



# HEART FAILURE: THE HIDDEN COSTS OF LATE DIAGNOSIS

*A report to identify the opportunities  
for earlier diagnosis*



# EXECUTIVE SUMMARY

Heart failure affects nearly one million people in the UK, but the road to diagnosis is often lengthy and convoluted. The result is a significant cost to the NHS. Heart failure accounts for approximately 2% of the total NHS budget and 5% of unplanned admissions per year. Heart failure also has an emotional, social and economic impact on those who live with it.

An early and accurate diagnosis of heart failure is critical to ensuring rapid access to treatment, reducing the risk of long-term complications and preventing early deaths.

Heart Failure: The Hidden Costs of Late Diagnosis, by Roche Diagnostics and leading heart failure charity the Pumping Marvellous Foundation, highlights how opportunities for early diagnosis are being missed and the staggering reality of some patients' experiences.

Our research included a survey conducted by Censuswide with 625 people who have been diagnosed with heart failure; interviews with people living with heart failure; and analysis of Hospital Episode Statistics (HES) covering all hospital activity relating to seven heart failure ICD-10 codes between April 2018 and March 2019.

## OUR FINDINGS:



Three quarters (74.8%) of patients in 2018/19 received their initial heart failure diagnosis after their first hospital admission<sup>1</sup>



43.8% said their ability to work had been negatively affected by the length of time it took for them to be diagnosed<sup>3</sup>



There are a number of 'hidden victims' of heart failure. This includes female patients who are 96% more likely to be misdiagnosed than men<sup>3</sup>



The total number of bed days was 862,470, equivalent to 2,362 years – with admissions costing nearly £400m<sup>6</sup>



24% of patients who were admitted to hospital for heart failure died within a year of their admission in 2018/19<sup>6</sup>

**6X**

Men said they waited on average 3.6 weeks to receive a formal diagnosis after their initial GP visit, while women waited on average just over 20 weeks – a near-six-fold increase<sup>3</sup>



Less than a third (29.1%) of patients said their GP ordered a blood test to test for heart failure<sup>3</sup>



Almost half (46.9%) said their emotional wellbeing or mental health was impacted<sup>3</sup>

**44.5%**

of women surveyed were incorrectly diagnosed with another condition before receiving their heart failure diagnosis, compared to 22.7% of men<sup>3</sup>



29% of heart failure patients suffered a worsening of their symptoms during the COVID-19 pandemic<sup>3</sup>

# FOREWORD



**Professor Martin Cowie**

*Professor of Cardiology, Imperial College London, and Consultant Cardiologist, Royal Brompton and Harefield NHS Foundation Trust*

Despite a wealth of published evidence and clear guidance to the NHS, the speed of diagnosis of heart failure in the UK leaves a lot to be desired. Too often symptoms are misdiagnosed or are left to deteriorate to the extent that emergency hospital admission is required.<sup>6</sup> This is unacceptable for patients and their families, and also for healthcare professionals.

This new report highlights some major issues surrounding the contemporary diagnosis of heart failure. What struck me most were the patient stories: the chilling narratives around the fight to

be correctly diagnosed and to start therapy, with all the anxiety that this provoked. We need to ask why these problems exist, and why there is so much variation across a so called “national” health service. Why is the implementation of simple guidelines taking so long? Why do women seem to get a particularly poor deal?<sup>3</sup> What are the barriers that we need to pull down?

For many people with heart failure, we have effective therapies that not only improve symptoms and quality of life, but prolong life and reduce the need for emergency hospital admission. A rapid and accurate diagnosis is key to accessing such therapy and support. Recognising symptoms, taking a patient history and using natriuretic peptide testing (NT-proBNP) are all tools that can be used in primary and secondary care to identify heart failure. But although NT-proBNP is recommended by NICE guidelines for both acute and chronic heart failure, in addition to European Society for Cardiology guidelines, use across the country remains patchy. This research found nearly one in five patients (18.9%) surveyed were not offered a blood test for heart failure at any point during their journey to a diagnosis.<sup>3</sup>

It has been estimated that access to simple blood tests in primary care could help deliver a 50% reduction in likely unnecessary echocardiograms and referrals, amounting to about £15,000 per month in just one population around an acute hospital. Earlier testing holds the potential to spare patients and families the trauma of a hospital admission, and reduce costs to the NHS.<sup>8</sup>

I remember publishing one of the first scientific papers on the value of using natriuretic peptide testing in primary care – more than 20 years ago. Let’s hope that at last we can bring such benefits to everyone who uses the NHS. We have the tools – let’s use them!



