



The handbook of multidisciplinary and integrated heart failure care



September 2018

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All members provide their time for free.

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.

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The Heart Failure Policy Network

This handbook is dedicated to the many patients, patient advocates, clinicians and scientists who have worked tirelessly to improve the lives of people living with heart failure over several decades, often in the face of many obstacles. It is our privilege to have the opportunity to play a part in this most urgent and human mission, and to work with and for those who refuse to accept the inequality and suffering they see.

On behalf of the Heart Failure Policy Network Steering Committee,
Project Advisory Group (2018) and Secretariat.

What and whom is this handbook for?

Since 2015, the Heart Failure Policy Network has set out to make a meaningful difference to care for people living with heart failure.

In 2017–18, we aimed to provide national policy advocates with a pragmatic tool to engage decision makers in implementing integrated heart failure care. The result, *The handbook of multidisciplinary and integrated heart failure care*, has several aims:

- To help patient advocates and healthcare professionals communicate a shared, compelling and evidence-based policy case for change
- To win the support of key decision makers to challenge the status quo
- To encourage, facilitate, measure and, ideally, resource more consistent implementation of best practice.

Help us take the case for change to national governments.



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Call to action

We call on governments to recognise heart failure (HF) as an urgent sustainability challenge for 21st-century healthcare systems. Governments across Europe must:

- **Have a formal strategy on HF** and the changing impact it will have on the healthcare system and society, including future scenario-modelling. This should be developed in close consultation with patient and clinical advocates.
- **Invest in sustainable, specialist HF care models** outside of acute care, for example HF specialist nurses and HF outpatient centres. They should also promote professional education and, where appropriate, additional specialist accreditation for GPs, internists, primary care nurses and expert patients.
- **Ensure national guidelines and local care pathways embed the vision of quality in routine delivery**, working with professional societies, patient advocacy groups and healthcare providers to do so.
- **Prepare robust and public national audits of performance** to ensure accountability to citizens on patient survival, quality of life and experience of care, and to guide investment and incentives. The safe reduction of hospital readmissions should be a major strategic goal, indicating a sustainable approach to HF care.

We call on governments to demonstrate measurable improvement for the following minimum standards and core indicators of quality for all HF patients:

- **Specialist-led diagnosis.** It is vital to achieve a definitive diagnosis with an echocardiogram, ensuring the underlying causes of HF are fully understood, addressed and communicated to patients.
- **Natriuretic peptide testing.** This should be a routinely available tool in both primary and secondary care settings.
- **Specialist-led care in hospital.** Patients should receive input from a cardiologist and HF specialist nurse.
- **Hospital discharge with a care plan.** Discharge plans should include clear points of contact and timely follow-up by specialists.
- **Cardiac rehabilitation, patient therapeutic education and psychological support.** HF care must be built on the maximum engagement of patients.
- **A shift in management of HF from the acute to primary care setting.** This shift should occur wherever it is safe and effective to do so.

The following organisations support and endorse this handbook.



Executive summary

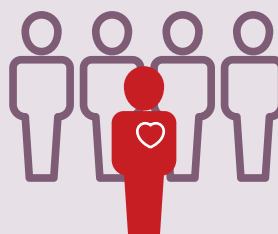
Heart
failure

#1



cause of
unplanned
admissions

1 in 5



can expect to live with
HF at some point
in their lives

+50%



rise in hospital admissions
due in the next 25 years

Best-practice
care achieves

↓ 30%

reduction
in hospitalisations



Heart failure (HF) is a healthcare sustainability challenge.

- **HF is a common condition.** It occurs as a result of the heart becoming too weak or stiff,¹ affecting its ability to pump enough blood around the body.²
- **At least 15 million people live with HF in Europe.**³ One in five of us can expect to live with HF at some point in our lives.⁴
- **The burden of HF is high.**^{5,6} Quality of life and survival remain poor – worse than for most common types of cancer.⁷
- **HF is the leading cause of unplanned hospital readmissions.**⁸ It is also the most common cause of admissions in people over 65.⁹
- **The burden of HF will rise.** This is partly due to an ageing population and improved survival from other cardiovascular and chronic diseases.^{10,11}
- **Hospital admissions due to HF are projected to rise by 50%** over the next 25 years.⁹



Although the prognosis is poor, the right package of care makes a huge difference to people living with HF.

- **The right care and support can allow people with HF to recover many years of life, and quality of life.**^{12 13} Hospitalisation can also be reduced by up to 30%.¹⁴⁻¹⁷
- **Care and support must be flexible to the individual needs and preferences** of the person living with HF. This can improve clinical outcomes and patient activation to live and self-manage HF.^{2 6 18}
- **The best model of care is an HF management programme:** a package of person-centred care, which includes self-management support, rehabilitative and preventive care, routine reviews and escalation in the event of crisis.^{6 19}
- **Best practice is for multidisciplinary care to be led by specialists,** including cardiologists (ideally with a sub-specialty in HF) and HF specialist nurses, working out of HF clinics.^{6 12} Other vital roles include GPs, cardiac rehabilitation specialists, physiotherapists and pharmacists.
- **Home visits and structured telephone support (led by HF specialist nurses) are innovative models** in reducing HF-specific admissions and mortality.¹⁷

European health systems are currently unprepared for HF.

- **Healthcare systems often struggle with a chronic disease model,** and HF is no exception. Care is often fragmented^{6 19} and guideline-based care too rare.^{2 9 20}
- **The greatest challenges and missed opportunities lie at five points across the HF journey:** presentation and diagnosis; hospital discharge and follow-up; clinical management; patient empowerment and self-care; and advance care planning.
- **We need to train new roles and reinforce existing ones** if we are to keep patients out of hospital. In particular, we lack HF specialist nurses,¹⁹ and need to better train and involve GPs and pharmacists. Every healthcare professional should recognise basic symptoms.
- **We need to overcome inertia, low awareness and low scrutiny at all levels,** including among policymakers, government agencies, professionals, patients and the public.

What heart failure is, and why we need to find a better solution to its care

Heart failure is a very common but complex clinical syndrome

There are at least 15 million people living with heart failure (HF) in Europe,³ although the true number may be higher.^{10 11 21 22} HF occurs when the heart can no longer pump enough blood around the body as it has become too weak or stiff.^{1 2} It is characterised by symptoms that include breathlessness, swelling (especially of lower limbs and abdomen), extreme fatigue, and signs such as oedema (accumulation of fluid in the body). Symptoms can severely impact a person's quality of life, and may be life-threatening. People with HF frequently experience comorbidities such as atrial fibrillation, diabetes, chronic obstructive pulmonary disease and chronic kidney disease, and the contribution of these conditions to HF is not easy to predict.^{6 23 24} It is important to identify HF at a very early stage, as pre-symptomatic management can improve clinical outcomes.⁶

Heart failure has clear
'red flag'
symptoms
to look for



HF imposes a heavy physical and psychological burden

The burden on people living with HF, their carers and their families is comparable to many other major chronic diseases.^{5 6 21} Patient quality of life and survival rates remain poor, and are worse than for many types of cancer.⁷ For example, a national registry in Sweden has reported that every year around 126,000 premature life-years are lost due to HF, compared with close to 120,000 due to cancer.²¹

HF is a sustainability challenge for healthcare systems

The financial burden of HF is significant.^{9 25} Inpatient hospital care is a major cost driver, accounting for up to 70% of HF health costs in Western countries.²⁶ In Germany in 2006, it accounted for 45% of the €2.9 billion spent on HF.²⁶ HF is the most common cause of hospital admissions in people over 65,⁹ and the leading contributor to unplanned hospital readmissions.⁸ Outcomes for HF are poor. One in four HF patients is readmitted to hospital within one month of discharge,⁹ and two in three are readmitted within one year.²



