

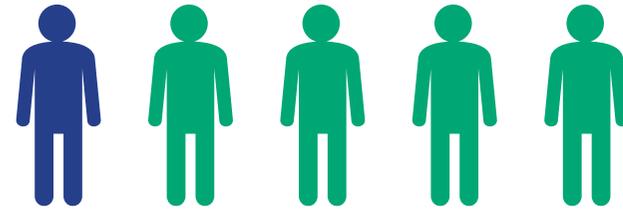
# Heart Failure Country Barometer: Ireland



This report was written by the Health Policy Partnership with content also provided by: Professor Ken McDonald (Consultant Cardiologist, St Vincent's University Hospital & HSE National Clinical Lead in Heart Failure), Dr Pat Nash (Consultant Cardiologist, Galway University Hospital), Dr Yvonne Smyth (Consultant Cardiologist, Galway University Hospital), Liz Killeen (Community Heart Failure Clinical Nurse Specialist, Galway), Fidelma Hanley (Heart Failure Clinical Nurse Specialist, Sligo General Hospital), Attracta Madden (Heart Failure Clinical Nurse Specialist, Sligo General Hospital), Dr Joe Gallagher (General Practitioner), Dr Austin Byrne (General Practitioner), Orlagh Harrington (Croí Heart Failure Project Manager), Michael Delappe and Claire OConnell. This publication has been supported by Novartis Pharma AG.

# Why is action on HF needed now?

Heart failure (HF) is a common condition that imposes a huge burden on society:



**1 in 5 people**

can expect to develop HF in their lifetime.<sup>1</sup>



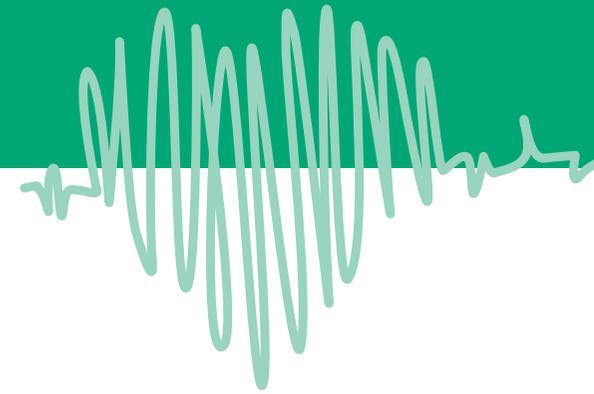
Some **90,000** people live with HF in Ireland,<sup>2</sup> and **10,000** people are newly diagnosed with HF each year.<sup>3</sup>

Economic and social participation can be severely restricted for most people living with HF.

**“The impact of HF on the individual and society has been underestimated for far too long”**

Dr Pat Nash, Consultant  
Cardiologist, Galway  
University Hospital



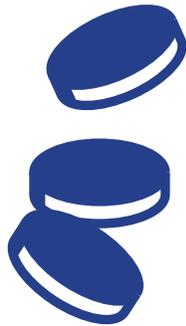


**HF is a leading cause of hospitalisation, and has high admission and re-admission rates in Ireland.**

HF related admissions account for approximately 4% of all inpatient admissions, about 7% of all inpatient bed days and approximately 5% of all emergency and acute admissions.<sup>4</sup>

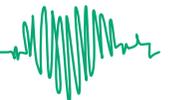
**HF costs Ireland approximately**

**€660m**

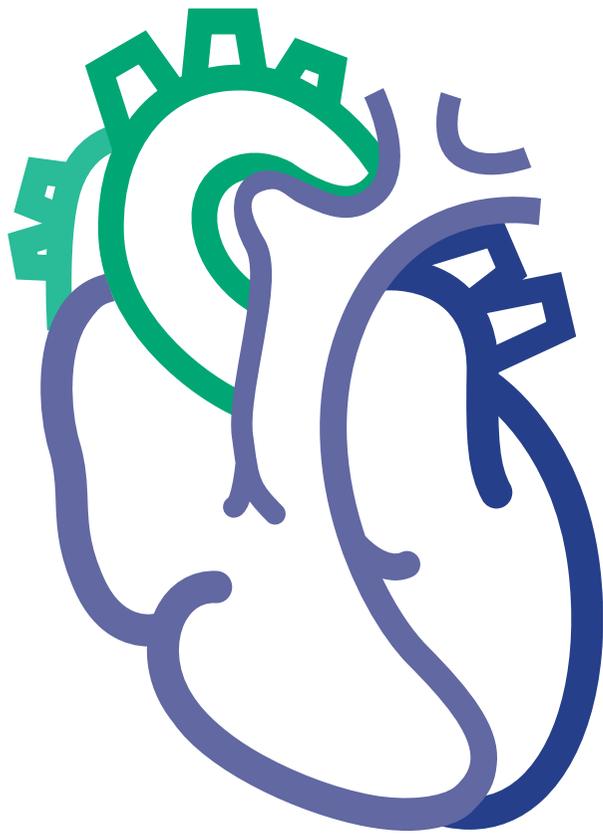


per year – of which €158m is a direct healthcare cost to the State, equivalent to 1.2% of the total healthcare budget.<sup>4</sup>

**The burden of HF is likely to increase.** Prevalence is rising, in part due to the ageing of the population, improved survival rates from myocardial infarction and more effective treatments for heart diseases.<sup>5</sup>



Yet much can be done to improve the prevention, treatment and management of HF:



**Awareness of HF is low in Ireland:**

Only **7%** of the Irish population can correctly identify three symptoms of HF and one in four patients with HF symptoms would wait a week or more before seeking medical advice.<sup>6</sup>

**Many cases of HF are preventable** through positive lifestyle changes, greater public awareness and early identification of patients who are at risk of developing the condition.<sup>7,8</sup>



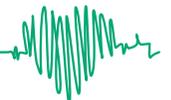


**Person-centred approaches to care** can improve quality of life and reduce hospital admissions for patients with HF.<sup>3</sup>

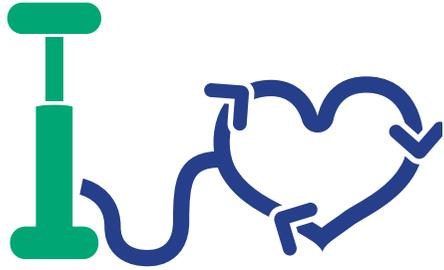
**Access to high quality information and support** can positively influence self-care.<sup>9</sup>



**Ensuring HF is an explicit national priority** – from national policies and plans, to implementation in local practice – helps drive improvements in care and creates much needed visibility for HF.



# What is HF?

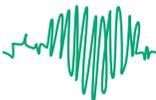


HF is a serious chronic condition where the pumping efficiency of the heart is impaired and it is unable to pump enough blood to support the needs of other organs in the body.<sup>8</sup>



Symptoms of HF include: shortness of breath, swollen ankles or legs, fatigue and sudden weight gain.<sup>5,9</sup>

According to international data, the majority of patients with HF are over the age of 65.<sup>10</sup>





HF, if ineffectively treated, has a worse prognosis than many common forms of cancer<sup>12</sup> and can lead to very poor quality of life for patients.<sup>9</sup>

A light green map of Ireland is shown on the right side of the slide. Above the map, a white ECG (heart rate) line is drawn across the top of the page. The text is overlaid on the map.

