STRATEGIC CONSENSUS FOR HEART FAILURE IN PORTUGAL

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This document is the result of a project conducted with the Method of Consensus developed by the Institute of Health Sciences of the Catholic University of Portugal (Universidade Católica Portuguesa, UCP).

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 whose goal is to raise awareness of unmet needs surrounding HF and its care. The network is financed by Novartis (global), AstraZeneca and Vifor Pharma.

The UCP invited the HFPN to lead the scientific coordination of this project. The project was financed by the UCP with financial support from Novartis Portugal and Medtronic Portugal, and additional time was donated by the HFPN to fully complete the work. The project was developed with total independence from funders. For more information on the methodology, please see the chapter "Development of the Consensus for Heart Failure" on pages 14-17.

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Foreword

In a year when healthcare has dominated public discourse due to the COVID-19 pandemic, this document, calling for action to improve the national response to Heart Failure (HF), is particularly timely.

HF is a serious, complex and common syndrome. It has a very significant impact on those living with the syndrome, and therefore on the National Health Service (SNS) and society. It has been testing the sustainability of the SNS for far too long, as it is one of the most common causes of hospitalisation and the source of high and increasing costs, yet there is limited awareness of this. Several experts have called for action to address HF, such as greater support for primary care settings and development of pathways that integrate care, but this is not yet a reality. Awareness of HF among policymakers, healthcare professionals and the public is poor, which has dictated the inaction we have been seeing.

COVID-19 has shed a light on many issues in the SNS, demonstrating the need for integrated management of chronic diseases and syndromes, and for better support of people with multimorbidity, something that often affects those living with HF. It is important to recognise these challenges and strengthen the SNS, not only to address current needs, but also as preparation for future challenges. The disruption of care services seen because of COVID-19 can be very problematic, and we should ensure that a second wave or a new pandemic does not interrupt ongoing care for people who need it.

This document results from the efforts of a multidisciplinary working group, which discussed the challenge of HF in Portugal and came together to develop a roadmap for a coherent response to HF in our country. It was developed before the COVID-19 pandemic hit us, and the current reality calls for even greater urgency. The difficulties highlighted or brought on by the pandemic mean some of the measures that the working group did not initially consider urgent may have become so. In anticipation of a recession and in order to strengthen our SNS, it is crucial to implement evidence-based and cost-effective initiatives to limit the unnecessary personal burden and expenditure of avoidable hospitalisation, which is frequently seen in HF.

In a pre-COVID-19 world, finding a coherent response to HF was important. In a world where it has become very clear that at any point an infectious disease can monopolise the SNS, implementing a strategy to address HF is imperative. I hope that the "Strategic Consensus for Heart Failure in Portugal" can act as a catalyst in the development of new health policies, and can help to reshape how our country will address the increasing burden of HF.

Dr Luís Filipe Pereira

President, Association for Support to Patients with Heart Failure (AADIC)
Minister of Health 2002–2005

Executive summary

The impact of Heart Failure (HF) in Portugal has not been acknowledged or sufficiently valued. Despite the publication of documents highlighting this problem and the constitution of a government-appointed working group to improve healthcare in HF, few advances have been noted and there are still numerous failures in the system.

HF is a common and complex syndrome that has a very significant impact on quality of life.[1] People with HF find it difficult to perform daily tasks and often live with anxiety and depression. Mortality from HF is high – higher than for several common cancers.[2] HF care depends heavily on the support provided by informal carers, such as family members, and therefore HF affects not only people living with the syndrome but also those around them.

HF represents a sustainability problem for the Portuguese National Health Service (SNS). The actual prevalence of HF in our country is unknown, but estimates point to about 400,000 people with the syndrome in mainland Portugal and an increase to half a million by 2060.[3] HF has been reported as the third most common cause of hospitalisation in our country, and one in five people hospitalised for HF is readmitted with an HF exacerbation at least once in the first year following hospital discharge.[4] Hospital readmissions in the first year after discharge cost the SNS around 27 million euros annually. The costs associated with HF in Portugal represent about 2.6% of public health expenditure,[5] and hospitalisations account for about 30% of these expenses.[4]

Despite the significant impact of HF in Portugal, there is no national strategy to address the challenge. Diagnosis is often delayed, there are no clinical protocols to ensure continuity of care, infrastructure and funding tools are inadequate and there are no methods for monitoring and assessing initiatives implemented. There is still a lack of awareness of HF from policymakers, healthcare professionals and society in general. An integrated and coherent strategy for HF can improve awareness, care delivery and clinical outcomes. For example, more than half of hospitalisations for HF could be prevented with better coordination of care.[6]

In view of the need for a clear and coordinated response to the HF challenge, a multidisciplinary group carried out a structured work not only to identify the main flaws in the system, but also to propose key measures to improve it. This working group undertook an in-depth analysis of the Portuguese system with regard to HF according to the Method of Consensus of the Catholic University of Portugal. The group defined eight priority measures, including: development of an awareness campaign on HF, financing of diagnostic tests for HF in primary care, development of integrative protocols with a clear referral network, assessment and adequate financial recognition of HF care.

The models of excellence in HF currently in place in our country cannot continue to be the exception – it is necessary to overcome the inertia that has been observed in this area and concentrate efforts in developing a national strategy. The involvement of health authorities and all healthcare professionals involved in the provision of HF care is critical. Only then will it be possible to reduce the impact of HF at the individual level, on the health system and on the Portuguese society.

Key consensus measures proposed to address HF in Portugal

A1. National HF awareness and information campaign, highlighting signs, symptoms and prognosis and promoting healthy lifestyle behaviours

A2. Integrated Assistance Process (Processo Assistencial Integrado, PAI) for HF involving multidisciplinary teams and with national reach, based on a referral network between different levels of care

A3. Multidisciplinary palliative care as an integral part of HF care

A4. Panel of indicators to assess HF care in various settings

A5. Interoperability and standardisation of information technology systems and data sharing between the various care levels, leading to an appropriate national registry in HF

A6. Funding for measurement of natriuretic peptides for the diagnosis of HF when requested by family doctors

A7. Valuation and funding of HF services provided in outpatient HF clinics, and specific funding for programmes of integrated primary and hospital care

A8. Undergraduate, postgraduate and continuing training in HF for the various healthcare professionals and formal recognition of HF skills in nursing

What is Heart Failure and what is its impact?

