



Foreword				3
Introduction				4
Under aware				5
Under diagnosed				10
Under treated				15
Under supported				18
How do we change this situation for women in Scotlar	nd?	?		21

Foreword

This report is about the women who are dying needlessly or recovering poorly from heart disease.

Decades of research have transformed the likely outcome for someone suffering a heart attack. In the 1960s standard treatment was bed rest and pain relief, and more than seven out of ten heart attacks in the UK were fatal.

Today these numbers have been reversed so now, on average, seven out of ten people will survive a heart attack. We now better understand the steps which need to be taken when a patient presents with symptoms suggestive of a heart attack. We are better and quicker at running the appropriate diagnostic tests, and we have better techniques available to treat the cause of the heart attack and to prevent another from happening in the future.

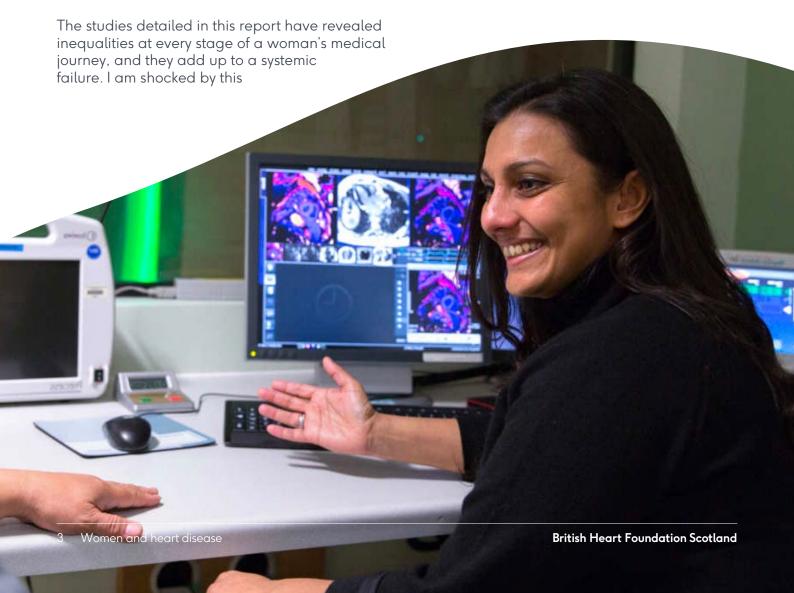
Yet if you're a woman, the odds are stacked differently.

injustice, especially as a cardiologist. Doctors work hard to give their patients the best possible care and no doctor would want half of their patients to be at a disadvantage due to their gender.

It is important to highlight that this is not the fault of any single organisation or individuals. This is a problem which manifests in a series of unconscious biases we all hold. This report is not intended to paint a picture of blame; we want to change the whole public perception of women and heart disease. Our aim is to start a conversation today so that, in the future, more women's lives are saved, and women make a better recovery from heart disease.

Dr Sonya Babu-Narayan

Associate Medical Director, British Heart Foundation



Introduction

Ischaemic heart disease (including heart attacks and angina) is a leading cause of death among women in Scotland—claiming the lives of almost one in ten—or around 2600 women each year. Seven women die every day in Scotland from ischaemic heart disease¹.



What's more, there are around 100,000 women in Scotland today² who are living with ischaemic heart disease. The impact this has on their quality of life is an important consideration.

Ischaemia occurs when blood flow to the heart is reduced, preventing the heart muscle from receiving enough oxygen. Heart attack and angina are symptoms of ischaemic heart disease.

Heart attacks and angina are sometimes thought of as conditions that affect men. This misperception is impacting on the quality of women's lives and, ultimately, costing their lives. At every stage—from the moment they experience symptoms through to their rehabilitation—women with heart disease can face disadvantages.

This has to change. We need to improve understanding of the risks of heart disease for women, encourage women to understand the symptoms of a heart attack, and promote equality of treatment for women with heart disease within the healthcare system, at every point in the journey.

