Executive summary

Heart failure (HF) is a serious chronic condition where the heart cannot pump enough blood to support the needs of other organs in the body.¹

The burden of heart failure in Europe is substantial and likely to grow. HF is the leading cause of hospitalisation in people over the age of 65 and carries a high cost to healthcare systems. It also exerts a significant economic toll on patients, their families and society in general.¹

At present, 15 million people are living with heart failure in Europe², and it is one of the few cardiovascular conditions whose prevalence continues to rise.³

Heart failure is a largely neglected condition and many cases could be avoided through lifestyle and behavioural changes. Low awareness of HF (and its causes and symptoms) amongst the public and healthcare professionals¹,⁴ is coupled with poor understanding of the condition by policymakers. As a result, diagnosis often comes too late, and many health systems lack the expertise and capacity needed to control the problem.¹

Outcomes for people with heart failure are unacceptable – and can be poorer than many forms of cancer.⁵,⁶ Despite some notable improvements in survival rates, approximately 1 in 3 patients admitted to hospital with HF still die within one year.⁴ Beyond the risk of death, HF has a considerable, and lasting, impact on patient’s health and wellbeing. The debilitating nature of the condition can impact on all aspects of life and increase patient’s dependency on caregivers, which can lead to social isolation, anxiety and depression.⁷

Inequities in the way heart failure is diagnosed and managed has resulted in large variations in access to, and availability of, integrated models of care.⁸ We urgently need more uniform application of guidelines, equitable access to modern treatment, and holistic models of care.

Heart failure must be recognised as a condition that can be managed effectively. Evidence-based clinical guidelines exist to achieve this. Models that promote shared decision-making, patient education and support to self-manage have shown real improvements in care and patient outcomes. What is needed is leadership from policymakers at European, national and local levels to drive transformational change in health systems.
Policy recommendations

Improving the management and care for patients with HF will require policymakers at European, national and local levels to join together to address the following recommendations:

Make heart failure a strategic health policy priority

Create visibility for heart failure: integrate HF within national plans and policy platforms, and support the development of public awareness programmes.

Ensure the patient voice is heard at the highest level of policy: patient groups must be fully involved and consulted on national policy priorities, and be invited to help define quality care and support across the whole care pathway.

Expose the gaps in care: build a strategic and multi-disciplinary consensus on the pressure points and weaknesses in the system for HF, as well as its strengths, to identify urgent changes and best returns on investment in capacity building and workforce training.

Hold the system to account: encourage the development of registries, audits and monitoring systems, as well as financial incentives, to reward adherence to guidelines in primary and secondary care.

Support evidence-based policy objectives with sufficient resources: ensure national plans deliver on their objectives through investment in specialist clinics, professional capacity, devices and care, and guideline-recommended medicines.

Ensure that all patients with heart failure are provided with the best possible care throughout the course of their condition.

Improve diagnosis in primary and secondary care settings: promote HF education programmes for all healthcare professionals to recognise those at risk and ensure proper diagnosis of the condition.

Ensure quality education and support for patients and their families: invest in tailored resources, practical and appropriate professional support for patients and their families to effectively manage their condition.

Encourage person-centred approaches to care: develop comprehensive care models, including individualised care plans, patient and healthcare professional communication exercises, and shared decision-making protocols for patients with HF.
**Investment in professional capacity:** prioritise investment in HF specialist nurses, specialist HF clinics and cardiology care to reduce the risk of costly hospital admissions.

**Seamless transition of care:** develop HF management programmes from hospital to community care, or home settings, to ensure the seamless transition of patients.

**Equitable provision of medicines, devices and care:** focus on providing access to evidence-based medicines, devices and diagnostics tests that are appropriate for each patient.
A. Introduction

In 2012, the Heart Failure Association of the European Society for Cardiology (ESC) launched the Global Heart Failure Awareness Programme to help improve understanding and awareness of heart failure (HF). They issued a powerful call to action to policymakers, featured in their 2014 White Paper—calling upon all policymakers to give HF urgent attention at national, European and international level.

