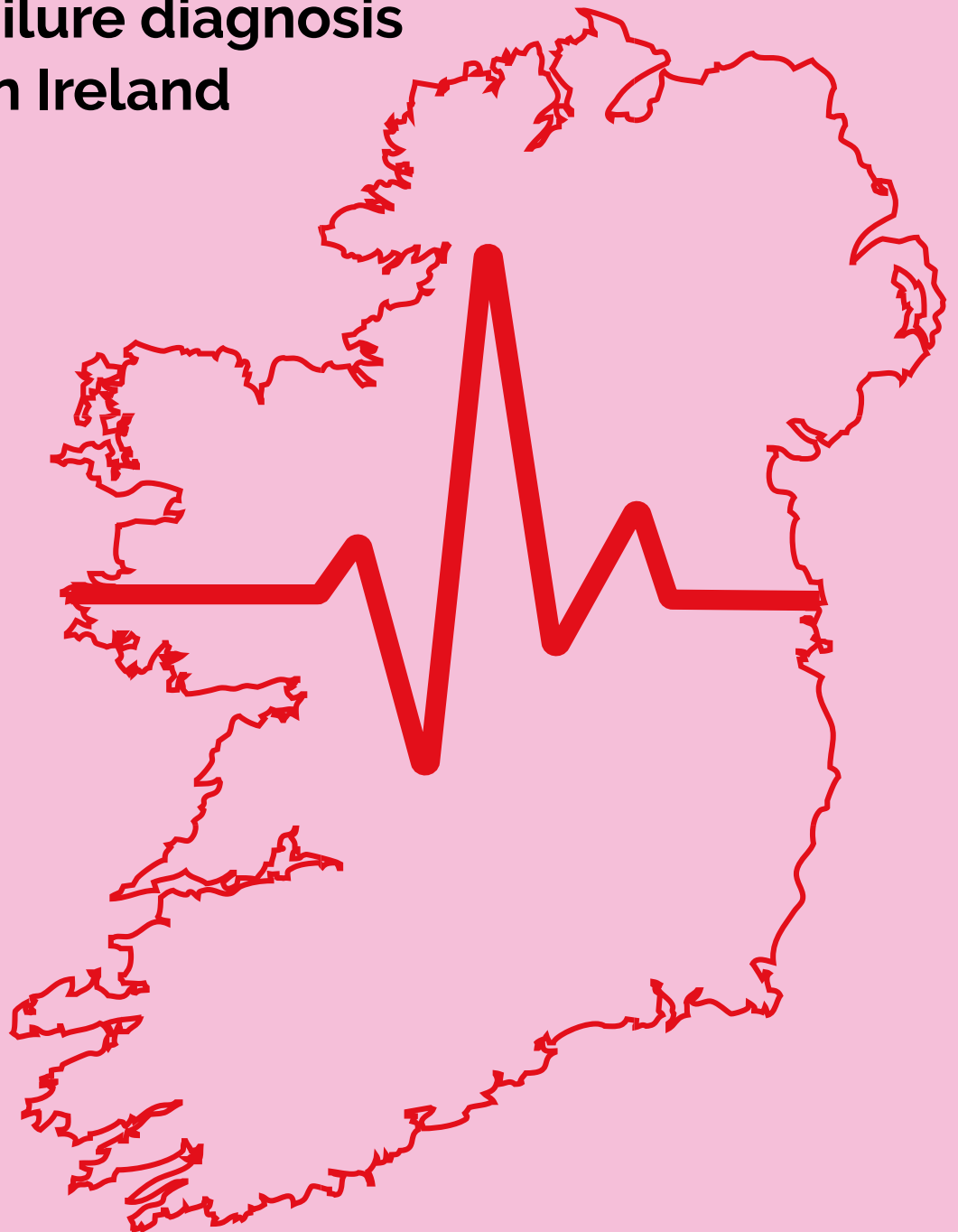


State of the Heart:

Examining the current state
of heart failure diagnosis
and care in Ireland



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This report was commissioned by Roche Diagnostics in collaboration with the Irish Heart Foundation and is designed to examine the current state of heart failure diagnosis and care across the Republic of Ireland.

The report makes a series of recommendations for how we can work together to improve heart failure care for patients. The findings in this report were informed by a survey of 372 heart failure patients in Ireland, conducted by Censuswide at the end of 2021. The patients shared their experiences of being diagnosed with heart failure; the impact of their diagnosis; and how COVID-19 has affected the way they live with the condition. Alongside this, we also spoke with patients directly about their experiences living with heart failure – their testimony is included throughout this report.



Dr Angie Brown

Medical Director, Irish Heart Foundation

"This survey confirms the negative impact that a heart failure diagnosis has on patients' lives. It also demonstrates that we have to do much more to facilitate a prompt diagnosis and help patients live as well as possible with their condition.

"With almost one in three respondents reporting anxiety or depression following their diagnosis, and 79% feeling their mental health was negatively impacted by a delay in diagnosis, it's especially important that more emphasis is placed on access to practical and emotional supports to protect and enhance the wellbeing of patients. A particular concern is the delay in diagnosis for women which may have a further deleterious impact on their lives.

"We need policymakers to understand that service improvements focusing on the health and wellbeing of people living with heart failure, can be highly cost effective, particularly against the backdrop of unacceptably high readmission rates among those affected. Such community based services need to be an integral part of a heart failure pathway that extends beyond hospital care to meet patient needs at every stage of their journey after diagnosis.