Heart Failure is characterised by several symptoms

Heart Failure (HF) is a common and complex syndrome that occurs when the heart is unable to pump enough blood to meet the needs of the entire body.[7] HF symptoms are nonspecific and include shortness of breath (dyspnoea), extreme fatigue and fluid retention, which causes swelling of the feet, legs and abdomen (oedemas) with consequent weight gain.

HF has an impact at the individual and societal level

HF is associated with low functional capacity (ability to perform daily activities) and a high number of hospitalisations.[8] Mortality from HF is high – in fact, higher than from several common cancers. For example, in Scotland, mortality from HF is worse than from prostate or bladder cancer in men, and worse than from breast cancer in women.[9] In Sweden, more years of life are lost due to HF than to cancer.[10] People with HF often live with anxiety and depression, isolate themselves and have low quality of life.[12]

Comorbidities contribute to the complexity of HF

People with HF often have other diseases or syndromes, called comorbidities, for example hypertension (high blood pressure), acute myocardial infarction (heart attack), atrial fibrillation (irregular heart rhythm), diabetes, lung disease and kidney disease.[11] Comorbidities make clinical management of HF more difficult, namely because they can accentuate HF symptoms, worsen prognosis and lead to polypharmacy – which results in drug interactions and low treatment adherence. Additionally, comorbidities may complicate the optimisation of HF treatment, limiting its benefit.

Risk factors for HF include diseases and lifestyle behaviours

There are several factors that can lead to the development of HF (risk factors), including cardiovascular diseases, high blood pressure and diabetes. For example:

- coronary artery disease (obstruction of blood vessels that carry blood to the heart muscle, called myocardium) is estimated to be the cause of HF in up to a third of people with the syndrome[12]
- hypertension increases the risk of HF by two to three times compared with people with normal blood pressure[13]
- diabetes increases the risk of HF by two to five times[14]
- atrial fibrillation increases the risk of HF fivefold.[15]

Unhealthy behaviours and lifestyle can also contribute to the development of HF, for example smoking and excessive consumption of alcohol.[16] Lack of physical exercise and an unhealthy diet (for example, with little intake of fruits and vegetables) also increase this risk.

HF represents a challenge to the sustainability of health systems

General patterns and causes of hospitalisation may shift due to the COVID-19 pandemic, which increased global hospital admissions in 2020, but the impact of HF on hospitalisation and healthcare costs is undeniable. HF has been reported as the leading cause of hospitalisation in Europe for people over 65.[17] The first months after hospital discharge represent the period of greatest risk of hospital readmission. In economically developed countries, HF typically contributes to 1–2% of health expenditure,[18] and hospitalisations for HF often account for up to 70% of this.[19] In addition to the cost of hospitalisations, indirect costs resulting from the involvement of informal carers and the loss of productivity are also significant in HF.[2] For example, in Ireland this is the highest cost component, having been estimated at 364 million euros – twice as much as direct costs.[20]

The impact of HF is increasing

The prevalence of HF is increasing due to the ageing of the population and the decrease in mortality rates from cardiovascular and other chronic diseases, as longer survival often results in progression to HF.[2] Naturally, this increase in the number of people with HF raises overall costs of the syndrome and increases its impact on the health system.

A coherent strategy for HF based on multidisciplinary and integrated care can reduce its impact

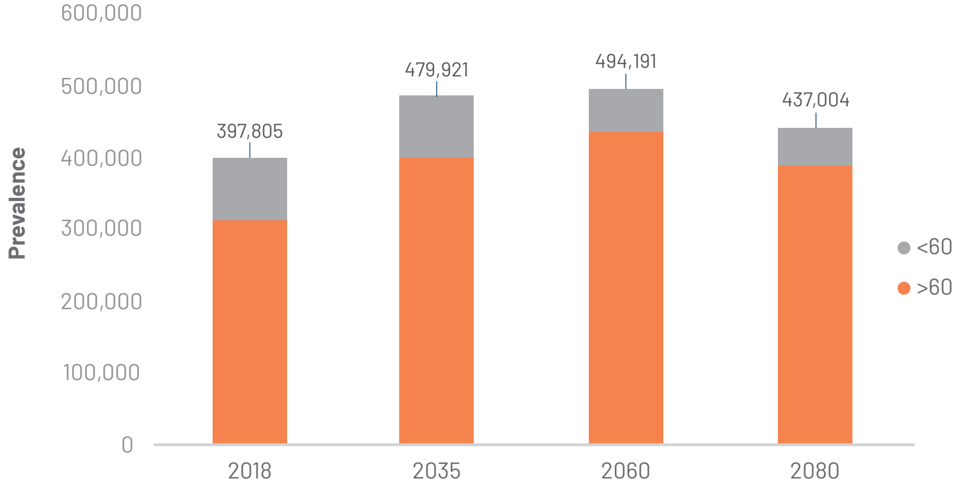
Successful HF strategies should involve health authorities and be based on coordination between healthcare professionals, social workers, the person with HF and their family/carers, covering different levels of care.[2] Integrated and multidisciplinary care based on clinical recommendations, namely those of the European Society of Cardiology (ESC),[11] can improve quality of life of people living with HF and survival rates.[2] A coherent and appropriate strategy can also help to prevent or delay the development of HF.

Heart Failure in Portugal

The prevalence of HF in Portugal is high, but real figures are unknown

Portugal has a high prevalence of risk factors for cardiovascular diseases,[1] which contributes to a high number of people living with HF. However, actual prevalence figures for HF are unknown as estimates have several limitations, namely because they are based on the observational study *Epidemiologia da Insuficiência Cardíaca e Aprendizagem* (EPICA, Epidemiology of Heart Failure and Learning).[21] This study was published in 2002 and looked at the population being followed in primary care, not the general population. Current estimates and projections suggest that in 2018 there were almost 400,000 people with HF in mainland Portugal and point to almost half a million by 2060, with this increase being particularly significant in the age group above 60 years *(Figure 1)*.[3] Projections point to a decrease in the number of people with HF between 2060 and 2080, but this is due to the forecast of a reduction in the size of the Portuguese population and not the prevalence rate of HF. The uncertainty associated with these figures reflects the strong need for updated studies to better understand the epidemiology of HF in Portugal.

