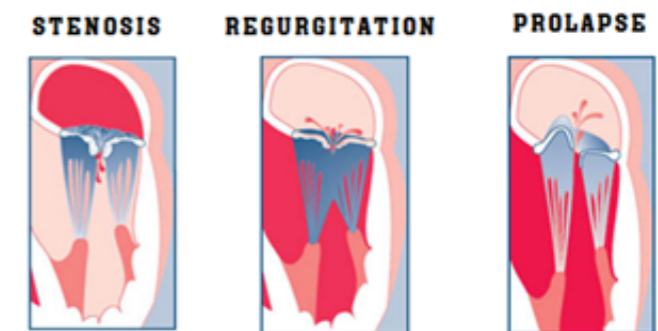
A valve can either become exceptionally narrow (stenosis) or have a blockage (obstruction). Either of these can limit the blood flow through the valve, which may result in a 'back up' of blood behind the valve. This can cause the heart to pump inefficiently, and for blood pressure to build up in the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



Patients may also be diagnosed with **mitral valve prolapse**, a commonly diagnosed form of valve regurgitation caused by the thickening and degeneration of valve tissue (myxomatous degeneration). Mitral valve prolapse is where the mitral valve 'bulges' into the heart's left upper chamber (left atrium) like a parachute, during the heart's contraction.<sup>iii</sup> Despite its frequency, it usually causes no symptoms for many years as the heart can compensate by overworking. But this leads to the deterioration of the left ventricle function and eventually to heart failure, if left untreated.



In Wales, the most common type of heart valve disease is aortic stenosis, followed by mitral regurgitation.<sup>iv</sup>

## 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>v,vi</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

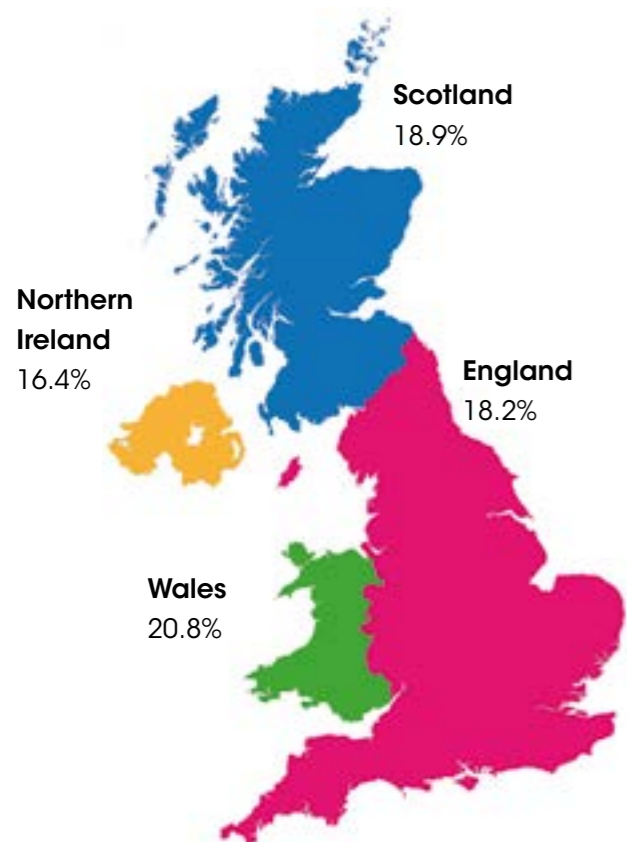
Image credit: RajNursing

# Wales's Ageing Population

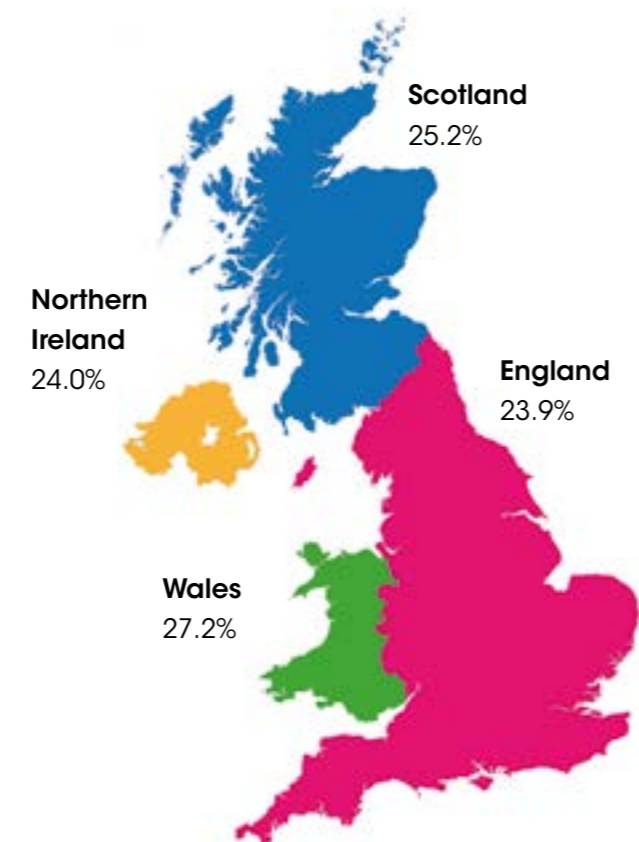
As detailed on page 11, ageing is a primary cause of heart valve disease and as a result, the incidence of heart valve disease increases significantly with age.<sup>vii</sup>