"Health service decision makers and political leaders need to step up and address the policy vacuum in this area that will mean continued under-resourcing resulting in a needless failure to maximise outcomes. The National Cardiac Services Review promises to go some way to addressing this hole in the national health policy, but we need an overarching and fully funded National Cardiovascular Policy and Strategy to ensure optimal treatment and care of people across the full spectrum of heart conditions."



"The State of the Heart report highlights the challenges of diagnosing heart failure and need for ready access to appropriate diagnostics and specialist advice.

"It also highlights the initiatives that are being undertaken to ensure these are made available consistently across the country. This has involved significant work by a number of stakeholders in the midst of the pandemic. With appropriate resourcing the provision of community care for heart failure can ensure patients receive optimal diagnosis and treatment close to home and reduce hospital admissions."

Dr Joe Gallagher

General Practitioner,
ICGP Clinical lead for
Cardiovascular Disease.
Clinical Associate
Professor UCD



"I would first of all like to congratulate the organisations involved in this very important report. It fills a critical gap in the overall awareness of the impact of heart failure on our society. Also, thanks to the patients for taking the time to provide their insights on how heart failure has affected them and their families.

"The report highlights several important aspects of heart failure management in Ireland which indeed resonate with international experience. These include the diagnostic challenge of heart failure and the consequent delay in diagnosis and occasional diagnostic inaccuracy that can be made along the way. While these issues are frustrating, it is encouraging to note that ready solutions are at hand. Indeed, the HSE are putting in place robust systems to address these and other needs related to heart failure and I would hope that revisiting many of these questions with heart failure patients in a few years will highlight important advances."

Professor Kenneth McDonald

Clinical Professor at
UCD and Consultant
Cardiologist at St
Vincent's Healthcare
Group. Clinical Lead of
the HSE National Heart
Programme



Neil Johnson

Chief Executive, Croí,
the West of Ireland
Cardiac & Stroke
Foundation & National
Institute for Prevention
and Cardiovascular
Health

"Patient testimonials worldwide, evidenced also in this report, highlight that a diagnosis of heart failure can have an enormously negative impact on the individual and on their family. A delayed diagnosis further exacerbates an already challenging situation by impacting quality of life and adding emotional and often financial strain.

"Almost 60% of those surveyed in this study received their diagnosis from a heart specialist in hospital but with a reported 14 month waiting time to see a specialist, this delay is just unacceptable when understood in terms of avoidable deterioration and mental distress.

"It is internationally recognised that heart failure merits the earliest possible diagnosis and treatment, ideally triaged or diagnosed in primary care settings. In Ireland, GP's have had their hands tied in this regard. Access to NT-proBNP blood tests and echocardiography has been entirely unsatisfactory. Recent attempts to improve this through Sláintecare are to be welcomed but GP access to echocardiography will not be solved overnight – urgent and prioritised investment is required and this needs to become a government priority.

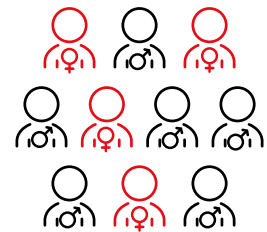
"Covid-19 has compounded the burden of heart failure on patients and their carers which makes it all the more necessary to now scale up some of the innovations that have been shown to improve diagnosis and management, such as virtual consultations and remote monitoring.

"While undoubtedly, the heart failure landscape, from a patient perspective has improved in recent years, there is much more to do. The internationally recognised evidenced based best practice patient pathway from diagnosis through to post hospital care in the community should be the goal for heart failure patients here in Ireland. The absence of a national cardiovascular health strategy which would guide this is something that needs to become a real political priority."

Executive summary



In 2014, heart failure was estimated to affect around 2% of the Irish population, with approximately 90,000 people in Ireland suffering from heart failure and another 160,000 people living with impending heart failure¹. Sourcing up to date prevalence data is challenging, but research carried out by IQVIA this year (using the European Society of Cardiology (ESC) guidelines to review medication prescribing), indicates that an estimated 119,291 people are likely to have heart failure, with women making up 40% of this figure.² Almost half of the people on heart failure treatment are aged 66 - 80 years.³ If we use the current Central Statistics Office population figures, that gives an overall estimate of 2.4% of people on heart failure treatment in Ireland.⁴

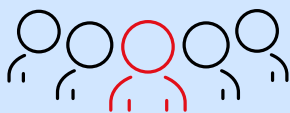


An estimated 119,291 people are likely to have heart failure, with women making up 40% of this figure.²

Diseases of the circulatory system are the second highest cause of death in Ireland behind cancers, with 5,886 deaths registered in the first 10 months of 2020, accounting for over a quarter (26.3%) of all deaths.⁵ In those over 80, diseases of the circulatory system are the leading cause of death, accounting for 31.5% of deaths in this age group.⁶

The diagnosis journey

This report examines the diagnosis journey for heart failure patients in Ireland and finds that more needs to be done to improve awareness among healthcare professionals and the public of the signs and symptoms of heart failure. In particular, our survey asked heart failure patients about their experience being diagnosed, finding that:⁷



1 in 5 patients

receive an incorrect diagnosis before being diagnosed with heart failure (19%)



