

British Heart
Foundation



Heart failure: a blueprint for change

Building a better
future for heart
failure together

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This report and the recommendations within it are supported by:



Foreword



The British Heart Foundation is proud to have produced this report which highlights the significant challenges facing the nearly one million people across the UK living with heart failure. Now is the time to speak out; in the wake of the Covid-19 pandemic which has so clearly exposed the huge inequalities in care that people have been experiencing for years. And now is the time for all of us to come together and seize the opportunity to build back better, to ensure that everyone with heart failure has their opportunity to live a better quality of life.

We are committed to playing our part in this process and hope this report provides a starting point for driving that change. We are grateful to everyone who has provided insight, data and analysis to inform its contents and are particularly thankful for the endorsements of the British Cardiovascular Society, British Society of Heart Failure, Primary Care Cardiovascular Society and Pumping Marvellous Foundation. Working together and with the wider health service, we're confident that we can improve the lives of people living with heart failure across the UK.

Professor Sir Nilesh Samani
Medical Director of the British Heart Foundation



In its 72 years, the health service has witnessed and surmounted many difficulties, but little prepared our dedicated frontline workers for the Covid-19 pandemic. Not only did the crisis stretch our resources to new limits but it exacerbated numerous systemic inequalities, otherwise known as variations in care. These particularly affected people from socioeconomically deprived and Black and minority ethnic backgrounds, but especially for all of those suffering with heart failure.

There is no cure for heart failure, and it tends to occur towards the end of a cardiovascular disease journey. It can occur as the result of a heart attack, congenital heart disease, cardiomyopathy and high blood pressure as well as sometimes being a consequence of cancer treatment. In 98% of patients, heart failure resides alongside another long-term condition and renders the patient multi-morbid and more complex to manage.

It is possible to live well with heart failure. There are now a number of proven treatments but more needs to be done to support patients; this is an important aim of the care we provide as heart failure specialists.

To help us achieve our aims, we need to be given credence to lead heart failure patient care and for there to be accountability at all points of care throughout the patient pathway. No patient with heart failure, no matter where they live, their ethnic origin or economic status should suffer due to variations in care anymore than others with the condition.

Covid-19 has shone a bright light on existing inequalities in the system and we, as the BSH, are committed to investigating the difficulties encountered by those with heart failure so we can better prepare for the possible, inevitable, resurgence of the pandemic.

Dr Simon Williams
Chair of the British Society for Heart Failure

1

Focusing on people, not structures

- NHS England (NHSE) and NHS Improvement (NHSI), and devolved-nation equivalents, should prioritise a full pathway approach to improving heart failure services – resourcing systems and holding them accountable to understand and improve their whole service from diagnosis through to end-of-life care, instead of focusing on individual parts of the pathway.

- Integrated Care Systems (ICSs), and equivalents in the devolved nations, should employ heart failure pathfinders to help services to understand the full patient pathway and population health, and to advise them on how to join up services in their area to support heart failure patients. This should inform commissioning of heart failure services that span care settings and include routine access to NTproBNP testing and echocardiography, referral to rehabilitation, psychological support and palliative care services as standard.

- Health Education England (HEE), and devolved-nation equivalents, should develop training programmes for healthcare professionals, to enable them to better support the psychological and emotional needs of people with heart failure and their loved ones, from diagnosis through to the end of life. This should include the importance of having early conversations about end-of-life care and the use of advanced care planning.

2

Reframing heart failure as a long-term condition

- HEE, and relevant bodies in the devolved nations, should offer enhanced education and quality improvement skills training to generalist health and care professionals to help them effectively and sustainably recognise, diagnose, code and manage heart failure. This should focus particularly on roles in primary care and community settings, as well as those most likely to encounter heart failure patients presenting at A&E or in relevant specialities, including diabetic clinics.

- HEE, and equivalent organisations across the UK, should work with the British Society for Heart Failure (BSH), Skills for Care and organisations such as the Primary Care Cardiovascular Society (PCCS) to define and map the competencies required to manage heart failure across the pathway and use this to inform training for professionals. Local systems should then use these to map the competencies of their staff across the full pathway and identify ways of best using teams to address the needs of heart failure patients.

3

Driving change with data

- NHSX should collaborate with others to accelerate the joining up of heart failure data across settings, identify gaps and develop a comprehensive data set that is accessible and useable for clinicians in a timely manner. This should include comprehensive demographic data to understand inequalities in access to care and equity of healthcare outcomes, as well as better reflecting citizens' experience of care. To progress this, NHSX should establish a working group with NHSE/I, BSH, the British Cardiovascular Society (BCS) and National Institute for Cardiovascular Outcomes Research (NICOR), the BHF Data Science Centre and other relevant partners.

- NICOR should work with stakeholders to review the Heart Failure Audit and make changes to allow it to realise its full potential to contribute to quality improvement of heart failure services across the UK. To achieve this, NICOR should work closely with partner organisations to expand the range of data collected to include primary and community care and to allow clinicians and system leaders to better access analysis of their own data in a timely fashion.

- UK governments and the NHS should work rapidly to identify and bring together data to understand the impact that the coronavirus pandemic has had on heart failure services to rapidly inform care of patients who have been affected by Covid-19, as well as the restoration of Covid-resilient services and future redeployment of staff.

- National audits and local data collection must be appropriately resourced to allow health system leaders to make evidence-based decisions. To achieve this, national audits should be adequately resourced to work with partner organisations to expand the range of data collected to include primary and community care and to allow clinicians and system leaders to better access analysis of their own data in a timely fashion. Local systems should be allocated funding for analysts, clinical leads, project managers and training for clinicians to optimise the use of existing data in their area to understand their heart failure population, supporting them to design services to meet their needs.

4

Leading across the pathway

- NHSE, and devolved-nation equivalents, should identify and recruit heart failure champions at regional and national levels to work together and drive a full pathway approach to heart failure care. These champions should be resourced by, and accountable to, strategic clinical networks and devolved-nation equivalents, for demonstrating improvements in patient outcomes and experience. These champions should be selected and trained based on criteria that define what good leadership across the pathway looks like for heart failure. These criteria should be developed by the NHS and BSH, with support from the PCCS and relevant charities.

Context

The NHS and wider health and care system are facing a historic challenge. The coronavirus pandemic has placed incredible pressure on the system and has resulted in previously unthinkable changes to the delivery of services including, in some cases, significant delays to care. System leaders are now faced with delivering on the ambitions to better integrate care and improve outcomes for people with heart and circulatory disease within the enduring context of the coronavirus pandemic.

In 2016, the BHF worked with the All-Party Parliamentary Group (APPG) on Heart and Circulatory Diseases and a range of partner organisations, including the Pumping Marvellous Foundation and the BSH, to make ten recommendations to improve heart failure care in England. This highlighted issues and opportunities across the patient pathway, including the need to commission diagnostics such as NTproBNP testing and build the workforce with the expertise to deliver a quick and accurate diagnosis for patients. The report also recognised the need to raise awareness of heart failure among generalist medical professionals, improve the information given to patients at the point of diagnosis, and ensure that all patients access the specialist care they need through a multidisciplinary team (MDT), as well as being able to access rehabilitation services and timely palliative care.

However, progress has been slow and our own insight tells us that services are still not always joined up or consistently addressing the needs of people with heart failure. Recent work by the Pumping Marvellous Foundation and Roche has shown that lack of routine access and proper use of key diagnostics, such as NTproBNP testing, remains an issue¹.

In 2019, heart failure was included as a priority in the NHS Long Term Plan for England, setting out a focus on driving earlier detection of heart failure in the community through primary care networks (PCNs), a stronger focus on MDT-led care, and faster access to specialist care in hospitals.

However, the coronavirus pandemic has since had a significant impact on the system, with clinical staff redeployed to address the immediate needs associated with the pandemic. Within weeks, heart failure services had disappeared or been depleted in many areas of the UK, leaving patients with limited support. Significant numbers of patients were either unable or unwilling to access care, with many calling charities for guidance on how to manage their condition in the absence of their usual support offer.

Official data show that nearly 185,000 people were waiting for investigations or treatment in cardiology or cardiothoracic surgery in England at the end of July 2020². An NHS Confederation report has projected that waiting list numbers could double by December 2020³. With thousands more patients waiting for cardiac diagnostic services, this could lead to more than half a million people with heart and circulatory disease waiting for NHS treatment.

Now, as the NHS charts a course for delivering care for heart failure patients in the context of Covid-19 and beyond, there is a unique opportunity to lay the foundation for more resilient services that are built around the needs of the patients they serve.

What is heart failure?

Heart failure is a complex clinical syndrome where the heart does not pump blood around the body as effectively as it should. Symptoms include breathlessness, fatigue and swelling, as a result of fluid retention. Heart failure more commonly develops gradually over time, but signs and symptoms can appear suddenly, with patients often experiencing several acute episodes leading to unplanned emergency hospital admissions, that lead to further deterioration of their health.

As a patient's condition progresses, it becomes increasingly difficult to remain active and perform day-to-day activities, with people requiring greater support as they approach the end of their life.

While there is currently no cure for heart failure, there are several proven treatments that, combined with lifestyle changes and holistic care and support, can allow many people with heart failure to live well for longer.

185,000

Number of people waiting for investigations or treatment in cardiology or cardiothoracic surgery in England at the end of July 2020

Heart failure in the UK

There are an estimated 920,000 people living with heart failure in the UK⁴. This represents a significant group of people living with a progressive long-term condition, many of whom require care and support to live well. Due to an ageing population and increased survival from acute cardiac events, such as heart attacks, the burden of heart failure in the UK is rising.

