The Other Side of Heart Failure

Time to act on heart failure with preserved ejection fraction and transthyretin amyloid cardiomyopathy

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Contents

Executive summary

This report sets out the urgent need to prioritise Heart Failure with Preserved Ejection Fraction (HFpEF) and Transthyretin Amyloid Cardiomyopathy (ATTR-CM) as part of wider efforts to tackle the growing burden of cardiovascular disease (CVD) in the UK. CVD remains one of the UK's most pressing public health challenges with decades of progress on overall outcomes beginning to reverse in recent years.[1]

HFpEF is characterised by a patient's heart's pumping capacity remaining normal, whilst the heart muscle has become too stiff to fill properly. For too long patients with HFpEF have faced longstanding inequalities during diagnosis and treatment, as compared to Heart Failure with Reduced Ejection Fraction (HFrEF) patients. Strikingly, according to surveys, over 40% of heart failure services do not manage HFpEF patients and 70% of heart failure patients are not coded by disease sub-type.[2,3] These patients are 'missing' from the system and are not benefiting from the personalised support that they need. Taking this into account, and the fact that HFpEF makes up roughly half of all heart failure diagnoses, it is clear that HFpEF is a critical but often underprioritised overlooked challenge.[2]

ATTR-CM, meanwhile, is an important underlying cause of HFpEF which is estimated to be present in 11% of HFpEF patients.[4] It involves the build-up of abnormal protein deposits in the heart, progressively impairing function. Limited awareness and gaps in diagnostic capacity mean that many patients do not receive a timely diagnosis, with the time to diagnosis often taking between 3-6 years.[5] ATTR-CM is a rapidly progressive condition and without disease-modifying treatment median survival for patients ranges from 2-5 years.[6]

The burden and impact of HFpEF and ATTR-CM is only expected to grow in the coming years, in line with the wider prediction that the prevalence of heart failure in England will double to over 2 million by 2040 – the highest percentage increase among other major conditions.[7] Heart failure is also a major driver of the pressure on hospital capacity and is the leading cause of hospital admission in people 65 years or older.[8]

With the Government's Modern Service Framework for CVD, there is now a generational opportunity to reshape heart failure care and outcomes over the next decade. This report sets out a series of practical, consensus driven recommendations to support the delivery of this vision. These recommendations are aligned to the key principles of the Government's 10 Year Health Plan, with short-term action focused on addressing key inefficiencies in the HFpEF and ATTR-CM diagnosis pathways, and medium-term action focused on building a cardiology workforce that can meet patient needs and establishing more consistent care pathways.

Immediate priorities

1. HFpEF and ATTR-CM should be prioritised as part of the early implementation of the high-impact interventions defined within the CVD MSF
2. The Quality and Outcomes Framework should be updated to include specific indicators for the diagnosis and management of HFpEF – this would ensure parity in approach between HFpEF and HFrEF – and would incentivise clinicians to code heart failure sub-types accurately
3. The Government's commitment to establish a networked care model for amyloidosis should be fully implemented, and the newly established regional centres should have sufficient resource to address inequalities in access to specialist amyloidosis care
4. Red flag symptoms for ATTR-CM should be incorporated within primary care IT systems to encourage practitioners to 'think ATTR-CM'

Medium-term

5. There should be regular evaluation of the roll-out of NHS England's HFpEF pathway support tool to ensure consistent uptake across ICBs
6. The cardiology workforce should use the upcoming NHS workforce plan refresh as an opportunity to adapt traditional workforce models, empowering wider members of the MDT to take a more active role in the diagnosis and management of heart failure patients
7. NICE should update the Quality Standard for Chronic Heart Failure in Adults to reflect innovations in treatment for HFpEF patients

How the report was developed

To inform the contents of this report and its recommendations, Bayer engaged with representatives of leading organisations across the CVD stakeholder community, to gather insights on the key policy and clinical challenges that are impacting the delivery of optimal care for HFpEF and ATTR-CM.

These insights and best practice case studies directly informed the seven policy recommendations in this report.

We are particularly grateful to the following experts who provided their time and input:

- David Gregory, Trustee and Interim Chair, Amyloidosis UK
- Kate Taylor, Chief Executive Officer, Amyloidosis UK
- Professor Gerry Carr-White, Joint Secretary and Consultant Cardiologist, British Inherited Cardiovascular Conditions Society
- Anna Clodfelter, Chief Executive, British Society for Heart Failure
- Carys Barton, Chair, British Society for Heart Failure
- Jo Sopala, Chief Executive, British Society of Echocardiography
- Professor Daniel Augustine, President, British Society of Echocardiography
- Katharine McIntosh, Director of Research and External Affairs and Interim CEO, Cardiomyopathy UK
- Dr Alex Simms, Consultant Cardiologist, Leeds Teaching Hospitals NHS Trust
- Professor Raj Thakkar, President, Primary Care Cardiovascular Society
- Dr Nick Hartshorne-Evans BEM, Founder and Chief Executive, Pumping Marvellous Foundation
- Dr Geraint Jenkins, Consultant Cardiologist, Swansea Bay University Health Board
- Becky Hyland, Heart Failure Nurse Consultant, Wiltshire Community Heart Failure Service
- Professor Rajiv Sankaranarayanan, Consultant Cardiologist and and Honorary Associate Professor, University of Liverpool

The recommendations in this report are supported by the following organisations:

Amyloidosis UK

BICCS British Inherited Cardiovascular Conditions Society

British Society of Echocardiography

British Society for Heart Failure

Pumping Marvellous The heart failure charity

Primary Care Cardiovascular Society Empowering primary care to deliver the best in cardiovascular health

