



Spotlight on

**HFpEF:  
heart failure with preserved  
ejection fraction**



*The Heart Failure Policy Network is an independent, multidisciplinary platform made possible with financial support from Vifor Pharma and Novartis Pharma. The content produced by the Network is not biased to any specific treatment or therapy. All outputs are guided and endorsed by the Network's members, who have full editorial control. All members provide their time for free.*

# Authorship and acknowledgements

This report was written by Ed Harding, Sara C Marques, Marissa Mes and Madeleine Murphy, members of the Secretariat of the Heart Failure Policy Network (HFPN).

Considerable thanks and acknowledgement are due to all members of the Project Advisory Group for their continued input throughout the development of the report:

- **Josep Comín-Colet**, Cardiologist, Bellvitge University Hospital, Spain
- **Joseph Gallagher**, General Practitioner and Irish College of General Practitioners Clinical Lead in Cardiovascular Disease, Ireland
- **Steven Macari**, Founder and President, Association Vie Et Cœur (AVEC), France
- **Sandra Mulrennan**, HF Specialist Nurse, St Bartholomew's Hospital Heart Failure Service, Barts Health NHS London, UK
- **Anne-Catherine Pouleur**, Cardiologist, Université Catholique de Louvain and Cliniques universitaires Saint-Luc, Belgium
- **Patricia Vlasman**, Founder and President, Let the Beat Go On, the Netherlands

The HFPN would also like to thank the following experts for sharing their knowledge in interviews:

- **Christi Deaton**, Professor of Nursing and Florence Nightingale Foundation Chair of Clinical Nursing Research, Primary Care Unit, Department of Public Health and Primary Care, School of Clinical Medicine, University of Cambridge, UK
- **Cândida Fonseca**, Senior Cardiologist and Internist, Head of Heart Failure Clinic of São Francisco Xavier Hospital; Professor of Medicine, NOVA Medical School, Faculdade de Ciências Médicas, Universidade NOVA de Lisboa, Portugal
- **Damien Gruson**, Head of Department of Clinical Biochemistry, Cliniques universitaires Saint-Luc, Belgium
- **Ian Philp**, Chief Executive Officer, Age Care Technologies; Professor in Global Ageing, Dementia and Ageing, Faculty of Social Sciences, University of Stirling, Scotland
- **Lilian van Doesburg**, Founder, Heart\_4\_Food; Volunteer, Perinatology Service, Radboud University Medical Centre (UMC), the Netherlands

# Contents

Executive summary	<b>4</b>
1. What is heart failure with preserved ejection fraction?	<b>6</b>
2. The burden of HFpEF on lives and healthcare systems	<b>10</b>
3. Diagnosis of HFpEF: facts and challenges	<b>12</b>
4. Challenges in care and management of HFpEF	<b>15</b>
5. Best practice in care and management of HFpEF	<b>17</b>
6. The way forward	<b>20</b>
References	<b>22</b>

# Executive summary

**Heart failure (HF) with preserved ejection fraction (HFpEF) is often forgotten.**

Many people think of HF only as HFrEF – HF with reduced ejection fraction – possibly because clinical trials have mostly focused on this type of HF, and because it is a more widely recognised clinical entity.

**Much needs to be done to improve HF care and outcomes, but the journey ahead is harder in HFpEF than HFrEF.** While there is a significant lack of awareness of HF in general, far less is known about HFpEF.

**The impact of HFpEF on those who live with it is significant.**<sup>1</sup> As with all types of HF, people living with HFpEF may struggle with tasks in the workplace and at home, and may see their independence impaired.<sup>2</sup> They often live with multiple comorbidities and require several hospitalisations, which contribute to a reduction in quality of life.<sup>1</sup> The fact that HFpEF is not a visible disease, meaning its impact on people is not always seen or understood, adds to its burden.

**HFpEF also has a significant and growing impact on healthcare systems.**

It accounts for almost half of all hospitalisations for HF, and this proportion increases in older age groups.<sup>3-5</sup> Projections point to an increase in prevalence of HFpEF, mostly due to population ageing and increased survival rates of other cardiovascular and chronic diseases.<sup>6</sup>

**The process of diagnosing HFpEF is complex.** HFpEF often goes unrecognised for a long time, leading to people being diagnosed in advanced stages, which prevents timely access to care.<sup>7 8</sup> Comorbidities, old age and inconsistent use of diagnostic tests, often due to lack of reimbursement, complicate this process. The limited knowledge of HFpEF among non-cardiology professionals is another factor delaying diagnosis.

**There are many challenges in clinical management – particularly the lack of medicines proven to treat heart function in HFpEF.** People with HFpEF have been largely excluded from clinical trials, partly due to the heterogeneity of the syndrome.<sup>9-11</sup> Medicines prescribed in HFpEF focus on management of symptoms and improving quality of life.

**There are also systemic barriers to effective HFpEF management, reflecting a lack of organisational readiness for long-term chronic disease care.** For example, HFpEF management usually falls under primary care, and professionals in these settings may not be sufficiently trained on HFpEF or supported by specialists.

**Despite all these challenges, much can be done to support people living with HFpEF.** Integrated and multidisciplinary care models can reduce hospitalisations and mortality, and improve quality of life.<sup>12</sup> People living with HFpEF can also benefit from person-centred care models, which ensure shared decision-making and support people to self-care.<sup>13</sup>

**There are clear policy priorities to improve HFpEF care.** Taking action in these areas will reduce the impact of HFpEF on each person, the healthcare system and society in general.

### Key actions to improve HFpEF care and policy

<b>1. Improve public awareness of HFpEF</b>	It is essential that the general public and healthcare professionals are alert for HFpEF signs and symptoms and do not dismiss them as signs of ageing or comorbidities.
<b>2. Invest in prevention of HFpEF</b>	It is crucial to diagnose and effectively manage conditions that are known to be risk factors for HFpEF, such as diabetes and hypertension.
<b>3. Equip healthcare providers with tools, resources and pathways to diagnose and manage HFpEF</b>	Multidisciplinary and integrated care must be supported, and this means investing in the development of tools and pathways that support each healthcare professional involved in HFpEF care. There is also a need to develop performance management systems that encourage accurate diagnosis and optimal care.
<b>4. Train and accredit healthcare professionals</b>	Education about HFpEF should be initiated as early as possible for healthcare professionals and continued throughout professional development, in particular for physicians in primary care settings.
<b>5. Empower people living with HFpEF and carers</b>	It is important to educate people living with HFpEF and their informal carers to ensure they are supported in daily HFpEF care.
<b>6. Support clinical research to improve understanding of HFpEF and identify treatment options</b>	There is a strong need for evidence-based treatment options that address heart function in HFpEF, and this requires new clinical trials focused on this syndrome.
<b>7. Support data collection and knowledge-sharing</b>	Data on epidemiology, hospitalisation and readmission rates in HFpEF are limited in many European countries; this impedes political oversight to address gaps and drive system improvement at scale, and an understanding of the economic and societal impact of HFpEF.