Indirect costs and productivity losses from HF are substantial

Informal care and other indirect costs add to the financial burden. HF is more likely to reduce workforce participation for those who live with it than asthma, diabetes, coronary heart disease or osteoarthritis.²⁹ Working-age people with HF may struggle to return to employment, for example where there is stress, a requirement to stand for long periods, or heavy physical work.²⁹ In Ireland, the cost of informal care has been estimated at more than double that of direct healthcare costs (around €364 million, against €158 million direct healthcare costs).²⁷

HF expenditure will grow

Hospital admissions due to HF are projected to rise by 50% over the next 25 years.⁹ The prevalence of HF is rising, partly due to an ageing population and improved survival from other cardiovascular and chronic diseases, thus the costs associated with HF will continue to grow.^{10 11 21}

Guideline-based care leads to gains for patients and healthcare systems

Although HF has a poor prognosis, it is treatable and preventable.⁶ Guideline-compliant care can significantly improve patient outcomes such as survival and quality of life.¹³ Currently available treatments can prevent or delay the progression of HF with reduced ejection fraction (HFrEF – approximately half of HF cases²¹), but we still lack effective treatments for another major type of HF, HF with preserved ejection fraction (HFpEF). This means that for people with HFpEF, care must focus on symptom management.⁶

What is multidisciplinary and integrated care in heart failure?



Multidisciplinary and integrated care is about delivering the best care possible

Integrated care has been defined as realising the potential of multidisciplinary teams to promote person-centred and coordinated care, tailored to the needs and preferences of the patient, their family and carers.²⁹ Guidelines are clear that the management of HF should be seamless; it should ensure management of comorbidities, changing needs and support throughout different care settings, involving HF specialists.⁶ Team members are expected to work in close coordination with one another – including the patient – with mutual respect, clear communication and clear division of responsibilities.¹⁹ This is especially important when a person with HF transitions between care settings.²

Multidisciplinary care should support and empower patients, their carers and families

Empowerment of patients, carers and families is vital for long-term engagement in self-care.² Every person living with HF has a unique journey. They may have to accommodate challenging physical, psychological, professional and therapeutic adjustments.^{2 11 27 30} The multidisciplinary team should be flexible in working with patients and adapting care to their circumstances, with their needs and preferences considered in all decisions.^{6 31} Many people want to be involved in their own care.^{32 33} The multidisciplinary team must therefore help those living with HF to develop the knowledge and skills to lead self-care and maintain as good a quality of life as possible.³⁴⁻³⁷ Patient groups may offer essential guidance in this effort.



High-quality HF care requires collaboration

Cardiologists, internal medicine specialists and GPs are the traditional HF clinical leads, but other roles have enormous potential.^{6 19} For example, HF specialist nurses are central to many modern best-practice models;^{35 38-40} they can provide routine monitoring, management and patient therapeutic education, and can run longer and more individualised consultations than other healthcare professionals.¹⁹ Other important roles are listed on page 17. Increasingly, peer support networks, coaching and patient advocacy groups are being recognised as intrinsic to success in HF care.²⁵

Multidisciplinary and integrated care changes across the HF journey

The needs of HF patients are not static; therefore, there is no single optimal care journey. There are three very typical phases of HF: diagnosis; care and follow-up; and living with HF.^{2 30} The last phase represents the long-term experience of people who learn to live with the condition and self-care. Depending on progression of the disease, people with HF may have episodes that require return to acute care or enhanced medical supervision.

There is an urgent need for improvement at five points in the HF journey

HF care is often fragmented.^{6 19} Research suggests there are five key areas of focus along the journey that are frequently identified as presenting the greatest challenges and missed opportunities. These 'pressure points' are: presentation and diagnosis; discharge and early follow-up; clinical management; patient empowerment and self-care; and advance care planning.

What is multidisciplinary and integrated care in heart failure?

Figure 1. Multidisciplinary and integrated heart failure care journey: key components of quality

Seamless transitions of care are required across moments of crisis and changing need, in all settings and stages of the patient journey.^{2 6}

The three stages of the patient care journey

Diagnosis

- HF signs and symptoms rapidly picked up by healthcare professionals working in close consultation across settings¹³
- Referral from primary care to specialist-led diagnostics, involving echocardiogram and B-type natriuretic peptide^{13 41}
- Definitive and timely diagnosis including type of HF and additional underlying conditions^{6 13 41}
- Initiation of self-care education to patients, carers and families^{6 13 41}

What does high-quality care look like?

HF is often preceded by other diseases, such as other heart conditions, diabetes and kidney disease.⁵

Why are multidisciplinary and integrated approaches vital?

- HF is often difficult to diagnose, and HF patients may present in different settings¹³
- Diagnosis, including understanding of HF causes, requires several tests and judgement from a specialist⁶
- Timely initiation of treatment is essential to prolong life and minimise symptoms⁶
- Many high-risk patients warrant rapid referrals⁶

Where does care usually fail patients?



1
Presentation and diagnosis

Key



Pressure points are well-known problematic areas where care and support fail many patients. Not all journeys are the same. Not all patients will be treated in hospital. Pressure points 4 and 5 may occur anywhere after diagnosis.

Care and follow-up

- Person-centred care led by a cardiologist (with a sub-specialty in HF) or internal medicine specialist¹³
- Efforts at rapid alleviation of symptoms;⁶ consideration of implantable cardioverter defibrillator; transition to oral medication upon stabilisation
- Hospital discharge planning and close follow-up with dedicated contact points⁴¹
- Individualised care planning initiated; patients enrolled in HF management programmes^{6 13 17}

Living with HF

- High-quality education to patients, carers and family to support long-term patient expertise and self-care behaviours^{13 41}
- Whole-person approach to rehabilitation and psychological support^{6 13 41}
- Seamless ongoing care including close monitoring, individualised management,¹³ and joint support from healthcare professionals, expert patients and patient peers

- HF patients have complex care needs, spanning specialists and generalists¹³
- In the weeks after discharge there is a risk for loss of key information, and delay and fragmentation of care^{6 41}
- Patients with the right post-discharge support and package of care return to hospital less often⁴²

- HF requires continuous, personalised clinical and psychosocial support¹³
- Unplanned hospital admissions can be prevented via leading models of multidisciplinary care^{14 15}
- Patients closely involved in self-care are at lower risk for hospital readmission and have better quality of life and clinical outcomes^{13 41}



2

Discharge planning and early follow-up



3

Clinical management



4

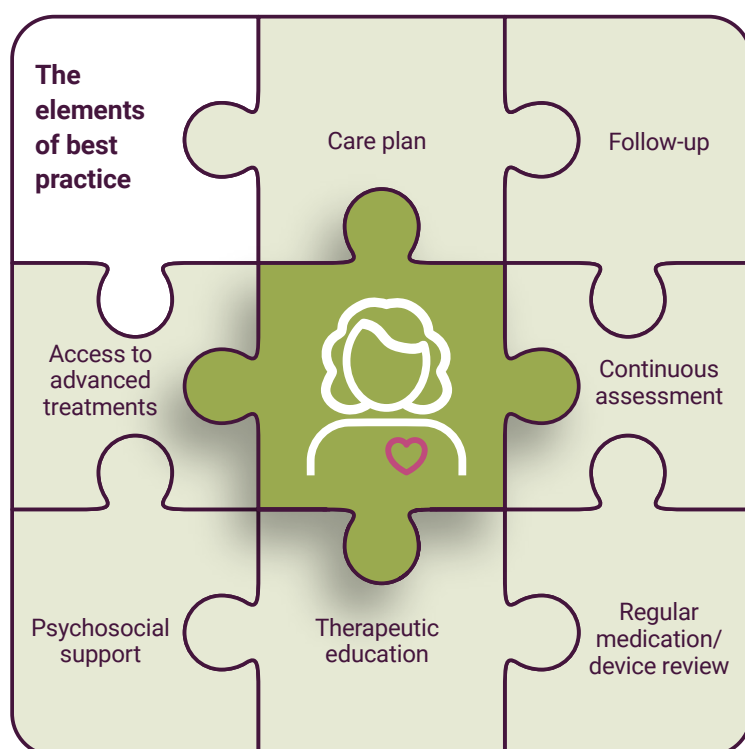
Patient empowerment and self-care



5

Advance care planning

What are the key components of high-quality, integrated management and care in HF?



