



This report was written by the Health Policy Partnership with funds provided by Novartis Pharma AG. Also contributing to the content of the report were: Professor Ken MacDonald (Consultant Cardiologist St Vincent's University Hospital & HSE National Clinical Lead in Heart Failure), Dr. Pat Nash (Consultant Cardiologist, University Hospital Galway), Michael Delapp (person with heart failure), Claire O'Connell (person with heart failure), Liz Kileen (Community heart failure Clinical Nurse Specialist in Galway), Fidelma Hanley (Heart failure nurse specialist, Sligo General Hospital), Dr Joe Gallagher (General Practitioner), Dr Austin Byrne (General Practitioner) Neil Johnson (Chief Executive, Croi)







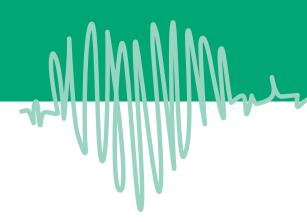
## Why action on HF is needed now

Heart failure (HF) is a common condition, carrying a huge cost to society:



can expect to develop HF in their lifetimes.1







## HF is a leading cause of hospitalisations, including high admission and re-admission rates in Ireland.

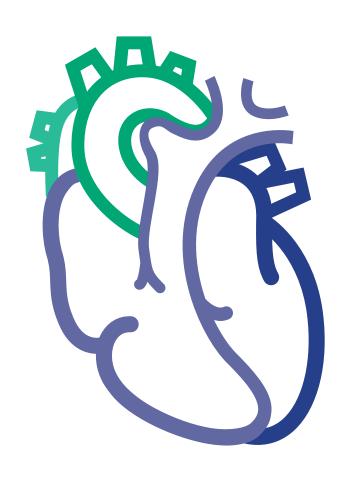
HF related admissions accounted for circa 4% all of inpatient admissions, about 7% of all inpatient bed days and; circa 5% of all emergency/acute admissions.<sup>4</sup>



per year – of which €158m is a direct healthcare cost to the State, equivalent to 1.2% of the total health 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. <sup>5</sup>

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





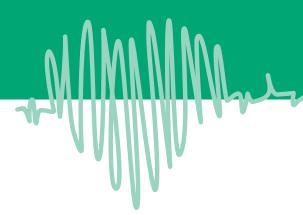
#### **Awareness of HF is low in Ireland:**

Only of the Irish population can correctly identify 3 symptoms of HF and 1 in 4 patients with HF symptoms would wait a week

with HF symptoms would wait a week or more to seek medical advice. <sup>6</sup>

Most types 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>78</sup>







Good patient experiences and person-centred approaches to care can improve quality of life and reduce hospital admissions for patients with HF.<sup>10</sup>

Access to high quality information and support can positively influence self-care.9





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 heart failure?

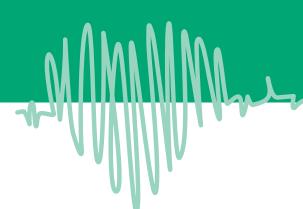


According to international data the majority of patients with HF are over the age of 65.13





Heart failure (HF) is a serious chronic condition where the pumping efficiency of the heart is impaired and cannot pump enough blood to support the needs of other organs in the body.<sup>11</sup>





HF, if ineffectively treated, has a worse prognosis than many of the most common forms of cancer<sup>14</sup> and can lead to very poor quality of life in patients.<sup>9</sup>



Symptoms of HF include: shortness of breath, swollen ankles or legs, fatigue and sudden weight gain.<sup>59</sup>

## What is needed in Ireland?



Explicitly mention HF within existing chronic disease policies and ensure there are sufficient resources to implement the National Clinical Program for HF (HSE) on a national level (adequately funding both General Practice (GP) and hospital care):

- HF needs much greater recognition within Ireland's national cardiovascular disease strategy.
- Implementation and resourcing of national plans and strategies for HF is inadequate.