# What is heart failure with preserved ejection fraction?

## Heart failure with preserved ejection fraction is one of three different types of heart failure

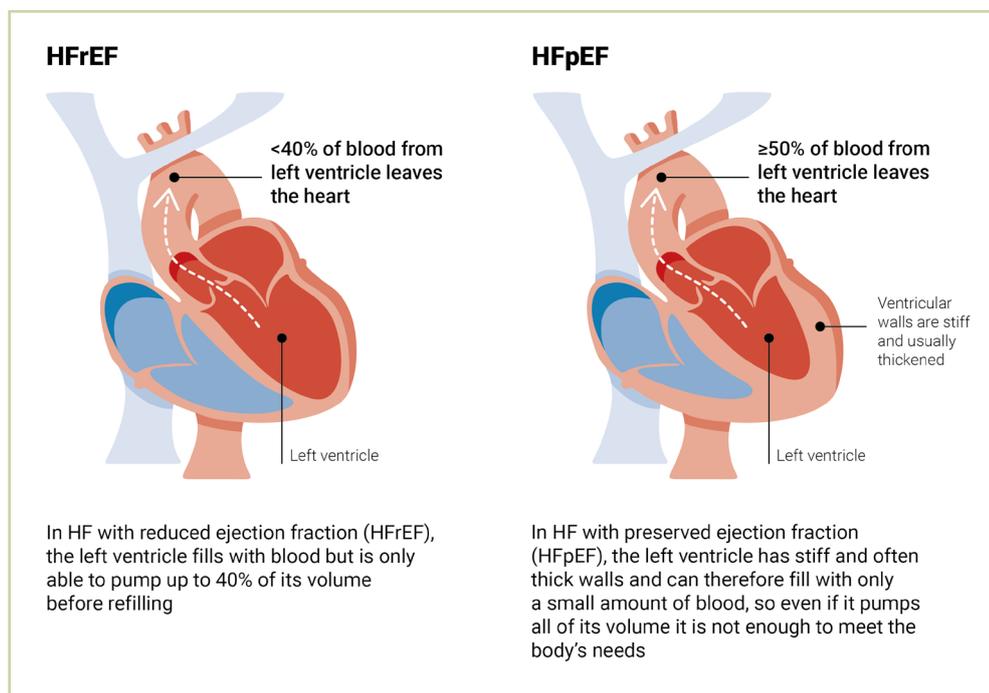
Heart failure (HF) occurs when the heart becomes too weak or stiff.<sup>1</sup> It is a complex clinical syndrome in which the heart is not able to pump enough blood to the rest of the body. Symptoms and signs include breathlessness, extreme fatigue, reduced exercise capacity and fluid retention resulting in weight gain and/or swelling. Current European guidelines distinguish three types of HF:<sup>1</sup>

- HF with reduced ejection fraction (HFrEF)
- HF with mid-range ejection fraction (HFmrEF)
- HF with preserved ejection fraction (HFpEF).

## HF types are defined by the left ventricular ejection fraction

Left ventricular ejection fraction (LVEF) is the proportion of oxygenated blood in the heart that is pumped out by the left ventricle to the rest of the body with each heartbeat.<sup>1 9</sup> In HFrEF, the LVEF is below 40%, while in HFpEF, it is at least 50% (Figure 1).<sup>1</sup> HFmrEF, which was introduced in the 2016 European Society of Cardiology HF guidelines, refers to HF with an LVEF between 40% and 49%, inclusive. This was initially considered a 'grey area' between HFrEF and HFpEF, and is now starting to be seen as a group with a clinical and risk profile closer to HFrEF based on clinical trials and retrospective sub-group analyses of previous studies.<sup>14-16</sup> There is ongoing discussion regarding the LVEF cut-offs currently used to distinguish types of HF, so it is possible that definition criteria may change in the future.

**Figure 1. The heart in HFrEF and HFpEF**



## **In HFpEF, the heart does not fill up entirely**

The LVEF in HFpEF is considered normal – this means the heart contracts effectively.<sup>1</sup> Unlike HFrEF, where the heart does not pump enough blood because it does not contract effectively, the challenge in HFpEF is the filling up of the heart chambers. In HFpEF, the heart only fills with a small volume of blood because the muscle tissue of the left ventricle has become stiff and is unable to relax appropriately, leading to increased pressures and congestion. Often there is also thickening of the left ventricular wall, which limits space to hold blood.<sup>1</sup> The reduced volume of blood in the left ventricle means that, despite the heart's ability to contract effectively, insufficient blood is pumped out to meet the body's needs.

## **Despite progress, HFpEF remains a poorly understood syndrome**

Much remains unknown about HFpEF, and this lack of comprehensive understanding is a substantial barrier to clinical decision-making and to research and development of effective treatment options. The physiological processes behind the development of HFpEF – its pathophysiology – are poorly understood.<sup>17 18</sup> These processes are different from those in HFrEF, which means that increasing knowledge of HFrEF does not translate into better understanding of HFpEF. What is known in HFpEF is that many cardiovascular risk factors are linked to its development, for example ageing, obesity, hypertension, metabolic syndrome (a combination of diabetes, hypertension and obesity), lack of physical activity, coronary heart disease and kidney disease.<sup>9 17</sup> Leading theories for the development of HFpEF suggest that risk factors accelerate normal age-related changes in the heart, or that it is an inflammatory response to other health conditions.<sup>7 17</sup> Therefore, HFpEF appears to be a systemic disease, rather than purely cardiac in nature.

***'There has been less understanding of the pathophysiology of HFpEF because it involves a different process from HFrEF. I think we're coming to more consensus around HFpEF being a pro-inflammatory response to comorbidities.'***

**Professor Christi Deaton, UK**

**Table 1. Characteristics of the different types of heart failure (HF)**

	<b>HFrEF</b>	<b>HFmrEF</b>	<b>HFpEF</b>
<b>How does the heart perform?</b>	Weakened heart muscle, typically with a dilated left ventricle, leading to problems with the pumping out of blood from the heart to the rest of the body	Unclear – problems with the relaxation and refilling of the heart, as well as the pumping out of blood from the heart to the rest of the body	Stiffened heart muscle, often with a thick left ventricular wall and increased filling pressures, leading to problems with relaxation and refilling of the heart
<b>Symptoms</b>	Breathlessness, extreme fatigue, reduced exercise capacity and post-exercise recovery, fluid retention, swelling (especially of lower limbs and abdomen)		
<b>Clinical attributes</b>	HF symptoms and signs LVEF is less than 40% (systolic dysfunction) Elevated NPs	HF symptoms and signs LVEF is 40–49% NPs are usually elevated Structural heart disease and/or diastolic dysfunction	HF symptoms and signs LVEF is at least 50% NPs are usually elevated Structural heart disease and/or diastolic dysfunction
<b>Focus of management</b>	Heart function treatment with medicines, cardiac devices and/or surgery to improve functional capacity and outcomes	Management of symptoms, risk factors, comorbidities and overall wellbeing	Management of symptoms, risk factors, comorbidities and overall wellbeing
<b>Proportion of cases in Western countries*</b>	37–49%	Research ongoing	51–63%

HFrEF: heart failure with reduced ejection fraction; HFmrEF: heart failure with mid-range ejection fraction; HFpEF: heart failure with preserved ejection fraction; LVEF: left ventricular ejection fraction; NPs: natriuretic peptides

NPs are hormones produced by the heart and their levels are usually elevated in people with HF.