Projection of HF prevalence in Portugal



Data available in Fonseca C 2018[3]

Figure 1. Prevalence of HF in Portugal

The impact of HF on the number of hospitalisations in Portugal is significant and has been increasing

Hospitalisations for HF doubled between 2000 and 2015.[3] HF was reported as the third most common cause of hospitalisation – in 2013, one in seven hospitalisations was due to this syndrome, and 57% were considered preventable had there been better coordination of care.[6] About one in five people hospitalised for HF is readmitted with HF exacerbation at least once in the first year after discharge.[4] As seen in other European countries, the vast majority of hospitalisations occur in people over the age of 65. HF hospitalisations are not equally distributed across the national territory, suggesting that there are parts of the country where HF care is of particular concern.[6]

There is a lack of studies in Portugal highlighting the impact of HF on quality of life

HF has a significant personal and social impact in our country. This is evident considering studies carried out in countries with similar economies and health systems, the experience of healthcare professionals who manage HF in Portugal and the high number of hospitalisations and rehospitalisations for HF. However, the true impact of HF on the quality of life of patients, their families and carers is unknown.

The considerable impact of HF on the Portuguese society and the National Health Service is growing

In 2014, HF contributed to almost 5% of the mortality rate in Portugal.[22] Mortality from acute HF (requiring hospitalisation) is alarming – about 25 out of 200 people hospitalised for an episode of acute HF do not survive it.[3] HF costs in Portugal account for around 2.6% of public health expenditure, and hospitalisations contribute to around 30% of HF expenditure.[5] Rehospitalisations for HF in the first year following hospital discharge cost the National Health Service (Serviço Nacional de Saúde, SNS) about 27 million euros annually.[4] Projections of the impact of HF point to an increase in expenditure from 405 million to 503 million euros between 2014 and 2036,[5] and an increase of 28% in the years of life lost due to disability in the same period.[22]

Why is this Consensus important?

Political efforts in the field of HF have been insufficient

Several documents have been published in recent years raising awareness of the HF challenge in Portugal, namely publications highlighting potential strategies to improve care and reduce the syndrome's impact.[1] In 2018, under Portuguese Dispatch 4583/2018 published in *Diário da República*,[23] the Portuguese Government created a Working Group on HF with the mission of defining criteria for integrated management programmes, ensuring their monitoring and assessment. However, these criteria have not yet been published, and a lack of awareness on the HF challenge remains among policymakers and the Portuguese population. Meanwhile, shortcomings in HF care persist.

This document aims to contribute to the development of a national strategy on HF

Strategic Consensus for Heart Failure in Portugal highlights the greatest failures in the system and presents specific measures to address the challenge. One of the key advantages of this document is that it results from collaborative work between experts from multiple areas involved in the provision and improvement of healthcare. Therefore, it takes into account all aspects of the HF challenge: the impact on people living with the syndrome, their families/carers, the health system and society as a whole.

The COVID-19 pandemic has highlighted the need to address the HF challenge

People with HF are among the population groups most vulnerable to complications after contracting COVID-19, which reflects the increased risks they already face and the importance of proper ongoing management to reduce these risks. The pandemic has made the urgency of addressing HF all the more important. The reorganisation of care for HF will support improvements in other areas of healthcare delivery, and the system will see economies of scale from the development of tools that can be used in other therapeutic areas. Therefore, addressing the HF challenge will be an investment in a more resilient and prepared SNS that is better equipped to respond to future challenges.

Development of the Consensus for Heart Failure

Consensus Method and project coordination

This project was developed using the Method of Consensus developed by the Institute of Health Sciences of the Catholic University of Portugal (Universidade Católica Portuguesa, UCP). Sandro Cortiço was responsible for project management, and the Heart Failure Policy Network (HFPN) was responsible for its scientific coordination through Sara Correia Marques.

The Method of Consensus aims to develop a consensus in health by establishing a broad and multidisciplinary working group to discuss the topic in three group sessions, each including discussions in subgroups. In this project, adaptations were made to this methodology to better respond to the needs of the participants – only the second session saw the topic segmented into subsections for discussion in smaller groups. The methodology is described below.

Think Tank and Steering Committee

A reflection group was established to carry out the project. The term "Think Tank" (TT) is often used to designate this working method, and this terminology was also adopted here.

Representatives of the various areas of care in HF were invited to the TT in order to cover the different dimensions of the syndrome in an exhaustive and multifaceted manner. Thus, the TT included:

- Cardiologists, Internists and General Practitioners (GPs, also known as family doctors), either as experts in the field or as representatives of scientific societies
- Nurses
- Pharmacists
- Representatives of Associação de Apoio aos Doentes com Insuficiência Cardíaca (AADIC, Association for Support to Patients with Heart Failure)
- Public Health Specialists
- Members of Ministry of Health services
- Policymakers
- Representatives of pharmaceutical and medical device industry associations

The list of members of the TT with their respective affiliations is included in the last chapter of this document.

An executive group, designated Steering Committee (SC), was established to support the project's coordination, the development of associated materials and their approval.

Plenary sessions and measures of consensus

Three meetings were organised with the TT, and two members of the SC moderated each meeting.

It is important to note that the Method of Consensus does not imply agreement on all aspects under discussion. Rather, it is intended to inventory the various readings, seek points of understanding and identify the various positions to discern how far it is possible to get to together. The methodology is based on the conviction that, by mobilising all the capacities and resources already existing in the health system (human, knowledge, material and financial), it is possible to increase its intelligence to more significantly reduce the suffering of patients and save more lives.

First plenary session

The first plenary session took place in July 2019 and focused on the current situation around HF in Portugal.

All members of the TT systematically stated key issues in HF in our country considering the epidemiological, sociological and clinical components to define the most problematic areas, in which intervention is critical. A family member of a person with HF, although not part of the TT, described failures and successes seen throughout the HF clinical journey.

Second plenary session

The second plenary session, which took place in September 2019, focused on HF care models and potential measures to address the challenge in Portugal.

The session started with the presentation and discussion of two multidisciplinary and integrated models currently implemented in our country. After joint discussion of these models, participants were distributed across three working groups. Each group focused on two of the six problem areas defined in the first plenary session and developed a list of relevant measures to address these challenges. Each group presented its conclusions to the entire TT at the end of the session.

Third plenary session

The third plenary session took place in November 2019. Its objective was to define the level of consensus of the measures considered important to address HF in Portugal.

