Heart failure

policy and practice in Europe

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The Heart Failure Policy Network

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About the Heart Failure Policy Network

The Heart Failure Policy Network (HFPN) is an independent, multidisciplinary network of healthcare professionals, advocacy groups, policymakers and other stakeholders from across Europe. HFPN was established in 2015 with the goal of raising awareness of unmet needs and seeking meaningful improvements in heart failure policy and care. To view our work so far, please visit: www.hfpolicynetwork.org/

All members of the HFPN provide their time for free. All Network content is non-promotional and non-commercial. The Secretariat is provided by The Health Policy Partnership Ltd, an independent health policy consultancy based in London, UK.

About this report

Heart failure policy and practice in Europe aims to equip national advocates across Europe with a clear picture of central leadership and overall performance in terms of major pillars of health services, treatment and care. It provides a comprehensive analysis of national policy issues in heart failure, key gaps and examples of best practice investigated in 11 European countries.

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Contents

The following organisations endorse this work:

Foreword

Since its inception in 2015, the Heart Failure Policy Network has sought to defeat political inertia in heart failure (HF). Winning this battle is more a political challenge than a scientific one. Best practice in HF care is well established, yet routine and tragic gaps persist for even basic components of care, contributing to a high rate of hospitalisations and mortality.

What is at stake is no less than millions of lives and billions of euros in healthcare costs that could be better invested in crisis prevention, rather than recovery. Current trends demonstrate clearly that our healthcare systems must master the prevention and community-based management of major conditions such as HF as a matter of urgency in order to avoid extreme pressures. To achieve this, a whole-system vision for HF will be needed over the long term to ensure that decision-makers set suitably ambitious goals and uphold commitments to invest in proven models of care.

Yet despite the fact that one in five of us can expect to develop HF at some point in our lives, HF advocates across Europe face persistent barriers in mounting political engagement efforts. These include fatalism and misunderstanding of what HF is, a lack of consensus as to national priorities for HF policy and practice, and a historical lack of scrutiny and accountability.

Heart failure policy and practice in Europe seeks to challenge these barriers in greater national specificity than ever before. It provides an evidence-based, consensus-driven tool to help advocates demand at least an answer from national leaders, and ideally an offer of partnership.

While the COVID-19 pandemic will continue to require significant political attention, governments must remember that HF remains a leading cause of hospital admissions in Europe. This has been the case for many years and will continue long after COVID-19 has been contained.

Much has changed in the five years since we started our Network. We have seen that policymakers will listen to evidence and value-based arguments, especially when stakeholders work together. This must inspire us all to accelerate our efforts.

Help us to take the case for change to in HF governments across Europe.

– Heart Failure Policy Network Secretariat

Executive summary

More than

15m

people in Europe are estimated to be living with heart failure[1,2]

Heart failure
is a major cause of hospitalisations and contributes to almost

2m admissions a year in Europe[3]

Heart failure healthcare cost over

€15bn

in 2012 in the 11 countries in this project combined[4]

Hospital admissions
for heart failure have been projected to rise by

50%

between 2010 and 2035[5,6]

Best-practice care models have the potential to reduce heart failure hospitalisations and costs by up to

30%[7,8]

Heart failure (HF) is a common syndrome and its prevalence is growing.
More than 15 million people in Europe, or around 2% of the population, are estimated to be living with HF.[1,2] These numbers are predicted to rise significantly, due to ageing of the population and increased survival rates of other cardiovascular conditions.[5,9,10]

This trend seems certain to be accelerated by the COVID-19 pandemic. Heart damage arising from COVID-19 infection is predicted to increase the number of HF cases.[11] The pandemic has also caused widespread disruption to existing HF services, stalling crucial efforts to prevent HF or delay its progression.[12-14]

Despite the far-reaching impact of HF, governments have been slow to recognise its significance. Of the 11 European countries included in this work, most lack a dedicated strategy on HF, and where plans are available, they are often out of date or underfunded. Existing cardiovascular or non-communicable disease policy initiatives commonly neglect HF, despite it falling into their scope.[15-18]

Few governments fully understand what is needed to address HF. Formal registries and audits of HF care are lacking, meaning that poor performance and unwarranted variations often continue unchallenged, obstructing best-value investments to reduce avoidable deaths, disability and costs.

Years of underinvestment in HF have left us unprepared for future pressures. Integrated HF care pathways, disease management models and key diagnostics are often unavailable, and information technology (IT) systems and telemedicine platforms are often lacking or unfit for purpose.

Our healthcare workforce is largely unprepared for HF. Specialist-led care is crucial to improving outcomes in HF,[19 20] but many countries face major shortfalls in HF specialist roles. Few European countries formally accredit HF specialism, holding back the long-term growth of these roles.

Most notably, primary and community care settings are ill-equipped to provide effective long-term management of HF. Across Europe, crucial gaps include use of medications, cardiac rehabilitation, self-care education, psychological support and palliative care.[2] Typical barriers include underfunding, poor continuity of care and limited access to HF specialists.[2 21-23]

These deficits come at a significant cost. Many people with HF are not treated until irreversible cardiac damage has occurred.[24] Hospital readmissions are common, despite a large number being considered avoidable.[25 26] Millions of patients live with a huge burden of symptoms – both mental and physical – that could be significantly alleviated.

Innovative care models are too slow to take hold. Many programmes have demonstrated the value of multidisciplinary HF care to reduce costs and improve outcomes,[7 8 27-29] but are often limited to a few centres of excellence. Encouragingly, the COVID-19 pandemic has increased the use of telemedicine,[12 13 30] and these models require expansion.

There are many opportunities to prevent HF and slow the progression of the syndrome. Guideline-based care is proven to save lives, improve quality of life and keep people with HF out of hospital.[20] With the right support, people with HF can manage their condition, return to work and continue to enjoy productive lives.

Decision-makers must now acknowledge and address HF in all its dimensions. High-level strategies and plans should commit to deliver on clear goals to reduce avoidable hospitalisations and improve outcomes in HF. With this goal in mind, we propose five actions to which governments across Europe must now commit.