Scale and impact of the challenge*

Rising prevalence

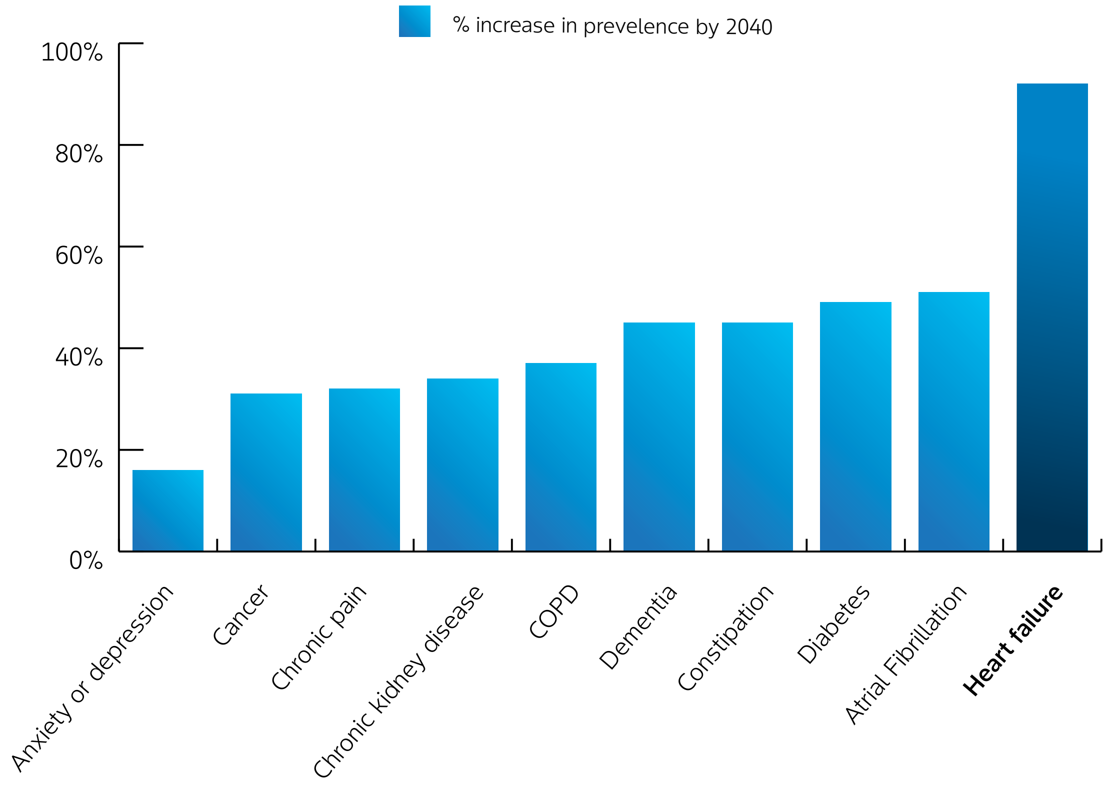
- 1 million people in the UK have heart failure and an estimated further 400,000 have undiagnosed heart failure[7]
- This is expected to rise by 92% to nearly 2 million by 2040 – the highest increase among the 10 conditions that have the greatest impact on health care use and mortality (see table 1 below)[6]

Condition	*Current prevalence*	*Expected increase by 2040*
Dementia	0.68m	45%
Constipation	1.05m	45%
Heart failure	**1.13m**	**92%**
Chronic Obstructive Pulmonary Disease (COPD)	1.66m	37%
Atrial Fibrillation	1.77m	51%
Chronic kidney disease	2.22m	34%
Cancer	2.44m	31%
Anxiety or depression	3.65m	16%
Diabetes	3.77m	49%
Chronic pain	5.23m	32%

*All statistics relate to England unless otherwise stated

Table source - The Health Foundation. REAL Centre. Health in 2040: project patterns of illness in England. July 2023. Available here. (Accessed March 2026)

Growth in prevalence of the 10 conditions that have the greatest impact on health care use and mortality by 2040



Burden on hospital settings

- // 2-4% of the total NHS budget is spent on managing heart failure[10]
- // Around 80% of heart failure diagnoses are made in hospital despite 40% of patients having symptoms that should have triggered an earlier assessment in primary care[10]
- // *Heart failure is the leading cause of hospital admission in people 65 years or older in the UK[8]*

Diagnostic inefficiencies

- // From a survey of heart failure patients diagnosed in England between 2000-2021, patients admitted to hospital had symptoms suggestive of heart failure noted in their health records on average more than 2 years earlier[11]

Economic impact

- // Heart failure is a major and growing contributor to the overall cost of CVD to the UK's economy which is estimated to be £29bn each year[12]
- // A recent European study revealed that 38% of heart failure patients will leave the workforce in the year after their diagnosis, the highest probability compared to other leading CV conditions[14]

Health inequalities

- // People in the most deprived socio-economic groups are 60% more likely to be affected by heart failure[13]
- // Women and people from the most deprived areas experience up to 5 times longer delays to diagnosis, have lower investigation rates in primary care and are more likely to be diagnosed in hospital[15]

Graph source - The Health Foundation. REAL Centre. Health in 2040: project patterns of illness in England. July 2023. Available here.
(Accessed March 2026)

Spotlight on HFpEF

Heart failure with preserved ejection fraction (HFpEF) is a type of heart failure in which patients experience the typical signs and symptoms of the condition, despite having a normal or near normal left ventricular ejection fraction (LVEF ≥50%).[16]

HFpEF patients are generally complex, with many having 1 or more other long-term condition which can mask or mimic the symptoms of heart failure.

- // Around half of people living with heart failure have HFpEF.[2]
- // HFpEF is largely a disease of the elderly and often diagnosed late when a patient is admitted to hospital with breathlessness and oedema or inability to cope at home.[16]
- // HFpEF is more common in women.[17]
- // HFpEF can be associated with or be the long-term consequence of many other conditions, including hypertension, diabetes, obesity, chronic kidney disease and atrial fibrillation.[16]
- // Some conditions can mimic HFpEF e.g. cardiac amyloidosis, hypertrophic cardiomyopathy, pulmonary arterial hypertension, and these need specific diagnostic tests and treatment.[16]
- // HFpEF continues to be underdiagnosed in both primary and secondary care, with over 70% patients not having their heart failure subtype recorded.[2]
- // Patients with HFpEF are often excluded from community heart failure services as these services were historically set-up for HFrEF.[3]
- // Surveys indicate that 40% of heart failure services do not manage patients with HFpEF.[2,3]
- // Rates of re-hospitalisation are higher for patients with HFpEF compared to HFrEF.[18]

> *"A lot of community heart failure services don't commission support for HFpEF, which leaves primary care in a very difficult position. Patients get stuck in this no man's land."*
>
> **Primary Care Cardiovascular Society**

Sandra is a fit 79-year-old lady who cares for her 80-year-old husband Bill who has mild dementia.