Prior to the session, all members of the TT were invited to vote via email for the 15 measures they considered a priority among the 34 on the list that resulted from the second plenary session. This vote made it possible to distinguish three levels of agreement:

1. Consensus Level A – measures considered a priority by the majority of TT members
2. Consensus Level B – measures considered a priority by a significant number of members of the TT, but not the majority
3. Consensus Level C – measures considered relevant by a small number of participants

Measures that obtained less than two votes were removed from the list to be discussed at the third meeting, in which the TT validated and classified all measures, grouping some to avoid repetition. The TT also discussed implementation of measures of Consensus Level A.

Write-up of this document

The HFPN and members of the SC were involved in the write-up of this document. All measures across the three levels of consensus are included here, not only for ethical reasons but also because it is considered that even minority positions are ways of enriching the debate, pointing out ways forward and discussing an issue that is complex in nature.

All TT participants were invited to review and comment on the text presented here.

Disclaimer

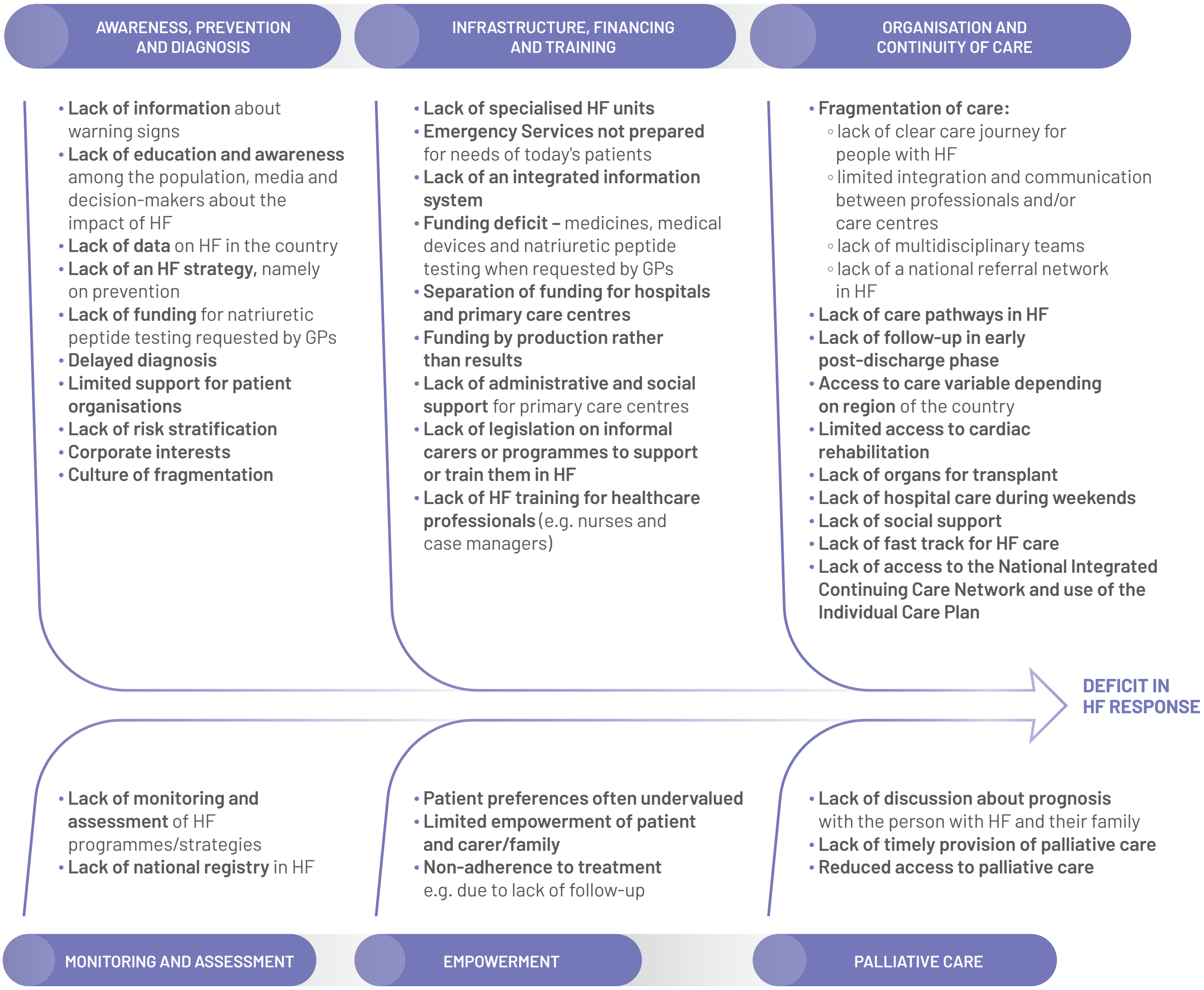
This project was proposed by the UCP, which invited the HFPN to lead the scientific coordination of the plenary sessions and the write-up of this document. The project was financed by the UCP with financial support from Novartis Portugal and Medtronic Portugal. Members of the SC were remunerated for their comprehensive engagement with the project; TT members were not given any type of remuneration. The project was developed with total independence from funders.

The HFPN is an independent and multidisciplinary network of healthcare professionals, advocacy groups, policymakers and other stakeholders from across Europe whose goal is to raise awareness of unmet needs surrounding HF and its care. The network is financed by Novartis (global), AstraZeneca and Vifor Pharma.

Failures in the response to Heart Failure in Portugal

The TT discussed the main causes of the inadequate response to HF in Portugal, noting that the failures occur throughout the clinical journey. Six main thematic categories were defined, each encompassing several issues (*Figure 2*).