In this report, we have focused on heart attacks and angina as a gateway to this discussion due to the scale of their impact on women in Scotland. However, that is not to say that women with other heart conditions do not face similar challenges. We believe that many of the recommendations in this report will, in time, provide the space for further, more detailed consideration of the issues relevant to women with other types of heart disease.

It is also recognised that women living in areas of social deprivation, or from black and minority ethnic groups may face further challenges and inequalities. Whilst we have not covered that in depth in this report, addressing this should also be at the core of any work on this area.

Seven women die every day in Scotland from ischaemic heart disease.



Under aware

- There is a tendency to think of heart disease as a man's problem
- Lack of awareness of their risk means women often delay seeking medical help when they experience symptoms of a heart attack
- A heart attack is a medical emergency delays in seeking help and receiving treatment are putting women's lives at risk

Under aware

The tendency to think of heart disease as something that affects men may contribute to women underestimating their risk.

We surveyed approximately 1000 women across Scotland about the impact of heart disease on women.

Ischaemic heart disease is a leading cause of death for women in Scotland. However, only 26% of those that responded to our survey identified it as such.

We also found that women were more concerned about their personal risk of breast cancer than their risk of developing ischaemic heart disease (57% vs 51% concerned).

This is despite the fact that ischaemic heart disease kills nearly three times as many women as breast cancer in Scotland.¹

Ischaemic heart disease kills nearly three times as many women as breast cancer in Scotland.

Furthermore, we know that in Scotland women have a worse rate of survival after a heart attack than men³. However 83% of respondents to our survey did not think that this would be the case.

The modifiable risk factors for heart disease are well established: high blood pressure, high cholesterol levels, smoking, obesity and diabetes. A UK study showed that smoking, diabetes and high blood pressure increase the risk of a heart attack more in women than in men⁴.

When we asked respondents to our survey about this, only 15% thought that these risk factors would present a greater risk to women compared to men. Women in Scotland may therefore be underestimating their personal risk of heart attack

The BHF has developed a 'heart age' tool that can be used, in conjunction with checking risk factors to help assess risk.

In addition to a general under awareness about the impacts of heart disease and its risk factors, women may be less likely to recognise the symptoms of a heart attack, often attributing them to a different cause or minimising their importance, and therefore delay seeking help for longer than men do. This means that women typically present to hospital later than men when they are having a heart attack⁵.

A heart attack is a medical emergency, and getting treatment as soon as possible is crucial to survival and long-term health. During a heart attack, blood flow to the heart is disrupted. The longer this goes on, the higher the risk of permanent damage to the heart muscle, risking heart failure or death.

Symptoms of a heart attack can vary from person to person, and everyone needs to know the different ways a heart attack can present.



Gwen Currie was shocked when she had a heart attack in 2011. Then aged 54, she had just returned from an active holiday and was feeling very fit and well. But one day, walking to the post office, Gwen experienced a very heavy feeling in her chest. She knew at once that it was something serious.

Gwen was taken to hospital where she was quickly fitted with a stent as there was narrowing in one of her arteries. After her heart attack, she was told she had high cholesterol and high blood pressure and was prescribed medication. Gwen had follow-up care from a community nurse and attended cardiac rehabilitation, which she found very useful. She made a good recovery but the event shook her confidence.

Gwen says: "The process in hospital is very quick – but you are changed. There is an immediate

fear. What if it happens again? To be honest, that worry never really leaves you, but you learn to live with it.

"I've found that you can regain some of your old confidence, but you constantly have to work on staying positive and not letting this event determine, or limit, the quality and direction of your life."

Gwen was able to return to work as a freelance coach and found that dancing and drama also helped with her recovery.

Symptoms of a heart attack

It's vital to recognise the symptoms of heart attack and seek medical attention fast by dialling 999.

The symptoms of a heart attack can vary from person to person, but the most common signs of a heart attack are:

- Central chest pain or discomfort in your chest that suddenly occurs and doesn't go away
- Feeling sick, sweaty, light-headed or short of breath
- It may feel like pressure, tightness or squeezing



Under aware

We must address this lack of awareness and understanding.

