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**PUBLIC POLICY PROJECTS**

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INSIGHTS



## Breaking the cycle: Tackling late heart failure diagnosis in the UK

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**Roche**

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# Acknowledgements

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## ABOUT ROCHE



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<sup>1</sup> Data on file

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# Foreword



## SIR MIKE RICHARDS

Chair of the National Screening Committee and author of the independent review into NHS diagnostics capacity: *Diagnostics: Recovery and Renewal*

Diagnostic services have historically been something of a Cinderella within the NHS, and inadequacies in diagnostic facilities combined with low workforce numbers have undoubtedly contributed to late diagnosis and poorer outcomes. Around 15 years ago, when I was National Cancer Director, I remember discussing this with my national clinical director colleagues. We all agreed that poor access to tests was a major problem for our patients. However, I genuinely hope and believe that this is now being rectified.

NHS England commissioned me to carry out an independent review of NHS diagnostic services as part of the NHS Long Term Plan in 2019. This was because many of the commitments in that plan – on heart disease, respiratory disease, stroke, cancer and other conditions – would only be achieved with better diagnostic services.

The pandemic then struck and hugely exacerbated all the pre-existing problems within diagnostics. However, the pandemic also shone an intense spotlight on the value of diagnostics and the clear need to improve these services.

My review was deliberately broad, covering all diagnostic modalities and was based on data on activity trends and on discussions with a wide range of clinical experts, policy makers, patient groups and charities across the healthcare system as well as with representatives from industry. The case for change was strong.

My report was published in October 2020 after the first peak of the pandemic and I am pleased to say that all my recommendations were accepted by NHS England. The report had three key themes:

1. A need to increase diagnostic capacity – equipment, facilities and workforce.
2. A need to do things differently – and in particular to separate ‘acute’ and ‘elective’ diagnostic activity wherever possible as this will promote efficiency and productivity.
3. A need for several other infrastructure changes: better networking of services, combined with digitisation and connectivity, leadership, data and commissioning.

The need to do things differently led to my recommendation to establish Community Diagnostic Hubs (now referred to as community diagnostic centres or CDCs). With funding from the Treasury and NHSE, almost 100 of these CDCs have now been established across the country, many in areas of high deprivation. These make access to diagnostics more convenient for patients and, where possible, provide a ‘one stop shop’ approach to diagnosis.

Breathlessness and heart failure are at the centre of these new developments. The set of symptoms most commonly associated with heart failure are ambiguous and common and it can be difficult for a GP to know whether to refer a patient with chronic breathlessness to cardiac or respiratory services. Working with leaders in cardiology, respiratory medicine and primary care we are now piloting new ‘breathlessness’ services in CDCs to improve the pathway for these patients.

This report is an important milestone in the journey of improvement our diagnostic services are on. By examining the heart failure pathway in more detail, it highlights the benefits of earlier diagnosis for patients and the wider health system, and clearly sets out recommendations for all those involved in the treatment and care of patients presenting with heart failure symptoms.



## DR CLARE TAYLOR MBE

Heart Failure Researcher, General Practitioner

I have worked in, and advocated for, improvements in the diagnosis, treatment, and care of people with heart failure for 15 years. In this time, it has never been more important to prioritise innovations and diagnostic capacity than now, as the NHS faces unprecedented pressure since the Covid-19 pandemic. My career as a GP and academic researcher has allowed me to examine the clinical pathway for patients diagnosed with heart failure in primary care - including the epidemiology of heart failure in the community and the patient experience of diagnosis - through a unique lens. Most crucially, tackling the late diagnosis of heart failure should be a collaborative effort, with healthcare professionals from primary and secondary care working together to ensure patients have access to treatments which we know from clinical trials can improve and extend their lives. Getting a timely heart failure diagnosis is the first crucial step.

### There are several opportunities for change:

1. Widespread awareness of heart failure onset for healthcare professionals – everyone working in primary care should have a good understanding of the signs and symptoms of heart failure so that the patient journey on the diagnostic pathway can begin sooner, allowing earlier access to life-saving treatment.
2. Easily recognisable symptom tracker for the general public – in addition to greater awareness amongst healthcare professionals, the public should be able to easily recognise the symptoms of heart failure. Our The Pumping Marvellous Foundation BEAT symptom checker ‘Breathless, Exhaustion, Ankle swelling, Time for a simple blood test,’ should be publicised more widely to encourage people with symptoms to come forward for testing.
3. Mandated NT-proBNP testing, with appropriate sensitivity thresholds, as part of early treatment pathways – our

research found a correlation between high natriuretic peptide levels and hospitalisation and death, demonstrating the need to commission mandatory rapid referral pathways to allow prompt echocardiography and specialist assessment for people presenting with heart failure symptoms. Timely NT-proBNP testing and referral in primary care is also a crucial first step in the diagnostic pathway.

4. Innovation to support healthcare professionals - tools such as the NT-proBNP test and greater use of artificial intelligence will be increasingly critical to support high patient demand as the prevalence of heart failure increases, coupled with ongoing workforce challenges in both primary and secondary care.
5. Top-down and bottom-up support – from a healthcare professional perspective, clearly communicated guidance from NHS England and our local Integrated Care Systems is vital, but so is the important work of patient organisations like the The Pumping Marvellous Foundation and, where appropriate, industry in driving awareness of heart failure and providing accessible educational materials.

This report provides invaluable insights into the impact of the delay to diagnosing heart failure. From an individual patient perspective, without a timely diagnosis, treatment will be delayed leading to worse outcomes. From a system perspective, emergency heart failure admission and lengthy hospital stays increase the burden on an already overstretched service. Early detection of heart failure is key for patients and their families to ensure life-saving treatments are delivered sooner, hospitalisation is prevented, and quality and quantity of life is improved. Now is the time for all pillars of the NHS to come together to prioritise earlier heart failure diagnosis and reduce the impact of this under-recognised, under-resourced, yet devastating condition.

# Executive Summary

Nearly one million people live with heart failure across the UK.<sup>1</sup> As a serious and chronic disease that prevents the heart from being able to pump enough blood to the body, the physical, emotional, and social impacts of heart failure can significantly lower a person's quality of life, while also resulting in high healthcare expenditure, and broader healthcare costs.<sup>2</sup>

This report summarises findings from an analysis of UK primary care and secondary care records conducted by IQVIA\* as well as a review of existing publications and Public Health England (PHE) 'fingertips' data by Anderson Strategy. It shines a light on the burden of heart failure and outlines a number of opportunities for service improvement that will facilitate more timely diagnosis of heart failure. It calls for vital policy recommendations at a national, regional and local level in order to create tangible change for the healthcare system as a whole, and more importantly in the lives of the hundreds of thousands of people who are diagnosed with heart failure every year in the UK.