Figure 2. Causes of inadequate response to HF in Portugal



AWARENESS, PREVENTION AND DIAGNOSIS

- **Lack of information** about warning signs
- **Lack of education and awareness** among the population, media and decision-makers about the impact of HF
- **Lack of data** on HF in the country
- **Lack of an HF strategy,** namely on prevention
- **Lack of funding** for natriuretic peptide testing requested by GPs
- **Delayed diagnosis**
- **Limited support for patient organisations**
- **Lack of risk stratification**
- **Corporate interests**
- **Culture of fragmentation**

INFRASTRUCTURE, FINANCING AND TRAINING

- **Lack of specialised HF units**
- **Emergency Services not prepared** for needs of today's patients
- **Lack of an integrated information system**
- **Funding deficit –** medicines, medical devices and natriuretic peptide testing when requested by GPs
- **Separation of funding for hospitals and primary care centres**
- **Funding by production rather than results**
- **Lack of administrative and social support** for primary care centres
- **Lack of legislation on informal carers or programmes to support or train them in HF**
- **Lack of HF training for healthcare professionals** (e.g. nurses and case managers)

ORGANISATION AND CONTINUITY OF CARE

- **Fragmentation of care:**
  - lack of clear care journey for people with HF
  - limited integration and communication between professionals and/or care centres
  - lack of multidisciplinary teams
  - lack of a national referral network in HF
- **Lack of care pathways in HF**
- **Lack of follow-up in early post-discharge phase**
- **Access to care variable depending on region** of the country
- **Limited access to cardiac rehabilitation**
- **Lack of organs for transplant**
- **Lack of hospital care during weekends**
- **Lack of social support**
- **Lack of fast track for HF care**
- **Lack of access to the National Integrated Continuing Care Network and use of the Individual Care Plan**

DEFICIT IN HF RESPONSE

MONITORING AND ASSESSMENT

- **Lack of monitoring and assessment** of HF programmes/strategies
- **Lack of national registry** in HF

EMPOWERMENT

- **Patient preferences often undervalued**
- **Limited empowerment of patient and carer/family**
- **Non-adherence to treatment** e.g. due to lack of follow-up

PALLIATIVE CARE

- **Lack of discussion about prognosis** with the person with HF and their family
- **Lack of timely provision of palliative care**
- **Reduced access to palliative care**

1. Awareness, prevention and diagnosis

In Portugal there is a significant lack of awareness of HF – among policymakers, the Portuguese population and healthcare professionals who are not HF specialists. This limited awareness is reflected, for example, in the delayed reporting of symptoms to healthcare professionals and in the absence of a national strategy to reduce the impact of HF in the country.

Health literacy, which includes an understanding of the importance of healthy behaviours in health promotion and disease prevention, is low among the Portuguese population, limiting the opportunity for prevention and delay in the development of HF.

One of the essential tests in the diagnosis of HF is the measurement of natriuretic peptides.[11] Although this test is not sufficient for a definitive diagnosis, a normal result may allow the exclusion of HF as cause of signs and symptoms, thus avoiding more expensive tests and unnecessary referral to Cardiology or Internal Medicine services dedicated to HF.[24, 25] However, testing for natriuretic peptides is not funded when requested by GPs, which may be one of the reasons for the often delayed diagnosis of HF in Portugal. This lack of funding was identified by the TT as one of the greatest failures of the system with regard to HF care in Portugal.

2. Infrastructure, financing and training

There are many shortcomings in terms of HF infrastructure and funding. For example, health units specialised in HF (such as outpatient HF clinics) make it possible to avoid hospitalisations and thus reduce the high costs associated with HF. However, the number of these units is low and the SNS does not financially recognise the services performed here. These services are classified as "other services" and financed at less than 25 euros.

Healthcare professionals who are not HF specialists often have limited knowledge of the syndrome. However, there are few opportunities for HF training. For example, despite the vital role of nurses,[2] there is still no formal HF specialisation in the nursing career.
HF training options are also limited for GPs, internists and cardiologists.

HF care is highly dependent on the support provided by informal carers, and here again there are few, if any, options for training or financial support.

3. Organisation and continuity of care

HF care should be multidisciplinary and integrated.[2] However, this is not the reality in Portugal, where care is usually fragmented.

Since 2013 the Directorate-General for Health has developed Integrated Assistance Processes (Processos Assistenciais Integrados, PAIs), which are care protocols to improve healthcare in several therapeutic areas, including diabetes and asthma, but this has not yet been developed for HF. In 2014, one PAI was launched to address vascular risk in adults, and it specifies as a non-inclusion criterion people with cardiovascular disease, such as HF.[26] The PAI states that people with these diseases/syndromes should be monitored "in integrated services between hospital care and primary care", but does not describe how this should work in practice.

4. Monitoring and assessment

In Portugal, there is no HF registry, and the current clinical registry in the SNS is not appropriate to fully understand HF as it does not include some key parameters, such as ejection fraction, which is critical in diagnosis and decision-making.[11] The lack of an HF registry is one factor that contributes to a limited understanding of the syndrome in all its dimensions – epidemiological, sociological, clinical and financial. There is also no formal system to assess HF initiatives and programmes, making their analysis difficult and their replication in other centres or hospitals unlikely even if they are successful models.

5. Empowerment

The preferences of people with HF are often undervalued, which goes against the healthcare trend of promoting patient-centred care.

The process of educating people with HF, usually called empowerment, is essential as HF requires daily self-assessment and management – self-care.[27] However, in the clinical management of HF in Portugal, there is no formal programme for the empowerment of people with the syndrome, which limits their involvement in their own care.

6. Palliative care

Palliative care is patient-centred care to relieve symptoms and improve quality of life, ensuring that the preferences and wishes of the person with a chronic disease are always taken into account.[28] It is, therefore, an important element in the management of HF, but is not sufficiently offered, which may have a direct impact on patients' quality of life. Palliative care is often confused with end-of-life care, which may contribute to its limited use in HF.

> *There is a lack of knowledge about Heart Failure and its warning signs, which jeopardises the diagnosis, the provision of care and consequently the prevention of episodes of decompensation and hospitalisations. It is essential to involve family doctors in the management of Heart Failure and to assess existing care models to ensure improved prognosis.*
>
> ***José Ravasco Pato**, person living with HF*

Measures to address Heart Failure in Portugal

We present here 16 measures to improve the response to HF in Portugal *(Table 1)*. As mentioned above, these measures are distributed over three levels depending on the degree of agreement between the members of the TT regarding the relevance of each one.

For the implementation of these measures, the TT considers essential the set-up of a multidisciplinary working group to support and advise the government-appointed group responsible for defining the national HF strategy.