This is particularly concerning in Wales as it has a higher elderly population than the rest of the UK.<sup>viii</sup>

**2018: % local population over 65**<sup>viii</sup>



**2036: % local population over 65**<sup>viii</sup>



In 2008, less than **1 in 4** of the Welsh population was over 65; by 2059 this is expected to increase to **1 in 3**.<sup>xiii</sup> This represents an increase of 250,000 in the next 40 years – a population roughly equivalent to that of Swansea.<sup>xiii</sup>

# Heart Valve Disease In Wales

In Wales, cardiovascular disease is the biggest killer with more than 9,000 deaths each year – an average of 25 each day.<sup>ix</sup> Recent efforts by NHS Wales and the Welsh Government have attempted to address this, with the launch of *Together for Health – a Heart Disease Delivery Plan* (2013), and the refreshed *Heart Conditions Delivery Plan* (2017).

However, despite this recognition of the need to improve cardiac care, there has been little-to-no focus on heart valve disease in Wales. Indeed, the aforementioned *Heart Conditions Delivery Plan* contains no mention of the condition. This contrasts with NHS England's Long Term Plan (2019), which expressly recognises the need to improve the early detection of those with heart valve disease.<sup>x</sup>

If the diagnosis pathway is not improved, the undiagnosed population with significant heart valve disease is expected to rise over the coming decades.<sup>xiv</sup> Furthermore, significant heart valve disease is linked to a worse prognosis for the patient, and is associated with a **35-75% higher risk of death** compared to those without significant valvular disease.<sup>xi</sup> In fact, the prognosis of patients with symptomatic aortic stenosis is worse than most cancers.<sup>xii</sup> This means NHS Wales will be forced to 'firefight' treatment of the condition, with a large number of patients presenting when their condition is severe and needing extensive and expensive inpatient care for the rest of their life.

## Prevalence in an ageing population

This lack of prioritisation of the condition in Wales belies its prevalence: across Wales, over **118,000** people over the age of 65 are thought to suffer with **moderate to severe** heart valve disease.<sup>xiii, xiv</sup> In the over-75 population, it equates to **nearly 1 in 5**.<sup>xiii, xiv</sup>

As demonstrated on p12 Wales is facing an increasing ageing population. **Within the next 40 years, the prevalence of heart valve disease in Wales is therefore expected to rise by 37%.**<sup>xiii, xiv</sup> By 2059, over 163,000 people over the age of 65 will be moderately or severely affected, and at least one third of these will have multiple valve lesions.<sup>xiii</sup>

