

# Denmark



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The Heart Failure Policy Network



#### November 2020

### 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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- Brian Bridal Løgstrup, Cardiologist, Aarhus University Hospital; President, Heart Failure Working Group of the Danish Society of Cardiology
- ▶ Inge Schjødt, Clinical Nurse Specialist, Aarhus University Hospital; Co-president, Danish Heart Failure Registry

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## Contents

| About Heart failure policy and practice in Europe                             | 5  |
|---|----|
| Heart failure in Denmark  | 6  |
| Heart failure policy in Denmark   | 8  |
| Formal plans on HF  | 8  |
| Investment in integrated HF models and facilitative tools                     | 8  |
| Development of the HF healthcare workforce                                    | 10 |
| Guidance and local care pathways for delivery of quality care                 | 10 |
| Public audits of performance and high-level assessment initiatives            | 11 |
| Heart failure practice in Denmark   | 13 |
| Diagnosis   | 13 |
| Hospital care and discharge   | 13 |
| Key components of quality care in community settings                          | 14 |
| Tools and methods to support multidisciplinary and integrated ongoing HF care | 16 |
| The way forward   | 17 |
| References  | 20 |

4 // Heart failure policy and practice in **Denmark** 



## **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 Denmark 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 Denmark

#### SUMMARY

The burden of heart failure (HF) in Denmark is high and growing, in terms of both its cost to the healthcare system and the wider economy, and its impact on people with HF and their families.<sup>12</sup> There is some concern that the true urgency of the challenge posed by HF has not been fully recognised by the Danish government – despite many investments, a national strategy on HF has yet to be developed.

Denmark has strong foundations on which to build effective policies and improve care. Clinical guidelines and a national clinical pathway for heart diseases (including HF) are available.<sup>3-5</sup> In addition, the Danish national HF registry has provided a high level of central oversight of HF services, which has allowed for improvement in care and outcomes.<sup>6</sup>

While care in HF is often of high quality, several aspects of the challenge remain to be addressed. For example, two years before receiving an HF diagnosis, individuals are incurring increasing healthcare costs,<sup>7</sup> highlighting the need for early detection of the syndrome. In addition, people at a socioeconomic disadvantage may experience worse outcomes,<sup>8-10</sup> and experts report that the transition from hospital to community care is often fragmented.<sup>11 12</sup>

## HF is a common syndrome with increasing prevalence

In 2017, an estimated 65,500 people were living with HF in Denmark.<sup>2</sup> However, the actual prevalence may be higher, as HF has been shown to be underdiagnosed in people over 60 with one or more risk factors.<sup>13</sup> Every year, almost 9,000 new cases of HF are identified.<sup>14</sup>



HF disproportionately affects older people. In 2013, approximately 5% of people over the age of 75 and 10% of those over the age of 85 were reported to be living with the syndrome.<sup>15</sup> However, the number of cases among younger adults has been increasing – between 1995 and 2012, HF incidence doubled among people aged 50 and under.<sup>16</sup> Prevalence of HF is expected to continue to rise, in part due to improved treatment of cardiovascular diseases and population ageing.<sup>14</sup>



## HF is associated with high expenditure

In 2012, it was estimated that HF consumed almost 2% of the total health expenditure in Denmark.<sup>1</sup> The annual cost of HF per person in 2016 was estimated at approximately €17,000, with direct costs accounting for 70% of this figure (almost €12,000).<sup>7</sup> Two thirds of direct costs are attributed to hospitalisation, with median length of stay between 4 and 20 days.<sup>7</sup> A substantial and steady increase in direct costs has been noted in the two years prior to diagnosis of HF.<sup>7</sup>



of annual health expenditure

Indirect costs of HF are also significant. National data have demonstrated that HF leads to lost productivity and reduced earning potential among those affected, and therefore increases welfare payments, such as unemployment benefits, sick pay and disability pension.<sup>7</sup> According to national registry data from 1997 to 2012, one in four people living with HF did not return to work in the year following their first hospitalisation.<sup>17</sup>