She has been taking tablets for hypertension for years. More recently she has put on some weight and been diagnosed with type II diabetes. She has had swollen legs and ulcers on both lower calves for about 2 years which the district nurse diagnosed as lymphoedema. She has had excellent care from the local lymphoedema service nurses who visit her at home 3 times per week to bandage her legs. Sandra prides herself on making tea and cakes for the nurses and she appreciates how busy they are.

While they were visiting their son Jeffrey recently, Jeffrey noticed that Sandra was much more breathless than before and took her to the local emergency department on a Sunday afternoon. Sandra was diagnosed with suspected heart failure based on an NT-proBNP blood test done in the department and she was admitted under the cardiologists and treated for suspected heart failure. Jeffrey, a judge, had to take emergency leave to care for Bill while Sandra was in hospital.

Sandra had an echocardiogram which showed a normal ejection fraction but features of HFpEF. She was treated with standard drugs for HFpEF and her hypertension and diabetes also received attention. The oedema in her legs cleared within a week and the leg ulcers started to heal. There were no features or history to suggest any other condition like amyloidosis or hypertrophic cardiomyopathy in Sandra.

Sandra was discharged after 13 days. A month later she was feeling much better, she was no longer breathless, had much more energy, and more importantly did not have to stay at home on alternate days for the lymphoedema nurses to bandage her legs as they were no longer swollen and her ulcers had healed.

Sandra's son Jeffrey was able to return to work as a judge. He enquired as to why the diagnosis had not been made earlier and learnt that GPs in Sandra's local area were unable to request an NT-proBNP test as it was not available. When he inquired about follow up for Sandra, he found that the cardiology service at Sandra's local hospital did not see patients with HFpEF as the service was not funded by commissioners or health boards. Private heart failure follow up was however available in a local private clinic and Jeffrey was delighted that he could facilitate this for his mother, which is not something that is available to all.

Spotlight on ATTR-CM

Transthyretin Amyloid Cardiomyopathy (ATTR-CM) is a progressive, life-limiting, and debilitating condition caused by the accumulation of amyloid fibrils in the heart muscle.[19] It is an underlying but often under-diagnosed cause of HFpEF which is estimated to be present in 11% of HFpEF patients.[4] Without access to disease modifying treatment, median survival for ATTR-CM ranges from 2-5 years, highlighting the importance of enabling faster diagnosis.[6]

There are two main types of ATTR-CM including wild-type that often affects older individuals and hereditary that is caused by a TTR gene mutation.

// Around 1,500 people across England have been diagnosed with ATTR-CM, but this is likely to be a significant under-estimation of the true prevalence due to historical under-diagnosis.[20]

// Patients will undertake an average of 6 tests, including both tests for heart failure and several more specialised tests, before receiving a confirmed diagnosis.[21]

// The average time from symptom onset to a definitive diagnosis of ATTR-CM is 3-6 years.[6]

John, a 68-year-old retired engineer, had always thought of himself as fit and capable.

A few years earlier, he'd had surgery for carpal tunnel syndrome in both wrists, but it barely registered as significant. In 2019, while on holiday in the USA, something changed. Simple sightseeing left him breathless and drained, and by the time he returned home, he could no longer lie flat without gasping for air. That same day, his wife called an ambulance. What followed was a long and uncertain journey through appointments and unanswered questions, ending in a diagnosis of ATTR cardiomyopathy a condition he had never heard of, but soon understood would change everything.

John describes reading about the disease as feeling like he'd been handed a "death sentence." Although treatments have helped manage his symptoms, and he later started a disease-modifying therapy, his world has steadily narrowed. Stairs have become an obstacle he can no longer face without help, leading to the installation of a stairlift in his home. Even short walks now leave him exhausted, with slopes feeling insurmountable. He finds himself stopping halfway up, gripping the handrail, willing his body to keep going. The frustration cuts deep, he can no longer run around with his grandchildren or enjoy the simple pleasure of a walk with his partner. What once felt effortless now requires determination, planning, and often, resignation.

The emotional toll has been just as profound. John has quietly withdrawn, avoiding social situations and mourning the loss of the life he once recognised. There are moments of deep sadness and fear about what lies ahead, which ripple through his family life. His partner has watched not only his physical decline, but a change in his spirit- his confidence, his patience, his sense of self. And yet, over time, a fragile sense of hope has begun to emerge. Through specialist care, connection with others, and the knowledge that new treatments are evolving, John is slowly finding a way forward. By adjusting his expectations and leaning on those around him, he is learning, day by day, to live with the condition, holding onto small but meaningful reasons to keep looking ahead.

Making the diagnosis pathway more efficient

There are challenges in accessing key diagnostic procedures that can support timely and optimal diagnosis. The government's commitment to expanding access to diagnostics in neighbourhood settings is a key opportunity for addressing challenges in diagnosis of HFpEF and ATTR-CM.

Heart failure is a complex clinical syndrome of signs and symptoms caused by impaired heart function and typical symptoms such as breathlessness, fatigue, reduced exercise tolerance and ankle swelling often overlap with other diseases such as asthma/COPD, obesity and typical signs of ageing. Stakeholders we spoke to explained that these symptoms can be difficult to distinguish from other conditions, particularly when they develop gradually, which can contribute to delays in recognising possible heart failure. When patients do present they will often have a complex physiology and several comorbidities, making it difficult for overstretched GPs to identify the potentially quite nuanced signs of heart failure.