## Heart valve disease in Wales

increase in prevalence:<sup>xiii, xiv</sup>



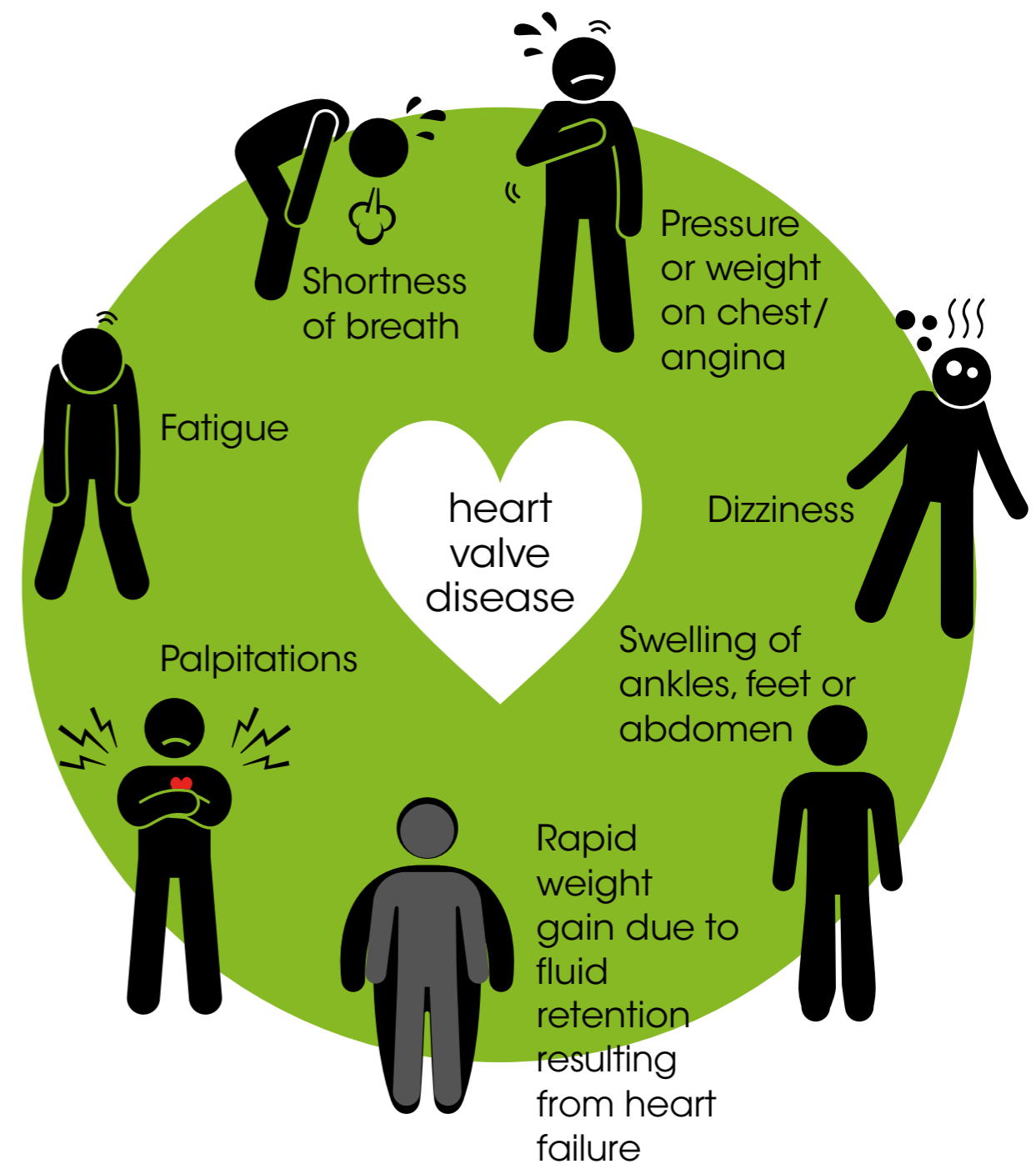
This projection clearly demonstrates the need to plan for the future: long-term assessment and planning for the diagnosis, treatment and management of the rapidly increasing numbers of heart valve disease patients.

## Recommendation

- 1 The omission of heart valve disease in the **Heart Disease Delivery Plan** should be recognised, and ongoing and future implementation activity should review the needs of heart valve disease patients.