The term 'integrated care' has also been used to refer to broader organisational and environmental change, including collaboration between organisations and coordination of care services, and governance and financial issues.⁴⁶⁻⁴⁸

The main elements of routine best practice are well documented in European guidelines,^{6 10 13 41} as well as in expert commentary on HF management programmes. Elements include:

- a comprehensive care plan ensuring regular contact points and rapid access to care in moments of worsening symptoms
- follow-up after discharge
- continuous assessment of risk factors, symptoms, signs, functional status and quality of life – and provision of a suitable response in each case
- regular review and optimisation of medication and devices
- therapeutic education to encourage self-care behaviours and to help optimise adherence to medication and exercise plans⁴³
- psychosocial support to patients, their families and carers
- access to advanced treatment options, as appropriate.^{6 44}

Many innovative models are moving the setting of routine HF management away from the acute or outpatient care into the home, for example offering regular review and patient education via nurse home visits and telephone-based support.¹⁷ This is possible even for more demanding procedures such as intravenous diuretics.⁴⁵



Which professionals should be involved in the multidisciplinary care team?

The key roles in the multidisciplinary team are well-established in best practice and expert commentary.^{2 6 12} They include:

- cardiologists (ideally with sub-specialty in HF)
- HF specialist nurses and primary care nurses
- primary care physicians (GPs)
- physiotherapists (and cardiac rehabilitation physiotherapists)

Other close roles are played by:

- internal medicine specialists
- pharmacists
- expert patients, coaches, support groups and patient associations
- geriatricians
- hospice care/palliative care staff
- interventional cardiologists
- psychologists
- dieticians
- social workers
- intensive care specialists
- cardiac surgeons from transplantation centres

Depending on the patient and comorbidities, they may also need care provided by pneumologists (lung specialists), nephrologists (kidney specialists), endocrinologists (diabetes specialists), and sleep apnoea specialists.

HF management programmes and clinics offer the best answer to HF care needs

While there are many possible models through which HF care and support can be organised, HF management programmes and HF clinics are widely recognised.

- **HF management programmes** are the gold standard of care in European guidelines.⁶ They are local protocols for comprehensive and, ideally, guideline-driven care and support for people living with HF. Programmes typically aim to follow patients across phases of care, from discharge planning through to long-term monitoring and therapeutic education. They should span primary and secondary care settings, as well as home-based follow-up.⁶
- **HF clinics** are recognised by experts as effective settings (i.e. a 'base of operations') for specialist-led care, for example management programmes or other specialist services such as diagnostics.^{12 43} 'Traditional' HF clinics have focused on specialist nurse-led patient monitoring with cardiologist leadership, often in outpatient premises, which are well-suited to patients who are relatively stable and mobile.⁴⁰

The management of HF should be seamless. It must offer care and support throughout different care settings, across changing needs, led by HF specialists in a multidisciplinary team.



More flexible models of care can also be beneficial

The most advanced multidisciplinary and integrated care models have been orientated to patients with the highest needs.^{14 44} However, most patients are likely to benefit from care that is better coordinated and more adaptive to their needs and expectations.^{6 14} Many leading commentators advocate for expansion of multidisciplinary and integrated care models to all people living with HF.^{2 6 25 30}

In recent years, some clinic models have evolved into more flexible services that respond to different needs; innovations include part-time clinics, home visits, structured telephone calls and telemedicine platforms.¹⁶ Care settings other than HF clinics can also be effective in care delivery; for example, the needs of very stable patients may be met by effective support from a motivated and well-informed GP.¹²



Performance and barriers to date: the reality check

What is happening?

There is a lack of standardised data collection and analysis, but the available data show clear gaps in guideline-based care.^{2 9 20 49}



Diagnosis is often not rapid or detailed enough

Patients experience harmful misdiagnosis and delays in diagnosis, with most only being diagnosed at the late symptomatic stage after permanent damage to the heart has occurred.^{25 50-54} There is inconsistent use of key diagnostic tests, such as echocardiogram (echo) and electrocardiogram (ECG).⁵⁵

Existing estimates of delays from first presentation to definitive diagnosis range from several months in Germany⁵⁶ to up to a year in Ireland,⁵⁷ with serious delays also noted in England and Scotland.^{25 52}

Many people living with HF still do not see the right specialists

Even when diagnosis is confirmed, too many HF patients are not seen by the right professionals, despite some countries having clear guidelines for specialist-led care.⁵⁸ HF inpatient care is fragmented relative to that of other cardiovascular patients, such as those suffering heart attacks, with little coordination for a true whole-patient approach.⁵⁹

In England and Wales, 20% of HF inpatients are not seen by HF specialists.⁵⁸





HF is often diagnosed too late

Patients leave hospital with substantial needs



Patients and families often do not know whom to contact after leaving hospital.⁶⁰ The medication plan prescribed on hospital discharge is often not compliant with guideline recommendations,⁹ even when HF patients have been seen by specialists.⁵⁸

In England and Wales, about half of HF patients with in-hospital care led by specialists are discharged with all core medications, reducing to one in four if patients are not seen by a specialist.⁵⁸

Fewer than

half

of patients receive recommended dosages of basic medications in some countries.

Few patients are followed-up properly after discharge

Few countries meet the European guideline recommendations for HF patients to see a specialist within two weeks of discharge.⁶¹ Poor coordination between hospital doctors and GPs is a noted problem in HF and other chronic diseases.⁶²⁻⁶⁵ For example, GPs commonly receive discharge summaries lacking key information such as medication indications or follow-up instructions.^{8 54} Prescribed dosages of vital medications are frequently below guideline recommendations.⁶⁶

In France, only 30% of patients see the cardiologist within one month of discharge, and most are irregularly followed-up.⁶¹ In Italy, Poland and Greece, under 50% of patients receive recommended dosages of angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers (ARB) and beta-blockers, while in Norway and Sweden there is significantly better alignment with recommendations.⁶⁶

What is happening? (cont.)



HF programmes and clinics are not consistently available

While there are positive examples of HF management programmes, they are rarely formalised and delivered nationally.⁶ Access may also be limited in practice by uneven coverage of HF clinics.³⁰

In Ireland, six HF clinics operate in Dublin and only five can be found across the rest of the country, causing regional variation in HF survival and rehospitalisation rates.⁶⁷

The full potential of all healthcare professionals is not realised

Despite the existence of models for pharmacist-led reconciliation of medicines for HF patients, this aspect of discharge and care transitions is generally underdeveloped.⁶⁰ The benefits of physiotherapy-led cardiac rehabilitation are well proven,⁵⁸ yet access is very limited for people living with HF.^{25 70} Meanwhile, GPs are frequently involved in HF care, especially during key transitions such as at diagnosis and after discharge, yet they often demonstrate knowledge gaps in core treatment options and low confidence in managing HF effectively.^{54 71} This highlights a need for implementation of proven care models and professional training to fully explore the potential of GPs in HF care.

