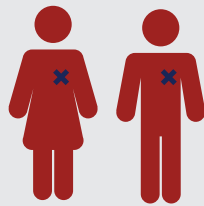


# Alliance for Heart Failure

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# Heart Failure

## A call to action



A review of the 2016 'Focus on Heart Failure'  
recommendations to improve care and  
transform lives

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This report has been compiled and funded by The Alliance for Heart Failure. It reviews the recommendations in the 2016 report by the All Party Parliamentary Group on Heart Disease: 'Focus on Heart Failure'.

This is not an official publication of the House of Commons or the House of Lords, nor a publication by the APPG or its members. The views expressed in the paper are those of the Alliance for Heart Failure.

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“Heart failure patients deserve better, no matter where they live. Access to early diagnosis, specialist multidisciplinary support, high-quality information, cardiac rehabilitation and end-of-life care makes a real difference and should be universal.”

Louise Clayton & Richard Corder  
Co-Chairs, Alliance for Heart Failure

# Foreword

Where heart failure care is at its best, patient outcomes can be greatly improved, significantly prolonging life expectancy and restoring some quality of life. However, widespread regional variation means that service delivery is patchy and inconsistent. That was the conclusion of an Inquiry into heart failure services by the All Party Parliamentary Group on Heart Disease\* in 2016.

The APPG heard from a wide range of organisations and individuals with an interest and expertise in heart failure. It found that, while many patients receive excellent care, in line with guidance from the National Institute for Health and Care Excellence, many do not.

Four years on, with heart failure featuring prominently in the NHS Long Term Plan and a growing number of regional NHS plans, this report looks at the progress that has been made on the APPG's recommendations, and evaluates what further action needs to be taken.

With over 900,000 people in the UK now affected by the condition<sup>1</sup>, 200,000 new cases being diagnosed every year<sup>2</sup>, and heart failure accounting for around two per cent of the annual NHS budget<sup>3</sup>, heart failure and its management need to be higher up the agenda for policy makers and healthcare leaders. Heart failure patients deserve a better deal!

Multiple studies also point towards Covid-19 potentially causing myocardial damage and heart failure.<sup>4,5</sup> The additional harm caused by two-thirds of patients failing to present with heart failure symptoms during the pandemic is a serious concern for patient well-being, long term outcomes, and services in the future.

We strongly urge all organisations and stakeholders referenced in the recommendations to note where further progress is needed and take urgent action.

NHS England / Improvement should also prioritise joined-up data gathering to improve care, supported by the extension of the National Institute for Cardiovascular Outcomes Research (NICOR) Audit to include primary and community service and ensure it reaches these teams.

We have an opportunity to create a world-class heart failure programme to deliver high quality care that every patient deserves. We must come together and make it happen.



**Louise Clayton**

Co-chair, Alliance for Heart Failure/  
Advanced Nurse Practitioner, Deputy Chair  
of the British Heart Failure Nurses Forum  
and British Society for Heart Failure Board  
Observer



**Richard Corder**

Co-chair, Alliance for Heart Failure/  
Secretary of the Cardiovascular Care  
Partnership

\*Now the All Party Parliamentary Group on Heart and Circulatory Diseases

# Status of original 2016 recommendations



Good progress



Some progress



Inadequate progress



1. Health Education England should work with heart failure specialists to **improve awareness, knowledge and understanding of the condition** in general medical colleagues, including GPs. This should cover the need to consider the history of heart disease in the patient, and their family.



2. All Clinical Commissioning Groups (CCGs) should **commission cost-effective NT-proBNP testing** to support the diagnosis of heart failure. NHS England should consider how CCGs can be incentivised to do this.



3. NHS England and Health Education England should take urgent action to implement the recommendations in the Strategic Review of Cardiac Physiology Services on meeting workforce challenges, to **ensure that demand for echocardiography can be met**.



4. Clinicians should **ensure that when patients are diagnosed they are provided with information about heart failure**, how it may impact on their lives, and how they can help manage this, in a form that is suitable for them. Patients should also be provided with a single point of contact for any questions and concerns.



5. All patients admitted to hospital for heart failure should **receive early specialist input to their care**. NHS England and NHS Improvement should seek further improvements in the percentage of patients receiving specialist input through the Best Practice Tariff for heart failure and expand it to include other measures such as **follow up from the multi-disciplinary team (MDT)**.



6. Health Education England should work with the Royal College of Nursing, Nursing and Midwifery Council and others to **build a picture of the number, location and qualifications of heart failure specialist nurses (HFSNs)** and other cardiac nurses treating people with heart failure; and urgently develop plans to ensure that the workforce is sufficient to meet demand.



7. All CCGs should commission heart failure services centred on MDTs including HFSNs, to **provide an integrated approach to care**. NHS England should consider how CCGs can be incentivised to do this.



8. All CCGs should **commission exercise-based cardiac rehabilitation programmes** suitable for heart failure patients and increase referrals to them. NHS England should expand its proposal for a Best Practice Tariff for cardiac rehabilitation to include appropriate patients admitted to hospital with heart failure.



9. As part of the Government's commitment to offer people approaching the end-of-life honest discussions, Health Education England should work with professional bodies to ensure all those caring for heart failure patients **receive training in advanced communication skills**.



10. As part of the Government's commitment to offer this opportunity to everyone approaching the end-of-life, CCGs and providers should ensure that all heart failure patients can make informed personalised decisions about their care using **advanced care planning**.

# Our recommendations

The Alliance for Heart Failure has reviewed progress since the 2016 APPG report and makes the following additional recommendations:

**1** Health Education England and primary care professional organisations should **support initiatives to raise awareness and improve education** among all healthcare professionals likely to encounter heart failure patients. **Each Primary Care Network (PCN) should appoint a heart failure champion.**

**2** All Clinical Commissioning Groups (CCGs) should commission **NT-proBNP testing to eradicate any residual regional variation** in access. Health Education England should **support initiatives to encourage its use** for diagnostic purposes by GPs, community diagnostic hubs, and emergency departments. NHS England should **support pathway adherence by providing access to the Pathway Transformation Fund.**

**5** NHS England and NHS Improvement should **improve the inter-hospital variation of specialist input and review**, ensuring specialist care or outreach to non-specialist teams, is available everywhere. Acute Trusts should **include the percentage of heart failure patients seen by the specialist multidisciplinary team on their Annual Safety and Quality Report.**

**8** All CCGs should **prioritise uptake and equitable access to cardiac rehabilitation.** Professional bodies like the Royal College of General Practitioners (RCGP) should **increase awareness of the benefits among GPs and primary care professionals** to increase uptake in line with the NHS Long Term Plan.

