

NOVEMBER 2022

Heart Valve Disease: Community Pathway

ENTER



Wilmington
Healthcare

What is heart valve disease (HVD)?

HVD is a potentially serious condition involving damage to one of the four valves within the heart that ensure blood flows in a single, efficient direction. HVD can affect anyone at any age and is an increasing problem in the UK and across the world.

What do patients need?

Patients need early identification and prompt intervention when indicated. However, the UK has significant variation in care pathways for HVD. Many people wait too long for a diagnosis, often due to a lack of patient and clinician awareness of the condition, which can have major ramifications for their symptom management, quality of life and life expectancy.

HVD is a national priority

The NHS Long Term Plan highlights the need for increased access to testing in primary care and the creation of multi-disciplinary networks that will serve to speed up appropriate care.

Burden of underdiagnosis

The prevalence of HVD continues to grow as the population ages. Early detection is essential in order for patients to access prompt treatment. Underdiagnosis has dire effects on patient outcomes and incurs higher costs for services over the long term. By keeping HVD in mind in the context of cardiac symptoms, especially for patients attending annual review for conditions such as type 2 diabetes, coronary heart disease and hypertension, primary care professionals play an important role in enabling HVD patients to access the care they need.

A resource for primary care

This integrated care pathway resource has been created in a collaborative effort by a team of experts to address the role of primary care in patients with HVD. We hope the pathway will be a useful resource locally for both healthcare professionals and commissioners, to map the HVD patient journey and best practice care. We encourage you to use and adapt this resource to help you to reflect on, develop and improve your local service.

Heart valve function can be impaired by:

- **Stenosis:** a narrowing or stiffening of the valve, which restricts its opening and obstructs the forward flow of blood.
- **Regurgitation:** failure of the valve to close completely, which allows blood to flow backward.

Primary valve disease: affects the valve structure. May be congenital or acquired. Acquired valve degeneration is currently the main cause of heart valve disease, leading to the most common types of calcific aortic stenosis and myxomatous or calcific degeneration of the mitral valve.

Secondary disease: results from enlargement or dysfunction of the heart chambers (atria or ventricles) with otherwise normal mitral or tricuspid valve structure.

Prevalence

- Dysfunction is more likely in older people because the heart valves stiffen with age.
- Over 50% of over 65s in the UK may have asymptomatic HVD.¹
- Around 11% of over 65s in the UK have clinically significant HVD.¹
- Prevalence of HVD among the over 65s in the UK is predicted to rise from 1.5 million to more than 3 million people in 2046.¹

Symptoms

- Some people are asymptomatic.
- Breathlessness is the most common symptom.
- Associated heart rhythm problems, such as atrial fibrillation or heart block, may cause palpitations, or dizziness and light-headedness, respectively.
- Untreated severe disease can lead to valvular heart failure, with symptoms including breathlessness, reduced exercise capacity, tiredness and swollen ankles.

[NICE \(2019\) Guideline scope: heart valve disease presenting in adults: investigation and management](#)

1. d'Arcy JL et al. Eur Heart J 2016; 37(47):3515–3522.

HVD is a common, serious and yet treatable disease

A big problem

Around 1.5 million people in the UK currently have moderate-to-severe HVD¹.

High mortality rate

Cardiovascular disease causes a quarter of all deaths in the UK.²

Staggering level of undiagnosed patients

Patients with a diagnosis are the tip of the iceberg. The vast majority of people with HVD do not have a diagnosis and are not accessing any form of treatment (see Fig 1).³

Problem is worsening

HVD is a demographic time bomb, with numbers expected to rise to 2.7 million by 2040¹.

Small changes can make a big difference

Patients benefit from changes to care pathways. Watch Malcolm's journey with HVD to learn more (see Fig 3).⁴