In most European countries, fewer than half of all cardiovascular patients, including people living with chronic HF, access cardiac rehabilitation.⁷⁰ In Ireland, fewer than 1% of people living with HF are referred to these services.²⁸



Patients face unacceptable variation in care



Few patients are supported to play their part in care and management

People living with HF commonly report low understanding of HF, its symptoms and risks, and a lack of suitable information.^{13 72 73} There is sporadic patient education and support,⁷⁴⁻⁷⁷ contributing to poor clinical outcomes for people living with HF and low confidence in their ability to self-care.⁷⁸⁻⁸² Care centres and patient groups are frequently left to develop their own education programmes and materials.^{49 83}

In Germany, structured and evaluated therapeutic educational programmes are not routinely available,⁷⁶ and in Italy, patients and carers may lack education and training to appropriately monitor their condition.⁷³

Palliative and end-of-life care is poorly planned

The use of advance care planning appears rare,^{84 85} and palliative care professionals are frequently not recognised by people living with HF as a member of the care team.⁸⁶ Physicians rarely discuss prognosis, death and palliative care with patients.⁸⁵ This may partly explain why people living with HF are only referred to palliative interventions relatively late.^{87 88}

A Dutch study in the outpatient setting found that end-of-life care was discussed with only 4% of people living with HF.⁸⁵ In the UK, fewer than 10% of people living with HF have been registered in the palliative care registry, compared with almost half of all cancer patients.⁸⁸

Why is this happening?



There are several well-established barriers to best practice.

Awareness of HF is limited

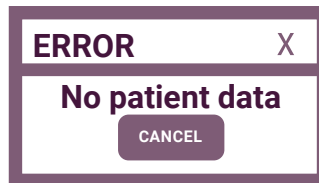
Policymakers, payers and the public appear to have poor awareness of HF. Across Europe, there is a limited understanding of HF signs and symptoms.⁸⁹⁻⁹¹

Best practice is not effectively communicated to healthcare professionals

There is a general lack of guidelines adapted to non-specialists or national contexts.^{2 30 70 92} The price of this is likely to be high. GPs consistently report low familiarity with European guidelines, driven in part by concerns as to their relevance to typical decision-making challenges faced in general practice.⁹² Even where guidelines are translated into national languages, it may not be feasible to expect non-specialist physicians (e.g. internists and GPs) to keep up to date with the most recent versions.

There are not enough specialised settings or professionals

Across Europe there is insufficient access to HF specialised settings and models of care, such as HF clinics and cardiac rehabilitation,^{2 19 30 70} and limited availability of key staff, such as nurses.^{30 93 94} The role of HF specialist nurses is generally poorly developed across Europe,⁹⁵ and those that exist may be overworked.⁹⁶ There is limited professional training on HF outside of specialist centres,⁹⁷ and there is usually no accredited professional standard or designated funding to support multidisciplinary working.^{38 70 98} As a result, it is still common for people living with HF to be managed by GPs or internists alone, without the support of a multidisciplinary team.^{54 73 99}



Healthcare professionals may struggle to share data



Some healthcare professionals are resistant to multidisciplinary working

Healthcare professionals caring for people with HF at both primary and specialist level do not necessarily have automatic confidence in multidisciplinary working, for example patient referral processes.^{92 99 100} Multidisciplinary working in HF can, in fact, challenge existing hierarchies between professionals, and this can generate resistance as to who is in charge of care.^{101 102} For example, cardiologists commonly report concerns about transferring HF patients to primary care, and GPs report fear of loss of skills and responsibilities when working with specialists.⁹²

Healthcare professionals may struggle to share patient data

HF patient records are frequently of poor quality,¹⁰³ and different care settings often have differing data platforms and practices, which hinders information-sharing.¹⁰⁴ For example, primary care professionals have low expectations of information-sharing by secondary care colleagues,⁹² and pharmacists mention difficulties accessing patient data.¹⁰⁵

Poor performance data inhibit evaluation and public scrutiny

Comparable performance data between localities are important for many reasons, including transparency in reporting of performance, accreditation or certification of institutions,¹⁰⁶ evaluation of new care models, determination of value-based pricing and development of financial incentives.¹⁰⁷ However, there are persistent issues with the quality and coverage of data in HF. For example, clinical charts and electronic health records are often not standardised and they usually exclude patient-centred measures, such as quality of life or symptoms.¹⁰⁷ Public access to data is often poor,^{103 107} limiting health systems' accountability and improvement of HF care.

Pressure point 1: Presentation and diagnosis

1 What is the issue?

Timely and appropriate diagnosis of HF is the foundation of effective management.^{12 108}

This ensures patients receive care as early as possible and achieve the best possible outcomes.^{2 6 13 51 57} Unfortunately, HF diagnosis is often confirmed late, once severe damage to the heart has already occurred.¹⁰⁹

Many healthcare professionals and the general public may have difficulty recognising HF symptoms.^{12 51 89} Fatigue and shortness of breath, for example, may be dismissed or confused with symptoms of diabetes, respiratory conditions or other heart diseases.^{2 9 110}

2 What is best practice?

There is no one diagnostic test for HF.^{6 44} Multiple tests, such as physical examination, echo, ECG or X-ray, and patient information such as medical history, are required for comprehensive diagnosis, including identification of underlying causes. HF specialist centres should aim to provide an integrated 'one-stop' diagnostics service.¹²

Specialist-led diagnosis with an echo is the gold standard.⁶ This provides comprehensive information on the heart and its capacity to pump blood, which is crucial in establishing the most appropriate treatments and prognosis.²⁵

Diagnosis is therefore a team effort. People with HF typically present in primary care,¹¹ yet initiation of treatment depends on symptoms being recognised, investigated and followed-up via effective referrals to secondary care specialists.

3 What works and what can be gained?

- We can reduce onset of HF among high-risk groups.^{2 44 111} For example, intensive treatment of high blood pressure can reduce progression to HF by 40%.¹¹²
- Direct referral to echo by GPs can safely reduce referrals to cardiologists by as much as two-thirds.^{113 114}
- Natriuretic peptide (NP) blood testing has been shown to be cost-effective by safely ruling out patients for echo.^{25 115 116} The Irish Cardiac Society estimates that it could reduce demand on specialist diagnostic services by 30%.⁵⁷
- Commonly available medications in guideline-compliant dosages, such as ACE inhibitors and beta-blockers, reduce hospitalisation and mortality in early HF.^{6 66}



Selected case studies



Challenging policy inertia for HF care, The Belgian Charter for Heart Failure

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.¹¹⁸ The initiative has been led by leading cardiac organisations and has been signed by 12,000 people to date.



Quality standards for integrated, specialist-led diagnostics, Spanish Society of Cardiology, Spain

The Spanish Society of Cardiology has published quality and accreditation standards for HF units.¹¹⁷ These align with guideline-based diagnosis, treatment and clinical follow-up of HF patients and set minimum standards of interaction with primary care. The programme recommends that primary care professionals order an NP test if they suspect HF.



More case studies are available at
www.hfpolicynetwork.eu



Pressure point 2: Discharge planning and early follow-up

1 What is the issue?

Discharge from hospital after an acute HF episode marks the beginning (or continuation) of care, not the end. Many patients leave the hospital with substantial needs, even when judged fit to go home by physicians.^{11 119} Transition from hospital to community settings is a vulnerable period^{43 60 120} as patients withdraw from close medical supervision.

People leaving hospital after an acute HF episode remain at high risk of death⁶⁰ and hospital readmission for up to three months.^{43 121 122} This period carries a higher risk of mortality than during hospitalisation.¹²³ Appropriate follow-up after discharge is critical to improve symptoms, quality of life and survival.⁶

2 What is best practice?

Every patient leaving the hospital should have a personalised discharge plan and should be followed-up by a GP within one week, and by a specialist within two weeks.⁶

This process should take a multidisciplinary approach to the person's clinical and other needs, and must ensure plans are in place for appropriate follow-up, monitoring and care.¹³ Plans must be communicated to key healthcare professionals, such as GPs.