### Outcomes in HF are often poor

In 2017 alone, there were more than 22,000 hospital admissions and 6,000 readmissions for HF, the majority in people over the age of 75.<sup>2</sup> In the same year, 30-day all-cause mortality for people with HF was estimated at 4% and one-year all-cause mortality at around 8%.<sup>2</sup>

Data from national registries, such as the Danish National Heart Failure Registry and the Danish National



Hospital admissions per year

Patient Registry, have shown that HF outcomes are often worse for people at a socioeconomic disadvantage. People with a low income typically have a higher risk of hospital readmission and mortality following a diagnosis of HF,<sup>9</sup> whereas higher educational attainment is linked to lower mortality.<sup>10</sup> In addition, being unemployed at the time of first hospitalisation for HF has also been shown to increase the risk of mortality.<sup>8</sup> This was comparable to the risk of mortality associated with diabetes or stroke in a person with HF.

HF diagnoses and hospitalisations have declined in 2020, following the onset of the COVID-19 pandemic.<sup>12 18</sup> This raises concerns regarding the lack of diagnosis and management of HF, which in the longer term may impact prognosis.

8 // Heart failure policy and practice in **Denmark** 



## **Heart failure policy** in Denmark

### Formal plans on HF

#### Denmark lacks a dedicated strategy for HF

The Danish government has yet to develop a formal plan on HF. In the absence of a dedicated strategy, other policy initiatives could hold promise in advancing HF care, if able to secure an expansion in focus to encompass HF. One such initiative is a Committee for Heart Diseases, established by the Danish Health Authority in 2008. The committee typically meets twice per year to discuss and improve the national response to heart disease. However, so far it does not appear to have addressed HF.<sup>19</sup> Another promising initiative is a task force backed by the government and the five regions of Denmark. Originally focused on cancer, it was expanded in 2010 to cover heart disease and renamed the Task Force for Cancer and Heart Patients.<sup>20</sup> It is responsible for monitoring developments in these areas and proposing solutions to the identified challenges, mostly around organisation of care and capacity pressures, but there is no evidence of a focus on HF.<sup>21</sup>

## Investment in integrated HF models and facilitative tools

#### Key diagnostic tests are not consistently reimbursed

Reimbursement policies of core diagnostic tests may contribute to inequalities and constitute a barrier to HF diagnosis. Echocardiography, the most accurate diagnostic test, and natriuretic peptide (NP) testing, which is a key step in the diagnosis of HF as it can help avoid unnecessary echocardiography, are fully reimbursed in hospital settings.<sup>12</sup> However, reimbursement of NP testing in primary care settings varies across the regions.<sup>22</sup>



#### Government interest in telemedicine for HF is growing

Overall, policymakers have supported telemedicine care models, for example via investment in telemedicine pilots (see *Case study 1*). In 2018, Healthcare Denmark, a public-private partnership fostering innovation in the national health system, highlighted the benefits of telemedicine in several therapeutic areas, including HF.<sup>23</sup> National experts report that the Danish Health Authority has subsequently convened a group of experts and patients to develop a national strategy for the use of telemonitoring for HF, aiming to improve care for people who cannot easily access HF clinics.<sup>24</sup> Work on the strategy is currently ongoing.<sup>12</sup>

## Inadequate information technology infrastructure hinders integration of care

Denmark is widely regarded as a leader in terms of the application of information technology (IT) systems in healthcare.<sup>25</sup> The country has introduced three hospital IT systems that allow for data linkage – therefore, information can be seen across hospitals.<sup>22</sup> However, these do not communicate with systems in primary care, where there is a great number of different IT infrastructures. National experts note that the high number of IT systems in fact limits access to clinical information and hinders communication across care settings,<sup>24</sup> which may negatively impact health management. Plans are underway for primary care settings to be added to the hospital IT system in the next few years, which would improve the opportunity for communication and collaboration.<sup>22</sup>