Building on this call to action, this report aims to serve as a backgrounder to focus policy discussions on what politicians and policymakers can do to improve the lives of 15 million patients with HF across Europe.

We hope this document will stimulate debate and tell you more about the proposed work programme for the European Heart Failure Policy Network—a unique group of parliamentarians, patient representatives, clinicians and other key stakeholders working together to help improve the prevention, management and care of heart failure. The Network has tasked itself to help define what governments can do to help turn existing policy recommendations into concrete, sustainable action at a European, national and local level. It offers participating policymakers, patients and all relevant stakeholders a unique opportunity to step up to the challenge for the benefit of patients, their families, and society.

B. What is heart failure?

Heart failure (HF) is a serious chronic condition in which the heart cannot pump enough blood to meet the needs of the body. This means that blood cannot deliver enough oxygen and nourishment to the body to allow it to function normally.

Key facts about heart failure:

- Fifteen million people in Europe have heart failure, and this number is increasing.
- Heart failure accounts for 1-2% of total healthcare expenditure in Europe.
- Worldwide, over one million new diagnoses of heart failure are made every year.
- Heart failure is the most common cause of hospital admissions in people over the age of 65.
- Up to one in five people at some point in their life will develop heart failure.
- Close to 80% of people with HF are over the age of 65, but symptoms are by no means a natural result of ageing.
Several important factors need to be considered about HF:

- **HF is not a disease as such, but a clinical syndrome occurring as a result of other conditions.** Typical signs and symptoms include breathlessness, fatigue and swelling of the ankles, resulting from an abnormality of cardiac structure or function.\(^4\)

- **HF is a chronic condition punctuated by acute episodes.** Poor management of the condition can increase the risk and frequency of acute episodes resulting in hospital admissions, poor quality of life for patients and high burden on healthcare systems. Each acute episode can, in turn, worsen the chronic condition leading to reduced cardiac function, high morbidity and mortality.\(^1\)

- **Clinically, a distinction is also often made between heart failure with reduced ejection fraction (HFrEF) and heart failure with preserved ejection fraction (HFpEF).** HFrEF (also referred to as systolic heart failure) occurs when the heart muscle does not contract effectively, whilst HFpEF (also known as diastolic heart failure) is when the heart muscle contracts but the ventricle does not fill with blood well in the relaxation phase (Figure 1).\(^12\)

**Figure 1:** Systolic and diastolic heart failure

Source: Cowie *et al* 2014\(^1\)
The diagnosis of heart failure is complex and many cases go undetected

Early diagnosis and recognition of heart failure are critical to ensuring patients receive the best available treatment as early as possible.4

Yet heart failure, particularly in its early stages, can be difficult to diagnose for doctors and hard to recognise for patients: There is no single test for HF; often signs and symptoms (e.g. swelling of the ankles, breathlessness or fatigue)1 are not specific to HF, and do not easily discriminate between HF and other possible diagnoses, such as chronic obstructive pulmonary disease (COPD).10,11 Recognition and appreciation of HF symptoms is difficult for patients as well - a European wide survey from nine countries reported that only 29% of patients believed that HF signs and symptoms indicated a ‘severe’ condition.4

In addition, heart failure often presents with multiple co-morbidities: HF may be caused by an underlying cardiac problem, or other factors which can be self-contained diseases in their own right (e.g. diabetes, high blood pressure, chronic obstructive pulmonary disorder) (see Figure 2).1,4 The presence of co-morbidities also makes management more complex for patients and physicians.4 Co-morbid patients usually have worse prognosis, and treatments for co-morbidities may interact with those for HF, with some drugs even causing worsening of HF in some patients.11

Figure 2: Common causes of heart failure
Why is heart failure a neglected condition despite the considerable burden it represents in human life and healthcare costs?

*Despite rising prevalence and a growing toll on society, HF remains somewhat of an unknown entity.* A fundamental issue with HF lies in its name: ‘failure’ which, in the minds of many people, implies death or irreversibility - a ‘lost cause’. In other words, HF is often viewed as an endpoint, reached as a result of other diseases and co-morbidities, not a condition in itself that is amenable to treatment.