**3** **The echocardiography workforce shortage should remain an urgent priority** for Health Education England. CCGs and Trusts should **ensure that the correct diagnostic tools**, such as the use of NT-proBNP testing to rule out heart failure, are used to alleviate pressure on echocardiography services.



**4** Professional bodies, such as the Royal Colleges – in particular the Royal College of Nursing – should **ensure members are aware of the high-quality patient education materials available via patient organisations.**



**6** All CCGs should **urgently address delays to post-discharge follow-up.** Community providers and Acute Trusts should **urgently review and increase the number of heart failure specialist nurses (HFSNs)**, in the range of 2-4 whole-time equivalent per 100,000 population, to ensure numbers match workloads and patients are seen by highly skilled specialists.

**7** All CCGs should **commission heart failure services centred on MDTs**, ensuring they follow up patients to full capacity, following the NICE recommendation that all patients are discharged with two-week follow-up appointments.



**9** Health Education England, in collaboration with professional bodies, should **increase the roll out of training in advanced communication skills.**



**10** CCGs and providers should **ensure that all those who manage heart failure patients have the resources to develop end-of-life care** with palliative and primary care colleagues. Heart failure practitioners should formally communicate Advanced/Anticipatory Care Planning (ACP) to all appropriate professionals involved with the patient.



# What is heart failure?

Heart failure is a complex clinical syndrome of signs and symptoms that suggest the heart is not pumping blood around the body as efficiently as it should. It is most commonly caused by damage to the heart muscle, for example as the result of a heart attack, cardiomyopathy or related to high blood pressure. It can also be caused by heart valve problems, congenital heart disease, a viral infection affecting the heart muscle, an abnormal heart rhythm and some types of cancer treatment such as chemotherapy.

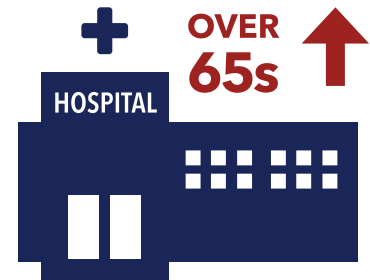
Symptoms include breathlessness, fatigue and swelling as a result of fluid retention. Heart failure can be chronic, meaning the signs and symptoms develop gradually over time; or acute, meaning the signs and symptoms develop suddenly. Someone with chronic heart failure may also have episodes of acute heart failure.

## Why is this important?

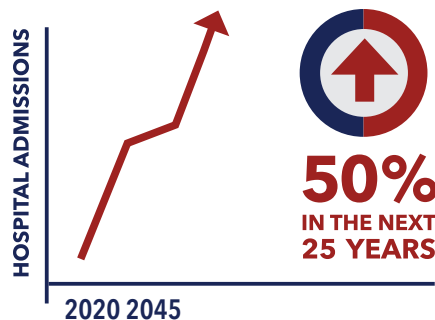
### Prevalence



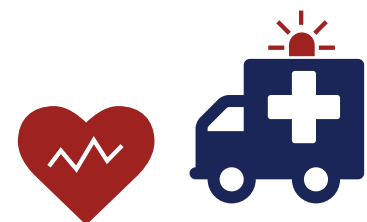
In the UK, heart failure affects over 900,000 people with 200,000 new cases annually.<sup>ii</sup>



Heart failure is the leading cause of hospital admissions in over 65s.<sup>iii</sup>



Projections indicate that hospital admissions for heart failure are set to rise by 50 percent in the next 25 years.<sup>iv</sup>

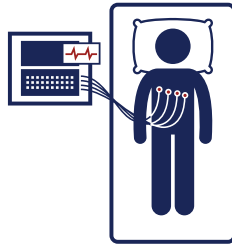


HEART FAILURE ACCOUNTS FOR 5%

of all emergency medical admissions to hospital.<sup>v</sup>

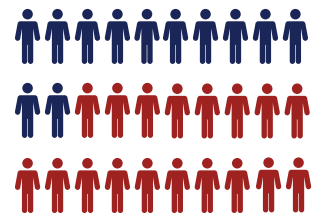
## Mortality

**5 YEAR** SURVIVAL RATE FOR **HEART FAILURE IS WORSE THAN BREAST OR PROSTATE CANCER**<sup>vi</sup>



**THE MORTALITY** of patients hospitalised with heart failure remains high overall at **10.1%**<sup>vii</sup>

**UP TO 40%** of people diagnosed with heart failure die within one year.<sup>viii</sup>

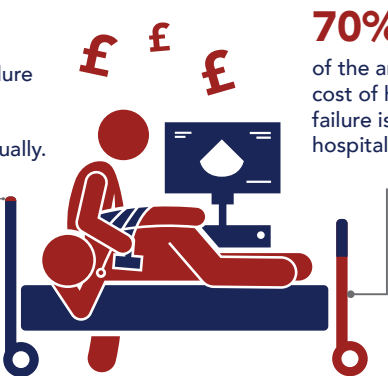


## Cost

The overall cost of heart failure to the **NHS** is currently

**£2.3 billion** annually.

Approximately **2%** of the total health service budget.<sup>ix, x</sup>



**70%** of the annual cost of heart failure is related to hospitalisation.<sup>xi</sup>

**£400m annually**

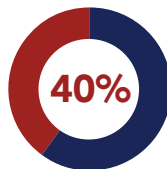
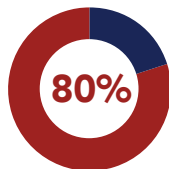
**80%** of heart failure diagnoses are made after an emergency admission, compared with 7.2% via a GP.<sup>xii</sup>



**862,470 BED DAYS** **HEART FAILURE**

accounted for the equivalent of 2,362 years of in-patient stays in 2018/19.<sup>xiii</sup>

## Diagnosis



**THE NHS LONG TERM PLAN** STATES THAT **80% OF HEART FAILURE CASES** IN ENGLAND ARE DIAGNOSED IN HOSPITAL, despite **40%** of patients having symptoms that could have triggered an earlier assessment in primary care.<sup>xv, xvi</sup>