Heart failure is a common cause of unplanned hospital admissions in the UK - there are more than 100,000 hospital admissions each year where heart failure is the primary diagnosis, and admissions have risen by nearly a third in the past five years⁵. Admissions can occur for several reasons, with patients presenting with breathlessness, chest pain and significant fluid retention. When admitted, patients have a length of stay that is twice that of the average (10 days, compared to the 5-day average) and up to a quarter of patients are readmitted within 30 days of discharge⁶. More broadly, each year, there are 1.25 million hospital visits in England alone that include a heart failure diagnosis as the cause or contributing factor - that's 1 in every 18 visits⁷. Admissions for heart failure are largely preventable and are a significant financial burden on the NHS.

100,000

Number of hospital admissions in the UK each year where heart failure is the primary diagnosis

In current practice avoidable heart failure admissions appear commonplace, and around half of those diagnosed with heart failure in the UK die within five years of their diagnosis⁸.

As well as the significant impact of acute presentations, heart failure is also a long-term, chronic condition with wide-ranging implications for the health and quality of life of those affected. Around 80% of inpatients with heart failure in the UK are classed as having heart failure that is significantly or extremely life-limiting (New York Heart Association stage III or IV)⁹. People in these later stages of heart failure may struggle with simple tasks such as household chores or walking short distances.

People with heart failure often have complex care needs. An estimated 98% of those diagnosed in the UK live with at least one other long-term condition, such as diabetes or chronic obstructive pulmonary disease (COPD)¹⁰. Such conditions require regular review and support in a variety of settings, including through primary care and community services. People with heart failure also often need psychological and emotional support to live well with their condition, and the BHF has identified this as a significant unmet need amongst heart failure patients, with approximately a third describing feelings of anxiety and depression¹¹. It is important that support is provided right through until the end of life, with the progressive nature of heart failure requiring increasing amounts of care and support until the need for palliative care.

Though heart failure affects nearly one million people across the UK, diagnosed prevalence varies significantly across different regions. Contrary to popular belief, heart failure is not just a disease of the very old, and many people live with heart failure from an earlier age. While the average age of a UK heart failure patient is 75, this drops to 69 for people from Black and minority ethnic backgrounds. The average is in the low 60s for some cohorts, including the most socio-economically deprived¹².

Socio-economically deprived groups have also been shown to have consistently worse outcomes than the most affluent groups. They face a 20% higher risk of all-cause hospitalisation, even after adjustment for other factors. This inequality has persisted for over 20 years¹³.

Despite improvements in heart failure therapies over the past two decades, risk of mortality remains high amongst heart failure patients, with inequalities linked to characteristics including age, ethnicity, and gender, and details such as geographical location and socioeconomic status¹⁴. This variability in mortality can be attributed to a number of factors, including how quickly someone is diagnosed with heart failure and therefore the severity of their condition at diagnosis, the number of times they are readmitted to hospital, and whether they receive support following discharge from hospital. Access to important services, such as rehabilitation and other relevant recovery and support services in primary care and the community, also play a role. This is >

> partly due to a disconnect between acute and community-led services, and patients subsequently not being offered the services and support they need.

Although NICE guidance for the management of acute¹⁵ and chronic heart failure¹⁶ has been in place for over a decade, it has not been universally implemented, and heart failure services remain variable across the country. Upon admission to hospital, there is significant regional variation in the quality of care patients receive, with the percentage of patients seen by a specialist reported as 100% in some hospitals, but just 40% in others¹⁷. Specialist input during admission is key, as it increases the likelihood that patients receive the disease-modifying drugs they need, leading to reduced in-hospital and post-discharge mortality.

Variation is exhibited not only in hospital admissions but across the entire patient pathway, starting with diagnosis.

Symptom recognition and diagnosis

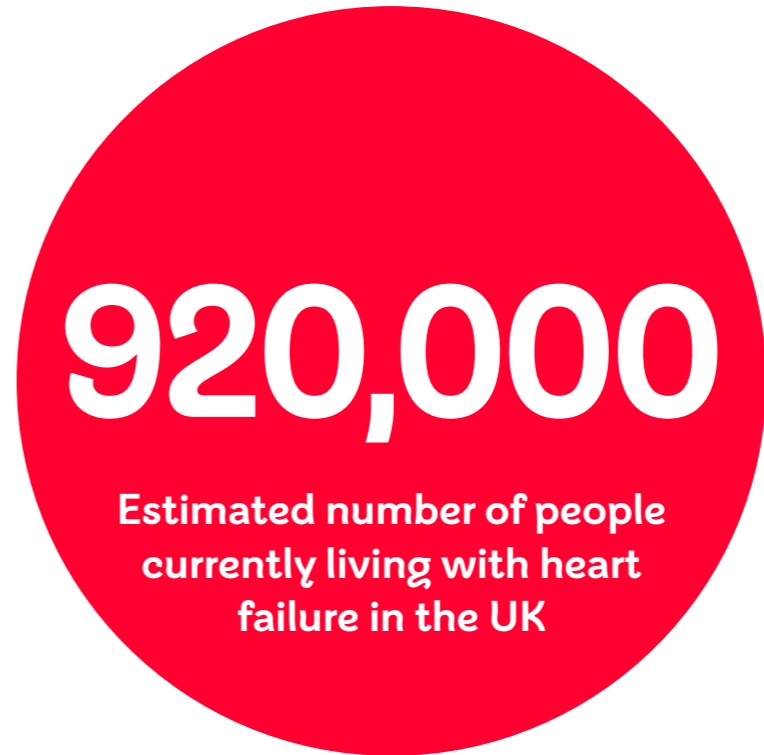
An early and accurate diagnosis that is properly recorded is critical to improving outcomes, as early intervention allows people with heart failure to live with a better quality of life for longer. Research suggests that although 40% of heart failure patients display symptoms that should trigger an assessment in primary care, as many as 80% of heart failure cases in England are diagnosed in hospital¹⁸. There are several reasons for this, including a continued inability for some services to access the necessary diagnostics in primary care and the community. Diagnosis in an emergency hospital setting, rather than in the community, can have devastating consequences. Research has shown that when patients are diagnosed with heart failure in an acute setting, they have significantly worse

outcomes and higher mortality rates¹⁹. This may be explained by a combination of factors including presentation in a medical crisis, delayed diagnosis, a higher burden of other long term conditions, and lower prescribing of first-line preventative medications, leading to more severe heart failure at the point of diagnosis.

Heart failure can be challenging to diagnose. Symptoms are variable and can be confused with those of other conditions, meaning it is easy for those without specialist expertise to miss the signs of heart failure²⁰. When symptoms are spotted, routine access to the necessary diagnostics is still not consistent across the country. Despite playing a critical role in the diagnosis of heart failure, and being a cost-effective test, NTproBNP testing is still not routinely available or appropriately used across primary and secondary care settings across the country.

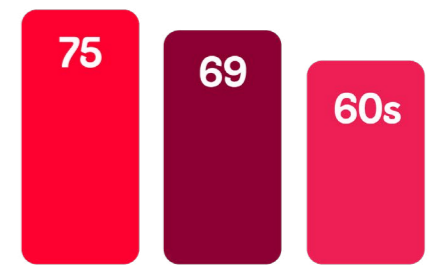
Following a test that confirms an elevated level of NTproBNP, patients should then be referred for an echocardiogram to confirm their diagnosis, its cause, and the extent of their condition.

Historic staffing shortages and variable access to echocardiography in primary care and the community add a further layer of complexity and variation to a patient's experience of diagnosis across the country. Despite the significant focus on improving early diagnosis of heart failure patients in the community, many people are still diagnosed late in sub-optimal settings. For those diagnosed as part of a hospital admission, the type of ward and access to specialist input are critical factors in their access to echocardiography. Patients admitted to cardiology wards are more likely to have echocardiography than those on general wards (95% vs 84%), with this rate dropping as low as (69%) for those on general wards with no access to specialist care²¹. >



98%

of UK heart failure patients are living with at least one other chronic (long term) condition



While the average age of a UK heart failure patient is 75, for patients from Black and minority ethnic backgrounds this drops to 69. For the most socioeconomically deprived, it drops to the early 60s

Every year there are around

200,000

new diagnoses of heart failure in the UK

In 2018/19 there were more than

100,000

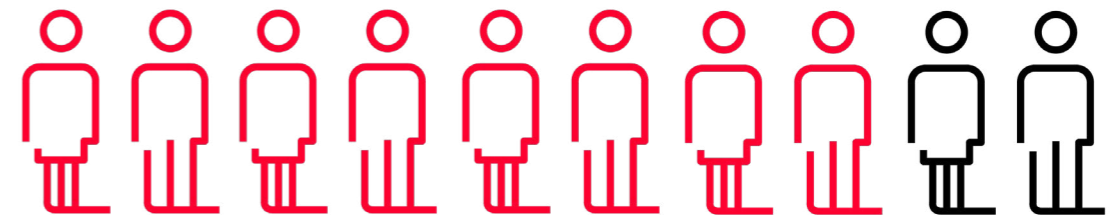
hospital admissions across the UK where heart failure was the primary diagnosis

The BHF estimates that at least

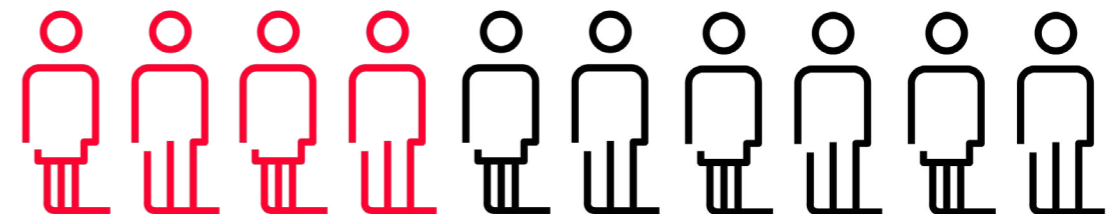
50,000

patients in the UK are discharged to the community each year with life-limiting heart failure