Diastolic dysfunction occurs when the heart does not appropriately relax and fill with blood.

Systolic dysfunction occurs when the heart does not contract appropriately, limiting the volume of blood pumped out.

\* Depending on definition, clinical setting, age and sex of studied population

Source: Ponikowski *et al.*, 2016<sup>1</sup>; Loai and Cheng, 2019<sup>8</sup>

## Comorbidities contribute to the complexity of HFpEF

Comorbidities are health conditions that may worsen HF or change the way HF is treated.<sup>19</sup> They are very common in all people living with HF; however, prevalence is higher among people with HFpEF than HFrEF.<sup>1</sup> Between 12% and 15% of people living with HFpEF have one or two comorbidities, and almost half of all people with HFpEF have at least five.<sup>20 21</sup> Comorbidities increase the complexity of HFpEF management. They include hypertension, coronary artery disease, atrial fibrillation, diabetes, chronic kidney disease and obesity. The greater burden of comorbidities in HFpEF compared with HFrEF has contributed to the limited understanding of its pathophysiology.<sup>17</sup>

***'We keep looking for one unique answer to HFpEF and I don't think this will ever exist. HFpEF is not one disease only; it varies widely in cause and presentation. This could be the main reason for the more limited understanding of HFpEF.'***

Professor Cândida Fonseca, Portugal

# 2

## The burden of HFpEF on lives and healthcare systems

### HFpEF has a drastic impact on people's lives

As with other types of HF, the symptoms and psychological strain associated with HFpEF can affect a person's lifestyle, relationships, work and routines.<sup>22 23</sup> Learning to manage physical activity and making lifestyle adjustments, for example reducing liquid and sodium intake, may be particularly challenging.<sup>24</sup> People living with HFpEF may struggle with tasks in the workplace and/or at home, and may therefore become more dependent on others to manage everyday life.<sup>2</sup> Challenges are amplified by the fact that HFpEF is not a visible disease, meaning that other people may not see or understand its impact.<sup>23</sup>

*'People don't see that I'm sick. I look like a healthy woman, but I'm not. Only people that live with me see that I'm not able to do what I used to. That's difficult to explain.'*

Ms Lilian van Doesburg, the Netherlands

### HFpEF is highly prevalent

HFpEF currently affects between 1% and 5% of the general population.<sup>25</sup> In Western countries, it accounts for 51–63% of all HF cases.<sup>9</sup> It is linked to older age, more so than HFrEF, as people living with HFpEF are on average six years older than those with HFrEF.<sup>25 26</sup> Between 55% and 73% of people living with HFpEF are women,<sup>8</sup> which may be due to sex-based differences in ageing or cardiac function/structure, but this has yet to be confirmed.<sup>26 27</sup>

## **The societal burden of HFpEF is growing**

The number of people living with HFpEF is rising due to an ageing population and increased survival rates of other cardiovascular and chronic diseases.<sup>25</sup> HFpEF is estimated to become the most common type of HF in the future – its prevalence is increasing 1% more per year than that of HFrEF.<sup>18 28</sup> Some projections have suggested that by 2020 more than 8% of people over the age of 65 would have HFpEF, placing a significant strain on healthcare systems.<sup>7</sup>

## **HFpEF has a high hospitalisation and readmission rate**

HF is the most common cause of unplanned hospital admissions,<sup>12</sup> which are costly for healthcare systems and highly distressing for the person hospitalised and their family/carers.<sup>29</sup> Almost half of all hospitalisations for HF are due to HFpEF, and this proportion increases in older age groups.<sup>3-5</sup> People living with HFpEF have been reported to spend a median of 10 days in hospital, with 22% being readmitted within 12 weeks of discharge, spending a median of 11 more days in hospital.<sup>3</sup> The readmission rate within one year of discharge following hospitalisation for HFpEF is also significant, reported at 30% in Italy and 65% in Romania, where it rises to 73% in people over the age of 65.<sup>4 30</sup> While data from the US suggest that hospitalisations for HFrEF are decreasing and those for HFpEF are on the rise,<sup>25</sup> there are no similar data available in Europe.

# 3

## Diagnosis of HFpEF: facts and challenges

### HFpEF often goes unrecognised, more so than other types of HF

HFpEF is often diagnosed in advanced stages, hindering timely access to treatment and support.<sup>7 8</sup> On one hand, older people may dismiss health issues as a normal part of ageing or may not know where to seek help.<sup>31</sup> On the other hand, people presenting with HFpEF signs and symptoms may initially be misdiagnosed – for example, they may see a respiratory specialist for non-specific symptoms such as breathlessness before they are referred to a cardiologist.<sup>2</sup> In the Netherlands, 15% of older people experiencing breathlessness have undiagnosed HF, and HFpEF accounts for 76% of these cases.<sup>32</sup> In addition, HFpEF symptoms in young people may be dismissed as stress or burnout because the syndrome is often associated with old age.<sup>23</sup>

*'Many older people do not report problems because they believe that the problem is just due to old age and can't be improved with intervention, they think that people won't help them, or possibly they don't know where to go for help.'*

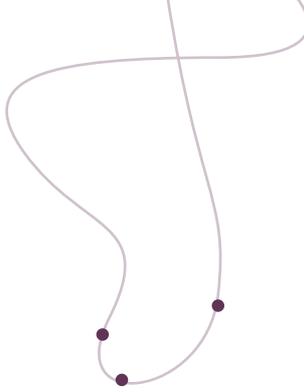
Professor Ian Philp, UK

### There is no single diagnostic test for HFpEF

The scientific gold standard for identifying HFpEF is a test to measure cardiac pressures, but this is time-consuming, costly and invasive, and therefore unsuitable for most patients.<sup>8 33</sup> To diagnose HFpEF, current guidelines recommend conducting a detailed clinical history, physical examination, blood tests for natriuretic peptides (NPs, hormones produced by the heart), electrocardiography (ECG, a test that checks the heart's rhythm and electrical activity) and echocardiography (echo, a scan that provides a detailed overview of the heart).<sup>1</sup> In addition to an LVEF of 50% or higher, people with HFpEF have elevated NP blood levels, structural heart disease (the result of 'wear and tear' or a congenital condition) and/or diastolic dysfunction (problems with how the heart relaxes and fills with blood).

