



**The Heart  
Failure Policy  
Network**

# **Pressure point 1: Presentation and diagnosis**



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# About the Heart Failure Policy Network

The Heart Failure Policy Network is an independent, multidisciplinary group of healthcare professionals, patient advocacy groups, policymakers and other stakeholders from across Europe whose goal is to raise awareness of the unmet needs surrounding heart failure (HF) and its care. All members donate their time for free. All Network content is non-promotional and non-commercial.

Network secretariat functions and the development of *The handbook of multidisciplinary and integrated heart failure care* and supplementary material, including pressure points, were supported by Novartis Pharma over 2017–18 and St Jude Medical (now Abbott) in 2017. Novartis Pharma has commented on drafts without a right of veto. More information on the Network, its members and Terms of Reference is available at [www.hfpolicynetwork.eu](http://www.hfpolicynetwork.eu). The secretariat is provided by The Health Policy Partnership, an independent health policy consultancy based in London.

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Considerable thanks and acknowledgement is due to members of the HF Policy Network, in particular members of the 2018 Project Advisory Group, and case study leads who volunteered for an interview:

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# 1. Top five things you need to know


**1 A timely and appropriate diagnosis of heart failure (HF) is the foundation of effective management.**<sup>1</sup> It ensures patients receive treatment as early as possible, avoid hospitalisation and achieve the best possible outcomes.<sup>2-5</sup>


**2 Both non-specialist healthcare professionals and the general public may have difficulty recognising HF symptoms.**<sup>2 6 7</sup> Tiredness and shortness of breath, for example, may be dismissed as inevitable signs of ageing or confused with other conditions such as diabetes, respiratory conditions or other heart diseases.<sup>5 8 9</sup>

**3 There is no one diagnostic test for HF;<sup>4 10</sup> however, specialist-led diagnosis with an echocardiogram (echo) is the gold standard.**<sup>4</sup> It provides comprehensive information on the heart and its capacity to pump blood around the body, which is crucial in establishing diagnosis, the most appropriate treatment and prognosis.<sup>11</sup>

**4 Unfortunately, diagnosis is routinely suboptimal in many European countries.** HF is often only confirmed after severe damage to the heart has taken place.<sup>5 12</sup> Poor multidisciplinary working and lack of capacity frequently leads to harmful delays<sup>2 11 13-15</sup> and inconsistent application of key diagnostics.<sup>16</sup> Assistive diagnostic tools such as natriuretic peptide (NP) testing are still not fully reimbursed or recommended by national guidelines<sup>11 17</sup> despite recognition in European guidelines.<sup>4</sup>

**5 There are options to tackle bottlenecks in diagnostics.** The Irish Cardiac Society estimates that NP testing could reduce demand on the specialist diagnostic services by 30%.<sup>3</sup> Direct referrals to echo by GPs can safely reduce referrals to cardiologists by as much as two-thirds.<sup>18 19</sup>

 **See section 2:**  
What is the issue?

 **See section 4:**  
What is good practice?

 **See section 6:**  
What is really happening, and why?

## 2. What is the issue?



**See PP:**  
Patient empowerment and self-care



**See PP:**  
Clinical management

### It is vital to diagnose HF early

The accurate and timely diagnosis of HF is critical in guiding appropriate treatment and therefore maximising patient outcomes,<sup>1 10 12 20</sup> for example reducing hospitalisation.<sup>4</sup> Diagnosis should occur at early stages of disease, as disease progression is irreversible<sup>5</sup> and effective pharmacological and lifestyle management for HF requires time to be optimised.<sup>21</sup> However, most patients are diagnosed at the late symptomatic stage after permanent damage to the heart has occurred.<sup>21</sup>

### Diagnosis of HF is challenging

HF is difficult to diagnose.<sup>10 22</sup> Symptoms such as tiredness and shortness of breath may be dismissed as inevitable signs of ageing or consequences of other conditions, such as diabetes or other heart diseases,<sup>8</sup> particularly in older patients.<sup>15</sup> People with HF often have comorbidities and are not always admitted to a hospital cardiology ward, where they would be more likely to receive appropriate HF diagnosis and treatment.<sup>23 24</sup>

### There is no single diagnostic test for HF

It is vital to correctly diagnose the type of HF (see box on page 6) and its causes to make effective treatment decisions.<sup>4 10</sup> Diagnosis is likely to include many tests as key information arises from various sources, from patient medical history to physical examination, NP testing (blood analyses) and other tests such as echo, electrocardiogram (ECG) or X-ray.

### ‘Red flag’ symptoms should trigger investigation

Although many of the symptoms of HF are common to other conditions, the combination of three key symptoms (shortness of breath, fatigue and swollen limbs) is a clear ‘red flag’ for a possible diagnosis of HF.<sup>5</sup> Basic awareness of HF may help many professionals with referral to specialists.