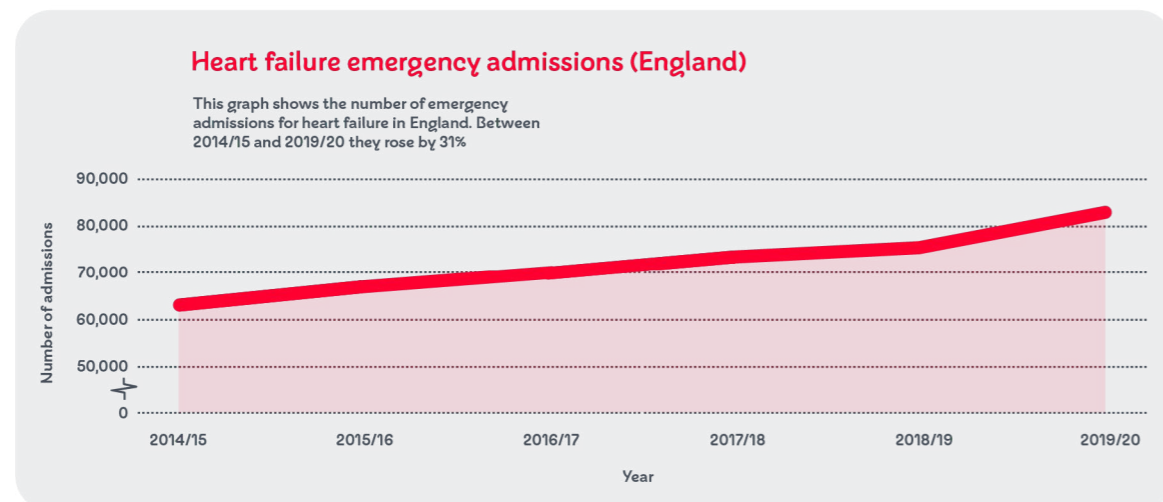
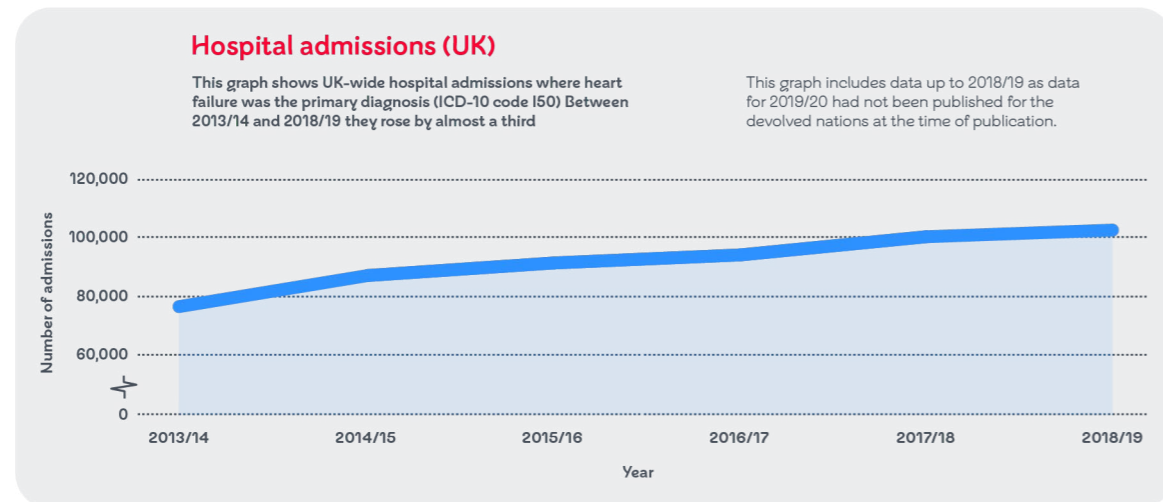
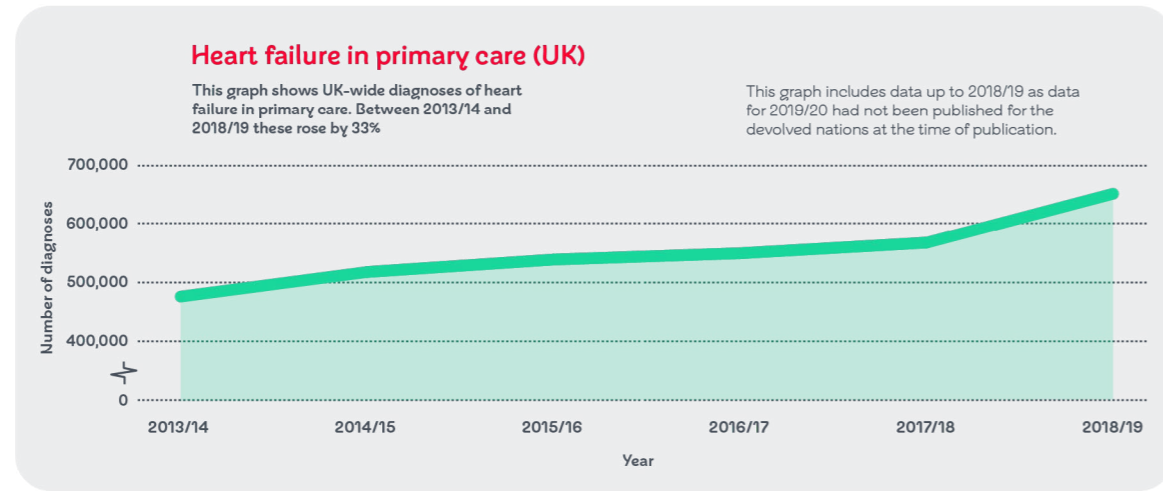
Around 8 in 10 heart failure diagnoses in England are made in hospital



But 4 in 10 have symptoms that should have triggered an earlier assessment



Heart failure in numbers



1 in 27

In England in 2012/13, 1 in 27 consultant episodes involved a patient with a heart failure diagnosis



1 in 18

By 2018/19, that number had risen to 1 in 18



Management of heart failure

Regardless of where a person is diagnosed, NICE guidance recommends that heart failure should be managed by a multidisciplinary team (MDT) with the relevant expertise for optimising medications, providing the necessary information about heart failure and its treatment to the patient, and referring the patient to other services such as rehabilitation and palliative care as appropriate. This service can be based in secondary care or the community, with primary care working with the MDT to regularly review patients as required, potentially as part of wider long-term condition reviews.

Variation in the quality of heart failure services across the country has led to significant variation in patient experiences and outcomes. Access to MDT-led care, as well as treatment and support through primary care, is important for helping patients understand their disease and avoid hospitalisation. The MDT should also act as a first port of call for patients to access the support they need during exacerbations of their condition that would otherwise lead to them presenting at hospital.

Unfortunately, we have a limited understanding of what happens to patients outside of the secondary care setting, due to a lack of readily available data. However, data from secondary care show that in 2017/18 only 37% of patients discharged from hospital in England and Wales were recorded as having relevant follow up with a member of the MDT within two weeks of discharge.

Of those admitted to hospital, only 15% of patients are referred to cardiac rehabilitation services at the point of discharge²². There are limited data available to understand whether patients are accessing this support through other channels, such as through referral to services from the community, or through relevant recovery and support services integrated into their local heart failure service. >

NTproBNP testing

The N-terminal proB-type natriuretic peptide (NTproBNP) test is used to measure the level of natriuretic peptides in the blood. These peptides are a type of hormone, and high levels can indicate that a person has heart failure. Testing allows healthcare professionals to rule out the possibility of heart failure in people for whom levels are normal. Testing can therefore be used to triage patients with suspected heart failure, and patients with elevated levels can be referred for echocardiography to confirm their diagnosis. NICE guidelines recommend measuring natriuretic peptide levels in patients with suspected heart failure whether this is done in a hospital or primary care.

Echocardiography

An echocardiogram is an ultrasound of the heart and is an essential step in confirming a heart failure diagnosis, as well as clarifying its cause and the extent of a person's condition. Echocardiography is recommended by NICE for those who have elevated levels of NTproBNP in their blood, and this test should be performed on high resolution equipment by a professional with the relevant expertise.

End-of-life care

While there are a number of treatments and a range of support options to help heart failure patients live longer and improve their quality of life, there is still no cure, and access to palliative care is a critical part of a heart failure patient's pathway. Conversations about end-of-life care should start as early as possible in a person's journey, increasing their chances of receiving the care they need and meeting their wishes at this critical time.

At the end of life, patients with heart failure and their family and friends should have access to professionals with palliative care skills as part of the MDT. However, very few people with heart failure are referred to palliative or hospice support, and people with heart failure remain disadvantaged when it comes to end-of-life care compared with

other conditions, such as cancer²³. This is partly due to the disease trajectory of heart failure. Many patients experience several acute episodes and then recover well. This means that end-of-life care decisions may be made late for many heart failure patients, limiting the time for advanced care planning and increasing the chances of professionals without access to the necessary palliative care skills delivering care at the end of patients' lives.

Research has shown that greater collaboration between cardiology and palliative care teams, as well as increasing the patient's own involvement in decision making, can improve patients' experience of palliative care²⁴. However, progress in these areas has been slow.

Joined up heart failure care The role of the multidisciplinary team

NICE recommends that heart failure patients should receive care delivered by a MDT in a way that is integrated across care settings. The core specialist heart failure team should include a lead physician with a subspecialty in heart failure, a specialist heart failure nurse, and a professional with expertise in prescribing for heart failure.

However, the MDTs can be broader than this, and include a number of allied health professions such as pharmacists, dieticians and physiotherapists responsible for addressing the holistic needs of the patient. The MDT is tasked with diagnosing heart failure and ensuring that patients receive the necessary information and support they need

to manage their condition and live well. The MDT also coordinates treatment for patients during exacerbations, optimises medications and supports patients whose heart failure is not responding to treatment. Importantly, the MDT plays a coordinating role for heart failure care, ensuring that the patient has an appropriate care plan and that the patient is referred to any services they need, whether that be cardiac rehabilitation, access to palliative care, or psychological support.