**Nick Hartshorne-Evans**

*Chief Executive of the Pumping Marvellous Foundation*

A heart failure diagnosis changes your life forever. The difference between hearing those words from your GP or being rushed – petrified – into A&E after potentially years battling for the answer to your unresolved symptoms leaves an indelible mark – on your mental health, your finances and your ability to cope. We know this is not easy to hear either way, but receiving a diagnosis in a controlled manner can help people deal with the potential challenges they now face.

With reliable and cost-effective diagnostic innovations at our disposal, including a widely available, simple blood test, NT-proBNP, which can help to rule out heart failure, it is not good enough that three quarters (74.8%) of heart failure patients admitted in 2018/19 received their initial diagnosis in a hospital setting,<sup>6</sup> and almost 50% of these are told they have heart failure in A&E.<sup>6</sup>

Delays to diagnosis mean delays to treatment, which in turn means pressing pause on living the full life that heart failure patients can have and importantly deserve. The emotional impact of this is overwhelming. And the added layer of COVID-19 aggravates an already traumatic experience. More than one third (38.4%) of patients have had their GP appointments cancelled as a result of service alterations and we also know that COVID-19 risks causing a 10% rise in heart failure, so there is an even greater sense of urgency.

We want to see a diagnostic pathway that works for healthcare professionals and all patients, regardless of age, gender or other factors. This is within our reach. GPs and cardiologists need more support to make a diagnosis by accessing the right intervention at the right time. The positive impact of this on patients and their families – both their physical and emotional wellbeing – will be transformative.

# KEY FINDINGS

## SIGNS AND SYMPTOMS

Early and accurate diagnosis is critical to ensuring people with heart failure can access treatment to help manage their symptoms, improve their quality of life and reduce the risk of long-term complications.<sup>4</sup>

### WHAT ARE THE SYMPTOMS?

The three main symptoms of heart failure aren't exclusive to the condition, which means it can be difficult to identify



**Breathlessness**



**Swollen ankles and legs**



**Increased fatigue**

Ryan, from Suffolk, was 36 at the time of his diagnosis.

*"My advice to anybody really is: if you have experienced anything like that – shortness of breath, palpitations, tiredness, fatigue... I'd recommend anyone go see their GP."*

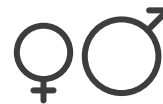
### HOW CAN HEART FAILURE BE DIAGNOSED?

Diagnostic tools including NT-proBNP, echocardiograms and specialist referral are recommended by NICE to enable early diagnosis.

### HOW OFTEN IS HEART FAILURE MISDIAGNOSED?



32.5% were given the wrong diagnosis by a medical professional<sup>3</sup>



Women were almost twice as likely to be misdiagnosed than men<sup>3</sup>



43.9% of respondents aged under 45 received an incorrect diagnosis<sup>3</sup>



**25%**



**20.7%**



**18.7%**

Asthma (25%), anxiety or depression (20.7%) and acid reflux (18.7%) are the most common heart failure misdiagnoses<sup>3</sup>



### SARAH'S STORY

Sarah, from Hull, was 42 years old at the time of her diagnosis. She had visited her GP multiple times across 10 months before receiving a final diagnosis of heart failure.

During those 10 months, she received red-herring diagnoses like rheumatological concerns, despite having a family history of cardiac problems and Type 1 diabetes, a common comorbidity. She was even told her symptoms were unlikely to be related to her heart because she was 'young and female'.