## 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>xv</sup>

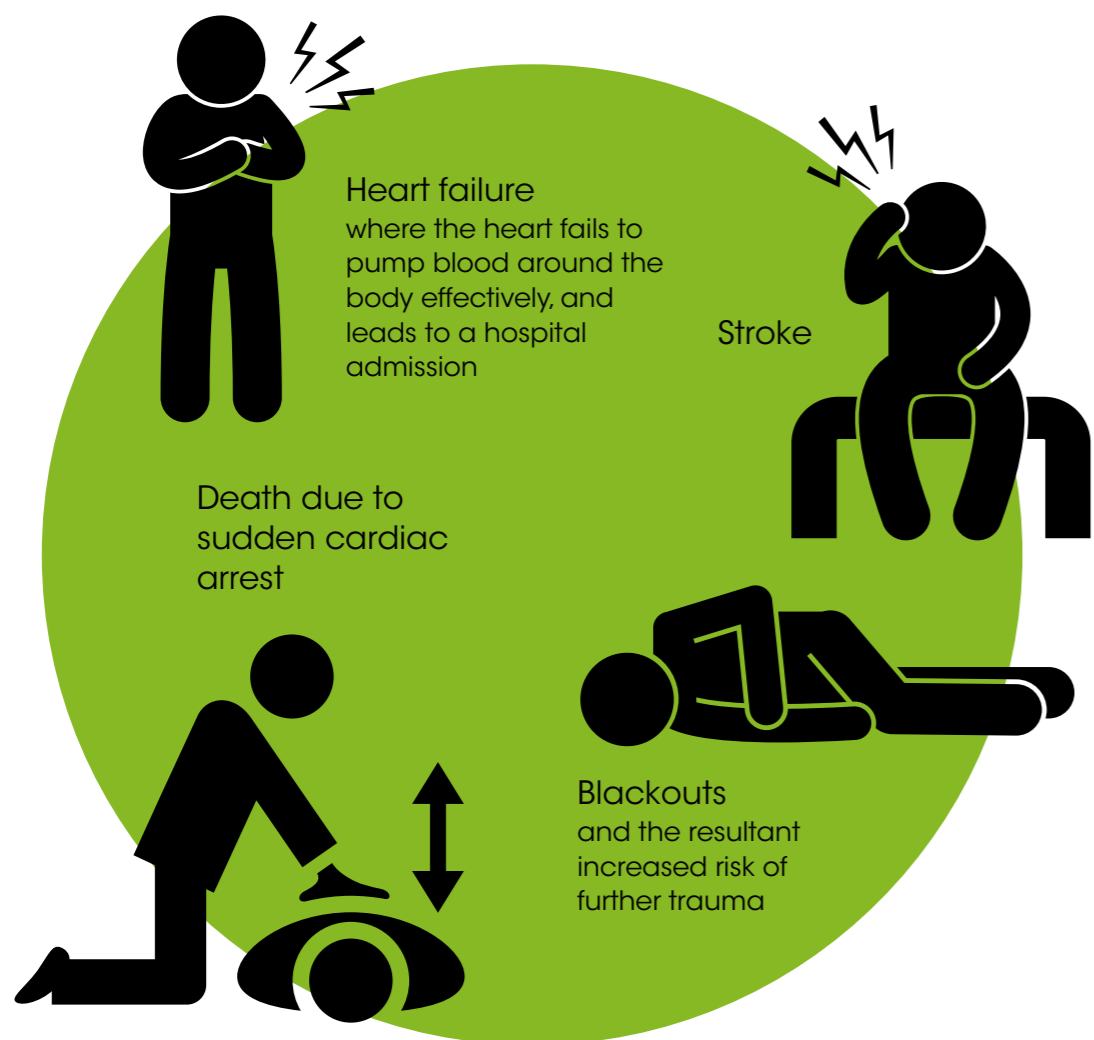




In addition, untreated heart valve disease shortens their lives significantly. But successful treatment will prolong their lives and can therefore enable patients to return to work, care for their families, travel, or take up a new hobby they have previously been unable to manage.

However, many people living with heart valve disease are asymptomatic – they don't show any symptoms and, as a result, their condition is often missed by health care professionals.<sup>xiv</sup>

If not treated, heart valve disease can lead to:<sup>ii</sup>



# 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 50% chance of living for two years, if they are not in receipt of effective treatment.<sup>xvi</sup> Therefore, it is vital that people are 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.

## Detecting heart valve disease

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

However, in 2016 a patient survey revealed that **82% of Welsh patients over 60 say their GP 'rarely' or 'never' checks their heart with a stethoscope** during a GP visit. This is in comparison to 77% and 63% in the South West of England and Northern Ireland respectively. Furthermore, 98% of Welsh patients over 60 are not aware of what aortic stenosis is, meaning they are unlikely to proactively request a heart check with stethoscope even when displaying symptoms.<sup>xvii</sup>

Heart Valve Voice recognises that there is an ever-increasing demand on primary care practitioners in Wales, not just in terms of 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 technological solutions

Within the last year, evidence has emerged suggesting that screening for significant aortic stenosis with digital stethoscopes and machine learning is both fast and effective. In the near future, front-line clinicians may be able to use digital stethoscopes to more accurately refer patients for an echocardiogram.<sup>xviii</sup>

Heart Valve Voice is looking to run a pilot to assess how digital devices can help GPs to detect heart valve disease; we look forward to working further with Welsh clinicians and policy makers to embed our findings into standard practice.

## Recommendations

- 2 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.
- 3 All individuals over the age of 65 should have their hearts routinely checked with a stethoscope by a trained primary care healthcare professional.
- 4 All patients diagnosed with heart murmurs, as per recommendation 2, should be referred for echocardiography to assess the severity of the valve pathology.



## 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.<sup>xix</sup> 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.

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 two weeks, while asymptomatic patients must be referred for an echocardiogram within six weeks.<sup>xix</sup>