The British Heart Foundation hopes that this report will contribute to raising awareness of heart disease in women.

We also think that it's important that Scottish Government plays a role in raising awareness and understanding of heart disease in women and we would like to work collaboratively to develop these opportunities.

Whilst raising awareness and understanding among women is important, we do not believe that this is solely a matter of personal responsibility. In fact, the responsibility for addressing this challenge is for all of us working in research, health care policy, government and the health care system. Educating and empowering women is only one part of this complex puzzle.

A lack of awareness of the risks of heart attack and angina for women may also be present among health care professionals. Studies from the US and Europe suggest that physicians often classify women as lower risk compared to men^{6,7} and this can have a subsequent impact on whether women receive appropriate treatment.

To accelerate the pace of change in this area, a national Women's Heart Champion could be appointed. This role could feed into the National Advisory Committee on Heart Disease and, where appropriate, into the National Advisory Council on Women and Girls.

One role for the champion could be to scope health care professionals' understanding of heart disease in women and work in collaboration with relevant stakeholders to develop tailored education.

An interesting study from the US highlighted the potential for health care professionals working within obstetrics and gynaecology to play an important role in supporting the work of the American Heart Association in developing

and disseminating female-specific guidelines⁸. Health care professionals working in this field are in a position to identify women with risk factors for future heart disease including: pregnancy complications like pre-eclampsia⁹, gestational diabetes¹⁰, miscarriage¹¹ and early menopause¹².

Appointing a Women's Heart Champion could provide a national point of focus for bringing together different medical professions to enhance collaboration on this issue.

Clinical champions have been utilised successfully in other areas to drive change, most notably with regard to cardiac rehabilitation redesign in Scotland. A national Women's Heart Champion could therefore be a useful step in identifying and addressing the current challenges.





- Women are more likely to face challenges in getting a diagnosis of heart attack or angina
- Some of the tests and tools used for diagnosis are more suited to identifying heart attack and angina in men
- This picture shows that women are disadvantaged compared to men at the outset

Under diagnosed

Diagnosis of heart disease is an important step in a person's health care journey. It allows for appropriate treatment to be given which can improve a person's quality of life or their chances of survival.

We have already highlighted that women typically take longer than men to present to health care with symptoms of heart attack. Once they present, they are less likely to be referred for timely diagnostic tests. A BHF-funded study showed that women who have an NSTEMI (non ST elevation myocardial infarction) – a type of heart attack where the coronary artery is usually partially blocked – are 34% less likely to receive coronary angiography within 72 hours of their first symptoms, compared to men¹⁹.

Coronary angiography is a procedure where a long, thin, flexible tube called a catheter is inserted into a blood vessel in a person's groin or arm. Using X-ray images as a guide, the tip of the catheter is passed up to the heart and coronary arteries. A special type of dye called contrast medium is injected through the catheter and X-ray images (angiograms) are taken. The contrast medium is visible on the angiograms, showing the blood vessels the fluid travels through. This clearly highlights any blood vessels that are narrowed or blocked.

It is a critical step in heart attack care, helping doctors to decide what to do next.

In addition, many of the tests and tools that are used for diagnosis have been more suited to men's biology. A number of researchers are working hard to find ways to change that.

For example, BHF-funded researchers at the University of Edinburgh have carried out work to investigate troponin – a protein that is released from heart muscle when it is damaged – to discover if more sensitive tests could potentially save lives by enabling doctors to detect and treat heart attacks that would previously have gone undiagnosed.

They found that using a higher sensitivity troponin test, which allowed for a lower diagnostic threshold for women to be used, noticeably improved the diagnosis of heart attacks in women¹³. This led national guidelines to recommend higher sensitivity troponin testing on arrival in hospital for people with a suspected heart attack.