Women have to wait five weeks

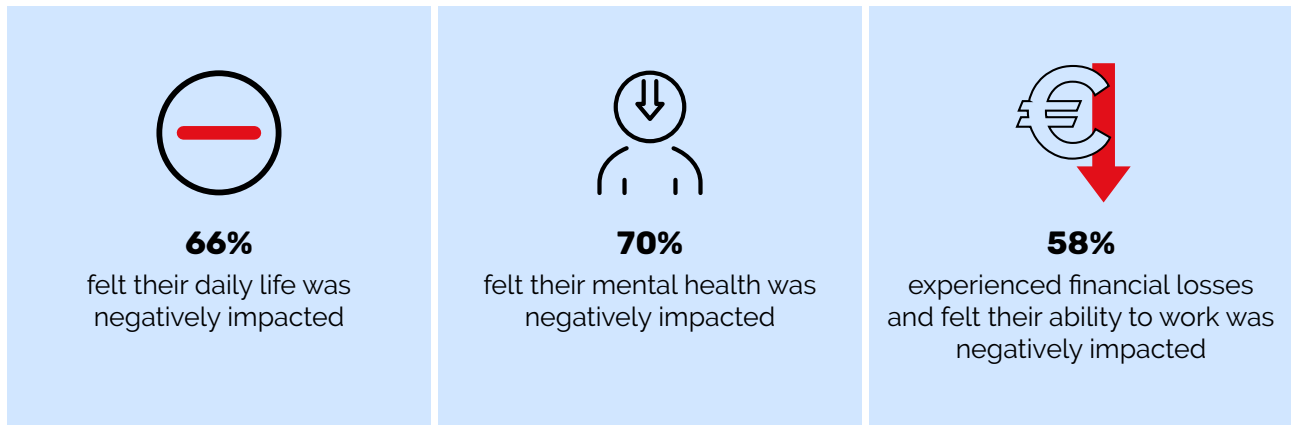
to receive a formal diagnosis of heart failure compared to men who have to wait three weeks



Three quarters

believe that an early diagnosis would have made their lives better (72%)

Many of the patients we surveyed experienced difficulties while waiting to receive a diagnosis, with our survey finding that a delayed heart failure diagnosis has a significant impact on patients' quality of life:⁷



The future of heart failure diagnosis and management

Positive steps are being taken to improve heart failure care in Ireland – the Sláintecare Vision is aiming to drive positive reform across the health service to ensure the right care is provided in the right place and at the right time.⁸ Since its publication there has been some progress, including through the Sláintecare Integration Fund initiatives; the Integrated Care Programme for the Prevention and Management of Chronic Diseases (ICPCD); the 2019 GP Contract; and the Structured Chronic Disease Management Programme (CDM). These are driving improvements to heart failure care in the community and incorporating innovative new models of care, including virtual consultations and remote monitoring.⁹

However, there is still more to be done to support improvements to heart failure diagnosis and management. Since the expiry of the previous strategy in 2019, no formal review of the implementation of its recommendations has taken place and there has been no national cardiovascular strategy developed in Ireland to take its place.¹⁰



There is currently no national cardiovascular strategy in Ireland¹⁰

COVID-19 and heart failure

For those living with heart failure, the impact of the pandemic has presented significant challenges, with our survey finding that a third of respondents felt their symptoms have deteriorated during the pandemic.⁷ Patients with chronic heart disease were among the cohorts worst affected by COVID-19, comprising 44% of deaths and 49% of related ICU admissions in Ireland.¹¹

Our survey highlighted the challenges heart failure patients faced throughout the pandemic, with it affecting their daily life; mental health and ability to access health services. In particular, we found:⁷



49% of COVID-19 related ICU admissions in Ireland were patients with chronic heart disease¹¹



A third
have had a HCP appointment cancelled (34%)



42%
have had issues picking up prescription medication due to COVID-19



41%
agree that their quality of life has declined



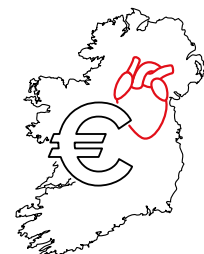
A majority
say their mental health has been negatively affected (69%)

The pandemic has also impacted on the implementation of policy initiatives aimed to improve heart failure care,¹² and pressures across the health system will pose challenges to providing heart failure services into the future.¹³

The financial cost of heart failure

Heart failure has significant personal and socioeconomic costs in Ireland. The Irish Government is estimated to spend 1.2% of their healthcare budget on heart failure, with the total cost of heart failure in Ireland estimated to be approximately €660m.¹⁴ Our survey found that 58% of patients experienced financial losses and felt their ability to work was negatively impacted while waiting to receive a diagnosis of heart failure.⁷

There have however been important initiatives introduced through the Sláintecare reform programme, which have the potential to reduce costs for patients and the healthcare system – continuing to accelerate and implement learnings from these will be vital to reduce costs in the future.



The Irish Government spends an estimated 1.2% of their healthcare budget on heart failure¹⁴

Key recommendations:

Throughout this report we have made a number of recommendations around how we can improve heart failure in Ireland. These include:

- 1. Development of a new national cardiovascular strategy**
- 2. Increased focus on prevention of heart failure**
- 3. Accelerate access to diagnostic tools in primary care**
- 4. Enhanced training on the signs and symptoms of heart failure for healthcare professionals**
- 5. Appropriate provision for emotional and social support for heart failure patients and public education around the symptoms of heart failure**
- 6. Support for the expansion of innovative diagnosis and management tools**
- 7. Prioritisation of heart failure post COVID-19 to accelerate community care - Stay Left, Shift Left**

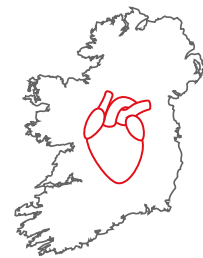
The diagnosis journey



Recognising the symptoms

A key challenge is that many people are not fully aware of the symptoms of heart failure, which presents a barrier to seeking help. According to the heart failure country barometer: Ireland, only 7% of the Irish population can correctly identify three symptoms of heart failure.¹⁵

The most common symptoms include fatigue, shortness of breath, weight gain and swollen ankles and legs.¹⁶ These symptoms are not unique to heart failure and may be caused by other conditions, making it difficult to diagnose.¹⁷ In fact, heart failure can affect people in different ways and patients may not have any of the common symptoms at all.¹⁸ Symptoms can also start suddenly and be severe or they can appear over time and gradually get worse.¹⁹ This means it can be difficult for patients and healthcare professionals to recognise the early signs of heart failure.