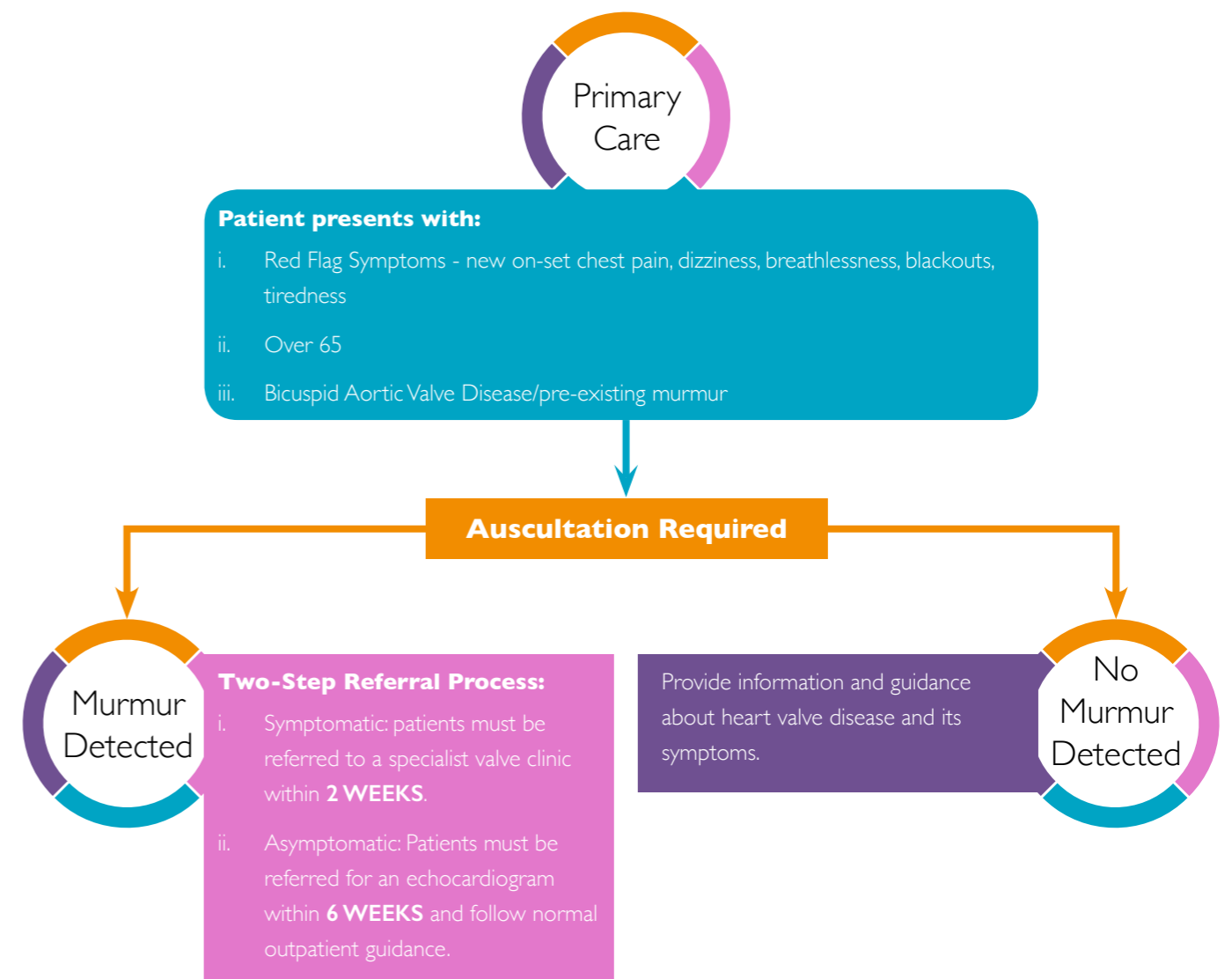
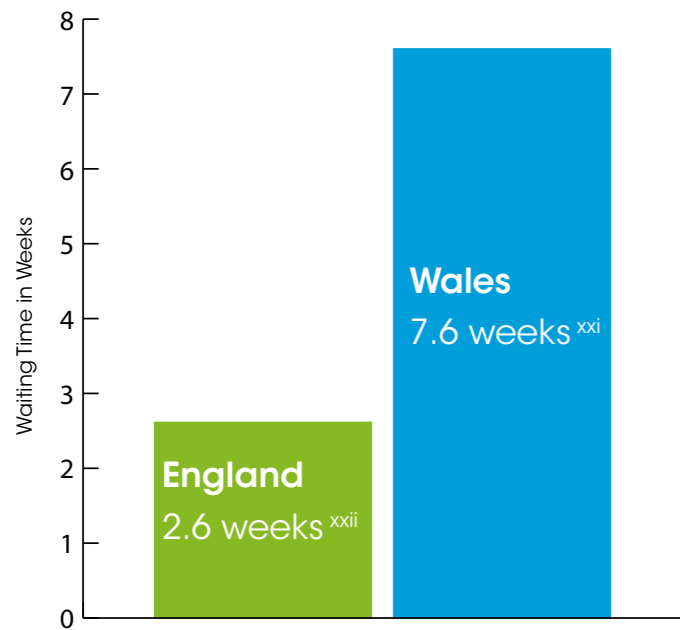


Image credit: Heart Valve Voice

However, data from a recent Freedom of Information (FOI) request to Welsh Health Boards revealed they are currently working towards a target of eight weeks for the average wait for an echocardiogram.<sup>xxi</sup> While the FOI demonstrated that all Health Boards are meeting this target, anecdotally we know that many cardiac centres are being forced to work through full evening and weekend lists to achieve this eight week wait, which in itself Heart Valve Voice does not consider best practice care.