*"My GP never mentioned that they thought I might have heart failure," she says. "In fact, one of them actually said, your symptoms are probably not to do with your heart because you're young and you're female. Even though my father had had a heart condition and even though I've been Type 1 diabetic for 40 years, it was never considered."*

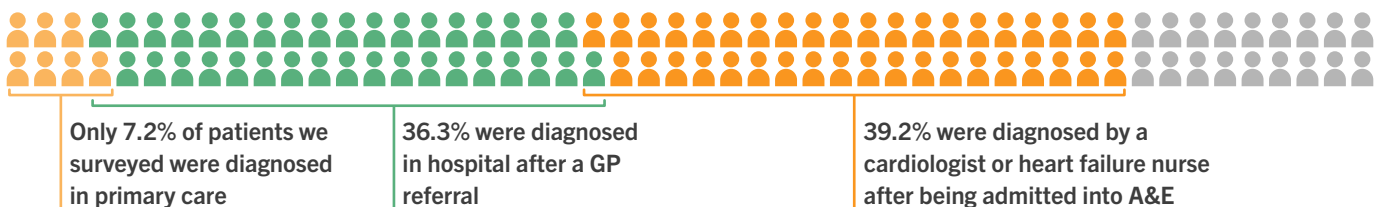


# KEY FINDINGS

## DIAGNOSIS: GP

The first port of call for many patients concerned about their health is their GP. NICE guidelines<sup>15</sup> and the NHS Long Term Plan both emphasise the need for earlier diagnosis in primary care, which can be achieved through the use of NT-proBNP, which either rules out heart failure or enables referral to hospital for an echocardiogram.

### ARE PATIENTS BEING DIAGNOSED BY THEIR GP?



### HOW LONG DOES IT TAKE TO BE DIAGNOSED AFTER AN INITIAL GP VISIT?



It takes on average nearly three months (10.9 weeks) from a patient's initial GP visit to diagnosis<sup>3</sup>

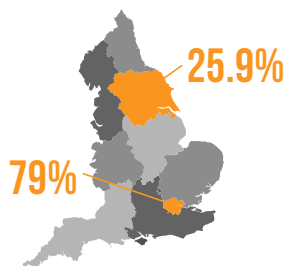


3.6wks



20wks

Men wait on average 3.6 weeks for their diagnosis, while women wait over 20 weeks<sup>3</sup>



More than three quarters (79%) of Londoners could expect their diagnosis within a week. This dropped to 25.9% of respondents in Yorkshire and the Humber<sup>3</sup>

### ARE GPs USING NT-proBNP?



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>3</sup>

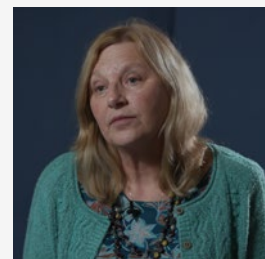


74.7%



25.3%

Of those who were tested by their GP, 74.7% were men and 25.3% were women<sup>3</sup>



### ANNETTE'S STORY

Annette, from East Devon, was 53 years old when she was diagnosed, having waited two years and eight months to be told she has heart failure.

*"The delay in the diagnosis caused me to be unreliable at work, which I hadn't been previously, and also to lose my independence," she says. "Whereas previously I was cycling 10 miles a day, now I was having to rely on other people to pick me up for work. For my family, it was extremely frustrating - I had grandchildren I couldn't pick up. I had to start sleeping downstairs; I couldn't get upstairs because I was so tired, having to rely on other people and eventually having to give up work."*

*“Delay in diagnosis is particularly relevant to primary care and though the presenting symptoms of heart failure are non-specific and commonly seen in other conditions, there is clear evidence that this diagnosis is not being considered at an early stage where investigations such as natriuretic peptide testing (NT-proBNP) are critical to further assessment and, where indicated, urgent referral. Access in primary care to NT-proBNP may not be universal but the use of the test when available appears to be highly variable and another important factor in late diagnosis.*

*“The widespread use of cost-effective diagnostic tools such as NT-proBNP must be our priority to save lives, reduce costs and improve patients’ quality of life in the future.”*



**Dr Jim Moore**

General practitioner with special interest in cardiology,  
Gloucestershire Heart Failure Service  
and President, Primary Care Cardiovascular Society

# KEY FINDINGS

## DIAGNOSIS: HOSPITAL

Three quarters (74.8%) of patients received their initial heart failure diagnosis after their first hospital admission in 2018/19<sup>6</sup> – and nearly half (48.3%) of those diagnoses took place in emergency care.<sup>6</sup>

Using NT-proBNP as the first step in diagnosing suspected heart failure holds the potential to make the diagnosis more accurate and efficient; reduce the number of echocardiograms; reduce the length of stay in hospital; facilitate early discharge of low risk patients and accelerate the triage of high risk patients to cardiology departments for treatment.