Discharge planning should be individualised to each person's clinical and personal circumstances – including their wishes and preferences. Consideration for their social and family circumstances and psychological wellbeing are vital to ensure they can adapt to the demands of treatment, and adopt self-care behaviours and self-monitoring.¹⁸ Patients of working age may have pressing concerns and barriers in returning to employment.³⁰

3 What works and what can be gained?

- Effective discharge planning in HF supports integration of care and efficient use of resources,¹⁸ and improves patient outcomes, which may lead to reduced costs.⁹
- HF patients with an outpatient follow-up appointment scheduled at the point of hospital discharge have lower readmission rates than those who do not have this follow-up.⁴²
- Appointments in the first week or month after discharge further reduce the risk of hospital readmission.¹²⁴



Selected case studies



Person-centred discharge planning, Gothenburg University, Sweden

The Gothenburg University Centre for Person-Centred Care has developed an internationally recognised model of hospital discharge and follow-up emphasising joint care planning.¹⁸

The model is typically led by nurses, who provide therapeutic education and develop care plans with patients, closely considering their wishes, values and needs. The model has safely shortened hospital stay without compromising patient outcomes.



Ten-point discharge checklist, University College London Partners, UK

In 2015, the University College London Partners, working with St Bartholomew's Hospital, set up the Heart Failure Improvement Collaborative. The Collaborative developed a checklist of elements of high-quality discharge summaries.¹²⁵ Though not exhaustive, the list was considered to meet the needs of clinicians, patients and carers. It can support the audit of discharge summaries and ultimately improve performance. The Collaborative has demonstrated improvements in services following use of the checklist.



More case studies are available at
www.hfpolicynetwork.eu



Pressure point 3: Clinical management

1 What is the issue?

HF carries a continuous risk; therefore, clinical management of HF is lifelong. The goals of care include maximising capacity of the heart, preventing disease progression, avoiding hospitalisation, and improving quality of life and survival.⁶ Patients require regular consultations to assess symptoms, adjust medication, and assess the need for device treatment and monitoring.^{6 126}

Most people living with HF have comorbidities. For example, around one in three HF patients has diabetes, and close to one in five has chronic obstructive pulmonary disease. Comorbidities add complexity to decision-making and goal-setting, making individualised clinical judgement and communication across care settings even more important.^{19 99}

2 What is best practice?

HF clinical management is best delivered by a multidisciplinary team led by an HF specialist.^{6 12} This may be a cardiologist or internal medicine specialist, although patient advocates and clinicians widely recognise the role of HF specialist nurses in leading care,^{6 12 25 127} often based in HF clinics.³⁰ Other important roles include GPs, primary care nurses, pharmacists, physiotherapists, dieticians and the patient's family and carers.⁶

HF management programmes are the gold standard for long-term multidisciplinary care of HF. They combine medical and device management with other protective and supportive strategies, such as cardiac rehabilitation, patient education and psychological support.¹²⁸

3 What works and what can be gained?

- HF management programmes reduce the risk of hospitalisation¹⁴⁻¹⁶ by up to 30%.¹⁷
- HF management programmes can reduce mortality and healthcare costs, and improve quality of life.^{14-16 43}
- Involvement of an HF specialist cardiologist or HF specialist nurse in inpatient care and follow-up are predictors of lower mortality after hospital admission.¹²⁹
- Cardiac rehabilitation independently reduces hospitalisations, improves quality of life and boosts survival by as much as 12%.^{58 68 69}



Selected case studies

Multidisciplinary care pilot projects, Polish Cardiac Society, Poland

The HF Working Group of the Polish Cardiac Society, the Polish Ministry of Health, and other primary care associations are launching new multidisciplinary HF clinic models (including specialist nursing) in five hospitals in different cities in 2019.

The project aims to better understand patient needs and develop a long-term reimbursement model for HF care.



Nurse-led diuretics, British Heart Foundation and National Health Service (NHS), UK

The British Heart Foundation led a two-year pilot project in ten NHS organisations to determine the safety of community-based intravenous diuretic service. It concluded that 1,040 patient bed days were saved, for an average saving of £3,003 per community-based intervention. All patients said they preferred treatment in the community to hospital.⁴⁵



Nurse-led HF management programme in primary care, Barcelona, Spain

Healthcare institutions in the Litoral Mar area in Spain and the Catalan Health Service developed a nurse-led multidisciplinary HF care model that integrated care and reduced the risk of readmission and death.¹⁵ Adding a telemedicine component has further reduced hospital readmission, length of hospital stay at readmission and cost per patient.¹⁶ This care model is being implemented and improved in South Metropolitan Barcelona with coordination from the Bellvitge University Hospital.



More case studies are available at
www.hfpolicynetwork.eu



Pressure point 4: Patient empowerment and self-care

1 What is the issue?

People living with HF have an essential role in improving their own health outcomes.

Adjusting to life with HF requires continual and personalised support, both clinical and psychosocial.¹³⁰ Most people living with HF can and should practise self-care to better manage life with HF; this ranges from dietary restrictions to monitoring of vital signs, exercising, adhering to the medication plan and notifying their doctor of changing symptoms.^{6 131}

The effective adoption of routine self-care is linked to individual personal motivations, life circumstances and levels of social support.¹³² People living with HF can develop their own coping strategies to remain engaged and motivated.⁹ This is critical, as making the lifestyle changes required to maintain health, and monitor and manage HF signs and symptoms, is often challenging.^{6 9 133}

2 What is best practice?

Self-care education and support should start as soon as possible after diagnosis, ideally in hospital.^{6 9} Effective self-care models have been demonstrated in both inpatient and outpatient settings.^{6 13 18 35 36}

It is important to involve a multidisciplinary team in the delivery of self-care education.^{6 9} People living with HF, carers, family members and healthcare professionals are vital partners in this effort.^{134 135} Two roles deserve particular focus: HF specialist nurses¹⁹ and patient advocacy groups.^{9 31}

3 What works and what can be gained?

- Effective self-care lowers the risk of hospital readmission^{9 136-138} and clinical outcomes such as depression.^{18 132 139}
- Engaging people in their own HF care makes them more likely to adopt lifestyle changes that help maintain health and manage symptoms, such as showing greater adherence to treatment,^{134 135 137} and can reduce healthcare spending per patient.¹³⁶



Selected case studies



ITERA and PRISMA programmes, Spain

The ITERA programme has made a number of tools available to support people to live well with HF.¹⁴⁰ The tools include: a guide explaining what HF is, from symptoms and causes to possible treatments;¹⁴¹ a chart for control of medication;¹⁴² a guide with detailed dietary recommendations;¹⁴³ a guide of recommended exercises;¹⁴⁴ and a chart to record weight measurements and help trigger escalation to a healthcare professional.¹⁴² The programme has supported the development of HF clinics in Spain, and preliminary results showed an improvement in self-care, functional capacity and quality of life.¹⁴⁵ It has developed into the programme PRISMA, also focused on promoting integrated HF management programmes.



Mobile patient support, Italian Association of Heart Failure Patients, Italy

The Italian Association of Heart Failure Patients (Associazione Italiana Scompensati Cardiaci) has developed a travelling programme to provide support to people living with HF and to raise awareness of HF across the country.^{146 147} The association distributes educational material at meetings and provides specialist visits on the spot.