*The fact that HF occurs mainly in the older population may also explain part of our neglect for the condition.* Many people may not recognise symptoms or signs of HF until it has reached a severe stage, or they may mistake symptoms as being the natural result of ageing. They may prefer to “suffer in silence” instead of drawing attention to their suffering and becoming a potential burden for their families. Many may also lack the knowledge, confidence and support to self-care and live with HF.

*Only limited data exists on the global incidence of heart failure.* This can be attributed to a lack of data in some geographies such as the Middle East or Asia and even in some European countries. In addition, some countries’ guidance on death certificates states that HF is a mode of death, which can discourage doctors from recording it as the cause of death. As a result, the recorded number of deaths attributed to HF may be underestimated.

*Finally, compared to other heart conditions, heart failure has seen relatively little innovation* in terms of treatment and care in the past several decades. For example, the last new drug to receive approval for HF was launched nearly 10 years ago.
C. Heart failure should be a policy priority

As patient numbers and economic costs associated with heart failure continue to rise with the ageing of our population, the public health imperative to reduce this burden is critical. Adding to the case for investment is the fact that reducing the burden of HF will have a ripple effect on public health, given that HF shares many risk factors with other chronic diseases, and often presents itself at the same time as other conditions.

Six reasons why heart failure should be a policy priority

1. It is one of the few heart conditions where prevalence is rising.\(^\text{13}\)
2. It poses a considerable, and growing, cost to society.\(^\text{1}\)
3. Many cases of heart failure could be prevented.\(^\text{14}\)
4. Public awareness is low - most people would not recognise signs and symptoms of HF.\(^\text{15}\)
5. It has poorer outcomes than many of the most common forms of cancer.\(^\text{6,8}\)
6. The management of HF is suboptimal and significant inequities exist.\(^\text{4,11}\)

1. Heart failure is one of the few heart conditions where prevalence is rising.\(^\text{13}\)

Increasing prevalence is due mostly to improved survival following myocardial infarction and other chronic conditions (which may cause damage to or place an extra burden on the heart), coupled with detrimental lifestyle behaviours and ageing of the population.\(^\text{4,13,16}\)

2. Heart failure carries a considerable cost to society

Heart failure is the leading cause of hospitalisation in people over the age of 65\(^\text{17}\) accounting for 5% of all acute hospital admissions in Europe.\(^\text{16}\) Its demand on our healthcare systems is expected to grow with the ageing of the population and rising prevalence of the condition.\(^\text{1}\)

Hospital costs for HF are high and account for the major part of HF healthcare costs.\(^\text{18}\) HF accounts for 1-2% of direct healthcare expenditure in developed countries.\(^\text{1}\) For example, the average cost in the UK has been estimated as €26 million per million
population; €37 million per million population in Germany; and €39 million per million population in France.\textsuperscript{19}

Re-hospitalisation rates are high and range from 24\% at 12 weeks to 44\% at 1 year post-discharge depending on the study.\textsuperscript{1} In addition to hospital costs, specialist outpatient cardiology care, GP services, community care and palliative care also impose a high cost.

Beyond the direct healthcare costs, the burden of HF on patients and their families is considerable. Caregivers bear a significant emotional, physical and economic toll from looking after a relative with HF.\textsuperscript{4} Similarly, lost productivity for patients is an important social cost.

3. Many cases of heart failure can be prevented by managing risk factors

Patients often do not recognise that many of the risk factors associated with HF can be managed by making lifestyle changes, such as regular exercise, a balanced diet and reducing alcohol consumption.\textsuperscript{1,14} Many cases of HF could be prevented if patients with these underlying risk factors were identified and treated at an earlier stage.\textsuperscript{1}

As noted previously, HF is a clinical syndrome occurring as a result of other conditions, many of which are themselves largely preventable. For example ischaemic heart disease (IHD) is thought to be the leading cause of heart failure,\textsuperscript{14,20} and it is estimated that over a third of patients will develop HF approximately 7-8 years after a heart attack.\textsuperscript{14} Policymakers should consider these commonalities when developing chronic disease prevention strategies.