Professor Nicholas Mills, Chair of Cardiology, Butler BHF Senior Clinical Research Fellow and Consultant Cardiologist said:



It is clear that using a single troponin level to both rule in and rule out a heart attack in all individuals is too simplistic. Troponin levels differ in men and women, and in those with and without other conditions. To continue to improve outcomes from heart disease we need to recognise this variation and use these tests more effectively to identify and target treatment to those individuals





Jen Stevens was taken to the Royal Infirmary of Edinburgh after collapsing with chest pains, aged 42. Doctors swiftly identified a heart attack thanks to the new troponin test.

"I was having symptoms for six weeks before it happened," explains Jen. "I remember a crampy feeling across my chest and being slightly out of breath. I never for one moment suspected a heart attack. I thought it was a bit of stress or a chest infection. When I was taken into hospital, I didn't know at the time that I was getting a troponin test. Within ten minutes, a nurse appeared and

told me I'd had a cardiac episode. One of my arteries was almost completely blocked."

"Thankfully I have now made a full recovery. I have changed my lifestyle and would advise anyone that if they're even slightly worried about anything please get it checked out. I was incredibly lucky. It could have been very different."

Under diagnosed

We also now know that for some people, the cause of their heart attack and angina differs from the typical pattern of disease, which is a blockage of a large artery in the heart (coronary artery obstruction).

A number of people have heart attacks and angina which are not caused by such a blockage, but rather, by microvascular disease, which is when the problem originates in the small vessels that supply the heart¹⁴.

Previously, when people presented with angina and were shown not to have a blockage in the large coronary arteries visible on their coronary angiogram, they were typically given reassurance that they did not have more serious heart disease.

However, now we understand that some of these people may have microvascular angina. People with microvascular angina still have a raised risk of heart attack, may suffer from anxiety as a result of their chest pain, may have similar physical limitations to those with angina as a result of a blockage in the large coronary arteries, have an impaired quality of life and may spend a lot of time receiving health care for their symptoms^{15,16}.

A higher proportion of people with this pattern of disease are women. More than half of women undergoing coronary angiography are found not to have coronary artery blockage, while this is true for one third of men¹⁷.

Many people with angina without a large coronary artery blockage may be left undiagnosed, and therefore not optimally treated. A number of research studies are looking at techniques and tests to diagnose microvascular angina. At the moment none of these techniques are widely available.

BHF-funded researchers at the University of Glasgow looked at the issue of diagnosis of anginal chest symptoms for people without large coronary artery obstruction in the BHF CorMicA study.

The study found that around half of people referred for invasive coronary angiography with suspected angina did not have any blockages of their large coronary arteries visible on their coronary angiogram.

151 of these people were divided randomly into two groups. Both groups received further tests of the small heart blood vessels (too small to be seen on the angiogram). The test added 15 minutes to the angiogram, which usually lasts up to one hour.

After the tests, the cardiologists looking after patients in the 'treatment' group were shown the test results and were asked to reconsider the patient's diagnosis and treatment plan. The researchers found that patients who received the additional tests with linked treatment had improved outcomes, including less angina and a better quality of life¹⁸.

Therefore, the CorMicA study holds the promise of better diagnosis and better quality of life for people who have microvascular angina, a majority of whom may be women.

Professor Colin Berry, Professor of Cardiology and Imaging (Institute of Cardiovascular & Medical Sciences) told us:

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The BHF CorMicA study is the first to show that tests and treatment for small vessel problems in the heart can make a difference to patients, most of whom are women. We need to be careful to avoid bias in how patients are diagnosed and treated. Women and men should have an equal chance of receiving the correct diagnosis and treatment. This is work in progress.



Mirren Robertson began suffering from chest pain and breathlessness in 2016 while she was on holiday, and went to see her GP. Thinking it might be angina, he prescribed medication but it didn't seem to help so Mirren was sent for further tests.

She was referred to the Golden Jubilee National Hospital, where she was offered the opportunity to take part in the BHF-funded research project in the case study above, working on a new test to improve diagnosis of 'hidden' heart diseases caused by problems with the smaller blood vessels supplying the heart.

Mirren says: "I was so lucky to be sent to the Golden Jubilee, where this research was taking place. I was involved in the research for about a year – they were looking for people like me who appeared to have angina but results of traditional tests were unremarkable.