The most common cause of HF in Ireland is coronary heart disease.<sup>11</sup>

# What is needed in Ireland?



**Explicitly mention HF within existing cardiovascular disease policies and ensure there are sufficient resources to implement the National Clinical Programme for HF (HSE) (adequately funding both general practice and hospital care):**

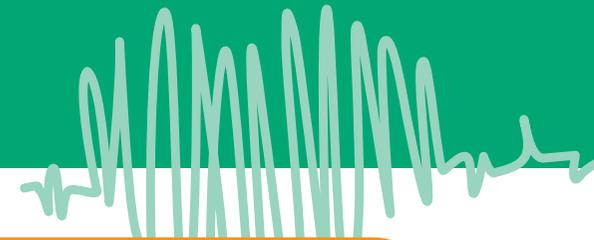
- HF needs much greater recognition within Ireland's National Cardiovascular Health Policy.
- Dedicate more resourcing to the implementation of national plans and strategies.
- Demand reliable epidemiological data on HF for the whole country, and develop a national audit on HF.



**Ensure that patients with symptoms of HF are diagnosed without delay:**

- Improved strategies for detecting HF earlier in its development can delay its progression. Diagnosis of HF is often late or suboptimal due to inadequate availability of diagnostic tools, particularly at general practice level.
- Develop a national rapid access community diagnostic service, for new onset HF – making better use of diagnostics, such as natriuretic peptide testing and echocardiography. Enable greater access to specialist opinion for GPs and other healthcare professionals.
- Provide high quality information and support on the particular issue of symptom recognition (i.e. to the public) and diagnosis (i.e. to medical professionals).





### **Create a co-ordinated national programme between the hospital and community to provide greater continuity of care and encourage patient self-management:**

- Better models of shared care, and clinical programmes and guidelines that set out roles and responsibilities of GPs, outpatient departments, emergency rooms (ERs) and specialist services, can help provide greater continuity of care.
- We need the best available care to be consistently provided to all patients with HF through the efficient use of resources.
- Specialist HF units offering multidisciplinary care should be the standard of care for HF patients.



### **Support a national HF prevention programme by raising public awareness of the risk of developing HF, and ensuring access to high quality information and support:**

- Invest in public campaigns to raise awareness of HF and its risk factors (e.g. high blood pressure, high cholesterol, diabetes or a prior heart attack) to enable better prevention and lifestyle changes to prevent the progression to HF.
- People with risk factors for developing HF should be screened and optimally managed as this can reduce the overall cost of care that occurs once patients develop HF.



# The economic cost of HF in Ireland

## HF poses a huge human and economic cost

Some 90,000 people live with HF in Ireland,<sup>2</sup> and at least 160,000 people live with asymptomatic HF.<sup>3</sup> Economic and social participation is severely restricted for most people living with HF.

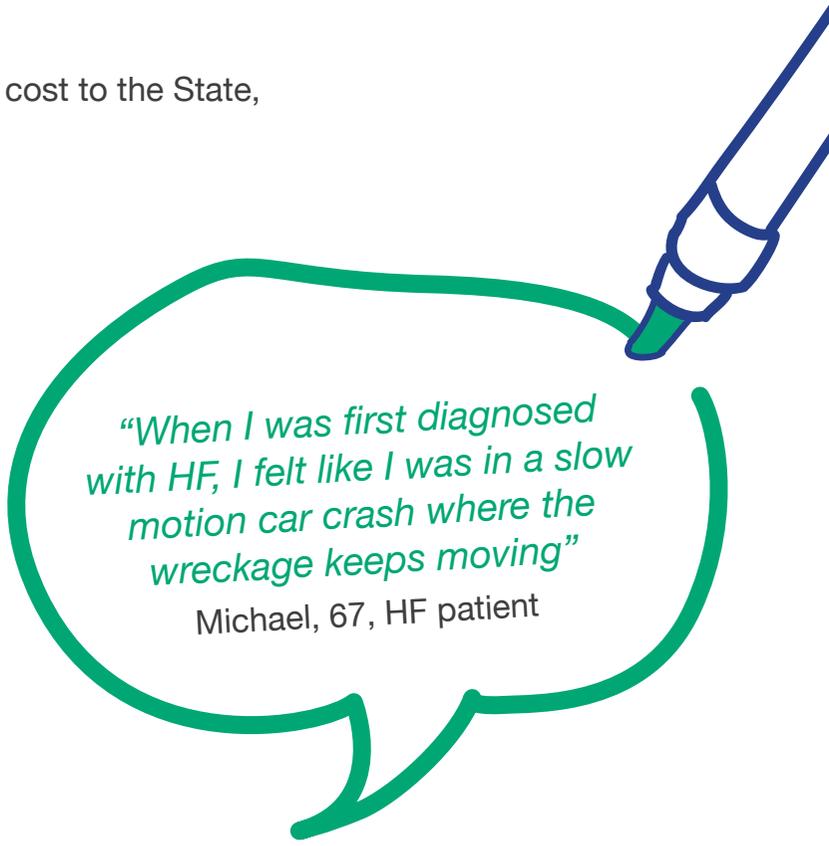
HF costs Ireland approximately €660m per year – of which €158m is a direct healthcare cost to the State, equivalent to 1.2% of the total healthcare budget.<sup>4</sup>

HF is a large driver of hospitalisations and an economic burden. HF related admissions account for about 4% of all inpatient admissions, 7% of all inpatient bed days and 5% of all emergency and acute admissions (2012 HSE figures).<sup>4</sup>

Informal care, which includes assistance in day-to-day living provided by professional carers or family members, is estimated to cost €364.2m and represents the largest component of the cost of HF.<sup>4</sup>

*“Especially as a young person, HF can be a very alienating condition. Most of my friends had no experience with it, so they did not understand my disease. They found it difficult to understand that as a HF patient you really have to plan ahead and might have to cancel plans at the last minute when you don’t feel well. Not only was I unable to do anything physically demanding, but I found it very difficult to concentrate. Fatigue in combination with the inability to concentrate meant that even watching a film or reading was impossible to do. I felt like I was existing rather than living.”*

Claire, 35, HF patient



*“When I was first diagnosed with HF, I felt like I was in a slow motion car crash where the wreckage keeps moving”*

Michael, 67, HF patient



## The burden of HF will grow in years to come

The human and economic cost of HF in Ireland over the coming decades is very likely to expand, as the population ages and the conditions that lead to HF increase.<sup>5</sup> The number of people over the age of 65 in Ireland is expected to increase by 150% over the next 30 years.<sup>13</sup>

By 2020, the Institute of Public Health (IPH) have predicted a 40% increase in people living with high blood pressure and a 50% increase in coronary heart disease – both of which are major drivers of the incidence of HF.<sup>14</sup>



*“Chronic illness threatens to overrun our healthcare systems. HF, as the most complex of these illnesses, can be used as a test case to establish effective methods of value, not only to HF, but also to chronic disease in general”*

Prof. Ken McDonald, Consultant Cardiologist,  
St. Vincent’s University Hospital



***“For too long HF has been the forgotten condition in health policy, despite its human and economic impact. We need to make HF a truly national priority, which we can do by establishing a national strategy, increasing public and clinical awareness of the condition, and investing in reliable data to support policy decisions.”<sup>15</sup>***

Seán Kyne TD, Minister of State for Gaeltacht Affairs and Natural Resources





Explicitly mention HF within existing chronic disease policies and ensure there are sufficient resources to implement the National Clinical Programme for HF (HSE) (adequately funding both general practice and hospital care)

### HF as a national priority: WHAT CAN BE DONE?



**Raise HF on the policy agenda:** grant HF the recognition it deserves in the national cardiovascular disease strategy and other relevant policy frameworks.