4. Low awareness and understanding carries a high price

As individuals are often unaware of the signs and symptoms of HF, they are unlikely to seek treatment until they have an acute episode, leading to poor diagnosis, increased risk of hospitalisation and premature mortality.\textsuperscript{1} Lack of recognition of symptoms is also thought to explain the long delay between onset of symptoms and seeking medical care in HF patients.\textsuperscript{1} Poor recognition of HF among many healthcare professionals also contributes to rates of under-diagnosis.\textsuperscript{4}

In a large survey in nine European countries, 3\% of respondents were able to identify correctly the symptoms and signs of heart failure, as compared to 28\% who could do so for a heart attack. Two thirds considered heart failure to be a normal part of the ageing process.\textsuperscript{15}
5. Heart failure has poorer outcomes than many forms of cancer

Although there have been notable improvements in survival rates for people with HF in Europe over the past few decades,\(^4\,21\) we are still failing people with HF. Every patient admitted for an acute heart failure episode has a high risk of readmission and death,\(^22\) and outcomes overall remain very poor, with 1 in 3 patients admitted to hospital with HF dying within 1 year.\(^4\)

**Outcomes for people with heart failure:**

- Approximately 1 in 10 patients hospitalised with HF will die in hospital\(^1\)
- An estimated 1 in 4 will be readmitted to hospital within one month\(^1,3\)
- Around 1 in 3 will die within 1 year\(^4\)
- Approximately 1 in 2 will die within 5 years\(^24\)

Research from both Scotland\(^5\) (Figure 3) and Sweden\(^6\) show patients admitted to hospital with HF have a lower chance of surviving 5 years than patients admitted with a heart attack or many of the most common forms of cancer.\(^5,6\) These results were similar for both women and men.

**Figure 3:** Five-year survival following admission to hospital for heart failure compared to myocardial infarction, prostate, bowel, and lung cancer (Scottish data)

![Graph showing survival rates for different conditions](https://example.com/graph.png)

Adapted from Stewart et al. 2001\(^5\)
Beyond the risk of death, HF has a lasting negative impact on a person’s health and quality of life. Symptoms of breathlessness and extreme fatigue, for example, may make patients less able to work or participate in their usual social activities, leading to social isolation, anxiety and depression.7,23

6. The management of HF is suboptimal and significant inequities exist

Too often, heart failure is merely regarded as the end stage of other heart disease and is not treated in its own right – but much morbidity and mortality could be prevented through timely diagnosis and coordinated disease management at an earlier stage.4,11 This includes a combination of patient education, support for healthier lifestyles medical therapy, disease monitoring and multidisciplinary care.

Multidisciplinary care has been recognised as critical for the care of patients with HF, however it is poorly implemented. In addition to physicians and nursing teams, care teams should involve dieticians, pharmacists, social workers and physiotherapists and provide tailored, evidence-based education and support to help patients self-manage.24 Effective patient self-management has been shown to be critical to health outcomes.25

Up-to-date clinical guidelines, and evidence-based solutions in terms of models of care and specific interventions, exist for the management of chronic heart failure and of acute episodes of HF. However, adherence to guidelines is low and varied between settings, contributing to disparities in outcomes for patients.4

Disparities have been observed in terms of:

- **Diagnosis:** Many of the symptoms of HF are not unique to HF patients,11 therefore it is important that the full range of diagnostic tools and methods is used to ascertain a definite diagnosis of HF.4

- **Specialist care:** Patients treated in cardiology wards are less likely to die either in hospital or after discharge from hospital, compared to patients treated in non-specialist wards. For example, data from the Heart Failure Audit in the UK show that mortality after discharge is much lower for patients treated in a cardiology ward and this survival advantage is evident even 3 years after discharge (Figure 4).26 Yet in many hospitals in the UK and elsewhere, cardiologists do not lead the management of patients with HF.

- **Patient education and support roles:** Knowledge of HF combined with a supportive relationship with healthcare professionals has been shown to improve outcomes.24 Specialist heart failure nurses, for example, can reduce
hospitalisations, improve quality of life for patients with HF and reduce mortality. However in Europe, only the UK, France, and the Netherlands have specialist heart failure nurses. In other countries, such as Belgium, specialisation in heart failure is not remunerated by the government and is left to the discretion of individual hospitals.