Fig 2. Population projection for HVD in the UK¹

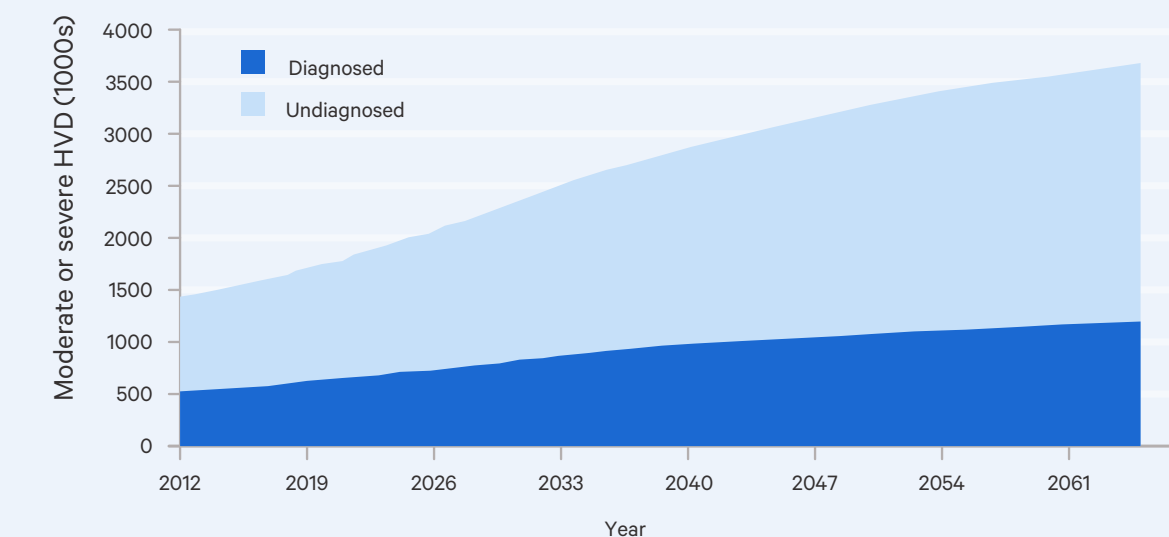


Fig 1. Estimated patients with severe symptomatic aortic stenosis by age in the EU³

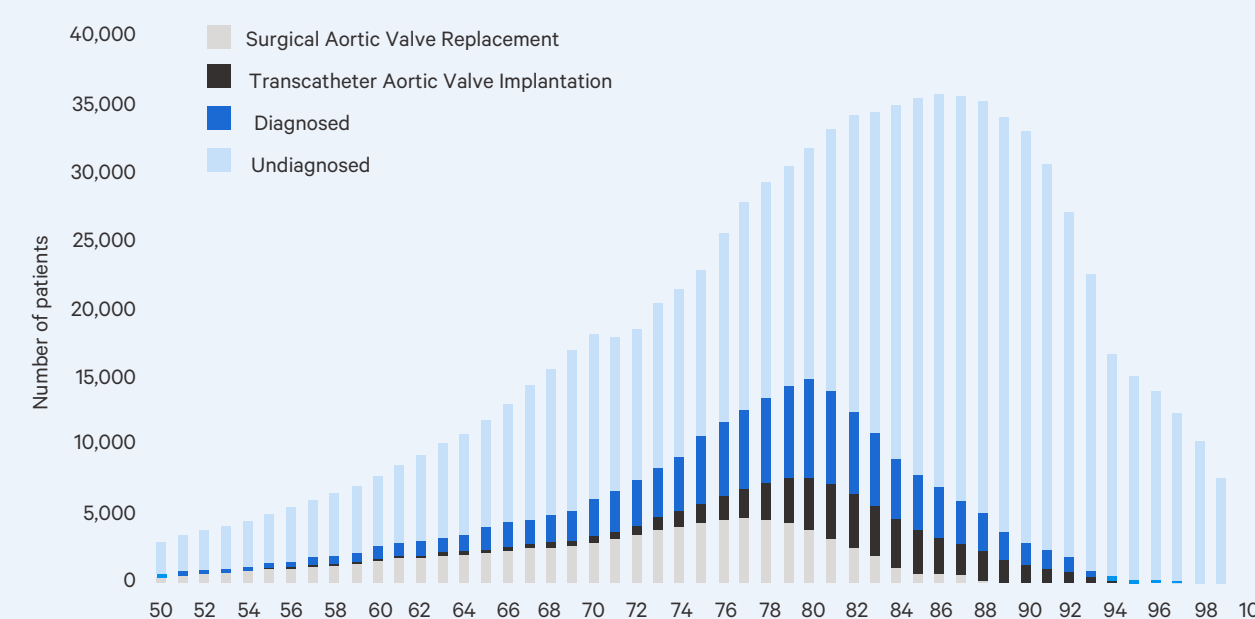


Fig 3. Patient perspective of HVD care pathways⁴



[Watch Malcolm's journey with HVD](#)



The HVD integrated care community pathway is easy to navigate by clicking on the menu tabs. Click on icons in the pathway to open further information:



Information



Red flags & alerts

The pathway is designed to be viewed electronically.

Some links redirect to resources that will open in your internet browser – these will require an internet connection.

Objectives of the HVD pathway

- Improve early detection rates of HVD.
- Initiate timely referral and treatment for people with HVD.
- Identify those needing **urgent referral** within 2 weeks.
- Ensure equity of access to specialist assessment, diagnosis and treatment.
- Reduce morbidity and mortality due to HVD, including reducing hospitalisation.
- Give patients access to education about their condition.