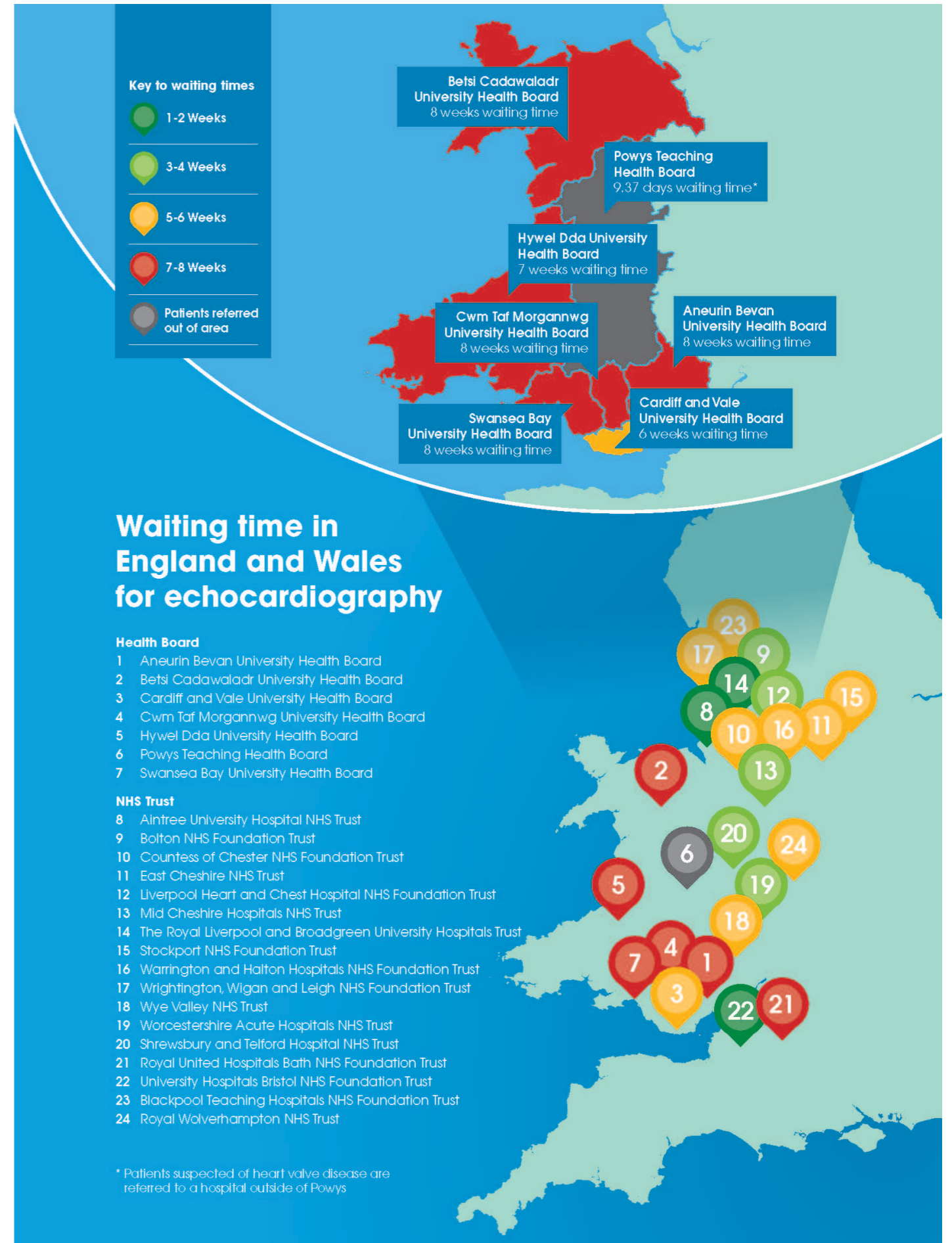
Furthermore, waiting times in Wales are longer than those in England; for those referred across the border, they will face a shorter wait for treatment compared to that expected in Wales.<sup>xxi</sup>

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>xx</sup>



### Median waiting times for an echocardiogram

Just across the border at Aintree University Hospital NHS Trust, the wait is 2.3 weeks; at University Bristol NHS Foundation Trust it is 10 days. In fact, only one Welsh-bordering English NHS Trust (Royal United Hospitals Bath NHS Foundation Trust) responding to our FOI reported its echocardiography wait as longer than six weeks.<sup>xxi</sup>



Heart Valve Voice believes that patients in Wales are being unfairly penalised in late access to echocardiography, compared to their English counterparts.

In 2016, the Welsh Government provided £850,000 to fund community cardiology services, with objectives including: timely access to cardiology diagnostics; a shift to community care; and improving patient flow and waiting lists. The investment was intended to test and scale a more community-orientated provision of cardiac diagnostics and assessment.

The programme involved pilot schemes across the country, some of which provided extra training and funding for GPs to conduct tests and reporting traditionally carried out by cardiologists.

In early 2018, the Welsh Institute for Health and Social Care, University of South Wales produced a report assessing the impact of the investment and community services. It found that while some services were more advanced than others, they had all made a demonstrable impact on the patient. Many experienced similar issues, including those of governance and accountability, workload implications and infrastructure which should be considered in the potential roll out of further community cardiac services.<sup>xxiii</sup>

The desire of Health Boards and local networks to establish the community cardiology services in the face of extreme workforce and funding pressures should be congratulated. In the next 12 months, Heart Valve Voice would like to see a further assessment of their services' successes, failures and strategy for roll out.

## Recommendations:

- 5 The target waiting time for echocardiography should be reduced to six weeks, in line with recommended standards and English targets, and in symptomatic patients the target should be lowered to 2-3 weeks.
- 6 GPs should have improved access to echocardiography for all patients with a heart murmur or suspected heart valve disease.

## Optimal treatment of heart valve disease

If diagnosed in a timely manner, 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.

There is currently no medicine available that can cure heart valve disease, although lifestyle changes and medicines can alleviate symptoms successfully and delay problems for many years.<sup>i</sup>

However, regardless of lifestyle changes, over time a valve problem can progress and become more severe.<sup>xxiv</sup> In these cases, the only way to treat the condition is by repairing or replacing the damaged valve(s) with surgical treatment. Heart Valve Voice believes these treatments can be considered curative in most patients if operated on in a timely manner before the heart muscle suffers irreversible damage. This is based on medical literature for the past several decades.