### **CASE STUDY 1.** TeleCare North Heart Failure Trial

The TeleCare North Heart Failure Trial, which was conducted in the North Denmark Region in 2016–17, examined the benefits of a nurse-led telemedicine intervention compared with routine care.<sup>26</sup>

The programme provided education on HF to participants, who received the equipment necessary for self-monitoring at home, including devices to measure pulse rate and blood pressure, and a tablet for communication with their care team.<sup>14 23</sup> Self-care was supervised by hospital staff, who responded to any signs of HF exacerbation, ensuring rapid adjustment of medication in order to avoid hospital admission. The intervention aimed to facilitate transparent and patient-centred collaboration between people living with HF, their families and healthcare professionals across care settings. The overall goal was to support self-monitoring and care adherence.

The programme achieved a 35% reduction in annual healthcare costs per person living with HF, mainly due to a decrease in hospitalisations.<sup>14</sup>

### **Development of the HF healthcare workforce**

#### National professional societies offer HF training opportunities, but HF specialist roles are not formally recognised

In Denmark, there is no national accreditation for HF specialist physicians.<sup>12</sup> Cardiology is a sub-specialty of internal medicine that requires several years of specialisation,<sup>27</sup> after which there are opportunities for physicians to acquire skills in HF care. To advance specialist knowledge in HF, physicians undertake courses and exams organised by the Heart Failure Association of the European Society of Cardiology (ESC).

Further postgraduate training opportunities in HF are provided by national professional societies. The Danish Society of Cardiology (Dansk Cardiologisk Selskab, DCS) delivers two-day training courses on cardiovascular diseases, including HF, for cardiology trainees,<sup>28</sup> and continuing medical education in HF for qualified cardiologists.<sup>29</sup> A joint initiative between the DCS and the Danish Association of Palliative Medicine offers training in HF palliative care for cardiologists and palliative care specialists.<sup>5</sup>

National accreditation is also unavailable for the role of HF specialist nurse. According to experts, nurses have been lobbying for specialist education in cardiovascular nursing for several years.<sup>11</sup> Lack of funding was initially the major barrier to the formal recognition of HF specialist nurses.<sup>11</sup> Experts also report recommendations that postgraduate training of nurses adhere to the European Credit Transfer and Accumulation System (ECTS), which poses additional challenges.<sup>11</sup>

Despite the lack of formal HF accreditation, opportunities for further education in this area are offered by professional societies. For example, every two years, the HF working group of the Danish Society of Cardiovascular and Thoracic Surgical Nurses holds two-day HF training courses, with a focus on nurses working in HF clinics.<sup>1130</sup>

## Guidance and local care pathways for delivery of quality care

## National clinical guidelines and care pathways exist alongside regional care protocols

The DCS has endorsed the 2016 ESC guidelines for HF and developed national guidelines for the management of acute and chronic HF.<sup>31-33</sup> Other national and regional guidance for cardiac care also covers the syndrome, such as the 2013 Danish Health Authority guideline for post-discharge cardiac rehabilitation for people with heart disease, which outlines recommendations in HF.<sup>3</sup> More recently,



in 2019, the Capital Region of Denmark launched a comprehensive programme of rehabilitation in cardiac conditions that includes HF and goes as far as outlining the responsibilities of each healthcare professional involved.<sup>34</sup>

In 2018, the Danish government, regions and municipalities updated the national clinical pathway for heart diseases, featuring HF, to cover the organisation of care and workforce, as well as clinical recommendations.<sup>4</sup> The pathway is aligned with HF treatment guidelines published by the DCS, and emphasises the need for timely access to care across the entire patient journey.