**Make the economic case for sufficient resourcing of services now,** and allocate more appropriate funding relative to the burden of ill health and potential return on investment.



**Demand reliable epidemiological data on HF for the whole country, and develop a national audit on HF** (as was done on stroke by the Irish Heart Foundation<sup>16</sup>) to enable evidence-based care planning for the healthcare system.

## HF needs much greater recognition within Ireland's national cardiovascular disease strategy

Ireland has many successes in cardiovascular health – it has had a major cardiovascular disease strategy since 1999, and it was the first country in the world to ban smoking in the work place in 2005.<sup>3</sup> Ireland has actually seen an overall decline in mortality from CVD over the past few years.<sup>3</sup>

However, ongoing focus and commitment will be required to tackle the significant issue that is HF.

With an ageing population and rising number of people living with chronic disease, a reversal of this trend is needed and policy makers need to keep pace.<sup>3</sup>



### WHY IS THIS IMPORTANT?

Reductions in HF mortality cannot be maintained without a clear national plan across the whole healthcare system and population.<sup>3</sup>



### WHY IS THIS IMPORTANT?

Investment and planning for HF care services is essential to manage the expected rise of people with HF, and could help prevent a crisis in the future.<sup>18</sup>

## Implementation and resourcing of national plans and strategies for HF is inadequate

The National Clinical Programme for HF set out to improve healthcare and quality of life for patients.<sup>17</sup> However, implementation in practice is still far behind the policy aspiration, in part because of insufficient resources.

Relative to other countries, Ireland spends much less on cardiovascular health.

Only 6% of the Irish healthcare budget is spend on cardiovascular health – lower than the EU average of 10%.<sup>3</sup>



## The true burden of HF in Ireland is still not fully understood

A lack of epidemiological data is undermining efforts to drive change. For example, HF is recorded as a *mode* rather a *cause* of death on death certificates in Ireland.<sup>19</sup> As a result, the recorded number of deaths attributed to HF may be underestimated. There have been few studies and reviews of morbidity from cardiovascular disease conducted in Ireland and datasets are generally not publicly available.<sup>20,21</sup>

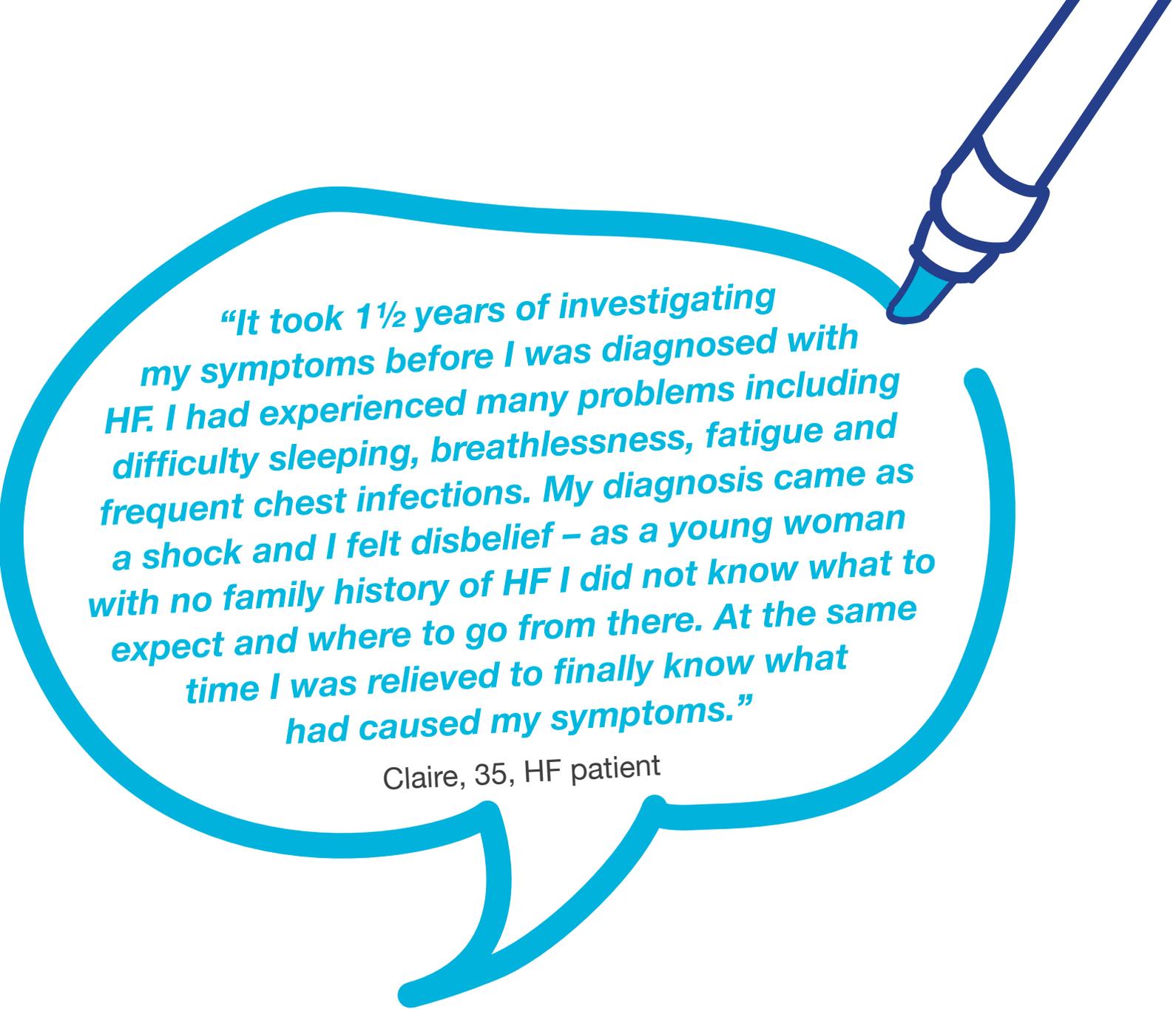
More specifically, there is no national HF registry in Ireland, meaning that information on mortality and outcomes from HF is not available on a national level. Data that is available from Ireland's Hospital In-Patient Enquiry (HIPE) has been described as being of poor quality and is likely to underestimate the burden of HF.<sup>18</sup> Additionally, it does not capture data from the community setting.



### WHY IS THIS IMPORTANT?

Access to reliable, comprehensive data about the incidence of disease leads to a better understanding of HF, the causes of re-admissions, the outcomes of interventions and the causes of mortality.<sup>22</sup>





***“It took 1½ years of investigating my symptoms before I was diagnosed with HF. I had experienced many problems including difficulty sleeping, breathlessness, fatigue and frequent chest infections. My diagnosis came as a shock and I felt disbelief – as a young woman with no family history of HF I did not know what to expect and where to go from there. At the same time I was relieved to finally know what had caused my symptoms.”***

Claire, 35, HF patient





# Ensure that patients with symptoms of HF are diagnosed without delay



## Diagnosis of HF: WHAT CAN BE DONE?



**Develop a national rapid access community diagnostic service**, for new onset HF – making better use of diagnostics, such as natriuretic peptide testing and echocardiography. Enable greater access to specialist opinion for GPs and other healthcare professionals.



**Develop quality information and support on the particular issue of symptom recognition** (i.e. public) and diagnosis (i.e. medical professionals) to improve the awareness and understanding of HF and avoid delays in diagnosis and treatment.



**Greater professional training and education of GPs** is needed to encourage better awareness of symptoms and adherence to guidelines, timely referral and outreach to specialists, and better support and information to patients with new onset HF.