It is crucial to understand that, regardless of country, failing to implement an effective system of care and management of HF will test the limits of our healthcare systems as well as social and economic sustainability.

What is heart failure?

Heart failure is a common and complex syndrome

Heart failure (HF) occurs when the heart becomes too weak or stiff to pump enough blood to meet the body's needs.[20] Symptoms vary depending on a person's age, weight and additional health conditions (comorbidities). Typically, they include breathlessness, extreme fatigue, reduced capacity to exercise and retention of fluids, which may present as rapid weight gain or swelling in the lower limbs and abdomen, and in severe cases as fluid in the lungs (pulmonary oedema).[20] HF symptoms can develop gradually and slowly (chronic or slow-onset HF) or suddenly and rapidly (acute HF), the latter often as a result of exacerbation of chronic HF and requiring immediate medical attention.[20 31]

SEE *The handbook of multidisciplinary and integrated heart failure care*[2]

Current clinical guidelines differentiate between three types of HF based on left ventricular ejection fraction, which is the proportion of blood in the heart that is pumped with each heartbeat from the left ventricle to the rest of the body: HF with reduced ejection fraction (HFrEF), HF with mid-range ejection fraction (HFmrEF), and HF with preserved ejection fraction (HFpEF).[20] HFrEF is the better-known type of HF, while the two other types are less well understood.[20 32]

SEE *Spotlight on HFpEF: heart failure with preserved ejection fraction*[32]

Risk factors for HF include underlying health conditions and lifestyle behaviours

There are several risk factors for HF, ranging from other conditions or diseases to lifestyle behaviours. HF can be preceded by coronary artery disease, high blood pressure (hypertension), heart attack (myocardial infarction), diabetes, high cholesterol (hyperlipidaemia) and obesity,[20] all of which are growing contributors to the rising prevalence of HF in Europe. An inactive lifestyle, unhealthy diet, excessive alcohol consumption or smoking can also increase the risk of developing HF.

SEE *Understanding HF guidelines*[36]

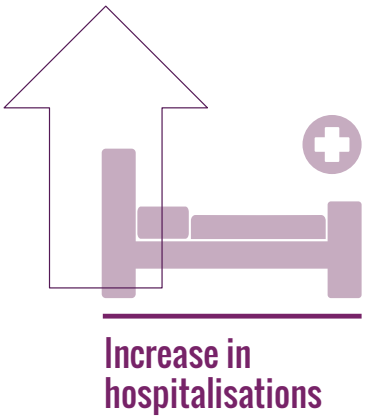
HF is often associated with comorbidities – three in four people with HF have at least one other illness,[33] and almost half of those diagnosed with HFpEF have at least five.[34 35] Comorbidities may aggravate HF and create additional challenges to clinical management,[20] as well as having a negative impact on quality of life.

The case for change

HF is a fundamental concern for the long-term sustainability of healthcare systems

The number of people living with HF is high and growing. More than 15 million people are estimated to be living with HF in Europe,[1 2] a figure that represents around 2% of the population.[20] One in five people can expect to be diagnosed with HF at some point in their lives.[37] HF disproportionately affects older people, with more than 80% of cases in people aged 65 and older.[9] Ageing populations and improved survival rates for cardiovascular and other long-term conditions are predicted to contribute to an increase in the prevalence of HF.[5 9 10] In Europe, the population aged 65 and over is projected to grow by almost 50% in the next 30 years,[38] which suggests that the number of people living with HF will continue to rise.[2 6]

HF is a major driver of hospitalisations and mortality



People living with HF are at high risk of hospitalisation, which becomes more frequent and lengthy in later stages of the syndrome.[9] HF has been reported as the most common cause of hospital admissions in people over the age of 65 and a leading cause of all hospital admissions for all age groups.[3 6] In 2015, there were 1.7 million hospital admissions for HF in the European Union (EU) alone, with a mean duration of 9.5 days.[3] HF-related rehospitalisation is common in the first months after discharge; this is a period of high vulnerability[6] and, therefore, a missed opportunity in terms of improving care and reducing the burden of HF.

Despite improvements in treatment options and care in the past two decades, mortality from HF remains high.[39 40] In many European countries, mortality from HF is higher than from several common cancers.[41 42]

The right package of care can improve outcomes

HF has been identified as a major source of preventable hospitalisation in the EU, alongside diabetes, hypertension, chronic obstructive pulmonary disease and asthma.[3 43] But proven models of care have realised significant reductions in hospitalisations for HF.[44-46] A large proportion of morbidity, mortality and healthcare costs from HF can be avoided if integrated, multidisciplinary models are followed. Care should involve health and social care professionals to ensure a seamless transition between hospital and community settings, as well as person-centred approaches.[2 19 20]

Best-practice care can reduce hospitalisations

The challenge in addressing HF is not lack of best-practice models or proof of their impact, but rather one of their wider implementation. Several models implemented locally have demonstrated positive impact by reducing the number and length of hospitalisations and improving patient outcomes, but these have not been rolled out at scale.[2]

The COVID-19 pandemic is likely to accelerate the growth of the HF population

The COVID-19 pandemic is known to be driving the emergence of new cases of cardiovascular disease and the exacerbation of existing conditions, including HF.[13 47-51] This is due both to the infection and the symptoms it causes, and to service disruptions from the pandemic, which have created a backlog of missed or delayed diagnoses and care.[13 30 52-58] Combined, these factors are likely to create a significant growth in demand for HF services, driven by new cases of HF as well as deterioration in those previously diagnosed.[12 14]

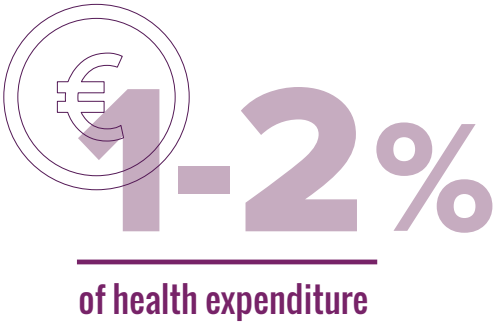
HF changes lives forever – it has a significant impact on people and their families