Official clinical guidance is supplemented by position statements from the DCS, including one on palliative care in advanced HF, published in 2019.<sup>5</sup> According to its president, the Heart Failure Working Group of the DCS is now developing an opinion piece on the value of NP testing, to increase its use in the diagnosis of HF across all care settings, including HF clinics, emergency departments and primary care.<sup>12</sup>

## A mandatory national hospital accreditation programme includes indicators for HF

The Danish Institute for Quality and Accreditation in Healthcare (Institut for Kvalitet og Akkreditering i Sundhedsvæsenet, IKAS) developed a mandatory national hospital accreditation programme that includes indicators for HF.<sup>35</sup> Accreditation of hospitals has been associated with increased compliance with HF guidelines and delivery of optimal care.<sup>36 37</sup>

### Public audits of performance and high-level assessment initiatives

## Denmark has a high-quality HF registry that supports research and drives improvements in care

The Danish Heart Failure Registry is a world-leading policy initiative that has provided valuable oversight of HF services and allowed for improvement in care and outcomes (see *Case study 2*). In addition, publicly funded databases monitor healthcare delivery, clinical outcomes and other societal parameters, providing important feedback to healthcare workers, administrative staff and policymakers.<sup>38</sup> Relevant examples include a cardiac rehabilitation database, a national patient registry and a public benefits database, which has been used to assess the impact that educating patients in HF cardiac rehabilitation has had on the likelihood of their returning to work.<sup>39-41</sup>

### **CASE STUDY 2.** Danish Heart Failure Registry

The Danish Heart Failure Registry was developed in 2003 to monitor and improve the quality of care provided to people living with HF across the country.<sup>6 42</sup> Participation is mandatory for all hospital departments involved in HF care, with patients being added at the point of diagnosis.<sup>43</sup> The registry has yet to include data from primary care settings, and experts report that such indicators are currently under review by the Danish College of General Practitioners (Dansk Selskab for Almen Medicin) for inclusion.<sup>11</sup>

The registry collects process and outcome measures of HF care, including the use of tests and treatments, as well as hospitalisation and mortality rates.<sup>43</sup> It produces monthly feedback reports that enable performance assessment and comparison across care providers, and findings are reviewed every year to identify barriers to best practice. The quality indicators used in the registry were selected by a multidisciplinary panel, which was guided by national and international guidelines as well as published literature.<sup>42</sup> The panel meets annually to review the indicator framework and make changes if needed.<sup>44</sup> The fact that every Danish resident has a unique personal identification number enables data linkage between the HF registry and other administrative and medical registries.<sup>43 45 46</sup>

The introduction of the registry has improved guideline-based HF practice and helped to reduce mortality within one year of diagnosis.<sup>47</sup> Experts state that the indicators have also helped to deliver better care systematically by providing a structure to the organisation of care in HF clinics.<sup>11</sup>



## **Heart failure practice** in Denmark

### Diagnosis

## The diagnosis of HF in community settings is hindered by limited professional expertise and long waiting times for diagnostic tests

HF diagnosis is often delayed in Denmark.<sup>13</sup> In some primary care settings, NP testing is used to assess whether a referral to a cardiologist or HF outpatient clinic is needed, so an echocardiogram may be performed to confirm the diagnosis.<sup>22</sup> The value of NP testing in the diagnosis of HF, however, may not have been fully recognised yet as the test is not consistently used in primary care settings.<sup>22</sup>

Experts state that difficulties in identifying HF symptoms and accessing diagnostic tests in primary care may contribute to late referral and delayed diagnosis.<sup>24</sup> Other barriers to diagnosis include limited awareness of HF symptoms among the general public and long waiting times for echocardiography in some parts of Denmark (due to economic constraints and personnel shortages).<sup>12</sup>

### Hospital care and discharge

## Acute HF care is well organised but there is a need for better support following hospital discharge

People with acute HF may be admitted to different wards, depending on their condition and whether there is initial suspicion of acute HF. According to experts, management of acute HF is typically multidisciplinary – the care team generally involves various healthcare professionals, including internists, cardiologists and physiotherapists.<sup>22</sup>