Ensure that patients with symptoms of heart failure are diagnosed earlier, without delay:

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







Create a coordinated, community-based national program between the hospital and community care at general practice level to provide patients greater continuity of care and encourage patient self-management:

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



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

- We need public campaigns to raise awareness of HF and its risk factors (e.g. hypertension, prior myocardial infarction and diabetes mellitus) this will be crucial to enable better prevention and lifestyle changes to prevent progression to HF.
- People with risk factors for developing HF (e.g. high blood pressure, high cholesterol, diabetes and a prior heart attack) 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 carries a huge human and economic cost

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

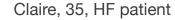
Heart Failure (HF) costs Ireland approximately €660m per year – of which €158m is a direct healthcare cost to the State, equivalent to 1.2% of the total health budget.<sup>4</sup>

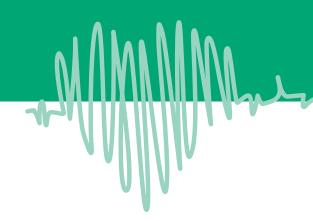
HF is a large driver of hospitalisations and a substantial driver of costs and economic burden. HF related admissions account for about 4% all of inpatient admissions, 7% of all inpatient bed days and; 5% of all emergency/acute admissions (2012 HSE figures).<sup>15</sup>

Informal care, which includes assistance in day-to-day living provided by professional carers or family members, is estimated at €363.4m and represents the largest component of the cost of HF.<sup>16</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."

"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 heart failure 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. The number of people over the age of 65 in Ireland is expected to increase by 150% over the next 30 years.<sup>17</sup>

By 2020, the Institute of Public Health (IPH) have predicted a 40% increase In people with high blood pressure and a 50% increase in coronary heart disease – both of which are major drivers of the incidence of HF.<sup>18</sup>

"Chronic illness threatens to overrun our healthcare systems - heart failure, as the most complex of these illnesses, can be used as a test case to establish effective methods of value, not only to heart failure but also to chronic disease in general"

Prof. Ken McDonald, Cardiologist, St. Vincent's University Hospital

"For too long heart failure has been the forgotten condition in heath policy, despite its human and economic impact. We need to make HF truly a 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." 20

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 Program for HF (HSE) on a national level (adequately funding both GP and hospital care)



HF needs much greater recognition within Ireland's chronic disease policy and the national cardiovascular disease strategy.

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

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

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



Raise HF on the policy agenda: Grant HF the recognition it deserves in the chronic disease policy and 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 burden of ill health and potential return on investment. Since the majority of the management of chronic disease needs to take place at in the community, more funding for the diagnostic and clinical management of HF patients needs to be made available to GPs.



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>19</sup>) to enable evidence-based care planning for the health care system.

## HF needs much greater recognition within Ireland's chronic disease policy and the 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>21</sup>

However, on-going 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 likely 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 health system and population.<sup>3</sup>



### WHY IS THIS IMPORTANT?

Investment and planning for HF care services now is essential to manage the expected rise of people with HF, and could help prevent a crisis in the future.<sup>23</sup>

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

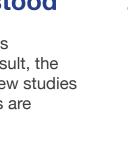
The National Clinical Program for HF set out to improve healthcare and quality of life for patients.<sup>22</sup> However, implementation in practice is still far behind the policy aspiration, in part because of insufficient resources.

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 than *cause* of death on death certificates in Ireland.<sup>24</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>25 26</sup>

Most specifically, there is **no national HF registry in Ireland**, so that information on mortality and outcomes from HF is not available on a national level. Other 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>23</sup> 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 better understanding of HF, the causes of re-admissions, the outcomes of interventions and the causes of mortality.<sup>27</sup> "It took 1 ½ years of investigating
my symptoms before I was diagnosed with
heart failure. 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 heart
failure 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, Heart failure patient



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



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

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

## Making HF a priority for everyone: 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 – enabling 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 (e.g. medical professionals).



**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 improve the support and information they offer to patients with new and 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 of detecting 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>28 29</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, an ECG, natriuretic peptides tests and an echocardiography.<sup>28</sup> However, it has been shown that some of these tests are often carried out less frequently than is recommended by the ESC across Europe and that proper diagnosis is still neglected.<sup>30</sup>

The community setting is vital for improving diagnosis and communicating diagnosis with patients.

The HSE (Health Service Executive) has called for rapid diagnostic services to be available in the community.<sup>23</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>27</sup> It is important to note that General Practitioner and Practice Nurse care is the cornerstone of community care as specialist nurses will have a limit to the number of patients they will be able to see every day.