N-terminal pro-B-type natriuretic peptide testing (NT-proBNP)

NT-proBNP testing can be used to diagnose or rule out heart failure in the community and inform initial management decisions, including referral to specialist care. However, according to recent data, only 17% of heart failure patients received an NT-proBNP test prior to diagnosis, and there is not consistent access across the recently established Community Diagnostic Centres.[22,23] Where the test is available, this is often at hospital-based sites rather than in the community.[23] As a result of this varied access to NT-proBNP testing, a key opportunity to rule out heart failure or diagnose lower risk patients in the community is regularly being missed with some patients being referred for an echo unnecessarily. This is putting further pressure on already stretched echocardiography services and increasing waiting times for the patients that need this test the most.

There is scope for expanding access to NT-proBNP and echocardiography through the ongoing rollout of Community Diagnostic Centres (CDCs). As the Neighbourhood Health Framework sets out a commitment to review the diagnostics available in CDCs, there is opportunity to ensure that the needs of HFpEF and ATTR-CM patients are addressed.

Echocardiography

Demand for echocardiography services has grown significantly in recent years, linked to the rising prevalence of many cardiovascular (CV) conditions and an increasingly multi-morbid patient population that requires more detailed assessment. Over a third of patients are waiting over six weeks for an echocardiogram (echo), despite NICE guidance recommending that patients should receive this test within 2 weeks, and the British Society of Echocardiography have issued repeated warnings about the capacity of their workforce to meet this growing demand.[24]

Stakeholders underlined that limited career progression opportunities have led to a growing exodus of senior staff, with many departments now lacking the required expertise for training and quality assurance. Over 10% of the echocardiology workforce is made up of locums, and half of staff report doing unpaid work to keep services running.[24]

Impact of diagnostic challenges on patients

These capacity pressures are having a particular impact on HFpEF patients, as their preserved ejection fraction means they require detailed assessment of diastolic function, filling pressures, and structural abnormalities from an echo scan.[25] Waiting times for echo scans can be very long and HFpEF patients subsequently face an increased risk of an acute presentation.[25]

In addition, HFpEF patients are not benefitting from timely access to the new treatment options that have been made available for their condition in recent years. These challenges are even more acute in the case of ATTR-CM, with patients often facing lengthy diagnostic journeys that take between 3-6 years.[26]

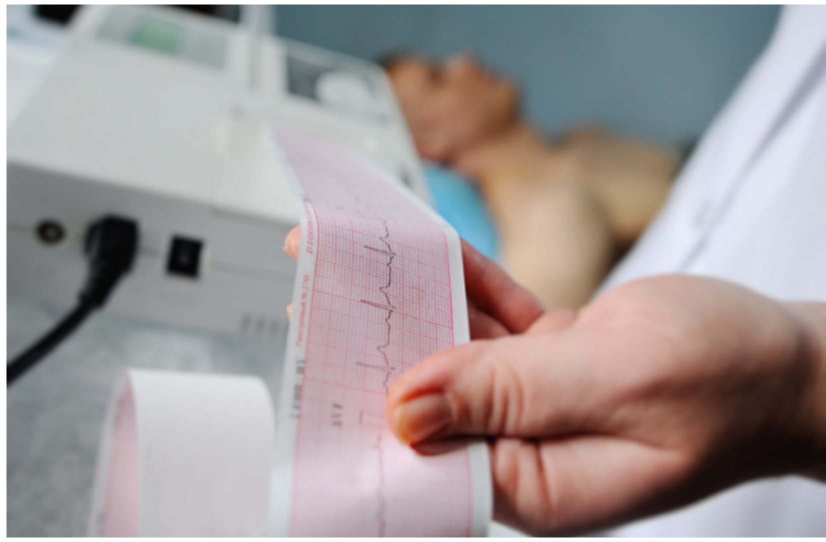
> *"HFpEF is not included in the new QOF contract despite us now having therapies to treat. We would like to see this included to improve diagnosis and management for this high risk under supported cohort"*
>
> **British Society for Heart Failure**

As well as the delays that many heart failure patients experience during stage one and two of this process, there is limited awareness of the key red flags for ATTR-CM that will emerge early in the pathway and should prompt further investigation. Awareness of these red flags can be critical, particularly as echo scans will likely only be effective at picking up the signs of severe cardiac amyloidosis, and not early or mild cases. In these mild cases, patients will often be labelled with a diagnosis of heart failure with no further investigation into the potential underlying cause.