Glossary

DGH - District general hospital

GPwSI - GP with special interest

HCP - Healthcare professional

HF - Heart failure

HVD - Heart valve disease

Further reading

- d'Arcy JL et al. [Large-scale community echocardiographic screening reveals a major burden of undiagnosed valvular heart disease in older people: the OxVALVE Population Cohort Study](#). Eur Heart J. 2016;37(47):3515-3522
- NHS (2019) [NHS Long Term Plan](#)
- British Heart Valve Society (2020) [Network based care for heart valve disease](#)
- Baumgartner H et al. [2017 ESC guidelines for the management of valvular heart disease](#). Eur Heart J. 2017;21;38(36):2739-2791
- NICE guideline (2021) [Heart valve disease presenting in adults: investigation and management](#)
- Heart Valve Voice (2016) [Towards a heart healthy future: a 2020 vision for heart valve disease](#)
- Wilmington Healthcare (2018) [Unwarranted variation scenario: the variation between suboptimal and optimal pathways](#). Malcolm's story: inoperable aortic valve disease versus transcatheter aortic valve implantation (TAVI) procedure
- Thoenes M et al. [Patient screening for early detection of aortic stenosis \(AS\)—review of current practice and future perspectives](#). J Thorac Dis. 2018;10(9):5584-5594
- Yang H et al. [Echocardiographic screening for non-ischaemic stage B heart failure in the community](#). Eur J Heart Fail 2016;18(11):1331-1339
- British Cardiovascular Society (2020) [The future of cardiology: a paper produced by the British Cardiovascular Society Working Group on the future of cardiology](#)

Organisations

[BCS](#) - British Cardiovascular Society

[BHF](#) - British Heart Foundation

[BHVS](#) - British Heart Valve Society

[BSE](#) - British Society of Echocardiography

[HVV](#) - Heart Valve Voice

[PCCS](#) - Primary Care Cardiovascular Society

[RCGP](#) - Royal College of General Practitioners

[SCTS](#) - Society for Cardiothoracic Surgery in Great Britain and Ireland

Acknowledgements

Our thanks to the following individuals who contributed to the development of the integrated care pathway:

- Professor Huon H Gray CBE, Formerly [Cardiac Network](#) Clinical Lead, NHS England (London Region)
- Dr Benoy Shah, President of [British Heart Valve Society](#), Consultant Cardiologist, Wessex Cardiac Centre
- Dr Rick Steeds, Immediate Past President British Society of Echocardiography, Consultant Cardiologist, [University Hospitals Birmingham](#)
- Dr Jim Moore, President of [Primary Care Cardiology Society](#)
- Dr John de Verteuil, GPwSI in Cardiology, [North East Hants and Farnham CCG](#)
- James Wood, CEO, [Community Pharmacy Surrey and Sussex](#)
- Hinal Patel, Service Development & Support Pharmacist, [Community Pharmacy Surrey and Sussex](#)
- Wil Woan, CEO, [Heart Valve Voice](#)

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Contact us

Please contact us with your feedback, questions or comments about your local service. We are keen to collaborate with services across the country. By working together we can build improved models of care for HVD and support commissioners to deliver the best care for patients.

Professionals:

Wilmington Healthcare, 5th Floor, 10 Whitechapel High Street, London. E1 8QS

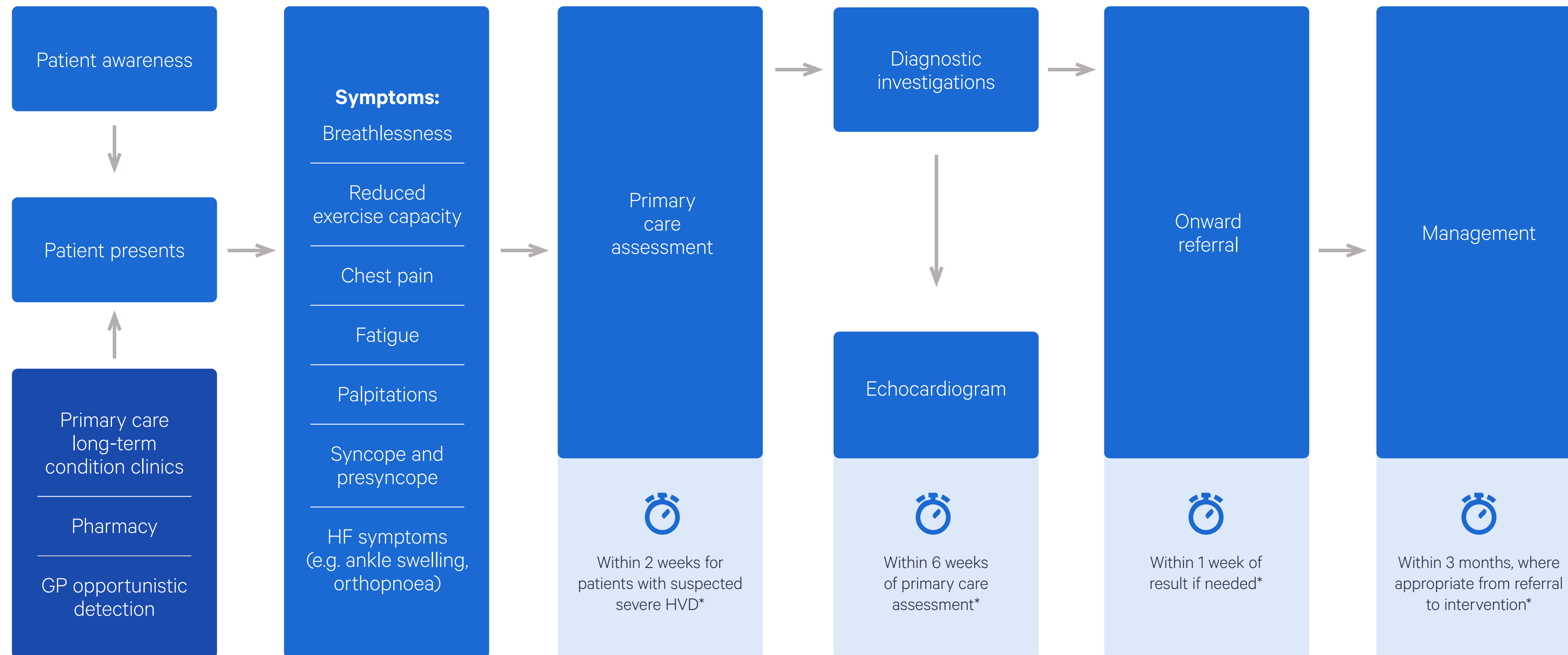
E: info@wilmingtonhealthcare.com

W: wilmingtonhealthcare.com

T: 01268 495600

Patients:

For patient support contact [Heart Valve Voice](#) and [British Heart Foundation](#)



*Shorter time intervals may be appropriate if clinical deterioration occurs. Timelines will not be met during the COVID-19 pandemic.

Audit points

1. Time from presentation to diagnosis.

2. Time from specialist assessment to diagnosis.

3. Time from presentation to intervention.

4. Timing of referrals:
 - **Urgent referral** <14 days Specialist assessment
 - **Routine referral** <8 weeks Specialist assessment

5. Proportion of diagnosed patients versus expected prevalence.

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Key performance indicators

Identified benefit to patients:

- Equity of access.

- Appropriate referral pathway based on evidence-based clinical assessment.

- Access to the specialist team.

- Integrated patient records.

Benefit to primary care:

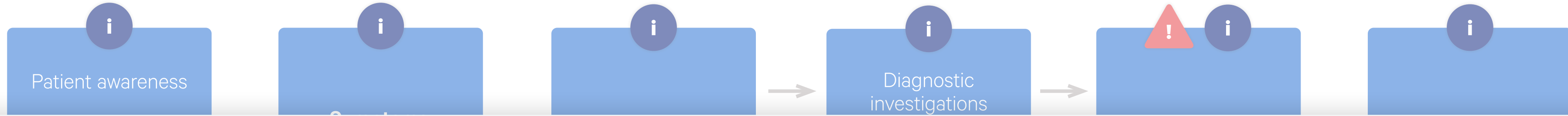
- Appropriate and clear referral pathways and prioritisation of patients.

- Standardisation of assessment and referral process.

- Relevant investigations and patient information available, reducing delays in patient's journey later in pathway.

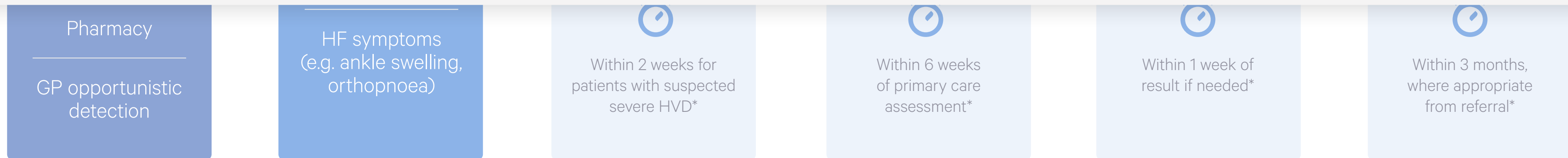
- Cost-and time-effective management.

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Standards

- 2017 ESC guidelines for the management of valvular heart disease. [Baumgartner H et al. Eur Heart J. 2017;21;38\(36\):2739-2791](#)
- [NICE guideline. Heart valve disease presenting in adults: investigation and management. November 2021](#)



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Suspect HVD

HVD is more common in those over 65 years, in those with hypertension, diabetes etc. It is also common for HVD to present as deterioration in chronic lung diseases, including COPD. See [symptoms](#) for more information.