Table 1. Proposed measures to address HF in Portugal

Consensus Level	Measure
A	**A1.** National HF awareness and information campaign, highlighting signs, symptoms and prognosis and promoting healthy lifestyle behaviours
	A2. PAI for HF involving multidisciplinary teams and with national reach, based on a referral network between different levels of care
	A3. Multidisciplinary palliative care as an integral part of HF care
	A4. Panel of indicators to assess HF care in various settings
	A5. Interoperability and standardisation of information technology systems and data sharing between the various care levels, leading to an appropriate national registry in HF
	A6. Funding for measurement of natriuretic peptides for the diagnosis of HF when requested by family doctors
	A7. Valuation and funding of HF services provided in outpatient HF clinics, and specific funding for programmes of integrated primary and hospital care
	A8. Undergraduate, postgraduate and continuing training in HF for the various healthcare professionals and formal recognition of HF skills in nursing
B	**B1.** Empowerment of the person with HF and family members/carers
	B2. Outcomes-based funding with tools that promote access to innovation
	B3. Telemonitoring programmes for people with HF
	B4. Rehabilitation clinics for people with HF
	B5. Meetings between professionals in centres of excellence and those in other levels of care
C	**C1.** Ability for people with HF to access their own clinical records from home
	C2. Clear referral for end-of-life care
	C3. "High-resolution" consultations in HF outpatient clinics

Consensus Level A

Measures in Consensus Level A represent the elements for which there was total or majority agreement on their urgency.

A1. National HF awareness and information campaign, highlighting signs, symptoms and prognosis and promoting healthy lifestyle behaviours

Timely and adequate HF diagnosis is important to achieve the best possible clinical outcomes.[29] It is important that the general public is aware of HF, recognises signs and symptoms, and reports them without delay to a healthcare professional, ideally the GP. Therefore, an awareness campaign on the syndrome is needed. The campaign should focus not only on the recognition of HF but also on what can be done to prevent or delay its development. At a time when public health messages are focused on the COVID-19 pandemic, there may be a case for an awareness campaign in the immediate future highlighting the links between HF and COVID-19, such as the increased risk of complications.

SUGGESTIONS FOR IMPLEMENTATION

A national campaign on HF should include the dissemination of information in several ways, such as on billboards, on the radio, in the press, on social networks and on television, both in advertisements and in high-rating programmes. Dissemination can also take place in waiting rooms of health institutions, for example through flyers, screens and posters, and in the workplace. For the latter strategy it would be important to engage with multiple companies, which can be done through representative associations, to develop social-responsibility policies that consider the HF challenge. Several other institutions should be involved in this campaign, in particular AADIC and possibly also Instituições Particulares de Solidariedade Social (IPSS), União das Misericórdias Portuguesas and Universidades Seniores.

The TT considers this measure extremely important and urgent. However, it should be noted that if an awareness campaign were developed in isolation, there is a risk that demand for appointments in primary care and Cardiology centres would increase significantly but the system would not be capable of responding to this. This means that instead of an improved system, a congested system would be the result. It is therefore important that the implementation of the measures recommended below is started alongside an awareness campaign, or in anticipation of it.

EXAMPLES

Successful awareness campaigns have been organised in Portugal, namely in the area of acute myocardial infarction. Strategies used in this campaign could serve as inspiration for an HF campaign.

A2. PAI for HF involving multidisciplinary teams and with national reach, based on a referral network between different levels of care

The existence of a PAI for HF care involving different healthcare professionals and levels of care is an essential condition for improving the response to HF and reducing its impact. The PAI on HF should rely on a referral network between primary care (health centres) and secondary care (hospitals). This network should have clear access criteria and ensure that the complexities of each person with HF are appropriately matched to the competencies of the different levels of care.

For the HF referral network to be functional and to avoid unnecessary congestion in Cardiology services, it is essential that GPs identify people who need access to specialised services. Given the non-specificity of HF symptoms, it is essential that GPs have access to natriuretic peptide testing for the diagnosis (or exclusion) of HF, as discussed in measure A6.

SUGGESTIONS FOR IMPLEMENTATION

An appropriate referral network on HF should include several types of centres, at least some of which must have the tools and personnel to deal with complex cases, for example people with signs and symptoms that are difficult to control or with multiple comorbidities (multimorbidity). Similarly, some services should have extended opening hours, but others may only work on weekdays.

The development of an Individual Care Plan (Plano Individual de Cuidados, PIC) in HF would be important to ensure continued management, as PICs allow easier communication between healthcare professionals involved in the care of each person with a chronic disease, the recording of care objectives and a periodic assessment of results.[30]

For the development of a PAI for HF in Portugal, it may be useful to consider the integrative process on HF of the Public Health System of Andalusia, updated in 2012,[31] as the Andalusian system was the basis of the PAIs already developed in our country.[26]

EXAMPLES

The São Francisco Xavier Hospital developed a multidisciplinary and integrated HF programme that reduced the number of hospital readmissions.[32] This care model is based on structured transition of care, treatment optimisation, empowerment of the person with HF (measure B1) and fast access to specialised care in the event of exacerbation. The model considers the involvement of GPs in the care of each person with HF: the GP receives the discharge note and has access to a referral system to hospital care, with immediate access to the outpatient HF clinic and an HF specialist appointment within two weeks, depending on the patient's needs. The outpatient HF clinic, which is coordinated by nurses under the supervision of a physician who specialises in HF, has protocols with other departments and hospitals in order to address the needs of each person with HF.

Another HF model was recently implemented at the Local Health Unit (Unidade Local de Saúde, ULS) in Matosinhos. This model promotes a continuum of care as it integrates primary, hospital, ongoing and palliative care, and therefore enhances collaboration between healthcare professionals at various care levels. Clinicians from the outpatient HF clinic in the São Francisco Xavier Hospital were involved in the training of nurses at the ULS in Matosinhos.

There are examples of integrated models for HF in several European countries, such as at the Bellvitge Hospital in Barcelona, Spain, which is led by nurses and integrates hospital care with primary care. This model has reduced mortality and the risk of rehospitalisation.[33]

Another model that led to a decrease in hospitalisations and mortality due to HF was the Insuffisance CArdiaque en LORraine (ICALOR) programme, implemented in France. This model included structured education for people with HF, home monitoring by specialist nurses, automatic alerts on relevant clinical or biological changes, and a web-based medical electronic system that served as a basis for communication between healthcare professionals.[34] ICALOR averted the need for spending almost two million euros on hospitalisations in 2010 alone.[35]

In the United Kingdom (UK), the British Heart Foundation in collaboration with the National Health Service (NHS) developed a programme for administration of intravenous diuretics in the community. This pilot project involved 10 hospital organisations, and treatment was administered at home or in a nearby location, avoiding a hospital visit. The pilot project ensured savings of £162,740 (about €200,000),[36] avoiding 1,040 bed-days and contributing to greater patient satisfaction.