The MDT approach is vital not only for ensuring patients receive the treatment they need, but for coordinating care across a range of health and care settings that can be difficult for patients to navigate.

Sarah's story



Sarah developed heart failure after suffering a heart attack. She also lives with diabetes.

"I found out I had heart failure in a very unusual way. I was given a BHF book called *Everyday Guide to Living with Heart Failure* by a cardiac rehab nurse who told me it would be useful to read. I asked why she was giving this book to me, and she said, 'hasn't the consultant told you where you're at?' To be honest, I was taken a back a bit. I went into a bit of a head spin.

Heart failure has changed my life completely. I try not to let it rule my life or define me, but it kind of does. When I am overtired I can't speak or think properly. I can get emotional. I get very breathless. My condition has recently deteriorated quite a lot. I now spend many hours of the day asleep as even the smallest task exhausts me, including showering, which I'm ashamed to say I don't manage every day anymore. Though heart failure affects me in so many ways, it is such a hidden disability and few people seem to be aware of how debilitating it can be. People are surprised when they find out about my story because I look so well.

I live in a rural area, which can make accessing specialist heart failure services difficult. I get frustrated because I'm very isolated here where I live. There are no cardiac services, there are no specialists, and no heart failure resources – certainly not for somebody my age. Healthcare practitioners just don't understand it. They are used to dealing with much older people. They look at me and I look quite normal from the outside. Unfortunately, they just don't seem to understand that I'm still suffering that same way as someone much older."

The impact of Covid-19

The coronavirus pandemic has had a significant impact on people with heart and circulatory disease and the services they use, including those for heart failure. Research suggests that people with heart failure are at increased risk of mortality if infected with coronavirus²⁵. For this reason, many people with heart failure have been asked to shield by their healthcare professionals, and some have taken a personal decision to shield, with implications for their quality of life.

However, it is now becoming clear that the more significant impact of the coronavirus pandemic on people with heart failure may be indirect, through a reduced ability and confidence to access the care they need. During the pandemic, people with heart failure have experienced significant delays to their care as a result of the NHS adapting to the challenges of Covid-19. Redeployment of staff, combined with a need to maintain social distancing, has resulted in a significant amount of routine care and treatment being postponed. This includes routine appointments that allow review, opportunities for medication optimisation, and access to treatments such as diuretics to prevent exacerbations. This has not only led to delays in care for patients but also means there is now a backlog of care for systems to deal with as we move towards winter.

The number of echocardiograms conducted in England fell by 67% in April and May 2020 compared with February in the same year, with a continued reduction of 40% into June. As a result, many people are likely to receive a late diagnosis of heart failure in the future with

implications for their long-term health and quality of life. The fall in people presenting to hospitals with heart failure has been equally dramatic, dropping by 66% by the end of April and remaining around this level into May, according to data from NICOR²⁶. A decrease in admissions has also been shown across a number of hospitals as part of the Clinical Care for CVD in the Covid-19 (4C) emergency initiative²⁷. A collaboration between the BHF Data Science Centre and Health Data Research (HDR) UK is working with several participating hospitals across the UK to assess the unintended consequences of the coronavirus pandemic on specialist services for cardiovascular diseases. A lack of consistent and joined-up data across health and care settings makes it difficult to understand the complete picture of the care received by heart failure patients during the pandemic, underscoring the continued challenge in directing resources where needed. That being said, there is sufficient data to suggest that the health and care system should expect a large backlog in diagnosis and later presentation in the disease process.

There is also a concern that the impact of Covid-19 will lead to an increase in people living with heart failure, due to delayed access to routine care, the direct effects of Covid-19 illness and a result of late presentation of heart attacks. While there is some evidence that severe Covid-19 can lead to acute changes in heart function, determining the presence and degree of long-term effects on the heart will require greater research and understanding as the pandemic progresses. >

Reduction in Heart Failure admissions during Covid-19



Source: Clinical Care for CVD in the COVID-19 emergency initiative²⁷

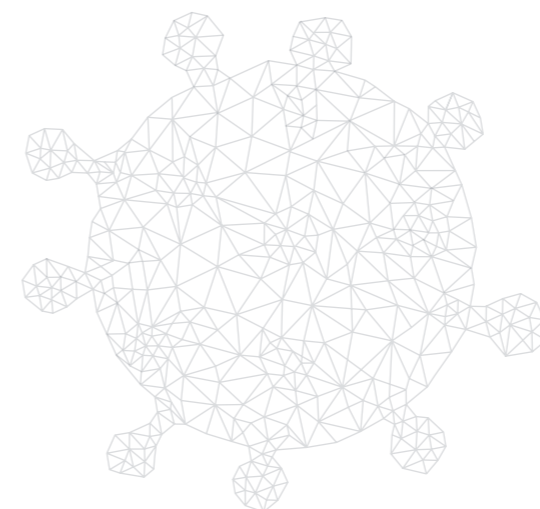
Heather's story

Heather is 72 and lives in rural Scotland. She lives with heart failure and several other heart and circulatory conditions including coronary heart disease, unstable angina, and atrial fibrillation. She also has a leaking mitral valve.

"I had an appointment with the consultant cardiologist in February. He examined me and said I needed an angiogram because he wasn't sure what was going on and needed more information. I was supposed to have one quite soon, but I'm now getting it on Friday [at the end of August] because everything was stopped.

I was told to shield in March, so have been isolating at my home in rural Scotland since then. I've had to keep in, not mixing with anybody. I got a phone call from hospital about two weeks ago to say when my appointment was going to be. Other than that, I am not getting any support at all.

I have found self-management difficult during the pandemic. I know I can phone the doctor if I am having trouble, but I don't want to. When my angina gets bad, and I've used the spray a certain amount of times, I am supposed to phone 999. But I don't want to go into hospital."



> At the peak of the pandemic, the BHF reported a 50% reduction in the number of people presenting at A&E in England with the symptoms of a heart attack, with many of those attending presenting later than they normally would²⁸. This pattern was seen all over the world, driven by a fear of accessing care and being a burden on already pressured systems. While presentation numbers have largely returned to normal, it is possible that this could lead to an increased prevalence of heart failure in the future, with very real implications for the NHS.

Due to a lack of coordinated data about heart failure services outside of secondary care, we have a limited understanding of the care that heart failure patients have accessed in primary and community settings. This has meant that a significant proportion of the heart failure community has been largely invisible to the system during the pandemic.



I go to a phase four cardiac rehab class, so I was meeting people in a similar situation. That stopped during Covid

David, focus group

In the absence of comprehensive community data, we must rely on qualitative insight from patients and practitioners who have described the impact of the coronavirus pandemic as significant and varied.

This variation has manifested in many ways, due to a complex mixture of changes in help-seeking behaviour, variable changes to heart failure services through redeployment, and from moving care online. The impact of the virus itself has also varied across the country not only at the peak, but in subsequent local resurgences and different regional approaches to surge planning for future outbreaks. This combination of reduced availability of services, as well as an increased fear of accessing care, has led to significant decreases in the support being provided to heart failure patients in many parts of the UK.

While some parts of the country lost heart failure services altogether due to redeployment of heart failure specialist teams to the initial Covid-19 response, others have maintained a skeleton service. This impact on services, combined with the continuing reduced capacity to deliver face-to-face care, has meant that many people with heart failure have struggled to access the support they need. A rapid move to supported self-management and digital-first approaches to care has been beneficial for some, but risks exacerbating inequalities in outcomes that existed before the pandemic.

At the peak of the pandemic, just one in four GP consultations took place face-to-face²⁹, with routine aspects of heart failure >

> care such as in-person blood pressure monitoring and blood tests deprioritised. While this approach has been beneficial for some, it has caused anxiety for many people with heart failure who need face-to-face support to manage their condition.

Work by the Health Foundation³⁰ and surveys conducted by the BHF have also shown that fear of contracting Covid-19, being a burden on the NHS, or breaking lockdown restrictions has been a significant factor in people with heart and circulatory disease choosing not to access care.

Cardiac rehabilitation services were also significantly depleted by the pandemic, with many services disappearing altogether and others moving online. Cardiac rehabilitation



“Contact with my GP has all been telephone or email. When it's a routine thing there are advantages to doing it on the phone. Less time is wasted. In some respects that is an improvement”

John, focus group

services offer a range of support to patients, including exercise to improve cardiac function, advice on living healthily, and psychological and peer support. Improving uptake of cardiac rehabilitation has been recognised as a key priority for the NHS Long Term Plan in England, with a recognised need to broaden the range of services available to patients, particularly those with heart failure. People with heart failure who had been referred to rehabilitation services described this as having a major positive impact on their wellbeing, with many people relying on services to help them exercise safely, and provide emotional support. Losing this support has impacted on many patients' confidence to remain healthy during the coronavirus pandemic with the potential for long term consequences.

Access to palliative care for heart failure has also been severely disrupted by the coronavirus pandemic, and significant numbers of opportunities for healthcare professionals to recognise that patients are reaching the end of life have been missed. The number of excess deaths at home and in care homes suggest that people are missing out on the end-of-life care they need and deserve where community services have not been available³¹, but the data to fully understand the impact on heart failure patients is limited.

The coronavirus pandemic has exacerbated existing variations in services, and even as services are starting to be restored, many people remain unable to access the care they need. It is critical that the Government and NHS act now to fully understand the impact of coronavirus pandemic on patients and take action to restore the full breadth of safely accessible services.