**Figure 4**: All-cause post-discharge mortality by place of care

![Graph showing survival post-discharge](source: Heart Failure Audit 2012-3)
D. What can policymakers do?

“Change at the policy level has the potential to save lives and make more efficient use of health resources.”

A number of seminal reports have issued clear policy recommendations aimed at improving the lives of people with HF in Europe. The challenge is to convert our knowledge of ‘what needs to be done’ into concrete proposals for ‘how can this be done’, taking the particular context, resources and priorities of each country into account.

We see policy action running into two main pillars focused on key policy goals:

1. Make heart failure a strategic health policy priority
2. Ensure that all patients with heart failure are provided with the best possible care throughout the course of their condition.

- Make heart failure a strategic health policy priority

From national policies and plans...

...to implementation in local practice

- Create visibility for HF
  - National HF plan
  - Appropriate positioning of HF in other relevant policies (chronic disease, prevention, ageing)
  - Public awareness campaigns
  - Targeted prevention campaigns
  - Involvement of HF patient representatives at highest level

- Holding the system to account
  - Monitoring and audit of HF performance measures that are meaningful to patients
  - Financial incentives for adherence to guidelines (GPs)
  - Local pathways supported by professional training

Targeted resources

- Invest in reliable data to enable evidence-based care planning
- Ensure equitable access to appropriate medicines, devices and care
- Invest in capacity to allow for uniform implementation of guidelines
- Develop person-centred care models with strong patient engagement and support for self-care
Governments can provide an important steer by making HF an explicit national priority and giving it ‘a room of its own’ in relevant policy frameworks. But setting goals at the national level is not enough -- goals and targets need to be translated into consistent implementation in local practice and performance monitored closely.

Governments should:

- **Create visibility for heart failure**: HF needs to be clearly positioned within national plans and relevant policy platforms, such as chronic disease or healthy ageing strategies. Governments should explicitly back public awareness programmes, which can convey the message that HF is a condition that can be attenuated and effectively managed. Messages about the importance of modifying behavioural risks, learning to recognise signs and symptoms, and seeking appropriate care immediately, are also needed.

- **Ensure the patient voice is heard at the highest level of policy** – create national policy priorities, quality frameworks and reimbursement frameworks in genuine consultation with patient groups, exposing the real gaps in care as experienced by patients, and the challenges and needs facing people living day-to-day with HF.

- **Expose and help reduce gaps in the health and care system** – modern care guidelines, best practice case studies, data benchmarking and consultations with patients, carers and professionals can all help to build a picture of the pressure points and weaknesses in the system, where the need is greatest for improvement and the best returns on investment may lie.

- **Hold the system to account** - set up registries for hospitals and primary care to improve the evidence base; conduct regular audits to monitor performance in patient care; introduce financial incentives for physicians to encourage and reward adherence to guidelines; consult patients closely on what measures of care matter to them, balancing process-driven or clinical indicators with patient-relevant outcomes, including quality of life measures.

- **Support evidence-based policy objectives with sufficient resources** in terms of professional capacity, specialist HF clinics, and funding for guideline-recommended medicines, devices and care – to ensure that national plans can deliver on their objectives.
ii. Ensure that all patients with HF are provided with the best possible care throughout the course of their condition

Clinical guidelines and expert reports contain clear recommendations on what the core components of good-quality prevention and care for HF should be. Governments cannot enforce the implementation of guidelines, however they can encourage clinicians to adhere to evidence-based guidelines through financial incentives (e.g. Quality and Outcome Framework for GPs in the UK) and ensure that the best care possible is made available to all patients with HF regardless of where they access the health care system.

In addition, greater prominence should be given to HF within other relevant clinical guidelines (e.g. diabetes, hypertension and myocardial infarction guidelines) to improve detection within primary care settings, and help prevent HF in patients at risk.