A3. Multidisciplinary palliative care as an integral part of HF care

Palliative care is crucial in HF as it helps reduce the number of hospitalisations and length of hospital stay, and improve symptom management (for example nausea and anxiety), quality of life and patient satisfaction.[28] Therefore, advance care planning and palliative care should be integrated into HF care models and, preferably, made available at time of diagnosis.

EXAMPLES

The HF palliative care model Palliative advanced home caRE and heart FailurE caRe (PREFER) in Sweden involves a multidisciplinary team and uses a patient-centred methodology with care provided at home.[37]

A4. Panel of indicators to assess HF care in various settings

Care must be monitored and assessed to ensure an optimal HF response in the long term. This is only possible with an appropriate panel of indicators that is common to each level of care. The panel should consider the entire clinical journey of people with HF, focusing on results and therefore encouraging good practice.

To support the evaluation process, objectives specific for HF and measurable with the panel of indicators must be defined for each care level. Although comparison between providers can sometimes be discouraging, it is important to identify those that are achieving the proposed objectives and those that need additional support. The panel of indicators may also contribute to a more effective allocation of funding, as discussed in measures A7 and B2.

EXAMPLES

The Kent Surrey Sussex Academic Health Science Network in the UK developed two panels of indicators to assess acute and community care in HF.[38] These panels, called dashboards, allow for a monthly analysis of each hospital according to national quality parameters.

The University College London Partners, in collaboration with St Bartholomew's Hospital (UK), developed a checklist to assess hospital discharge following hospitalisation for HF.[39] This checklist verifies, for example, that discharge summaries include:

- echocardiographic evidence to support the diagnosis of HF
- pharmacological recommendations
- a scheduled follow-up appointment within two weeks of discharge.

This checklist has improved the quality of discharge summaries and facilitates audit processes.[39]

A5. Interoperability and standardisation of information technology systems and data sharing between the various care levels, leading to an appropriate national registry in HF

The information technology systems of the different levels of care should communicate with each other so that the person's record is available wherever they present for care. This would support the integration of care. The information collected, and therefore shared, should be comparable and easy to understand.

The standardisation and sharing of information between different levels of care will allow the natural development of a registry in HF. This is essential to understand the epidemiology of the syndrome, the use of diagnostic procedures and treatment, which will allow for ongoing adjustment of the national strategy to the real challenge.

EXAMPLES

SwedeHF, the registry for HF in Sweden, includes information on the aetiology of HF, clinical characteristics and medication of each patient.[40] Since 2005 the registry has included information on symptoms and quality of life.[41] SwedeHF contributes to a better understanding of HF in Sweden, improves clinical practice and is currently the basis for recruitment for a clinical trial.[42]

A6. Funding for measurement of natriuretic peptides for the diagnosis of HF when requested by family doctors

Natriuretic peptide testing is recommended by the ESC for the diagnosis of HF, considering its crucial role in this process.[11] International scientific societies consider access to this test by GPs a parameter of quality of HF care.[43] However, as mentioned above, this test is not currently funded in Portugal if requested by GPs. It is urgent to correct this system failure to allow for a timely and adequate diagnosis of HF, while avoiding congestion of Cardiology services.

EXAMPLES

In Italy, funding for the measurement of natriuretic peptides varies across regions, but in 2012 a reference value per test was set – €24.68.[44]

A7. Valuation and funding of HF services provided in outpatient HF clinics, and specific funding for programmes of integrated primary and hospital care

Care provided in outpatient HF clinics is key not only for the person with HF but for the health system, as it helps reduce the need for emergency services, hospitalisations and the high associated costs. The COVID-19 pandemic has highlighted the importance of managing chronic diseases in the community and outpatient settings, and reserving acute care settings for emergency situations. Thus, it is crucial to understand the impact of each care programme and value it appropriately. It is essential to review the contracts with the Central Administration of the Healthcare System (Administração Central do Sistema de Saúde, ACSS) so that services in outpatient HF clinics are valued, for example through the inclusion of indicators for avoidable hospitalisations.

SUGGESTIONS FOR IMPLEMENTATION

To recognise the value of care in outpatient HF clinics, it is important to undertake an analysis that assesses the financial impact of these services, taking into consideration all costs involved. This study could, for example, be developed in a ULS as these units cover the entire healthcare pathway.

EXAMPLES

As discussed above (measure A2), the integrated care programme ICALOR led to a decrease in hospitalisations and mortality from HF in Lorraine, France, but was interrupted in 2014 due to a cessation of funding.[45] After this decision, hospitalisations for HF increased in the region, eliminating the benefits achieved with ICALOR.

A8. Undergraduate, postgraduate and continuing training in HF for the various healthcare professionals and formal recognition of HF skills in nursing

All healthcare professionals involved in HF care should receive specialised training on HF to ensure proper management and alignment with clinical recommendations. The academic curriculum for different healthcare professionals should include clear education on HF, but this is not enough. Opportunities for postgraduate and continuing education play a vital role in the provision of HF care. This is of particular importance for nurses, given their crucial role in HF management.

SUGGESTIONS FOR IMPLEMENTATION

Several formats can be considered for postgraduate and continuing education, for example courses, dissemination of case studies and clinical recommendations, and formal accreditation by the respective Unions. Another option would be to create internships (for example, 1–3 months) in HF clinics, ideally as part of the specific training in each professional area.

It is important to involve professional bodies and scientific societies in the discussion on HF training, as they will have a role in the development and recognition of such initiatives.

EXAMPLES

The outpatient HF clinic at São Francisco Xavier Hospital receives around 20 interns annually from various professional areas and hospitals across the country, for training of around three months.

Some models of HF training found in Europe, for example in Spain and the Netherlands, include sessions for primary healthcare professionals with HF specialists (cardiologists or specialist nurses).[46]

Consensus Level B

The measures for Consensus Level B represent those for which there were some different positions or which were considered important but not as urgent as the measures discussed above. The TT believes that after implementing measures of Consensus Level A, the aspects described at Consensus Level B should be the focus for improving HF care.

B1. Empowerment of the person with HF and family members/carers

Self-care in HF reduces the risk of hospitalisation, bringing benefits for the person with HF and the system.[27] Given the importance of informal carers in the management of HF, it is essential to have clear methods of empowering not only people with HF but also their carers. Time is limited for medical appointments and there is often a great deal of information to convey, so it is important to use alternative methods of empowerment.