**FEWER THAN ONE IN THREE PATIENTS SAY THEIR GP ORDERED A BLOOD TEST FOR HEART FAILURE**<sup>xvii</sup>

# Current status and new recommendations

## 1

### APPG Recommendation 1

**Health Education England should work with heart failure specialists to improve awareness, knowledge and understanding of the condition in general medical colleagues, including GPs. This should cover the need to consider the history of heart disease in the patient, and their family.**



#### Current status

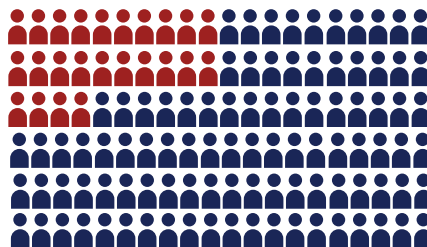
Patients with heart failure often present with breathlessness and can therefore often be misdiagnosed with respiratory conditions such as Chronic Obstructive Pulmonary Disease (COPD), asthma, or other respiratory conditions. Many patients also have other long-term cardiovascular related illnesses such as diabetes, hypertension, and chronic kidney disease. Awareness of heart failure symptoms among primary care clinicians, the significance of current and past medical history, in addition to relevant family history for conditions such as cardiomyopathy, are therefore key to ensuring patients receive an early and accurate diagnosis and follow the correct pathway.

- Some progress is being made to improve awareness among clinicians. For example, since 2016, initiatives have been undertaken by several organisations including the Alliance for Heart Failure, the Heart Failure Policy Network, and the British Heart Foundation, to build awareness of heart failure among national and regional clinical stakeholders.
- The Primary Care Cardiovascular Society (PCCS) has produced a set of educational materials for General Practitioners and nurse practitioners. There are plans to roll this out in 2021.
- Awareness among GPs is needed to address the issue of late diagnosis. A 2017 study found that, among 36,000 patients with a diagnosis of heart failure, only 24% followed a pathway aligned with guidelines (echocardiogram and/or serum natriuretic peptide test and specialist referral), while 44% had no echocardiogram, natriuretic peptide test or referral.<sup>6</sup>



## Only 24% of patients followed a pathway aligned to the guidance.

Source: Bottle A, et al.



- Some steps have been taken to ensure patients receive adequate follow-up. In Spring 2020, changes to existing Quality Outcomes Framework (QOF) domains, including heart failure, were made following Covid-19. This includes a change in timeframe for the percentage of patients with a diagnosis of heart failure which has been confirmed by specialist

assessment. Formerly 3 months before, or 12 months after, entering onto the register<sup>7</sup>, this has now changed to 6 months after entering on to the register.<sup>8</sup> There is now an additional requirement for heart failure patients to have had an annual review which includes an assessment of functional capacity and a review of medication.

- The risk of increasing numbers of patients presenting with complications from Covid-19 makes the issue of awareness among general medical professionals an even greater priority.<sup>5</sup>

“It’s important that GPs are aware of the symptoms and signs of heart failure and the tools available to them such as the NT-proBNP test in order to provide a patient with as early a diagnosis as possible.”

Daniel Smith, Nottingham  
Heart failure patient

### FURTHER RECOMMENDATION

Health Education England and primary care professional organisations should **support initiatives to raise awareness and improve education to all healthcare professionals** who are likely to encounter heart failure patients. **Each Primary Care Network (PCN) should appoint a heart failure champion.**

Picture courtesy of Pumping Marvellous Foundation

# 2

## APPG Recommendation 2

**All Clinical Commissioning Groups (CCGs) should commission cost-effective NT-proBNP testing to support the diagnosis of heart failure. NHS England should consider how CCGs can be incentivised to do this.**



### Current status

Measuring the presence of natriuretic peptide in patients with suspected heart failure is recommended by NICE. The most reliable type of test, N-terminal proB-type natriuretic peptide (NT-proBNP) testing, costs under £28 per test and can reduce the number of echocardiograms and referrals by 50% if appropriate pathways are in place.<sup>9</sup> It is estimated that the implementation of natriuretic peptide testing in primary care in line with NICE guidelines could lead to potential annual savings of £3.8 million.<sup>10</sup> The 2016 report found varying access to testing.

### Primary care

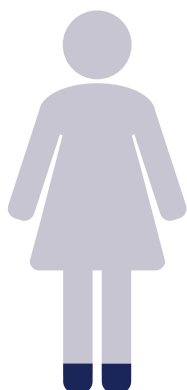
- A study in 2020 estimated that in England around 72% of trusts in primary care have access to NT-proBNP.<sup>11</sup> Despite being available for use in primary care, less than a third (29.1%) of patients said their GP ordered a blood test to test for heart failure<sup>12</sup>, and only 7.2% of patients received their diagnosis via their GP.<sup>13</sup>

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**GP diagnosis is an important factor in improving patient outcomes.**

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- There are also differences between male and female patients: 85.8% of men received a blood test, compared with 71.9% of women.<sup>13</sup> In over half of cases, someone other than the patient's GP ordered the test.<sup>13</sup>
- GP-diagnosed patients were more than twice as likely to be on the NICE-recommended pathway of an echocardiogram and/or serum natriuretic peptide test and a specialist referral than those diagnosed in hospital.<sup>6</sup>
- Despite this, the majority of patients still receive their initial diagnosis in a hospital setting (74.8% of heart failure patients in 2018/19).<sup>12</sup> Survival of people with heart failure admitted to hospital around the time of diagnosis has been found to be significantly worse than in those not requiring hospital admission, with a median difference of 2.4 years.<sup>14</sup>



## 7.2% of patients receive their diagnosis via a GP.



Source: Censuwide

- GP diagnosis is an important factor in improving patient outcomes. However, from the GP's perspective, diagnosis is made harder by the lack of specificity of heart failure symptoms, limited time availability – and, notably – limited access to investigations and low confidence in interpretation of investigation results.<sup>6</sup> This further underlines the need for GP education and access to appropriate diagnostic investigations and specialist review.

### Secondary care

- Access data from 2018 points towards wide access in secondary care, with BNP / NT-proBNP reported as available in 84.2% of hospitals<sup>15</sup>, while 78% of heart failure organisational teams reported that natriuretic peptide testing for diagnostic purposes was available.<sup>16</sup>
- However, there are issues in uptake of this key diagnostic test. Studies suggest infrequent testing in newly diagnosed patients (17.9%).<sup>15</sup>
- The figures are lower for emergency departments, in which only 8.5% of patients had a measurement of natriuretic peptides.<sup>15</sup>

Despite wide access, there are issues with uptake of NT-proBNP testing in secondary care.