### Clinical factors complicate diagnosis of HFpEF

HFpEF diagnosis is a complex, and often lengthy, process. Some characteristics of HFpEF are difficult to detect;<sup>8</sup> for example, in early stages people may only exhibit symptoms during exercise, having normal test results at rest.<sup>34</sup> Echo images for HFpEF may be difficult to interpret – more so than those for HFrEF.<sup>35</sup> Comorbidities and old age may influence the interpretation of HFpEF signs and symptoms, as well as the results of diagnostic tests like NP levels.<sup>8 33 34</sup> Although the measurement of NP levels is crucial in the diagnosis of all types of HF, some people living with HFpEF may have normal levels.<sup>36</sup>



***'It is important to adjust clinical thresholds for confounding factors to improve diagnosis and decision-making. This is fundamental for truly individualised care. For example, age, gender, body mass index and kidney function should be considered when determining NP thresholds.'***

Professor Damien Gruson, Belgium

### **Limited professional knowledge of HFpEF hinders diagnosis**

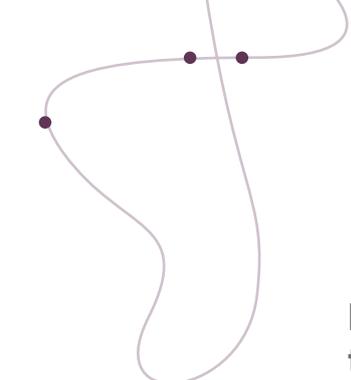
People living with HFpEF often present in primary care when they start experiencing symptoms,<sup>10</sup> but knowledge of this syndrome among healthcare professionals outside of cardiology is limited.<sup>28</sup> Therefore, to ensure accurate diagnosis, it is crucial that primary care professionals have better knowledge of HFpEF, along with access to diagnostic tests and mechanisms of referral to cardiologists. A referral system is also needed in acute care, as emergency room physicians may see people experiencing an exacerbation of HFpEF even before they have a diagnosis of chronic HFpEF.

***'It took about a year, I think, to be diagnosed with HFpEF and cardiomyopathy.'***

Ms Lilian van Doesburg, the Netherlands

### **Challenges to diagnosis of HFpEF also include issues with reimbursement and performance assessment**

Reimbursement of NP testing varies depending on setting and country. In Portugal, for example, it is not reimbursed when requested by a general practitioner (GP).<sup>37</sup> There is also a lack of performance assessment mechanisms rewarding accurate diagnosis of HF. For example, the performance management system of primary care in the UK, which rewards practices for the quality of care they provide, does not include codes specific to HFpEF, which may serve as a disincentive to healthcare professionals to diagnose it or refer to it in records.<sup>35</sup> All these challenges contribute to the poor diagnosis rates of HFpEF.



## Healthcare professionals often struggle to communicate the diagnosis of HF – especially of HFpEF

Healthcare professionals sometimes use indirect terms to describe HF, such as an ‘ageing’ or ‘stiff’ heart, to avoid upsetting or shocking patients with the term ‘heart failure’.<sup>29</sup> Clinicians may feel that busy hospital wards are unsuitable for the communication of an HF diagnosis, and this can result in people not being aware of their condition until they read the discharge summary or even until a later medical appointment. This can be very distressing. Communicating a HFpEF diagnosis has the added challenge of the lack of HFpEF-specific therapeutic options available,<sup>10</sup> and clinicians may be wary of causing despair.

*‘Patients want that diagnostic label – they want to know why they’re having problems.’*

Professor Christi Deaton, UK

## HFpEF biomarkers are needed to improve diagnosis

Despite the importance of NPs in diagnosing HF, their levels are not always reliable in people living with HFpEF.<sup>8</sup> There is a need to find new and more specific biomarkers – ideally biomarkers that can help identify early stages of HFpEF and monitor progression, potentially in community rather than only laboratory settings.<sup>38</sup> The early recognition of HFpEF could improve clinical outcomes and increase the number of people eligible for clinical trials. The identification of biomarkers can also support additional research on therapeutic options and add to efforts to prevent the development of the syndrome.<sup>8</sup>

## 4

## Challenges in care and management of HFpEF

### Unlike in HFrEF, there are no medicines proven to treat HFpEF

HF clinical guidelines currently lack reliable evidence to recommend treatment for heart function in HFpEF, hence treatment focuses on management of symptoms.<sup>1 39</sup> This is mostly the result of the exclusion of people with HFpEF from clinical trials until recently due to the lack of clear HFpEF criteria and the different response in people with HFpEF compared with HFrEF.<sup>9-11</sup> Both factors can be attributed in part to the heterogeneity of the syndrome. Landmark clinical trials in HF have resulted in approved treatment options for HFrEF but not HFpEF. This lack of options has contributed to the low quality of life, low survival rates and frequent hospitalisations still seen in people living with HFpEF.<sup>25 28 40</sup> However, clinical research is ongoing in HFpEF, and there is the hope that this will ultimately help improve outcomes for people with HFpEF.

### Our healthcare systems are not ready to address HFpEF

As with other types of HF, people living with HFpEF face barriers from fragmented and incomplete care, partly due to healthcare systems being poorly designed for the prevention and management of chronic diseases. For example, there are not enough HF specialist nurses to provide care in the community, due to a lack of recognition and accreditation of the role and an overload of work where they are available.<sup>12 29</sup> Lack of communication between healthcare professionals and across care settings may limit access to specialist services and cause the loss of critical information such as referrals, discharge summaries and test results.<sup>29</sup> This can be frustrating for people with HF and their families/carers, and may impact care.

***'There is not enough financial support for prevention of HFpEF across Europe. There is a lot of discussion about prevention but, concretely speaking, there is no financial structure or policy at the European level that supports prevention.'***

Professor Damien Gruson, Belgium



*'Actions in healthcare are focused on immediate results; there is no long-term planning. Chronic diseases like HF require planning. We need decision-makers to look around and see how effective care in HFpEF can improve the whole system, for example by reducing hospitalisations and costs.'*

Professor Cândida Fonseca, Portugal

### **Management of HFpEF places a significant burden on informal carers**

Informal carers for people living with HF (often partners, children or other family members) are an integral part of HF management – they coordinate care, advocate for the person living with HF, attend medical appointments and provide assistance in daily life.<sup>41 42</sup> They are particularly important for people living with HFpEF, who are typically older and have a more significant comorbidity burden. Carers for people living with HF report significant challenges, such as difficulty maintaining their own health and wellbeing, the need to balance caring with their responsibilities at work and at home, a lack of knowledge of HFpEF and limited support from healthcare professionals and friends/family.<sup>42</sup>