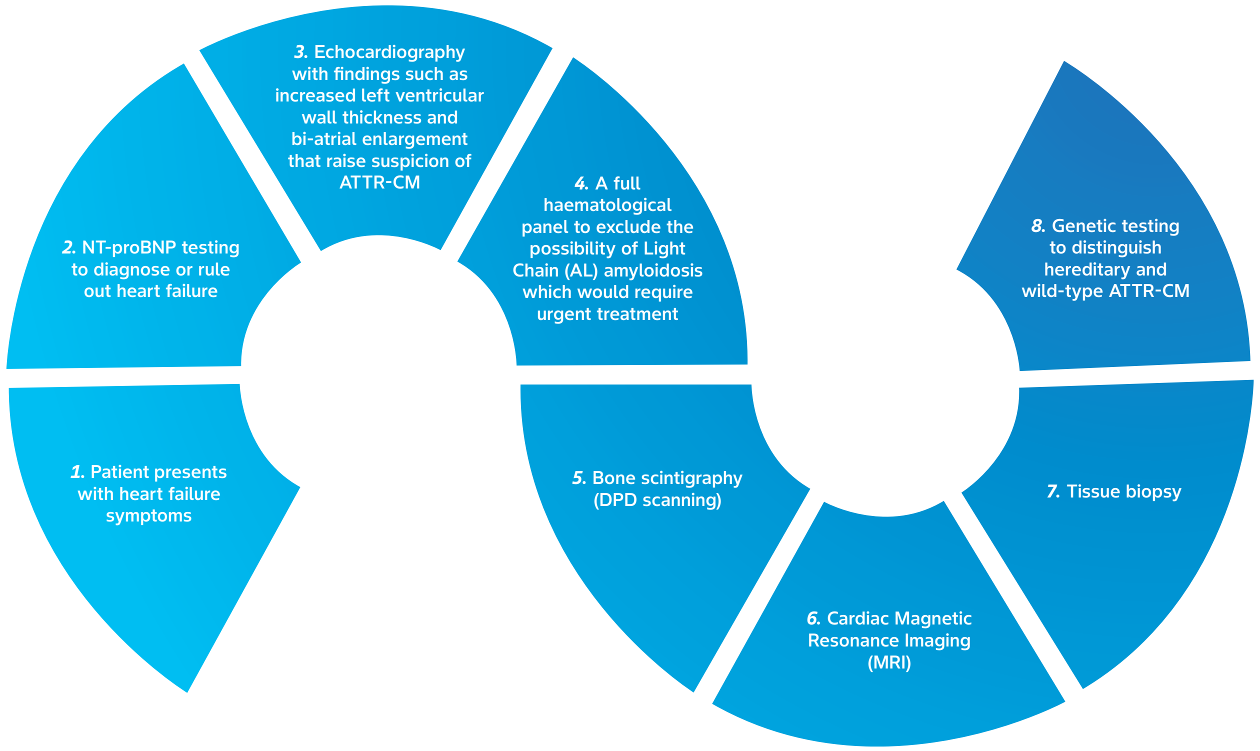
> *"So many amyloid patients still consider themselves lucky to have even got a diagnosis"*
>
> **Amyloidosis UK**

Progression through steps three to seven is then reliant on complex clinical interpretation and assessment of several highly specialised tests. Clinicians that we spoke to explained how there are particular challenges around access to both DPD scanning and Cardiac MRI, leading to many long-distance referrals and lengthy turnaround times.

Taken together, there is an increasingly urgent need to make the heart failure diagnostic pathway more efficient and streamlined and reduce the avoidable delays which result in many patients being diagnosed late and often following an acute admission. This improved efficiency can also be beneficial for ATTR-CM patients, through expediting access to the highly specialised tests that are needed to confirm their diagnosis.



Diagnosing a patient with ATTR-CM will typically involve many if not all of the following key steps:[27]



What does a shift from hospital to community mean for HFpEF and ATTR-CM?

The barriers in the HFpEF and ATTR-CM pathways are closely aligned with the challenges that the 10 Year Health Plan seeks to address – this includes the benefits that could be gained, both in terms of patient outcomes and system efficiency, through shifting heart failure diagnosis and care out of hospital and into the community. The success of this approach will rely on workforce optimisation, improved symptom awareness and recognition, and more robust referral pathways.

Workforce optimisation

Stakeholders that were consulted in the development of this report highlighted two leading examples of workforce optimisation that have upskilled different parts of the workforce to take a more active role in the diagnosis and management of heart failure patients, while also reducing pressure on staff in acute settings. Crucially these examples of workforce optimisation do not rely on the recruitment of additional staff, the emphasis is on doing things differently within existing resources.

// **British Society of Echocardiography – scientist-led clinics:** As part of wider efforts to tackle shortages across the cardiology workforce and enable more staff to work at the top of their skill set, the British Society of Echocardiography are piloting new physiologist and scientist-led clinics. The pilot programme is being rolled out across three key pathologies including heart valve disease, inherited cardiac conditions, and heart failure. The pilot aims to streamline services and enhance patient pathways and involves training cardiac physiologists and clinical scientists to undertake comprehensive echocardiography, alongside clinical assessment, to actively contribute to complex management decisions.[28] All clinics will operate within strict scopes of practice. Rather than multiple visits, patients are seen and assessed in a single visit Crucially the clinics also free-up consultant capacity to focus on the most complex cases, improving patient flow and the accuracy of referrals to specialist care.

A new BSE Level 3 accreditation is being developed to establish a national governance and competency framework for advanced physiologist and scientist-led practice.[29] This accreditation will help address recruitment and retention challenges which have contributed to significant shortages across the echocardiography workforce.

> *"This will be transformative for cardiac services. You've got to understand the depth of the workforce problems, and this is a solution that directly addresses them."*
>
> **British Society of Echocardiography**

// **At Leeds Teaching Hospitals NHS Trust,** a pilot programme was established to train community pharmacists in the management of heart failure patients. Pharmacists were embedded in primary care teams to manage heart failure patients that are on chronic disease registers, receiving training in:

- Medicines optimisation and delivery
- Identifying red flag symptoms and patients who require care escalation
- Adherence to treatment guidelines
- Case-finding for patients who are missing treatment opportunities

> *"The ethos was that we're not just going to do what secondary care often does and go in and tell primary care how to do it. Instead, we wanted to show that we're all invested in this as a group to build a supporting care structure that can persist."*
>
> **Alex Simms**
> **Consultant Cardiologist, Leeds Teaching Hospitals NHS Trust**

Consultants provide ongoing oversight of the programme, and weekly MDT meetings enabled continuous feedback and learning. Over the duration of the pilot, pharmacists were able to manage more complex patients, building a model of shared ownership between primary and secondary care. The programme has enabled more heart failure patients to be managed in the community, with patients benefitting from more personalised care. A concerted effort was made at the outset of the programme to bring primary care on board and address concerns that the initiative would simply add to their workload.

More broadly, from a workforce perspective, there was consensus among stakeholders about the critical role played by heart failure specialist nurses (HFNS) and their importance to enabling more community-based approaches to heart failure care. Indeed, it was noted that patient concern about moving out of hospital and into the community can often be mitigated by appropriate support from HFNS. Drawing on their advanced knowledge of the condition, HFNS are well equipped to optimise heart failure treatment programmes, identify signs of decompensation and the need for consultant referral, and meet the complex and varied needs of comorbid patients.

