Heart failure policy and practice in Europe

Portugal

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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. It was established in 2015 with the goal of raising awareness of unmet needs and seeking meaningful improvements in heart failure policy and care. Our aim is to help reduce the burden of heart failure – on people living with it, those supporting them, health systems and society at large.

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.

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For a full list of members of the Project Advisory Group, please see **www.hfpolicynetwork.org/project/heart-failure-policy-and-practice-in-europe/**

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About Heart failure policy and practice in Europe

Heart failure (HF) is a common and complex condition responsible for extensive avoidable morbidity, mortality and healthcare costs. There is a clear need to advance HF policy and practice across Europe, and this requires recognition of the real challenge in each country.

To this end, the Heart Failure Policy Network (HFPN) has developed *Heart failure policy and practice in Europe* – a comprehensive analysis of key gaps and best practice both in HF policy and in clinical performance across 11 European countries. In this work, we investigate each country's progress in addressing the HF challenge, for example in terms of the existence and implementation of HF policies and the provision of multidisciplinary and integrated HF care. Findings are presented in an overarching report, which outlines the methodology for this work and includes a pan-European narrative, and in standalone country profiles with dedicated national-level analysis.

Urgent action is needed to address the growing burden of HF and ensure the sustainability of our healthcare systems. This country profile aims to assist HF advocates across Portugal in engaging healthcare system leaders to demand constructive changes to HF policy and care provision, to reduce the impact of HF on people living with the syndrome, their families and carers, the healthcare system and society.

Heart failure in Portugal

SUMMARY

The burden of heart failure (HF) in Portugal is high, not just in terms of pressures on the healthcare system but also in terms of its impact on people with HF and their families.[1,2] Almost 60% of hospitalisations for HF in Portugal have been considered preventable.[3]

Policymakers have yet to widely recognise HF as a priority and public awareness is low. In 2018, the government created a working group to define measures to improve the response to HF,[4] which gave hope of progress, but decision-makers have yet to make its findings public and implement the proposed recommendations.[5] Experts have called for investment in HF to optimise care, from the development of proper infrastructure to funding of key diagnostic tests and training of an HF healthcare workforce, particularly nursing staff.[2] Currently, funding of diagnostic tests in primary care settings is insufficient, there is a lack of HF units and expertise in HF, and the HF specialist nurse role is not yet recognised.[6,7]

Centres of excellence are leading the way in terms of multidisciplinary and integrated care[5,8] but, overall, management of HF remains fragmented.[9] Urgent improvements are needed in diagnosis, hospital care and discharge, and community care to achieve better outcomes for people living with HF and reduce the burden of HF in Portugal.[5]

HF is common but its real prevalence is unknown

HF is highly prevalent in Portugal, estimated to affect around 400,000 people – almost 4% of the population.[10] However, available estimates are based on a dated study published in 2002 and focused on primary care,[11] so there is significant uncertainty concerning its true prevalence.[12] To address this, the Portuguese Society of Cardiology (Sociedade Portuguesa de Cardiologia, SPC) has recently initiated an epidemiology study – the PORTuguese Heart failure Observational Study (PORTHOS).[13,14]

Outcomes are often poor for people with HF

HF is a significant cause of hospital admissions. In 2013, it was the third most common cause of hospitalisation, mostly in people aged 65 years and over.[3] In 2016, HF was reported to contribute to almost 19,000 hospitalisations.[15] A panel of primary care experts suggested that 57% of hospitalisations for HF could have been considered preventable had there been more timely interventions in primary care settings.[3]

19,000

hospitalisations

Hospital readmission is high, with approximately one in five people hospitalised for HF being readmitted with HF exacerbation at least once in the first year after discharge.[16] Hospitalisations are not equally distributed across the country; higher rates occur in northern and inner Portugal, which can be explained by older populations and poorer access to healthcare services.[3]

Mortality rates for people living with HF are high. In 2014, HF was responsible for almost 5% of all deaths in Portugal.[17] About one in every eight people hospitalised for acute HF is reported to not survive it.[10,15]