Laurence's story

Laurence is 66 years old and lives in Central London. He has atrial fibrillation and was diagnosed with heart valve disease following a heart attack six years ago. He has had surgery twice to repair and replace the affected valves and was then fitted with a pacemaker three years ago. He was subsequently diagnosed with heart failure.

“Since being diagnosed with heart failure I have been careful to manage my medicine and exercise routine. But it's the first thing that tips you over the edge. The minute you get an infection your water retention goes up, your lungs fill up, and you have to be ultra-careful. So Covid-19 is quite scary.

During the pandemic I have not had any blood tests which is slightly concerning because I'm used to having blood tests every six months or so just to make sure I'm keeping well and that the medication I take is not doing me any long-term harm. I have had a pacemaker check during the pandemic. I have not been to see my GP, but I use the GP online for ordering medicine, and that's been working extremely well – from the NHS straight to the pharmacy. I have had one telephone appointment and my local GP was brilliant. Other than that, my interaction with the medical profession has been minimal.

I am worried that my condition might make me less likely to receive treatment if hospitals are put under severe pressure again, so Covid really frightens me.”

The future of heart failure

A blueprint for change

As the NHS and health and care system comes to terms with the continued impact of the coronavirus pandemic and work to restore services, there is a window of opportunity to build back better than before. Through analysing a wide array of insight collected before and during the pandemic, we have identified key issues and opportunities that need to be addressed to lay the foundations for joined up person-centred heart failure services. These include:

- 1 Focusing on people, not structures
- 2 Reframing heart failure as a long-term condition
- 3 Driving change with data
- 4 Leading across the pathway

1 Focus

2 Framing

3 Data

4 Direction



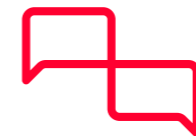
Focusing on people, not structures

The role of the specialist, and the relationship between primary, community and acute settings, are key to ensuring heart failure patients receive care tailored to their individual needs and circumstances. However, we do not see this consistently across the country, with services being available based on how they fit into the local system rather than the needs of the patients they serve.

Over time this has led to disjointed services and considerable variation in access to heart failure care across the pathway, as well as a lack of communication between care settings.

Better joining up of care and working across settings is a core ambition of the NHS Long Term Plan in England, as well as health and care strategies across the rest of the UK. This requires complex changes to the way that services are delivered, with a greater focus on multimorbidity and a whole pathway approach to understanding and addressing people's needs. While the integration of care represents a significant challenge, it is a vital step in improving services for heart failure that meet a wider range of needs.

Prior to the coronavirus pandemic, a BHF survey revealed that many heart failure patients have significant unmet needs relating to the psychological and emotional wellbeing (Table 1), as well as a need for support in returning to exercise and for activities around the home. There is a need for broader support for people with heart failure so they can live well. >

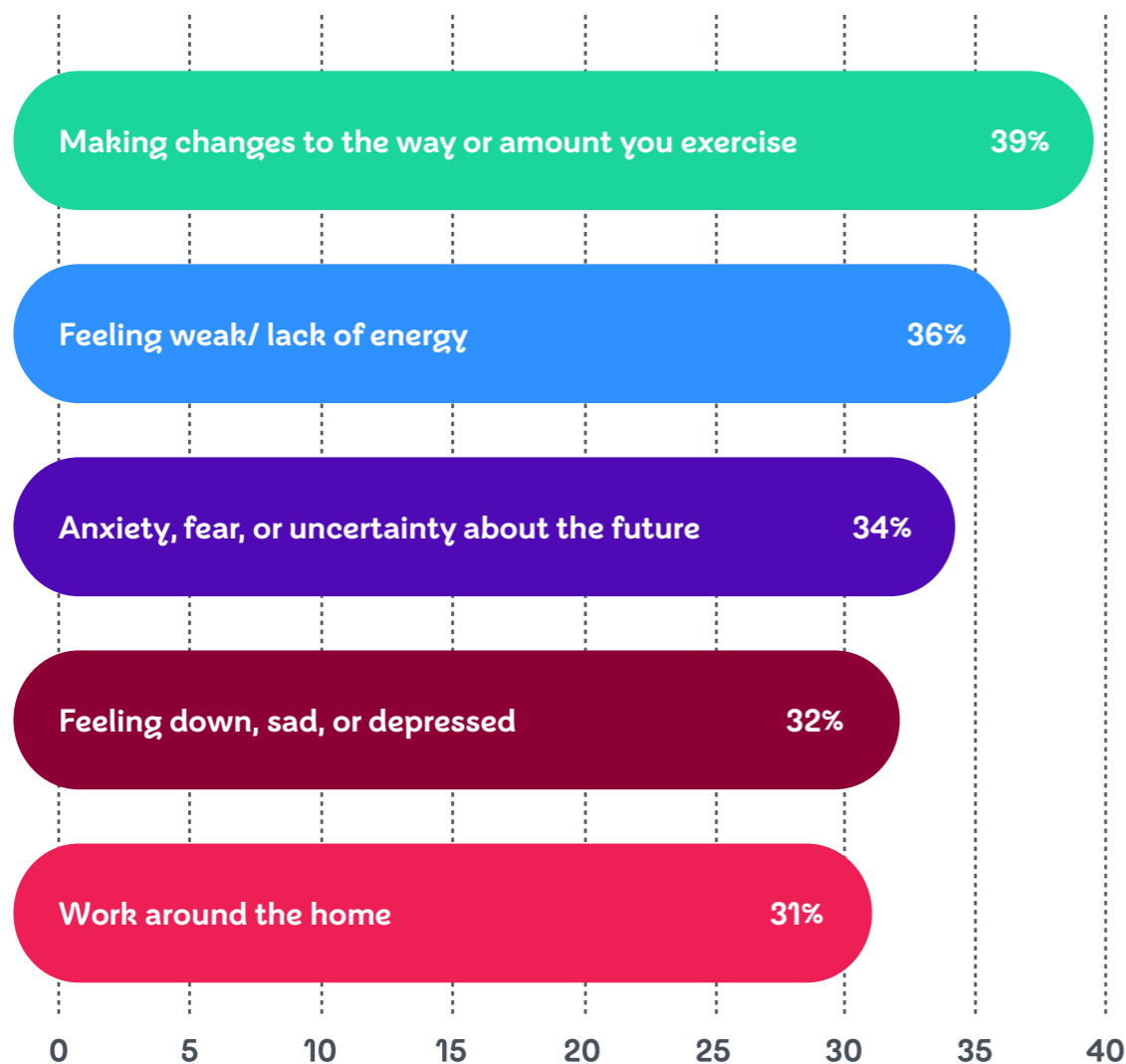


“ To be told it's natural to feel like that. Maybe a heart failure counsellor with some knowledge on how you will be affected, and I know it all depends on money but to be put in touch with someone who understands

Heart failure patient, online survey

The biggest challenges for heart failure patients

Table 1
The top 5 challenges for those with Heart Failure
 Ranked by percentage of responses indicating that they experience that challenge and have a high to moderate need for help. Number of respondents as a percentage indicating a high or moderate need is displayed.



Psychological and Emotional Support

The prevalence of depression in heart failure patients in the UK is estimated to be around 29%³², and is higher still (37%) for those of working age³³. This is higher than the prevalence of depression in the general adult population³⁴, and is likely due in part to the loss of normal physical function common in heart failure, as well as the impact of the condition on relationships and income³⁵. Studies have shown the prevalence of depressive disorders is higher still in inpatient settings (up to 70%)³⁶. Generalised and specific anxiety relating to heart failure are common, covering a range of issues from anxiety about overexertion to a fear of dying while asleep. People told us that the term 'heart failure' can lead to anxiety for patients. Though the psychological impact of heart failure is widely recognised, clinical research in this space is under-developed and largely out of date. More work is needed to better outline the needs of patients and ensure they get the right support at the right time.

The relentless and progressive nature of heart failure can affect how people feel, and struggling emotionally can make it more difficult for them to self-manage their condition and deal with the burden of appointments. This can be particularly pronounced for people living with multiple conditions³⁷. Poor emotional health can lead to deterioration in the patient's physical health - emergency admission rates for heart failure patients with depression are two to three times higher than those without³⁸.

A number of people told us about the importance of maintaining psychological wellbeing in controlling their heart failure, and some reported that the impact of the coronavirus pandemic has made this more difficult, with the existing uncertainty around their condition now exacerbated by the additional uncertainty of when they will be able to access routine care. >



“ People need support groups, and they need contact. To know they're not alone fighting this. As much as it's your heart that's the problem, it's your head that's dealing with it and that needs so much support as well

Margaret, focus group

> For some, anxiety around their condition was more to do with the effect it had on those around them rather than the impact of the disease on their own health. Some people with heart failure feel the need to protect their close relatives and friends from the impact of their condition, meaning they often try and hide their concerns.

Those who were receiving psychological support often described a particularly good relationship with a healthcare professional such as a Heart Failure Specialist Nurse or GP. Others often felt that they were only able to discuss their physical condition, and expressed a desire for psychological support from a person with specific knowledge of heart failure. This need is echoed amongst other long-term conditions, such as diabetes³⁹, highlighting a need for better integration of physical and mental health services across long-term conditions more generally.

This all points to a need for psychological support to be more easily accessible for heart failure patients, whether that is through referral to mental health services or support provided through members of the MDT, cardiac rehabilitation programmes or peer support groups. A number of people described how the coronavirus pandemic had removed, changed or decreased their access to this kind of support, with support groups and rehabilitation sessions ending due to social distancing or moving onto online formats.

Improving access to cardiac rehabilitation

Support provided through rehabilitation includes physical exercise to improve cardiac function, optimisation of medications, and information and support for people to make positive lifestyle changes. Rehabilitation services can also provide an opportunity for people to access the psychological and emotional support they need to cope with the wider impacts of heart failure.

Heart failure patients frequently reported a fear of getting back into exercise, and rehabilitation services offer a safe space in which to do this.