"When they told me I have microvascular angina, and it is treatable, it lifted a weight off my shoulders. I've always been a busy person and now I'm back to enjoying my usual activities, walking and volunteering. I know how to look after my symptoms, so I feel much happier and more confident. Life is good."



Under treated

- There is some evidence that women don't receive the same standard of care as men when they have a heart attack
- Small differences across their pathway of care added up to create significant gender gaps in the treatment of heart attack
- Understanding the root causes of these disparities will be a vital way to improve heart attack care for women

Under treated

There is some evidence to suggest that women with heart disease face inequality in treatment.

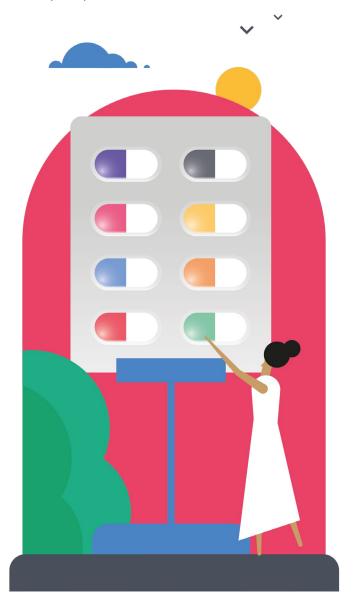
BHF-funded researchers at the University of Leeds looked at quality indicators recommended by the European Society of Cardiology. These are recommended life saving treatments for people who have a heart attack.

The researchers mapped these indicators against the data held by the Myocardial Infarction National Audit Programme (MINAP) and found that women were less likely to receive 13 of the 16 recommended quality indicators after they had a heart attack, including:

- Women who have a STEMI (ST elevation myocardial infarction) – a heart attack where the coronary artery is completely blocked – were 2.7 per cent less likely to receive timely reperfusion (restoration of blood flow, using procedures such as drugs or stents) than men.
- Women who have an NSTEMI a heart attack more usually caused by a partially blocked coronary artery – were 34 per cent less likely to receive a coronary angiography imaging test within 72 hours of their hospital admission.
- Women were less likely to be prescribed several drugs that help to reduce the chance of a second heart attack.
- They were 4.2 per cent less likely to receive dual antiplatelet therapy—this involves taking two antiplatelet drugs, often aspirin and an antiplatelet agent.
- They were 2.7 per cent less likely to be prescribed statins and 7.4 per cent less likely to be prescribed beta-blockers.

The conclusion of this study was that there are systematic differences in the use of evidence-based medicine that disadvantages women and that a greater attention to the delivery of guideline recommended care for women having a heart attack has the potential to reduce avoidable deaths among women.

This paper estimated that if parity was achieved, 8243 female deaths in England and Wales over a ten-year period could have been avoided¹⁹.



Under treated

Professor Chris Gale, Professor of Cardiovascular Medicine at the University of Leeds and Honorary Consultant Cardiologist said:

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We know women are dying due to unequal heart attack care – and now we've identified the shortfalls we need to target to save lives.

For example, women not receiving coronary angiography when they arrive at hospital puts them at a disadvantage right from the start, and has knock on effects creating further shortfalls down the line. In isolation the differences may appear small, but even in a high performing health system like the UK, small deficits in care across a population add up to reveal a much larger problem and a significant loss of life.

It is not wholly clear what underpins this inequality in treatment but the authors suggest that it is likely to be a mix of 'biology and bias'.

There are two issues here for Scotland. The first is that we must improve our data collection and linkage. The second is that we must find a way to address the unconscious bias that may contribute to the under diagnosis and under treatment of women with heart disease.

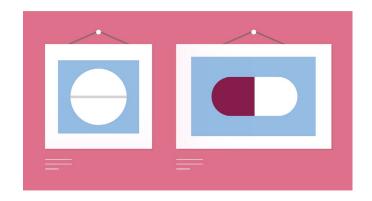
Let's address the data issue first. England and Wales collect data for the Myocardial Infarction National Audit Programme. This is a registry of data about the health care journey of people who receive treatment for a heart attack. Scotland has recently agreed to contribute to this audit, but currently the system for reporting contemporary secondary care activities and

related patient outcomes is not joined up. This has limited the ability for similar quality improvement work to take place here and it is vital that Scottish Government addresses this.