HF is associated with high expenditure

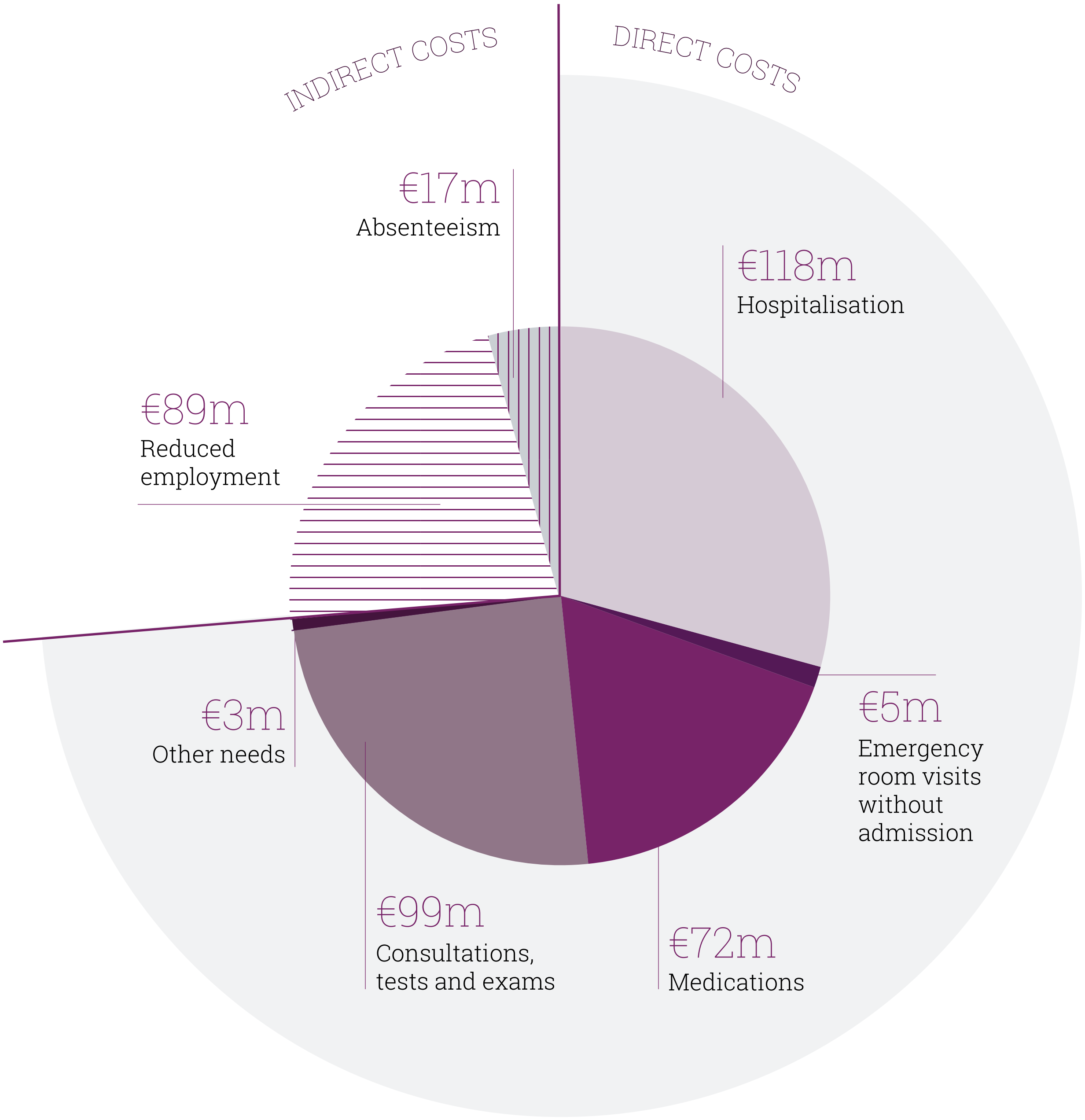
HF is responsible for significant costs, equivalent to around 2.6% of public health expenditure (see *Figure 1*).[1,10] Total HF costs in 2014 were estimated at €405 million, with direct costs accounting for about 74% of this figure. Rehospitalisations are a significant cost component. Each year from 2011 to 2015, hospital readmission in the first year following discharge cost an average of €27 million, approximately 42% of total HF inpatient expenditure.[16] Indirect costs are also significant, estimated at around €106 million in 2014. This is mostly due to reduced employment.[1]

2.6%

of public health expenditure

Forecasts of HF expenditure point to an increase of around 24% from 2014 to 2036, when HF is anticipated to cost €503 million.[1] Years lost due to HF-related disability are estimated to increase by 28% in the same period.[17]

FIGURE 1. **Estimated cost of heart failure in Portugal (2014)**[1]