HF can be devastating. People living with HF describe the diagnosis as a life-changing event for themselves and their families, requiring complete physical and psychological readjustment to manage the syndrome.[59 60] Diagnosis is often preceded by a period of uncertainty as people try to navigate their lives with symptoms such as breathlessness and extreme fatigue.[61]

Symptoms of HF may limit a person's ability to work, travel and socialise, and consequently lead to a significant reduction of quality of life.[62] This may affect the person's mental health – in fact, depression has been suggested to affect around one in five people with HF.[63] This is significant, as depression is linked to decreased

self-care behaviours and increased hospitalisation and mortality.[20 63] The impact of HF on mental health extends to the person's family and carers, who may themselves experience social isolation, loneliness and limitations in daily life.[64]

HF has a considerable economic impact on healthcare systems



In high-income countries, HF typically accounts for 1–2% of total health expenditure.[4 6] This is particularly significant considering that all types of cancer combined are estimated to account for around 6% of total health expenditure in Europe.[65] In 2012, the national cost of HF was estimated to have surpassed USD $4.5 billion (approximately €3.5 billion) in Germany, France and the UK, and to be more than USD $1 billion (approximately €781 million) in Italy, Spain and Belgium.[4] Most of the direct costs linked to HF are attributable to frequent and lengthy hospitalisations.[4 9]

In 2012, the combined cost of HF healthcare services in Belgium, Denmark, England, France, Germany, Greece, Ireland, Italy, Poland, Portugal and Spain amounted to more than €15 billion.[4]

HF is a major factor in societal costs and workforce productivity

Many people may not return to work

The economic impact of HF is compounded by significant indirect costs, mostly owing to the demands on partners or other family members to provide care.[64 66] Indirect costs also relate to lost productivity of people living with HF, and use of sickness benefits or welfare schemes.[67] For example, in Denmark, data from 1997 to 2012 show that one in four people living with HF did not return to work in the year following their first hospitalisation for HF.[68]

In some European countries, indirect costs of HF are estimated to outweigh direct costs.[64] In Ireland, for example, informal care is the largest cost component of HF expenditure, estimated at €364 million in 2012.[66] In Spain, 37% of people living with HF require informal care, with an estimated annual cost of up to €12,870 per person.[69]

The risks associated with HF reflect existing health inequalities

While trends appear to vary between countries, people at a socioeconomic disadvantage (for example, those with lower income and educational attainment) may experience higher risk of HF and HF-related hospitalisation, or have higher mortality and poorer outcomes overall.[70-72] For example, in people facing socioeconomic disadvantages HF has been shown to occur as much as 3.5 years earlier than in people with a higher socioeconomic status.[73]

Heart failure policy and practice indicators

This study analyses HF policy and practice in 11 European countries. It began with the development of a list of elements for consideration in each country: the HF policy and practice indicators (*Table 1*). The indicators are not intended as a quantitative checklist or scorecard for HF policy and care, or as quality indicators for clinical practice or research. Rather, they served as an internal framework to guide the development of this work.

The indicators fall into two domains: policy indicators are those that focus on the status and comprehensiveness of HF policies and guidance, while practice indicators aim to capture the reality of clinical practice.

TABLE 1. **Heart failure policy and practice indicators**

Policy	Formal plans on HF
	Investment in integrated HF models and facilitative tools
	Development of the HF healthcare workforce
	Guidance and local care pathways for delivery of quality care
	Registries, audits and high-level assessment initiatives
Practice	Diagnosis
	Hospital care and discharge
	Key components of quality care in community settings
	Tools and methods to support multidisciplinary and integrated ongoing HF care

HF: heart failure
Note: The HF policy and practice indicators were used to guide desk research and analysis for this report and are not intended to be used as quality indicators for clinical practice or research.

As each country has its own set of obstacles to overcome, this overarching report is accompanied by 11 country profiles that explore the reality in each country: Belgium, Denmark, England, France, Germany, Greece, Ireland, Italy, Poland, Portugal and Spain.

Heart failure policy across Europe

Formal plans on HF

*Why **it matters***

Formal HF plans create political accountability and vision, and provide a blueprint to address the challenge

HF-specific policies or formal plans should seek to enable the system-wide implementation of best practice. This may involve addressing barriers to the reorganisation of care and investing in the establishment of HF specialist settings and services. Governments should also clarify optimal system function across the diagnostic and care pathway, including interactions between settings and involvement of primary care.[2]

Strategies should set clear and measurable goals for success, make available the resources and tools healthcare professionals need to deliver best-practice care, and outline methods to collect, analyse and make use of data.

Awareness of HF is too low, with many countries lacking dedicated strategies

Several countries have no dedicated strategy on HF, and in others the plans may need to be updated, lack funding or may have stalled (*Table 2*).

Recognition of HF is still too low among decision-makers and the wider public. Recent surveys in Germany, Italy, Spain and the UK found a significant lack of understanding of the symptoms and seriousness of HF, among both the public and policymakers.72 Very few members of the public understand the scale of mortality in HF and national policymakers show low awareness of HF and its role in driving healthcare demands. Fewer than 15% of national policymakers surveyed recognised HF as the leading cause of avoidable hospitalisations.72 These low levels of awareness translate into low prioritisation of HF in long-term national healthcare plans and policies.

TABLE 2. **Formal plans on heart failure or relevant guidance on chronic disease management**

Belgium	⊗ No formal plan on HF 2015 national plan on integrated care for chronic diseases published,[18] but lacks focus on HF
Denmark	⊗ No formal plan on HF Committee for Heart Diseases established in 2008[75] and Task Force for Cancer and Heart Patients established in 2010,[76] but neither has yet focused on HF
England	2019 *NHS Long Term Plan* includes a section on HF with commitments to improve diagnosis and management[77]
France	⊗ No formal plan on HF 2018 strategic vision My Health 2022 states a need to improve management of HF,[78] but there is little presence of HF in subsequent strategies
Germany	⊗ No formal plan on HF
Greece	⊗ No formal plan on HF
Ireland	2012 National Clinical Programme for HF[79] has received limited investment
Italy	⊗ No formal plan on HF 2019 strategy *Pact for Health*[80] and 2016 *National Plan for Chronic Conditions*[81] recognise need to address HF
Poland	⊗ No formal plan on HF National Programme for the Prevention and Treatment of Cardiovascular Diseases 2017–2020 recognised need to address HF[82] but received limited investment
Portugal	⊗ No formal plan on HF A government-commissioned working group proposed measures to improve the response to HF,[83] but no further action has been taken[84]
Spain	Ministry of Health announced national strategy on cardiovascular health in 2020, including recommendations for HF[85]

Additional information can be found in the country profiles.