- Late diagnosis has a major impact on patient outcomes. Almost one in five (18%) patients who were admitted to hospital for heart failure died within six months of their admission in 2018/19, rising to almost one quarter (24%) within a year. Nearly 10% of patients were also readmitted for the same cause within 90 days.<sup>17</sup>

### FURTHER RECOMMENDATION

All Clinical Commissioning Groups (CCGs) should **commission NT-proBNP testing to eradicate any residual regional variation in access**. Health Education England should support initiatives to encourage its use for diagnostic purposes by GPs, community diagnostic hubs, and emergency departments and to educate about the interpretation of results. NHS England should support pathway adherence by **providing access to the Pathway Transformation Fund**.

# 3

## APPG Recommendation 3

**NHS England and Health Education England should take urgent action to implement the recommendations in the Strategic Review of Cardiac Physiology Services on meeting workforce challenges, to ensure that demand for echocardiography can be met.**



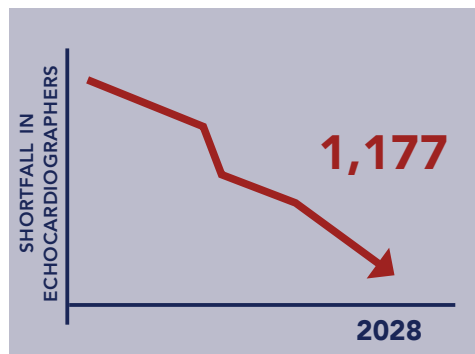
### Current status

Echocardiography is essential to confirm a diagnosis of heart failure, its cause, and the patient's prognosis, and usually follows a positive NT-proBNP test. Demand for echocardiography has been increasing on average by three to four per cent a year. Furthermore, the impact of Covid-19 on echocardiography services is expected to be significant, from deferred patient appointments to cardiac damage as a complication of the Covid-19 virus. However, the 2016 report identified a serious shortage of staff to meet this growing demand.

- In 2015 it was estimated that there would be a shortfall of 663 Whole Time Equivalents (WTEs) in echocardiography by 2018/19.<sup>18</sup>
- The situation since then has not improved. The most recent workforce planning expects the shortfall to increase to up to 1,177 by 2028, based on a conservative 5-6% increase in demand for diagnostics.<sup>19</sup>
- As a result, a third of echocardiography departments report that they cannot fill at least one post and a further third of these have at least two unfilled posts.<sup>20</sup> More than a third of departments have at least 50% staff from locum agencies.<sup>20</sup>
- The chronic shortage has led the National School for Healthcare Science to highlight the need for echocardiographers on the Migration Advisory Committee (MAC) Shortage Occupation List.
- There is also an ageing group of echocardiographers with 1 in 5 planning to retire within 5 years.<sup>21</sup>
- There is evidence to suggest that this shortage is impacting on services. In 2016, 89% of patients were given an echocardiogram during hospital admission. Rates were higher for those admitted to cardiology (96%) rather than general medical (84%) wards.<sup>22</sup> By 2018, these rates had declined. 88% of patients were given an echocardiogram during hospital admission. Rates for those admitted to cardiology were lower (92%), while the rate on general medical wards remained the same at 84%.<sup>23</sup> NHS England also reports significant regional variation.<sup>24</sup>

## 1,177 The expected shortfall in echocardiographers by 2028.

Source: NHS England



- To address the workforce shortage, a three-year national programme for Clinical Scientists, funded by the National School for Healthcare Science, was introduced in 2011. The current intake is approximately 350 trainee Clinical Scientists each year, of which around 50 are in cardiology.
- The National School of Healthcare Science has developed a new 18 month fast-track integrated training programme in echocardiography, funded by Health Education England, aimed at increasing the potential workforce by identifying graduates from other areas where science and healthcare are embedded in the academic program.

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There is evidence to suggest that this shortage is impacting on services.

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- The first pilot cohort of 12 trainees has now been recruited. The course leads to a Post Graduate Certificate in Clinical Echocardiography and BSE Level 2 Accreditation in Adult Transthoracic Echocardiography. The National School is also seeking to fund a second, larger cohort and is actively seeking training departments to host them nationally.

### FURTHER RECOMMENDATION

**The echocardiography workforce shortage should remain an urgent priority** for Health Education England. CCGs and Trusts should **ensure that the correct diagnostic tools**, such as the use of NT-proBNP testing to rule out heart failure, are used to alleviate pressure on echocardiography services.

# 4

## APPG Recommendation 4

**Clinicians should ensure that when patients are diagnosed they are provided with information about heart failure, how it may impact on their lives, and how they can help manage this, in a form that is suitable for them. Patients should also be provided with a single point of contact for any questions and concerns.**



### Current status

Timely and accurate information about a patient's condition is essential in helping them deal with the emotional and psychological impact of being diagnosed with heart failure, and to help them manage their condition; this was emphasised in the 2018 NICE Chronic Heart Failure guidelines for adults. The 2016 APPG report into heart failure highlighted that, while patient groups provide excellent information, patients often have to find it themselves.

- The 2018 NICE guidelines underlined the importance of heart failure specialist nurses (HFSNs) being at the centre of the patient's team. The care plan, as detailed in the guidelines, indicates that patients should have their own understandable care plan as a conduit of communication between the patient and their family, the multi-disciplinary team (MDT), and the wider team that surrounds people with heart failure. However, these care plans do not exist as a standard, are inconsistent in approach, and their usage is limited.<sup>25</sup>
- Patients without access to a specialist MDT are unlikely to receive tailored advice in a format suitable to them. Even when patients have access to a specialist MDT there is no consistency of approach. Variation in reporting makes it difficult to measure the size of the problem. Furthermore, some communication systems have broken down during the Covid-19 pandemic, with the British Heart Foundation reporting significant unmet need and many people calling its helpline for advice on how to manage their condition at home in the absence of GP or specialist care.