**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.<sup>xxv</sup>

**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>xxv</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>xxvi</sup>

However, it is possible for minimally invasive techniques to be used in order 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>xxvii</sup>

**Transcatheter aortic valve implantation (TAVI/TAVR)** 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 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.<sup>xxviii</sup>

**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>xxviii</sup> During the procedure, the replacement valve is usually inserted through the femoral artery in the thigh (transfemoral). In 15% of cases it is inserted via another route, for example the aorta or subclavian arteries. All of these methods require general anaesthetic.<sup>xxix</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.

*"With the introduction of TAVI, our options for treating aortic stenosis – the most common type of heart valve disease in Wales – are vastly improved. I have treated patients with TAVI who would not have been eligible for the traditional surgical route so this can be a life-saving procedure; in addition, those who have TAVI experience a shorter recovery time, meaning patients are up on their feet and out of hospital quicker. For many of my patients, access to TAVI has given them their life back."*

**Dr Dave Smith**  
**Consultant Cardiologist**  
**Morriston Hospital**

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 hospital.<sup>xxx</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.<sup>xxx</sup>

The paper concluded that TAVI is an 'economically dominant strategy', and provides both greater quality-adjusted life expectancy and lower short- and long-term costs.<sup>xxx</sup>

# Access to Optimal Treatment

Evidence suggests that approximately 1 in 3 patients with severe aortic stenosis who presented with symptoms are left untreated.<sup>xxxi</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%**.<sup>xvi</sup>

Two main Health Boards are able to provide valve repair and replacement treatments in Wales: Cardiff and Vale, and Swansea Bay. In their respective hub hospitals – University Hospital Wales and Morriston Hospital – about 580 heart valve operations took place in 2017/18.<sup>iv</sup> Of these, 89 were TAVI operations.<sup>xxxii</sup>

Of the other Health Boards, neither Cwm Taf, Aneurin Bevan nor Powys performed any heart valve operations in the same period.<sup>iv</sup> Betsi Cadwaladr reported 1-2 mitral valve repairs.<sup>iv</sup> Instead, patients presenting with moderate to severe heart valve disease in the north and middle of Wales are often referred for treatment in English hospitals. For example, in 2017/18, 556 Welsh patients diagnosed with heart valve disease were admitted to the Countess of Chester and Liverpool Heart and Chest Hospital NHS Foundation Trusts, having been transferred from Betsi Cadwaladr or Powys.<sup>xxi</sup>

North Wales is unique, as its patients who live there are often transferred to an NHS England Trust for heart valve disease treatment. It's therefore essential that NHS Wales ensures effective links with its English counterpart. Lack of access to patient records or echocardiogram images can hamper a patient's care and outcomes.

In 2018/19, Liverpool Heart and Chest Hospital NHS Foundation Trust charged Welsh Health Boards £1,780,627 for valve procedures on Welsh patients.<sup>xxi</sup> In recent months, funding issues in England have caused friction between English Trusts and Welsh Health Boards, with reports that hospitals, including the Countess of Chester, were not receiving full payment for caring for Welsh patients.