Investment in integrated HF models and facilitative tools

Why *it matters*

Policy and reimbursement frameworks must encourage a shift in the focus of care from acute to outpatient and community settings

Effective management of HF must start with early diagnosis and include ongoing support delivered outside of hospital.[2 20] For optimal diagnosis, measurement of natriuretic peptide (NP) levels, recommended in clinical guidelines,[20 86] should be reimbursed in primary care. This low-cost test can rule out HF, saving unnecessary referrals to cardiology services and echocardiography, which is the gold-standard diagnostic test[20] but is more expensive and may require longer waiting times.[87 88]

Complex, long-term care requires data-sharing and communication across all healthcare professionals involved in HF management. Information technology (IT) systems that are applicable to different care settings are therefore essential in multidisciplinary and integrated care.[9] Platforms that allow the delivery of care remotely can also be important for high-quality ongoing HF care.[89]

SEE *Spotlight on telemedicine in ongoing heart failure care*[89]

Inconsistent reimbursement of diagnostic tests and limited investment in technology hinder optimal HF diagnosis and ongoing care

Policies for reimbursement of HF diagnostic tests across Europe force significant deviation from best-practice recommendations. For example, NP testing is not consistently funded across care settings (*Table 3*). NP testing in primary care settings is feasible and recommended by leading clinicians, who have called for it to be implemented in primary care to avoid late HF diagnosis and bottlenecks around access to echocardiography.[90-95]

TABLE 3. **Reimbursement of natriuretic peptide (NP) testing**

	General practitioner, primary care	Specialist physician, outpatient care	Specialist physician, inpatient care
Belgium	⊗ Not reimbursed	⊗ Not reimbursed	⊗ Not reimbursed
Denmark	Not consistently reimbursed	Reimbursed	Reimbursed
England	Usually reimbursed	Reimbursed	Reimbursed
France	Reimbursed	Reimbursed	Reimbursed
Germany	Reimbursed	Reimbursed	Reimbursed
Greece	⊗ Not reimbursed	⊗ Not reimbursed	Reimbursed
Ireland	Not consistently reimbursed	Reimbursed	Reimbursed
Italy	Reimbursed	Reimbursed	Reimbursed
Poland	⊗ Not reimbursed	Reimbursed	Reimbursed
Portugal	⊗ Not reimbursed	Reimbursed	Reimbursed
Spain	⊗ Not reimbursed	Reimbursed	Reimbursed

Additional information and sources can be found in the country profiles.

Some European countries are in more advanced stages of developing collaborative IT systems, including electronic health records, but overall there is a need to invest in IT platforms that collect key HF parameters, share information and enable collaboration and multidisciplinary working (*Table 4*). Where existing platforms are able to link across settings, they may typically collect few clinical parameters relevant to HF and may lack features that promote optimal data-sharing and communication between healthcare professionals and care settings.

TABLE 4. **Healthcare information technology systems**

Belgium	The government has invested in IT hubs to support information exchange between care settings.[96] The HF care team can share discharge information, consultation reports and laboratory test results, but sharing echocardiography footage and medication plans is difficult.[94 97]
Denmark	IT systems allow for communication among hospitals but not between hospitals and primary care settings.[98]
England	The National Health Service has committed to improving IT systems to support multidisciplinary care, but HF-specific investment is lacking.[99]
France	IT systems differ between healthcare settings. Patients can delete information from electronic health records, which may affect the value of the system.[100]
Germany	IT systems differ between healthcare settings, and medical information is often only accessible to different healthcare professionals when a direct referral is made between care settings.[101]
Greece	Electronic health records are being implemented,[102] but the IT system remains inadequate for communication between settings, which has been reported as a critical barrier to integrated HF care.[103]
Ireland	There is no standardised IT system in hospitals. The more advanced system in primary care allows for communication between professionals working in those settings.[104]
Italy	The IT system allows for data linkage and promotes communication, but there is a need to collect additional clinical parameters.[105]
Poland	There is no standardised or advanced IT system allowing for communication across care settings.[106 107] Experts believe this is under development.[95 108]
Portugal	The IT system enables data-sharing,[26 109] but additional features are needed to optimise communication between healthcare professionals.[110]
Spain	IT systems differ between healthcare settings and do not allow for communication across settings.[111 112]

HF: heart failure; IT: information technology.
Additional information can be found in the country profiles.

Before the COVID-19 pandemic, investment in telemedicine-based models of care for HF had not been a priority across Europe.[89] The pandemic is widely recognised to have acted as a major catalyst for remote monitoring of HF, generating rapid uptake across whole systems[14] and potentially leading to greater political will for the reimbursement of these care models to continue. While there is great potential in telemedicine models, especially to provide care to people living in rural or remote areas, it is important to consider that telemedicine should be used to supplement, not replace, in-person appointments. It should be part of HF care programmes, tailored to the person's needs and preferences.[89 113 114]

Development of the HF healthcare workforce

*Why **it matters***

Specialist HF skills in the healthcare workforce reduce hospital admissions and improve patient outcomes

HF specialism and improved professional knowledge of HF are crucial for long-term management and positive outcomes.[2 9 19] For example, HF nurse-led programmes have been shown to reduce hospital admissions.[19 115] Healthcare systems should thus invest in professional HF training for all healthcare professionals, spanning the entire patient journey.

Formal accreditation of HF specialism allows for consistent and transferable skill sets, certifiable professional development, and incentivisation via enhanced professional status and greater financial reward. Accreditation is crucial to expansion of the specialist workforce.

The development of the HF specialist workforce is being undermined by poor funding and lack of formal accreditation

Several countries are facing a shortfall in key healthcare professionals required for HF care, including specialists and primary care professionals.[98 106 116-118] This contributes to major pressures on the existing workforce.