Only 7% of the Irish population can correctly identify three symptoms of heart failure¹⁵

Raising awareness of heart failure

There has been positive progress in Ireland to raise the awareness of heart failure and its symptoms. An awareness campaign by The Irish Heart Foundation, found that almost half of Irish adults mistakenly believed that heart failure means that the heart stops beating, confusing the condition with a cardiac arrest.²⁰ The Foundation developed a symptom checker which includes the main symptoms of heart failure to help patients evaluate potential symptoms and serve as a basis for discussion with a healthcare professional.²¹

While progress to increase the awareness of heart failure has been made, there is clearly still a need for education to help people in recognising the symptoms of heart failure so they can seek the treatment they need. Our research found that, on average, it takes three weeks after developing symptoms for people to first visit a healthcare professional.²² There is also a clear gender divide, with females seeking help at four weeks, almost twice as long as males.²³ It is also more common for older generations to hold off longer, with those aged 60 – 69 year olds waiting over 6 weeks to seek help after developing symptoms.²⁴

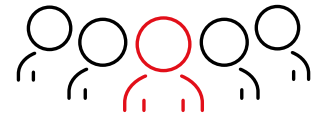
Misdiagnosis of heart failure

Our research also found that 1 in 5 patients receive an incorrect diagnosis by a medical professional before being diagnosed with heart failure.²⁵ Asthma is the most common condition that is incorrectly diagnosed for heart failure, with a third receiving this misdiagnosis (32%), followed by anxiety or depression (29%) and chronic obstructive pulmonary disease (25%).²⁶ Use of tests, such as N-terminal-pro B-type natriuretic peptide (NT-proBNP) and Electrocardiogram (ECG) in General Practice can help triage patients suspected of having heart failure.²⁷ NT-proBNP is part of the enhanced community care initiative to increase access to diagnostics for GPs and funding is being provided to public laboratories for the provision of a ring-fenced direct NT-proBNP service to GPs.²⁸

Confidence among clinicians to diagnose heart failure is often low, with a study finding that only 58% of cardiologists, 43% of general physicians and 7% of GP feel confident diagnosing the condition.²⁹

To find out more about the signs and symptoms of heart failure, as well as the support available to heart failure patients, please visit:

<https://irishheart.ie/heart-and-stroke-conditions-a-z/heart-failure/>



1 in 5 patients receive an incorrect diagnosis by a medical professional before being diagnosed with heart failure²⁵

The diagnosis experience - Impact on patients

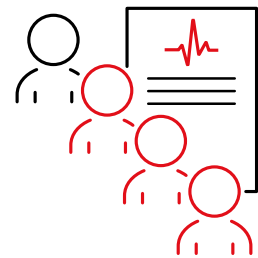
A delayed diagnosis of heart failure can have a significant impact on the quality of a patient's life – it can have considerable emotional, social, and financial impacts.³⁰ In fact, our survey found that 72% of patients acknowledged that their lives would have been better if they had received their diagnosis earlier. This increased to 89% for those aged 30 – 39-years old.³¹

The most identified negative impact of a delayed diagnosis, according to our survey, was mental health, with 70% of respondents saying their emotional wellbeing or mental health was affected.³² This increased to 89% for 30 – 39-year-olds, and females (73%) also experienced a greater mental health impact than males (69%).³³

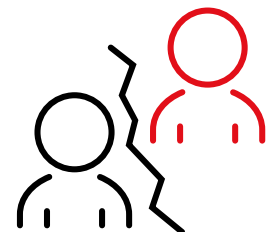
Impact on family and personal lives

It also found that 66% of patients felt that their daily lives were negatively impacted due to the length of time it took to receive a final diagnosis.³⁴ The impact was particularly stark for younger patients, with eight in ten (79%) of 30 – 39-year-olds agreeing their daily life was negatively affected.³⁵ In addition, over half of patients also suffered financial losses (58%) and noted that delayed diagnosis had impacted on their work, with over half (58%) stating that their ability to work had been impacted and over a third (37%) stating their career development was hindered.³⁶

A delayed diagnosis also influences patients' personal relationships and their family life. This is more common for women, with 39% feeling their relationship with their partner was negatively impacted compared with a quarter of men (25%).³⁷ 37% of women also felt that their relationships with their children and family were impacted compared with 25% of men.³⁸ An impact on personal relationships was also more common for those aged 50 – 59 years old, with 42% identifying a negative impact with their partner, wife or husband and 39% stating their relationship with their children or wider family was negatively impacted.³⁹



72% of patients felt their lives would have been better if they had received their diagnosis earlier³¹



39% of women felt their relationship with their partner was negatively impacted by a delayed diagnosis, compared to 25% of men³⁷

Emotional impact

Not having a clear understanding of their condition can impact significantly on the daily lives of patients, and some people will find it very difficult to live with the uncertainty, which can cause patient distress and anxiety.⁴⁰ Our survey found that this is more typical for women, with 43% noting they did not understand their prognosis compared with 35% of males.⁴¹ In addition to this, 28% of patients said they didn't receive support from a HCP while waiting for their diagnosis. Again, this increased for females (38%) compared to males (24%).⁴²