Heart failure policy in Portugal

Formal plans on HF

A dedicated strategy for HF is lacking

The Portuguese government has yet to develop a formal plan on HF. In May 2018, it created a working group to define measures to improve HF care, with a mandate until March 2019.[4] The scope of this work was comprehensive – the group was to: propose measures to help improve diagnosis and ensure integration of care in agreement with international recommendations; identify successful pilots and the benefits they brought about; explore the use of technology in HF care; and define criteria for a relevant and standardised information technology (IT) system. The working group delivered the report to the Ministry of Health in 2019,[18] but this has not been made public as yet and the proposed measures have not been implemented.[7]

In the absence of a dedicated HF strategy, other policy initiatives might be expected to help address the significant challenge that HF poses. A notable initiative is the National Programme for Cerebral and Cardiovascular Disease (Programa Nacional para as Doenças Cérebro-Cardiovasculares), however, it does not include HF-specific objectives.[15]

Investment in integrated HF models and facilitative tools

HF diagnostic tests are not consistently reimbursed, missing opportunities to streamline resource use and care pathways

Limited reimbursement of core diagnostic tests likely constitutes a barrier to HF diagnosis. Echocardiography, the most accurate diagnostic test, is reimbursed across care settings. However, natriuretic peptide (NP) testing, which is key to diagnosis of HF as it can help avoid unnecessary echocardiography,[19] is only reimbursed when prescribed by a specialist physician.[2 5] This suggests that diagnostic pathways and resource allocation could be improved.

The national healthcare IT system enables data-sharing, but flaws in its execution and limited clinical data hinder communication and integrated care

Portugal's healthcare IT system is built around electronic health records and unique personal identification numbers, and its data can be accessed from different care settings.[3 20] However, despite the data-sharing capabilities, experts state that the features of the system often prevent multidisciplinary communication and integration of care. For example, while clinicians in primary care can use the system to see whether a patient was recently admitted to hospital, including cause of hospitalisation and treatment, there is nothing to alert them to this when they open that patient's file; they must instead follow a specific path to find this information.[6] In addition, the system does not allow for direct communication between healthcare professionals; for example, discharge notes and care plans cannot be sent straight to the general practitioner (GP).[21]

As the IT system was developed with a whole-system view across different areas of healthcare, some clinical parameters that are essential for the management of HF are not included.[7] For example, as there is no field specific to ejection fraction, this crucial information may not be recorded.[21]

Funding of care does not reflect the importance of integration, but policymakers recognise the value of telemedicine in HF management

Policymakers have not yet fully recognised the importance of integrated management of HF. For example, the reimbursement of services in primary care does not incentivise collaboration with other care settings or provision of some crucial elements of HF care.[9]

On the other hand, policymakers have been supportive of telemedicine models. Following five successful pilot studies in the management of a respiratory condition, in 2016 the national health system started funding remote appointments in other areas, including HF.[7 22] The COVID-19 pandemic has further emphasised the value of telemedicine for people living with HF, which experts believe should become standard practice in the near future.[23]

Development of the HF healthcare workforce

HF specialist roles are not formally recognised but national professional societies offer training opportunities

The healthcare workforce needs greater training opportunities and formal recognition of specialist roles to become better equipped in their response to HF. In particular, despite the widely reported benefits of nurse-led HF management,[19 24] there is no accreditation for HF specialist nurses.[5] Experts report that nurses have organised to call for the recognition of the HF expertise in their career path, and believe that the Nurses' Union may soon recognise this as a formal postgraduate qualification (competência acrescida).[6] However, the COVID-19 pandemic has stalled progress in this area.

Professional societies, including the SPC, lead courses in cardiovascular disease and specifically in HF. One SPC course, focusing on advanced support in HF (Suporte Avançado de Vida em Insuficiência Cardíaca, SAVIC), is open to all physicians managing HF and particularly targets cardiologists, internists and GPs.[25] Another comprehensive course can be seen in a programme that comprises eight modules, of 12 hours each, including a mixture of teaching sessions and workshops or clinical training in actual care settings.[26] The HF working groups of both the SPC and the Portuguese Society of Internal Medicine (Sociedade Portuguesa de Medicina Interna, SPMI) also lead training initiatives.[9]

Clinical training in real-life care settings is crucial in the development of an HF workforce, but these opportunities are limited. The outpatient HF clinic at São Francisco Xavier Hospital in Lisbon offers training of up to four months to doctors from different areas across the country – particularly cardiologists, internists and GPs.[7] It is unclear whether similar examples of successful training models exist elsewhere, possibly because of a scarcity of HF units.