## Develop a national rapid access community diagnostic service, for new onset HF

Healthcare professionals need to dramatically improve their response to symptoms of HF and the application of best practice guidelines for diagnosis.

The diagnosis of HF is often late, or suboptimal due to inadequate availability of diagnostic tools. Improved strategies to detect cardiomyopathy (heart muscle damage) earlier could delay the progression of the disease.

HF is notoriously difficult to diagnose, and many patients with suspected HF face long and sometimes unnecessary diagnostic uncertainty, complicated further by co-morbidity, creating anxiety and delays in treatments.<sup>23,24</sup>

Clinicians need to be given adequate resources to allow application of best practice as advocated by international guidelines. For example, the most recent ESC guidelines recommend a number of tests to investigate and diagnose HF, including a thorough clinical examination, ECG, natriuretic peptide testing and an echocardiogram.<sup>23</sup> However, it has been shown that some of these tests are carried out less frequently than is recommended by the ESC across Europe and that proper diagnosis is still neglected.<sup>25</sup>

The HSE has called for rapid diagnostic services to be available in the community.<sup>18</sup> Engaging patients through community HF services (i.e. GP and Practice Nurse care) and specialist nurses has been shown to improve uptake in treatments as well as diagnosis at a much earlier stage.<sup>22</sup> It is important to note that GP and Practice Nurse care are the cornerstone of community care. This is because specialist nurses, whilst known to offer high quality care and support, only have capacity to see a limited number of patients every day.



### WHY IS THIS IMPORTANT?

Survival rates from HF can be improved through earlier and more appropriate diagnosis, management and treatment by GPs.<sup>8</sup>

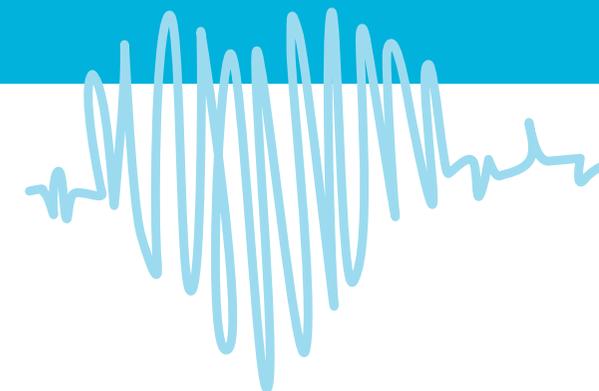


## Develop quality information and support on the particular issue of symptom recognition (i.e. public) and diagnosis (i.e. medical professionals)

Low awareness of HF is also a major factor behind poor diagnosis and coordination of care, for both professionals and members of the public. From new medical trainees to experienced clinicians, we need to increase training and improve skills in the management of HF. For example, it is generally accepted that HF patients are frequently admitted to general medicine wards and not cardiology wards, which is not the case for other cardiovascular diseases (CVDs) such as myocardial infarction. In addition, the majority of trainees opt for subspecialty training in interventional subspecialties in cardiology and not HF management.

Poor understanding of HF is also a wider societal problem. Many cases of HF could be avoided through adoption of healthier lifestyles and behaviours, yet public awareness of HF and its causes are generally poor. In a European-wide survey sponsored by Novartis which looked at awareness and knowledge of HF among 1000 adults in Ireland, aged 50 years old and above, 75% could not correctly describe HF or identify the true definition for HF.<sup>6</sup> The survey found that there was also lack of awareness of the common causes of HF. Some 84% of those surveyed were unable to identify three common causes (e.g. high blood pressure or other underlying conditions such as coronary heart disease, diabetes or kidney disease) – despite the fact that 64% of respondents knew someone who suffered from HF.<sup>6</sup>

Individuals themselves are often required to recognise their symptoms and seek care when medical attention is vital. For example, delaying hospital treatment by as little as 4–6 hours after the symptoms of acute HF first appear can increase the chances of death.<sup>8</sup>



### WHY IS THIS IMPORTANT?

A large number of premature deaths occur as a result of lack of knowledge of HF and its symptoms. Better recognition would prompt people to seek treatment at an earlier stage, leading to more accurate diagnosis, decreased risk of hospitalisations and premature mortality.<sup>5</sup>



*“HF in the community needs to be managed by GPs and Practice Nurses, with access to specialist care when appropriate. Developing structured HF care as part of the GP contract will ensure that patients are cared for by their own GP and will ultimately result in less people needing to be hospitalised which is good for patients and the healthcare system.”*

Dr Joe Gallagher, GP





# Create a co-ordinated national programme between the hospital and community to provide greater continuity of care and encourage patient self-management

## Co-ordinated, community-based care for HF: WHAT CAN BE DONE?



**Develop models of shared care, and clinical protocols and guidelines** which set out the roles and responsibilities across GPs, outpatient departments, emergency rooms, and specialist services (e.g. hospital-based cardiology wards or HF clinics), to provide greater continuity of care for patients after discharge from hospital.<sup>3,18</sup>



**Invest in specialist HF units offering multidisciplinary care** – these should be the standard of care for HF patients.<sup>23</sup>



**The provision of HF specialist nurses in community settings** should be explored to help improve the quality of life for patients once they are back in the community.<sup>3</sup> This role should be developed in the community in conjunction with GPs and Practice Nurses.

## There are no formal models of shared care, which set out the roles and responsibilities of GPs and specialist (hospital) services for HF patients in Ireland<sup>18</sup>

As the HSE Chronic Disease Management Programme aims to shift the management of chronic diseases from hospitals to the community, transitions between hospital care and general practice will be an increasingly vital link for quality care and good health outcomes in HF.

When patients leave hospital they are in the so-called “vulnerable phase”, at risk of being re-admitted. Patients need to be supported by their GP and not just rely on follow-up care from specialist HF units, once they have been discharged back into the community.<sup>3,22</sup> Patients also need to be monitored in the community for events or conditions that may increase their risk of re-admission to hospital, such as clinical depression or non-adherence to lifestyle guidelines for HF.<sup>3,9</sup> In addition, patients’ self-care is vital to the reduction of re-admissions. The link between the patient, the GP and the hospital specialist is the critical building block not only for HF care but chronic disease care in general.<sup>26</sup> Improved funding and management of chronic diseases in the community should encourage a focus on simple and early interventions, patient empowerment and on preventing acute episodes from occurring, which may help to reduce hospitalisations.

Yet, huge progress is needed if GPs in Ireland are to respond effectively and consistently to this challenge. In a report which looked at the experiences of Irish patients with HF in 2009, some participants reported that they lacked continuity of care with their GPs in the community.<sup>27</sup> GPs need to be resourced adequately so they can follow-up patients when they leave hospital.



### WHY IS THIS IMPORTANT?

GPs managing and caring for patients in the community can reduce hospitalisations and mortality, and this is a vastly more sustainable model of care than costly hospitalisations.<sup>3,22,27-29</sup>



## Structured programmes for people with HF in general practice are needed

A shared care approach is required to provide care through the different phases of illness in HF. Central to the provision of care is an integrated approach between the GP and the hospital with structured care programmes in general practice. This approach has also been recommended by the HSE National Clinical Programme for HF.<sup>17</sup>

In 2015, the Asthma and Diabetes Cycle of Care was introduced in general practice, a first step in expanding the scope of GPs into chronic disease management. These allowed for some new chronic disease specific services to be provided by GPs to patients with Type 2 diabetes and asthma. This is a positive first step towards the development of functional integrated programmes of care to provide GP led chronic disease management in the community.

Despite the success of the model for diabetes and asthma, there is no structured care programme for HF in general practice.