## The Challenge

Heart failure is often diagnosed at a late stage<sup>3</sup>, in part due to difficulties in symptom recognition, existing pressures on the NHS

and access to diagnostic testing in primary care. In addition, 32.5 per cent of heart failure patients were initially misdiagnosed.<sup>4</sup> The majority of heart failure cases are identified and diagnosed in emergency settings - 80 per cent of patients receive their heart failure diagnosis following an emergency admission to hospital, despite 40 per cent of patients experiencing symptoms that should have triggered an earlier assessment.<sup>5</sup> Analysis from IQVIA shows that those diagnosed via this route have considerably worse outcomes in terms of quality and length of life.

A pivotal barrier to early diagnosis is that the three key symptoms of heart failure – breathlessness, exhaustion and ankle swelling – are common symptoms for many other conditions, and so may be mistaken for other illnesses. Comorbidities can make it more difficult to identify symptoms of heart failure, and as a result, people often wait years for a correct diagnosis, significantly delaying their ability to access appropriate care.

## The impact

The mental and physical impacts of late heart failure diagnosis are often worse when treatment is started too late.<sup>6</sup> With diagnosis

**80%**

of patients receive their heart failure diagnosis following an emergency admission to hospital

**DESPITE**

**40%**

of patients experiencing symptoms that should have triggered an earlier assessment

\*IQVIA analysed two distinct datasets to gather insights for this report, namely the proprietary IQVIA Medical Research Data (IMRD) primary care record and NHS Digital Hospital Episode Statistics (HES) data which includes secondary care records. The IMRD data comprises longitudinal pseudo-anonymised patient records from a robust representative panel of GP surgeries in the UK. NHS Digital HES comprises pseudo-anonymised longitudinal patient records from all hospitals in England (Copyright (c) 2022, NHS Digital. Re-used with the permission of NHS Digital. All rights reserved.). The analysis periods were 2011 – 2021 for IMRD and 2016 – 2021 for HES. An important limitation of this project was that the two datasets (IMRD and HES data) were not linked and therefore it was not possible to track individual patient data between primary and secondary care.



in the UK tending to occur at a more severe stage of heart failure, given that patients visit accident and emergency only with prominent or life-threatening symptoms, the impacts of heart failure are felt much more severely than they should be. In addition to the physical impact of the condition, the significant mental health implications<sup>7</sup> of heart failure are often serious and overlooked.

In addition, socio-economic deprivation levels contribute to the likelihood of late-stage diagnosis of heart failure, leading to unnecessary hospitalisations.<sup>8</sup> This adds significant system-wide pressures in these areas, as higher healthcare and broader costs are accrued in trusts which are already less well resourced, creating unnecessary pressure on the wider healthcare system.

Women often also face significant disparities in the diagnosis of heart failure. Despite an almost even split between diagnosis in men and women, a lack of awareness of symptoms – particularly in primary care – means that female patients are twice as likely to be misdiagnosed than men.<sup>9</sup>

Finally, the impacts of late diagnosis can be found across the NHS. Heart failure accounts for approximately one million inpatient days,<sup>10</sup> with an already stretched NHS workforce feeling the strain of unnecessary unplanned admissions. NT-proBNP testing is not being fully utilised in the UK.<sup>11, 12</sup> This means that a proportion of patients are being referred for echo unnecessarily<sup>13</sup> and is likely contributing to the huge pressures on cardiology services and long echo wait times.

### **The solution**

Direction must come from NHS England that heart failure is a priority, and should be treated as such at all levels of the NHS. Increasing awareness of the signs and symptoms can support the earlier diagnosis of heart failure, as can greater uptake of NT-proBNP testing, which can rule out heart failure or aid in the triage of patients to confirm diagnosis. Increased cooperation throughout all levels of the NHS, industry partners and patient groups is key, and the adoption of innovative solutions, including digital technologies and artificial intelligence, will also provide much needed improvement to care for those with heart failure.

# Recommendations

Based on the scale of the problem in the UK, this report contains nine recommendations to improve heart failure diagnosis across the whole system. They range from calls for NHS England to prioritise heart failure at a national level, through to local Primary Care Networks and Cardiac Networks, and to disseminate and tailor national advice to work on a local level.

## **NHS England (NHSE)**

1. NHSE should prioritise CVD and heart failure as part of their upcoming Long Term Plan refresh, with specific targets and milestones (akin to those already in place for stroke and cardiac arrest), to ensure ambitions outlined in the original plan remain a commitment.
2. The Network Contract Directed Enhanced Service (DES) for 2023/24 must financially incentivise heart failure in line with other key health areas to ensure greater provision and prioritisation of heart failure early diagnosis and management.
3. The BEAT symptom checker – Breathlessness, Exhaustion, Ankle Swelling, Time for a simple blood test – should be universally agreed upon, recognised, and promoted at all levels of the NHS.

## **Health Education England (soon to be NHSE, 2023) / Professional Organisations**

4. Training for new and existing healthcare professionals in primary and secondary care should include promoting the value of NT-proBNP testing and the appropriate diagnostic pathway in line with NICE heart failure diagnosis and management in adults' guidelines [NG106]. Specific focus should also be applied to ensuring detailed knowledge of the signs and symptoms of heart failure, including on the risk of heart failure in women, to begin to address gender disparities.

## **Primary Care Networks (PCNs) and Cardiac Networks**

5. Cardiac Networks to introduce breathlessness pathways using NT-proBNP testing in line with NICE recommendations and working with PCN CVD leads to improve the early identification of patients with potential heart failure.
6. Collaboration between patient organisations, industry, and the NHS should be prioritised to ensure those who typically receive inequitable outcomes in healthcare (women, people from ethnic minority backgrounds, those living in deprived areas) receive quality and appropriate resources and information on heart failure. Patients should feel empowered to seek investigation from their GP, should they have concerns.