People who attended rehabilitation services told us that they played a role in rebuilding their confidence after their diagnosis, but acknowledged that more could be done to promote overall wellbeing.

Unfortunately, uptake of cardiac rehabilitation among eligible people with heart and circulatory disease remains low (50%) and variable across the country, with lower uptake among women, people from ethnic minority backgrounds, and socio-economically deprived communities⁴⁰. This rate is significantly lower for heart failure patients, with only 15% of heart failure inpatients referred to rehabilitation services. This percentage drops to only 9% for heart failure patients treated on a general ward in hospital, as opposed to 22% for those in cardiology wards⁴¹. Some cardiac rehabilitation services do not accept heart failure patients unless they have also experienced a heart attack or had a recent procedure, meaning access to rehabilitation services for heart failure patients can be very challenging.

The proportion of cardiac rehabilitation services with a psychologist is also very low, with only one in three services having a psychologist or counsellor as part of the team⁴². Patients can therefore face a postcode lottery both >

Maya's story



Maya is 53 and lives in Essex. She was diagnosed with heart failure eleven years ago following a heart attack which resulted in a cardiac arrest. She also has a left ventricular aneurysm.

“I’m sure of the fact that our emotions do affect our hearts. I can see the correlation, so I have been very aware of how my emotions affect my heart. I was recently bereaved, and during the grief period the heart failure was horrible. I couldn’t do anything – I just lay in bed.

I find with heart failure there is an increased anxiety and fear that comes along with my day-to-day experience. I’ve done a lot of work trying to find ways to use mind-body techniques to manage my emotions. I try hard to balance the physical needs of the body with the emotional needs. I need to balance things out and maintain low levels of stress and manage my emotions. That way I manage to keep well, and the heart failure is stable. I believe that’s made the difference”.

Lisa's story



Lisa was diagnosed with lupus (systemic lupus erythematosus) at 16 and has since suffered several different complications. She had two heart attacks and was diagnosed with heart failure in 2011. She also has a leaking heart valve. Lisa has worked in the NHS for over 20 years and is currently working as a Senior Operational Manager.

“I had very good input at rehab classes and an amazing nurse, but after those ended, I was just left alone to get on with it. I came out of rehab, knowing my maximum heart rate I shouldn't go above when exercising and that was fine, but there were other things I wasn't sure about and there are danger points with that.

Even though I'm now considered to be an established heart failure person there are still times when I'm not quite sure what I should be doing. When I'm having a bit of a worry, or if I have a question, there is nobody at the end of the line I can contact at the hospital. It's just a bit of assurance that's lacking. If I had someone I can contact when I have a concern, that would ease my worries.

We are all patients, but we're humans as well, and we need that continuous interaction. My nephew once stated “if you're dying, they can save you, but once they've saved you, you're on your own”. But afterwards we still need that help. I suppose it's the preventative side that's missing. What can we do to help ourselves as much as possible? It's great having a leaflet and generic help with exercise and diet, but you need more information that's personal to you. After my diagnosis my first question was: how does someone at 32 go back to work after heart surgery? And the information wasn't there.

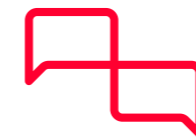
It is about that ongoing support, that recognition that we're with hospitals for life until we kick the bucket. That ongoing support needs to be there.”

> for the availability of rehabilitation services, but also for finding avenues to meet their psychological support needs as part of rehabilitation. This has now been exacerbated by many cardiac rehabilitation services stopping or moving online as a result of the coronavirus pandemic.

Unfortunately, we do not have reliable data telling us how many people with heart failure are referred to rehabilitation services from the community and primary care, and how many of those referred engage in services. It is also likely that some heart failure patients access some form of rehabilitation through their specialist heart failure service rather than being referred to a separate service.

Regardless of how patients access this care, there is a clear need for a more personalised offer. Patients should be able to access the components that make up rehabilitation services in a way and at a time that is suitable for them. This could be through traditional programmes, or through accessing resources in the community that provide alternative options for physical activity and access to peer support. Understanding the barriers and opportunities to reimagining recovery and support services for people with heart and circulatory disease continues to be a priority both for the BHF and the NHS.

With innovations in service delivery such as the REACH-HF facilitated home-based rehabilitation approach^{43,44}, there is potential to improve the number of heart failure patients accessing services. This is a step in the right direction, but a range of models are needed to address the broad needs of people with heart failure. To ensure that heart failure patients are still able to benefit from this approach to rehabilitation, the BHF, as part of our Hope for Hearts Fund, is supporting the development of a digital version of the programme for people to access more easily at home during this time. >



“**I've improved but if I hadn't known what I was doing, and if I hadn't had a reasonable idea about how hard I could push myself and how I could go about doing my rehab that I've done, I'd probably still be sat in a corner on the settee watching the telly, hardly able to move**

Heart failure patient, interview

Better palliative care for heart failure patients

Despite a range of treatments and support options for people with heart failure, there is still no cure. Palliative care is therefore a vital component of a heart failure patient's journey, and when delivered properly can allow people with heart failure to have as much control as possible over the end of their life.

Unfortunately, compared with cancer patients, people with heart failure have been shown to have less understanding of their illness, and have less access to support and palliative care towards the end of their life⁴⁵. Many people with heart failure die in hospital while receiving interventions they may not have wanted if they had the opportunity of advanced care planning. This not only prevents many people with heart failure from dying in an environment of their choice, but also causes significant distress for their loved ones.

The disease trajectory of heart failure can be complicated, with many people experiencing several acute episodes and recovering well. It can be challenging to know when to refer patients for palliative care, and many health and care professionals do not have the necessary communication skills and confidence to have end-of-life conversations with patients. As a result, very few people with heart failure are referred to palliative or hospice support by their primary care or hospital cardiology teams. Though there are examples of good practice across the UK, people with heart failure remain disadvantaged compared to people with other diseases when it comes to end-of-life care.

The BHF has previously worked with Marie Curie and NHS Greater Glasgow and Clyde to improve the quality of palliative care for patients with end-stage heart failure. By developing services in conjunction with their users to deliver a shared approach to palliative care, the programme improved symptoms and quality of life for service users, provided better individual planning for patients' end-of-life care, and reduced hospital admission and healthcare costs⁴⁶.

However, access to vital end-of-life care and advanced care planning are still variable across the country. The coronavirus pandemic has led to a significant increase in the number of people with heart and circulatory disease dying at home⁴⁷, and we have little or no understanding of the support these people were able to access.

The coronavirus pandemic has seen many areas working better across settings, collaborating in new ways and delivering new models of care. As the system looks to restore normal levels of service, now is the time to ensure that heart failure services for the future are joined-up services that meet people's needs. Getting this right for heart failure can work as a model for improving the treatment and management of a range of other, often comorbid, long-term conditions.



Recommendations

- **NHSE/I, and devolved-nation equivalents, should prioritise a full pathway approach to improving heart failure services – resourcing systems and holding them accountable to understand and improve their whole service from diagnosis through to end-of-life care, instead of focusing on individual parts of the pathway.**
- **ICs and their equivalents in the devolved nations should employ heart failure pathfinders to help services to understand the full patient pathway and population health and advise them on how to join up services in their area to support heart failure patients.** This should inform commissioning of heart failure services that span care settings and include routine access to NTproBNP testing and echocardiography, referral to rehabilitation, psychological support and palliative care services as standard.
- **HEE, and its devolved-nation equivalents, should develop training programmes that enable healthcare professionals to better support the psychological and emotional needs of people with heart failure and their loved ones from diagnosis through to the end of life.** This should include the importance of having early conversations about end-of-life care and the use of advanced care planning.



Hope for Hearts Fund REACH-HF

The Rehabilitation Enablement in Chronic Heart Failure (REACH-HF) intervention is an evidence-based cardiac rehabilitation programme for patients with heart failure that has been shown to be both clinically and cost effective. The programme comprises four elements: a patient symptom checker and exercise manual, a patient progress tracker, a family and friends' resource, and support from health professionals.

The Hope for Hearts fund will support the digitisation of the core programme, to enable it to be tested and then delivered to a wider audience and extend the reach of rehabilitation programmes to people with heart failure. It aims to produce structured and easy-to-navigate information, with patient and clinician-delivered summary videos for key sections, interactive elements with self-assessment of sleep quality, stress and anxiety, and an online 7-level progressive exercise training programme. The exercise programme includes video demonstrations of the required exercises and interactive tools allowing progress-tracking and feedback that can be shared with health care professionals.

This work will make rehabilitation more accessible to the relevant cohort of heart failure patients while face-to-face options are still unavailable.

John's story



John is 73 years old and lives in a small village in Hertfordshire. He has had three heart attacks and also has atrial fibrillation. He was diagnosed with heart failure around seven years ago but is relatively symptom free.

"I fully retired eight years ago, and then seven years ago I was diagnosed with heart failure which was an accumulation of all the things that had gone before.

I'm not generally an anxious person, but I have suffered with stress over the years, particularly in relation to my work, which led to my initial cardiac diagnosis of angina twenty years ago. I joined the local BHF cardiac support group, and that really helped. It's not formal psychotherapy, but the effect is the same. It's informal – you all share common problems. I think that's very therapeutic. I also sing a lot in choirs, it's very beneficial physically and emotionally. A lot of potentially stressful emotion gets out of your system partly through that, as it's so expressive. With the impact of Covid, of course these activities have been curtailed, sadly.

In many respects it's worse for the family who are observing. Nobody can really relieve their heightened anxiety and fear. I think my wife is more worried about my heart failure than I am. I think that I know my physical capabilities, but she often doubts that. So the prospect, say, of having to mow the lawn creates more anxiety in my wife than in me."