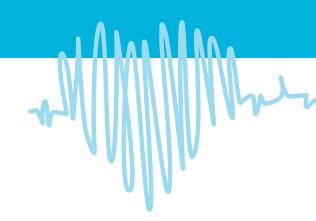
Survival rates from HF can be improved through earlier and more appropriate diagnosis, management and treatment of HF by GPs.8

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

Low prioritisation and low awareness 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 and supported by the fact that HF admissions are admitted frequently under the general medical teams and not cardiology – which is not the case for myocardial infarctions. 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 understanding of HF and its causes is 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.6 The survey found that there was also lack of awareness of the common causes of HF and 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), and despite the fact that 64% of respondents knew someone who suffered from HF.6

Individuals themselves are often the first line of care in a condition where rapid medical attention is vital. For example, delaying hospital treatment by as little as 4–6 hours after the symptoms of acute heart failure 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>

"Heart failure in the community needs
to be managed in by GPs and practice nurses,
with access to specialist care when appropriate.

Developing structured heart failure 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 coordinated, community based national program between the hospital and community care with GPs to provide patients greater continuity of care and encourage patient self-management.



There are no models of shared care, which set out the roles and responsibilities of general practitioners and specialist (hospital) services for HF patients in Ireland.<sup>23</sup>

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

Specialist HF units offering multidisciplinary support are the standard of care for HF patients.<sup>28</sup>

Specialist HF nurses can support in the provision of critical follow-up care to patients whilst both in hospital and after discharge.

#### **Co-ordinated, community-based care:** 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 (ERs), and specialist services (e.g. hospital based cardiology wards or HF clinics), to provide greater continuity of care for patients after discharge from hospital. 10 23



Invest in specialist HF units offering multidisciplinary care – these should be the standard of care for HF patients



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>10</sup> This role should be developed in the community in conjunction with the GP and Practice Nurse.

## There are no models of shared care, which set out the roles and responsibilities of general practitioners and specialist (hospital) services for HF patients in Ireland.<sup>23</sup>

As the HSE chronic Disease Management Programmes want to shift the management of chronic diseases from hospitals to the community, transitions between general practice and hospital care are a vital link for quality care and outcomes and in HF.

When patients leave hospital they are in the so-called "vulnerable phase", at risk of being readmitted. 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. Patients also need to be monitored in the community for events or conditions that may increase their risk of readmission to hospital, such as clinical depression or non-adherence to lifestyle guidelines for HF. In addition, patient's self-care is vital to the reduction of re-admissions. The overall concept of 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. 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 and follow-up with their GPs in the community.<sup>32</sup> GPs need to be resourced adequately so they can follow-up their 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. 10 27 32-34

## 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 heart failure. 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>22</sup>

In 2015, the asthma and diabetes cycle of care was introduced in general practice, a first step in expanding the scope of general practice into chronic disease management, allowing for some new chronic disease specific services to be provided by GPs to patients with Type 2 Diabetes (people with medical cards and GP visit cards) 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 heart failure.<sup>35</sup> General practice models for cycle of care for heart disease could reduce hospital admissions by 7%, resulting in €30 million in hospitals' savings.<sup>36</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>37-41</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>41</sup> Telemonitoring has also been shown to save health care costs in the long run<sup>37 42</sup> and can improve patients self–management in treatment.<sup>37 39 43</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>44</sup>

## Specialist HF units offering multidisciplinary support are the standard of care for HF patients<sup>28</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. In an interview study on the perspectives of HF patients attending outpatient clinics in Ireland in 2009, out of 98 patients recruited, 4 (25% of total HF patient cohort) died within a year, a much higher mortality rate than expected.

Ireland has 11 national HF units where patients are supported by a multidisciplinary team of hospital HF specialists that are linked to GP led care in the community. The hospital based multi-disciplinary team (MDT) is a cardiologist led team comprising specialist nurses, doctors, physiotherapists and dieticians. These units offer a variety of programmes, including exercise and information sessions.<sup>32 45</sup> Outcomes from these programmes have been very positive, with patients feeling confident enough to exercise and engage in more everyday activities.<sup>32</sup>

However, not all HF patients have access to the programmes, as there are a limited number of places and facilities.<sup>24</sup> For example, 6 of the HF units operate in Dublin and only 5 in the rest of Ireland. In Cork there is a large need for specialised HF care and currently limited specialised services are 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>46</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 even made it to 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>47</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>27 29</sup> Yet such teams are not consistently available across the whole country.