### Who is at risk of developing HF?

HF is often the end-result of illnesses that damage the heart and interfere with its normal functioning.<sup>5</sup> Measures for preventing HF should target all preventable causes, including high blood pressure, coronary heart disease, diabetes, heart valve disease and heart muscle disease (e.g. alcohol-related). Some diseases that cause HF, however, cannot be prevented. For example, HF may be caused by a virus or can occur because of heart problems that arise during pregnancy (peripartum cardiomyopathy).<sup>5</sup>

## 3. Evidence of effectiveness

### Research has shown the benefits of early HF diagnosis and prevention:

- Delays to hospital treatment as little as 4–6 hours after acute onset of HF symptoms can increase a patient’s risk of death.<sup>5</sup>
- NP testing has been shown to be cost-effective, primarily by safely ruling out patients for echocardiography.<sup>11 25 26</sup> For example, the Irish Cardiac Society estimates that NP testing could reduce demand on specialist diagnostic services by 30%.<sup>3</sup>
- Direct referrals to echo by GPs can safely reduce referrals to cardiologists by as much as two-thirds,<sup>18</sup> save time and potentially allow GPs to effectively treat patients themselves.<sup>19</sup>
- Much can be done to reduce progression to HF among high-risk groups.<sup>5 10 27</sup> This requires intensive therapy and management of risk factors, such as high blood pressure, high cholesterol and type 2 diabetes.<sup>28</sup> For example, intensive treatment of high blood pressure in people with no HF can reduce progression to HF by as much as 40%.<sup>29</sup>
- Using preventive measures, for example management of blood pressure, and commonly available medications, such as angiotensin-converting enzyme (ACE) inhibitors and beta-blockers, can reduce the frequency of hospitalisation for people with early (asymptomatic) HF.<sup>4</sup>

## 4. What is good practice?

### HF specialist centres should act as a 'one-stop' diagnostic service

Achieving a comprehensive HF diagnosis, which includes identifying the underlying causes and origins of HF, requires multiple tests.<sup>4</sup> HF clinics should aim to work as a 'one-stop' service.<sup>6</sup>

### Prompt diagnosis is a team effort, spanning primary and secondary care

Timely diagnosis is vital for all patients, particularly those with acute symptoms.<sup>5</sup> Multidisciplinary teams must clarify diagnosis, address symptoms and reversible factors, initiate evidence-based therapies and treat comorbidities.<sup>6</sup> People with HF typically present in primary care,<sup>30</sup> yet initiation of treatment depends on symptoms being recognised, investigated and followed-up via effective referrals to secondary care specialists.

### Specialist-led diagnosis is vital to definitive diagnosis

Echocardiography is the definitive investigation into heart tissue changes and underlying causes of HF.<sup>31</sup> It may be performed by electrocardiologists, but typically requires interpretation by a trained specialist cardiologist. Other physicians, such as GPs or internal medicine specialists, may attempt a working diagnosis based on the signs and symptoms alone, or proceed to alleviate symptoms. However, they will lack vital medical information as to the true underlying causes, and therefore the most appropriate treatment.<sup>5 32</sup>

### HFpEF and HFrEF: the two main types of HF

One of the most important considerations for treatment of HF is to distinguish between HF with reduced ejection fraction (HFrEF) and HF with preserved ejection fraction (HFpEF). This typically requires an echo conducted by a specialist. The symptoms of both types of HF may be similar and both are routinely referred to as 'heart failure', but the underlying causes, treatments and prognosis are significantly different.<sup>4</sup>

### Primary care must make good use of effective screening techniques

Blood tests for NP levels are recommended by European Society of Cardiology (ESC) guidelines as an initial diagnostic test, if available.<sup>4</sup> NP testing, potentially combined with an ECG to help ensure robust screening,<sup>31</sup> can help reduce specialist diagnostic bottlenecks through better risk-profiling<sup>33 34</sup> (ruling out HF). Some approaches combining NP testing with other diagnostics may help guide preventive treatments<sup>4</sup> and referrals to cardiologists.<sup>35</sup>

### Echocardiography, electrocardiography and NP testing: the key diagnostic tests and how they work

**Echocardiography** is indispensable in establishing a definitive diagnosis and in determining appropriate treatment.<sup>4</sup> An echo enables this by providing information on the heart and its capacity to pump blood around the body, such as chamber volumes, ventricular systolic and diastolic function, wall thickness, valve function and pulmonary hypertension.<sup>6</sup>



**Electrocardiography** is much more widely available than echocardiography and is recommended for preliminary investigation.<sup>6</sup> The ECG provides information on causes of disease (aetiology) and may provide indications for treatment. HF is unlikely in those presenting with a completely normal ECG, so this test may help rule out HF.<sup>4</sup>

**Blood tests for NP levels** are a relatively affordable lab test and can be used as an initial diagnostic tool.<sup>4</sup> NP concentrations in blood plasma suggest heart tissue damage, and so patients with normal levels may be excluded from further (typically expensive) diagnostics.<sup>4 25</sup>

5. Involving a multidisciplinary team



Comprehensive diagnosis of HF involves a range of professionals.