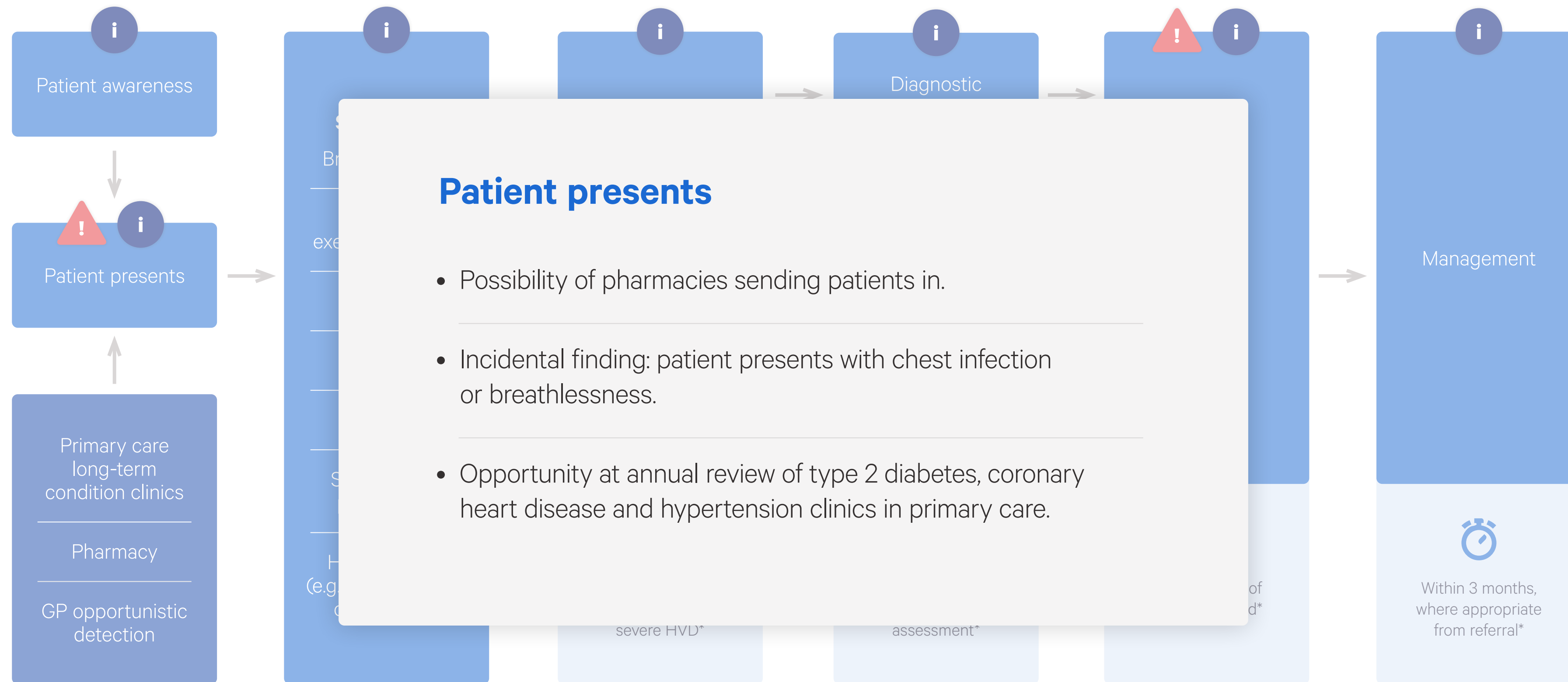
Consider HVD in the context of “recognised” cardiac symptoms such as:

- Chest pain
- Shortness of breath
- Ankle swelling
- Fatigue

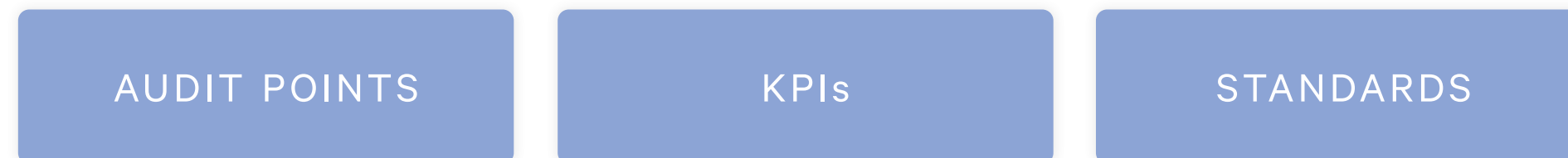
However, suspicion should be increased with symptoms of palpitations, presyncope/syncope, or signs of a heart murmur or atrial fibrillation.