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**Care plans do not exist as standard and are inconsistent in approach.**

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- On the other hand, patient groups continue to generate and promote high-quality material, including:
  - The Pumping Marvellous Foundation, which operates one of the largest global digital channels for heart failure, reaching tens of millions of people every year with educational material. Its digital channels provide patients and their families with well-moderated peer-to-peer educational support. Digital downloads of educational material equate to in excess of 250,000 downloads from its website. Its printed material reaches over 250 NHS teams, mainly in heart failure, but also in cardiac rehabilitation, atrial fibrillation, and stroke. The charity delivers around 100,000 pieces of printed material on a rolling 12-month basis to patients. It also runs the world's largest educational heart failure awareness campaign, reaching over 6 million people in 29 countries.



# Over 7 million

The number of people reached by heart failure awareness campaigns.

“Sharing of information is paramount to me. The MDT approach means they are all singing from the same page in terms of my healthcare.”

Bev Keddo, Surrey  
Heart failure patient



- Cardiomyopathy UK provides education via its nurse-led helpline, national conference, support group network, printed resources, and website. It also runs an annual awareness campaign aimed at highlighting the signs and symptoms of cardiomyopathy and heart failure. Between 2016 and 2019 it recorded over 1.3 million interactions with patients and clinicians.
- The British Heart Foundation has increased its education in heart failure since 2016, with content and materials aimed at patients and healthcare professionals. Orders and downloads of its heart failure booklets for example totalled around 200,000 in 2018, and increased significantly in 2019. It also has extensive online resources, which generated 268,000 unique page views over the 12 months until August 2020.

## FURTHER RECOMMENDATION

Professional bodies, such as the Royal Colleges – in particular the Royal College of Nursing – should **ensure members are aware of the high-quality patient education materials available** via patient organisations. NICOR should include measurement as part of the core dataset to ensure teams are sharing appropriate information.

Picture courtesy of Pumping Marvellous Foundation

# 5

## APPG Recommendation 5

**All patients admitted to hospital for heart failure should receive early specialist input to their care.** NHS England and NHS Improvement should seek further improvements in the percentage of patients receiving specialist input through the Best Practice Tariff for heart failure and expand it to include other measures such as follow up from the multi-disciplinary team (MDT).



### Current status

Outcomes for patients who receive early specialist input have been shown to be better than those treated on general medical wards. They are also more likely to receive treatment and care that meets NICE guidelines. However, the 2016 report pointed to significant variation across the country.

- In 2018, 88.2% of hospitals stated that they had a specialist heart failure service. Follow-up by a specialist team in either the hospital or the community was available in 97% of hospitals.<sup>15</sup>
- This is having a beneficial effect on patients' experience; in 2019 it was reported that, although there are still significant improvements to be made, more patients admitted with heart failure are being identified and seen during their admission by heart failure specialists.<sup>26</sup> In fact, data suggests that 82% of patients were seen by a specialist during admission in 2018<sup>23</sup>, compared to 80% in 2016.<sup>22</sup>

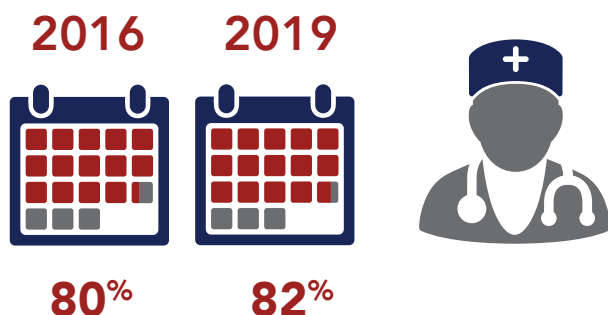
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**Specialist input remains an indicator with huge inter-hospital variability.**

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- This includes nearly half (49%) of patients seeing a heart failure specialist nurse during their admission<sup>23</sup>, in comparison with 31% in 2016.<sup>22</sup>
- Despite this, specialist input remains an indicator with huge inter-hospital variability and there is still room for improvement in specialist review rates. For example, the proportion of hospitals achieving specialist review rates of over 80% was around two-thirds in 2018.<sup>22</sup>





The number of patients seen by specialists has increased, but there is room for improvement.

Source: NICOR

- The 2018 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) found room for improvement in the timing of the first consultant review in 17.1% of in-patient cases. Review by a specialist heart failure team only occurred in 33% of in-patient cases among patients who died in hospital.<sup>15</sup>
- There is also room for improvement in specialist input across wards. NICOR reports that on the cardiology ward, the number of patients seen by consultant cardiologists has remained good (92% in 2016, 93% in 2018), however, those seen by a HFSN has not improved, standing at 53% in 2016 and 52% in 2018.<sup>22,23</sup> On general medical wards, the proportion of patients seen by a HFSN has remained static at 44% since 2016.<sup>23</sup>

#### FURTHER RECOMMENDATION

NHS England and NHS Improvement should **improve the inter-hospital variation of specialist input and review**, ensuring specialist care or outreach to non-specialist teams, is available everywhere. Links with community teams should allow patient care to transition between services. Acute Trusts should **ensure timely review by the heart failure team and access to rapid diagnostics**. Acute Trusts should **include the percentage of heart failure patients seen by the specialist multidisciplinary team on their Annual Safety and Quality Report**.

# 6

## APPG Recommendation 6

**Health Education England should work with the Royal College of Nursing, Nursing and Midwifery Council and others to build a picture of the number, location and qualifications of heart failure specialist nurses (HFSNs) and other cardiac nurses treating people with heart failure; and urgently develop plans to ensure that the workforce is sufficient to meet demand.**



### Current status

Much heart failure care is provided in the community by heart failure specialist nurses (HFSNs). HFSNs play a vital role in improving patients' quality of life, reducing hospital admissions and costs to the NHS, and facilitate better communication across primary, secondary, and community care. The 2016 report identified a gap in data around community services and reported anecdotal evidence that not all patients are receiving care outside hospital that meets NICE standards.