More case studies are available at
www.hfpolicynetwork.eu



Pressure point 5: Advance care planning

1 What is the issue?

Advance care planning is the process of enabling the person living with a chronic disease to understand and define palliative treatment goals at late disease stages.¹⁴⁸ It is not intended to hasten or postpone death, but rather to understand and address the individual's needs, wishes and preferences to ensure they are comfortable throughout the entire course of the disease.^{148 149} This is vital, as worsening symptoms and comorbidities of advanced disease^{150 151} call for continual reassessment of care objectives.^{87 152 153}

2 What is best practice?

Advance care planning should start early; palliative care decisions should not be reactive in response to urgent needs.^{6 10 13 86 87} This ensures people living with HF are able to fully communicate their wishes and preferences in good time, for example on the subject of resuscitation or the deactivation of implanted devices.⁸⁵ This also gives the individual and their family more time to cope.¹⁵⁴

All members of the HF team have a role in providing high-quality palliative care¹⁵³ and should adapt conversations to the person's health literacy, values, and communication style and ability.¹⁴⁸ In late-stage HF, palliative care specialists may be required to take over coordination of care.¹⁵⁴

The benefits of palliative interventions depend greatly on settings and supportive infrastructure. End-of-life care is typically understood to be best provided at home or in a residential facility, such as a hospice.⁸⁷ Healthcare providers must coordinate responsibilities and enable data-sharing across different organisations and settings, potentially via electronic health records.¹⁵⁵

3 What works and what can be gained?

- Models of advance care planning and palliative care can reduce hospitalisations and symptom burden, while improving patient self-efficacy, satisfaction and quality of life.^{150 156-159}
- Many high-quality advance care planning and palliative care models are cost-effective – reducing costs, for example from hospitalisations.^{148 149 159}



Selected case studies



Palliative advanced home care and heart failure care, Sweden

Palliative advanced home caRE and heart FailurE caRe (PREFER) is a palliative care model developed in Sweden.¹⁵⁷ It involves a comprehensive team of healthcare professionals who collaborate for provision of patient-centred care. The model has been shown to improve health-related quality of life, nausea, total symptom burden, self-efficacy and HF functional class.¹⁵⁷



Advanced Heart Failure Improvement Programme, Brent and Harrow, UK

St Luke's Hospice in Harrow, UK developed a programme with local National Health Service trusts to improve advance HF care. The programme developed a tool to help community HF nurses identify patients who could benefit from palliative care.¹⁶⁰ The programme has increased the adoption of palliative care terminology, access to advance care planning and specialist palliative care services, death outside of hospital, and job satisfaction of community HF nurses.



More case studies are available at
www.hfpolicynetwork.eu



Conclusion

Healthcare systems may aim to be guided by scientific principles but are ultimately shaped by political will and beliefs. HF is certainly proof of this.

On the one hand, there is much to celebrate. HF has been transformed into a treatable and preventable disease – a huge triumph of collective human effort on many levels. Most people living with HF should now look forward to years of life lived with hope and effective support.

In reality, however, routine and tragic gaps persist for even basic components of clinical best practice. This, with the huge costs involved, is the urgent challenge that now falls to us.

The organisation of our healthcare systems is no distraction from front-line delivery of care. The consequences of structural unreadiness for chronic diseases models are very real in HF. Each year millions of families across Europe witness entirely avoidable suffering, isolation, despair and the irretrievable loss of years of rewarding life for those they love.

Nations or regions that lack robust scrutiny of performance are arguably in the greatest danger. Data are not an abstract luxury in a resource-constrained and complex healthcare system; they are the lifeblood of patient advocacy and political scrutiny. Data collection should help consistent leadership across short political cycles, and is increasingly central to service improvement at the ward and clinic level. Without data, strategic goals to reduce inequalities or pursue value-based investments are likely to be an empty promise.

This handbook aims to place a credible and comprehensive policy narrative into the hands of patient and clinical advocates. But it is of no use to those who live with HF if it does not generate political consensus for change.