Before discharge, hospital physicians are required to send an electronic letter to the patient's general practitioner outlining detailed plans for post-discharge care.<sup>12</sup> Nonetheless, experts indicate that despite all HF cases being referred to an HF clinic,

the transition of care from acute to community settings requires improvement.<sup>1112</sup> Typical failures in transitions may include limited communication between primary care and hospitals, reluctance among people living with HF to seek timely medical advice, long travel time to reach specialist care and a lack of HF specialists.<sup>2224</sup>

Referral to specialist settings following hospitalisation may need to be adapted to support post-discharge care. Upon discharge, people with HF may be referred to an HF clinic, after which they are monitored in primary care settings if their case is not deemed complex.<sup>22</sup> Referral to an HF clinic is initiated by hospital cardiologists, who may not refer a person if they consider it of little benefit to them (due to their age, frailty or cognitive impairment). However, HF experts believe that decisions regarding suitability for care in HF clinics should be the remit of specialists within the clinic.<sup>22</sup>

### Key components of quality care in community settings

#### HF clinics deliver high-quality ongoing HF care, but not all people living with HF are able to access them

At hospital discharge, people with HF are typically referred to an HF clinic for outpatient care, including adjustment of medication, evaluation of devices, physical rehabilitation and education in HF.<sup>48</sup> Some people, however, are discharged straight back to primary care settings.<sup>22</sup>

HF clinics are based in hospitals, and there are about 30 of them across the country.<sup>12</sup> They provide high-quality, multidisciplinary HF care, involving cardiologists, nurses (typically with more than five years' experience in cardiac care), dietitians and personnel delivering cardiac rehabilitation, among others.<sup>1112</sup> The care team is experienced in HF, and they typically follow up with people living with HF: aiming to do so by telephone within the first week of discharge and in person at the clinic within two weeks.<sup>22</sup> In some rare cases, if people cannot attend their clinic appointments, clinic nurses may cross over into the community setting to help with the transition from hospital care and to provide patient education.<sup>11</sup>

According to experts, people with HF typically receive care in an HF clinic for three to six months following hospitalisation. Before discharge, their condition is re-evaluated, with key tests to ensure suitability for ongoing HF management in primary care.<sup>22</sup> Follow-ups are scheduled to help monitor HF – these are often annual, but may be more frequent if needed. In addition, at any point after discharge, the person may contact the clinic for additional support or information, which is typically provided by the nurse who led their care. Experts cite low



numbers of re-referrals from primary care settings to HF clinics, suggesting that signs of deterioration may be missed in the community; this may contribute to rehospitalisation.<sup>22</sup>

Experts state that there is regional variation in access to HF clinics.<sup>22</sup> In some rural areas, waiting time for an appointment can be several weeks. Barriers may include limited staffing and lack of transportation, especially for older people.<sup>24</sup>

#### The provision of cardiac rehabilitation services is improving but models need to be available more widely

Provision of cardiac rehabilitation for people with HF is reported to be improving, with services typically being offered to people attending HF clinics.<sup>22</sup> However, referral may depend on HF type and class – experts report that cardiac rehabilitation is more often provided to people with HF with reduced ejection fraction (HFrEF) than those with preserved ejection fraction (HFpEF).<sup>11</sup> Not all people referred to cardiac rehabilitation actually join a programme, which can be due to frailty or limited ability to manage the intensity of the programme.<sup>22</sup> In addition, younger people with HF may prefer not to join a formal cardiac rehabilitation programme.

### Patient education and psychological support in HF are not standardised

Patient education is important for optimal treatment adherence, but this aspect of care is not formally standardised. Some healthcare professionals provide this in hospital and some HF clinics organise educational classes for people with HF (e.g. to teach them about medications, including side-effects), but this is not consistent practice.<sup>22</sup> Overall, experts believe there is a need to improve the situation to encourage self-care.<sup>1124</sup> Similarly, provision of psychological support is limited.