### HOW ARE ECHOCARDIOGRAMS BEING USED?

In 2018/19,  
**67,127**  
people received an echocardiogram with a subsequent admission for heart failure<sup>6</sup>



Patients waited on average  
**27 DAYS**  
between their first echocardiogram and first heart failure admission<sup>6</sup>

**412,323**  
people received an echocardiogram with no further heart failure or other outpatient admission within 90 days<sup>6</sup>

### WHAT IS THE COST?

An echocardiogram costs on average  
**£1,430**  
per patient.<sup>6</sup>  
NT-proBNP costs less than £28



In 2018/19, the total number of bed days was  
**862,470**,  
equivalent to  
**2,362 YEARS<sup>6</sup>**

The total cost for patients who had an echocardiogram with no further admission during this period was  
**£590 MILLION<sup>6</sup>**



### HANNAH'S STORY

Hannah, from Leeds, was 39 years old at the time of her diagnosis, and was originally misdiagnosed because heart failure was not thought to affect a younger person. Instead, she was checked out for anxiety. By the time she was eventually diagnosed in hospital she had dilated cardiomyopathy, by which point she had very severe symptoms and difficulty breathing.

*"I have children with special needs and not being able to look after them was incredibly difficult," she says, "and the fact that I had to be taken away from them for 11 days because of such a late diagnosis. Had they diagnosed me sooner, I wouldn't have been in hospital and I wouldn't have been taken away from them in that time. I couldn't walk my children to school, so I had to get people to help me walk the children to school."*



*“Even in the hospital setting NT-proBNP is underused – the NCEPOD report showed that although NT-proBNP was available in 90% of Trusts, only 17% of new heart failure cases had NT-proBNP testing. This led to incorrect triage, delayed specialist review and suboptimal treatment. Most hospitalised patients experience delays for an echocardiogram to confirm the diagnosis – prolonging length of stay which is even less acceptable post COVID and in the face of rapidly increasing heart failure admissions.”*



**Dr Lisa Anderson**

Heart Failure Consultant,  
St. George's University Hospitals NHS Foundation Trust



# KEY FINDINGS PROGNOSIS

Heart failure has worse survival rates than breast, prostate and bladder cancer. Mortality rates remain significant, particularly in areas of social deprivation.

The key to reducing mortality, morbidity and costs associated with heart failure is early, accurate diagnosis and appropriate management.<sup>14</sup> Although there is no cure for heart failure, timely diagnosis means that patients can access treatment to help them manage their symptoms, improving their quality of life.<sup>4</sup>

## WHAT ARE THE MORTALITY RATES?

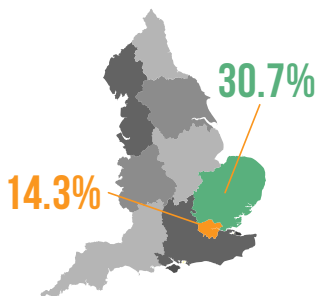
With heart failure admissions rising by a third over the past five years, it is critical that early and accurate diagnosis in primary care is prioritised to prevent avoidable deaths from heart failure.



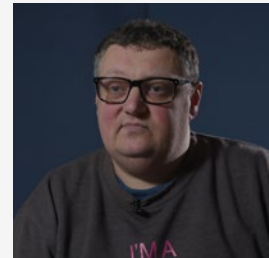
Almost one in five (18.6%) patients who were admitted to hospital for heart failure died within six months of their admission in 2018/19<sup>6</sup>



Almost one quarter (24%) died within a year<sup>6</sup>



At one CCG in Essex, the mortality rate a year after admission was as high as 30.7% in 2018/19, while one East London CCG was at 14.3%<sup>6</sup>



## DAN'S STORY

Dan, from Nottingham, was 35 years old at the time of diagnosis. He had a very difficult experience being diagnosed with heart failure. After six months of symptoms, and multiple trips to the GP, he collapsed at home and had to be admitted to hospital with dilated cardiomyopathy.

