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Endorsements







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Foreword

Heart Disease remains a major cause of death and ill health in Scotland.

Thanks to improvements in how we treat heart attacks and other acute events, more people than ever are surviving. While this progress is welcome, heart disease is far from being solved and action is needed now to improve the treatment and support of the increasing number of people who are living with the long-term impacts of cardiac conditions.

This document sets out a vision for the next steps in improving the prevention of heart disease, as well as the diagnosis, treatment, and care of those affected by heart disease.

Central to the development of this vision has been the collaboration and input of the clinical community, patients, and the public. In particular, we would like to thank the members of the Strategy Development Group (SDG) for their time, knowledge and expertise. As a group of professionals, representative of the multidisciplinary team that is key to the provision of cardiology services in the modern NHS, their willingness to engage and their ability to collaborate brought forward new ideas, sensible suggestions and compromise where necessary to balance idealism with pragmatism and provide a realistic template to improve Cardiology Care in Scotland.

The strategy document has three themes, each containing a number of priorities and actions. Firstly, this strategy is built upon the need to improve the prevention of heart disease through the diagnosis and management of key risk factors. There is also a focus on actions to enable seamless, timely access to pathways of diagnosis, treatment and long-term management. Finally, the document highlights the need for investment in digital health systems to better support the collection and use of clinical data for the management, development and improvement of Cardiology services.

This strategy consolidates and builds on previous strategies plus recent developments in NHS Scotland which have brought tremendous advances in the management of heart disease in Scotland. The new strategy demonstrates that research, knowledge and improved technology highlight the need for continuing service improvement.

It is our hope that the clear vision and framework set out in this document provides the impetus to those who determine healthcare priorities in Scotland to focus on this vital issue and release the investment that is required to tackle heart disease. Ultimately, we hope that the actions outlined will drive improvements that will support the thousands of people affected by heart disease in Scotland.

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1. Introduction

1.1 Background and Context

Heart disease remains a significant problem in Scotland.

There have been improvements in survival from heart attacks and other acute events over the last half century. However significant challenges remain. The reduction in deaths from heart attacks means that more people are living with heart disease as a long-term condition. Combined with this, larger numbers of people are living into old age, increasingly people are living with associated comorbidities requiring extensive, long-term support; the numbers of people living with risk factors continue to increase, and health inequalities persist and, in some cases, have worsened.²

It is vital that national plans to tackle heart disease seek to address these challenges and keep pace with the changing needs of people living with heart disease. This underpins the development of this plan.

The Covid-19 pandemic has brought this into even sharper focus, having had a significant impact on people with heart disease and on the services that support them. A recent study of severe Covid-19 cases across the UK revealed that the most common comorbidity is chronic heart disease (29%).³ Ischaemic (coronary) heart disease has been the second most common pre-existing condition for Covid-19 fatalities in Scotland, behind dementia and Alzheimer's disease.^{4.5}

Tackling the threat posed by Covid-19 has meant that healthcare services have had to be creative, resilient and innovative about how they can provide the right support to patients at this time. The use of technology and care closer to home has been vital to maintaining care throughout the crisis and has important lessons for delivering person-centred care in the future. An appropriate long-term framework must be in place to enable evaluation and wider adoption of those innovations deemed to be successful and efficient in a way that ensures equitable delivery of evidence-based diagnosis, treatment and care for people with heart disease.

Health inequalities, already significant in Scotland, have increased during the pandemic as Covid-19 has had a disproportionate impact on people living in areas of socioeconomic deprivation,⁶ and on people from black, Asian or minority ethnic backgrounds. The health service acting alone cannot reduce these inequalities but can help by delivering person-centred care through efforts to engage more effectively with people from disadvantaged groups. The move towards digital services and the use of technology in the delivery of care, could widen health inequalities. This must be considered in the implementation and evaluation of such models.

This plan addresses the needs of people with, and those at risk of developing, heart disease. It does not directly address diabetes or other cardiovascular conditions such as stroke. These are addressed separately in <u>A Healthier Future:</u> type 2 Diabetes Prevention, Early Detection and Intervention Framework and The Stroke Improvement Plan, overseen by the National Diabetes Group, and the National Advisory Committee on Stroke, correspondingly.

Despite this, there are many common themes in providing timely and equitable care for people with all cardiovascular conditions and many people live with more than one condition so collaborative working is necessary, and many actions may be applicable across boundaries.

Similarly, this plan focuses on the provision of diagnosis, treatment and care for people with heart disease and does not specifically address wider societal public health measures as several policy commitments exist in Scotland in relation to this. This does not diminish the importance of such measures. This plan supports the measures set out in Raising Scotland's Tobacco-Free Generation: Tobacco Control Action Plan 2018; A Healthier Future: Scotland's Diet & Healthy Weight Delivery Plan 2018; A More Active Scotland: Scotland's Physical Activity Delivery Plan 2018; Cleaner Air for Scotland: The Road to a Healthier Future and deems it to be vital that those commitments are implemented. In 2020, ten charities, including British Heart Foundation Scotland produced a <u>document</u> calling for further action in this area.



Heart and circulatory diseases kill 3 in 10 people in Scotland

1.2 The Scale of the Problem in Scotland

Heart disease remains a major cause of death and disability in Scotland, accounting for around 10,000 deaths each year. There has been a steady rise in life expectancy over decades, but this has recently stalled, partly due to a slowdown in the progress in reducing mortality from heart disease, especially in people between the ages of 55 and 74.8

Ischaemic heart disease, which can lead to a heart attack, is still Scotland's single biggest killer, responsible for 11.3% of all deaths in 2018.9 It accounts for 25,000 hospital admissions each year.10

Other forms of heart disease also have a significant and growing impact on people in Scotland. The incidence of conditions like heart failure, heart valve disease and atrial fibrillation are increasing, partly as a result of an ageing population, improved detection and increased survival from acute coronary events. Many people are living longer with heart disease and require care and support for significant lengths of time.