### Numbers

- Evidence suggests that HFSNs are overstretched. In 2017, 84% of heart failure services employed one HFSN per 100,000 population. Of these, 32% managed to see more than 65% of patients within two weeks.<sup>26</sup> This is in line with the recommended number of HFSNs (1 per 100,000), proposed in 2002.<sup>27</sup> This recommendation has remained in place, despite increased prevalence, considerable advances in therapies, and new recommendations from NICE.<sup>26</sup>

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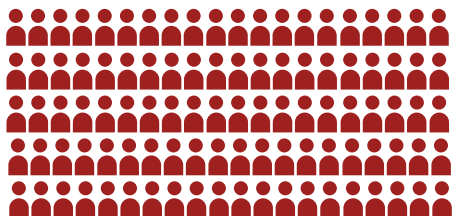
**Evidence suggests that HFSNs are overstretched.**

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- There is further evidence of community HFSNs struggling with 'unmanageable caseloads', which creates risk. However, no provision has been made for additional community HFSNs.<sup>26</sup>

### Qualifications

- A 2018 audit of heart failure teams found the majority of teams consisted of Band 6 or 7 nurses.<sup>16</sup> In nursing, Band 6 roles include Nursing Specialist or Senior Nurse, meanwhile Band 7 is typically defined as an Advanced Nurse Practitioner, usually requiring a Masters level degree or equivalent.<sup>28</sup>



**1 HFSN per 100,000 population.  
84% of heart failure services  
meet this target, but it is  
considered outdated.**

Source: British Journal of Cardiac Nursing

- Over 80% of teams had nurses who held clinical examination skills either at degree or Masters level. 85% of teams had accessed a heart failure module at an academic institution, and 90% of teams stated they had at least one member of the team who is a non-medical prescriber.<sup>16</sup>
- However, anecdotal evidence from across the UK suggests that services are diluted by HFSNs undertaking non-specialist roles, such as community risk assessments.
- Data from NCEPOD also points to the need for more specialist input. In 23.7% of in-patient cases it reviewed in 2018 there was room for improvement. In 14.8% of the peer reviewed cases, one of the areas for improvement related to cardiology input being delivered by too junior a member of the team.<sup>15</sup>

### Location

- The 2015 NICE Acute Heart Failure Quality Standards recommended that adults with acute heart failure have a follow-up clinical assessment by a member of the community or hospital-based specialist heart failure team within two weeks of hospital discharge.<sup>29</sup>

Services that cover populations in urban areas are better able to meet or come close to meeting the two-week standard than services covering rural populations.<sup>26</sup>

### FURTHER RECOMMENDATION

All CCGs should urgently address delays to post-discharge follow-up. Community providers and Acute Trusts should **urgently review and increase the number of heart failure specialist nurses (HFSNs)**, in the range of 2-4 whole-time equivalent per 100,000 population, to ensure numbers match workloads and patients are seen by highly skilled specialists. Further work should be commissioned to look at HFSN workload and its nature to ensure it is appropriate. Health Education England should work with the Royal College of Nursing, Nursing and Midwifery Council and others **to assess education and training budgets to ensure they are sufficient to meet such demand.**

# 7

## APPG Recommendation 7

**All CCGs should commission heart failure services centred on MDTs including HFSNs, to provide an integrated approach to care. NHS England should consider how CCGs can be incentivised to do this.**

[N.B. As lead clinicians are employed by NHS Trusts, they should also be incentivised to provide integrated care.]



### Current status

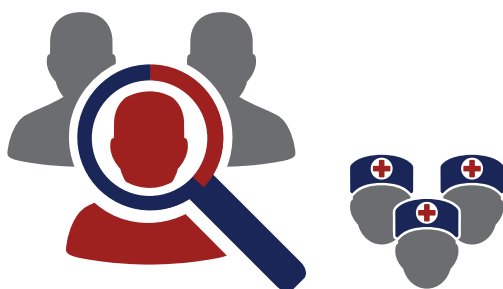
Outcomes for heart failure patients treated on a cardiology ward are better, compared with those treated on a general medical ward. NICE guidelines recommend that heart failure care should be delivered by a multi-disciplinary team (MDT) with an integrated approach across the healthcare community, to ensure that the wider needs of patients are addressed. But the 2016 APPG report found that improvements in provision were needed.

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**Although the number of heart failure MDTs has improved, patient access needs to improve.**

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- Overall, heart failure team numbers remain good. A report by Pumping Marvellous in 2018 found that 84% of heart failure teams had access to an MDT<sup>16</sup>, while according to NCEPOD there was no heart failure team in place to provide care in only 6.2% of in-patient cases.<sup>15</sup>
- However, patient access to their support has remained static. In 2017/18, only 37% of patients were recorded as having a clinical assessment from a member of a multi-disciplinary heart failure team within two weeks of discharge.<sup>23</sup> Overall, 47% of those discharged had cardiology follow-up (47% in 2016), and 58% had HFSN appointments post discharge (57% in 2016). These rates are higher for those being admitted to cardiology wards, at 63% and 69% respectively (64% and 69% in 2016).<sup>22, 23</sup>
- Although heart failure specialists are more likely to manage patients that will benefit from their interventions, specialist care has been proven to improve patient outcomes. In 2018, in-hospital mortality was 10.1%. Mortality for patients admitted to cardiology was 7.1% compared with 10.7% for patients admitted to general medical wards. For those accessing specialist care, mortality was 8.6%, compared with 14.6% for those who did not.<sup>22, 23</sup>



## Only 37% of patients had a clinical assessment from an MDT in 2017/18 two weeks after discharge.

Source: NICOR

- This variation in in-patient mortality by place of care and specialist input underscores the need to improve comprehensive, state of the art multidisciplinary heart failure care in all wards and hospitals.<sup>23</sup> It also highlights the need to strengthen the links between primary, community and secondary care through an integrated MDT approach.
- Other specialist input, such as pharmacy care, has been found to safely improve adherence to heart failure medications and quality of life.<sup>30</sup>
- Economic evaluations have compared a MDT involving a cardiologist experienced in geriatrics, specialist heart failure nurses, and a primary care physician, to usual care. This found that this approach saves £4,042 per death and/or heart failure-related admission avoided, highlighting the need for greater emphasis on the role of geriatricians alongside palliative care specialists and pharmacists within the multidisciplinary team.<sup>25</sup>
- During the Covid-19 pandemic, virtual meetings can be used to improve access to the MDT, organised around the following criteria:
  1. Specialist reviews following NICE guidance;
  2. Escalation of care (palliative care should be involved in heart failure care planning, following NICEPOD and NICE recommendations); and
  3. Appropriateness to refer patients to hospital services for specialised treatment, advanced heart failure therapy, or device implantation.<sup>31</sup>

### FURTHER RECOMMENDATION

All CCGs should **commission heart failure services centred on MDTs** (including palliative care teams<sup>32</sup>, pharmacists<sup>30</sup> and geriatricians<sup>43</sup>), ensuring they follow up patients to full capacity, following the NICE recommendation that all patients are discharged with two-week follow-up appointments.<sup>29</sup> Variation across wards and hospitals should be reduced **to decrease in-hospital mortality and ensure better outcomes for all patients.** Virtual meetings should be used to improve access to MDTs.