## **Integrated Care Systems (ICSs) / Integrated Care Boards (ICBs)**

7. ICBs, PCNs and Cardiac Networks should work collaboratively to ensure NT-proBNP testing is accessible across primary care and in community diagnostic centres to ensure patients suspected of heart failure have timely access to testing that can inform whether an echocardiogram is needed.
8. Further evaluation and adoption of digital technologies, including artificial intelligence (AI) and portable echocardiography, to support earlier diagnosis of heart failure.
9. Industry should collaborate to provide essential capacity and resource support to healthcare system leaders and heart failure advocates, by providing information, research and tools that will drive improved outcomes for people with heart failure. This cooperation should focus on the entire patient pathway, from prevention and diagnosis, through to treatment.



# Introduction

Heart failure is one of the leading causes of illness and death in the UK, with 200,000 new diagnoses each year.<sup>14, 15</sup> It is a condition in which the heart does not pump enough blood for the body's needs, and can occur at any age.<sup>16</sup> Heart failure patients often experience early identifiable symptoms, including breathlessness, exhaustion and ankle swelling due to fluid retention, which tend to develop gradually over time.

Rates of early diagnosis for heart failure in the UK remain low, increasing the risk of premature mortality as diagnosis occurs, on average, two years after the first symptoms present.<sup>17</sup> Regional inequalities in diagnosis of heart failure mean that people of a lower socio-economic background are far more likely to suffer and die from more severe instances of heart failure, with mean survival rates after a diagnosis shorter in areas with higher

deprivation.<sup>18</sup> In addition, women are much more likely to receive a misdiagnosis than men,<sup>19</sup> leading to poorer outcomes.

The findings of this report are based on IQVIA analysis for Roche Diagnostics, as well as Anderson Consulting, and reveal new insights into the impact of heart failure on patients and NHS services. Crucially, the report also highlights the opportunities for service improvement that more timely diagnosis of heart failure will create. Faster identification of key early warning symptoms supports improvements to the life expectancy and quality of life of patients, as well as easing system pressure by potentially reducing emergency admissions.<sup>20</sup> The report crystallises these findings into a series of recommendations designed to improve national policy on heart failure, as well as supporting healthcare providers to enhance capacity for early diagnosis.

*A heart failure diagnosis is a devastating one and unfortunately, most people have their diagnosis confirmed in A&E after years of living with unresolved symptoms which have been misdiagnosed or were left to worsen. A diagnosis doesn't have to mean the end for people, however. Instead, it is the vital first step in identifying treatment options to allow the condition to be managed appropriately, leading to people living better with their heart failure.*

**NICK HARTSHORNE-EVANS** Heart Failure patient, Founder and CEO,  
The Pumping Marvellous Foundation

# Chapter One

## THE SCALE OF HEART FAILURE IN THE UK

There are around 920,000 people living with heart failure in the UK.<sup>21</sup> Despite this, The British Heart Foundation (BHF) estimated in 2019 that 580,000 people in the UK are on their GP's heart failure register.<sup>22</sup> This indicates that 340,000 patients are 'missing' from GP registers and could be living with heart failure without support or treatment.

The burden of heart failure in the UK has increased in recent decades, due to population ageing, increasing obesity levels, and reduced mortality rates for cardiovascular conditions overall.<sup>23</sup> Currently, heart failure is the leading cause of hospitalisation for people aged 65 and over in the UK, creating a significant burden, compromising patients' quality of life, and costing the NHS approximately 1-2 percent of its annual budget.<sup>24, 25</sup> Two of the main factors contributing to late-stage diagnosis of heart failure are challenges with signs, symptoms and comorbidities, as well as variation in adherence to NICE guidelines for heart failure.

### Challenges with signs, symptoms and comorbidities

A key factor contributing to delayed diagnosis is the fact that the three key symptoms of heart failure – breathlessness, exhaustion and

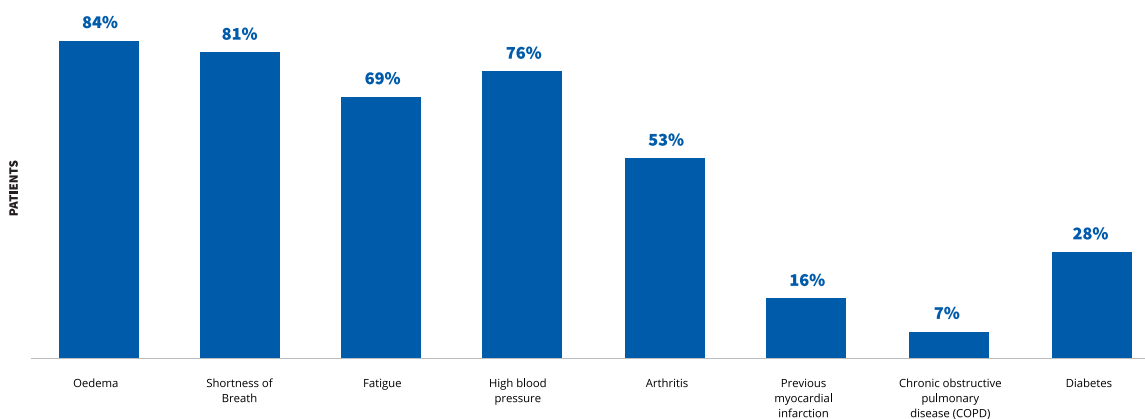
ankle swelling can be caused by a number of conditions, so patients may be given the wrong diagnosis. Analysis shows that among those who are diagnosed with heart failure, 32.5 per cent were initially misdiagnosed, and among those under the age of 45, this figure rose to 43.9 per cent.<sup>26</sup> With 98 percent of heart failure patients having at least one other long-term condition,<sup>27</sup> identification and diagnosis of heart failure is further complicated as those with symptoms might dismiss them and choose not to seek medical attention immediately. From 2016 to 2021, only 15 percent of heart failure patients had heart failure recorded as their primary diagnosis, or as the reason they initially sought care.<sup>28, 29</sup> Additionally, one in five patients with heart failure presenting at hospital also had COPD.<sup>30</sup>



**32.5%**

were initially misdiagnosed

FIGURE ONE: PROFILE OF PATIENTS WITH HEART FAILURE



This bar chart shows the percentage of symptoms patients had at the time of their heart failure diagnosis  
C Taylor et al, 2017, Primary care REFerral for Echocardiogram (REFER) in heart failure: a diagnostic accuracy study



The majority of patients who received a heart failure diagnosis overwhelmingly demonstrated one of the three key symptoms – 84% with oedema; 81% with shortness of breath; and 69% with fatigue.<sup>31</sup> In addition, 64% also presented with symptoms of atrial fibrillation or flutter.<sup>32</sup> With so many patients having these symptoms, it's essential people are educated on recognising that these may be a sign of heart failure when going to see their GP.