- 46,000 people have been diagnosed with heart failure in primary care. 13
- Around 73,000 people are estimated to have non-rheumatic heart valve disease.¹⁴
- More than 100,000 people have been diagnosed with atrial fibrillation. 15

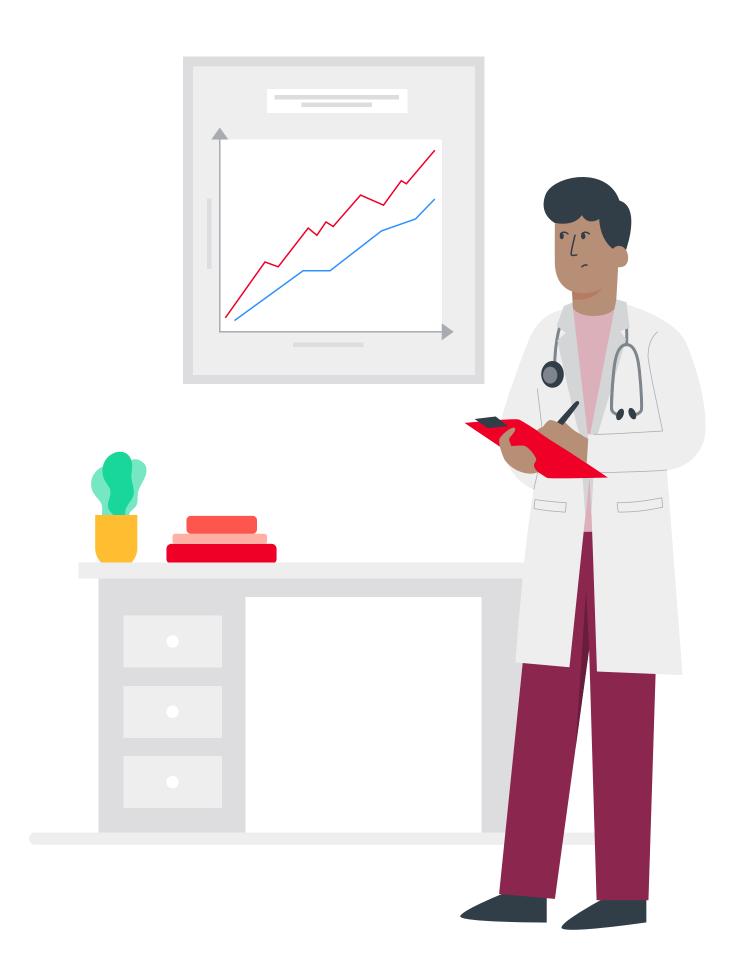
There is also a need to consider less common, but no less important conditions, such as congenital heart disease and inherited heart conditions.

- Around 28,000 people in Scotland have an inherited heart condition, the most common of which is hypertrophic cardiomyopathy.¹⁶
- Congenital heart disease is one of the most common birth defects in Scotland, affecting around one in every 150 births. Improved survival rates mean that a growing number of people are living into adulthood with congenital heart disease.¹⁷

The Covid-19 pandemic is likely to have a longer-term impact on mortality and morbidity as people with heart disease have an increased risk of complications when infected with Covid-19. Furthermore, during the lockdown period of the pandemic, overall attendance at A&E decreased18 and this period coincided with a 30% decrease in emergency cardiology admissions in Scotland.¹⁹ There was also a deferral and reduction of other services, including diagnostics, access to specialist support in the community and cardiac rehabilitation. There are concerns that all of this will have implications for mortality and morbidity for people with heart disease and result in an increase in the number of people who require continued support from the health system. The long-term impact of this should be monitored and considered carefully throughout the delivery of this plan.



Heart and circulatory diseases cause nearly **50 deaths** each day in Scotland



1.3 Policy Context

This plan seeks to address the challenges detailed in the previous two sections in ways that are closely aligned with the vision and principles of the National Clinical Strategy which are: a focus on quality, change guided by evidence, allowing people and communities to manage their own health, new models of community-based provision, equitable access, encouraging collaboration and the establishment of a new clinical paradigm of <u>realistic medicine</u>.

Realistic medicine aims to put the person receiving care at the centre of decision making through meaningful conversations around what matters most to people, with a shared understanding of what healthcare might realistically contribute to this. This ethos of realistic medicine is reflected within this plan in the need to co-produce pathways to support identification of unwarranted variation, build consideration of inequalities and patient experience into the evaluation of new models of care, and in establishing a culture of supported improvement.

To deliver the shift towards models of communitybased provision, this plan considers a whole system approach which encompasses primary, secondary and specialist care within the development of pathways and seeks to incorporate the principles set in the General Medical Services Contract 2018 which builds on the strengths of general practice and moves towards more collaborative working across general practice clusters, sets the GP as a senior leader in the community, with care provided by a multidisciplinary team of health and social care professionals. The establishment of GP clusters was designed to support quality assurance and improvement through peer review and working with the wider system including Health and Social Care Partnerships (HSCPs). HSCPs are responsible for the planning and commissioning of primary care services in Scotland.

The rapid development of the use of telemedicine necessitates that work on this plan aligns with Scotland's Digital Health and Care Strategy: <u>Enabling, Connecting and Empowering</u> which aims to empower citizens to better manage their health and wellbeing, support independent living and gain access to services through digital means. It has a focus on service transformation and prioritises the delivery of remote monitoring of long-term conditions within priority pathways of care. The response to Covid-19 has accelerated work in this area in order to maintain services during social distancing. It is important to support the continued adoption of this transformation at scale and pace, while ensuring that changes are evaluated carefully to assess their impact.

1.4 Vision and Priority Areas

Our Vision

To minimise preventable heart disease and to ensure that everyone with suspected heart disease in Scotland has timely and equitable access to diagnosis, treatment and care that supports them in living well with their condition.

Priority One: Prevention – tackling risk factors

Minimising preventable heart disease by improving the detection, diagnosis and management of risk factors.

Priority Two: Timely and equitable access to diagnosis, treatment and care

Ensuring that everyone with suspected heart disease in Scotland has equitable access to timely and evidence-based diagnosis, treatment and care with all parts of the healthcare system working together to establish this.

Priority Three: Effective collection and use of health data

Ensuring that high-quality, standardised data is available and used effectively to support clinical decision-making, understand patient outcomes and enable better service-planning, so that people experience better quality of care, and improved outcomes.











Shared Strategic Priorities











Scottish Government National Clinical Strategy

Focus on quality

Guided by evidence

Self-management

Community-based provision

Equitable access

Realistic medicine

2. Priority One:

Prevention – tackling risk factors

2.1 Overall Ambition

Minimising preventable heart disease by improving the detection, diagnosis and management of cardiovascular risk factors.