# 8

## APPG Recommendation 8

**All CCGs should commission exercise-based cardiac rehabilitation programmes suitable for heart failure patients and increase referrals to them. NHS England should expand its proposal for a Best Practice Tariff for cardiac rehabilitation to include appropriate patients admitted to hospital with heart failure.**



### Current status

The 2016 Inquiry heard anecdotal reports from patients who had experienced the benefits of cardiac rehabilitation and found evidence that such services can help reduce mortality and hospital admissions. NICE recommends that patients are offered cardiac rehabilitation support, however fewer than 20% of patients admitted to hospital are referred and there are gaps in provision in some heart failure programmes. In addition, mortality is 12% higher in those not referred for rehabilitation.<sup>23</sup>

- The updated 2018 NICE guidance on chronic heart failure recommends offering ‘people with heart failure a personalised, exercise-based cardiac rehabilitation programme’. The guideline expressed concern about continued low uptake of cardiac rehabilitation in people with heart failure, stating that ‘delivery of home-based rehabilitation may increase access and uptake’ and ‘even a modest increase has the potential to result in a marked improvement in patient outcomes at the population level’.<sup>25</sup>
- This is reinforced by the NHS Long Term Plan which states: ‘Access to and uptake of cardiac rehabilitation services varies across England, and only 62,822 patients (52%) of the 121,500 eligible patients per year take up offers of cardiac rehabilitation’. The Plan sets out aims to increase the uptake to 85% of all eligible patients with cardiovascular disease by 2028, the highest rate in Europe.<sup>33</sup>
- Variation was highlighted in a survey of 100 health professionals in 79 heart failure centres in 2018, in which one in five (20%) reported that they did not provide personalised exercise rehabilitation programmes for people with heart failure, while around two-thirds (68%) reported insufficient resources to provide an optimum personalised rehabilitation service.<sup>34</sup>



## 33%: NHS England’s target for uptake of cardiac rehabilitation among heart failure patients (it is 8% currently).

Source: NHS England Long Term Plan

- NHS England has set a specific uptake target for heart failure patients of 33% for cardiac rehabilitation (from the current 8%). It has allocated initial funding of £11.9m by 2023 for all patient groups with recurrent funding of £15.8m per annum from 2023-24.
- Progress has been made to support the uptake of home-based cardiac rehabilitation, including:
  - The REACH-HF Manual, an evidence-based self-help manual<sup>35, 36</sup>, is being rolled out at several NHS Beacon sites. Covid-19 funding from the South West Academic Health Science Network (AHSN) has helped provide free online training to health care professionals to deliver it. In 2020, REACH-HF won the BMJ Stroke and Cardiovascular Care Team of the Year Award.
  - The BHF is funding an 18-month project to digitise the REACH-HF intervention in 2020.

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### Access to and uptake of cardiac rehabilitation services varies across England.

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- In the wake of the Covid-19 pandemic, the British Association for Cardiovascular Prevention and Rehabilitation (BACPR), British Cardiovascular Society (BCS), and British Heart Foundation (BHF) highlighted evidence for alternatives to traditional cardiac rehabilitation based on web / manual-based cardiac rehabilitation delivered by appropriately qualified health and exercise professionals.<sup>37</sup>

### FURTHER RECOMMENDATION

All CCGs should **prioritise uptake and equitable access to cardiac rehabilitation**. Professional bodies like the Royal College of General Practitioners (RCGP) should **increase awareness of the benefits among GPs and primary care professionals** to increase uptake in line with the NHS Long Term Plan. In addition, CCGs should commission self-care rehabilitation intervention, including home-based exercise programmes.

# 9

## APPG Recommendation 9

**As part of the Government’s commitment to offer people approaching the end-of-life honest discussions, Health Education England should work with professional bodies to ensure all those caring for heart failure patients receive training in advanced communication skills.**



### Current status

The 2016 APPG report highlighted a growing relationship between HFSNs and palliative care but reported that progress was slow and inconsistent across the country. Honest and sensitive conversations with heart failure patients is crucial, but advanced communication skills training is not provided to all staff caring for people with heart failure.

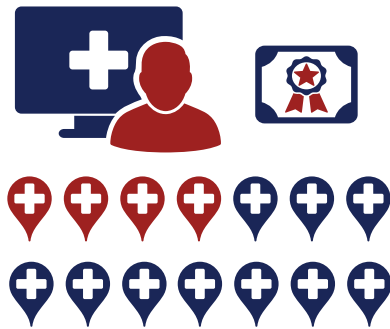
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**Progress in rolling out training in advanced communications skills has been slow.**

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- NICE 2018 guidelines on palliative care were updated to state that 'If the symptoms of a person with heart failure are worsening despite optimal specialist treatment, discuss their palliative care needs with the specialist heart failure multidisciplinary team and consider a needs assessment for palliative care'.<sup>25</sup>
- In 2016, the Department of Health and Social Care stated that it will ensure the right people with the right knowledge and skills are available to deliver high quality personalised care, and had agreed deliverables on improving end-of-life care education, training and workforce provision and planning with Health Education England.<sup>38</sup>
- The Department also outlined that, to achieve the quality improvements it wants to see, it will place improvements tailored to hospital, community, and care home settings, including asking local systems to account for how they will manage implementation of choice, particularly at end-of-life, as part of their programme to hand power to patients.<sup>38</sup>





4 out of 14 services across the East Midlands had no access to advanced communications training in 2019.

Source: NHS England and NHS Improvement

- However, data from 2019 shows that around a third of services (4 out of 14) surveyed across the East Midlands had not been able to access advanced communication training.<sup>39</sup>
- Two of these four services reported that they did not have access to continuing professional development (CPD) funds from their Trust.<sup>39</sup> Access to appropriate funding is therefore essential.

### NEW RECOMMENDATION

Health Education England, in collaboration with professional bodies, should **increase the roll out of training in advanced communication skills.**

# 10

## APPG recommendation 10

**As part of the Government's commitment to offer this opportunity to everyone approaching the end-of-life, CCGs and providers should ensure that all heart failure patients can make informed personalised decisions about their care using advanced care planning.**



### Current status

Patients with advancing disease who are considered to be approaching end-of-life, and their families, should have an advance care plan (also known as an anticipatory care plan) that reflects evolving discussions related to their preferred care wishes, timely deactivation of devices, DNA CPR (do not resuscitate), and management guidance of escalating physical and psychological needs. This was strongly recommended for all heart failure patients in the 2016 APPG report.