#### **Variations in adherence to NICE guidelines**

Despite being a complex condition to diagnose, the current NICE guideline for the diagnosis and management of chronic heart failure in adults (NG106) is not being followed universally. The NICE guidance includes a review of the patient's medical history, a clinical examination, measurement of N-terminal pro-B-type natriuretic peptide (NT-proBNP) levels, and subsequent referral for assessment of those with high levels of NT-proBNP.

Patients with an NT-proBNP level between 400ng/litre and 2000ng/litre should be urgently

referred for specialist assessment and transthoracic echocardiography within six weeks. This rises to two weeks if the NT-proBNP level is greater than 2000ng/litre,<sup>33</sup> as evidence shows these patients are at a higher risk of heart failure-related hospitalisation and mortality.<sup>34</sup> Despite the NICE guidance in place levels of NT-proBNP testing remain low. Data analysis from IQVIA found that only 18.3 per cent of heart failure patients had an NT-proBNP test recorded.<sup>35</sup> Of those patients tested who had an NT-proBNP result above the cut-off, approximately 60 per cent did not meet the NICE recommended referral time and 23 per cent did not get a referral at all.<sup>36</sup>



**ONLY 18.3%**

of heart failure patients had an  
NT-proBNP test recorded

# Chapter Two

## THE IMPACT OF A LATE HEART FAILURE DIAGNOSIS

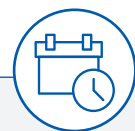
Late heart failure diagnosis means that patients often have a worse prognosis, require more treatment, and a poorer quality of life.<sup>37</sup> The impact of a late diagnosis is also felt on patients' mental health.<sup>38</sup> These issues are compounded for those who typically face poorer health outcomes, those who live in more deprived areas of the country,<sup>39</sup> and for women.<sup>40</sup> The impact of late diagnosis is also felt across the healthcare system, as later diagnosis leads to greater demand for services and resources.

### Patient outcomes impact

Late-stage diagnosis, whether due to a lack of symptom recognition or variation in adherence to NICE guidance, can mean years without a diagnosis. Shockingly, the median gap between patients first presenting in primary care with breathlessness and receiving a test for NT-proBNP is 3 years, increasing to a median of five years if presenting with oedema (See figure two).<sup>41</sup>

The below boxplot chart outlines the median time to diagnosis following the presentation of key symptoms associated with heart failure.

At present, 80 per cent of patients receive their heart failure diagnosis following an emergency



### 3 YEARS

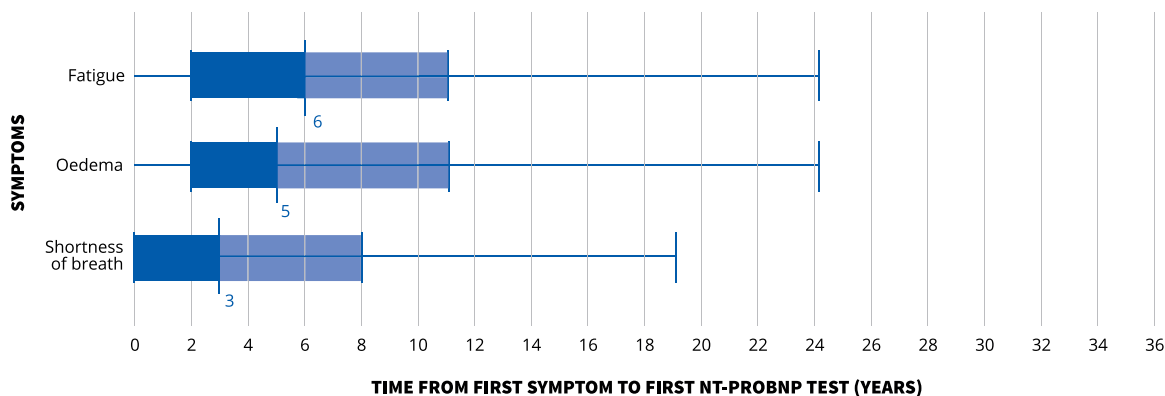
is the median gap between patients first presenting in primary care with breathlessness and receiving a test for NT-proBNP, increasing to a median of five years if presenting with oedema

admission to hospital, despite 40 per cent of patients experiencing symptoms that should have triggered an earlier assessment.<sup>42</sup>

Diagnosis in hospitals tends to be at a more severe stage of heart failure, given that patients tend to visit accident and emergency only with prominent or life-threatening symptoms.

The New York Heart Association (NYHA) classification provides an important framework for diagnosing the different stages of heart failure. It classifies patients into one of four categories, based on the limitations they experience during physical activity.<sup>43</sup> The life expectancy of patients diagnosed at class IV is half that of patients diagnosed at class I, with the average stage of heart failure diagnosis in the UK between class III and class IV.<sup>44</sup>

**FIGURE TWO: TIME FROM FIRST SYMPTOM TO FIRST NT-PROBNP TEST (YEARS)**



The above boxplot chart outlines the median time to a NT-proBNP test following the presentation of key symptoms associated with heart failure. Source: IQVIA Medical Research Data, IQVIA Ltd, incorporating data from THIN, a Cegedim database, 2011 - 2021



**FIGURE THREE: NYHA CLASSIFICATION OF HEART FAILURE**

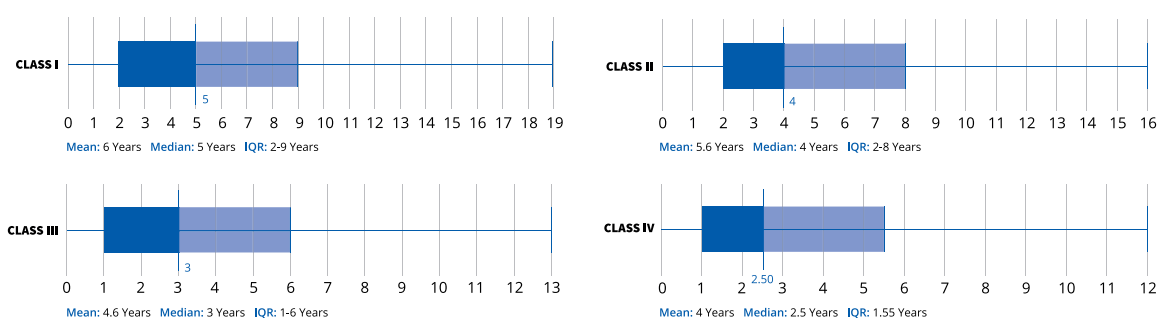
- 1 CLASS I** No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
- 2 CLASS II** Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
- 3 CLASS III** Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
- 4 CLASS IV** Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