In the West of Scotland, a project supported by the National Advisory Committee on Heart Disease linked secondary care electronic records for patients hospitalised with a heart attack²⁰. The creation of this e-registry enabled analysis of heart attack hospitalisations and could have important implications for quality improvement and research.

Although this is a wider issue, we believe that it would have a transformational impact in supporting health care professionals to identify and address where gaps in treatment between men and women exist in Scotland.

Now let's move on to the bias. Addressing unconscious bias is a significant challenge. The national Women's Heart Champion could work to address unconscious bias through identifying the challenges, drawing attention to the real life impact that it has and working to support the implementation of guideline recommended care for women.



A study found that women were less likely to be prescribed drugs that help to reduce the chance of a second heart attack.



Under supported

- The proportion of women recruited to cardiac rehabilitation programmes is lower than expected
- Women may have different needs and preferences for cardiac rehabilitation
- Modernisation of cardiac rehabilitation services could support personalised care

Under supported

Cardiac rehabilitation is a programme of exercise and information sessions to help people in their recovery from a heart attack, heart surgery or procedure.

Cardiac rehabilitation programmes can help people to understand their condition, support their recovery from a heart attack or heart surgery, and encourage and support them to make lifestyle changes to improve their heart health.

Across the UK, the proportion of women recruited to cardiac rehabilitation programmes from those eligible is lower than expected. Women from certain ethnic backgrounds are also less likely to attend²¹.

There is no easily accessible national data for cardiac rehabilitation currently available in Scotland. It will be important to include cardiac rehabilitation journeys and outcomes as part of any data collection and linkage work that takes place in Scotland.

The reasons women may not attend cardiac rehabilitation include that they have divergent views on their rehabilitation needs and preferences for how exercise, group interaction and emotional support aspects of these programmes are delivered. Other factors include old age, obesity, and severity of the disease, comorbidity, and family obligations²². There is increasing recognition that cardiac rehabilitation services should be more patient-led and make use of digital technology in order to support individuals to personalise the care they receive to their needs.

The Scottish Government has recognised the need to modernise cardiac rehabilitation services and the development of self-management programmes for patients with heart disease, creating a 2020 vision statement for cardiac rehabilitation in Scotland which states:

"Cardiac rehabilitation will be delivered by an

integrated, clinically competent, multi-disciplinary team with a central focus on specialised assessment providing an individualised programme of care to improve patient outcomes."

The modernisation of cardiac rehabilitation in Scotland has been driven by a Cardiac Rehabilitation Clinical Champion within Scottish Government. This service redesign is an opportunity to consider the ways in which such programmes can be improved for women and ensure that changes are evaluated with women's engagement in mind.

It is important that the barriers facing women are addressed and the impact that redesign has on women's attendance, engagement and outcomes is measured.

Frances Divers, Cardiac Rehabilitation Clinical Champion for Scotland and Cardiology Nurse Consultant told us:

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The redesign of cardiac rehabilitation in Scotland has looked to provide a much more individualised experience for people. This has meant more focus on the assessment at the beginning to ensure that we can best tailor the service to people's needs.

This is important for many groups, including women, who may have different needs and preferences. We are moving towards a model that is much more personalised and flexible in order to address some of the barriers to participation.



Margaret Davis had a heart attack in May 2018 while on holiday in the Lake District. She was taken to hospital and diagnosed with a SCAD — a spontaneous coronary artery dissection — when a tear appears in the wall of a coronary artery, which supplies blood to the heart. It can lead to a heart attack, heart failure, cardiac arrest and can be fatal. Margaret later underwent cardiac rehabilitation.

"My first thought was that my life was over," explains Margaret. "That I wouldn't be able to do all the things I used to, like work or boxercise three times a week or go out. I couldn't believe it. A heart attack—that wasn't possible? I was fit, healthy, happy. I had never had any heart, blood pressure or cholesterol problems. I was in total shock. I felt lost, scared and alone."