Recommended Actions for Scottish Government

- Collaborate with key partners including the British Heart Foundation to fund and implement a community-based detection and diagnosis programme for high blood pressure and high cholesterol across Scotland which is personcentred, co-designed and incorporates the use of digital technology for home monitoring.
- Improve data collection for all three conditions (high blood pressure, high cholesterol and atrial fibrillation), by developing the SPIRE reports to include high blood pressure and high cholesterol (including familial hypercholesterolaemia (FH)), allowing measurement of diagnosis and management within primary care to support quality improvement. This data should also be made available at national level to support national pathway development.

- Agree national pathways for the detection, diagnosis and management of high blood pressure, familial hypercholesterolaemia and atrial fibrillation and identify relevant indicators for inclusion within the Atlas of Variation to identify variation and set ambitious targets for improvement at a national level.
- 4. GP clusters should be supported to establish baseline measurement of patients within the cluster appropriately treated for atrial fibrillation (AF), high blood pressure and high cholesterol and set appropriate local targets in line with the national ambition agreed as part of the pathway development. These targets should aim to increase the number of people appropriately treated for high blood pressure, atrial fibrillation and high cholesterol over five years with a greater increase seen in SIMD 1 and 2 (areas of highest deprivation) to close inequality gaps.

2.2 Context

Many people in Scotland live with cardiovascular risk factors such as high blood pressure or high cholesterol putting them at increased risk of heart disease or stroke.

Atrial fibrillation (AF), the most commonly diagnosed type of arrhythmia (or irregular heart rhythm), is associated with an up to fivefold increased risk of stroke. Though AF differs slightly from the other risk factors as it is a heart condition with an increased risk of stroke, many of the actions to improve detection, and management of AF in primary care are similar to those required to tackle high blood pressure and high cholesterol and so it is included within this section. Actions on other risk factors such as obesity and smoking are covered in other policy commitments.

It is vital to ensure appropriate detection, diagnosis and optimal management of these risk factors to reduce heart disease and stroke in Scotland. As with all actions within this plan, work in this area must be mindful of health inequalities and actively consider how to provide care in a way that minimises these.



2.2.1 High Blood Pressure

Usually, high blood pressure does not have any symptoms so people may not realise that they have the condition. It is estimated that as many as 610,000 adults in Scotland don't know they have high blood pressure.

Lowering blood pressure significantly reduces the risk of heart and circulatory disease and death.²⁰ Despite this, it is estimated that only 27% of adults with high blood pressure in Scotland have their blood pressure treated and controlled to below the SIGN recommended threshold of 140/90mmHg.²¹

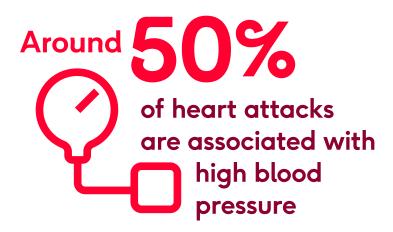
Examples from other countries have shown that community models of detection, diagnosis and management of high blood pressure are effective. Community models of care give an opportunity to consider ways to reach those who may be less likely to engage with healthcare services. Such models should be developed based on engagement with key delivery partners including the third sector and community pharmacy.

Following the implementation of the Cardiovascular Health Awareness Programme it is estimated that 57% of people in Canada who have high blood pressure are treated and controlled to target. ²² If Scotland could reach the equivalent levels of detection and management for high blood pressure, then an estimated 17,000 heart and circulatory events, including heart attacks and strokes, could be avoided over a ten-year period. ²³



Case Study: Canada's Cardiovascular Health Awareness Programme

In Canada, the Cardiovascular Health Awareness Programme introduced integrated community-based cardiovascular health promotion and chronic disease management activities. It did this through partnership with primary care providers, community pharmacists, community groups and locally trained volunteers acting as peer health educators. The programme was associated with a 9% reduction in hospital admissions at population level for stroke, heart attack and heart failure among working age people (under 65), compared to communities that did not implement the programme.²⁴



Innovative ways to support diagnosis and ongoing self-management of high blood pressure are also important. Self-monitoring is an increasingly common part of blood pressure management and can increase adherence to lifestyle changes or medication.

Combining self-monitoring with support from a healthcare professional can result in decreases in blood pressure where self-monitoring alone did not have the same impact. ²⁵ One way in which this additional collaboration might be achieved in a more time efficient manner is through telemonitoring. This is supporting an individual to self-monitor their blood pressure remotely, using a validated monitor with an automatic electronic transmission of data to a healthcare professional.

Any efforts to reshape detection, diagnosis and self-management should build on the work of the Scale-Up BP programme.

There is scope to consider how to incorporate the detection and management of high cholesterol and AF within the models of care described here.



Scale-Up BP is part of the Technology Enabled Care (TEC) programme funded by Scottish Government.

People with suspected high blood pressure are given a validated blood pressure monitor and are prompted regularly to check their blood pressure at home and then asked to text back the readings through a text messaging system. The system informs them immediately if their blood pressure is on target or to contact a doctor or nurse if it is worryingly high. This model can support with diagnosis, and with longer term self-management.





2.2.2 High Cholesterol (Hypercholesterolaemia)

High cholesterol is when there is a higher than normal amount of cholesterol in the blood. It increases the risk of heart disease and stroke.

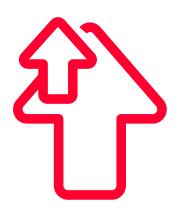
High cholesterol could comfortably fit within models of community detection, diagnosis and supported self-management as described in the previous section on high blood pressure.

The reporting of data about high cholesterol at a national level has been challenging since the Quality Outcomes Framework was discontinued. It is important that the systematic collection of data and resulting improvement opportunities around high cholesterol, cardiovascular risk and possible familial hypercholesterolaemia are improved. This should form part of the development of the SPIRE reporting function discussed in more detail in section 2.2.3.