Governments should focus on the following:

- **Improve diagnosis in primary and secondary care settings:** Professional training of primary care physicians is needed to (a) identify people at risk of developing HF, such as those with diabetes, obesity and hypertension and (b) recognise the signs and symptoms, and properly diagnose HF in their patients. Also, as is true for stroke or acute myocardial infarction (heart attacks), hospitals need to be able to provide rapid diagnosis, assessment and early intervention for
patients presenting to hospital with signs of HF, as any delay increases their risk of death.\textsuperscript{28,29}

- **Ensure quality education and individual support for patients and their families**: Patients are uniquely situated to closely monitor their general health status, detect early signs of worsening HF,\textsuperscript{18} and engage actively in their own day-to-day care, for example, through treatment adherence and regular exercise.\textsuperscript{13} Population measures to improve the visibility of HF should be combined with resources and tailored practical support to empower and educate patients with HF on how to manage their condition. These educational materials are likely to be more impactful when supported by greater investment in professional capacity (see below).

- **Encourage person-centred approaches to care**: Person-centred approaches (such as shared decision making, engaging with patient narratives, and personalised care planning) have been shown to be effective in shortening hospital stays and maintaining functional performance in some patients with HF,\textsuperscript{30} as well as in improving quality of life and morbidity\textsuperscript{31} and reducing patient uncertainty and confusion.\textsuperscript{32} Investment in comprehensive care models that include individualised care plans is urgently needed.

- **Investment in professional capacity**: Data from several settings show that follow-up care by cardiologists and HF specialist nurses, and treatment in specialist heart failure clinics, results in reduced re-hospitalisation and death rates and improves the quality of life of patients compared to care received on general medical wards.\textsuperscript{28} Governments should prioritise investment in these services to achieve not just clinical benefits, but to reduce risks of costly hospital admissions.\textsuperscript{1}

- **Seamless transition of care**: Diagnosis and initial treatment are only the beginning of the patient journey in HF, and should be part of a comprehensive long-term care management plan for patients that includes follow-up, monitoring, adjustments to lifestyle and support.\textsuperscript{4} One of the most vulnerable transitions in HF is when a patient is discharged from hospital. Governments should invest in HF management programmes in hospitals to ensure the seamless transition of patients from hospital to home settings.\textsuperscript{1}

- **Equitable provision of medicines, devices and care**: Substantial gains in HF will be realised if governments focus on implementing treatments that are known to be effective. Clinical guidelines recommend the use of evidence-based medicines and devices as well as diagnostic tests as appropriate for each patient.\textsuperscript{11} Adherence to guidelines has been found to be associated with improved outcomes, lower rates of re-admission and reduced mortality for HF.\textsuperscript{26,33}
E. Conclusions – the agenda of the HF policy network

The number of people affected by heart failure is growing, calling for an urgent response from policymakers. Heart failure needs to be recognised as a chronic, manageable condition with care focused on reducing the risk of death and improving the quality of life of those affected throughout the course of their condition.

We have the means to reduce the significant burden posed by this debilitating condition. The challenge now is to convert existing policy recommendations into feasible and sustainable policy actions that will have a lasting impact on patients with HF in different countries.

This is the challenge that the European Heart Failure Policy Network has set itself. This document is intended as a think-piece to stimulate debate on what policymakers can do to reduce the burden of heart failure across Europe. It is our hope that it may serve as a starting point for transformational change in the policy landscape for heart failure and contribute to driving real improvements for patients across all European countries.

The following questions may be useful in helping to shape the agenda of the network going forward:

- What levers do parliamentarians (EU and national level) have to challenge and drive health policy change in HF, and how can we make best use of them?
- How can national (or regional) strategies drive consistent and sustainable change on the ground?
- How can we best expose and help reduce existing gaps in care?
- How can patients, healthcare professionals and policymakers work together at the national or regional level – (e.g. formulation of national strategies, quality improvement frameworks) to help achieve meaningful change for patients with HF?
- What changes need to be made to health policies and systems of care to ensure that patients can be more involved in their care?
- How do we improve capacity and adapt the healthcare workforce to meet the needs of HF patients? What measures are needed to offer integrated and sustainable solutions?
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