Professional education and training programmes are typically offered by national professional societies and may combine online and in-person training.[119 120] In some countries, HF centres also deliver training.[84 121]

Among the countries analysed, the HF specialist nurse role is formally accredited only in England, Germany and Ireland (*Table 5*). Potential barriers in other countries include lack of funding, a complex and lengthy national approval process for new healthcare roles, a lack of degree programmes, and limited awareness among decision-makers of the benefits brought about by HF specialist nurses.[122 123]

The Heart Failure Association of the European Society of Cardiology (ESC) has published a proposal for a two-year curriculum for HF specialist nurses to act as a blueprint for training and accreditation programmes.[124] This is a promising step, and implementation will require the involvement of national professional bodies or unions to formally grant the accreditation.

TABLE 5. **Recognition of heart failure specialist nurse role via accreditation**

Belgium	⊗ No
Denmark	⊗ No
England	Yes
France	⊗ No
Germany	Yes
Greece	⊗ No
Ireland	Yes
Italy	⊗ No
Poland	⊗ No
Portugal	⊗ No
Spain	⊗ No

Guidance and local care pathways for delivery of quality care

*Why **it matters***

Formal guidance and local care pathways are essential for the effective organisation of care

Clinical guidelines define best practice based on scientific consensus, and guideline-based care is linked to better outcomes for people living with HF.[20] It is therefore vital for guideline recommendations to be put into practice, which may be supported by HF pathways and decision-making protocols. These pathways may be either included in national guidelines or produced as standalone documents. Accreditation of HF-specific care settings can also help deliver high-quality HF care.[125]

Most cardiology societies endorse ESC guidelines or create their own, but there are gaps in guidance for primary care

The ESC revises its HF guidelines every five years and, whenever relevant, publishes consensus statements with updates.[20 31 126 127] Several cardiology societies across Europe have formally endorsed the latest ESC guidelines on HF (2016) as the national standard for HF care, and some countries have their own national guidance (*Table 6*). Professional societies and statutory health agencies sometimes develop guidance on specific aspects of HF care, such as cardiac rehabilitation or palliative care.[128-130]

HF guidelines typically recommend that HF care be led by cardiologists. However, in some countries, management of HF, particularly acute HF, is often led by internists. There may be a need to standardise clinical involvement in HF care, with experts highlighting the importance of involving both cardiologists and internists.[84 131-133]

Challenges specific to primary care settings are not typically covered in cardiology guidelines.[104] For this reason, the European Primary Care Cardiovascular Society has developed guidance on the diagnosis and management of HF in primary care,[134] and some national and regional professional societies have also introduced HF guidance for primary care professionals.[135-138]

Established guidelines may not always be adopted and followed, for reasons including limited awareness, guideline complexity and lack of national-language versions.[139] Lack of direct incentives, such as performance assessment linked to guideline-based care, may be another barrier. It is therefore important that statutory and professional bodies work together to formally endorse and disseminate guidelines or adapt them to the national context,[140] preferably with input from people living with HF.[139]

Guideline-based care in HF is held back by an absence of care pathways and networks to support implementation

Some professional societies have established national or regional clinical pathways and care protocols to support high-quality HF care and better integrated working (*Table 6*). Joint protocols, arising from multi-stakeholder efforts, are particularly useful. However, they are not developed consistently, and, where available, they may not benefit from formal recognition from central authorities.

Equally, national clinical networks for the management of HF are crucial to promote transfer of clinical and organisational best practices, but they remain widely underdeveloped across Europe.

TABLE 6. **Guidelines, care pathways and protocols for heart failure**











	Belgium	Denmark	England	France	Germany
Established clinical guidelines	ESC HF guidelines endorsed as national standard for cardiologists and nurses Professional societies developed national guidelines for primary care[137 138]	ESC HF guidelines endorsed as national standard of HF care Professional societies developed national and regional guidance for elements of HF care, such as cardiac rehabilitation[128 143] and palliative care[144]	National Institute for Health and Care Excellence develops national guidelines and resource impact reports[86 146 147]	ESC HF guidelines endorsed as national standard of HF care French Society of Cardiology developed national guidance for elements of HF care, such as therapeutic education[149]	National Healthcare Guidelines on HF make clinical recommendations for all healthcare professionals and cover their implementation[151]
Guideline-based **care pathways and protocols**	Regional HF care pathways span hospital and community settings[141 142]	National clinical pathway for heart diseases covers diagnosis and management of HF[145]	Local rapid access pathways support diagnosis and management of HF,[148] but a national approach is lacking	National HF care pathway introduced in 2014, but implementation is inconsistent across the country[150]	HF-NET programme links outpatient and hospital HF services within regional networks through care pathways and standard operating procedures[152]

	Greece	Ireland	Italy	Poland	Portugal	Spain
Established clinical guidelines	ESC HF guidelines endorsed as national standard for cardiologists University of Crete Clinic of Social and Family Medicine developed guidance for primary care[153]	ESC HF guidelines endorsed as national standard of HF care Irish College of General Practitioners developed a national guide on HF care for general practitioners[135]	ESC HF guidelines endorsed as national standard of HF care Professional societies developed guidance for elements of HF care e.g. management of acute HF,[155] palliative care[156] and telemedicine in HF care[157]	ESC HF guidelines endorsed as national standard of HF care	ESC HF guidelines endorsed as national standard of HF care Professional societies developed guidance for elements of HF care e.g. cardiac rehabilitation[159] and acute cardiac care[160]	ESC HF guidelines endorsed as national standard of HF care Professional societies developed guidance for elements of HF care e.g. management of acute HF[161]
Guideline-based **care pathways and protocols**	No pathways or protocols outlining integration of HF care	National implementation underway for an HF referral pathway incorporating an electronic referral system and virtual consultations between general practitioners and cardiologists[154]	No pathways or protocols outlining integration of HF care	Professional societies have developed guidance to support collaboration between general practitioners and cardiologists[158]	No pathways or protocols outlining integration of HF care	Professional societies developed national consensus documents outlining palliative care for HF[162] and joint care processes between cardiology and internal medicine,[131] and cardiology and primary care[163]

ESC: European Society of Cardiology; HF: heart failure
Additional information can be found in the country profiles.