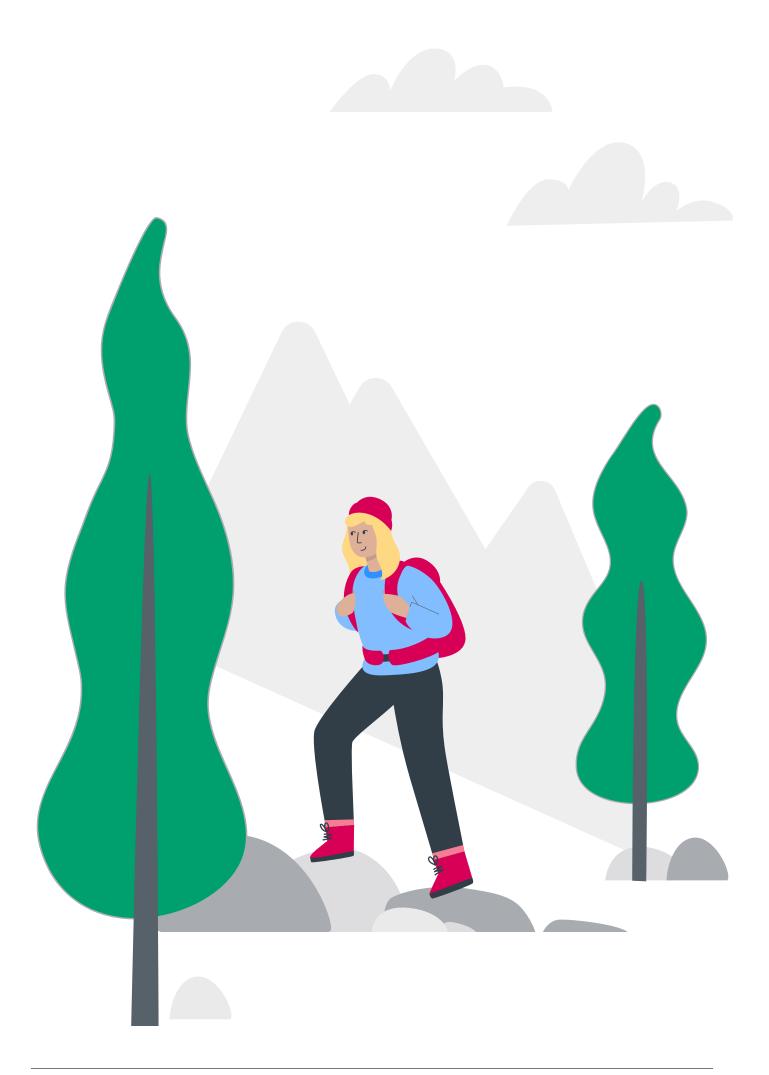
Familial hypercholesterolaemia (FH) is a specific inherited condition characterised by raised blood cholesterol levels and increased risk of early atherosclerosis, heart attack and stroke. ²⁶ Early treatment with lipid-lowering drugs is very important for people with FH. It is estimated that at least 20,000 people in Scotland have FH, but as few as one in 10 have been diagnosed.

Because it is an inherited condition, parents, siblings and children of people with an FH gene mutation possess a 50% chance of having the faulty gene and NICE guidelines recommend a cascade testing system to support identification of FH.²⁷

Across Scotland there are variations in the models for the diagnosis and management of FH. There is also significant variation in access to testing. A more standardised approach, the inclusion of FH within the SPIRE reporting function and the development of quality indicators for FH for inclusion within the Atlas of Variation could support with identification of unwarranted variation and allow for more strategic decisions around service provision.



Familial hypercholesterolaemia (FH) is an inherited condition in which a gene mutation leads to abnormally high cholesterol. At least 20,000 people in Scotland are estimated to have FH



2.2.3 Atrial Fibrillation

Atrial fibrillation (AF) is the most common type of significant arrhythmia (irregular heart rhythm). People with AF are at an increased (up to fivefold) risk of stroke. Many people living in Scotland have AF without even being aware of it, and many more, even after their diagnosis, do not receive the appropriate treatment and support to reduce their risk of stroke.

Population level screening of AF is not currently recommended by the UK Screening Committee. Further evidence as to the most appropriate systematic approach to the detection of asymptomatic AF should be available on conclusion of the SAFER study. It may therefore be appropriate to revisit this area in detail within the timeframe set for the implementation of this plan.

The focus of this section is to address the management of AF within primary care.

SPIRE is the Scottish Primary Care Information Resource. It is a service which allows information to be requested from GP practice records and collected centrally to produce statistics for Scotland as a whole. SPIRE also provides a platform for practices to see information about their patients, through a report on certain conditions. One of the reports in development is for AF. It focuses on identifying people documented as having a diagnosis of AF within their patient record, and determines if that person has received appropriate treatment, based on their risk score.

This information supports GP cluster-level learning, but it would be useful to be able to extract it at national level as part of the development of the Atlas of Variation in order to identify unwarranted variation across Scotland. As part of the national pathway development detailed in Priority Two, baseline measurement of the current rate of appropriate anticoagulation should be determined, and an ambitious Scotland-wide target for improvement set.

This tool could also be used to support improvements in the management of high blood pressure and high cholesterol. SPIRE reports for these conditions should, therefore, also be developed and linked to national pathway development in a similar way.



More than 100,000

people have been diagnosed with atrial fibrillation in Scotland

2.3 Recommended Actions for Scottish Government

- 1. Collaborate with key partners including the British Heart Foundation to fund and implement a community-based detection and diagnosis programme for high blood pressure and high cholesterol across Scotland which is person-centred, co-designed and incorporates the use of digital technology for home monitoring.
- 2. Improve data collection for all three conditions (high blood pressure, high cholesterol and atrial fibrillation), by developing the SPIRE reports to include high blood pressure and high cholesterol (including FH), allowing measurement of diagnosis and management within primary care to support quality improvement. This data should also be made available at national level to support national pathway development.
- 3. Agree national pathways for the detection, diagnosis and management of high blood pressure, familial hypercholesterolaemia and atrial fibrillation and identify relevant indicators for inclusion within the Atlas of Variation to identify variation and set ambitious targets for improvement at a national level.
- 4. GP clusters should be supported to establish baseline measurement of patients within the cluster appropriately treated for AF, high blood pressure and high cholesterol and set appropriate local targets in line with the national ambition agreed as part of the pathway development. These targets should aim to increase the number of people appropriately treated for high blood pressure, atrial fibrillation and high cholesterol over five years with a greater increase seen in SIMD 1 and 2 (areas of highest deprivation) to close inequality gaps.



3. Priority Two:

Timely and equitable access to diagnosis, treatment and care

3.1 Overall Ambition

Everyone with suspected heart disease in Scotland should have equitable access to timely and evidence-based diagnosis, treatment and care.