2

Reframing heart failure as a long-term condition

Heat failure is a long term, manageable condition, just as diabetes and dementia are. However, it is rarely perceived in that way. The limitations of heart failure awareness were recently highlighted in work by Astra Zeneca and the World Heart Federation which showed that 52% of the general public in the UK could not recognise a correct description of heart failure, and only 12% know that half of those diagnosed with heart failure currently die within five years of their diagnosis⁴⁸.

Importantly, this lack of awareness also extends to policy makers with the power to drive changes in heart failure care, with two-thirds agreeing that there is a need to reduce hospital admissions in the UK but only 13% of them recognising that heart failure is amongst the leading causes of avoidable hospitalisations in the UK⁴⁹.

Similarly, many health and care professionals also lack awareness. Significant numbers of people with heart failure describe returning to their GP with symptoms multiple times before receiving an accurate diagnosis. This is due in part to the fact that the signs and symptoms of heart failure are not unique, and people presenting with heart failure often have comorbidities. Without an awareness of heart failure, it can be easy for the symptoms of heart failure to be misdiagnosed or overlooked. For instance, breathlessness and fatigue are symptoms of heart failure common to many other conditions.

One in five patients with heart failure presenting at hospital also have COPD⁵⁰. Research funded by the BHF has shown that among people diagnosed with heart failure, those who also had COPD experienced the longest lag from onset of symptoms to diagnosis – on average 1,189 days, over a third longer than those without COPD (888 days)⁵¹. Better training for generalist health and care professionals to meet the challenge of an ageing population and increasing burden of long-term conditions will be vital in order to identify and manage the signs and symptoms of heart failure now and in the future.

This includes improving awareness of the risk factors of, and signs and symptoms of heart failure, creating a culture to drive heart failure diagnosis, but also awareness and accessibility of the key diagnostics for healthcare professionals to confirm a patient has heart failure. Healthcare professionals need routine access to NTproBNP testing in the community and hospitals, followed by rapid referral to echocardiography and a health professional with the necessary expertise to provide an accurate diagnosis. In areas with robust systems for identifying, referring and supporting patients in primary care, this has led to improved outcomes for patients both in terms of mortality and number of admissions.

An understanding of heart failure beyond symptom recognition and diagnosis is also important for improving care for heart failure patients. While specialist care is vital, the progressive nature of heart failure means there is a role for the wider health and care system, particularly in primary care and the community, to optimise therapies and understand and identify the early signs of deterioration in heart failure patients. Early identification of issues such as increased tiredness, weight gain, breathlessness and a reduced ability to cope can help patients get the support and specialist care they need to prevent future admissions. >

> Even within hospitals, there are differing levels of awareness. Rates of in-hospital and post-discharge mortality are significantly lower for those admitted to cardiology wards than those on general wards⁵². In such cases, access to specialist input remains vital, leading to an increased likelihood of referral to an MDT and a subsequent reduction in mortality and readmission.

This is particularly important in the context of the coronavirus pandemic, where an inability or lack of confidence to access care has meant many generalist healthcare professionals are increasingly supporting patients with complex needs, often remotely. Recent initiatives, including the formation of PCNs and the Additional Role Reimbursement Scheme (ARRS) in England, as well as the formation of community diagnostic hubs will bolster community and primary care services and offer an opportunity to approach heart failure care in new ways. New roles and networked ways of working can be used to improve awareness of heart failure across disciplinary boundaries and will allow services to use resources innovatively to address patient needs. There is no single or prescribed solution, and what this means in practice will vary across the country, but it is vital that local services are tailored to meet the specific needs of their heart failure community.

As services are restored across the UK, local systems should work to understand how they can best use staff to address the needs of people with heart failure, while maintaining core specialist services for future surges in Covid-19.

Recommendations

- HEE and relevant bodies in the devolved nations should offer enhanced education and quality improvement skills to generalist health and care professionals to effectively and sustainably recognise, diagnose, code and manage heart failure. This should focus particularly on roles in primary care and community settings as well as those most likely to encounter heart failure patients presenting at A&E or in relevant specialities, including diabetic clinics.
- HEE and equivalent organisations across the UK should work with the BSH, Skills for Care and organisations such as PCCS to define and map the competencies required to manage heart failure across the pathway and use this to inform training for professionals. Local systems should then use these to map the competencies of their staff across the full pathway and identify ways of best using teams to address the needs of heart failure patients.

“
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The Darlington integrated heart failure service model

The Darlington Integrated Heart Failure model is a joint venture between primary and secondary care. Led by Prof Ahmet Fuat and Professor Jerry Murphy, the area set up the UK's first one stop clinic run by a GP with specialist interest and a specialist nurse in January 2002.

GPs and nurses across all 11 Darlington CCG/PCN practices were trained in heart failure diagnosis and management. As part of long term condition clinics, these GPs and nurses now pro-actively ask patients about symptoms of possible heart failure in patients with conditions predisposing them to the condition, including hypertension, coronary heart disease, diabetes, stroke, COPD, and chronic kidney disease. CVD Lead clinicians in all 11 practices were given extra training, and if heart failure symptoms presented, they had access to BNP testing to guide the need for echocardiography and referral to the one stop diagnostic clinic. Between 2013 and 2017, 59 to 79% of patients referred annually were confirmed as having heart failure, much higher than published rates referred to heart failure clinics.

GP practices were also provided with technology that enabled real time interrogation of patient records to identify patients with heart failure that may not have been coded properly, investigated, and as to whether or not they had been offered evidence-based treatments. Giving a more accurate picture of prevalence and improving treatment.

Latest data show that Darlington has one of the highest diagnosed prevalence rates for heart failure in the country⁵³ but has one of the lowest rate of admission to hospital for the condition⁵⁴, at 105 per 100,000 population, considerably lower than the England average (160), while also having one of the lowest mortality rates for heart failure in the region.

Margaret's story

Margaret is 61 and lives in the Wirral. She was diagnosed with idiopathic cardiomyopathy when she was 38 and is currently living with heart failure.

"I spent years trying to find out why I was tired. I was always very tired and used to faint a lot. I went to the doctor God knows how many times saying 'I'm tired', to be told 'well what do you expect, you're teaching full time with two young children, of course you're tired'. I can remember standing in front of the mirror with dark circles and every part of my body screaming with aches and pains.

My periods were heavy, and everything was blamed on that. I was put on the pill and that helped a little bit, but I still didn't feel well. I thought I was a hypochondriac. I thought it must all be in my head. It went on for years.

During a routine procedure for another health condition, the medical team discovered that I had cardiomyopathy and diagnosed me with heart failure. They said the left side of my heart was like that of a 70-year-old, but I was only 38."

3

Driving change with data

Services across the UK often described how a lack of reliable, comprehensive, whole pathway data is a significant barrier to improving heart failure services.

Currently, the only nationally available mandated dataset for heart failure is the Heart Failure Audit managed by NICOR. The audit contains data collected about heart failure patients admitted to hospital in England and Wales. NICOR data includes trends in symptoms and demographics, as well as data relating to patients' access to diagnostics, specialist input to their treatment and the types of treatment they are prescribed. The audit also provides data on mortality both in hospital and post-discharge. However, this information is not linked to primary and community data. Local systems currently struggle to get their own data back out of the audit, making it more useful for describing the national picture than informing local improvements. In addition, data is currently published annually which results in a lag between establishing and acting on findings, an issue that has clearly been highlighted by the coronavirus pandemic. >



Kent Surrey Sussex Heart failure dashboard

The Kent Surrey Sussex Academic Health Science Network heart failure dashboard for acute and community services is a good example of data that is routinely published and discussed to support and encourage improvement. A product of a local collaborative of the specialist heart failure teams, the two dashboards are updated monthly, providing a means for teams and commissioners to measure changes in care quality and a benchmark for the 16 hospitals and 13 community services across the region.

The acute dashboard is aligned to the national heart failure audit data collection for the quality measures, includes detail from HES for length of stay, mortality, and readmissions as outcome measures, and aligns each trust to the Best Practice Tariff. The community data is a new dataset created locally that captures two key measures of medication and waiting times.

The reports enable commissioners and providers to examine and understand how they can deliver better care and outcomes for people with heart failure and address the considerable variation that is often exposed. In the first six years of implementation, the top performing trusts reduced length of stay by just over half a day, equating to potential spare capacity of 452 bed days. The three trusts that saw the biggest improvements in mortality saved proportionally 35 more lives combined against baseline.

> While the Heart Failure Audit provides value in understanding the experience of heart failure patients when admitted to and discharged from hospital, it tells us very little about heart failure patients' interactions with other parts of the health and care system, including the extensive amount of care and support provided by heart failure specialists and generalists in the community and primary care.

Data held locally in primary care and community services, including that available from the Quality and Outcomes Framework (QOF), go some way to helping us build a picture of heart failure outside of secondary care, but significant gaps remain, particularly in the community and in measures of patients' experience of care. Recent improvements in data linkage across whole patient pathways have provided some new insight, but these examples tend to be highly localised and do not always provide a whole system picture.

People working in heart failure services also expressed a lack of confidence that the heart failure data that is routinely available is accurate. This all means that data is not informing and driving improvement in ongoing heart failure care after hospital admission. Without improving the collection and sharing of data, it is almost impossible for the system to have a clear picture of heart failure care across the country, and the impact of changes to models of care.

However, collecting and joining up data is just the start. A culture of regularly accessing and using data for more than performance management is vital to driving improvements in care. To build this culture, we need widespread understanding of data analysis, as well as analysts to communicate and visualise data in a way that is useful to those designing and commissioning services.

The onset of the coronavirus pandemic has shown just how problematic this lack of readily available, comprehensive heart failure data is. It has been difficult for the system to truly understand the impact of the pandemic on heart failure services and patients. A more comprehensive view of heart failure patients' interactions with health and care services could have gone some way to helping GPs identify and support those most in need during lockdown and those who needed to shield. Stronger data could also have highlighted professionals and services in the community that are particularly important for supporting people to stay out of hospital. Such data could play a role in deciding which services to protect from redeployment in future surges of Covid-19, protecting heart failure patients from the indirect consequences of the pandemic.