"However the cardiac rehabilitation team at my local hospital were fantastic. They not only offered to work with me but went to exceptional lengths to explain how cardiac rehabilitation could help me. The team rightly identified that I was living in fear and was terrified to move – mental rehabilitation is as important as physical. They knew I loved to dance and gently restored my confidence. I had to learn to live again – the easiest thing would have been to wrap myself up in cotton wool and stop doing everything I had done before. I had to force myself back out there but I'm glad I did.

The doctors saved my life but the cardiac rehabilitation team gave me my life back."

How do we change this situation for women in Scotland?

There is a clear need to accelerate change in the awareness, diagnosis, treatment and support of women with heart disease.

We believe that there are five key areas which should be addressed to achieve this. These are:

- Improved awareness among the public and health care professionals of heart disease in women.
- Improved data collection and linkage for heart disease.
- A review of SIGN guidelines on heart disease to identify and address any relevant gaps relating to sex-specific issues.
- The modernisation of cardiac rehabilitation to ensure that everyone can access personalised, responsive and flexible services suited to their needs.
- The appointment of a national Women's Heart Champion to implement these changes.

Improved awareness among the public and health care professionals of heart disease in women.

The British Heart Foundation is committed to raising awareness about heart disease in women.

We call on other stakeholders, including Scottish Government, to join and support us in this effort. In particular, we believe that this could form a key part of the role of a national Women's Heart Champion.

Improved data collection and linkage for heart disease

In order to support these changes in an evidence based way, we must address the lack of comprehensive, linked data on patient journeys and outcomes for heart disease in Scotland. This is a broader issue, but could provide important insight into the specific issues that must be addressed to improve outcomes for women with heart disease.

A review of SIGN guidelines on heart disease to identify and address any relevant gaps relating to sex-specific issues

The under diagnosis, treatment and support of women with heart disease is not a challenge specific to Scotland. Many other countries are grappling with this complex problem. The United States of America has acknowledged and addressed this challenge, driven by the work of the American Heart Association's Go Red for Women

programme²³, which is a comprehensive and strategic approach to challenging heart disease in women.

As part of this, in 2004, evidence based guidelines for health care providers were published, addressing primary and secondary prevention strategies specifically for women.

We believe that it would be appropriate for a review of current guidelines on heart disease in Scotland to identify and address if there are gaps relating to sex-specific issues, or conditions that disproportionately affect women. This work could be led by the national Women's Heart Champion.

The modernisation of cardiac rehabilitation to ensure that everyone can access personalised, responsive and flexible services suited to their needs.

Cardiac rehabilitation services in Scotland are undergoing a period of redesign to ensure that they are personalised, modern and responsive to individuals' needs. As part of this, it would be useful if the impact that this redesign has on women's engagement and outcomes was measured and reported.

A national Women's Heart Champion should work closely with the Cardiac Rehabilitation Clinical Champion to support and promote the changes to cardiac rehabilitation and to support in understanding the impact that this has for women in Scotland.

The appointment of a Women's Heart Champion to facilitate and implement these changes.

We have previously detailed the success that Scotland has had through the appointment of clinical champions to accelerate change in service delivery, notably in the field of cardiac rehabilitation. We believe that a similar role could drive forward the necessary changes to support increasing awareness among the general public and health care professionals, take an evidence based approach to advocating for

the improvement of diagnosis and treatment for women with heart disease, and support in the development of evidence based guidelines for heart disease to ensure that sex-specific issues are considered.

Conclusion

The responsibility for tackling this inequality is on all of us, and the British Heart Foundation is committed to working with partners to face the challenge.

Many women are dying, or recovering poorly, from heart disease where this might be avoided. This report does not seek to blame or cause division, but is instead a rallying call for everyone to work together to address the inequalities faced by women with heart disease.

In doing so, we can ensure that in the future, gender does not define a woman's chance of survival from heart disease.



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