Recommended Actions for Scottish Government

- 5. The National Advisory Committee on Heart Disease should develop standardised evidencebased national pathways for heart conditions which set out key interventions, timeframes, milestones and outcomes and take a whole systems approach including primary care, acute and specialist care, cardiac rehabilitation, psychological support and palliative care. These should be used to improve equity and reduce unwarranted variation in local pathways.
- 6. A framework to provide practical guidance and resource to support health boards and health and social care partnerships in implementing and evaluating new models of care in line with the agreed pathways should be published and resourced. This must consider the integrated nature of pathways, set out a clear governance

- for their implementation, identify services best planned at regional or national level, address key workforce issues and identify training and education opportunities.
- 7. A sub-group of the National Advisory Committee on Heart Disease should be established to address the workforce requirements of the framework. This group should work closely with key stakeholders to improve the data held by Public Health Scotland on the cardiology workforce. The group should also carry out a gap analysis and make recommendations to the Scottish Government Health Workforce, Leadership and Service Reform Directorate on the workforce requirements of the framework, including training needs and capacity for clinical research.
- 8. A nationally co-ordinated approach to addressing workforce and training issues for physiology services should be taken.

3.2 Context

There are several challenges to achieving timely diagnosis and equitable access to evidence-based treatment, care and support for people with heart disease.

An ageing population, and increased survival from acute events, means that many more people are living with conditions which require long-term support. Increasing numbers of people with congenital heart disease are surviving into adulthood, often requiring complex, lifelong care, while the understanding and improved diagnosis of inherited conditions means more people require access to genetic services for diagnosis and resulting specialist cardiology care.

There are documented challenges in capacity for delivering diagnostic CT coronary angiography in line with current guidelines, ²⁸ and workforce issues within cardiac physiology limit the capacity to provide timely and equitable diagnostic tests including ECG and echocardiography. Work carried out by NHS Education for Scotland's Healthcare Science Team²⁹ highlighted that over the last five years there has been a 46% increase in the demand for cardiac physiology services in NHS Scotland, but vacancies in half of cardiac physiology units across Scotland are at 15%, with a comparable fraction within five years of retiring. Most departments (70%) have one or more vacancies.

Cardiology admissions have increased every year in the last decade,³⁰ with an increase of 25% since 2009 for overall admissions. Within this, emergency admissions have risen 30%.

To ensure capacity within acute services, it is important that where possible, care is provided close to home and seeks to avoid hospital admission. Transformation in models of care, and the use of digital technology to support new ways of interacting with patients, can enable this. The Covid-19 pandemic has accelerated some of this transformation because, in response to the challenges of delivering care during a pandemic, new models of care have been adopted, and digital technology used more widely. The adoption at scale of digital technology will support many of the ambitions of this plan and should be prioritised by Scottish Government. However, it remains important that there is a longer-term framework for delivery of this transformation and an ability to assess the changes and encourage the spread of those that are effective.

Throughout the provision of care for people with heart disease is the need to support people in their recovery and in living well with their condition. Services like cardiac rehabilitation are instrumental to this but are often limited to people who have had a heart attack, cardiac arrest or cardiac surgery. There is scope to consider how to incorporate a wider spread of heart conditions within such services. There is also a need to recognise that heart disease can have a significant impact on people's emotional and psychological wellbeing, and to explore how best to support people in coping with these impacts.

Living well with heart disease also means that where necessary, people are supported at the end of their life. At present, many people who die from heart disease are not considered for a palliative approach, or palliative care when they would benefit from it.





3.3 Integrated Clinical Pathways and a Framework for their Implementation

Integrated clinical pathways will be key to transforming diagnosis, treatment and care for people with heart disease in line with the vision of the National Clinical Strategy. This will involve collaboration, agreeing certain principles of the diagnosis, treatment and care for people with heart disease at national level and a resourced framework to support the implementation of pathways of care across Scotland that align with those principles.

A pathway refers to the varying services and healthcare professionals that a person may encounter throughout their experience of diagnosis, treatment and living with heart disease. Such pathways can differ depending on the condition and can sometimes be complex, involving several professionals and varying tests and interventions. Local areas will have existing pathways, which vary depending on local needs or service availability.

This document refers to nationally-agreed pathways. These are model pathways agreed at a national level that set out the standards regarding the diagnosis, treatment and care for people with heart disease so that local pathway development can be supported through the sharing of best practice and unwarranted variation in local pathways can be identified. They should be comprehensive, covering all heart conditions and services, adhere to SIGN and NICE guidelines, integrate the whole multidisciplinary team by including primary care, acute and specialist care, psychology, cardiac rehabilitation and palliative care as specific domains and be co-produced with healthcare professionals, and people with lived experience of heart disease.

The agreement of model pathways at national level enables the identification of quality indicators based on those. This is the mechanism by which it is possible to identify unwarranted variation in the delivery of pathways across Scotland and support local areas with improvement where necessary. This is discussed in detail in section 4.2.1.

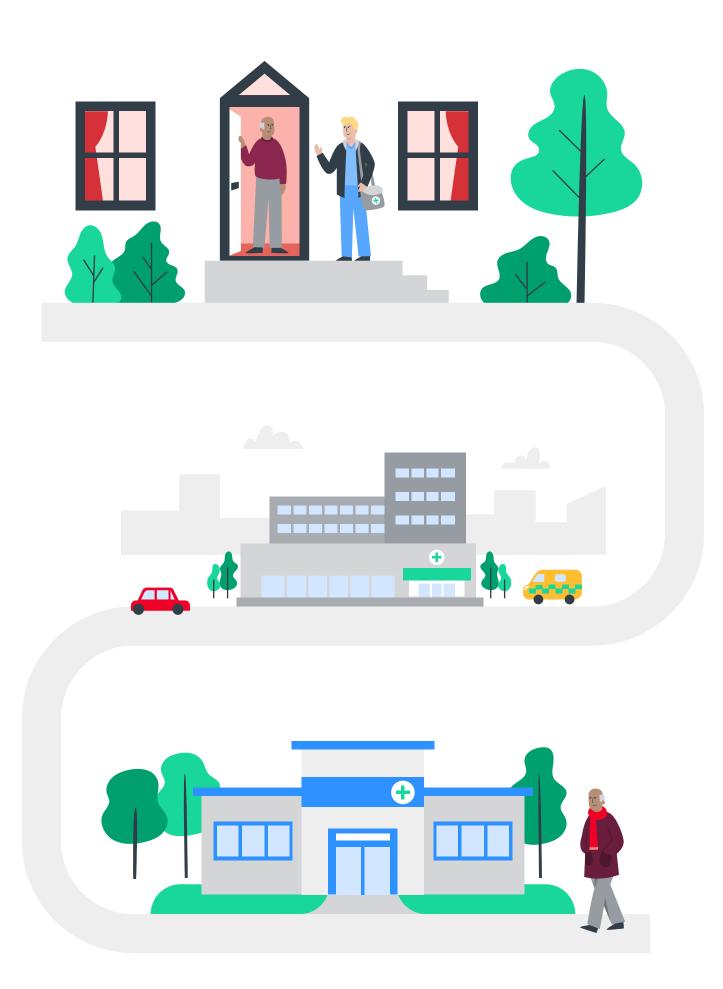
There are several areas where pathway development work is already ongoing. This includes the Scottish Obstetric Cardiology Network's development of pathways of care to ensure that pregnant women with heart disease have access to specialist care and advice; the Heart Failure Hub's remit to continue to maintain up-to-date pathways information; and the Network for Inherited Cardiac Conditions Scotland development of nationally-agreed protocols and