## 5

## Best practice in care and management of HFpEF

### Clinical management of HFpEF focuses on alleviating signs and symptoms

Clinical management of HFpEF should include diuretics to manage fluid retention and may also consider physical activity to improve exercise capacity and quality of life.<sup>1</sup> Management of comorbidities is also important – it can help reduce hospitalisations and mortality, as their cause in people living with HFpEF is often non-cardiovascular.<sup>25</sup>

### Long-term care for HFpEF should be multidisciplinary and integrated

As with HF overall, optimal management of HFpEF involves integrated care from a multidisciplinary team with continuity across settings.<sup>12 29 43</sup> It should include community-based care, which may help reduce unplanned hospitalisations by providing accessible and regular support.<sup>13</sup> This may be particularly important in people who are unable to attend hospital appointments.<sup>44</sup> GPs and HF specialist nurses can manage HFpEF from primary care settings, and additional support may be provided in home visits. This continuity of care is essential following hospitalisation.<sup>39 43</sup> Advance care planning and palliative care is crucial, perhaps more so in HFpEF given the greater comorbidity burden and older age of people living with this type of HF.<sup>20</sup>

### Optimal HFpEF care should be person-centred

People living with HFpEF should be involved in decision-making, and care and support should be adapted as much as possible to their unique needs, preferences and circumstances.<sup>12</sup> This is particularly important for people with multiple comorbidities and taking several medicines.<sup>45</sup> Healthcare professionals should actively support those living with HFpEF to understand their condition and engage with routine self-care behaviours.<sup>46</sup> This is crucial in all types of HF as people play a significant role in managing their syndrome in daily life<sup>47</sup> – and those who are engaged with their own care have better outcomes.<sup>24</sup>

Find more information on best practice in HF in *The handbook of multidisciplinary and integrated heart failure care*.<sup>12</sup>



## Innovative technologies may facilitate flexible and multidisciplinary working

Some additional components of care are currently being tested or have been shown to improve outcomes in HFpEF, for example the use of a monitoring device measuring pulmonary arterial pressure.<sup>48</sup> An internet-based conferencing platform to connect GPs with cardiologists has also been tested and improved GPs' knowledge and confidence in HF management.<sup>49</sup> This may be particularly relevant in HFpEF, which usually falls under the responsibility of primary care professionals.

*'Primary care professionals should be able to get specialist support to manage HFpEF.'*

Professor Christi Deaton, UK

## Best-practice models for HF are applicable in HFpEF

There is great potential to improve prognosis and quality of life for people living with HFpEF. This is because optimal management of HFpEF can lead to periods of reduced signs and symptoms, such as normalisation of NP levels.<sup>50</sup> Multidisciplinary and integrated care is the cornerstone of care for all types of HF, and this is particularly crucial for HFpEF given its complexity.

### Case study

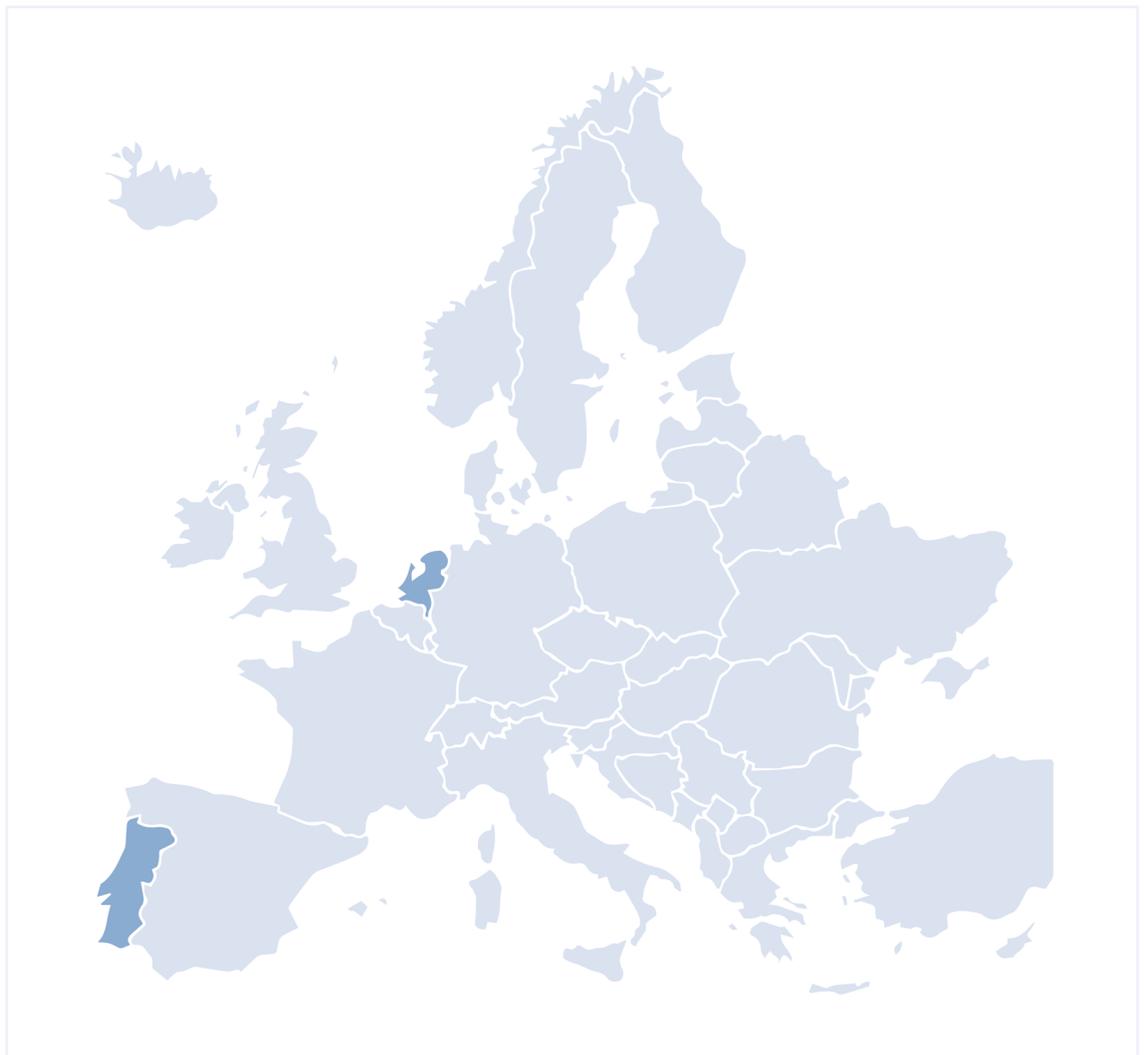
#### Continuity of care and multidisciplinary collaboration across healthcare settings

The São Francisco Xavier Hospital in Portugal has implemented a multidisciplinary HF management programme that welcomes all people living with HF regardless of their LVEF.<sup>50</sup> The programme relies on a multidisciplinary team working across an acute HF unit, an HF outpatient clinic and an advanced HF consultation.<sup>51</sup> Patients are discharged only after complete stabilisation and referred to an appointment at the outpatient clinic in 7–14 days. Discharge summaries are sent to each person's GP. The programme includes an agile referral system between primary care centres and both the acute unit and the outpatient clinic, so that GPs can send people in need of urgent care directly to the acute unit, and those in need of non-urgent HF consultations to the outpatient clinic.<sup>50</sup> The outpatient clinic is led by nurses, and at the centre of care is the provision of education to the patient and carer(s).<sup>51</sup> The clinic helps avoid hospital admission by supporting people in early stages of decompensation.