Awareness raising

From an education and awareness perspective, there is a need to increase awareness of HFpEF and ATTR-CM across primary care, to support earlier identification of patients and improve patient coding and management. This awareness raising also needs to be targeted at non-cardiologists.

// **The Pumping Marvellous Foundation BEAT Campaign** has significantly increased awareness of heart failure and its key symptoms across the country. The campaign is based on the now internationally recognised BEAT acronym, representing the three most common symptoms of heart failure and the action that people should take if they notice any of these symptoms.[30,31]

B	Breathlessness
E	Exhaustion
A	Ankle swelling
T	Time for a NT-proBNP blood test

BEAT is an increasingly integral part of the heart failure diagnostic pathway and its wider adoption can enable proactive heart failure case-finding and support more community-based diagnosis. The acronym also applies to the key symptoms of decompensating heart failure and supports patient self-management.

B.E.A.T®
HEART FAILURE TOGETHER

// **The British Society for Heart Failure** have developed a new dashboard as part of their 25in25 campaign to support staff in primary care to identify undiagnosed heart failure and high-risk patients who require further investigation. The Dashboard is currently being validated by the University of Nottingham's PRIMIS before it will be made available for GP practices across the country. The Primary Care Cardiovascular Society is also developing new education tools and training specifically for HFpEF, in recognition of the condition's complexity. This training will support GPs to distinguish HFpEF from other causes of breathlessness, particularly given that patients will likely be presenting with severe frailty.

Stakeholders we consulted also explained how there is growing need to provide education for HCPs in what to do once they have identified at-risk patients and increase their overall levels of confidence to take the appropriate action.

Robust pathways

ICB-level guidance from NHS England has sought to address some of the challenges impacting the diagnosis of HFpEF through the development of a new pathway support tool.[2] Crucially the tool aims to implement a more standardised approach to HFpEF diagnosis and management in recognition of the historic variation in HFpEF service provision across the country. This variation has led to many HFpEF patients either returning to their GP or remaining in secondary care and subsequently missing out on access to specialist care and input.[2] Importantly the tool also recognises the complexity of many HFpEF patients and the importance of delivering more personalised care that is tailored to individual needs.

With wider uptake of the pathway, more patients will be able to benefit from recent innovations in HFpEF treatment. The pathway sets out clear diagnosis and referral criteria for HFpEF, supporting clinicians to make the distinction between HFrEF and HFpEF. It also establishes the principles by which HFpEF patients, after the required specialist input, can be empowered with the right tools to self-manage their condition in the community, supported by regular reviews. It is vital that this pathway is adopted across the country with frequent evaluation of its uptake across local ICB areas.

From a pathway perspective, NICE also made several welcome updates to its guidance on 'Chronic heart failure in adults: diagnosis and management' (NG106) to include several new recommendations on treatment combinations for patients with HFpEF.[32] It is now important that this increased recognition of HFpEF is reflected in other NICE products such as the Chronic Heart Failure Quality Standard.

How can a digital shift help to transform care for HFpEF and ATTR-CM patients?

The delivery of the proposed shift from analogue to digital can also play a key role in making heart failure diagnosis and management along the pathway more efficient. There are a number of opportunities to adopt technologies and enable better ways of working through digital innovations that can support earlier diagnosis, case finding, and improved initial management of HFpEF and ATTR-CM patients. As The Government continues to embed a digital shift across the NHS, it is important that these issues are considered within key policy initiatives in the cardiovascular disease space.

Digitally enabled rapid heart failure diagnosis

// **The Pumping Marvellous Foundation** has pioneered a new rapid point of care (POC) diagnosis pathway that aims to dramatically reduce the typical heart failure diagnostic journey from months to just 60 minutes, incorporating digital innovation at every key stage. The pathway builds on the BEAT acronym and is divided according to the following key steps:[30,31]

Step 1

Identifying BEAT symptoms and presenting to a pharmacy, GP practice, community or emergency setting. BEAT symptoms are embedded into GP systems

Step 2

Deliver a rapid POC NT-proBNP blood test with assessment guided by EMIS algorithms to rule out heart failure or prompt further investigation

Step 3

For patients with NT-proBNP levels above >400 ng/L they should then receive AI-assisted echocardiography, completed within 15 minutes, enabling rapid clinical assessment and risk stratification

Step 4

These results should all be assessed by the Clinical Lead for the hub at the end of the visit to inform an initial management plan, including starting heart failure medications immediately if this is clinically appropriate. Patients should then recieve a full structural echo (community or hospital-based) and should be followed-up by the local heart failure team.

If implemented more widely, the BEAT to TREAT pathway has the potential to have a transformative impact on heart failure diagnoses, enabling early identification, timely initiation of guideline-directed therapies when they will have the greatest impact on outcomes, and reduced costs to the NHS.[30,31] The pathway also improves patient experience by empowering patients with the knowledge and confidence to report both the initial signs of heart failure and symptoms that may indicate decompensation after their diagnosis.

The BEAT to TREAT pathway has been used to support several community-based Healthy Heart Testing events, which have delivered over 12,500 tests across the country.[33] The events have drawn on strong neighbourhood-based partnerships to shift heart failure diagnosis into the community and reduce health inequalities. A recent event in Speke, South Liverpool – which sits within the top 10% most deprived communities in England –provided over 370 comprehensive heart health checks with the following clinic outcomes:[33]

// 24 NT-proBNP tests performed

// 12 AI-assisted echo

// 10 new heart failure diagnoses identified by a Consultant Cardiologist specialising in heart failure including:

- 7 with HFpEF including 2 with suspected ATTR amyloidosis
- 2 HFrEF
- 1 HFmrEF

These newly diagnosed heart failure patients were all immediately prescribed prognostic medications, with many other local residents connected to wider prevention and support services. These events have the potential to serve as a blueprint for the diagnosis and initial management of heart failure under a modern NHS, that is technology enabled and much closer to home.