Supporting materials for people with HF are available on the internet, for example ESC's website *Heart Failure Matters* (available in Portuguese)[47] and HFPN's *Understanding Heart Failure Guidelines: Patient empowerment and self-care* (available in English).[16] Their dissemination among people with HF may be useful.

Nursing teams usually provide education for self-care in HF, so consultations conducted by nurses should be developed to reduce the impact of the syndrome. These consultations can be in person, via telephone or even carried out at home. The empowerment of people with HF and their carers can also be supported by the distribution of information leaflets in waiting rooms of healthcare institutions (as suggested to increase awareness of HF, measure A1) or group training sessions led by nurses. Another alternative is the creation of a permanent helpline, possibly within the scope of SNS24.

B2. Outcomes-based funding with tools that promote access to innovation

Financing of health systems is shifting towards payment for outcomes – outcomes-based payment or value-based healthcare – to support the system's sustainability. According to this, funding is dependent on outcomes rather than a fixed amount per service, and therefore care is patient-centred. These funding models require monitoring and assessment of services and their results, and actual payment (and possibly investment) is dependent on this assessment. Therefore, the implementation of these funding models is dependent on the development of the panel of indicators described in measure A4.

Although the TT acknowledges the importance of this measure, two perspectives were presented. On the one hand, it was pointed out that its non-inclusion in measures of Consensus Level A could suggest a devaluation of this strong trend in healthcare. On the other hand, it was said that this measure will depend on elements discussed in Consensus Level A, and will in fact be a subsequent step for some of them. These positions led to the attribution of Consensus Level B to this measure, the majority of the TT having agreed that a second formal strategy in HF should ensure the development of outcomes-based payment.

B3. Telemonitoring programmes for people with HF

Telemonitoring allows healthcare professionals to monitor HF signs and symptoms remotely.[46] TT members were considerably divided over the importance of telemonitoring in HF care in Portugal. An in-depth discussion led to the conclusion that there was no urgency in its implementation as there were more urgent failures to be addressed, which is why this measure was assigned Consensus Level B. However, the COVID-19 pandemic has necessitated remote monitoring of HF, and it is anticipated that moving forward there will be a need for, and interest in, developing formal telemonitoring programmes.

B4. Rehabilitation clinics for people with HF

One of the components of high-quality, integrated care in HF is access to rehabilitation,[46] as cardiac rehabilitation reduces hospitalisations and mortality and improves the quality of life of people with HF.[2] However, just like the other measures in Consensus Level B, the majority of TT members believed that access to rehabilitation clinics will be important in a second strategy for HF, once measures of Consensus Level A have been implemented.

B5. Meetings between professionals in centres of excellence and those in other levels of care

Given the importance of multidisciplinary care in HF, it is crucial that different healthcare professionals are aware of up-to-date clinical recommendations. It was previously mentioned that there is a need to create training opportunities in HF for healthcare professionals (measure A8), and it may also be beneficial to implement a schedule of meetings between professionals in centres of excellence and primary care.

Consensus Level C

Consensus Level C measures represent suggestions that were considered non-essential, having been supported by a small number of TT participants. Some of the measures may become unnecessary when measures of Consensus Levels A and B are implemented.

C1. Ability for people with HF to access their own clinical records from home

Access to clinical records from home was considered an element that may improve HF care as it increases the patient's involvement with their own care.

C2. Clear referral for end-of-life care

As previously mentioned, it is important to distinguish between palliative and end-of-life care. The existence of clear criteria for referral to end-of-life care may help improve HF care.

C3. "High-resolution" consultations in HF outpatient clinics

"High-resolution" appointments are all-encompassing, which means that the diagnostic process and the development of a treatment plan are all performed in one day. Advantages of this model include a reduction in the number of hospital visits and the time between diagnosis and treatment plan.

Conclusion

HF is a common and complex syndrome that poses a challenge to the sustainability of healthcare systems across Europe, including Portugal. The prevalence of HF in our country is high and its impact is negative, in terms of symptoms, functional capacity, quality of life, hospitalisations and mortality. In the face of COVID-19, the importance of addressing HF has become even more clear – so that the long-overdue shift of care from acute to community and outpatient settings can finally be achieved, and people with HF can be protected.

The lack of preparedness of the Portuguese healthcare system to deal with HF is dramatic. Care is usually fragmented, inadequate in both technical and human resources, and does not involve the different levels of care for people with HF in a coordinated and systematic way. Knowledge about HF is limited among some healthcare professionals, and there are no training programmes to address this. There is also no system to assess care, nor a registry to allow for a better understanding of the epidemiological, sociological, clinical and financial elements of the problem.

Despite the numerous negative factors, it is worth celebrating the existence of some successful HF care models in Portugal. These models have led to positive outcomes, but unfortunately do not result from a coherent policy but rather from the isolated efforts of professionals who have been working with limited support. There is growing motivation among different stakeholders to improve the response to HF in an organised way, namely using strategies similar to those put into practice in other cardiovascular areas.

But this is not enough. Motivation and scarce models of excellence will not lead to an appropriate national model and a significant reduction in the impact of HF.

The complexity of HF urgently calls for an understanding of the challenge and a coordinated response. It is essential to implement a national strategy that involves health authorities and all professionals involved in the provision of HF care. Only with this wide circle of collaboration can a successful strategy be developed, one capable of reducing the impact of HF at an individual level, on healthcare systems and on Portuguese society.

It is our hope that the measures proposed here contribute to this collective effort.

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Glossary of abbreviations and acronyms

AADIC | Association for Support to Patients with Heart Failure (Associação de Apoio aos Doentes com Insuficiência Cardíaca)

ACSS | Central Administration of the Health System (Administração Central do Sistema de Saúde)

ESC | European Society of Cardiology (Sociedade Europeia de Cardiologia)

HF | Heart Failure

IPSS | Private Social Solidarity Institutions (Instituições Particulares de Solidariedade Social)

PAI | Integrated Assistance Process (Processo Assistencial Integrado)

PIC | Individual Care Plan (Plano Individual de Cuidados)

SC | Steering Committee

SNS | National Health Service (Serviço Nacional de Saúde)

SPC | Portuguese Society of Cardiology (Sociedade Portuguesa de Cardiologia)

SPMI | Portuguese Society of Internal Medicine (Sociedade Portuguesa de Medicina Interna)

TT | Think Tank

UCP | Universidade Católica Portuguesa

ULS | Local Health Unit (Unidade Local de Saúde)

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