### Case study

#### Ongoing specialist support for patient empowerment and self-care

The Radboud University Medical Centre in the Netherlands follows a comprehensive multidisciplinary care approach when managing HFpEF. Diagnosis and care are typically overseen by cardiologists, who communicate with each person's GP in writing.<sup>23</sup> An HF nurse is available for two hours every morning to provide ongoing support over the phone and via follow-up consultations. These consultations cover a range of HF topics: basic information about the syndrome and its impact, lifestyle changes, post-operative care, monitoring of signs and symptoms, review of medication plans, and referrals to other specialists as needed.<sup>52</sup> Some people with HFpEF, depending on their needs, are given a 'Free Call Card' to be able to reach the outpatient clinic First Heart Help (Eerste Hart Hulp)<sup>53</sup> even without a referral from the GP.<sup>23</sup> The care model includes a cardiac rehabilitation programme that focuses on lifestyle factors, such as diet and exercise, and the long-term management of HFpEF in everyday life.



## The way forward

### **HFpEF presents challenges in research, diagnosis and care**

There is much to be done to improve HF care and outcomes, but it must be recognised that the journey ahead is harder in HFpEF than HFrEF. Across all types of HF, prevalence and mortality are high, contributing to high costs for the healthcare system.<sup>12</sup> Delayed diagnosis and fragmented care can result in poor outcomes for people with HF. However, while there is a significant lack of awareness of HF among the public and healthcare professionals, in HFpEF there is also a lack of understanding of its pathophysiological processes – which has contributed to the lack of treatment options.

### **Concerted action is required to improve the situation in HFpEF**

We propose actions to improve HFpEF care and reduce its impact on each person, the healthcare system and society in general.

#### **1. Improve public awareness of HFpEF**

It is essential that the public and healthcare professionals are alert for HFpEF signs and symptoms and do not dismiss them as signs of ageing or comorbidities. Awareness campaigns should clarify the impact of HFpEF on each individual person, their family and carers, healthcare systems and society in general. There may be a case for including HFpEF awareness in a comprehensive campaign on health in old age,<sup>31</sup> but it is important not to imply that HFpEF exclusively affects older people.

#### **2. Invest in prevention of HFpEF**

There is a huge missed opportunity to delay and even prevent the onset of HFpEF. To achieve this, it is crucial to diagnose and effectively manage the chronic conditions known to be risk factors.<sup>19</sup> For example, there is a need for strategies to prevent the progression of obesity and type 2 diabetes to HFpEF.<sup>17</sup> There is also a need for greater health literacy, especially among older people, to help them maintain a healthy lifestyle (including weight management, diet and exercise) and support them in seeking professional help when experiencing symptoms.<sup>19</sup>

#### **3. Equip healthcare providers with tools, resources and pathways to diagnose and manage HFpEF**

Healthcare commissioners and policymakers should invest in multidisciplinary and integrated HFpEF care. This should include funding for the development and implementation of tools and pathways that enable optimal diagnosis and management. For example, it is important to invest in community-based HFpEF care and explore the role of virtual platforms and shared information technology systems to connect care settings.

#### **4. Train and accredit healthcare professionals**

Education about HFpEF should commence as early as possible, preferably during formal training for all healthcare professionals, and should continue during professional development – particularly in primary care settings. It is also crucial to recognise the vital role of HF specialist nurses through accreditation.

#### **5. Empower people living with HFpEF and carers**

It is important to educate people living with HFpEF and their informal carers, potentially with the support of expert patients, who are particularly skilled in managing HF in everyday life. Knowledge-sharing should consider adequate HFpEF diagnosis (signs and symptoms), comorbidities, care and communication throughout each person’s HFpEF journey, including palliative care.

#### **6. Support clinical research to improve understanding of HFpEF and identify treatment options**

More clinical trials focused on HFpEF may help develop evidence-based options to treat heart function.<sup>9 17</sup> Research in HFpEF can be increased by improving rates of accurate diagnosis – a greater number of people could then qualify for clinical trials. Trial design could be reconsidered to better take account of the heterogeneity of the syndrome,<sup>54</sup> and studies could use clinical endpoints beyond prevention of morbidity and mortality; for example, quality of life and exercise capacity.<sup>17 55</sup> This could help address the significant challenge of demonstrating therapeutic efficacy and assessing cardiovascular mortality in people living with HFpEF – which is more difficult than in people living with HFrEF. However, payers may not be willing to fund interventions designed to improve those endpoints.<sup>17</sup> There may be a need to involve decision-makers in discussions about research and reimbursement to encourage innovation in HFpEF.

#### **7. Support data collection and knowledge-sharing**

There are limited data on HFpEF – understanding of its epidemiology and hospitalisation rates is insufficient in many European countries. This prevents clear oversight from policymakers, resulting in persistent gaps. It is important to consider that HF impacts not only the person living with the syndrome but also their family and carers. This impact should be measured, from both an economic and a societal point of view, to inform policymakers and support them in developing policies that can address the HFpEF challenge.

### **The time has come to recognise the impact of HFpEF**

We hope this report and the actions proposed may lead to positive changes in policy, diagnosis and care – ultimately improving the lives of the millions of people living with HFpEF across Europe.