New York Heart Association, 1994

These issues have been compounded by the hugely disruptive impact of the Covid-19 pandemic. Echocardiograms - which are used to diagnose heart failure - are in short supply, and workforce challenges mean people are waiting longer to receive this important test. Even before the pandemic, longstanding workforce shortages impacted access to echocardiography.<sup>45</sup> The impact of Covid-19 further exacerbated this access barrier - the number of echocardiograms conducted in England fell by 67 per cent in April and May 2020, compared with February 2020. This

reduction continued by 40 per cent into June 2020.<sup>46</sup> This backlog persists, with the number of people waiting for an echocardiogram in England reaching 172,000 in May 2022, the highest figure ever recorded. Of these, nearly half (43 per cent) have been waiting for six weeks or more, and one in five (20 per cent) have been waiting for 13 weeks or more.<sup>47</sup> The average class of diagnosis (between class III and IV) patients receive in the UK translates to a 50 per cent mortality rate within five years,<sup>48</sup> so it is clear that the delay in diagnosing heart failure is costing lives.

**FIGURE FOUR: TIME FROM DIAGNOSIS TO DEATH BY NYHA CLASS**



The above boxplot diagram outlines the mean, median and IQR time to death at each class of heart failure diagnosis. Source: IQVIA IMRD (2022)

### Mental health impact

In addition to the physical impact of the condition, the significant mental health implications of heart failure are often overlooked. One study found that symptoms of depression were present in 52 per cent of heart failure patients, and in 12 per cent of cases, depression was classed as ‘extremely severe’. In the same study, anxiety was diagnosed in 53 per cent of patients, with 18 per cent of cases classed as ‘severe’.<sup>49</sup> Additionally, studies suggest that the prevalence of depression doubles as patients progress from class I to class II and III heart failure,<sup>50</sup> and almost half (46.9 per cent) of patients said their emotional wellbeing or mental health was impacted by the length of time it took to be diagnosed.<sup>51, 52</sup>

### Regional impact

The impact of heart failure is often felt more severely in areas with the worst health outcomes. Research by the All Party Parliamentary Group (APPG) on Left Behind Neighbourhoods demonstrated that ‘left behind’ areas have the worst health outcomes in England.<sup>53\*\*</sup> Analysis by IQVIA shows a clear impact on diagnosis and treatment pathways at a regional level in correlation with levels of deprivation. For example, data comparing the number of hospital admissions due to heart failure and the index of multiple deprivation in England, shows a significant correlation between deprivation levels and hospitalisation resulting from heart failure. In 2021, all 20 areas with an

*Delays in diagnosing heart failure have both physical and mental health implications. In addition to untreated symptoms worsening over time, this leads to many unnecessary trips to A&E, severely impacting a person’s quality of life. Depression and anxiety are already common outcomes following a heart failure diagnosis, and these symptoms often become more severe should there be an unnecessary delay.*

**NICK HARTSHORNE-EVANS** Heart Failure patient, Founder and CEO, The Pumping Marvellous Foundation

\*\* Left Behind Neighbourhoods are classified as having:  
 • a higher proportion of people who self reported their health to be ‘bad’ or ‘very bad’ (9.1 per cent) than other deprived areas (8.1 per cent) and England as a whole (5.5 per cent)  
 • a higher prevalence of 15 of the most common 21 health conditions compared to other deprived areas and England as a whole, including high blood pressure, obesity and chronic lung conditions (COPD).

annual heart failure hospital admission rate at, or below, the national average were also placed equivalent to, or below, the national average on the index of multiple deprivation, except Cornwall and the Isles of Scilly.

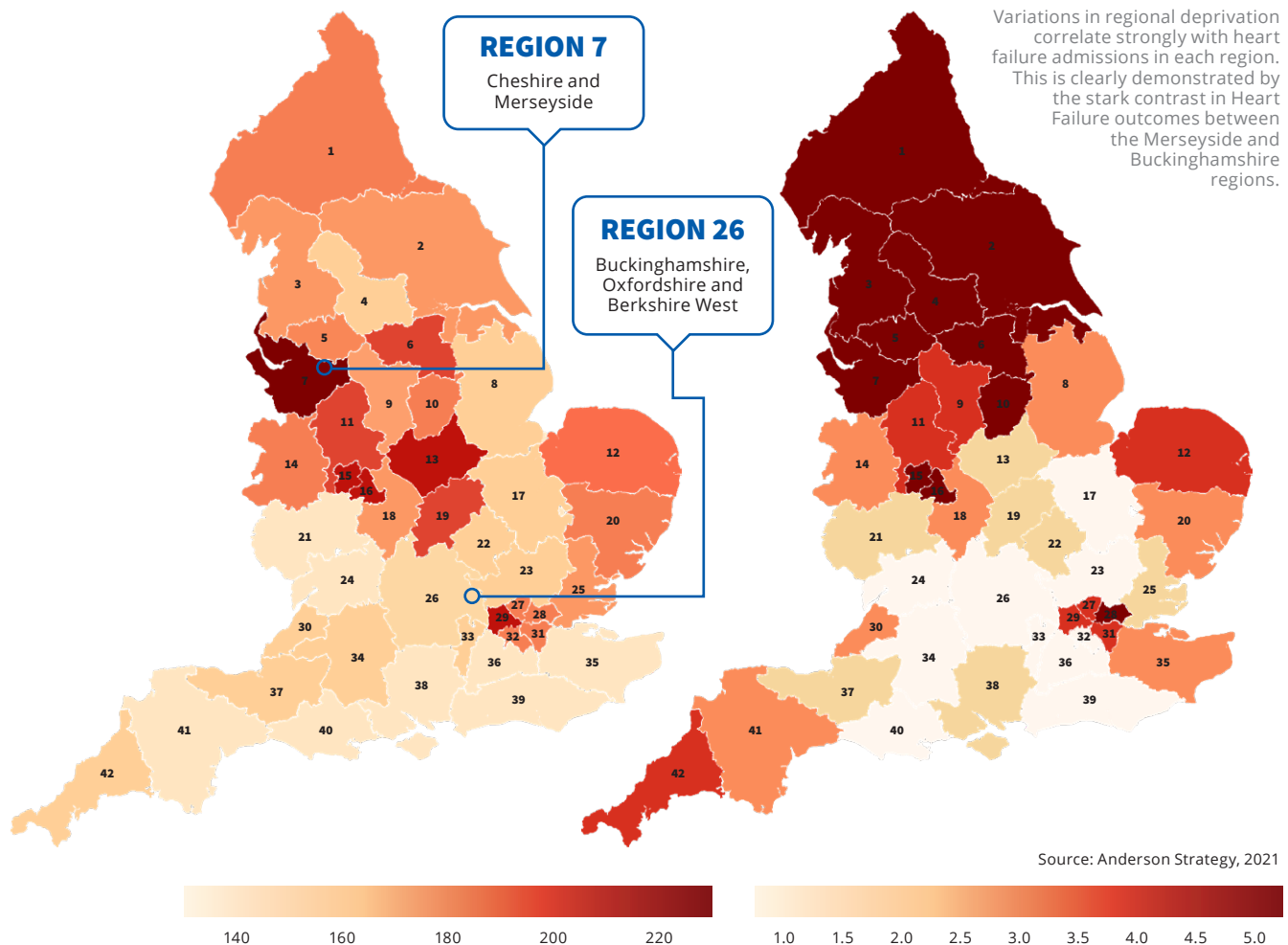
Furthermore, the region with the lowest index of multiple deprivation, Buckinghamshire, Oxfordshire and Berkshire West, has a