Guidance and local care pathways for delivery of quality care

HF guidance and care pathways are lacking

The SPC has formally endorsed the 2016 European Society of Cardiology guidelines for HF.[27] It developed a Portuguese version as the national standard for HF care.[28]

Other recommendations provide guidance for the management of HF. In 2018, the Working Group on Exercise Physiology and Cardiac Rehabilitation of the SPC developed criteria for cardiac rehabilitation based on European and international guidelines.[29] The document includes people living with HF as one of its target populations, and aims to serve as the foundation for accreditation of cardiac rehabilitation centres. In 2020, the Working Group on Cardiac Intensive Care of the SPC published advice on the organisation of acute cardiac care, including in HF.[30]

There is, however, no formal HF care pathway or national clinical network, and most care processes called for by experts have yet to be implemented. The Directorate-General for Health has established care protocols in different areas of healthcare – called Integrated Assistance Processes (Processos Assistenciais Integrados) – but none has been developed for HF.[5] A care protocol for vascular risk in adults in fact excludes cardiovascular disease (and thus, HF).[31]

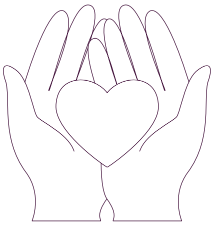
Experts have highlighted the lack of an HF care pathway or protocols, including fast-track protocols such as Via Verde, and the absence of an HF referral network as barriers to a proper response to the HF challenge.[5 12]

Public audits of performance and high-level assessment initiatives

The lack of HF care assessment has held back oversight of HF services

There is no HF registry or formal audit of HF care, which hinders efforts to gain an understanding of the benefits of any new initiatives, or the HF challenge more broadly.[5] While the PORTHOS study is expected to shed light on the prevalence and clinical characteristics of the HF population,[13 14] there is still a need for an ongoing national registry that would provide oversight of HF services. Some single-centre studies have been conducted to help understand management of acute HF,[32] but were not sufficient to gain a clear understanding of the national situation.

Barriers to the establishment of a comprehensive and ongoing registry are reported by experts to include funding, time pressures on healthcare professionals and the limited number of HF units or dedicated services within other departments.[9 21] People with acute HF are often admitted to internal medicine wards, but the development of HF expertise within this specialty has been a slow process. This may hinder not only the improvement of HF care, but also participation in non-mandatory HF registries. The need for collaboration between healthcare professionals in data collection and analysis, and the limited recognition of the value of care assessment, may be additional stumbling blocks on the path to creating a national HF registry.[9 21]



Heart failure practice in Portugal

Diagnosis

The diagnosis of HF is hindered by low awareness of the syndrome and inconsistent access to key diagnostic tests

HF diagnosis is often delayed.[8] This is attributed to several factors, including limited awareness among healthcare professionals. Awareness is also limited among the general population, which leads to delays in seeking medical attention to investigate HF signs and symptoms.[5 12 33] When people do seek care, experts state that primary care professionals may dismiss signs of early HF, often due to lack of expertise or the very limited time set for each appointment.[6 7] Furthermore, GPs do not have access to NP testing. This means that when they suspect HF, they must either refer patients to a specialist or send them for an echocardiogram, which often includes a long waiting period and requires considerable expertise for interpretation of results.[7 9]

Hospital care and discharge

The limited number of HF units is a barrier to consistency in management of acute HF

It often varies which medical specialist will lead management of acute HF, as it depends on the clinical profile of the person with HF and the department they are admitted to. Acute HF is typically managed by cardiologists or internists; cardiologists generally lead care for people who need complex treatment options (for example, invasive treatment), while those with multiple comorbidities are admitted to internal medicine departments, where they are managed by internists.[7 9 34]

There are several issues in the management of acute HF, from fragmentation of care to the lack of infrastructure. There is a significant lack of HF units, leading to inequalities in care.[5 9] Experts report that in hospitals without HF units, expertise in HF may be low, which can potentially be a barrier to guideline-based care.[9]

Provision of discharge planning is inconsistent

While some hospitals have discharge programmes led by nurses or physicians experienced in HF, experts report that this is not standard practice.[6] Similar to the variation seen in management of acute HF, hospital discharge with a care plan and seamless transition to the community is the reality for only a small number of people with HF, typically those treated in centres of excellence. In other hospitals, most people with HF are discharged with little support and without a care plan to ensure stabilisation and adaptation to life in the community.[23]