Not only does heart failure cause physical symptoms, but it also causes emotional distress such as anxiety, anger, sadness and depression.⁴³ Management of heart failure should be seen as a shared responsibility between patients, their carers and healthcare professionals, and early recognition of symptoms is key.⁴⁴ Patients and their carers need access to structured support programmes to help build their knowledge and skills required to help patients understand the impact of their condition and so they are guided to the correct tools and services to improve their quality of life.⁴⁵

“People often feel shock, trauma, and isolation after a diagnosis of heart failure, but with the right supports, it is manageable”

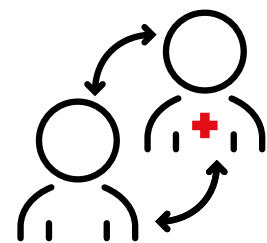
Lucinda McNerney, Irish Heart Foundation.⁴⁶

Receiving a diagnosis – secondary care

Heart failure accounts for around 96,000 outpatient department visits a year⁴⁷ and is also a significant cause of hospital admissions, accounting for 5% of emergency admissions in Ireland.⁴⁸

Where is heart failure diagnosed

The most common method of receiving a diagnosis for heart failure, according to the patients we surveyed, was from a heart specialist (cardiologist) at hospital after a GPs referral (59%), with only a small percentage diagnosed by their GP (2%) and the rest diagnosed by a cardiologist either as an outpatient (27%) or after an emergency admission (11%).⁴⁹ This is in line with the patient pathway. However, females (16%) were also found to be twice as likely to receive their diagnosis from a cardiologist after an admission to the emergency department than males (8%) suggesting that their journey to diagnosis and ability to obtain an early diagnosis may be more challenging.



59% of patients received their diagnosis from a cardiologist after GP referral⁴⁹

Impact of the pandemic

The pandemic has also posed challenges to ensuring an early and accurate diagnosis, with waiting times for cardiac services in secondary care increasing. Due to the current lack of a complete patient registry for heart failure in Ireland, the full impact of this has been difficult to estimate, but even before the pandemic, cardiologists reported waiting times of up to 14 months.⁵⁰ The ICPCD is currently working to build a patient registry which will allow for a greater understanding of the patient population and an evidence-based, person-centred approach to decision making for heart failure patients.⁵¹

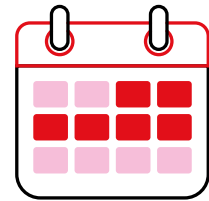
Receiving a diagnosis – primary and community care

It is important that patients are diagnosed with heart failure at the earliest opportunity – a six-month delay in diagnosis has been found to increase the rate of emergency hospitalisation by 23% for those with suspected heart failure.⁵²

Heart failure is notoriously difficult to diagnose.⁵³ Natriuretic peptide testing, including NT-proBNP, is available in hospitals, however availability to GPs has been variable.⁵⁴ Referral to echocardiography has also been a key challenge for GPs, with direct access limited to a small number of hospitals.⁵⁵

Promisingly, recent changes introduced through the Sláintecare Vision, the 2019 GP Agreement and the Winter 2020/2021 plan have meant there has been a push for GPs to have access to these tests. This has resulted in the introduction of the Enhanced Community Care (ECC) Programme, which, since 2021, has been facilitating a phased direct access to NT-proBNP blood testing for GPs for the full adult population.⁵⁶ This will support GPs to triage patients with heart failure for referral, which as part of the Structured Chronic Disease Management Programme (CDM), will allow GPs to better prevent and manage chronic diseases, including heart failure.⁵⁷ Direct referral for echocardiograms is also being made available to GPs in 2022 via the ECC.⁵⁸

These are positive steps to improving the diagnosis of heart failure, however in order to succeed, the planned access to NT-proBNP and echocardiography must be implemented consistently across the country. All GP practices must have access to the right tests to ensure equity of access for all patients regardless of location. Progress so far has been encouraging, but it must be accelerated to ensure access to these tests is available for all patients with suspected heart failure.



A six-month delay in diagnosis has been found to increase the rate of emergency hospitalisation by 23% for those with suspected heart failure⁵²

The future of diagnosis and management



New models of care

The Integrated Care Programme for the Prevention and Management of Chronic Diseases (ICPCD) is driving positive change, creating a new model of care to support easy access to diagnostics and specialist support in the community.⁵⁹ Under their guidance, the National Heart Programme is using this new model of care to implement an integrated cardiovascular service in the community, including empowering GPs to make more decisions around their patients' care.⁶⁰

The national framework for implementation of Ambulatory Care Hubs for chronic disease has been published by the ICPCD.⁶¹ These Hubs are supporting early intervention and specialist care within the community. These began to be established in 2021, with the first phase of 18 hubs being set up in association with 11 large hospitals and 7 new cardiology positions sanctioned to support the process.⁶² The commitment to establishing these care hubs is reiterated in the HSE's 2022 National service plan.⁶³

Heart Failure Virtual Clinics (HFVC) are also providing a knowledge sharing forum between specialists and GPs to improve the integration of services. A "virtual consultation" service is enabling them to discuss cases to determine the appropriate care and need for referral. This has reduced the need for outpatient department referral by 80% and improved GP confidence.⁶⁴

Alongside this, the Structured Chronic Disease Management Programme (CDM) introduced as part of the 2019 GP Agreement is facilitating changes in primary care settings to prevent and manage chronic diseases using a population-approach.⁶⁵ For patients already living with heart failure, the CDM Treatment Programme (TP) facilitates two structured reviews a year to support management of the condition and prevention of potential comorbidities. For eligible patients deemed at risk of cardiovascular disease or type 2 diabetes, they will receive annual CDM Prevention Programme (PP) reviews from their GP. The reviews can involve testing, including NT-proBNP, as well as developing an individual care plan, and providing patients with education around prevention.⁶⁶ Use of this test can also help identify patients with other chronic diseases who are at risk of developing heart failure.⁶⁷

Ultimately, the Programme aims to support early detection of risks for developing chronic diseases, including heart failure, and early detection of complications or new conditions for those with an existing chronic condition.