hospitalisation rate of 148 per 100,000 due to heart failure. In contrast, Cheshire and Merseyside, a region high on the index of multiple deprivations, has a hospitalisation rate of 232 per 100,000 heart failure cases, an increase of 57 per cent (see figure five).<sup>54</sup> This suggests that in more deprived areas, heart failure is not adequately diagnosed at an early enough stage.

**FIGURE FIVE: HEART FAILURE ADMISSIONS PER 100,000 AND INDEX OF MULTIPLE DEPRIVATION BY QUINTILE.**

HEART FAILURE ADMISSIONS PER 100,000

INDEX OF MULTIPLE DEPRIVATION BY QUINTILE  
(1 = LEAST DEPRIVED, 5 = MOST DEPRIVED)



In addition, the average survival length after a diagnosis of heart failure is 4.6 years in the least deprived areas of the UK, and 4.1 years in the most deprived areas - a six month difference.<sup>55</sup>

Trends in mental health in more deprived areas mean that the social burden is further exacerbated. A growing body of evidence, predominantly from high income countries, shows that there is a strong socioeconomic gradient in mental health, with people of lower socio-economic status having a higher likelihood of developing and experiencing mental health problems.<sup>56</sup>

### Gender disparities

Of the 1,529,175 patients diagnosed with heart failure between 2016-2021, 55 per cent were male and 45 per cent were female.<sup>57</sup> Despite this, and even though women are twice as likely to die from coronary heart disease as they are from breast cancer,<sup>58</sup> heart failure is a condition often associated as being most prevalent in older men. It is the case, however, that pregnant women are at higher risk of heart failure. There is a more than 40 per cent increase in the volume of blood circulating in a mother's body during pregnancy, while conditions such as pulmonary arterial hypertension and postpartum cardiomyopathy can potentially develop during this time.<sup>59</sup>

Even though the statistics indicate heart failure is prevalent in both men and women, women are twice as likely to be misdiagnosed, which as discussed, carries significant implications for patient outcomes. A 2020 study by Roche Diagnostics and the The Pumping Marvellous Foundation into heart failure diagnosis found that 44.5 per cent of women were incorrectly diagnosed with another condition before being diagnosed with heart failure – this compares with just 22.7 per cent of men.<sup>60</sup> A more recent survey of heart failure patients found that 75 per cent of men were tested for heart failure by their GP when presenting with symptoms,



**2X**

women are twice as likely to be misdiagnosed

compared to just 25 per cent of women. In addition, it was found that women waited an average of 20 weeks for their diagnosis following their initial appointment, compared to an average of 3.6 weeks for men.<sup>61</sup>

### Wider health and care system impact

At present, heart failure accounts for approximately two per cent of the total NHS budget, five per cent of unplanned admissions per year,<sup>62</sup> and is responsible for approximately 1 million inpatient days (2 per cent of all NHS inpatient bed days), per year.<sup>63</sup> In 2020/21, there were 72,758 emergency admissions due to heart failure and the average length of stay was 8 days.<sup>64</sup> Readmissions are also common, with a quarter of patients readmitted within three months.<sup>65</sup>

In addition to the capacity challenges that the above statistics indicate, not following the pathway recommended by NICE guidance increases the financial burden of the condition.<sup>66</sup> An echocardiogram costs £337 per patient, while an NT-proBNP test – which can help rule out the need for an echocardiogram – costs £28.<sup>67</sup> In 2018/19, the total cost for patients who had an echocardiogram with no further admission was £139m.<sup>68</sup> Therefore, in addition to the financial implications, there are patients waiting for echocardiograms who do not need them, in already extensive waiting lists. This leads to further delay in diagnosis and treatment, which results in higher costs and worse patient outcomes. Using NT-proBNP testing as part of the NICE recommended pathway has been shown to be a cost-effective strategy.<sup>69</sup>



Taking into account areas with higher deprivation, diagnosis is further complicated, especially where NHS trusts are already diverting resources to address patient needs associated with comorbidities. This can add significant system-wide pressures, as higher

costs are accrued in areas which are already less well-resourced, creating unnecessary pressure on the wider healthcare system and facilitating a spiral of poorer outcomes from those already the most at risk to inequity of care.



# Chapter Three

## DELIVERING FUTURE CHANGE

The data presented in this report clearly highlights the impact of a late diagnosis of heart failure on worsening outcomes, increased pressure on the NHS, and delays in receiving effective treatments. However, heart failure is a treatable and manageable condition if diagnosed early, so adherence to the NICE guidelines and use of recommended diagnostic testing is essential to achieving better patient outcomes. It is therefore crucial that partners from across the heart failure pathway come together and prioritise early diagnosis.