Though data are now emerging about reductions in admissions to hospital and missed appointments, we still have a limited view of how many people are currently in the community with unmanaged heart failure. We also note that there are limited ways of measuring the impact of adaptive measures taken during this time. As well as building systems for better collection and sharing of data in the future, there is a vital need to quickly understand the true impact of the pandemic on heart failure patients across the UK.

Despite this, there are examples of systems using existing available data well, to better understand their population and to help systems design heart >



Heart Failure Pathways Imperial College Health Partners and the BHF

The BHF worked with Imperial College Health Partners to examine the health and care interactions of patients before and after diagnosis of heart failure. Research suggests that 80% of heart failure patients are diagnosed in hospital, despite 40% having symptoms that should have triggered an earlier assessment. However, there is much we do not know about the pathway patients take before this point of diagnosis, and what happens afterwards.

The study involved analysing a cohort of patients in North West London (NWL) with a first diagnosis of heart failure in 2017/18, from the Whole Systems Integrated Care (WSIC) dataset that covers NWL, providing data on primary and secondary care. Whilst this cohort does not cover the whole of the UK, it is a sizable sample (2.4 million patients) and has wide demographic diversity. Findings from this analysis helped with understanding the experience of people with heart failure both leading to and following their diagnosis across health and care settings, and will help inform future questions to ask of joined up data sets. For instance, analysis of the data revealed that amongst this group of heart failure patients' symptoms of anxiety and depression were common prior to diagnosis, alongside a range of physical issues such as hypertension and diabetes. The data also revealed that 67% of heart failure patients experienced an A&E admission prior to their diagnosis, with negative implications for their future mortality.

By joining up data in this way and better understanding patient journeys, we can better design services to meet their needs. This approach to data ultimately allows for early intervention that maximises the chances of a longer better-quality life for people with heart failure.

> failure services. Initiatives that join up data across settings are helping us to better understand the experience of people with heart failure both before and after their diagnosis, and a more universal approach to this could lead to marked improvements in services in the future. With community services and primary care playing an increasingly important role in the management of heart failure patients, and an increasing move towards more remote self-management, it is imperative that we join up data better and make it freely available to those best placed to use it to improve people's care.

Recommendations

- NHSX should collaborate with others to accelerate the joining up of heart failure data across settings, identify gaps and develop a comprehensive data set that is accessible and useable for clinicians in a timely manner. This should include comprehensive demographic data to understand inequalities in access to care and equity of healthcare outcomes, as well as better reflecting citizens' experience of care. To progress this, NHSX should establish a working group with NHSE/I, BSH, the British Cardiovascular Society (BCS) and National Institute for Cardiovascular Outcomes Research (NICOR), the BHF Data Science Centre and other relevant partners.
- NICOR should work with stakeholders to review the Heart Failure Audit and make changes to allow it to realise its full potential to contribute to quality improvement of heart failure services across the UK. To achieve this, NICOR should work closely with partner organisations to expand the range of data collected to include primary and community care and to allow clinicians and system leaders to better access analysis of their own data in a timely fashion.
- UK governments and the NHS should work rapidly to identify and bring together data to understand the impact that the coronavirus pandemic has had on heart failure services to rapidly inform care of patients who have been affected by Covid-19, as well as the restoration of Covid-resilient services and future redeployment of staff.
- National audits and local data collection must be appropriately resourced to allow health system leaders to make evidence-based decisions. To achieve this, national audits should be adequately resourced to work with partner organisations to expand the range of data collected to include primary and community care and to allow clinicians and system leaders to better access analysis of their own data in a timely fashion. Local systems should be allocated funding for analysts, clinical leads, project managers and training for clinicians to optimise the use of existing data in their area to understand their heart failure population, supporting them to design services to meet their needs.

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4p

Leading across the pathway

The landscape of heart failure care is complex, with services commissioned across multiple settings and patients accessing a myriad of services both for their physical and psychological needs. Understanding these services and the data that represents them requires a significant commitment of both time and resource. It also relies on establishing leaders who are willing and able to look beyond their regular role to understand the full breadth of heart failure care.

Across the UK, the type and extent of leadership for driving improvements in heart failure care is variable. Leadership roles are generally filled by passionate individuals, including secondary care specialists, heart failure specialist nurses, and GPs with a special interest in heart failure. As system leaders move to prioritise both management of long-term conditions and keeping patients out of hospital, we can see the coronavirus pandemic as a significant opportunity to build stronger leadership for heart failure at a national and regional level – and a role for organisations like the BSH, the PCCS, and charities to help define what this leadership looks like. This leadership is key for tackling the issues and driving the improvements outlined in this report, from informing national bodies on the design of training for healthcare professionals to identifying and using the data available to understand the landscape of heart failure care. As systems are increasingly integrating across the UK, the role of such leaders will be >



The Scottish Heart Failure Hub

The Scottish Heart Failure Hub is a sub-group of the National Advisory Committee for Heart Disease in Scotland. Led by Dr Clare Murphy, the Hub was developed to identify issues and opportunities to improve care across the pathway for people living with Heart Failure in Scotland. The Hub and the workstreams that sit under it are supported by clinicians, patients and charities and have a direct link to decision makers in government and the NHS. Through collaboration and exchange of ideas, the Hub aims to equip NHS Boards across Scotland to strengthen the delivery

of consistent, evidenced-based heart failure management. The work of the Hub covers a number of areas, including initiatives to improve coding of heart failure to better inform care and improve available heart failure data, as well as projects to share and develop models of care to support urban, remote and rural; primary, secondary and tertiary heart failure services in Scotland. The Hub also works to improve access to integrated palliative care for heart failure patients as well as driving improvement in access to psychological therapy for patients.

> vital in ensuring that all health and care settings that treat and support heart failure patients are involved in the development of the full patient pathway.

Strong leadership in some areas has also allowed services to adapt, so as to best support heart failure patients during the pandemic. This was not the result of a specific role across the country; rather, it generally involved a person or group of people with sufficient expertise who were able to look across and understand the full heart failure pathway. These areas were also the most able to act on standards set out by the BSH during this time⁵⁵, with strong local leadership forming a core component of this guidance to ensure that minimum standards of heart failure care were maintained, and continue to be prioritised as services are restored.

Strong leadership in heart failure services has led to significant improvements in care in Scotland, with the Scottish Heart Failure Hub working to raise the profile of heart failure amongst decision makers and spread best practice across the nation. This has also allowed them to respond quickly to the impact of the coronavirus pandemic.

As services are restored and we seek to improve heart failure services across the UK, identifying strong leaders for heart failure services and giving them the resources they need to drive change across the pathway will be vital.

4 Recommendations

- **NHSE, and devolved-nation equivalents, should identify and recruit heart failure champions at regional and national levels to work together to drive a full pathway approach to heart failure care.** These champions should be resourced by and accountable to strategic clinical networks and devolved-nation equivalents, for demonstrating improvements in patient outcomes and experience. Champions should be selected and trained based on criteria developed by the NHS and BSH, with support from the PCCS and charities, that define what good leadership across the pathway looks like for heart failure.

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As services are restored, identifying strong leaders for heart failure services and giving them the resources they need to drive change across the pathway will be vital”

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Conclusion

Throughout the coronavirus pandemic, health and care professionals have worked hard to support patients, with organisations like the BSH leading the way in defining standards of care for heart failure patients during this difficult time. Charities like the BHF and the Pumping Marvellous Foundation have also stepped up to provide enhanced support for people with heart failure, including much needed guidance and information to help people with heart failure live well in the absence of their usual support offer.

The pandemic has shone a light on the fragmentation and variability of heart failure services across the UK, and the negative impact this has on patients' health and wellbeing. As the NHS battles to recover from one of the biggest challenges in its 72-year history, it is imperative that we build back better instead of simply switching services back on for the 920,000 people with heart failure across the UK. Greater collaboration and new ways of working developed during the pandemic should be the start of creating joined-up person-centred services that are resilient to future threats to our health and care system.

By identifying people with heart failure early, getting them the specialist care they need, and putting systems in place to support them to live well and avoid hospital admissions, we can create a service that better serves people with heart failure.

This report has set out a blueprint for building better heart failure services. Working with government, the NHS, organisations like the BSH and the wider health and care sector, we stand ready to support systems in driving the changes needed to improve care for people living with heart failure. We must create services built around the needs of people that allow heart failure patients to live well for longer.

To support you in your work, sign up to our Professionals email to receive updates, insight and analysis about cardiovascular care and the NHS and other useful resources.

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Appendix

Insight used in this report

To identify key barriers to quality heart failure care across the UK and make these recommendations for improvements, we have used insight gathered over three years of working with system leaders and frontline services, combined with readily available health and care system data, and up-to-date scientific literature.

We also used views collected from people with heart failure in surveys and focus groups before and during the coronavirus pandemic to understand its impact on heart failure services. This includes insight gathered from the BHF Heart Helpline, our phone and email service staffed by cardiac nurses. This data has been used to define the unmet needs of people living with heart failure and the possible routes to improving patients' outcomes and experiences of care.

Throughout the coronavirus pandemic, we have maintained strong ties with heart failure services, monitoring the information shared by professionals in the health and care system, with the majority of this insight coming from clinicians or from senior strategic leads or bodies. This largely aligns with what is being reported across the sector and represents the impact of the pandemic on a range of services that are not currently well-represented by available datasets.

This diverse range of quantitative and qualitative data has allowed us to build a strong understanding of the landscape of heart failure care across the UK and the impact that the coronavirus pandemic has had on heart failure services and the people who access them.

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