There are too few accreditation programmes for HF services

In a few countries, independent healthcare organisations or professional societies have led accreditation programmes for HF services, seeking to promote high-quality HF care. However, this is not yet standard practice (*Table 7*).

TABLE 7. **Accreditation of specialist settings for heart failure**

Belgium	National accreditation scheme for hospital care programmes was introduced in 2004.[164] In 2016, hospitals were asked to submit HF care pathways and protocols for accreditation, but progress has stalled[165]
Denmark	National hospital accreditation programme includes indicators for HF[125 166]
England	⊗ No accreditation initiatives for HF settings
France	⊗ No accreditation initiatives for HF settings
Germany	HF centres must obtain accreditation from the German Cardiac Society to participate in the HF-NET programme[152]
Greece	⊗ No accreditation initiatives for HF settings
Ireland	⊗ No accreditation initiatives for HF settings
Italy	⊗ No accreditation initiatives for HF settings
Poland	⊗ No accreditation initiatives for HF settings
Portugal	⊗ No accreditation initiatives for HF settings
Spain	Accreditation programme for HF units in cardiology departments;[167] similar programme underway for units in internal medicine departments[168]

Additional information and sources can be found in the country profiles.

Registries, audits and high-level assessment initiatives

Why ***it matters***

Centrally led, comprehensive and ongoing assessment of performance is vital to identify gaps, inequalities and opportunities for improvement

Ongoing registries (and the audits that draw on them) enable the assessment of care quality using comprehensive databases that collect data on standardised indicators.[19 140] Registries can improve understanding of gaps in care and the clinical characteristics of the challenge.[169 170] In addition, they can significantly improve accountability for care services, and can provide feedback to help to guide care improvements and healthcare investment.[2] To enable this, protocols should be in place to share data and audit findings with healthcare providers in a clear and timely manner.[23]

Ideally, registries should assess the full spectrum of care and thus include several categories of indicators.[171] Mandatory participation increases the likelihood of data being complete and representative.

SEE *Spotlight on quality assessment in heart failure care*[171]

Few governments have ongoing registries to assess performance in HF, obstructing central oversight and accountability

Most countries do not have registries that would provide ongoing assessment of HF performance and outcomes (*Table 8*). They may rely on less comprehensive sources, such as multicentre registries that are time-limited, regional, predominantly research initiatives, or which focus on selected care settings or types/stages of HF.

TABLE 8. **Collection and assessment of heart failure data**

	National registries or audits	Other notable assessment initiatives
Belgium	⊗ No national HF registry or audit	HF centre assessment initiative due to launch in 2021[165]
Denmark	Danish Heart Failure Registry collects data from all hospitals involved in HF care (mandatory)[172]	Publicly funded databases monitor healthcare delivery, clinical outcomes and societal factors.[173] Data can be linked to HF registry for comprehensive analysis
England	National Heart Failure Audit collects data on people admitted to hospitals (mandatory)[174]	National pay-for-performance schemes monitor and incentivise optimal HF care in acute and community settings[175 176]
France	⊗ No national HF registry or audit	Multi-year study on acute and chronic HF[177] and registry focused on acute HF[178] (voluntary). National healthcare database collects wide range of data, including on HF[179]
Germany	⊗ No national HF registry or audit	HF quality indicators for primary care and other ambulatory settings (voluntary)[180]
Greece	⊗ No national HF registry or audit	Regional assessment initiative collects data on HF management (voluntary)[103]
Ireland	⊗ No national HF registry or audit	Tools to assess HF care using the primary care IT system (voluntary)[181]
Italy	⊗ No national HF registry or audit	Different aspects of HF care monitored through various registries[182-185]
Poland	⊗ No national HF registry or audit	National DATA-HELP registry collects data on diagnosis and management of HFrEF[186]
Portugal	⊗ No national HF registry or audit	National study recently initiated to measure HF prevalence[187]
Spain	⊗ No national HF registry or audit	Registries explore the burden of acute HF,[188-190] the quality of care provided in HF units,[191 192] and frailty in heart transplantation candidates[193]

HF: heart failure; HFrEF: heart failure with reduced ejection fraction; IT: information technology
Additional information can be found in the country profiles.

Heart failure practice across Europe

Diagnosis

Why ***it matters***

Timely diagnosis of HF ensures early and vital access to support and treatment

A timely diagnosis is the foundation of effective HF management; starting treatment as early as possible may help avoid hospitalisation and achieve optimal outcomes.[19 20 91]

Proper diagnosis of HF requires several key tests, including a blood test for NP levels, an electrocardiogram, an echocardiogram and, in the case of acute HF, a chest X-ray.[20] Interpretation of results may not be straightforward[20] and specialist training is required to interpret imaging results.

SEE *Pressure point 1: Presentation and diagnosis*[87] in *The handbook of multidisciplinary and integrated heart failure care*

HF diagnosis is hindered by poor recognition of symptoms and limited access to and use of diagnostic tests

Delays to diagnosis are widely reported in the literature and by national experts – HF is often diagnosed when severe damage to the heart has already occurred.[2 87] This is partly due to patients and healthcare professionals misinterpreting symptoms of HF as signs of ageing or comorbidities.[194]

Overall, NP testing is used inconsistently. This may be due to lack of reimbursement in some settings, or for other reasons including dismissal of symptoms as not HF-related or a lack of understanding of the value of the test.[92 97 98 195] Underuse of NP testing misses an important step in the diagnostic pathway – one that may expedite specialist referral or assist healthcare professionals in ruling out HF, which may free up specialist capacity.

To address the need to improve HF diagnosis, national experts have called for greater involvement of primary care professionals in the process via more consistent reimbursement policies for NP testing.[90 92]

Communication of diagnosis may also be an issue. If healthcare professionals think that the term 'heart failure' will worry the person, they may refrain from using the correct terminology,[196 197] meaning the person may not comprehend the seriousness of their condition until much later.