### National prioritisation of heart failure

**Recommendation: NHSE should prioritise cardiovascular disease and heart failure as part of their upcoming Long Term Plan refresh, with specific targets and milestones (akin to those already in place for stroke and cardiac arrest), to ensure ambitions outlined in the original plan remain a commitment.**

**Recommendation: The Network Contract Directed Enhanced Service (DES) for 2023/24 must financially incentivise heart failure in line with other key health areas to ensure greater provision and prioritisation of heart failure early diagnosis and management.**

As a first step in shifting momentum towards greater prioritisation of heart failure, there needs to be national direction, and the NHS needs to be the driving force behind this. The main way this can be achieved is through the Long Term Plan refresh, due in the coming months. It should prioritise cardiovascular disease and heart failure as well as including specific targets and milestones, similar to those already in place for stroke and cardiac arrest, ensuring that ambitions outlined in the original plan remain a commitment.

Additionally, the BHF have suggested that NHSE and devolved-nation equivalents should seek to recruit 'heart failure champions', working regionally and nationally to drive a full pathway approach to heart failure care, and be accountable

to strategic clinical networks and their equivalents. These champions should be selected based on leadership criteria as developed by those such as the NHS, British Society for Heart Failure, and the Primary Care Cardiovascular Society.<sup>70</sup>

Strong NICE guidance and frameworks have been developed to identify and treat heart failure, but this has not yet been translated and effectively implemented at local trust level. Raising the priority of heart failure cannot be achieved by the dissemination of template pathway management approaches alone. The Network Contract Directed Enhanced Service (DES) for 2023/24 must financially incentivise tackling heart failure, in line with other key health areas, to ensure the greater capacity, provision and prioritisation of early heart failure diagnosis and management.

### Pathway transformation

**Recommendation: Cardiac Networks to introduce breathlessness pathways using NT-proBNP testing in line with NICE recommendations and work with PCN CVD leads to improve the early identification of patients with potential heart failure.**

Pathway transformation at a local level is crucial to enable the early identification of patients and reduce the number of patients diagnosed following an emergency admission. Heart failure champions and cardiac networks should provide a leadership role, bringing together stakeholders across the local healthcare system to create a pathway fit for the local population.

One example of transformation is in Cheshire and Merseyside Health and Care Partnership, which has developed a fully integrated heart failure pathway and supporting education material for clinicians to support the early identification and management of heart failure.

With evidence showing low adherence to the NICE recommended referral times for patients with a high NT-proBNP level,<sup>71</sup> networks should

include rapid referral pathways to allow prompt echocardiography and management of patients most at risk of hospitalisation.

New pathways should include clear guidance on which point of the pathway patients should be referred, and where they should be referred to. In Nottinghamshire, a heart failure traffic light guidance system has been produced, which categorises heart failure patients under 'green', 'amber' or 'red' based on the severity of their condition and gives clear guidance on who is responsible for the ongoing management of their care.<sup>72</sup> Although the pilot is in its early phase, the prioritisation and management at primary care where applicable is positive, as it attempts to reduce the pressures on secondary care services.

#### **Increased access to diagnostic testing**

**Recommendation: Integrated Care Boards (ICBs), PCNs and Cardiac Networks should work collaboratively to ensure NT-ProBNP testing is accessible across primary care and in community diagnostic centres to ensure patients suspected of heart failure have timely access to testing that can inform whether an echocardiogram is needed.**

The current low level of NT-proBNP testing and the high wait times for echocardiography services mean that increased access to, and appropriate use of, testing is a crucial element of this pathway transformation. In order to improve the early identification of heart failure, aid in the triage of patients to specialist assessment and rule out unnecessary echos, ICBs should ensure there is equitable access to NT-proBNP testing across their local system.

As the convener of primary care organisations at neighbourhood level, PCNs should be the mechanism through which NT-proBNP testing is universally administered. Increasing the awareness of the benefits of NT-proBNP testing and guidance on referring patients with high levels is key. To maximise this impact, PCNs should look

to partner with regional cardiac networks to obtain strategic advice, promote best practice on testing, and avoid regional testing variation.

In a recent The Pumping Marvellous Foundation survey of heart failure patients, respondents were asked to choose service changes or new models of care that they would prefer to be continued or to be introduced in their local Heart Failure services. An overwhelming majority (71 per cent) chose the 'one stop diagnostic Heart Failure clinics', consisting of a single visit incorporating heart failure consultant review and echocardiography.<sup>73</sup>

This aligns with the Richards Review into diagnostics in 2020, which recommended the establishment of 'one-stop shops' in communities.<sup>74</sup> CDCs could play a key role in the early diagnosis of heart failure by increasing diagnostic capacity and acting as a referral centre for patients with breathlessness. This in turn could reduce the wait times for key services such as echocardiography and relieve pressure on the acute sector.

#### **Educating healthcare professionals**

**Recommendation: Training for new and existing healthcare professionals in primary and secondary care should include the value of NT-proBNP testing and the appropriate diagnostic pathway in line with NICE heart failure diagnosis and management in adults' guidelines [NG106]. Specific focus should also be applied to ensuring detailed knowledge on the signs and symptoms of heart failure, including on the risk of heart failure in women to address gender disparities.**

While pathway transformation is important, the early recognition of signs and symptoms of heart failure is essential if patients are to be appropriately managed along these pathways.

Data shows us that many patients are initially misdiagnosed, especially women.<sup>75</sup> Furthermore, the majority of heart failure

patients have another long term condition that could complicate the identification of heart failure.<sup>76</sup> Therefore education for healthcare professionals on the signs and symptoms of heart failure, in the context of comorbidities, should be prioritised.