guidelines to support better, safer management of patients with inherited heart conditions. It is possible to learn from this work and support a similar approach across other heart conditions.

Integrated Clinical Pathways and a Framework for their **Implementation**

By the end of the timeline for this plan there should be nationally agreed model pathways relevant to all heart conditions. Each of these should include consideration of the following core aspects (detailed in sections 3.3.1-3.3.7):

- National and local availability of data to support quality improvement, implementation of best practice and identify unwarranted variation.
- Clearly identified integration of care pathways for people navigating the health and care system with multiple long term conditions.
- Equitable access to investigations, procedures, long term support and rehabilitation services regardless of patient postcode.
- Have health inequalities front and centre, when designing systems, services and mechanisms of support.
- Adopt a wider portfolio of modes and methods of interaction and support to maximise patient engagement.



3.3.1 Primary Care

A significant proportion of the care for people with heart disease takes place within primary care and this should be reflected within pathway development. This is vital to achieving the ambition outlined in the National Clinical Strategy of shifting care to the community.

The General Medical Services Contract 2018 sets the vision of the GP as an expert generalist and key influencer in wider healthcare systems approach and develops the wider multidisciplinary team within primary care to support people with

long-term conditions. In order to maximise the opportunities for the management of heart disease it is important that there is substantial primary care representation from local, cluster and national level in the development of these pathways.



3.3.2 Diagnostic Capacity

Diagnostics are an area of concern and have an impact on the timeliness of access to care for people with heart disease. Anecdotally, there is variation across Scotland in access to many diagnostic tests including ECG, echocardiography, Cardiac MRI and CT coronary angiography despite SIGN guidelines recommending standard approaches. For example, SIGN guideline 147³¹ sets out an appropriate approach to echocardiography in people with suspected heart failure, and SIGN guideline 151³² recommends the routine use of CT coronary angiography to aid the diagnosis of stable angina. It is important that we take a more structured approach to collating information on diagnosis at national level to accurately identify unwarranted variation.

New models of care in the provision of diagnostic services for people with heart disease should be included within pathway development. For example, one-stop diagnostic clinics, and the provision of tests like ECGs, blood tests or echocardiography in the community could improve the delivery of timely diagnosis for people with heart disease. An important aspect is ensuring that both primary and acute services have direct referral access to such services.

The GMS contract prioritises the development of community treatment and care services so collaboration with primary care, at local, cluster and national level will be important to the development of community diagnostic models. Scottish Government should identify a strong and appropriate mechanism to bring together those working in primary and secondary care on this issue.

There are significant workforce issues within diagnostics that should be addressed urgently and are discussed in section 3.4.1.



3.3.3 Cardiology Services for the Long-term Management of Heart Disease

Cardiology is a multi-professional discipline with care provided by cardiologists, cardiac surgeons and increasing roles for specialist nurses, physiologists, cardiac scientists, pharmacists and clinical psychologists. Although a high proportion of the workload relates to emergency and urgent care, the speciality of cardiology also provides elective care and long-term disease management which is increasingly provided in the community. How well integrated these services are with those provided by primary care will determine how seamless the experience of care for a person with heart disease will be.

Telemedicine and the shift towards community treatment and care centres (discussed in section 3.2) provide an opportunity to consider how specialist care can be provided in the community. It's important to consider how these new models of care could apply to all health professionals working in the multidisciplinary cardiology team but a useful example to highlight some of the challenges and opportunities in this regard is specialist nurses.

There are many examples of nurse-led models of specialist care for people with heart disease. People with heart failure are supported by the

Scottish Heart Failure Nurse service, many rapid access chest pain clinic services across Scotland are nurse-led, a genetic testing service for hypertrophic cardiomyopathy (HCM) is supported by four specialist nurses and a data analyst across Scotland. There are also examples of nurse-led models of care for FH and arrhythmias in some health boards in Scotland. There is a need to ensure the long-term sustainability of these posts, ensure staff resource is sufficient to deal with increasing capacity and consider whether people with other heart conditions could benefit from similar specialist support.



Case Study:

Development of a Heart Failure Remote Health Pathway

A collaborative approach has been undertaken by clinicians, digital technicians, patients and third sector organisations to develop a remote monitoring pathway specifically for people with newly diagnosed heart failure or unstable symptoms.

Heart failure clinicians remotely monitor a patient's blood pressure, heart rate, bodyweight (in some cases oxygen saturation) and answers to a number of health-related questions. Readings are submitted via an online portal or app.