Hospital care and discharge

*Why **it matters***

Specialist-led hospital care and effective discharge planning improve outcomes for people with HF

Following the correct identification of an episode of acute HF, optimal in-hospital care involves initiation or adjustment of treatment, management of comorbidities and risk factors, patient education and empowerment, and a tailored plan for discharge.[9 19] Care should be provided by a multidisciplinary team led by an HF specialist.

High-quality hospital care and discharge with a plan are crucial as the transition from hospital to community care is a critical period – risk of readmission and mortality remains high for up to three months following discharge.[2 6] Leading models of discharge may reduce length of hospital stay (without compromising patient safety),[198] along with costs and risk of hospital readmission.[6 44 46 199]

The unequal regional distribution of HF units and varying involvement of specialists may hinder best practice in hospital care

Geographical variation in access to HF specialist settings, which are often based in urban centres, is a significant barrier to high-quality care and contributes to inequalities.[26 200] Hospitals and clinics in remote and rural areas may struggle to recruit specialists, and people living in these areas often have much more limited access to specialist care.

Discharge planning remains a significant missed opportunity across Europe

Hospital discharge and post-discharge care often deviate from best-practice recommendations.[201] Across Europe, specialist-led hospital discharge tends to be available only in HF centres of excellence or smaller units that have developed their own protocols.[44 84] Barriers may include a lack of discharge processes supporting integration of care and a lack of IT systems promoting communication between healthcare professionals and care settings.[97 103]

To address the need to improve hospital discharge and post-discharge support, national experts have advocated for discharge checklists, consistent use of letters to general practitioners (GPs) with individualised guidance for ongoing care, and telemedicine appointments.[97 165 195 202]

Key components of quality care in community settings

*Why **it matters***

An integrated and multidisciplinary approach to HF management in the community is essential to optimise outcomes

The majority of HF admissions are considered preventable with effective community services.[25 26] Best-practice HF care has been well documented.[2 203-205] Crucial aspects of care include:

- **cardiac rehabilitation,** which may include structured exercise training adapted to people living with HF; it may help reduce hospitalisation and improve quality of life[206 207]
- **self-care education,** which helps people with HF follow important behaviours to optimise outcomes, such as monitoring their symptoms, adhering to their medication and care plan, maintaining a healthy lifestyle and recognising when to seek professional support[20 63]
- **psychological support,** which helps people deal with the substantial challenges of living with HF and can help them remain motivated and engaged with care[203 204]
- **palliative care,** which helps people understand and define future treatment goals and preferences, and prevent or relieve suffering.[127 208]

SEE *Pressure point 3: Clinical management,*[204] *Pressure point 4: Patient empowerment and self-care,*[203] *The handbook of multidisciplinary and integrated heart failure care,*[2] *Understanding heart failure guidelines: comorbidities*[209] and *Spotlight on iron deficiency in heart failure*[210]

Continuity of care is not a consistent reality for people living with HF

HF care typically transitions to the GP after a period of months in specialist outpatient care, and many people living with HF are referred directly to GPs on discharge,[86] particularly if there is no local specialist option. However, while GPs may be motivated to provide good standards of care, they may not always be sufficiently supported to follow best-practice recommendations in HF.[211] This means that HF is often not optimally managed in community settings, and considerable inequalities are seen in access to care and outcomes.

Guideline-recommended treatments for HF, including medications, are often not prescribed consistently,[185] and even in specialist community settings patient outcomes may be suboptimal.[212] HF clinics may themselves lack referral, communication and integrated protocols with a wider range of healthcare professionals in the primary care setting, including GPs.[213]

There is a significant lack of provision of cardiac rehabilitation for HF

Cardiac rehabilitation is rarely provided for people living with HF in Europe. One exception to this is Denmark, where it is consistently offered in HF clinics. Key barriers include a lack of HF-specific programmes, restrictive eligibility parameters, the fact that these services are usually based in hospitals, and lack of resources such as staff, infrastructure and funds.[104 112 214] Some barriers could potentially be addressed by non-traditional models of cardiac rehabilitation, such as home-based programmes with an exercise manual,[215] live classes streamed online[113] or telerehabilitation (using telemedicine platforms).[216]

Self-care education and psychological support are not consistently offered in HF care

Across Europe, there is a widespread lack of formal initiatives to empower people with HF to adopt self-care behaviours. Barriers to provision include a lack of HF specialist nurses or low numbers of practice nurses, the heavy workload of clinicians involved in HF care, limited training opportunities for professionals and the fact that self-care is not always seen as a priority.[103 104]

People living with HF and their families and carers do not receive enough psychological support. According to national experts, the lack of psychologists in HF care teams or their limited number in hospitals, in addition to hesitancy among some people to use this service due to stigma, may be a contributing factor.[110 112 118 217]

There is limited provision of advance care planning in HF

Referrals to advance care planning and palliative care may happen either late in the care journey or not at all.[107 165 208] Many national experts report that palliative care has yet to be established outside of cancer.[103 118 218 219] Reasons may include uncertainties regarding who should lead services and when they should be initiated, lack of structures for multidisciplinary collaboration and, finally, limited understanding of the severity and prognosis of HF among people living with the syndrome and their families or carers.[129 130] Healthcare professionals may be hesitant to discuss prognosis if they think the information could upset the person with HF.[165] In addition, the prioritisation of preserving years of life over quality of life is ingrained in healthcare provision, promoting medical interventions and delaying, or avoiding, end-of-life care discussions.