Heart Failure Virtual Clinics (HFVC) have reduced the need for outpatient department referral by 80%⁶⁴

Future of heart failure diagnosis and treatment

Together, these new policy initiatives provide a positive outlook for the future of heart failure diagnosis and treatment. Following the impact of the COVID-19 pandemic, it will be crucial to ensure that where these programmes have stalled, there is a renewed focus from HSE and policymakers across the health service to ensure their successful implementation.

Learnings from other nations will also be crucial to improving heart failure care in the future and the HSE should consider ways these can be implemented. In Scotland, for example, the Opera early diagnostic initiative for heart failure is using AI and Machine Learning to improve access to heart failure diagnostics in the community. The study is still ongoing, but initial readouts in 2021 found that wait times for investigations were reduced from almost 12 months to less than 12 weeks, and that the corresponding commencement of treatment earlier in the patients' disease has reduced hospitalisation episodes.⁶⁸



In Scotland, the Opera diagnostics initiative has reduced wait times for investigations from 12 months to <12 weeks⁶⁸

Spotlight on: Remote patient monitoring

As part of the ICPCD goal of providing care in the community to support patients to live well with chronic disease, new initiatives to support remote monitoring and self-management are being trialled in Ireland.

This includes the **Sláintecare Heart Optimisation project** in Midland Regional Hospital Portlaoise, where the introduction of an Advanced Nurse Practitioner (ANP) in Cardiology is improving patient access and continuity of care. The project allows remote monitoring of patients' blood pressure, heart rate and weight at home in collaboration with patientMpower, which has empowered patients to self-manage their condition, facilitated early discharge, reduced clinic visits and avoided admissions.⁶⁹

Similarly, a joint research initiative funded by Centric Health and Roche Diagnostics has enrolled over 100 patients across Ireland to the **HeartCare at Home** programme. The programme is providing patients with access to specialist care teams via remote supervision, with patients able to submit their heart rate, blood pressure, weight and symptoms into the HeartCare at Home app.

The patients' GP and cardiologist are kept updated on any changes to the patients' condition and the patient is contacted by a

remote monitoring nurse within 24 hours if any changes are observed. The programme aims to keep patients out of hospital through early intervention. The outcomes for patients, the health service and community are being captured in the research to support understanding of the potential for remote monitoring to transform patient care in the future.⁷⁰ Initial indications from the study suggest remote monitoring substantially reduces GP attendances and hospitalisations. Feedback from patients has been very positive and the programme is providing them with support to understand, manage and control their heart failure independently.⁷¹

Both of these remote monitoring initiatives are designed as Living Labs under the HSE Digital Transformation programme, which through working with external partners, aims to accelerate the co-creation and adoption of digital technology solutions in Ireland – providing a test bed for these initiatives to be trialled. Ultimately, the learnings will be used to deliver better outcomes for heart failure patients.⁷²

COVID-19 and heart failure



The COVID-19 pandemic has affected every aspect of life across Ireland. For those living with heart failure, the impact of the pandemic has presented significant challenges, with our survey finding that a third of respondents felt their symptoms have deteriorated during the pandemic.⁷³

Increased risk from COVID-19

People with heart failure have an increased risk of becoming severely ill from COVID-19⁷⁴ and were classified in the "High Risk" tier by the HSE for COVID-19.⁷⁵ Furthermore, those with a pre-existing heart disease are at a greater risk for severe cardiovascular and respiratory complications from COVID-19⁷⁶ and higher risk of intensive care mortality.⁷⁷ In addition, one year after recovering from their initial infection, COVID-19 survivors have been found to have a 72% higher risk of heart failure.⁷⁸

Being at higher risk has impacted on many aspects of patients' lives – 38% of patients in our survey found their ability to receive support from family and friends had been negatively impacted.⁷⁹

Accessing heart failure services

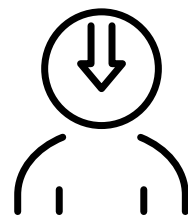
The pandemic also appears to have had an impact on patients' confidence using the health service – our survey found that 28% of patients had cancelled appointments themselves and 39% avoided going to the doctor's altogether, suggesting an increased nervousness in accessing care.⁸⁰ These findings are broadly similar to those of a study report from the TILDA (The Irish longitudinal survey on ageing) research group at Trinity College in 2021.⁸¹

Furthermore, patients experienced difficulties accessing services as a result of the pandemic. Over a third of patients (34%) with heart failure had an appointment cancelled, with this rising to almost three-quarters (72%) for those over 50.⁸² In addition, 42% of survey participants noted having issues regarding picking up prescriptions.⁸³

This has led to a significant personal cost for some patients. 41% felt their quality of life has declined; a significant majority (69%) say their mental health has been negatively impacted, with this increasing to 84% of those aged 30 – 49 years; and 64% responded saying their finances were negatively impacted during the pandemic as a result of having heart failure.⁸⁴