Total number of patients receiving surgical treatment for heart valve disease



In Wales: <2 in 1000<sup>xxxii, xiii</sup>



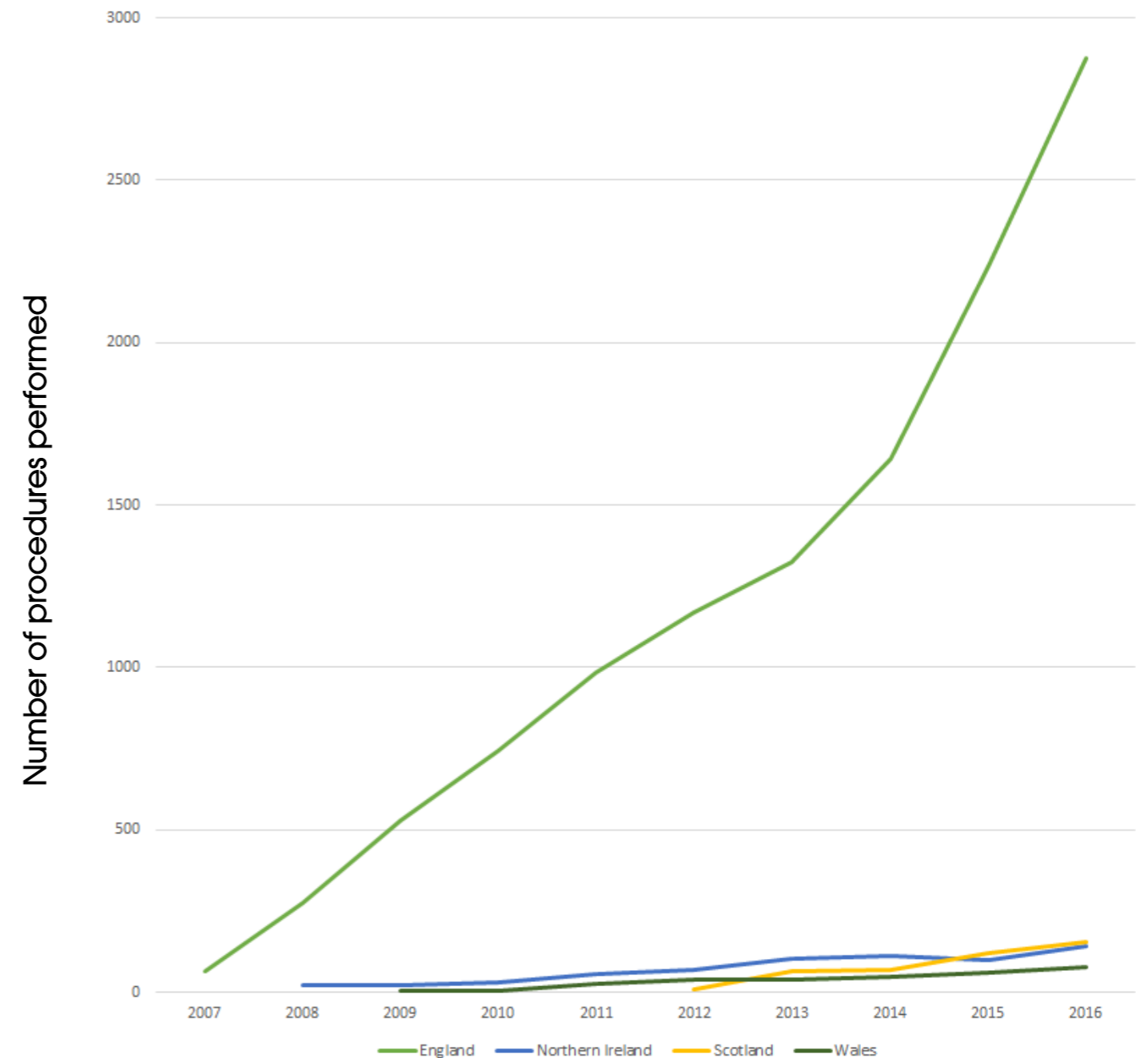
In England: <8 in 1000<sup>xxxiii</sup>

(of the total 75+ population)

Despite the clear advantages of treating heart valve disease, it is clear that many patients in Wales who could benefit from surgical intervention for severe heart valve disease are not receiving treatment. Recent studies have also demonstrated that a number of patients are not even being assessed by a surgeon before being denied surgery.<sup>xxxi</sup>

It is the opinion of Heart Valve Voice that NHS Wales should not be denying surgery to patients who face significantly poor survival and poor quality of life if not operated on, especially given the availability of less invasive procedures such as TAVI for high and intermediate risk patients.

## The number of TAVI procedures performed by year, grouped by country<sup>xxxiv</sup>



## Waiting times for surgery

Another key concern is waiting times for surgery. The FOI conducted confirmed that Health Boards do not centrally record the waiting time from diagnosis to treatment, however excessive waiting times for TAVI procedures is currently the subject of a Royal College of Physicians review, for which we are still awaiting the final report.

The review will investigate claims that 70% of deaths on the TAVI waiting list between 2015 and 2017 in Swansea were likely due to aortic stenosis, and therefore potentially avoidable had the waiting time not been excessive on all parts of the pathway.

Research has demonstrated that there is a higher mortality from four weeks on the waiting list than from actually having the procedure itself.<sup>xxxv</sup>



## Recommendations

- 7 Heart valve disease patients must have access to appropriate and effective treatments. Specifically:
  - a A multidisciplinary approach should be taken to ensure patients have a more informed choice of how best their disease can be managed.
  - b Recognition of the unique situation of North Wales and its patients who are often transferred into NHS England care, and the facilitation and enhancement of links between diagnostic centres in Wales and treatment centres in England.
- 8 The recommendations from the Royal College of Physicians review into waiting list management at all parts of the pathway should be implemented as soon as possible, to allow patients of Wales the timely service they deserve.

# 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.** <sup>xxxvi</sup>

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 he received long-term oxygen therapy and was subject to further A&E and GP visits before his death 2 years after his diagnosis.

## Optimal

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

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

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

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

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

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

# Conclusion

Significant progress has been made to address the high levels of cardiovascular disease mortality in Wales, with the launch of delivery plans and establishment of a Heart Conditions Implementation Group. However, heart valve disease has been overlooked as a consideration by these documents and taskforces. This is an oversight that could negatively affect the health of patients in Wales, as well as cause unnecessary cost to the NHS.

The findings of this report highlight the many challenges within the pathway of care for patients with heart valve disease. Resolving these issues is critical. Throughout, we have highlighted various recommendations, which would ensure significant improvements in the under-diagnosis and under-treatment of the condition are made.

Heart Valve Voice looks forward to continuing to work with patients, clinicians, policy makers and politicians to improve heart valve disease care in Wales.



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