Tools and methods to support multidisciplinary and integrated ongoing HF care

*Why **it matters***

Referral pathways and clear communication between healthcare professionals help deliver optimal HF care

Effective communication and collaboration across healthcare settings and between the HF care team, the person living with HF and their family/carers are crucial for the delivery of multidisciplinary and integrated HF care.[2 220]

Proven approaches to deliver this include referral pathways, multidisciplinary meetings, HF specialist same-day advice to GPs by email, and nurse-led telephone follow-up.[221-224] Increasingly, digital tools are allowing for a range of innovative models to improve integration of HF care, such as multidisciplinary virtual meetings and remote monitoring, often making use of tablets, smartphones and home-based medical equipment to support communication and information exchange.[178 225-228]

Specific tools and models to support this, particularly those involving telemedicine, have demonstrated immense value. For example, good evidence has been demonstrated for increased quality of life and stabilisation of HF symptoms, along with reduced mortality, hospital readmissions, length of admissions and associated healthcare costs.[229-233]

Truly multidisciplinary working in HF is not the reality in most areas, held back by lack of tools and low uptake of those that exist

Genuinely collaborative working methods still seem to be a distant reality for many professionals working in HF. In most areas, the lack of incentives or collaborative protocols, and the incompatibility of IT systems between care settings and regions, contribute to the fragmentation of care.[101 111] The absence of such models may be most keenly felt in geographically isolated areas,[195] where local access to HF specialists is either unavailable or infrequent.

Poor communication between settings arises even where standardised and integrated protocols for HF management are actively promoted, as the use of these protocols requires all relevant care settings to implement them, which does not happen consistently.[114 234 235]

While some regional programmes have implemented multidisciplinary protocols and pathways for the management of HF,[97 141] national approaches are often lacking. To date, governments appear to have neglected the strategic potential of such models to transform care services at scale, in line with the wider lack of strategic focus on HF as a whole. In the meantime, the development of such models seems to be largely dependent on commitment from professional groups or provider federations, regional initiatives, or local healthcare professionals with an interest in HF.[97 99 100 141]

A renewed focus on telemedicine is being driven by COVID-19 adaptations

Several HF care models using telemedicine have been developed across Europe,[27 29 46 236 237] and the wider interest in remote care models prompted by the COVID-19 pandemic has led to the rapid establishment of telephone and video consultations. While many adaptations were conceived as a necessary compromise in the face of social distancing rules, their use has served to highlight the benefits of telemedicine for people who cannot easily access care.[30 98] Some centres have shown promising results, for example reducing HF hospitalisations and deaths compared with the same period in 2019.[29] Others report that this has enabled clinicians to be more present in each patient's life and care, thanks to the more frequent and rapid contacts.[101]

Successful implementation of such approaches highlights the value of telemedicine as an important tool for the management of HF and its potential in supporting integration of care moving forward. The process has not been seamless, however, and concerns have been voiced as to potential deficits in such models – for example, the inability to adjust certain medications if blood pressure cannot be taken.

SEE *Spotlight on telemedicine in ongoing heart failure care*[89]

Where do we go from here?

The way forward

Addressing HF requires policies and care pathways that support multidisciplinary and integrated care, investment in a workforce prepared to respond to the challenge, and tools to promote clear communication and assessment of performance. Equally, all healthcare professionals involved in the management of HF must recognise the importance of collaboration and person-centred care.

Moving forward, a stark difference in public health and economic performance will emerge between countries that renew investment in effective HF diagnosis and care, and those that do not. Each country faces its own set of challenges, and we discuss national needs in the country profiles that accompany this report. There are, however, crucial actions that are needed in most, if not all, countries analysed in this study.

Increase awareness of HF among the public, healthcare professionals and decision-makers

Understanding of HF must be improved at all levels to overcome the inertia surrounding it. Awareness campaigns aimed at the public may encourage people to see a healthcare professional as soon as they start experiencing signs and symptoms. Training opportunities led by national professional societies can support healthcare professionals in the correct identification of signs and symptoms as well as optimal management of HF in line with the latest guidelines. Targeted messaging for decision-makers should include comparisons between the burden of HF and better-known conditions, such as cancer or type 2 diabetes.

Reimburse NP testing universally across care settings and incentivise its appropriate use to support diagnosis of HF

NP testing offers significant opportunities to streamline HF diagnosis and care. It can help prioritise referrals for echocardiography, which will likely reduce waiting lists for specialist examinations. However, reimbursement policies often fall short, paying for NP testing only when prescribed by a specialist physician, or not at all. It is also essential for NP testing to be used consistently in HF diagnosis. Professional bodies, particularly primary care societies, can help improve understanding of the value of NP testing in HF by providing training for primary care physicians on the correct use and interpretation of diagnostic tests.

Accredit and fund the HF specialist nurse role

The benefits of nurse-led HF management have been widely demonstrated, and it is now essential that countries across Europe formally recognise the HF specialist nurse role in order to expand the HF workforce. In some countries, nursing societies are guiding efforts to standardise requirements in terms of education and clinical responsibilities; in others, this has yet to happen. Such criteria can be incorporated into postgraduate training programmes, which should be formally recognised by the regional and national healthcare systems and professional societies. Accreditation should be linked to financial recognition of the role to foster interest.

Fund and facilitate multidisciplinary and integrated HF care though the development of care protocols, clinical networks and telemedicine models

Several professional societies have already laid the groundwork for high-quality HF care through the development of national guidance, and have called for policies and funding frameworks to support the proposed care models. However, across Europe, there remains a widespread need for HF-specific care protocols that articulate how healthcare professionals should collaborate in real-world settings, and for reimbursement to cover integrated care. Multidisciplinary care can also be advanced via the development of clinical HF networks with clear links between healthcare professionals working in different settings. The COVID-19 pandemic has underscored the value of telemedicine in HF care; such models should be more widely adopted to avoid unnecessary visits to care settings, which would help ensure care for people in remote areas and could reduce costs. Models of collaboration with patient associations should be explored to ensure people with HF and their families or carers can access accurate information and are empowered to adhere to self-care behaviours.

Invest in tools to support communication across care settings, including appropriate IT systems

Different countries are at different stages of developing IT systems that foster communication and collaboration between healthcare professionals, so the next steps vary significantly depending on the country. Integrated healthcare IT systems will be crucial to fully informed decision-making, helping to improve outcomes and reduce the burden of HF. Such systems will offer greater resilience and adaptability in the face of crises such as the COVID-19 pandemic. They can become the foundation for national HF registries.

We hope that this report and the accompanying country profiles contribute to the understanding of the challenge that HF currently poses across Europe, and drive multidisciplinary discussion and health system improvement. Ultimately, we hope the human and economic burden of HF is finally addressed via stronger policies and clinical care to improve the lives of the millions of people living with HF.

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