# References

1. Ponikowski P, Voors AA, Anker SD, *et al.* 2016. 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. *Eur J Heart Fail* 18(8): 891-975
2. Novartis. 2019. Living with HFpEF - a patient's story. [Updated 30/08/19]. Available from: <https://www.novartis.com/stories/patient-perspectives/living-with-hfpef-patient-story> [Accessed 04/10/19]
3. Lenzen MJ, Scholte op Reimer WJ, Boersma E, *et al.* 2004. Differences between patients with a preserved and a depressed left ventricular function: a report from the EuroHeart Failure Survey. *Eur Heart J* 25(14): 1214-20
4. Mavrea AM, Dragomir T, Bordejevic DA, *et al.* 2015. Causes and predictors of hospital readmissions in patients older than 65 years hospitalized for heart failure with preserved left ventricular ejection fraction in western Romania. *Clin Interv Aging* 10: 979-90
5. Crespo-Leiro MG, Anker SD, Maggioni AP, *et al.* 2016. European Society of Cardiology Heart Failure Long-Term Registry (ESC-HF-LT): 1-year follow-up outcomes and differences across regions. *Eur J Heart Fail* 18(6): 613-25
6. Miró Ò, Gil VÍ, Martín-Sánchez FJ, *et al.* 2018. Short-term outcomes of heart failure patients with reduced and preserved ejection fraction after acute decompensation according to the final destination after emergency department care. *Cin Res Cardiol* 107(8): 698-710
7. van der Velden J, van der Wall EE, Paulus WJ. 2016. Heart failure with preserved ejection fraction: current status and challenges for the future. *Neth Heart J* 24(4): 225-26
8. Loai S, Cheng HM. 2019. Heart failure with preserved ejection fraction: the missing pieces in diagnostic imaging. *Heart Fail Rev*: 10.1007/s10741-019-09836-8
9. Pfeffer MA, Shah AM, Borlaug BA. 2019. Heart Failure with Preserved Ejection Fraction in perspective. *Circ Res* 124(11): 1598-617
10. Deaton C. 2019. Interview with Sara C Marques and Marissa Mes at The Health Policy Partnership [telephone]. 21/10/19
11. Kelly JP, Mentz RJ, Mebazaa A, *et al.* 2015. Patient selection in heart failure with preserved ejection fraction clinical trials. *J Am Coll Cardiol* 65(16): 1668-82
12. The Heart Failure Policy Network. 2018. *The handbook of multidisciplinary and integrated heart failure care*. London: The Heart Failure Policy Network
13. Deaton C. 2019. *Optimising management of patients with heart failure with preserved ejection fraction in primary care: study protocol*. Cambridge, UK: National Institute for Health Research
14. Nadar SK, Tariq O. 2018. What is heart failure with mid-range ejection fraction? A new subgroup of patients with heart failure. *Card Fail Rev* 4(1): 6-8
15. European Society of Cardiology. 2019. PARAGON-HF misses endpoint in preserved heart failure, but benefit noted in some patients. Available from: <https://www.escardio.org/The-ESC/Press-Office/Press-releases/paragon-hf-misses-endpoint-in-preserved-heart-failure-but-benefit-noted-in-some-patients> [Accessed 22/10/19]
16. Pascual-Figal DA, Ferrero-Gregori A, Gomez-Otero I, *et al.* 2017. Mid-range left ventricular ejection fraction: Clinical profile and cause of death in ambulatory patients with chronic heart failure. *Int J Cardiol* 240: 265-70
17. Parikh KS, Sharma K, Fiuzat M, *et al.* 2018. Heart Failure With Preserved Ejection Fraction Expert Panel Report. *Current Controversies and Implications for Clinical Trials* 6(8): 619-32
18. van Heerebeek L, Paulus WJ. 2016. Understanding heart failure with preserved ejection fraction: where are we today? *Neth Heart J* 24(4): 227-36
19. The Heart Failure Policy Network. 2019. *Understanding heart failure guidelines: Comorbidities*. London: HFPN

20. Chamberlain AM, St. Sauver JL, Gerber Y, *et al.* 2015. Multimorbidity in heart failure: a community perspective. *Am J Med* 128(1): 38-45
21. Ergatoudes C, Schaufelberger M, Andersson B, *et al.* 2019. Non-cardiac comorbidities and mortality in patients with heart failure with reduced vs. preserved ejection fraction: a study using the Swedish Heart Failure Registry. *Clin Res Cardiol* 108(9): 1025-33
22. Chauhan C. 2017. Patient letter: living with heart failure with preserved ejection fraction. *JACC Heart Fail* 5(3): 236-37
23. van Doesburg L. 2019. Interview with Sara C Marques and Marissa Mes at The Health Policy Partnership [telephone]. 21/10/19
24. The Heart Failure Policy Network. 2018. *Pressure point 4: Patient empowerment and self-care*. London: HFPN
25. Oktay AA, Rich JD, Shah SJ. 2013. The emerging epidemic of heart failure with preserved ejection fraction. *Curr Heart Fail Rep* 10(4): 401-10
26. Dunlay SM, Roger VL, Redfield MM. 2017. Epidemiology of heart failure with preserved ejection fraction. *Nat Rev Cardiol* 14: 591
27. Scantlebury DC, Borlaug BA. 2011. Why are women more likely than men to develop heart failure with preserved ejection fraction? *Curr Opin Cardiol* 26(6): 562-68
28. Banerjee P. 2016. Heart failure with preserved ejection fraction: A clinical crisis. *Int J Cardiol* 204: 198-9
29. Simmonds R, Glogowska M, McLachlan S, *et al.* 2015. Unplanned admissions and the organisational management of heart failure: a multicentre ethnographic, qualitative study. *BMJ Open* 5(10): e007522
30. Senni M, Gavazzi A, Oliva F, *et al.* 2014. In-hospital and 1-year outcomes of acute heart failure patients according to presentation (de novo vs. worsening) and ejection fraction. Results from IN-HF Outcome Registry. *Int J Cardiol* 173(2): 163-69
31. Philp I. 2019. Interview with Sara C Marques and Marissa Mes at The Health Policy Partnership [telephone]. 23/10/19
32. van Riet EES, Hoes AW, Limburg A, *et al.* 2014. Prevalence of unrecognized heart failure in older persons with shortness of breath on exertion. *Eur J Heart Fail* 16(7): 772-77
33. Deaton C, Edwards D, Malyon A, *et al.* 2018. The tip of the iceberg: finding patients with heart failure with preserved ejection fraction in primary care. An observational study. *BJGP Open* 2(3): bjgpopen18X101606
34. Zakeri R, Cowie MR. 2018. Heart failure with preserved ejection fraction: controversies, challenges and future directions. *Heart* 104(5): 377-84
35. Deaton C, Benson J. 2016. Time for correct diagnosis and categorisation of heart failure in primary care. *Br J Gen Pract* 66(652): 554-55
36. Anjan VY, Loftus TM, Burke MA, *et al.* 2012. Prevalence, clinical phenotype, and outcomes associated with normal B-type natriuretic peptide levels in heart failure with preserved ejection fraction. *Am J Cardiol* 110(6): 870-6
37. Fonseca C, Brito D, Cernadas R, *et al.* 2017. For the improvement of Heart Failure treatment in Portugal - Consensus statement. *Rev Port Cardiol* 36(1): 1-8
38. Gruson D. 2019. Interview with Sara C Marques and Marissa Mes at The Health Policy Partnership [telephone]. 08/11/19
39. National Institute for Health and Care Excellence. 2018. *Chronic heart failure in adults: diagnosis and management*. London: NICE