## Specialist HF nurses can support in the provision of critical follow-up care to patients whilst both 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, where they can play an important role in the long-term management and quality of life of HF patients.<sup>5 27 48</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>32</sup>



## WHY IS THIS IMPORTANT?

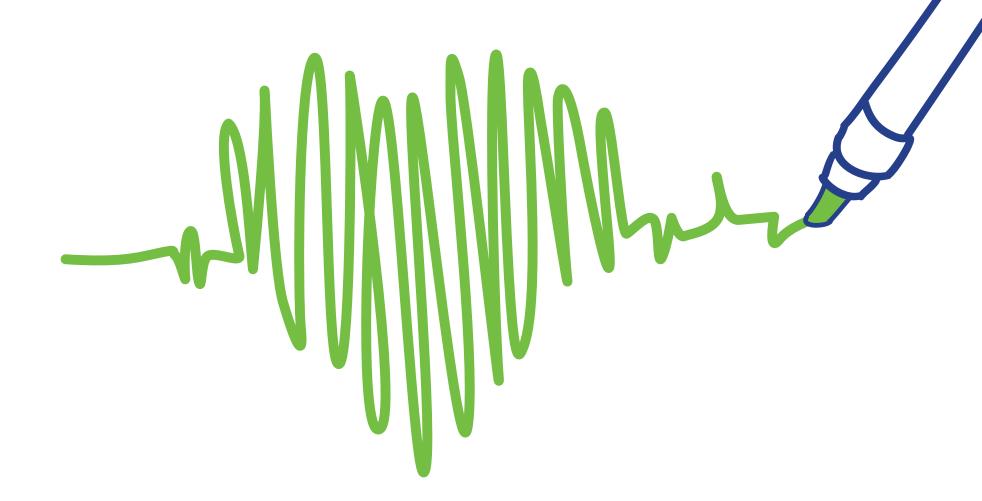
Programmes that include specialist nurses can help reduce hospital re-admissions, as well as improve patient knowledge of HF.<sup>48</sup>

Please see case study on **Community heart failure Clinical Nurse Specialist in Galway** for more information about specialist nursing in HF care.

Please see case study on **St Vincent's Heart Failure Clinic** for more information about
specialist HF units in Ireland.

"I found it very hard to come to terms with my HF diagnosis, but then I went to a 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





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



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

High risk populations should undergo preventative HF programmes.

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



**Investing in public campaigns** to raise awareness of HF and its risk factors and enable better prevention and lifestyle changes to prevent progression to HF.



**GP-led screening and optimal management of people with risk factors for developing heart failure** (high blood pressure, high cholesterol, diabetes and a prior heart attack) to diagnose HF early, slow the progression of disease, and improve health outcomes and reduce the overall cost of care that occurs if patients develop heart failure.

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

HF is increasing in Ireland due to the ageing of the population; better survival following acute coronary events and high cardiovascular risk factors, and it is estimated that 160,000 people in Ireland live with impending HF. 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>10</sup>

Yet awareness of risk factors for developing HF is low in Ireland.<sup>6 49</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. 6 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>49</sup>

Despite this, there is a lack of campaigns to raise public awareness in Ireland. While there were some HF awareness activities planned for HF Awareness Day in Ireland<sup>50</sup>, there is no on-going, large scale public awareness campaign.<sup>49</sup>

The Department of Health and Children has recognised the need for public awareness campaigns for cardiovascular disease risk factors, symptoms and responses to heart conditions, including HF, and has made it one of the priorities in the National Cardiovascular Health Policy.<sup>10</sup>



## WHY IS THIS IMPORTANT?

Low awareness for HF and its symptoms and causes leads to high levels of avoidable deaths in Ireland.<sup>49</sup>

## High risk populations should undergo preventative 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. This blood test could be used to rule out HF and other cardiovascular diseases in patients over 40 with a cardiovascular risk factor.

Prevention measures align with the National Cardiovascular Health Policy that identifies cardiovascular risk reduction and heart disease prevention as priorities.<sup>10</sup>



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%. 51 52



#### **Case Studies**

#### St Vincent's Heart Failure Clinic

The HF Unit within the St Vincent's Healthcare Group, incorporating St Vincent's and St Michael's Hospitals, provides continuous 7 day in-patient and out-patient 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 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 used a simple blood test called natriuretic peptide to help identify those most at risk of heart failure. 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 heart failure 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 repeated heart failure and hospital admissions for patients at high risk of cardiovascular disease, the study showed this approach reduced new onset of heart failure by 45% and led to a reduction in hospital admissions for other major cardiovascular episodes such as heart attack or stroke by 40%. The study was also shown to be cost effective.