Key components of quality care in community settings

Integration of HF care is not consistent practice

Despite efforts to integrate healthcare across settings, the system in Portugal is highly fragmented.[3] In HF, communication between healthcare professionals and levels of care is limited, and there is still a focus on management of acute episodes rather than continual care to avoid hospitalisation.[5 9] Outpatient HF clinics provide high-quality, integrated ongoing care and may be able to detect and treat early stages of HF exacerbation, which may prevent hospitalisation, but their limited number poses a barrier to optimal management of chronic HF.[5 21] In some regions, care is organised via Local Health Units (Unidades Locais de Saúde), which include hospitals and primary care settings under the same administration and budget. Here, too, experts state that integration of care for chronic disease, including HF, is not standard practice.[9 23]

Cardiac rehabilitation is not consistently provided in the management of HF

Rates of implementation of cardiac rehabilitation programmes in Portugal have been reported to be among the lowest in Europe,[29] and these services have been considered 'virtually non-existent' for people living with HF.[2] The COVID-19 pandemic is believed to have further disrupted the already limited provision of cardiac rehabilitation in HF, as this is traditionally offered in hospitals in group sessions.[35]

Barriers to cardiac rehabilitation in HF may include a lack of centres providing this service, lack of funding and care pathways, and limited understanding of the benefits of cardiac rehabilitation in HF care.[7] The unequal distribution of the few existing cardiac rehabilitation centres has been reported to be at the centre of inequality in access.[29]

Limited access to self-care education hinders people's involvement in their own care

Education around self-care is not consistent in HF. Patient empowerment to self-care is common practice in HF specialist settings but is lacking from care provided in other settings.[5 6 12] Notable barriers include the heavy workload of healthcare professionals managing HF and the lack of HF specialist nurses. In addition, there is a need for greater awareness of the value that self-care education can bring to people living with HF, and thus to the healthcare system and society at large. There may, however, be growing interest in HF self-care education, with centres of excellence sometimes receiving requests for visits from interested healthcare professionals in other care settings.[6]

There is limited provision of psychological support and palliative care in HF

Psychological support and formal palliative care programmes are rarely available in HF.[2 5] To date, these services have been offered mostly in cancer care. However, experts report that the number of palliative care units in community settings has been increasing, as has the number of hospitals providing care at home, for example to people with advanced HF.[21]

Tools and methods to support multidisciplinary and integrated ongoing HF care

Centres of excellence offer various tools and models to encourage multidisciplinary HF care, which are largely unavailable in other settings

Overall, the implementation of tools and working methods that can promote multidisciplinary and integrated HF care has been inconsistent.[21 23] There is a clear need for standardised and integrated protocols for HF management to address the widespread fragmentation in HF care. However, there are examples of successful models of integrated care and implementation of innovative tools, and wider roll-out would likely be beneficial (see *Case studies 1* and *2*).

CASE STUDY 1.

Multidisciplinary and integrated HF care

The São Francisco Xavier Hospital in Lisbon has developed a multidisciplinary HF management programme to ensure integration of care across settings.[8]Under the programme, care is delivered across three levels: an acute HF unit for urgent care integrated in the internal medicine service; an HF outpatient clinic for ongoing and critical care whenever necessary; and an advanced consultation for people at lower risk of exacerbation.[8 9] In addition, the hospital has agreed referral protocols with specialist centres that provide invasive cardiac treatment.[7]

Care is delivered by a truly multidisciplinary team that comprises cardiologists, internists, nephrologists (kidney specialists), nurses, pharmacists, physiotherapists and allied health professionals.[8] The outpatient clinic is coordinated by specialist nurses under supervision by a physician specialising in HF. People with HF are seen here 7–14 days after discharge to have their medications adjusted if required. Care provided at the outpatient clinic places significant emphasis on patient education and empowerment.

This care model recognises the value of close involvement of GPs in the management of HF. They receive the patient's discharge summary from the hospital team, and can use a referral system with immediate access to the outpatient HF clinic and an advanced consultation that can be arranged within two weeks, depending on the patient's needs.[5]

CASE STUDY 2.