### Provision of palliative care for people with HF is increasing, but this is not yet standard practice

Dedicated HF palliative teams are not widespread throughout Denmark, but interest in this care component seems to be growing among healthcare professionals.<sup>12</sup> For example, nurses from some cardiology wards and HF clinics provide palliative care at home, such as those from Aarhus University Hospital.<sup>11 12</sup> In some parts of Denmark, such as Vejle and Aarhus, cardiologists and palliative care specialists take part in multidisciplinary team meetings to discuss palliative care for people with HF.<sup>11 12</sup>

### Tools and methods to support multidisciplinary and integrated ongoing HF care

#### Several tools and methods have been implemented to promote multidisciplinary and integrated HF care, but more can be done to ensure high-quality care for all

Successful tools and working methods tested or currently in place at the local level include multidisciplinary palliative care meetings and telemedicine models.<sup>11 12 26</sup> Implementation and wide roll-out of these models, alongside programmes to ensure communication between primary care and specialist settings, could offer significant benefits. The national strategy for the use of telemonitoring in HF that is currently under development can contribute to strengthening the foundations for consistent provision of multidisciplinary and integrated HF care, if adopted by different healthcare professionals involved in care.<sup>12 24</sup>

The COVID-19 pandemic has increased the number of video consultations, highlighting the positive benefits of telemedicine as a supplement to routine care for people who cannot easily access HF clinics.<sup>22</sup>



## The way forward

HF poses a challenge to the sustainability of healthcare systems in countries across Europe, including Denmark. 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.

While HF care in Denmark is typically of high quality, several aspects of the challenge remain to be addressed, including diagnosis and care in the community. In addition, the recent disruption of existing healthcare services due to the COVID-19 pandemic may accentuate the rising burden of HF, making the need for a national response to HF even more pressing.

#### SEVERAL ACTIONS ARE ESSENTIAL TO ADDRESS THIS CHALLENGE.

## **Improve** HF diagnosis in primary care settings through education and enhanced access to diagnostic tests

There is a need to improve diagnosis of HF – this is essential in a coherent response to the challenge that HF poses. Better expertise is needed among healthcare professionals working in primary care settings, and it is crucial to reimburse NP testing in primary care in all regions of Denmark. NP testing can help prioritise referrals for specialist-led echocardiography, thereby facilitating timely diagnosis and access to treatment, and avoiding echocardiograms that may be unnecessary. 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.

### 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 in Denmark. Nursing 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 regional and national decision-makers and professional societies. 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.

### **Investigate** and address the barriers hindering smooth transition from specialist to primary care settings

It is crucial to fully understand common failures in transition across care settings. Decision-makers should examine the case for implementing successful local initiatives at a national or regional level, such as HF clinic nurses supporting care in the community. Primary care services are increasingly at the centre of integrated person-centred care and the successful management of HF in the community may reduce the pressure on specialist settings and improve quality of life for people with HF.

### **Explore** further the impact of socioeconomic factors on HF outcomes and develop strategies to reduce disparity

Socioeconomic inequality, in particular unemployment, low income and lower educational attainment, have independently been associated with an increased risk of hospital readmission and mortality in people living with HF. These disparities must be better understood and addressed. The inclusion of social indicators in the national HF registry may be crucial for this. People with HF who face socieconomic disadvantages could potentially benefit from care plans that incorporate additional social support and HF education.

### **Implement** telemedicine programmes shown to improve outcomes and reduce costs of HF care

Telemedicine has demonstrated huge promise in Denmark, driving new models to reduce the number of hospital admissions for HF and improve support in the community for people living with the syndrome. The success of pilot projects, such as the TeleCare North Heart Failure Trial, should be reinforced with funding for an enduring national model. Healthcare professionals with experience in the use of telemedicine for the management of HF could be brought in to facilitate the wide implementation of the programme through peer-learning.



### 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 Denmark.

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If you have any comments or questions, please get in touch with the authors at **info@hfpolicynetwork.org** 

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