 Role	Patient	Cardiologists	Primary care physicians	Internal medicine specialists	Primary care and HF specialist nurses	Carers and family
 Responsibilities	<p>People diagnosed with HF may feel overwhelmed and should be encouraged to ask questions to ensure they understand the condition and necessary lifestyle changes.<sup>36</sup> At diagnosis, it is helpful to focus on understanding their health condition, whom they should contact if they have questions or aggravation of disease, and how to self-care. Patients should be supported to be honest about their feelings when speaking to their families so families can provide the best support.<sup>36</sup></p>	<p>Cardiologists are usually the specialists that achieve the definitive diagnosis of HF and manage initiation of treatment.<sup>37</sup> They arrange and interpret exams,<sup>36</sup> such as echo and NP testing, being able to make a comprehensive diagnosis and develop a care plan. They should answer questions patients may have, and should work in collaboration with HF specialist nurses and primary care professionals to ensure patients receive the best possible care following diagnosis.<sup>6</sup></p>	<p>GPs have a crucial role in diagnosis of HF as they are usually the first point of contact for people experiencing HF symptoms and signs.<sup>30</sup> They should refer patients to specialists so diagnosis can be confirmed and underlying causes identified.<sup>6</sup> GPs should collaborate with specialists to ensure treatment is continued and the person diagnosed with HF is supported throughout this transitional period.<sup>28</sup></p>	<p>Internal medicine specialists are sometimes the physicians that diagnose and manage HF.<sup>38</sup> They should collaborate with cardiologists (ideally HF specialist cardiologists) to ensure a clear understanding of HF and results from diagnostic tests, and should also collaborate with HF specialist nurses and primary care professionals.<sup>6</sup></p>	<p>Nurses often play a major role in ensuring that patients who show symptoms and signs of HF are identified and seen by a physician. Upon diagnosis, HF specialist nurses have a vital and immediate role to support the person with HF,<sup>36</sup> helping them understand HF and self-care.<sup>6,39</sup></p>	<p>Family members of a person diagnosed with HF can offer support, both emotional and psychological, to help them cope with the diagnosis and overcome challenges that arise with progression of disease.<sup>36</sup></p>

## 6. What is really happening, and why?

### Diagnosis is often not rapid or detailed enough

The diagnosis of HF has not improved significantly in the past ten years.<sup>13 15 40-42</sup> Patients frequently report misdiagnoses and delays in obtaining an accurate diagnosis of HF, causing them significant distress. In one UK survey, 38% of HF patient respondents said they were initially treated for other conditions.<sup>11</sup> Delays from first presentation to definitive diagnosis (for example, from a cardiologist) range from several months in Germany<sup>43</sup> to up to a year in Ireland,<sup>3</sup> with serious delays also noted in England and Scotland.<sup>11 14</sup> This may be a result of inconsistent use of key diagnostics, such as echo and ECG.<sup>16</sup>

### Awareness of symptoms is low compared with other major diseases

A major study conducted in 2002 revealed that 86% of people in Europe had no understanding of HF; while half of participants could correctly identify major stroke symptoms, only 3% were able to link the three typical HF symptoms to HF.<sup>7</sup> Poor awareness of the symptoms of acute HF often leads to a time lapse between developing symptoms and seeking medical attention, which delays diagnosis and treatment.<sup>8</sup>

### Diagnostic services are insufficient

Access to specialist diagnostic services for HF is insufficient,<sup>2</sup> for example due to shortages of technical skills in echocardiography.<sup>14</sup> Primary care professionals report poor quality of interactions with secondary care and problems referring patients to specialist diagnostic services,<sup>13 15</sup> which may also obstruct diagnostic pathways.