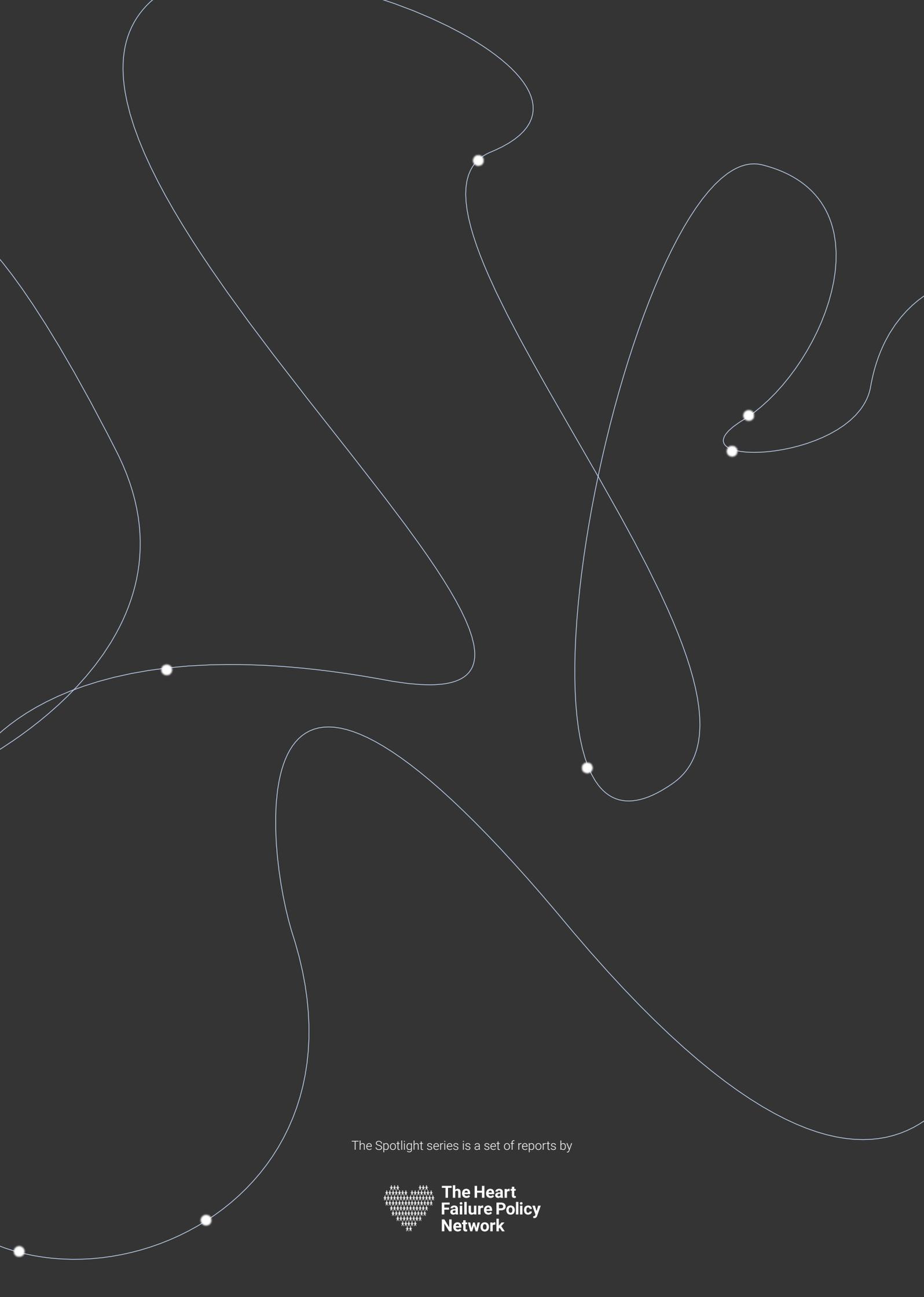
40. Cleland J, Dargie H, Hardman S, *et al.* 2013. *National heart failure audit April 2012 - March 2013*. United Kingdom: NICOR
41. Bell-Davies F, Goyder C, Gale N, *et al.* 2019. The role of informal carers in the diagnostic process of heart failure: a secondary qualitative analysis. *BMC Cardiovasc Disord* 19(1): 92
42. Grant JS, Graven LJ. 2018. Problems experienced by informal caregivers of individuals with heart failure: An integrative review. *Int J Nurs Stud* 80: 41-66
43. McDonagh TA, Blue L, Clark AL, *et al.* 2011. European Society of Cardiology Heart Failure Association standards for delivering heart failure care. *Eur J Heart Fail* 13(3): 235-41
44. Fry M, McLachlan S, Purdy S, *et al.* 2016. The implications of living with heart failure; the impact on everyday life, family support, co-morbidities and access to healthcare: a secondary qualitative analysis. *BMC Fam Pract* 17(1): 139
45. Forman DE, Maurer MS, Boyd C, *et al.* 2018. Multimorbidity in Older Adults With Cardiovascular Disease. *J Am Coll Cardiol* 71(19): 2149
46. Rijken M, Struckmann V, van der Heide I, *et al.* 2017. European Observatory Policy Briefs. In: Richardson E, Van Ginneken E, eds. *How to improve care for people with multimorbidity in Europe?* Copenhagen: European Observatory on Health Systems and Policies
47. The Heart Failure Policy Network. 2019. *Understanding heart failure guidelines: patient empowerment and self-care*. London: HFPN
48. Adamson PB, Abraham WT, Bourge RC, *et al.* 2014. Wireless pulmonary artery pressure monitoring guides management to reduce decompensation in heart failure with preserved ejection fraction. *Circ Heart Fail* 7(6): 935-44
49. Gallagher J, James S, Keane C, *et al.* 2017. Heart Failure Virtual Consultation: bridging the gap of heart failure care in the community - A mixed-methods evaluation. *ESC Heart Fail* 4(3): 252-58
50. Fonseca C. 2019. Interview with Sara C Marques at The Health Policy Partnership [telephone]. 23/10/19
51. Fonseca C. 2018. A Heart Failure Clinic. *Eur Heart J* 39(10): 826-28
52. Radboud UMC. Polikliniek hartfalen. Available from: <https://www.radboudumc.nl/patientenzorg/poliklinieken/hartfalen> [Accessed 27/10/19]
53. Máxima MC. Eerste Hart Hulp / Hartbewaking [First Heart Help/Heart Monitoring]. Available from: <https://www.mmc.nl/spoed/eerste-hart-hulp-hartbewaking/> [Accessed 05/12/19]
54. Cohen-Solal A, Logeart D. 2020. Is the glass half full or half empty after PARAGON-HF? *Cardiovasc Res* 116(1): e5-e7
55. Lewis GA, Miller CA. 2017. Outcome measures in HFpEF trials: should we refocus? *J Am Coll Cardiol* 69(10): 1358-59

## **About the Heart Failure Policy Network**

The Heart Failure Policy Network is an independent, multidisciplinary group of healthcare professionals, patient advocacy groups, policymakers and other stakeholders from across Europe whose goal is to raise awareness of unmet needs surrounding heart failure and its care. All Network members 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.







The Spotlight series is a set of reports by



**The Heart  
Failure Policy  
Network**