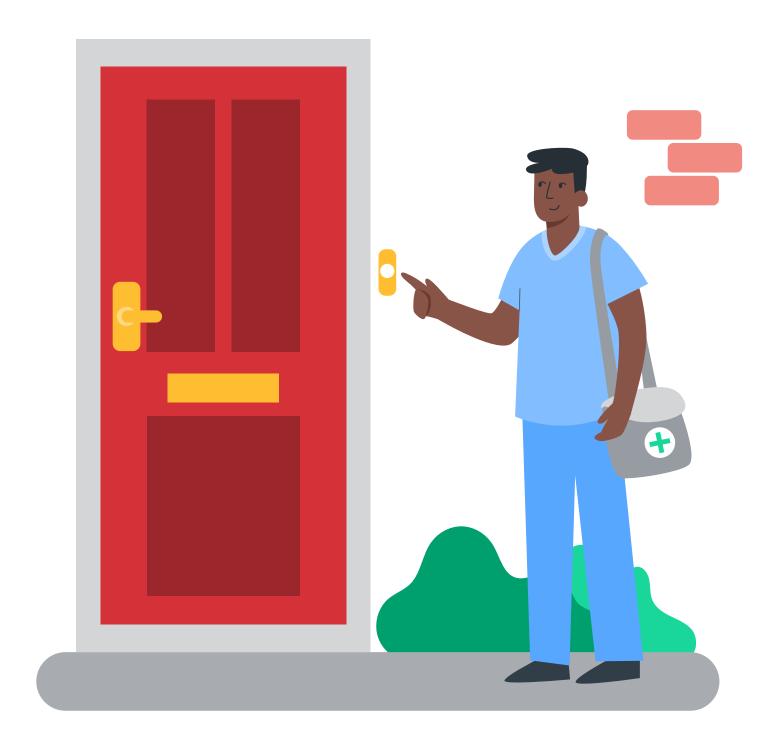
This will allow clinicians to:

- Efficiently optimise treatment for newly diagnosed patients to reduce likelihood of hospitalisation.
- Closer monitor patients with worsening symptoms, intervene earlier to improve quality of life and reduce risk of hospitalisation and premature death.

For example, there is a desire to explore whether the heart failure nurse service could provide specialist support to a wider range of people with, or at risk of developing, heart failure including people with normal ejection fraction (this is described as having heart failure with preserved ejection fraction), adults living with congenital heart disease (for whom heart failure is a common cause of morbidity and mortality), and people with heart valve disease (who may often display symptoms of heart failure such as dyspnoea and fluid retention).

Ensuring capacity to achieve this depends on a two-fold approach involving reshaping models of care and an approach to workforce planning that uses the skills of all professionals within the multidisciplinary team. The latter issue is discussed in section 3.4.1.

Many new models of care, particularly those using technology to support the delivery of care, were introduced or increased in response to the Covid-19 pandemic. It will be important to assess the impact of such innovation and explore the potential for these new models of care to continue and spread.



3.3.4 Cardiac Rehabilitation

Cardiac rehabilitation services are an important part of pathway development. These services provide vital support to help people get back to everyday life as much as possible after developing heart disease including heart attack, heart surgery or for people who have had an interventional procedure.

These services were severely impacted by the Covid-19 pandemic. Many had to implement virtual-only options and others lost services entirely while staff were redeployed. The BHF worked alongside partners including the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) to develop an *online platform* to enable people to access rehabilitation support during the pandemic. Long-term it will be important to maintain digital offerings alongside face-to-face services to improve choice and increase the uptake and reach of services.

The traditional model of cardiac rehabilitation is structured around exercise and education but rates of uptake across the UK have been stagnant and particularly poor among women and those from black and minority ethnic backgrounds. 33 At the moment, the service in Scotland is typically limited to those who have had a heart attack or cardiac revascularisation but the vision set in SIGN 150 is of a service 'with a central focus on a specialist assessment providing an individualised programme of care to improve outcomes'. 34 This provides scope for expanding the reach of the service to people living with other heart conditions if resource and guidance are provided to encourage spread and adoption of new models of care.



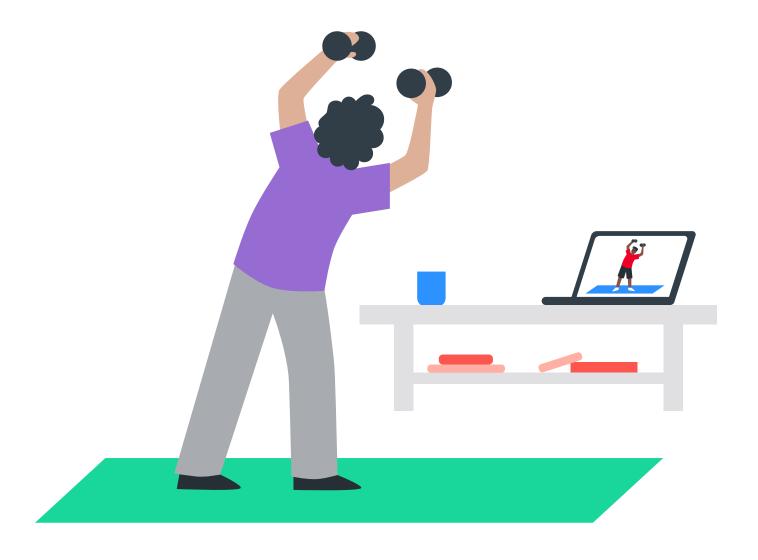
Case Study: Using Digital Solutions to Support Patients

Learning from the accelerated introduction and use of digital and non-traditional methods of support should be used to shape future service delivery models.

A hybrid delivery model of cardiac rehabilitation services (including digital, phone, email and face to face support) should be considered to personalise the offer and method of support throughout the patients rehabilitation journey. Offering a broader range of support methods

may help patients overcome some of the most evidenced barriers to engagement and improve uptake of cardiac rehabilitation services.

Digital information hubs such as the British Heart Foundation Cardiac Rehabilitation at Home have proven to be extremely successful in offering support in conjunction with the expertise of local cardiac rehabilitation teams. With over 90% of surveyed participants stating that the online information makes them feel more confident to do rehabilitation at home.



3.3.5 Psychological and Emotional Support

There is a need to ensure that the psychological and emotional needs of people with heart disease are met. Depression and anxiety are common problems for people with heart disease and are associated with excess mortality, excess disability, greater healthcare expenditures and reduced quality of life.³⁵ The Covid-19 pandemic has further heightened the need for such support.

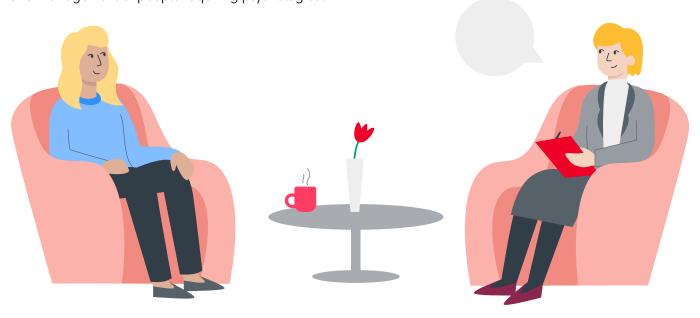
Several guidelines and standards, including those on heart failure³⁶ and cardiac rehabilitation,³⁷ recommend a collaborative stepped care approach to psychological intervention for people living with heart disease. This approach is one in which the least intrusive intervention is provided first. If a person does not benefit from this intervention, or has more severe psychological needs, then they should be offered an appropriate intervention at the correct level of the stepped care approach. Delivery of this approach must form a core part of all pathways for people with heart disease.