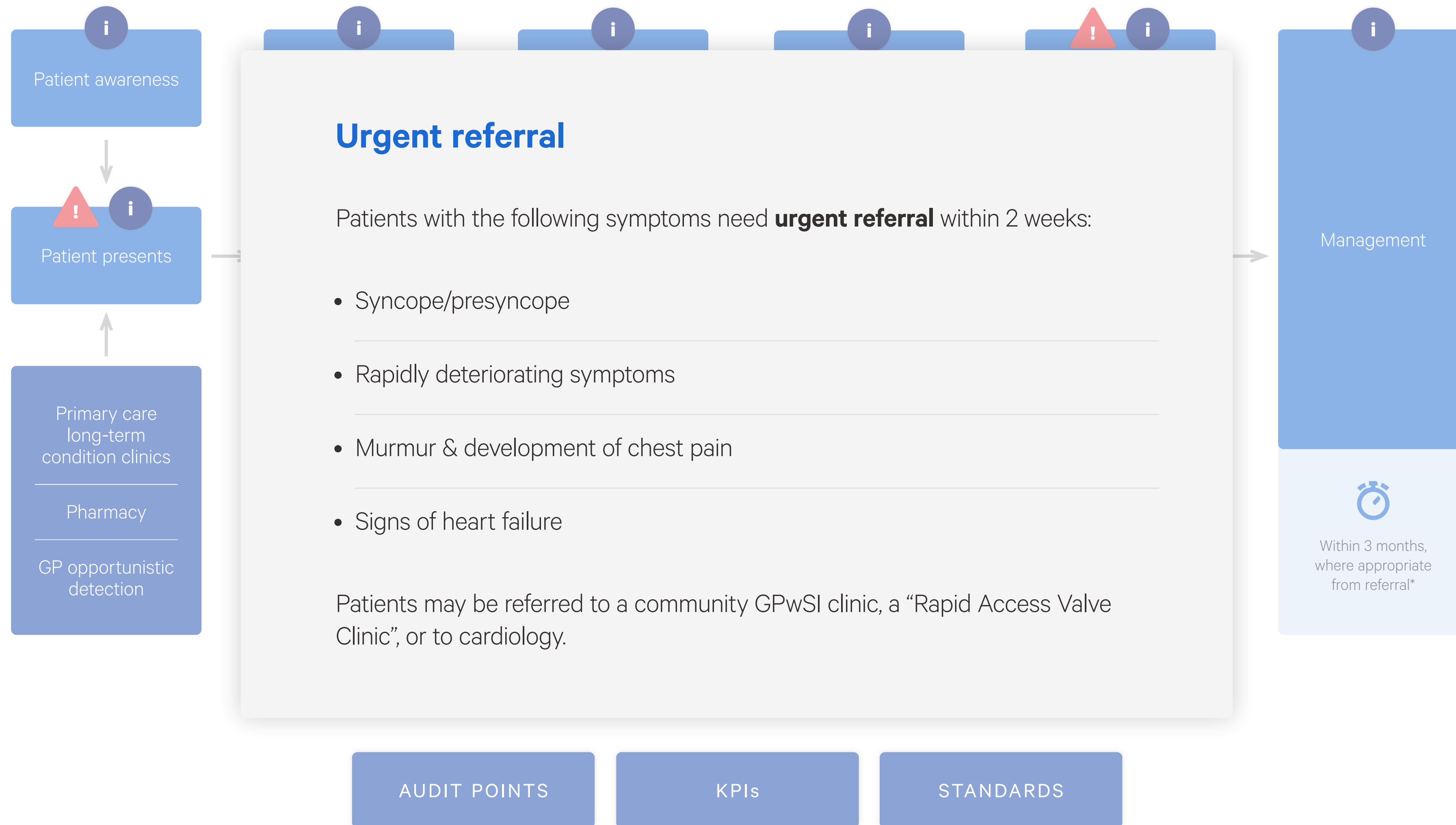
HVD frequently occurs in patients with other cardiac diseases such as:

- Heart failure
- Atrial fibrillation
- Coronary artery disease.



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i
Patient awareness

i
Patient presents

Primary care
long-term
condition clinics

Pharmacy

GP opportunistic
detection

i *i* *i* *i*

Urgent referral

Patients with the following symptoms need **urgent referral** within 2 weeks:

- Syncope/presyncope
- Rapidly deteriorating symptoms
- Murmur & development of chest pain
- Signs of heart failure

Patients may be referred to a community GPwSI clinic, a “Rapid Access Valve Clinic”, or to cardiology.

AUDIT POINTS

KPIs

STANDARDS

i
Management

Within 3 months,
where appropriate
from referral*

Patient information and the importance of awareness

It is important that patients are alert to HVD and that they understand what symptoms should prompt them to visit their general practitioner (GP). The H-E-A-R-T graphic pictured on the right is a helpful reminder of symptoms that could indicate HVD.

Some patients don't experience any obvious symptoms, which means they could be asymptomatic. Regular health check ups and annual stethoscope checks could help with early detection.

HVD symptom tracker

The [symptom tracker tool](#) has been developed by Heart Valve Voice to help people who think they maybe suffering from HVD, to capture their symptoms, ahead of visiting their

healthcare professional (HCP). It provides a two-week diary to track your symptoms and potential associated factors in a quick and easy way.

Knowing the symptoms, their frequency and the associated factors can be a very helpful talking point when visiting the GP or specialist and may enable them to more easily assess the cause and severity of a patient's symptoms.

REMEMBER: The symptoms of HVD can be similar to the symptoms of other forms of heart disease or problems with the lungs. Therefore, in addition to sharing your symptoms diary, it is important that you ask your doctor to give you a heart health check up by using a stethoscope to listen to your chest.

See Heart Valve Voice's resources for patients including [post-treatment pathway, checklist](#) and [recovery plan](#).



Recognised symptoms and signs of HVD

- HVD has a variety of symptoms which are compatible with but not diagnostic of HVD.

- Common symptoms and signs of HVD are similar to those for **heart failure** and **respiratory issues**.

- A heart **MURMUR** (heard by stethoscope) – this is an important sign of HVD.

- If HVD is suspected GPs should arrange an echocardiogram or make specialist referral.

Murmur refresher

[Click here](#) for a guide to heart murmur clinic skills and a refresher on the sounds of common murmurs.

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BREATHLESSNESS

- A distressing awareness of difficulty in breathing.
- Usually comes on slowly in valve disease over weeks or months.
- Can be a symptom of valve disease or heart failure.