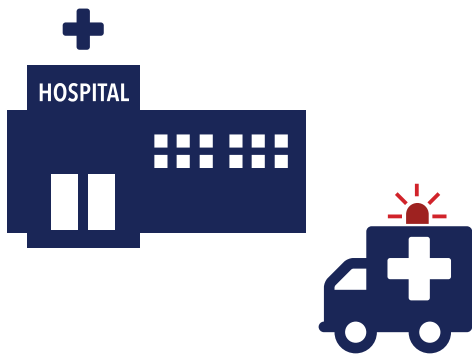
- The 2019 NICE guidelines on end-of-life care for adults state that 'Service providers should develop policies to ensure that advanced care planning is offered to adults who are approaching the end of their life.'<sup>40</sup>
- A report by Hospice UK<sup>32</sup> in 2017 recognised that coordinated care provided by palliative care teams in conjunction with cardiology, community heart failure specialist nurses and primary care reduces hospitalisations and is more likely to lead to the preferred care wishes of heart failure patients and their families being fulfilled.<sup>32</sup>

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**The care of patients with heart failure who are approaching the end-of-life has been recognised as deficient.**

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- Geriatricians frequently have input into the Acute Medical Unit. These teams need to be engaged and trained in order to manage heart failure patients and should have the resources to develop end-of-life care.<sup>25</sup> This requirement should be addressed within the specialist registrars training in Geriatric Medicine and recognised by the British Geriatrics Society specialist registrar training committee.<sup>15, 43</sup>



## 29.5% of final hospital admissions could have been avoided.

Source: NCEPOD

- However, the care of patients with heart failure who are approaching the end-of-life has been recognised as deficient, particularly when compared with other diseases such as cancer.<sup>41</sup>
- The 2018 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) found that in 29.5% of the hospital admissions examined, the final admission could have been avoided if an end-of-life plan had been in place.<sup>15</sup>
- Community based palliative care can support the management of medical illnesses at the end-of-life outside hospices and hospitals and prevent hospital admissions, easing pressure on beds and ensuring people die in their preferred place of care with their family able to be present.<sup>42</sup>

### NEW RECOMMENDATION

CCGs and providers should **ensure that all those who manage heart failure patients have the resources to develop end-of-life care** with palliative and primary care colleagues. Heart failure practitioners should formally communicate Advanced/Anticipatory Care Planning (ACP) to all appropriate professionals involved with the patient in line with NCEPOD recommendations.

# Alliance for Heart Failure

**The Alliance for Heart Failure** calls on those Government departments, agencies, and other organisations mentioned in these recommendations to take urgent action to address the inequity of care experienced by heart failure patients.

Together, we can make a difference and significantly improve patient outcomes.

# Our recommendations

The Alliance for Heart Failure has reviewed progress since the 2016 APPG report and makes the following additional recommendations:

**1** Health Education England and primary care professional organisations should **support initiatives to raise awareness and improve education** among all healthcare professionals likely to encounter heart failure patients. **Each Primary Care Network (PCN) should appoint a heart failure champion.**

**2** All Clinical Commissioning Groups (CCGs) should commission **NT-proBNP testing to eradicate any residual regional variation** in access. Health Education England should **support initiatives to encourage its use** for diagnostic purposes by GPs, community diagnostic hubs, and emergency departments. NHS England should **support pathway adherence by providing access to the Pathway Transformation Fund.**

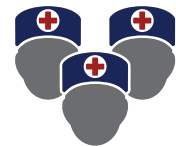
**5** NHS England and NHS Improvement should **improve the inter-hospital variation of specialist input and review**, ensuring specialist care or outreach to non-specialist teams, is available everywhere. Acute Trusts should **include the percentage of heart failure patients seen by the specialist multidisciplinary team on their Annual Safety and Quality Report.**

**8** All CCGs should **prioritise uptake and equitable access to cardiac rehabilitation.** Professional bodies like the Royal College of General Practitioners (RCGP) should **increase awareness of the benefits among GPs and primary care professionals** to increase uptake in line with the NHS Long Term Plan.

**3** **The echocardiography workforce shortage should remain an urgent priority** for Health Education England. CCGs and Trusts should **ensure that the correct diagnostic tools**, such as the use of NT-proBNP testing to rule out heart failure, are used to alleviate pressure on echocardiography services.



**4** Professional bodies, such as the Royal Colleges – in particular the Royal College of Nursing – should **ensure members are aware of the high-quality patient education materials available via patient organisations.**



**6** All CCGs should **urgently address delays to post-discharge follow-up.** Community providers and Acute Trusts should **urgently review and increase the number of heart failure specialist nurses (HFSNs)**, in the range of 2-4 whole-time equivalent per 100,000 population, to ensure numbers match workloads and patients are seen by highly skilled specialists.

**7** All CCGs should **commission heart failure services centred on MDTs**, ensuring they follow up patients to full capacity, following the NICE recommendation that all patients are discharged with two-week follow-up appointments.



**9** Health Education England, in collaboration with professional bodies, should **increase the roll out of training in advanced communication skills.**



**10** CCGs and providers should **ensure that all those who manage heart failure patients have the resources to develop end-of-life care** with palliative and primary care colleagues. Heart failure practitioners should formally communicate Advanced/Anticipatory Care Planning (ACP) to all appropriate professionals involved with the patient.

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### Prevalence:

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# Alliance for Heart Failure

**The Alliance for Heart Failure** is a coalition of charities, patient groups, professional bodies, and corporate members for the purpose of raising the profile of heart failure in Government, the NHS, and the media.

The Alliance for Heart Failure is supported and funded by Abbott, AstraZeneca UK, Boehringer Ingelheim Limited, Medtronic Limited, Novartis Pharmaceuticals UK Ltd, and Roche Diagnostics Ltd.

## **Member organisations:**

- Abbott
- AstraZeneca UK
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- British Association for Cardiovascular Prevention and Rehabilitation
- British Association for Nursing in Cardiovascular Care
- British Society for Echocardiography
- Cardiomyopathy UK
- Cardiovascular Care Partnerships
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- UK Heart Failure Pharmacy Forum