The Darlington Integrated Heart Failure model is a joint venture which has seen the increased role of training help to more accurately diagnose heart failure. The collaboration is between primary and secondary care, through GPs, nurses, and CVD leads, across all 11 Darlington practices who were given extra training. If heart failure symptoms presented, they had access to NT-proBNP testing to guide the need for echocardiography and referral to the one-stop diagnostic clinic. Between 2013 and 2017, between 59 and 79 per cent percent of patients referred annually were confirmed as having heart failure, much higher than previous rates.<sup>77</sup>

### **Increasing awareness amongst the general public**

**Recommendation: The BEAT symptom checker – Breathlessness, Exhaustion, Ankle Swelling, Time for a simple blood test – should be universally agreed upon, recognised, and promoted at all levels of the NHS.**

As well as healthcare professionals, it is essential that the public are also educated on the signs of heart failure, and are encouraged to speak to a doctor if exhibiting any of the symptoms. The patient organisation, The Pumping Marvellous Foundation, have developed a symptom checker which highlights the main symptoms of heart failure, as well as emphasising the importance of seeing a GP, while also communicating the simplicity of the NT-proBNP test.<sup>78, 79</sup>

**B** – breathlessness  
**E** – exhaustion  
**A** – ankle swelling  
**T** – time for a simple blood test

In raising awareness of strokes, the FAST acronym has been widely publicised to healthcare professionals and the public through mediums such as TV and newspaper adverts, as well as in GP services. To ensure an equitable understanding of the symptoms associated with heart failure, a similar approach should be taken by the NHS to increase levels of awareness among the general population.

### **Collaborative working to improve standard of care**

**Recommendation: Collaboration between patient organisations, industry, and the NHS should be prioritised to ensure those who typically receive inequitable outcomes in healthcare (women, people from ethnic minority backgrounds, those living in deprived areas) receive quality and appropriate resources and information on heart failure. Patients should feel empowered to seek investigation from their GP, should they have concerns.**

**Recommendation: Industry should collaborate to provide essential capacity and resource support to healthcare system leaders and heart failure advocates, by providing information, research and tools that will drive improved outcomes for people with heart failure. This cooperation should focus on the entire patient pathway, from prevention and diagnosis, through to treatment.**

As mentioned earlier in the report, women and those from areas with higher levels of deprivation often suffer worse outcomes

in heart failure care. It's therefore essential that patient groups, industry and the NHS come together to address these inequalities. By taking a holistic view of people living with heart failure, it will be easier to provide the appropriate resources and information to these groups, so that they feel empowered to speak to their GP about any worrying symptoms.

In addition to work being done by charity and professional organisation partners, industry should also join this collaborative effort to improve patient outcomes across the heart failure pathway. Industry has access to essential capacity and resources which are invaluable to healthcare leaders. These resources and insights will guide healthcare professionals to act where it's most needed, in turn improving patient outcomes.

### **Adoption of innovations**

**Recommendation: Further evaluation and adoption of digital technologies, including artificial intelligence (AI) and portable echocardiography, to support earlier diagnosis of heart failure.**

A number of projects are ongoing in the UK on the use of digital and AI technologies to optimise heart failure diagnosis. As an example, the GRASP-HF tool is a quality improvement solution, developed at the University of Nottingham, that has been shown to assist GP practices in identifying patients at risk of heart failure (case finding) and can also be used to integrate clinical data in order to improve the management and care of patients with heart failure.<sup>80</sup> Furthermore, CVD Prevent, a national primary care audit that automatically extracts routinely held GP data covering diagnosis and management of several high-risk conditions including heart failure, has been recognised by NHS England as an important tool for Primary Care Networks, as it provides the means to improve early diagnosis and subsequent outcomes.<sup>81</sup>

The OPERA trial in NHS Greater Glasgow and Clyde is another excellent example of the benefits of introducing innovative technologies into the heart failure diagnosis pathway. The project, which was conducted in collaboration with the West of Scotland Innovation Hub, investigated the impact of introducing a point of care (POC) echocardiography device, with integrated AI analysis within their heart failure diagnostic services. Since January 2021, more than 700 people referred from the community for investigation of suspected heart failure have consented to taking part in the trial. During the first quarter of 2021, wait times for investigations were reduced from almost 12 months to less than 12 weeks, and the corresponding commencement of treatment earlier in the patient's disease has been found to reduce hospitalisation episodes.<sup>82</sup>

The establishment of ICBs as statutory bodies on 1st July 2022 offers new opportunities to embed increased testing and AI tools as key regional priorities and fully integrated into ICS population health strategies, sharing best practice where applicable. To facilitate the adoption of such tools, ICBs across England should provide funding to evaluate and adopt new digital and AI technologies once regulatory approvals and licences are in place.

# Conclusion

Late diagnosis of heart failure is a serious and growing problem for the UK, having a hugely detrimental impact on the nation's health outcomes and unnecessarily increasing pressure on an already stretched NHS. Along with other areas of health and care provision, this issue has been compounded by the highly disruptive impacts of Covid-19. Fortunately, there are already tools and guidelines available to care providers that can mitigate this growing problem. Part of the solution lies in raising awareness of the assets at our disposal.

The health system requires a rejuvenated approach to heart failure diagnostics, with increased NT-proBNP testing, particularly within primary care, which could rapidly reduce average diagnosis time frames across the country. Harnessing innovative tools such as AI and machine learning will be critical, if the efficiency and accuracy of heart failure prognosis is to be improved.

As late diagnosis and its associated impacts tend to be more common in more deprived communities, and among women, the late diagnosis of heart failure contributes to existing health inequalities in the UK. The strategic prioritisation of the provision of NT-proBNP tests,

alongside a national education programme around the symptoms of heart failure and the benefits of the tests must be a priority.

While the scale of the task is undeniable, there currently exists a unique opportunity to address it. The present wave of health system reform and its onus on cross-system and cross-sector collaboration provides multiple avenues and mechanisms through which earlier heart failure diagnosis can be achieved. At system level, ICBs must work to place heart failure as crucial regional priorities, harnessing innovative tools already at their disposal and currently localised instances of best practice. Likewise, PCNs and their neighbourhood level connections must be harnessed to encourage greater testing as well as engaging in proactive outreach campaigns with local communities to raise awareness of heart failure.

It is only with a coherent and collaborative approach from all sector stakeholders that this challenge can be resolved. Change in the diagnosis of heart failure requires all players to seize the opportunity to tackle this socio economic health disparity in heart failure diagnosis.

*The NHS needs support to ensure the right interventions are available at the right time. For example, GPs and primary care teams need education on the signs and symptoms of heart failure and to have greater access to NT-proBNP testing. Patients must then be triaged effectively to reduce the waiting time between the test result and an echocardiogram – the positive outcomes to patients and their families and the wider NHS cannot be understated.*

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