REDUCED EXERCISE CAPACITY

CHEST PAIN

FATIGUE

PALPITATIONS

SYNCOPE AND PRESYNCOPE

HF SYMPTOMS, e.g. ANKLE SWELLING AND ORTHOPNOEA

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BREATHLESSNESS

REDUCED EXERCISE CAPACITY

- A gradual inability to do what has been done easily in the past.
- This can be variable:
 - In some, this can mean stopping halfway up a flight of stairs that has been done easily before.
 - In others, a lengthening of the time taken to complete a run or cycle ride.

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BREATHLESSNESS

REDUCED EXERCISE CAPACITY

CHEST PAIN

- A dull, heavy or tight sensation in the centre of the chest.
- Occurs on exertion.
- Eases within minutes of resting.

FATIGUE

PALPITATIONS

SYNCOPE AND PRESYNCOPE

HF SYMPTOMS, e.g. ANKLE SWELLING
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BREATHLESSNESS

REDUCED EXERCISE CAPACITY

CHEST PAIN

FATIGUE

When daily exertions cause unusual tiredness, compared to previously, or recovery times are longer.

PALPITATIONS

SYNCOPE AND PRESYNCOPE

HF SYMPTOMS, e.g. ANKLE SWELLING
AND ORTHOPNOEA

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BREATHLESSNESS

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CHEST PAIN

FATIGUE

PALPITATIONS

An unusual awareness of the heart beating, usually faster than would be expected but can be an awareness of a more forceful heart beat.

SYNCOPE AND PRESYNCOPE

HF SYMPTOMS, e.g. ANKLE SWELLING
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BREATHLESSNESS

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PALPITATIONS

SYNCOPE AND PRESYNCOPE

- Syncope: sudden loss of consciousness, most typically (but not always) associated with exertion.
- Presyncope: sudden severe light-headedness or sense of impending loss of consciousness, most typically (but not always) associated with exertion.

HF SYMPTOMS, e.g. ANKLE SWELLING
AND ORTHOPNOEA

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REDUCED EXERCISE CAPACITY

CHEST PAIN

FATIGUE

PALPITATIONS

SYNCOPE AND PRESYNCOPE

HF SYMPTOMS, e.g. ANKLE SWELLING AND ORTHOPNOEA

- New or worsening swelling of the foot, ankle and leg, usually on both sides.
- Skin may be stretched and shiny.
- Skin may retain a dimple after being pressed for about 10 seconds.
- Skin colour with swelling might be slightly pale.
- Feeling of heaviness in the limbs.

Murmur refresher

[Click here](#) for a guide to heart murmur clinic skills and a refresher on the sounds of common murmurs.

Clinical assessment in primary care

The symptoms of HVD are non-specific.
Always think valve disease.

Symptoms that could indicate HVD (compatible with but not exclusive to HVD):

- Breathlessness (may require some interpretation)
- Reduced exercise capacity
- Chest pain: tightness, pressure, band-like sensation
- Fatigue
- Palpitations
- Exertional syncope and presyncope
- HF symptoms such as ankle swelling and orthopnoea.

Some HVD patients will have heart failure too. Symptoms are:

- Orthopnoea / paroxysmal nocturnal dyspnoea
- Ankle swelling.

Examination:

- **Auscultation for murmur** (Guide to heart murmur clinic skills [here](#).)
- Pulse check (regular/irregular, weak/strong)
- Blood pressure and high systolic or low blood pressure can be indicative
- Jugular venous pressure (JVP) raised
- Basal crepitations – assessment?
- Peripheral oedema.

Family history – a minority of patients have a family history of valve disease.

Suspect a heart problem

HVD and heart failure symptoms overlap. If you suspect a heart problem, an echocardiogram will help determine the specific issue.

Research: smart stethoscope

Smart stethoscopes are currently in development. These are handheld digital tools which assist with auscultation which analyse heart sounds digitally to help identify significant murmurs.

NT-proBNP

N-terminal pro b-type natriuretic peptide (NT-proBNP) is continually produced in small quantities in the heart and released in larger quantities when the heart senses that it needs to work harder. NT-proBNP does not rule HVD in or out. Elevation is a possible sign of advanced HVD with patients more likely to progress to valve replacement or death. Raised NT-proBNP >400 ng/L raises possibility of (concomitant) heart failure and should be referred urgently for echocardiography.

Investigations

A complete set of investigations is recommended; however, the main investigation is an **echocardiogram**.

Patients with the following symptoms need **urgent referral** within 2 weeks:

- Syncope/presyncope

- Rapidly deteriorating symptoms

- Murmur

- Development of chest pain

- Signs of heart failure.

Echocardiography

Echocardiography is a semi-quantitative technique that requires skill and experience, particularly in the field of HVD. Provision of this service should meet standards, including proficiency accreditation, image storage, archiving, reporting and ability to transfer images for review.

Other investigations

- Bloods: FBC, serum electrolytes, lipid profile and random glucose.
- Electrocardiogram (ECG) – advised in primary care in breathless patients with suspected heart failure; may pick up atrial fibrillation (stroke risk), heart block or previous myocardial infarction. (NB: normal ECG does not exclude severe HVD.)
- Consider chest X-ray to exclude other significant cause of symptoms.