The success of the digital shift will rely on overcoming barriers to better embedding digital solutions and innovative models of care – including infrastructure challenges within the NHS. The quality of data relating to HFpEF and ATTR-CM patients is critical and there is a need to focus on improved coding of patients as a foundation of delivering a digital shift for these conditions.

> *BEAT to TREAT plays directly into the Government's 3 domains - shifting care into the community, adopting technology, and moving from sickness to prevention.*
>
> **Pumping Marvellous Foundation**

Infrastructure challenges

> *"AI, although useful in some settings, is not a replacement for clinical judgement, holistic assessment and individualised patient care. It may inhibit your expertise and ability to ensure that you've done everything you can for your patient."*
>
> **British Society for Heart Failure**

- **Artificial intelligence:** Stakeholders emphasised the importance of addressing often quite basic elements of infrastructure in order to realise the benefits of new innovations and technology. Modern echo machines are increasingly being designed to contain automated AI measurements, which could play a potentially key role in easing pressure on the echo workforce, however existing NHS reporting platforms often cannot interpret AI outputs. However, there was significant optimism about the role of AI – if these initial barriers can be addressed – in not only supporting clinicians with key administrative functions, but also in actively challenging and improving clinical decision-making.
- **System interoperability:** there is also still significant work to be done to deliver on the promise of an accessible and comprehensive single patient record by 2028, with many clinicians still having to work across multiple databases to access a patient's medical history. This comprehensive access is crucial for heart failure patients given the likelihood that they will be presenting with several comorbidities.
- **Digital monitoring:** stakeholders agreed that the opportunities to detect decompensation earlier, reduce unplanned hospital admissions, and manage more heart failure patients are significant, but current capability does not allow such opportunities to be realised. Typically, digital monitoring is limited to a patient's heart rate or blood pressure, which are poor predictors of acute heart failure episodes. Research and investment are needed in more advanced methods, such as CardioMems implants, which have been shown to reduce repeat hospitalisations by up to 40%, and to give heart failure patients the confidence to go about their daily lives and live well in the community.[34] AI-assisted echocardiography could also play a role in delivering enhanced heart failure monitoring, with a recent NICE Early Value Assessment recommending that the topic should be prioritised for further research.
- **Patient coding:** addressing the longstanding shortfalls that have impacted the coding of different heart failure subtypes is another key opportunity presented by the proposed shift from analogue to digital with recent primary care data indicating that *only 30% of heart patients have their subtype recorded.*[35] A key challenge is that the current heart failure QOF indicator only includes a specific measure for HFrEF. Accurate heart failure coding is essential to safe and effective care as this ensures that patients receive the right treatment for their heart failure subtype. It can also compliment the increasingly dynamic and evolving heart failure treatment landscape, providing opportunities to retrospectively review patients who were left without a treatment but could benefit from newly available options.

Coding saves lives

- **As part of their 25in25 campaign 'Coding isn't optional, it is life saving',** the British Society for Heart Failure has been leading important work to address this long-standing shortfall. The BSH have recently partnered with the NHS Benchmarking Network to develop the supporting infrastructure to code heart failure patients accurately.[36] This has included driving uptake and awareness of the 4 specific SNOMED codes for heart failure which are broken down by sub-type and ensuring that the appropriate SNOMED code is included in a patient's record at the time of diagnosis and during routine reviews.[37] The BSH have a developed a series of simple low-cost resources to increase clinical awareness of the codes, including stickers for laptops, notebooks with the all the SNOMED codes listed, and summary information papers.

> *"Good coding is really important retrospective for case finding. Whereas previously when a patient was diagnosed you might have only been able to give them diuretic management, with the right coding you can immediately identify if they will benefit from new disease-modifying treatments"*
>
> **Becky Hyland, Heart Failure Nurse Consultant, Wiltshire Community Heart Failure Service**

Heart Failure SNOMED codes

Heart failure sub-type	*SNOMED code*
HFrEF	703272007
HFrEF and Left Ventricular Systolic Dysfunction (LVSD)	407596008
Heart failure with mildly reduced ejection fraction (HFmrEF)	788950000
HFpEF	446221000

Table source - British Society for Heart Failure. Coding isn't optional – it's life saving. November 2025. (Accessed March 2026)

Tackling inequalities in care and access to services

Improving specialist care access for ATTR-CM

Since 1999, the National Amyloidosis Centre (NAC) at the Royal Free NHS Foundation Trust has been the UK's leading specialist centre for the diagnosis, research and management of amyloidosis.[38] The NAC has been at the forefront of many leading scientific innovations and discoveries in amyloidosis care throughout this period, and is widely recognised as the world's largest and most diverse amyloid service.[38]

In the past decade, the NAC responded to a surge in patient numbers due to increased awareness of amyloidosis among HCPs, improved diagnostic tools, and the availability of new treatments.[39]

In response to growing demand for amyloidosis care, the Government and NHS England committed to establish a networked care model for amyloidosis, providing a significant opportunity to expand access to specialist care for patients with amyloidosis and deliver care closer to home.[40] It was outlined that the model will follow a hub and spoke approach, similar to that for the management of inherited cardiac conditions, with several regional centres delivering more local diagnostic and monitoring services, with the NAC providing central oversight.[41]

It is hoped that the model will build on the NAC's well-established role as a centre of expertise while enabling more patients to access care closer to home, by addressing geographic-based inequalities in access and the long travel distances that many patients face, which can be particularly detrimental for people living with frailty.

The model is being established under NHS England's highly specialised services commissioning framework, with the aim of driving consistent standards across regional centres and supporting collaboration with local cardiology and heart failure services to enable the long-term management of patients. The regional model also importantly aligns with the growing emphasis on NHS regions that is set out in the 10 Year Health Plan, with regions acting as a crucial interface between DHSC at a national level and local ICBs.

So far two regional sites have been announced in Birmingham and Liverpool, with the centre in Birmingham now fully operational. Stakeholders we spoke to highlighted how the Birmingham centre has already been a notable success, following its formal designation as a specialist centre in October last year.[42] This success has been underpinned by strong clinical leadership, well-established referral pathways, and effective collaboration both with local cardiology teams and the NAC.