STOP-HF has been recognised internationally, winning numerous awards and adoption into 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 rehab at Sligo General Hospital

Sligo General Hospital offers the first HF support group in Ireland, which holds bimonthly 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 and offer the opportunity for newly diagnosed HF patients to talk to peers. 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 the initial information session, the HF support group set up a patient committee and adjusts the meeting content according to the patient's feedback and needs. The peer-to-peer support offered by the group can provide patients with information about their condition improve compliance and reduce isolation and anxiety in HF patients.

Since 2014 Sligo General Hospital also offers modified cardiac rehab led by HF nurses and physiotherapists for about 600 HF patients. The rehab program is open to suitable patients who have been assessed through the 6 min walking test and an echocardiogram. Modified cardiac rehab can improve mobility, aid weight reduction and helps identify patients who are more at high risk or patients who would benefit from device therapy.

#### **Case Studies**

#### **Community heart failure Clinical Nurse Specialist in Galway**

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

A component of her role is to support general practitioners in the management of their patients with heart failure and to follow up with patients referred following discharge from hospital. Liz 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. Liz also provides telephone support for patients and their families. 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. Working in an integrated manner with the hospital nurse specialists and cardiology consultants Liz is in a position to act as a liaison between hospital and general practice.

This shared care approach to the management of heart failure patients aims to enhance collaborative working between primary and secondary care for the benefit of patients living with heart failure in line with the national heart failure model of care.

### **Data summary**



#### **EPIDEMIOLOGY**

Estimated number of people with HF (prevalence)	90,000 <sup>2</sup>
Estimated prevalence of HF (% of total population)	2% in the adult population (25-69 years), increasing to 10% in those aged 70 years <sup>10</sup>
Estimated incidence (new cases per year)	10,000³
Incidence rate (%)	No data available

#### COSTS

Estimated annual national expenditure on HF	€158M¹6
Spending on HF as % of total healthcare expenditure	1.2% of total health budget (2012)4
Economic (premature life loss) plus Indirect costs (informal care)	€498.2m⁴

#### **MORTALITY**

Number of deaths due to HF per year	Estimate 537-775 deaths in 2012 <sup>53</sup>
% of deaths due to HF	No data available
In-hospital mortality from HF	9% (47% female & 53%male)15
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>32</sup>
5 year mortality after diagnosis	No data available
Inpatient morality for primary HF admissions	No data available

#### **Data summary**

#### **HOSPITAL DISCHARGES**

Estimated number of HF discharges per year (as a primary diagnosis)	6131 <sup>54</sup>
HF related admissions as a % of all hospital admissions	4% of admissions <sup>15</sup>
Average length of hospital stay (mean)	8.6 days <sup>15</sup>
Weighted average length of hospital stay	11.44
Median age at first admission to hospital	No data available

#### **HOSPITAL R-EADMISSIONS**

% of HF patients readmitted to hospital within 30 days of discharge

No data available

#### **POLICY ENVIRONMENT**

National Plans/ Strategies developed

- National Clinical Programme for Heart Failure, 2012
- Changing Cardiovascular Health. National Cardiovascular Health Policy 2010-2019.
- The 2001 Health Strategy Quality and Fairness, A Health System for You provides (developing services for heart failure and palliative care)
- 1999 The National Cardiovascular Health Strategy, Building Healthier Hearts
- 2002 Irish Heart Foundation strategy document on heart failure services From Crisis to Control: A cohesive strategy for hospital management of Heart Failure in Ireland



#### **CLINICAL GUIDELINES**

Clinical practice guidelines / standards	<ul> <li>ESC guidelines for the diagnosis and treatment of heart failure</li> <li>National Clinical Programme for Heart Failure 2012</li> </ul>
Audits / registries	
Reward and incentive programmes for clinicians	

#### **DISEASE AWARENESS**

Public disease awareness programmes/	There are currently no national
schemes	awareness schemes in HF. There is
	a very successful stroke awareness
	campaign.

#### **Key links**

Croí, the West of Ireland Cardiology 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 Preventative Cardiology <a href="http://www.nipc.ie/">http://www.nipc.ie/</a>

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