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Interpreting echocardiograms

The level of interpretation provided in echocardiogram reports which go back to GPs can vary. Know what you need to look out for: [guidance](#)

Service integration

It is important that all diagnostic services, reports and images including echo are incorporated into an integrated electronic patient record.

Onward referral

Patients with the following symptoms need **urgent referral** within 2 weeks:

Syncope/presyncope

Rapidly deteriorating symptoms

Murmur

Development of chest pain

Signs of heart failure.

Patients should be referred to a specialist who has an interest in HVD. Management of the patient depends on how the patient accesses an echocardiogram.

[Read more](#)

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Echocardiogram in primary care

Services that carry out echocardiogram in primary care are preferred. Storage of these studies for future review is essential, ideally to a cloud-based server and to be incorporated into an integrated shared patient record.

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Patients with the following symptoms need **urgent referral** within 2 weeks:

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Development of chest pain

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Read less

- Direct access – moderate/severe HVD managed in hospital.
- Via GPwSI – patient managed by GPwSI.
- Via private provider – echocardiogram report will make a specific recommendation or patients with moderate/severe HVD and heart failure are referred to specialist service for management

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Management plan for long-term monitoring

Management plans for patients with HVD cover the following:

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Monitoring

The GP/patient should be alert to increasing shortness of breath, ankle swelling, weight gain, development of chest pain etc, which may indicate worsening condition.

- **Mild disease**

Primary care can manage these patients who will need to have an echocardiogram every 3 to 5 years.

- **Moderate/severe disease**

Patient has a management plan that has had input from a specialist but which includes primary care monitoring.

- **Patient education**

The patient must take responsibility to return when symptoms change. Patients should be given information leaflets and be made aware of

symptoms of endocarditis or replacement valve failure.

- **Surgical & transcatheter intervention**

There must be clear and prompt communication with the patient's GP to include details of longer-term follow-up, frequency of echo (arranged by secondary care) and expectations of primary care, and a post-surgery check guidance for primary care.

- **Palliative care (medical management)**

Management plan for long-term monitoring

Management plans for patients with HVD cover the following:

Mild disease

Mild disease is very common, occurring in about 50% of patients >65 years. Most cases do not progress to severe.

- Advice should be available to GPs e.g. physiologist/scientist-led murmur clinic, comment on report from a cardiologist, automated advice in the conclusion from a drop-down menu.
- A local strategy should be agreed that can include no follow-up or repeat ECG in 3 to 5 years via open access or automated call back.
- Rapid review should be available if the clinical state changes. Patients with worsening symptoms and signs of HVD should be re-referred according to the **earlier guidance** in this document.
- Patients should receive advice about exercise, diet, hypertension, diabetes and dental care.

Management plan for long-term monitoring

Management plans for patients with HVD cover the following:

Moderate disease

Patients with moderate or severe valve disease are monitored in a general or specialist outpatient clinic located in, based in, or supervised from, a DGH or cardiac centre until the optimal time for intervention.

After initial assessment or discussion with the cardiologist supervising the valve clinic, some cases could reasonably be followed up in community clinics provided the necessary competencies and processes are in place.

- There must be clear and prompt communication with the patient's GP to include details of longer-term follow-up, frequency of echo (arranged by secondary care) and expectations of primary care.
- There should be strong links with the valve clinic at the hospital including tracking from the valve clinic.
- There should be clear guidance on indications for referral back to the valve clinic.
- Patients in this group are suitable for management by a community GPwSI clinic, where it exists.

Management plan for long-term monitoring

Management plans for patients with HVD cover the following:

Surgical & transcatheter management

Surgical and transcatheter management involve replacement of valves, mitral valve repair, tricuspid valve repair, surgery for aortic root and ascending aorta, and atrial fibrillation ablation. These would usually be decided by a multi-disciplinary heart valve team in a tertiary centre.

Post surgical and transcatheter management in primary care:

- There must be clear and prompt communication with the patient's GP to include details of longer-term follow-up, frequency of echo (arranged by secondary care) and expectations of primary care.
- Patient education should be a key component of outpatient surveillance and should include awareness of symptoms of endocarditis or replacement valve failure.
- After surgery patients should be offered psychological support with diet and exercise support. Relay the key messages of [the British Heart Foundation](#) to the patient.

Management plan for long-term monitoring

Management plans for patients with HVD cover the following:

Palliative care

Palliative care occurs when intervention is not feasible or is considered clinically inappropriate.

The option of optimal medical therapy as an alternative to intervention should be discussed, especially in patients with complex care requirements where quality of life benefits may be more limited.

There must be clear and prompt communication with the patient's GP to include details of longer-term follow-up, frequency of echo (arranged by secondary care) and expectations of primary care.

Primary care should have a central role to play in managing any patient who is at the end of life, with advanced care planning where symptom control is paramount and engaging palliative care specialist services where appropriate.

- Adopt the [ReSPECT process](#) (Recommended Summary Plan for Emergency Care and Treatment)