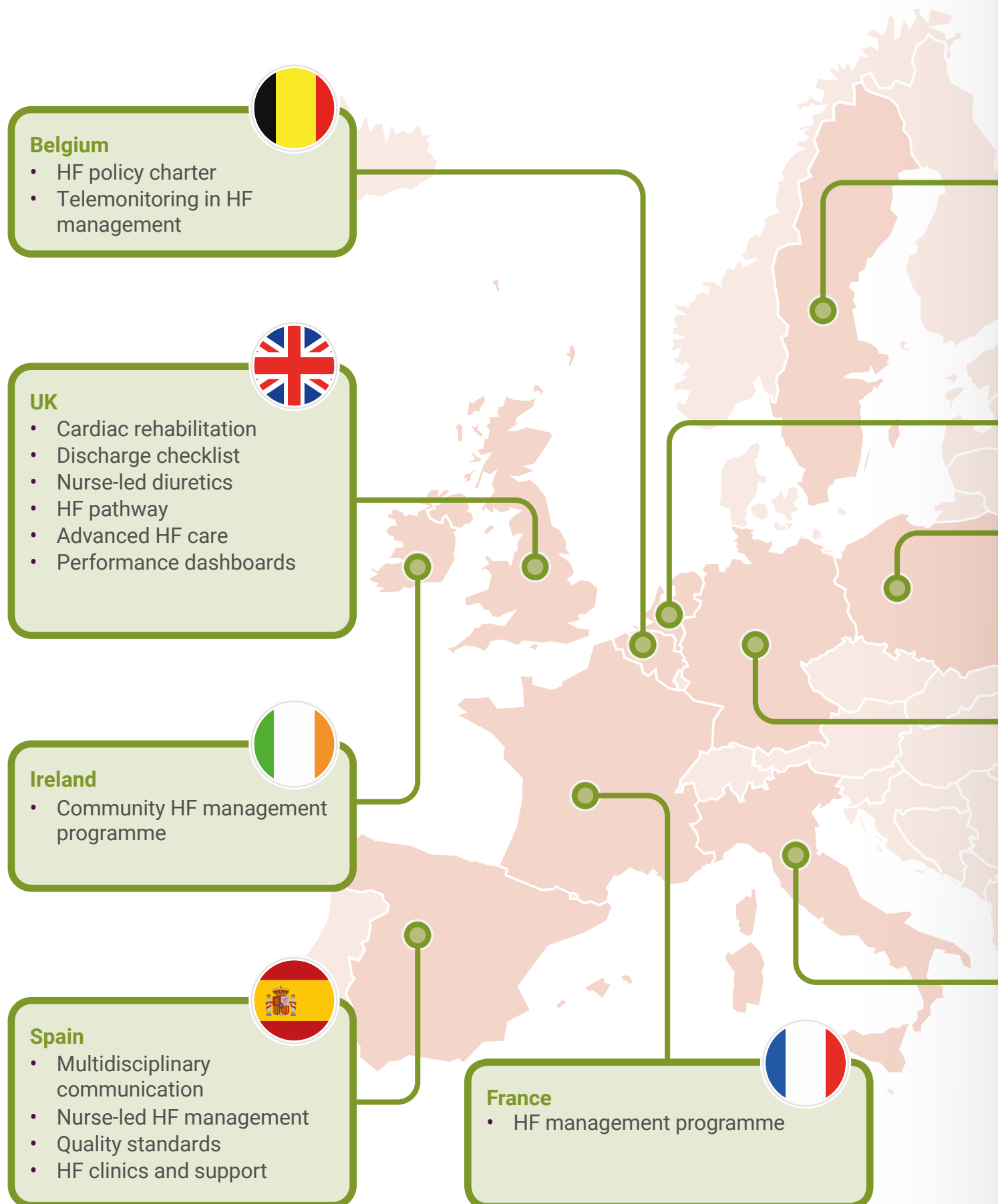


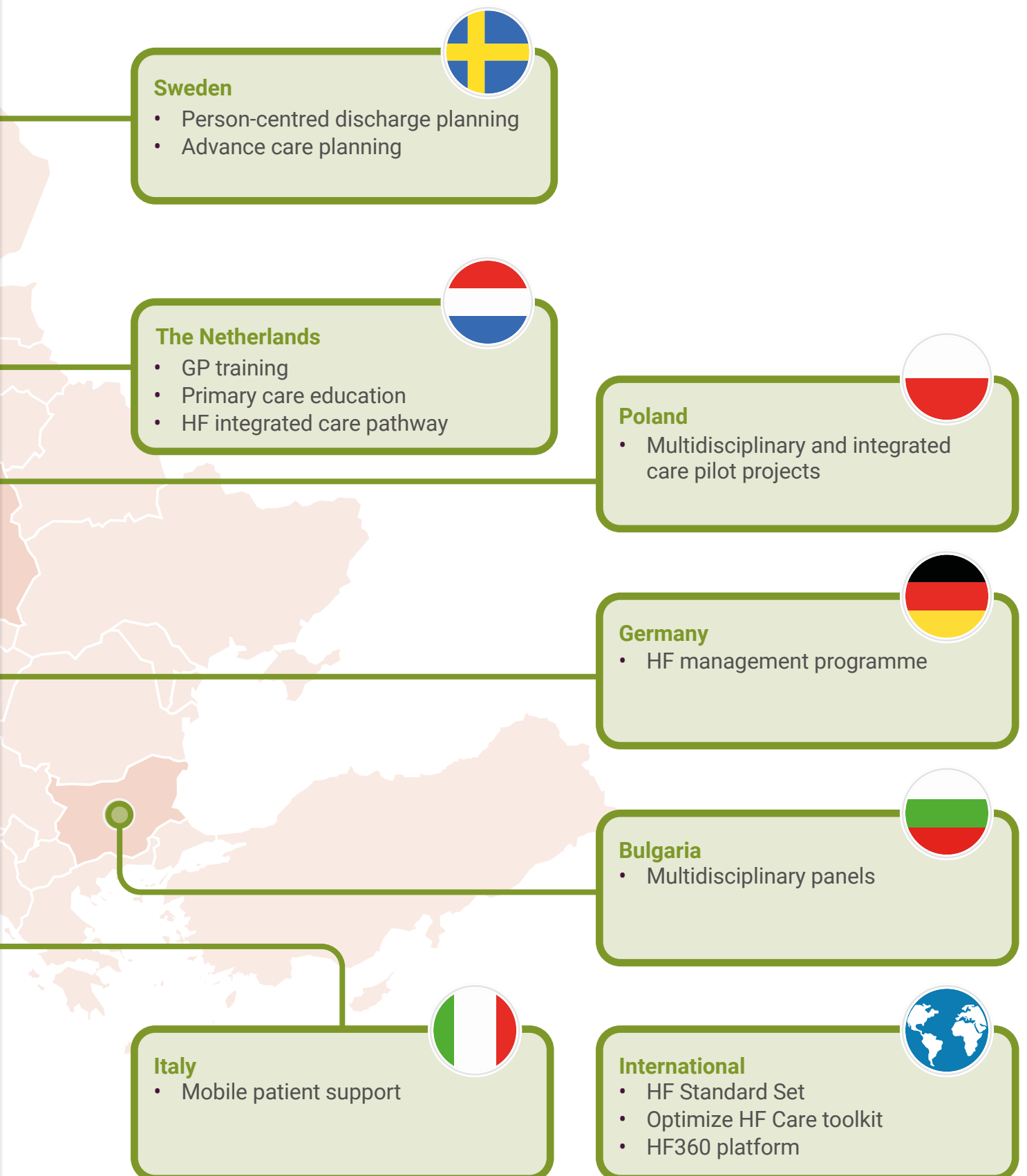
Help us take the case for change to European governments.

On behalf of the HF Policy Network Steering Committee, Project Advisory Group (2018) and Secretariat.








Case study map







Case study detail

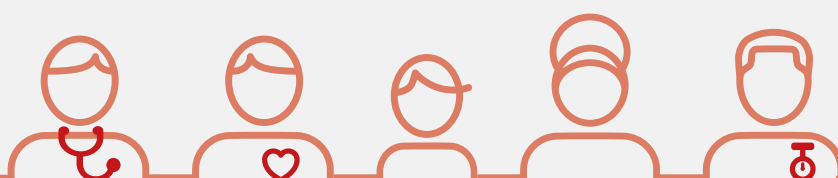
Country and case study	Description	Lead organisation
 Belgium		
TElemonitoring in the MAnagement of Heart Failure (TEMA-HF)	Telemonitoring-led GP/HF clinic collaboration in seven hospitals throughout Belgium	Genk Hospital
Belgian Charter for Heart Failure	The charter calls on health authorities to improve HF care, for example by providing reimbursement for guideline-recommended HF diagnostic tests	Belgian Working Group on Heart Failure (BWGHF), Mon Coeur Entre Parentheses, Belgian Society of Cardiology, Belgian Working Group of Cardiovascular Nursing and Ligue Cardiologique Belge
 Bulgaria		
Multidisciplinary panels	Multidisciplinary team discussions in hospital	Medical University, Pleven and Second City Hospital, Sofia
 France		
Insuffisance CARDiaque en LORraine (ICALOR)	Optimal patient management and ongoing education and monitoring	Centre Hospitalier Régional Universitaire de Nancy, INSERM and Université de Lorraine
 Germany		
HeartNetCare-HF	HF programme with telephone-based monitoring, nurse-coordinated care and patient education self-monitoring protocols	Comprehensive Heart Failure Centre Würzburg
 Ireland		
Community Heart Failure Management Programme (CHaMP)	HF specialist nurse-led follow-up and patient education, via outpatient and home visits	Joint initiative between Galway Primary, Community and Continuing Care (PCCC), University Hospital Galway, Portiuncula Hospital, Croí, Department of General Practice and National University of Ireland Galway


Country and case study	Description	Lead organisation
 Italy		
Mobile patient support	Itinerant programme of HF awareness and support	Italian Association of Heart Failure Patients (AISC)
 The Netherlands		
GP training	GP training to increase primary care knowledge and communication with specialists via small group educational meetings, led by an HF nurse and a cardiologist	Deventer Hospital
Primary care education	Specialist education for primary care clinicians on optimal care and patient education	Maastricht University Medical Centre
HF integrated care pathway	Nurse-led appointments in outpatient clinics. Several health and social care professionals are involved, and services are supervised by HF specialist cardiologists	University Medical Center Utrecht
 Poland		
Multidisciplinary and integrated care pilot projects	Pilot projects to ensure multidisciplinary working and improve integration of HF care between primary settings and hospitals	Heart Failure Working Group of the Polish Cardiac Society



Case study detail

Country and case study	Description	Lead organisation
 Spain		
Multidisciplinary communication	Initiate and increase communication between primary and secondary care	Department of Cardiology at the University Hospital Alava and Osakidetza (healthcare system of the Basque Country)
Nurse-led HF management	Nurse-led HF management programme in primary care	Bellvitge University Hospital and the Catalan Health Service
Quality standards	Quality and accreditation standards for HF units aligned with guideline recommendations to ensure high-quality HF care	Spanish Society of Cardiology
ITERA and PRISMA programmes	Programme that develops tools to help people living well with HF and supports the development of HF clinics	Laboratorios Menarini
 Sweden		
Person-centred discharge planning	Person-centred, nurse-led care and discharge planning	Gothenburg University
Palliative advanced home caRE and heart FailurE caRe (PREFER)	Provision of patient-centred, whole-team palliative advanced home care and HF care	Umeå University



Country and case study	Description	Lead organisation
 UK		
Cardiac rehabilitation	Cardiac rehabilitation and patient education from hospital to the community-based care team	NHS Ayrshire and Arran
Discharge checklist	Ten-point discharge checklist to support decision-making and audit of discharge summaries	University College London Partners and St Bartholomew's Hospital
Nurse-led diuretics	HF specialist nurse-led IV diuretics in the home and community setting	British Heart Foundation
HF pathway	Redesigning the HF pathway to ensure close liaison between GPs and specialists, including education sessions and 'virtual clinics'	Guy's and St Thomas' NHS Foundation Trust and King's College Hospital NHS Foundation Trust
Advanced HF care	Community HF nurses working to identify patients for palliative care	St Luke's Hospice, Brent and Harrow
Performance dashboards	Performance dashboards for two different pathways of care: hospital (acute) and community	Kent Surrey Sussex Academic Health Science Network
International		
HF Standard Set	HF-specific indicator set to measure patient outcomes and evaluate HF care	International Consortium for Health Outcomes Measurement
Optimize HF Care	Programme to improve HF care through affordable initiatives such as care protocols	Servier
HF360 platform	Collection of tools to support HF transitional care	Novartis Pharma AG

More case studies are available at www.hfpolicynetwork.eu 

Other work available from the Heart Failure Policy Network

Established in 2015, the HF Policy Network has published many innovative materials to help raise awareness of heart failure as an urgent policy priority.