The experience has taken a toll on his wellbeing, both mentally and professionally. After being misdiagnosed with depression and anxiety in the first place, he ended up suffering from these conditions as a result of the stress of heart failure symptoms.

*"I went to hell. I literally went to hell. It was the worst time of my life," he says. "I believed that I was suffering from anxiety, stress and depression, and I think I began to take on those symptoms. I was experiencing panic attacks and I was so desperate to find out what was wrong I even spoke to the Samaritans. It got that bad that I was looking for answers."*

***“It is vital that all primary care and hospital trusts in the UK have access to the blood test NT-proBNP to ensure timely referral to specialists who can diagnose heart failure. Once diagnosed, specialists can expedite access to therapies that make a real difference to people’s symptoms, these therapies not only improve quality of life but also enable patients to live longer.”***



**Carys Barton**

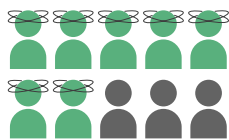
Heart failure nurse consultant,  
Imperial College Healthcare NHS Trust

# KEY FINDINGS

## QUALITY OF LIFE

A delayed heart failure diagnosis has a significant impact on patients' quality of life. As well as it being a debilitating physical condition, heart failure has an emotional, social and economic impact on those who live with it, as well as patients' families and carers.<sup>3</sup>

### WHAT IS THE EMOTIONAL IMPACT?



**69%** of patients said they were left feeling anxious or worried while waiting to receive a final diagnosis<sup>3</sup>



Almost half (**46.9%**) of patients said their emotional wellbeing or mental health was impacted by the length of time it took to be diagnosed<sup>3</sup>



This rose to **54.1%** amongst women<sup>3</sup>

Jill, from Cheshire, was 53 years old at the time of her diagnosis. Thinking about how long it took her to get a diagnosis of heart failure, she says:

*"In every way there was an impact. I have a 15 year old daughter – it's me and her... She had to see her mother having to sit up to sleep and get through the night. I travel a lot with work and have an international career. I had to stop working and work from home initially."*

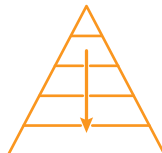
### WHAT IS THE ECONOMIC IMPACT?



**43.8%** said their ability to work had been negatively affected<sup>3</sup>



**30.2%** suffered financial losses<sup>3</sup>



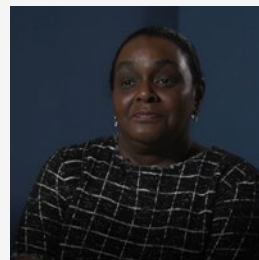
**32%** agreed that their career development had been hindered<sup>3</sup>

### WHAT IS THE SOCIAL IMPACT?



Over **30%** of patients agreed the length of time it took to receive a final diagnosis negatively impacted on their relationships with friends<sup>3</sup>

**27.5%** said their relationship with their partner, wife or husband was negatively impacted<sup>3</sup>



### BEVERLY'S STORY

Beverly, from south west London, was 50 years old when she was diagnosed. Beverly's experience of diagnosis was "very distressing". Her consultant told her that she had "the heart of an 80 year old" and that "one in three patients are dead within a year, even with all the treatment we have available".

"It would have been nice to have had some knowledge of heart failure because it changed my life dramatically," she says. "It really did have a massive impact on the way my life was. I was no longer able to work, no longer able to walk up the road, I couldn't go anywhere on my own. I had to have someone with me at all times for quite a long time."





# KEY FINDINGS

# HEART FAILURE AND COVID-19

COVID-19 has led to significant challenges across the country. The impact on an already overburdened health system has been particularly acute, with appointments and surgeries put on hold to mitigate the spread of coronavirus.