39% avoided going to the doctor's during the pandemic⁸⁰



69% of heart failure patients' mental health worsened during the pandemic⁸⁴

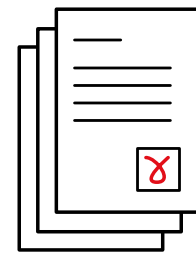
Changes to frontline services

Alongside the impact on patients, the health system has been put under severe pressure during the pandemic and existing services have been disrupted.⁸⁵ This has caused challenges with health service capacity, particularly in primary care settings.⁸⁶

The guidance during the pandemic within Ireland was to ensure that patients with heart failure were cared for in the community, where possible, and to ensure minimal need to visit hospital.⁸⁷

A positive consequence of this guidance was the acceleration of programmes to move care to a more community-based model. Heart failure care was delivered in the first instance through phone or video call contact with the patient's GP during the pandemic.⁸⁸ In particular, the Structured Chronic Disease Management (CDM) Programme was modified in response to the pandemic to facilitate the introduction of remote reviews.⁸⁹ As a result, 120,000 CDM registrations took place in 2020 – almost three times the 43,000 registrations planned.⁹⁰

While there has been significant negative impact on both patients and clinicians, progressive strategies have emerged as a result of the pandemic. However, the impact on primary care capacity and GP burnout is concerning – this has exacerbated issues that existed prior to the pandemic.⁹¹ Without support to retain and expand the GP workforce, ambitions to further implement the move to community care for heart failure may not be realised.



The Structured Chronic Disease Management programme received almost 3x more registrations than planned in 2020 due to the pandemic⁹⁰

Spotlight on: Community support for heart failure patients

By necessity, organisations such as the Irish Heart Foundation have used the restrictions forced by Covid-19 to develop a new brand of online and phone support for heart failure patients. This support is highly cost effective in an area of health service provision that is desperately underfunded and has a wide geographical reach.

Before the pandemic Royal College of Surgeons in Ireland (RCSI) and Irish Heart Foundation research found a growing community of often unsupported heart failure sufferers trying hard to cope with inadequate services, barriers to proper care and a dearth of community supports, particularly psychological support.⁹² The study identified significant levels of anxiety and depression, whilst 30% of heart failure patients reported being socially isolated.⁹³

To begin remedying this, the Irish Heart Foundation is working with the HSE's Chronic Disease Management Programme to deliver online, phone and face-to-face support enabling heart failure patients to live as well as possible in the community. The service helps to pre-empt serious health issues and increases patients' ability to cope with the psychological impact of a condition that is associated with high rates of isolation, anxiety and depression.

The service includes:

- Closed Facebook group moderated seven days a week
- Monthly Zoom meetings emphasising key health messages delivered in cardiac clinics
- Self-management training
- Individual access to health advice from IHF Support Line nurses
- Structured physical activity programmes and group sessions each weekday
- Peer to peer phone support
- Counselling services
- Mindfulness and psychological support programmes

These are essential supports for people living with heart failure and must be integrated into the post-hospital pathway to ensure they are automatically available to anybody requiring them.

The financial cost of heart failure



Heart failure is associated with substantial costs in Ireland – estimates from 2015 found that the Irish Government spends 1.2% of their healthcare budget on heart failure, with a direct cost of €158m.⁹⁴ The same study found that the total cost of heart failure within Ireland was approximately €660m. This cost incorporates the impact of premature deaths, the readmission rates and high number of bed days, as well as indirect costs including informal care, which was estimated to make up €363.4m of this cost.⁹⁵

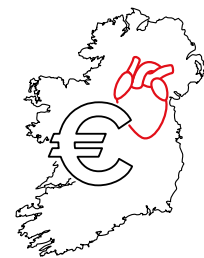
In particular, inpatient stay is a major driver of the cost of heart failure care. An Irish study from 2017 by Morgan and colleagues calculated the cost of a heart failure episode to be €10,474, with ward stay making up €6,068 of this. Other cost drivers include laboratory costs (€1,373) and cath lab costs (€1,415).⁹⁶

Total costs are rising – the prevalence of heart failure is increasing due to an ageing population; more effective treatments; and improved survival.⁹⁷ Investments have been made into a number of heart failure policy initiatives (outlined in more detail in the diagnosis journey section of this report).

Ensuring a prevention and management approach to heart failure in community settings will therefore be crucial to managing the rising cost of heart failure in the future. Delayed diagnosis has a profound impact on costs, with a 6-month delay leading to a 23% increase in emergency hospitalisations and contributing to an increased number of bed days.⁹⁸ Additionally, reducing readmission and overall length of stay for heart failure will also be imperative to finding cost savings in the future.⁹⁹

As discussed earlier in the report, investments have been made in a number of initiatives:

- GPs access to NT Pro-BNP - use of this test has been found to be cost effective as is dependent on the cut off used¹⁰⁰
- Structured Chronic Disease Management (CDM) will receive a total of approximately €80m between 2020-2023 under the CMS contract¹⁰¹
- Ambulatory Care Hubs for Chronic Disease
- Sláintecare Integration Fund - €20m (includes a variety of Heart Failure projects)



The Irish Government spends an estimated 1.2% of their healthcare budget on heart failure⁹⁴



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Changing patient demographics are a challenge to healthcare but have also provided the rationale for a population-based resource allocation, as outlined in the Sláintecare reform programme, which has the potential to improve the predictability and transparency of funding allocations in health.¹⁰² Against this backdrop and the COVID-19 pandemic, the improvement to heart failure care has been dramatic and this is in part thanks to the “remarkable investment” that was made by the HSE.¹⁰³