Remote monitoring for people at high risk of rehospitalisation

The Centro Hospitalar Universitário Lisboa Norte in Lisbon has operated a telemonitoring programme since 2017 for people with chronic HF who are considered to be at high risk of hospitalisation. The programme aims to reduce hospitalisations and even mortality, depending on the type of HF and the individual situation.[36]

Each person in the programme has access to medical equipment at home and a smartphone app to transmit a range of clinical parameters, including weight, blood pressure and body temperature.[37 38] Data are transmitted to an intermediary team of cardiopneumologists and HF-trained nurses automatically every day, or three times per week if HF is stable. Data can also be transmitted manually, if needed, for example if symptoms worsen.[39] When the team receives an alert, they communicate with the person with HF (or their carer) to gather further information, and, if needed, contact the hospital team, which comprises several cardiologists. Cardiologists then contact the person with HF directly with care instructions to achieve stabilisation and avoid hospitalisation.[37]

The telemedicine programme has reduced 12-month hospitalisation, average number of days lost due to unplanned hospitalisation and mortality.[38]

The way forward

HF poses a challenge to the sustainability of healthcare systems in countries across Europe, including Portugal. It is a manageable – and often preventable – syndrome, yet it continues to affect a great number of people and its burden on the national health system and society is significant.

There is an urgent need for concerted efforts to address the challenge that HF poses in Portugal, which has been further underlined by the recent impact of COVID-19 on the healthcare system. The government has yet to develop an HF strategy and recognise integrated HF management as a critical pillar in ensuring the sustainability of the healthcare system.

SEVERAL ACTIONS ARE ESSENTIAL TO ADDRESS THIS CHALLENGE.

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

Understanding of HF must be improved at all levels to overcome the political and societal inertia surrounding many aspects of care and system leadership. Awareness campaigns aimed at the public may encourage people to see a healthcare professional as soon as they start experiencing signs and symptoms of HF. Professional societies can also support healthcare workers to expand their knowledge of the correct identification of the signs and symptoms of HF, and the accurate use and interpretation of diagnostic tests, via training opportunities. Targeted messaging for decision-makers is important to raise awareness of the challenge that HF poses and drive the development of a coherent and robust national strategy.

Reimburse NP testing in community settings to support timely and appropriate diagnosis of HF

Reimbursement of NP testing is crucial not only in hospital settings but also in the community, as the test can help prioritise referrals for echocardiography. This can facilitate timely diagnosis and access to treatment, in addition to avoiding unnecessary use of echocardiograms and specialist care. Professional societies can support the correct use and interpretation of diagnostic tests for HF via training opportunities.

Promote multidisciplinary and integrated HF care through the development of an HF care pathway

Professional societies and working groups have laid the groundwork for high-quality HF care through the development of national guidance on crucial elements of care to improve the response to the HF challenge. It is now time for decision-makers to recognise the value in these recommendations and develop a comprehensive and integrated care pathway that leaves no person living with HF behind. The existing integrated care protocols developed by the Directorate-General for Health for other disease areas can be leveraged for the development of the HF care pathway. This should include specific care protocols for collaboration between professionals working across care settings, and rely on a referral network with clear access criteria. Reimbursement policies need to be revised to ensure they incentivise best practice in HF care.

Accredit and fund the HF specialist nurse role

The benefits of nurse-led HF management have been widely demonstrated, and it is important that the HF specialist nurse role be formally recognised. Professional societies can guide efforts to standardise requirements in terms of education and clinical responsibilities. These criteria can then be incorporated into postgraduate training programmes, which should be formally recognised by the Nurses' Union and the healthcare system. HF accreditation should be linked to financial recognition of the role to foster interest in the specialisation, which will likely support the development of an HF specialist nursing workforce and may support incorporation of these professionals into multidisciplinary HF care teams.

Enhance the existing IT system to strengthen communication across care settings and enable the development of an HF registry to ensure oversight of care

The Portuguese healthcare IT system is a unique platform to foster integration of HF care. Additional features will be crucial to improve multidisciplinary communication, in terms of both the system's interface and the clinical parameters collected. There is a need for regular assessment of HF data through a formal national registry or audit, and the further development of the IT system could allow it to feed into an ongoing, countrywide HF registry. Continual data analysis and feedback would help characterise the national HF challenge, highlight benefits of clinical practice across care settings and incentivise adherence to guideline recommendations.

Focusing on these priority areas will likely offer a cost-effective opportunity to improve life for people with HF, reduce hospitalisations and mitigate future pressures.

This is an investment in a more resilient and prepared health system, not just for HF but for chronic diseases more generally.

The creation and maintenance of national strategies and plans in HF is likely to be vital to long-term success. There are many strengths and existing resources within the healthcare system on which to build. Lasting success will require effective central oversight of inequalities and unacceptable variations, as well as long-term collaboration and commitment from decision-makers, patient representatives, healthcare professionals and the private sector. Failure to pursue the actions recommended in this report will allow HF to continue to challenge the sustainability of the healthcare system in Portugal.

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