2018

An in-depth briefing on each pressure point.

The Heart Failure Policy Network

Pressure point 1: Diagnosis



The Heart Failure Policy Network

Pressure point 2: Discharge planning and follow-up



2016/2017

The 'state of play' of diagnosis and care across 12 countries, and an awareness-raising infographic.

The diagnosis of heart failure: What is the state of play in Europe?

This summary represents first findings of a literature review into the diagnosis of heart failure (HF) at the European and national level in 12 countries: Belgium, Bulgaria, Finland, France, Germany, Ireland, Italy, the Netherlands, Portugal, Spain, Sweden and the UK. It is offered for discussion, as part of our work towards a comprehensive 'state of play in heart failure' report to be launched in Spring 2017. Many policy priorities are immediately apparent.

The stakes are high for heart failure

- HF is a leading cause of mortality across Europe. 12 million people in Europe are affected by HF, with a further 10 million at risk of developing the condition.
- HF is a leading cause of hospitalisation across Europe. 12 million people in Europe are affected by HF, with a further 10 million at risk of developing the condition.
- HF is a leading cause of disability across Europe. 12 million people in Europe are affected by HF, with a further 10 million at risk of developing the condition.

Early diagnosis of heart failure is critical

- Early diagnosis is a key to ensure patients receive appropriate treatment, and achieve the best possible outcomes.
- A delay to hospital treatment as little as 4 hours after onset of HF significantly increases a patient's risk of death.

HF delays and missed diagnosis are common for patients with heart failure

- Patients in other city-centred urban areas struggle to get to the heart failure clinic, often having to travel long distances.
- Patients in rural areas often struggle to get to the heart failure clinic, often having to travel long distances.
- Patients in rural areas often struggle to get to the heart failure clinic, often having to travel long distances.

We know what to do, but we are not doing it properly

- Research suggests that many patients with HF are not getting the right treatment.
- Research suggests that many patients with HF are not getting the right treatment.
- Research suggests that many patients with HF are not getting the right treatment.

The clinical management of heart failure: What is the state of play in Europe?

This summary represents first findings of a literature review into the clinical management of heart failure (HF) at the European and national level in 12 countries: Belgium, Bulgaria, Finland, France, Germany, Ireland, Italy, the Netherlands, Portugal, Spain, Sweden and the UK. It is offered for discussion, as part of our work towards a comprehensive State of Play in Heart Failure report to be launched in Spring 2017. Many policy priorities are immediately apparent.

We have not got the care and management of heart failure right

- HF is a leading cause of mortality across Europe. 12 million people in Europe are affected by HF, with a further 10 million at risk of developing the condition.
- HF is a leading cause of hospitalisation across Europe. 12 million people in Europe are affected by HF, with a further 10 million at risk of developing the condition.
- HF is a leading cause of disability across Europe. 12 million people in Europe are affected by HF, with a further 10 million at risk of developing the condition.

Best practice for HF is clear: namely multidisciplinary

- Clear UK and European guidelines exist for the prevention, diagnosis and management of HF.
- European Society of Cardiology (ESC) and other recognised professional bodies have developed comprehensive, evidence-based guidelines for the management of HF.
- HF management programmes can reduce mortality, hospital readmissions and healthcare costs, and improve quality of life for patients.

We know what to do, but we are not doing it

- Signs suggest that many people with HF are not getting the right treatment.
- Signs suggest that many people with HF are not getting the right treatment.
- Signs suggest that many people with HF are not getting the right treatment.

We must recognise and tackle policy barriers

- There are many barriers to the implementation of best practice for HF.
- There are many barriers to the implementation of best practice for HF.
- There are many barriers to the implementation of best practice for HF.

2015

The Heart Failure Policy Toolkit and infographics showing four priority areas for change.

The Heart Failure Policy Toolkit



Helping advance meaningful policy change on heart failure

The Heart Failure Policy Network is supported through grants from Novartis Pharma and St Jude Medical

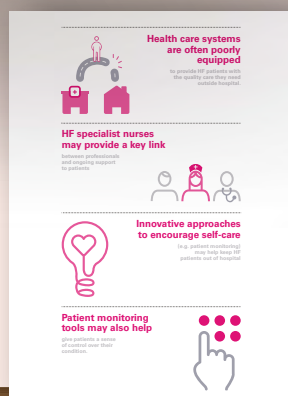
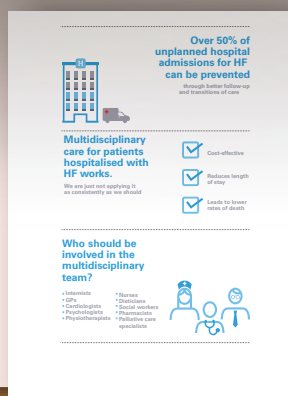
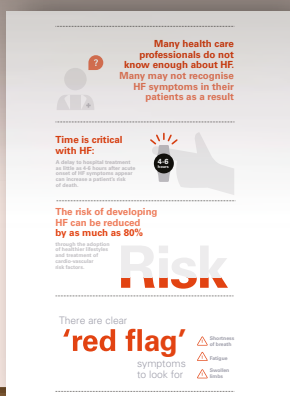
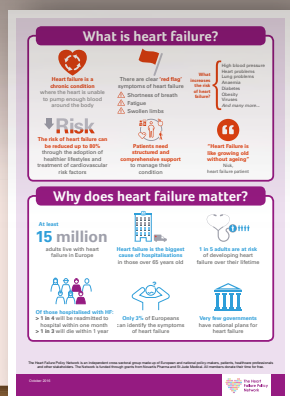
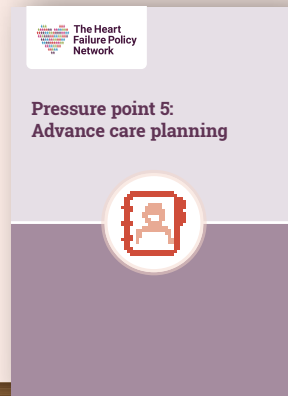
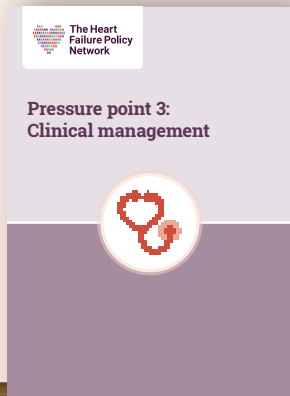
HF is the biggest threat to our health care systems and we are approaching tipping point

At least 15 million adults live with HF in Europe

1 in 5 adults are at risk of developing HF over their lifetime

And it's getting worse

Source: ESC, 2015



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Notes

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