### WHY IS THIS IMPORTANT?

Structured care programmes for HF have been shown to reduce hospitalisations and improve quality of life for people with HF.<sup>30</sup> General practice models for cycle of care for heart disease could reduce hospital admissions by 7%, resulting in €30 million in hospital savings.<sup>31</sup>



## Technology (e.g. remote monitoring) should be considered for the long term management of HF in certain populations

Although international evidence is mixed, applying remote monitoring to those at highest risk is an aspect of care that deserves attention.<sup>32-36</sup> Some studies have shown that telemonitoring, especially the remote monitoring of vital signs, can reduce hospitalisations for chronic HF by 21% and all-cause mortality by 20% on average.<sup>36</sup> Telemonitoring has also been shown to save healthcare costs in the long run<sup>32,37</sup> and can improve patients self-management in treatment.<sup>32,34,38</sup>

Telemonitoring is at a relatively early stage in Ireland, but there are some encouraging examples of innovative ways to use other types of technology in HF care. A key opportunity for development is that of virtual consultations. For example, the Heartbeat Trust and Cardiomark are providing virtual consultation services in Dublin for healthcare professionals who have concerns about patients with suspected HF. The initiative suggests that waiting times for consultations for HF patients could be reduced by up to 50%.<sup>39</sup>



## Specialist HF units offering multidisciplinary support need to become the standard of care for HF patients<sup>23</sup>

Despite some successful models of care, in-hospital care for HF has a long way to go. In-hospital mortality for HF decreased from 16.7% in 1998 to 11.8% in 2008 but it still remains very high in Ireland compared to equivalent countries.<sup>3</sup> In a study of HF patients in outpatient clinics in Ireland in 2009, 25% died within a year, a much higher mortality rate than expected.<sup>27</sup>

Ireland has 11 national HF units where patients are supported by a multidisciplinary team consisting of hospital HF specialists that are linked to GP led care in the community. The hospital based multidisciplinary team is a cardiologist led team of specialist nurses, doctors, physiotherapists and dieticians. These units offer a variety of programmes, including exercise and information sessions.<sup>27,40</sup> Outcomes from these programmes have been very positive, with patients feeling confident enough to exercise and engage more in everyday activities.<sup>27</sup>

However, not all HF patients have access to these programmes, as there are a limited number of places and facilities.<sup>19</sup> For example, six of the HF units operate in Dublin and only five in the rest of Ireland. In Cork only limited specialised services are currently available. While a specialised unit in Cork was planned in the HSE National Service Plan in 2011, it was never established due to funding constraints.<sup>41</sup> This uneven distribution of HF units has caused regional variation in survival and re-hospitalisation trends for HF in Ireland.<sup>4</sup> This issue has even been raised in the Dail and the Minister of Health has announced a national needs assessment for HF cardiac rehabilitation services in 2016 to tackle the issue of regional disparities.<sup>42</sup>



### WHY IS THIS IMPORTANT?

Specialist HF care has been shown to reduce rates of hospital re-admission, improve patients' quality of life and reduce mortality.<sup>22,24</sup> Yet such teams are not consistently available across the country.

## Specialist HF nurses can support the provision of care to patients in hospital and after discharge

HF specialist nurses have a very important role to play, working under the stewardship of medical specialists in the hospital (e.g. cardiologists) or GPs in the community, supporting long term management and patient self-care for HF, which may help to improve quality of life.<sup>5,22,43</sup>

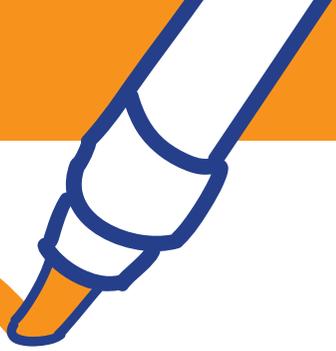
Without the support typically offered by this role, discharge from specialist hospital care may feel sudden and threatening for people with HF. For example, patients enrolled onto structured, time-limited HF programmes reported feeling “cut adrift” after the sessions ended, and that they would benefit from greater contact and assistance once they were back at home, to continue treatment and feel supported.<sup>27</sup>



### WHY IS THIS IMPORTANT?

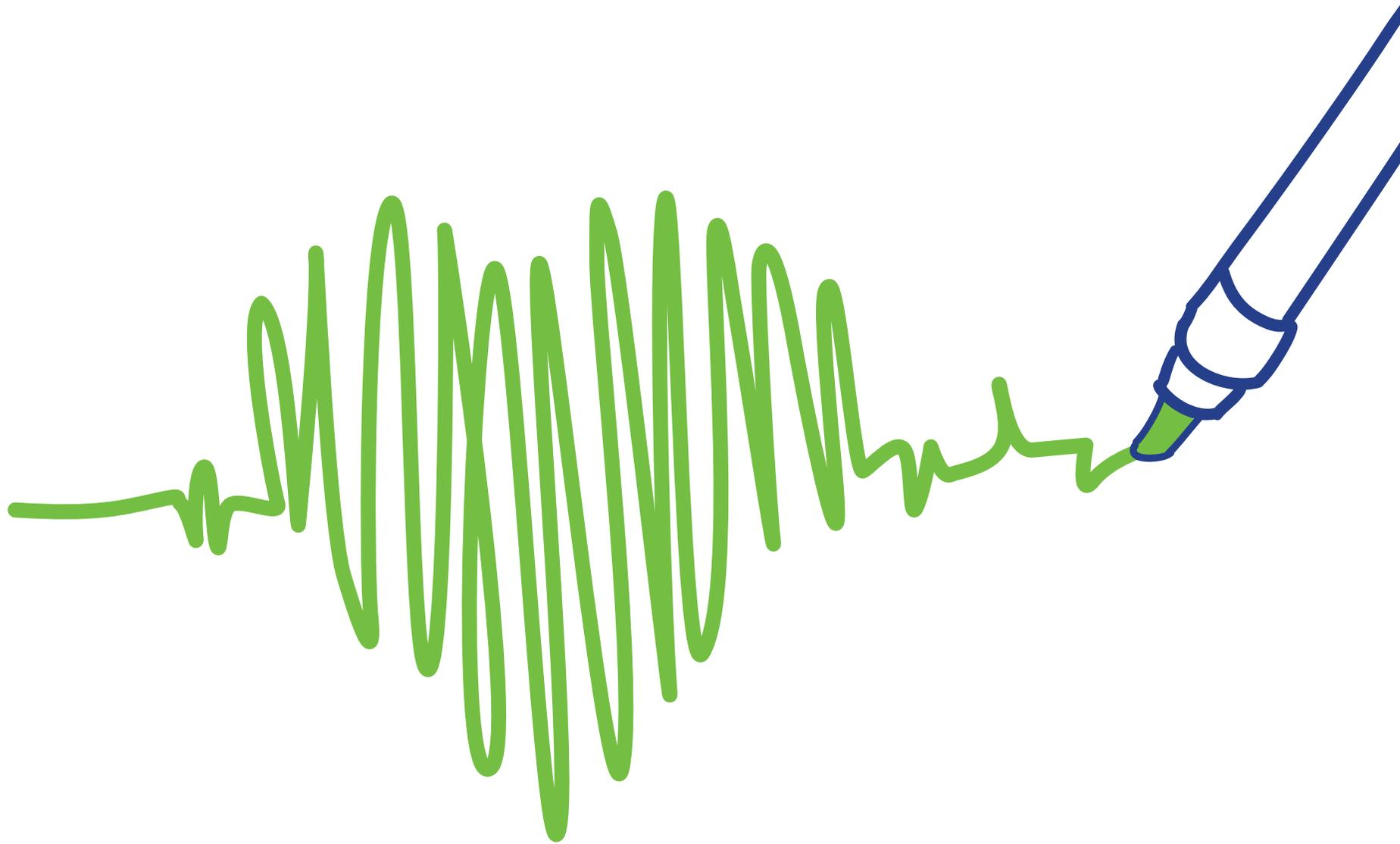
Programmes that include specialist nurses can help reduce hospital re-admissions, as well as improve patient knowledge of HF.<sup>43</sup>