Spotlight on: Sláintecare Integration Fund

There are a number of initiatives being funded through the Sláintecare Integration Fund which are driving changes to heart failure care in community settings. Examples of these initiatives include:

Heart Failure Virtual Consultation Service project

This innovative approach facilitates real-time, on-line specialist support to GPs, and provides prompt access to diagnostics. With the addition of community based Integrated Care Clinical Nurse Specialists, GPs are enabled to safely manage an at-risk population in the community.¹⁰⁴

The objective of this project is to provide an efficient service for heart failure patients presenting to GPs in the targeted areas, building on the excellent results achieved to date in Carlow-Kilkenny. This extended service will reduce unnecessary referrals to both in-patient and out-patient hospital services, provide improved treatment in the community through CNS-GP aided care, as well as save traveling time for our patients and families.¹⁰⁵

Midlands Regional Hospital Portlaoise’s Heart Optimisation project

This project highlighted in “The future of heart failure diagnosis and management” section of this report, has improved patient access and continuity of care through the introduction of an Advanced Nurse Practitioner in Cardiology.¹⁰⁶

Outcomes have included:

- High-risk patients are now seen within 24 to 48 hours;
- Most patients have an appointment within two weeks;
- Readmission for heart failure reduced by over 80% in patients attending the post discharge heart failure service.

Croí MySláinte

Croí MySláinte is a 12-week Virtual Cardiac Rehabilitation Programme designed for patients and families to support them after a cardiovascular event. The programme is delivered virtually by a specialist, interdisciplinary team (Cardiovascular Nurse Prescriber, Physiotherapist, Dietitian) with sessional Psychology and Cardiologist support.

Outcomes have included:

- 423 virtual consultations conducted;
- 6x increase in physical activity;
- Anxiety and depression levels more than halved;
- Blood pressure control improved from 24% to 68%.¹⁰⁷

Recommendations



Recommendation 1

Development of a new National Cardiovascular Strategy

The previous National Cardiovascular Health Policy 2010 – 2019 has not been replaced since its expiration.¹⁰⁸ A new strategy must include a detailed focus on the symptoms, diagnosis, treatment and management of heart failure and take account of initiatives across the health system to shift cardiovascular care to community settings.

Recommendation 2

Increased focus on prevention of heart failure

A new national cardiovascular strategy must have a focus on prevention of heart failure. This should be in the form of primary prevention activities such as public health education campaigns around healthy eating, exercise, smoking and obesity.¹⁰⁹ In addition, prevention and early detection of heart failure as delivered by the STOP-HF service (St. Vincent's Hospital Group) is another way of improving prevention.¹¹⁰

Recommendation 3

Accelerate access to diagnostic tools in primary care

The planned direct access to NT-proBNP and direct referral for echocardiograms in primary care must be implemented consistently across Ireland. All GP practices must have access to the right tests to improve the early detection of heart failure and reduce emergency hospital admissions. Unavoidable delays have occurred due to the pandemic, but now is the time to accelerate nationwide direct access to NT-proBNP and direct referral for echocardiography to ensure equity of access. Laboratory resources must also be supported to ensure acceleration of the direct NT-proBNP service to all GP practices.

Natriuretic peptide blood tests (like NT-proBNP) can also be measured in patients with type 2 diabetes to determine their risk of developing heart failure.¹¹¹ Through the Chronic disease management programme, patients with type 2 diabetes at risk of heart failure could be identified earlier.

Recommendation 4
Enhanced training on the signs and symptoms of heart failure for healthcare professionals

Greater provision of training is required for GPs to improve awareness of the signs and symptoms of heart failure, use of NT-proBNP and adherence to the referral pathways and guidelines. This should include information to support patients to understand their diagnosis and prognosis, as well as signposting to patient support organisations like the Irish Heart Foundation and Croí.

Recommendation 5
Appropriate provision for emotional and social support for heart failure patients and public education around the symptoms of heart failure

Every patient should have access to psychological therapies, social support and patient and peer support groups such as those operated by the Irish Heart Foundation.

Patients should have access to the right information available to them at the right time to understand the impact of their condition and be guided to the correct tools and services to improve their quality of life.¹¹²

A public education campaign should also be developed to support education of the general public and patients to increase awareness of symptoms and support earlier detection of the condition. This could take the form of something similar to the F.A.S.T. campaign for stroke¹¹³ or the F word (Freedom from Failure) in the UK.¹¹⁴

Recommendation 6
Support for the expansion of innovative diagnosis and management tools

Building on the learnings from recent innovative initiatives to improve the diagnosis and management of heart failure in the community, the HSE should explore ways to roll out successful initiatives nationally. These include virtual consultations, remote patient monitoring, and initiatives funded by the Sláintecare Integration Fund. This could include implementation through the National Heart Programme and Digital Transformation Programme.

If the introduction of virtual clinics are to be effective, some training should be provided to our healthcare professionals involved with delivering this new method of care.

Recommendation 7
Prioritisation of heart failure post COVID-19 to accelerate community care - Stay Left, Shift Left

The recent publication of the waiting list action plan is a welcome development to tackle the increased waiting lists due to the COVID-19 pandemic. The development of a modernised care pathway for deteriorating heart failure, as well as activities such as remote monitoring and virtual consultations, in the plan is welcome.¹¹⁵

Our report highlights a few of the innovative projects which show promise in community care for heart failure. There is now an opportunity to begin to scale these initiatives quickly (when success has been seen), see a return on the investment and free up capacity in secondary care by managing heart failure patients in the most appropriate setting. Acceleration of support for the establishment of the ambulatory care hubs will further improve heart failure care and accelerate the aims of Sláintecare.

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