### Primary care settings show the greatest inequalities

Diagnostic practices in primary care and general hospitals lag far behind specialist settings in adherence to guidelines,<sup>16 44</sup> leaving many patients with unacceptable diagnostic uncertainty.<sup>12 45</sup> Fear of side effects has contributed to underutilisation of ACE inhibitors and beta-blockers for patients with HF in primary care.<sup>46</sup>

### The primary care workforce is largely unprepared

Non-specialists often lack confidence and appropriate resources to establish an accurate HF diagnosis. Primary care physicians may struggle with knowledge of symptoms,<sup>2</sup> preliminary investigations,<sup>16 45 47</sup> interpretation of results from specialist tests,<sup>20</sup> and compliance with guideline recommendations and research evidence.<sup>13 15 48 49</sup> For example, a study of GP practices in Germany found that only 41% of HF patients had received an ECG, and a national Swedish study found that only half of primary care patients with suspected HF had a confirmed diagnosis upon presentation to specialists.<sup>12</sup>

### Several factors need addressing to support primary care professionals

Underlying factors for the limited preparedness of the primary care workforce may include time pressures, pace of change in guidelines, low availability of HF management programmes, limited participation in HF registries, and reimbursement and budgetary constraints.<sup>12 45 50</sup> Calls for greater education in diagnostics for primary care and other non-specialist professionals have been made by key commentators in several countries – such as England, Finland, Ireland and the Netherlands – and at the European level.<sup>4 5 10 11 48 51</sup>

### Modern diagnostic tests such as NP testing are hugely underused

Across Europe, the use of NP testing in HF is highly variable<sup>32</sup> despite evidence of cost-effectiveness and its recognition in European guidelines.<sup>11 25 26</sup> For example, in England, estimates suggest that one-third of GPs and one-third of hospitals do not have access to NP testing,<sup>11</sup> and in Belgium, a nationwide study found that only 11% of primary care patients with suspected HF received NP testing.<sup>16</sup> Reasons for this are varied but include challenges with reimbursement and exclusion from national clinical practice guidelines.<sup>44 52</sup> In Italy, the reimbursement of NP testing differs from one region to another; ten of 21 regions have a tariff for the use of biomarkers that is higher than the one suggested nationally.<sup>44</sup>

### Patients are frequently not given high-quality information at diagnosis

Most patients are given little information about their diagnosis, and too many report the belief that nothing can be done about their condition.<sup>53</sup> GPs often lack understanding of treatment options and fear that information on end-of-life may create anxiety, so they feel reluctant to fully communicate patients' prognosis.<sup>15</sup> Some cardiologists also feel they have not been appropriately trained to communicate an HF diagnosis or additional difficult information.<sup>15</sup>



**See PP:**  
Clinical  
management




**See PP:**  
Advance care  
planning

# 7. Case studies and reproducible tools


This section presents case studies from across Europe of innovative and best practice in presentation and diagnosis of HF, alongside tools to support and understand diagnosis.

## Case studies




### Irish Cardiac Society, Ireland

The Irish Cardiac Society established a working group with GPs and specialists to improve HF diagnosis in the community.<sup>3</sup> The goals of the project include an increase in access to relevant diagnostic tests within two to six weeks of presentation at primary care, and specialist opinion within the following four weeks.




### Consensus on standards for HF clinics, Spain

In 2016, the Spanish Society of Cardiology published a consensus for classification and quality standards of HF clinics.<sup>33</sup> It recommends that HF clinics develop integrated care pathways for HF management, which should incorporate diagnostic criteria and therapeutic recommendations of the ESC guidelines. The consensus further recommends that NP testing and echo be available in HF clinics.<sup>33</sup>



### Challenging policy inertia for HF diagnosis, The Belgian Charter for Heart Failure, Belgium


NP testing is not always reimbursed in Belgium despite being recommended across Europe. The Belgian Charter for Heart Failure demands reimbursement for guideline-recommended diagnostic tests as one of the five priorities for policy action.<sup>57</sup> The initiative has been led by leading cardiac organisations and has been signed by 12,000 people to date.



### Swedish HF registry, Sweden


In 2003, Sweden was the first European country to develop a comprehensive HF registry.<sup>54</sup> The SwedeHF gathers information on each patient, including aetiology of HF, clinical characteristics and medication.<sup>12</sup> Since 2005, it also includes patient-reported symptoms and quality of life.<sup>55</sup> Physicians and centres can access information on patients they register and some data for comparison with other participating centres. The goals of SwedeHF are to reduce morbidity and mortality, and to increase quality of life of people living with HF by ensuring guideline-compliant care. A registry-based randomised clinical trial to assess treatment of HFpEF is currently enrolling participants and will include follow-up until 2022.<sup>56</sup>

### Tools for assessing self-care education and practice



#### Algorithm for diagnosis, Sweden

Swedish guidelines for management of HF include an algorithm to support clinicians to diagnose HF.<sup>57</sup> The algorithm is based on European guidelines.<sup>12</sup>



#### Heart Failure Toolkit, Pumping Marvellous, UK

The UK's HF association Pumping Marvellous developed the guide HOPE to help people diagnosed with HF.<sup>58</sup> It provides information on potential causes of HF, possible treatments, roles in the care team and self-care behaviours.

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## Notes

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