*“I found it very hard to come to terms with my HF diagnosis, but then I went to an HF clinic and was put in touch with my HF nurse specialist Mary, who plays a huge part in my wellbeing. Her main concern was my psychological health - she took the time to explain my condition in detail and taught me a lot about acceptance. Now I get on much better and learn to appreciate life more. She gave me her mobile number, to ensure that I can call her anytime. Although I hope I don't have to use it, just knowing that I have it makes me feel very comforted and well cared for. While my doctors might change, she knows everything about my condition, medical history and medication. I see her about every 3 months for a cardiac check up and if I have a problem she puts me in touch with a cardiologist. Losing access to my HF nurse would be like losing a good friend.”*

Michael, 67, HF patient





Support a national HF prevention programme by raising public awareness of the risk of developing HF, as well as ensuring access to high quality information and support for both the public and the medical profession

### HF awareness and prevention: WHAT CAN BE DONE?



**Invest in public campaigns** to raise awareness of HF and its risk factors.

**GP-led screening and optimal management of people living with the risk of developing HF will help to diagnose HF early**, slow the progression of the condition, improve health outcomes and reduce the overall cost of care that occurs if patients develop HF.

## Public awareness of the risks of HF is low in Ireland

HF is increasing in Ireland due to an ageing population, better survival following acute coronary events and a high prevalence of cardiovascular risk factors.<sup>5</sup> It is estimated that 160,000 people in Ireland live with asymptomatic HF.<sup>3</sup> In addition, cardiovascular risk factors that raise the risk of developing HF are of particular concern in Ireland. For example, according to the SLÁN study, there have been no significant improvements in the reduction of smoking since 2002, the prevalence of overweight and obesity is increasing, more than 1/5 of adults are physically inactive and alcohol consumption is high.<sup>3</sup>

Yet awareness of risk factors for developing HF is low in Ireland.<sup>6,44</sup> A European survey showed that only 16% of Irish respondents knew the common causes of HF and only 39% were aware of the risk of developing HF.<sup>6</sup> In addition, a survey by the Irish Heart Foundation found that only 5% of respondents knew that treatment of high blood pressure could lower the risk of HF.<sup>44</sup>

Despite this, there is a lack of public awareness campaigns on HF in Ireland. While there have been some activities around HF Awareness Day in Ireland,<sup>45</sup> there is no on-going, large scale public awareness campaign.<sup>44</sup>

The Department of Health and Children has recognised the need for public awareness campaigns on cardiovascular diseases and has made it one of the priorities in the National Cardiovascular Health Policy.<sup>3</sup>



### WHY IS THIS IMPORTANT?

Low awareness for HF and its symptoms and causes leads to high levels of avoidable deaths in Ireland.<sup>44</sup>



## High risk populations should benefit from preventive HF programmes

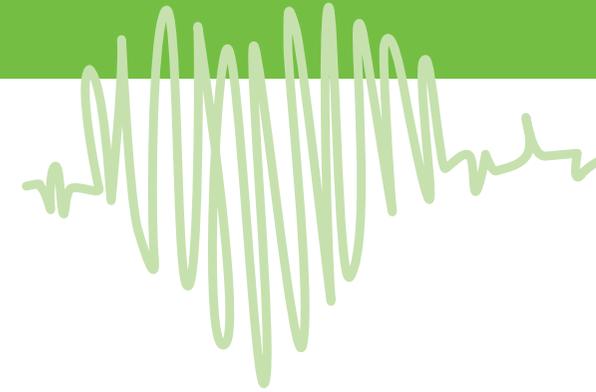
HF prevention programmes can help reduce the onset of HF and hospital admissions for other cardiovascular episodes. For example, The Heartbeat Trust's prevention initiative STOP-HF (Screening TO Prevent Heart Failure) uses community-based diagnostics in the form of a simple blood test (natriurectic peptide test) to identify those most at risk of HF.<sup>46,47</sup> This blood test could be used to rule out HF and other cardiovascular diseases in patients over 40 with a cardiovascular risk factor.

The need for prevention measures aligns with the National Cardiovascular Health Policy that identifies cardiovascular risk reduction and heart disease prevention as priorities.<sup>3</sup>



### WHY IS THIS IMPORTANT?

The STOP-HF study showed a reduction in new onset of heart failure by 45% and a reduction in hospital admissions for other major cardiovascular episodes such as heart attack or stroke by 40%.<sup>46,47</sup>



## Case Studies

### St Vincent's HF Clinic

The HF Unit within the St Vincent's Healthcare Group, incorporating St Vincent's and St Michael's Hospitals, provides continuous 7 day inpatient and outpatient care for patients with or at risk of developing HF, looking after approximately 5,000 patients. The outpatient service, functioning as a continuous ambulatory care unit, provides a template for the management of not only HF but also other chronic illnesses.

### The STOP HF Study

The Heartbeat Trust's landmark STOP-HF (Screening TO Prevent Heart Failure) study<sup>45,46</sup> used a simple blood test for natriuretic peptides to help identify those most at risk of HF. Natriuretic peptide is a protein released by the heart when it is under stress or strain. The study showed that in people aged over 40 with a cardiovascular risk factor, such as high blood pressure or diabetes, this simple blood test can predict not just HF but other cardiovascular diseases.

The research involved 1,350 participants from 39 GP practices in Ireland. Focused care was directed to at risk individuals. Participants with an elevated level of natriuretic peptide were given a heart ultrasound, lifestyle advice and reviewed by both their GP and cardiologist.

As well as reducing hospital admissions for HF patients at high risk of cardiovascular disease, the study showed this approach also reduced new onset of HF by 45% and led to a reduction in hospital admissions by 40% for other major cardiovascular episodes such as heart attack or stroke.<sup>47</sup> The study was also shown to be cost effective.<sup>46</sup>

STOP-HF has been recognised internationally, winning numerous awards and influencing international guidelines. STOP HF is now a routine clinical service along the East Coast and Midlands supported by The Heartbeat Trust.





## HF support group and modified cardiac rehabilitation at Sligo General Hospital

Sligo General Hospital offers the first HF support group in Ireland, which holds bi-monthly meetings open to HF patients, their carers and families. The meetings provide information for HF patients by inviting multidisciplinary speakers (e.g. dieticians, specialised nurses and physiotherapists). It offers the opportunity for newly diagnosed HF patients to share experiences.

The group was first started in 2013 after many HF patients had expressed an interest in such a service. In association with the Irish Heart Foundation, the hospital held an initial open public information session on HF in November 2013, which was attended by 250 people. Following this initial information session, the HF support group formed a patient committee and set the meeting content according to patient feedback and needs. The peer-to-peer support offered by the group provides patients with information on their condition, improves compliance and reduces isolation and anxiety in HF patients.

Since 2014, Sligo General Hospital also offers modified cardiac rehabilitation led by HF nurses and physiotherapists for about 600 HF patients. The programme is open to suitable patients who have been assessed through the six minute walking test and an echocardiogram. Modified cardiac rehabilitation can improve mobility and aid weight reduction. It also helps to identify patients who are more high risk, or patients who would benefit from device therapy.