To realise the potential of the proposed model, stakeholders highlighted the importance of alignment with local expertise, appropriate funding provision, speed of implementation, and ongoing consideration of patient needs. The process for awarding future regional centre designation needs to align with existing local expertise, particularly to prioritise areas where there are clinicians with significant interest and knowledge in the management of amyloid patients. The funding provision for the regional centres also needs to be sufficient to sustain the resource and staff capacity needed to meet the likely significant demand on services. This provision also needs to account for the probable investment needed in diagnostic tools and equipment, and wider administrative support.

Going forward, stakeholders agreed that the network model is still the right overall ambition and it is therefore vital that the commitments from the Rare Disease Action Plan are fully implemented.

Beyond models of care in England, ATTR-CM patients in the devolved nations who require complex diagnostic and treatment services will also be overseen by the NAC, with initial investigations conducted locally. To support these local investigations, the Scottish Heart Failure Hub announced a new Cardiac Amyloidosis Diagnostic Pathway in March last year which provides guidance for healthcare professionals on recognising red flags, diagnostic tests that are required, and referral options.[43]

Location of amyloidosis centers

Addressing the mental health burden

Patients with HFpEF and ATTR-CM also face significant but often under-appreciated mental health challenges. Studies have found that nearly a third of heart failure patients experience depression, rising to around 70% among inpatients.[44]

Heart failure itself is a daunting diagnosis, with patients immediately forced to confront the prognosis that they may have less than 5 years to live. Heart failure can severely impact a patient's quality of life, making daily activities a struggle and actively fuelling depression.

Heart failure also has a significant impact on workplace participation with a recent European study highlighting that heart failure patients were most likely to leave the workforce in the 12 months post-diagnosis, compared to other leading CV conditions.[12]

Patients with ATTR-CM face similar challenges and will often feel overwhelmed in the period following their diagnosis. Understanding the condition often involves engaging with a significant amount of complex scientific information. Patient organisations we spoke to reported that patients worry that they will experience quite rapid physical decline, with their likely lack of proximity to a specialist centre also causing concern. The intervening period post-diagnosis and while they are waiting to be seen by a specialist is especially difficult to manage.

// **Amyloidosis UK and Cardiomyopathy UK** have tried to address this unmet need by establishing the first online support group specifically for patients affected by cardiac amyloidosis.[45] The group provides a platform and safe space for patients to ask questions and discuss common concerns.[45]

Probabilities of being in employment 12 months after diagnosis

Heart valve disease	Ischaemic heart disease	Atrial fibrillation	Heart failure
75.5%	76.9%	78.9%	62.2%

Probabilities of detachment from employment within six months after return to work

Heart valve disease	Ischaemic heart disease	Atrial fibrillation	Heart failure
24.2%	25.1%	19.9%	30.3%

Tables source- Jorgensen et al. Diagnostic group differences in return to work and subsequent detachment from employment following cardiovascular disease: a nationwide cohort study. European Journal of Preventive Cardiology. 30(2): 182-190. November 2022. Available here. (Accessed March 2026)

Going forward, there needs to be a broader recognition of the significant psychological impact of HFpEF and ATTR-CM. Additional support should be targeted in the intervening period post-diagnosis and during the initial stages of treatment, to help patients overcome the initial shock of being diagnosed.

Comprehensive cardiac rehabilitation can be particularly beneficial in this context and should be appropriately prioritised as a key pillar of heart failure management, alongside treatment interventions.[46] Modern forms of rehabilitation are now much wider in scope than just exercise training, encompassing dietary advice, psychological support, education, and lifestyle modifications. When carried out effectively, it can provide the essential foundation to support patients to self-manage their condition.

Tackling gender and racial disparities

There are significant racial and gender disparities in heart failure diagnosis, treatment, and mortality. A study of over 16,000 heart failure conducted in 2024 found that ethnic minority heart failure patients had a 36% higher risk of death compared to white patients within 17 months.[47] Meanwhile from a gender-perspective, women face longer diagnostic delays and are less likely to receive optimal treatment.[45] Notably women are also two times more likely to develop HFpEF.[16]

There is welcome recognition of these disparities in the Government's Renewed Women's Health Strategy which commits to improving CVD risk management and care for women, primarily through measures in the CVD MSF.

In 2024, the British Cardiovascular Society and its affiliated societies published a consensus statement which set out several recommendations to advance access to CVD diagnosis and treatment among women, including specific actions for heart failure.[49] This statement emphasises the importance of ensuring that women are better represented in clinical studies, undertaking research into optimal treatment dosage for women, and taking greater consideration of risk factors that specifically relate to female biology.[49] Many of these recommendations are still relevant now and it is vital that they are considered when it comes to the implementation of the CVD MSF.

Policy recommendations – delivering parity, early diagnosis and accountability

Immediate priorities

1. HFpEF and ATTR-CM should be prioritised as part of the early implementation of the high-impact interventions defined within the CVD MSF
2. The Quality and Outcomes Framework should be updated to include specific indicators for the diagnosis and management of HFpEF – this would ensure parity in approach between HFpEF and HFrEF – and would to incentivise clinicians to code heart failure sub-types accurately
3. The Government's commitment to establish a networked care model for amyloidosis should be fully implemented, and the newly established regional centres should have sufficient resource to address inequalities in access to specialist amyloidosis care
4. Red flag symptoms for ATTR-CM should be incorporated within primary care IT systems to encourage practitioners to 'think ATTR-CM'

Medium-term

5. There should be regular evaluation of the roll-out of NHS England's HFpEF pathway support tool to ensure consistent uptake across ICBs
6. The cardiology workforce should use the upcoming NHS workforce plan refresh as an opportunity to adapt traditional workforce models, empowering wider members of the MDT to take a more active role in the diagnosis and management of heart failure patients
7. NICE should update the Quality Standard for Chronic Heart Failure in Adults to reflect innovations in treatment for HFpEF patients

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