Patients with heart failure are at an increased risk of health complications due to an infection and experience worse outcomes as a result, so it is vital that heart failure care is not deprioritised due to the pandemic.

## HOW IS COVID-19 AFFECTING PATIENTS?



**38.4%**

Nearly four in 10 patients (38.4%) had a hospital or GP appointment for heart failure cancelled<sup>3</sup>



**33.4%**

Over a third (33.4%) admitted they were avoiding going to the doctors to discuss the condition<sup>3</sup>



**20.5%**

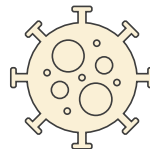
Over a fifth (20.5%) of patients struggled to pick up their prescription<sup>3</sup>

## WHAT IS THE IMPACT?



**29.3%**

Nearly three in 10 (29.3%) said their symptoms had got worse during the Covid-19 pandemic<sup>3</sup>



**36.8%**

agreed their quality of life had suffered<sup>3</sup>



**43%**

Just over 43% of patients agreed their mental health had been negatively impacted as a direct result of living with heart failure during COVID-19.<sup>3</sup>

We are also seeing a rise in people with heart failure due to COVID-19.<sup>13</sup> Patients hospitalised with COVID-19 are at increased risk of developing heart failure; recent research has found that heart failure and myocardial damage occur in at least 10% of patients hospitalised for COVID-19.<sup>9</sup> This rises to 25%–35% or more for critically ill patients or those with concomitant cardiac disease.<sup>13</sup> This is likely to place greater strain on cardiology departments if increasing numbers of patients are not being diagnosed in primary care.

# RECOMENDATIONS

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## 1. IMPROVED EDUCATION ON THE SIGNS AND SYMPTOMS OF HEART FAILURE IN PRIMARY CARE

To ensure people with heart failure receive a timely diagnosis, Health Education England should provide GPs with enhanced education and training to identify the signs and symptoms of heart failure. They should also be supported to follow NICE guideline NG106<sup>8</sup> which recommends taking a detailed patient history, performing tests to confirm the presence of heart failure and measuring NT-proBNP in those with suspected heart failure.

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## 2. EASIER ACCESS TO TOOLS TO AID SWIFT AND ACCURATE DIAGNOSIS IN PRIMARY AND SECONDARY CARE

Clinical commissioning groups (CCGs) should be incentivised to commission diagnostic tools such as NT-proBNP testing and echocardiography in primary care – as recommended by NICE – to improve the early detection of heart failure.

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## 3. MORE CONSISTENT USE OF NATRIURETIC PEPTIDE TESTING (NT-proBNP) IN HOSPITALS

Evidence shows that NT-proBNP testing, as the first step in diagnosing suspected heart failure, holds the potential to make the diagnosis more accurate and efficient and has the potential to reduce costs for the NHS. Secondary care should also ensure consistent use of these vital tools to aid heart failure diagnosis.

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## 4. MORE WORK TO REDUCE GENDER INEQUALITY IN HEART FAILURE DIAGNOSIS

Greater awareness of the inequality in the diagnosis and misdiagnosis of heart failure will be critical to closing the gender gap and improving the diagnosis, outcomes and experience of women living with heart failure.

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## 5. APPROPRIATE SIGNPOSTING TO EMOTIONAL AND SOCIAL SUPPORT FOR HEART FAILURE PATIENTS

To enable heart failure patients to experience less stress and anxiety around their diagnosis, patients should have access to appropriate emotional support. That could include timely signposting to psychological therapies, social support and patient and peer support groups such as the Pumping Marvellous Foundation.

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## 6. PRIORITISE HEART FAILURE POST-COVID-19

In light of the increased risk of people with heart failure falling seriously ill from COVID-19<sup>24</sup> – in addition to the increased incidence of COVID-19 in those hospitalised for heart failure<sup>13</sup> – it will be crucial that heart and circulatory diseases are considered a priority in any national, regional or local post-COVID recovery plans as normal services are resumed within the NHS.

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Roche Diagnostics Limited  
Charles Avenue, Burgess Hill, West Sussex, RH15 9RY  
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