## Case Studies

### Community Heart Failure Clinical Nurse Specialist in Galway

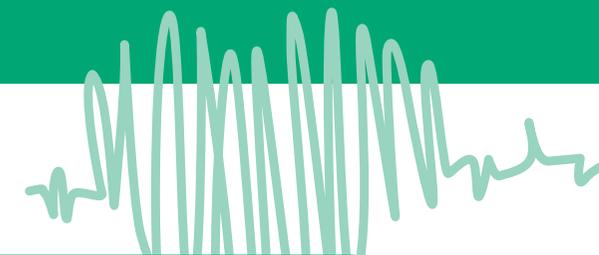
A Community Heart Failure Nurse Specialist has been employed by Galway Primary Care since 2009, as part of the Community Heart Failure Management Programme (CHaMP). CHaMP is a collaboration between Galway University Hospital, Portiuncula Hospital Ballinasloe, the Department of General Practice NUI Galway and Croí. This service was set up to provide a structured, coordinated and integrated approach to the diagnosis and management of patients with HF in the community and is the first of its kind in Ireland.

A component of the Clinical Heart Failure Nurse Specialist role is to support GPs in the management of their patients with HF and to follow up with patients following discharge from hospital. The Clinical Heart Failure Nurse Specialist is a registered nurse prescriber which allows for the adjustment of drug therapies to ensure timely and efficient optimisation of treatment.

Patients are cared for using a case management approach, which includes providing self-management skills to patients. The nurse also provides telephone support for patients and their families. Working in an integrated manner with the hospital nurse specialists and cardiology consultants, the Clinical Heart Failure Nurse Specialist acts as a liaison between hospital and general practice. Nurse led clinics are held in seven primary care locations across Co. Galway ensuring that patients living in rural areas have access to and support from specialist care.



## Data summary



### EPIDEMIOLOGY

Estimated number of people with HF (prevalence)	90,000 <sup>2</sup>
Estimated prevalence of HF as % of total population	2% in the adult population (25-69 years), increasing to 10% in those aged 70 years <sup>3</sup>
Estimated incidence of new HF cases per year	10,000 <sup>3</sup>
Incidence rate (%)	No data available

### COSTS

Estimated annual national expenditure on HF	€158m <sup>4</sup>
Spending on HF as % of total healthcare expenditure	1.2% of total health budget (2012) <sup>4</sup>
Economic (premature life loss) plus indirect costs (informal care)	€498.2m <sup>4</sup>

### MORTALITY

Estimated number of deaths due to HF per year	537 deaths in 2012 <sup>4</sup>
% of deaths due to HF	No data available
In-hospital mortality from HF	9% (47% female & 53% male) <sup>4</sup>
Short-term mortality (30 days) after discharge from hospital	No data available
Short term mortality (30 days) after diagnosis	No data available
One year mortality after diagnosis	25% amongst patients hospitalised for HF in one longitudinal study (2009) <sup>27</sup>
5 year mortality after diagnosis	No data available
Inpatient mortality for primary HF admissions	No data available

## Data summary

### HOSPITAL DISCHARGES

Estimated number of hospital discharges for patients with HF as primary diagnosis	6,131 <sup>48</sup>
HF related admissions as a % of all hospital admissions	4% of admissions <sup>4</sup>
Average length of hospital stay (mean)	8.6 days <sup>4</sup>
Median age at first admission to hospital	No data available

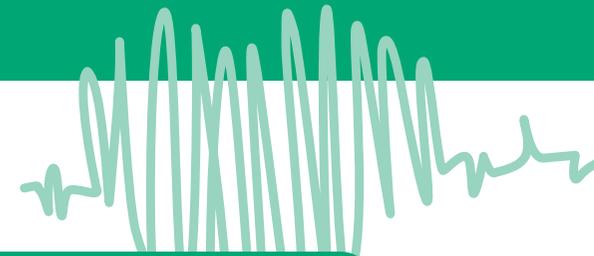
### HOSPITAL RE-ADMISSIONS

% of HF patients readmitted to hospital within 30 days of discharge	No data available
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### POLICY ENVIRONMENT

National plans/ strategies developed	<ul style="list-style-type: none"><li>• National Clinical Programme for Heart Failure, HSE, 2012</li><li>• Changing Cardiovascular Health. National Cardiovascular Health Policy 2010-2019, Department of Health and Children, 2010</li><li>• From Crisis to Control: A cohesive strategy for hospital management of heart failure in Ireland, Irish Heart Foundation Council on Heart Failure, 2002</li><li>• Quality and Fairness: A Health System for You, Department of Health and Children, 2001</li><li>• Building Healthier Hearts, Department of Health, 1999</li></ul>
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## CLINICAL GUIDELINES

Clinical practice guidelines and standards

- ESC guidelines for the diagnosis and treatment of heart failure
- National Clinical Programme for Heart Failure 2012

## DISEASE AWARENESS

Public disease awareness programmes and schemes

There are currently no national awareness programmes or schemes in HF.

## Key links

Croí, West of Ireland Cardiac Foundation <http://www.croi.ie/>

Heartbeat Trust <http://heartbeattrust.org/>

Irish Heart Foundation <http://www.irishheart.ie/>

National Clinical Programme on Heart Failure, 2012

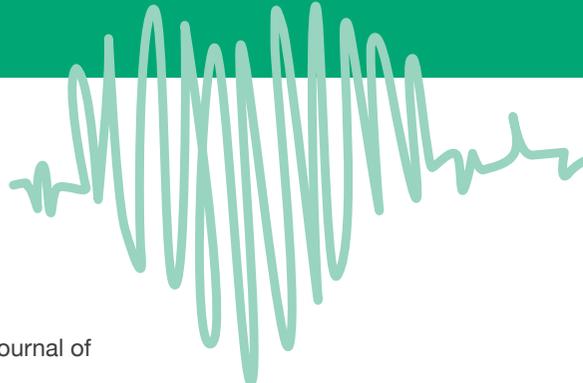
<http://www.hse.ie/eng/about/Who/clinical/natclinprog/heartfailureprogramme/>

National Institute for Preventive Cardiology <http://www.nipc.ie/>

## References

1. Lloyd-Jones D, Larson M, Leip E, et al. Lifetime risk for developing congestive heart failure: the Framingham Heart Study. *Circulation* 2002;106(24):3068-72.
2. Moran D, Buckley A, Daly K, et al. Heart rate awareness in patients with chronic stable heart failure. A multi-center observational study. *International Journal of Cardiology* 2014;177(2):380-84.
3. Minister for Health and Children 2010. Changing Cardiovascular Health 2010 – 2019. National Cardiovascular Health Policy 2010.
4. The Heartbeat Trust, Irish Heart Foundation, NUI Galway, et al. The Cost of Heart Failure in Ireland: The social, economic and health implications of Heart Failure in Ireland, 2015.
5. Cowie MR, Anker SD, Cleland JG, et al. Improving care for patients with acute heart failure: Before, during and after hospitalization. Heart Failure Association of the ESC 2014.
6. TNS UK Limited. Survey of 11,000 members of the public aged 50+ years in Europe. Secondary Survey of 11,000 members of the public aged 50+ years in Europe 2014. <http://pumpingmarvellous.org/2014/05/15/european-heart-failure-awareness-comparison/>.
7. Remme WJ, McMurray JJ, Rauch B, et al. Public awareness of heart failure in Europe: first results from SHAPE. *European Heart Journal* 2005;26(22):2413-21.
8. Ponikowski P, Anker S, AlHabib K, et al. Heart failure: preventing disease and death worldwide. European Society of Cardiology. 2014.
9. Jeon Y-H, Kraus SG, Jowsey T, et al. The experience of living with chronic heart failure: a narrative review of qualitative studies. *BMC Health Services Research* 2010;10(1):77.
10. National Medicines Information Centre. Chronic Heart Failure. 2012;3(18).
11. McGowan B, Heerey A, Ryan M, et al. Cost of treating heart failure in an Irish teaching hospital. *Irish Journal of Medical Science* 2000;169(4):241-44.
12. Stewart S, MacIntyre K, Hole D, et al. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *European Journal of Heart Failure* 2001:315-22.
13. Department of Health. Health in Ireland: Key Trends 2013. DoH, Information Unit. Dublin, 2013.
14. Balanda KP, Barron S, Fahy L, et al. Making Chronic Conditions Count: Hypertension, Stroke, Coronary Heart Disease, Diabetes. A systematic approach to estimating and forecasting population prevalence on the island of Ireland: Institute of Public Health in Ireland, 2010.
15. Kyne S. Topical Issue on a National Strategy for Heart Failure Care. Secondary Topical Issue on a National Strategy for Heart Failure Care, 2015. <http://seankyne.ie/topical-issue-on-a-national-strategy-for-heart-failure-care/>.
16. Irish Heart Foundation. The Irish National Audit on Stroke Care (INASC). 2008.
17. Health Service Executive. National Clinical Programme for Heart Failure. Secondary National Clinical Programme for Heart Failure, 2013. <http://www.hse.ie/heartfailureprogramme/>
18. Health Service Executive. Ireland: Take Heart, Audit of Progress on the Implementation of Building Healthier Hearts 1999 - 2005.
19. Irish Hospice Foundation. Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks: HSE and IHF, 2008.
20. Irish Heart Foundation. 50 Years of Heart Disease in Ireland, Mortality, Morbidity and Health Services Implications. The Irish Heart Foundation Council for Heart Disease in Women, 2001.
21. McGee H, O'Hanlon A, Barker M, et al. One island-two systems: a comparison of health status and health and social service use by community-dwelling older people in the Republic of Ireland and Northern Ireland. *Psychology Reports* 2005:13.
22. Gheorghiade M, Vaduganathan M, Fonarow GC, et al. Rehospitalization for heart failure: problems and perspectives. *Journal of the American College of Cardiology* 2013;61(4):391-403.
23. Ponikowski P, Voors A, Anker S, et al. 2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. *European Heart Journal*, 2016.



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24. Martin Cowie, et al. Acute heart failure – a call to action. *The British Journal of Cardiology* 2013 20(suppl 2):S1–S11.
  25. Remme WJ, McMurray JJ, Hobbs FD, et al. Awareness and perception of heart failure among European cardiologists, internists, geriatricians, and primary care physicians. *Eur Heart J* 2008;29(14):1739-52.
  26. McDonald K. Personal correspondence, 2016.
  27. Tully N, Morgan K, McGee H, et al. Quality of Life and Quality of Care in Heart Failure: Perspectives of Irish Patients. 2009.
  28. James S, Barton D, O'Connell E, et al. Life expectancy for community-based patients with heart failure from time of diagnosis. *International journal of cardiology* 2015;178:268-74.
  29. Heart Beat Trust. Irish Heart Researchers Win International Award. In: Trust HB, ed., 2013.
  30. Doughty R, Wright S, Pearl A, et al. Randomized, controlled trial of integrated heart failure management: The Auckland Heart Failure Management Study. *Eur Heart J* 2002;23(2):139-46.
  31. Gary Culliton. 'Structured, resourced' approach urged by GPs. *Irish Medical Times*, January 25, 2016.
  32. Inglis S, Clark R, McAlister F, et al. Which components of heart failure programmes are effective? A systematic review and meta-analysis of the outcomes of structured telephone support or telemonitoring as the primary component of chronic heart failure management in 8323 patients: Abridged Cochrane Review: Queensland University of Technology, 2011.
  33. Polisen J, Tran K, Cimon K, et al. Home telemonitoring for congestive heart failure: a systematic review and meta-analysis. *Journal of Telemedicine and Telecare* 2010;16:68-76.
  34. Schmidt S, Schuchert A, Krieg T, et al. Home Telemonitoring in Patients With Chronic Heart Failure. *Deutsches Ärzteblatt International* 2010;107(8):131-8.
  35. Maric B, Kaan A, Ignaszewski A, et al. A systematic review of telemonitoring technologies in heart failure. *European Journal of Heart Failure* 2009;11:506-17.
  36. Clark R, Inglis S, McAlister F, et al. Telemonitoring or structured telephone support programmes for patients with chronic heart failure: systematic review and meta-analysis. *BMJ* 2007;1-9.
  37. Seto E. Cost Comparison Between Telemonitoring and Usual Care of Heart Failure: A Systematic Review. *Telemedicine and e-health* 2008;14(7):679-86.
  38. Radhakrishnan K, Jacelon C. Impact of Telehealth on Patient Self-management of Heart Failure: A Review of Literature. *Journal of Cardiovascular Nursing* 2011;27(1):33-43.
  39. Mudiwa L. Virtual consultations 'a game changer'. *Irish Medical Times*. Dublin, 2015.
  40. Health Service Executive. Congestive Heart Failure. Secondary Congestive Heart Failure 2013. <http://www.hse.ie/eng/health/az/H/Heart-failure/>.
  41. Stanton D. Urgent Need for Specialised Heart Failure Unit in Cork 2015. <http://stanton.ie/2015/12/17/urgent-need-for-specialised-heart-failure-unit-in-cork-david-stanton/>.
  42. House of the Oireachtas. Secondary Dáil Éireann Debate, 2015. <http://oireachtasdebates.oireachtas.ie/debates/authoring/debateswebpack.nsf/takes/dail2015121700052?opendocument>.
  43. McDonald K, Ledwidge M, Cahill J, et al. Heart failure management: multidisciplinary care has intrinsic benefit above the optimization of medical care. *Journal of Cardiac Failure* 2002;8(3):142-48.
  44. Irish Heart Foundation. Lack of heart failure awareness causing 'needless waste of lives. 2012. <http://www.irishheart.ie/iopen24/lack-heart-failure-awareness-causing-%C2%91needless-waste-lives-n-319.html>.
  45. European Cardiac Society. Heart Failure Awareness Day: Countries Involved. 2015. [http://www.escardio.org/The-ESC/Communities/Heart-Failure-Association-\(HFA\)/Heart-failure-awareness-day/Countries-involved](http://www.escardio.org/The-ESC/Communities/Heart-Failure-Association-(HFA)/Heart-failure-awareness-day/Countries-involved).
  46. Ledwidge M, O'Connell E, Gallagher J, et al. Cost-effectiveness of natriuretic peptide-based screening and collaborative care: a report from the STOP-HF (St Vincent's Screening TO Prevent Heart Failure) study. *European Journal of Heart Failure* 2015;17(7):672-9.
  47. Ledwidge M, Gallagher J, Conlon C, et al. Natriuretic Peptide-Based Screening and Collaborative Care for Heart Failure: The STOP-HF Randomized Trial. *JAMA* 2013;310(1):66-74.
  48. Healthcare Pricing Office. Activity in Acute Public Hospitals in Ireland, Annual Report 2013: HSE, 2014.

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