Previously, the Scottish National Advanced Heart Failure Service secured funding for a team of psychologists to Improve Access to Psychological Therapy for Heart Failure (IAPT-HF). This project worked within heart failure services to support the delivery of a stepped care approach. It was identified that it is important for those professionals delivering psychological interventions to have regular and routine access to consultation and/or supervision with a suitable practitioner psychologist to optimise the competency and delivery of interventions. Recognition and management of people requiring psychological

intervention peaked when the clinical psychologist was embedded within the HF nursing team suggesting the competencies brought to the team by a clinical psychologist facilitated higher reported levels of psychological care and management.

It therefore stands that to appropriately support the spread and adoption of the stepped care approach, there is a requirement for psychology liaison roles. There are challenges for the psychology workforce identified in section 3.4.1, so these roles may be best organised at regional or national level and in collaboration with efforts to improve psychological provision for other conditions, including stroke.

The development of a framework for the implementation of whole system pathways should therefore include collaboration with the National Advisory Committee on Stroke and the Mental Health Delivery Board to scope the potential for psychological liaison roles to support with the implementation of a stepped care approach to delivery of psychological support for people with long-term conditions.



3.3.6 Palliative Care

Appropriate and optimal palliative care can reduce the number of hospital inpatient days, improve symptom control, increase the likelihood of people dying in the setting of their choice, and improve the satisfaction of the patients and carers.³⁸

Many people who die from heart disease are not considered for a palliative approach, or palliative care when they would benefit from it. Compared to other conditions, people with organ failure, including heart failure, are far less likely to have access to palliative care services or a palliative approach. Of those that died of a terminal illness in 2017/18 only 47% of those with organ failure had a Key Information Summary (KIS) on death, compared to 80% of people with cancer and 78% for those with dementia/frailty. Having a KIS on death is considered a good indicator that a person would have been in receipt of palliative care.

Case Study:
The Caring Together
Programme

This was an innovative partnership programme from Marie Curie, the British Heart Foundation and NHS Greater Glasgow and Clyde to improve the quality of palliative and end of life care for patients in the advanced stages of heart failure. An evaluation in 2016 showed that the programme:⁴¹

- Improved symptoms and quality of life for people with advanced heart failure.
- Provided individual patient planning.
- Reduced hospital admissions and healthcare costs.

The need for access to palliative care is increasingly acknowledged as important for people with advanced heart failure but it is also important to consider how to extend such support to people with other forms of heart disease, including coronary, valvular and congenital heart disease when required. Therefore, the development of all pathways should consider how to ensure the early detection of need for palliative care and the Palliative Care and End of Life National Advisory Group should be invited to collaborate on this development.

Many people with heart disease will be living with cardiac implanted electronic devices (CIEDs), such as an implanted cardioverter defibrillator. As a person moves closer to the end of life it may become appropriate for the device to be switched off. However, many cardiac devices are deactivated too late or not at all. There needs to be sensitive conversations between professionals and patients around deactivating devices and what this means, as well as how these conversations are recorded. This should be addressed within the relevant pathways.



3.3.7 Incorporating Lived Experience

The vision outlined in this document is of co-designed, whole system pathways. Co-design in relation to this plan includes the meaningful engagement of people living with heart disease in decisions about what pathways of care should look like, and the identification of indicators to measure what is important to those who use the services. A robust lived experience engagement process must therefore form a core part of the pathway development detailed here, and of the indicator identification detailed in section 4.2.1.

There is often under-representation of women, people from black and minority ethnic backgrounds, people with disabilities, and those living in areas of socio-economic deprivation in forums where engagement takes place. If we are to seriously address health inequalities and move towards the

provision of equitable care as outlined in the vision for this plan, then we must understand a wide range of lived experience and make a strong and consistent effort to seek and amplify the voices of those typically underrepresented in decision making processes.



3.4 Implementing Pathways Across Scotland – A Framework

The implementation of pathways across Scotland requires spread and adoption of new models of care. Scottish Government has a crucial role in providing leadership, ensuring collaboration and encouraging work across all parts of the healthcare system to drive this forward. The development, publication and resourcing of a framework providing practical guidance and resource to support health boards in implementing and evaluating new models of care in line with the agreed pathways will help achieve this.

The framework must:

- Consider the integrated nature of the pathways.
- Set out clear governance for their implementation.
- Identify services best planned at regional or national level.
- Address key workforce issues which will limit the ability for local areas to deliver on the agreed pathways.
- Identify training and education opportunities for healthcare professionals to support pathway implementation.



3.4.1 Workforce

Implementing pathways for people with heart disease depends on having the appropriate staff resource. A sub-group of the National Advisory Committee should be established to conduct a detailed gap analysis including consideration of age profile, turnover and deficit to ensure appropriate staff resource to deliver on the framework. This will require robust data and intelligence about the workforce. This is currently lacking, particularly in relation to cardiac physiology and specialist nursing across Scotland. A specific effort to improve workforce data in these areas should therefore be a core component of the work of this group, in collaboration with the sub-group focusing on data and quality improvement.

There are several areas of concern around workforce capacity which must be addressed. These are:

- Cardiac Physiology
- Specialist Nursing
- Clinical Psychology
- Research Capacity

A twin approach of reform and investment is encouraged. That is, where possible, the framework should identify and promote or develop models of care that maximise the skills and competencies of the existing multidisciplinary workforce across primary, community and specialist care. It should also identify areas where additional staff resource is required.

Cardiac Physiology

There are crucial workforce issues relating to diagnostic services. A significant shortage of cardiac physiologists impacts on the ability to deliver timely diagnosis, treatment and care for people with heart disease and requires urgent, national action.

In response to similar challenges facing radiology, NHSScotland Shared Services produced a business case that created solutions for IT, connectivity, data management and workforce. This received £3.1 million in funding to implement the solutions through a newly formed National Radiology Implementation Team.

A similarly nationally-coordinated approach is required to address the challenges facing physiology. Steps outlined in the Integrated Workforce Plan to support additional training places on the four-year BSc course in Clinical Physiology and promote recruitment into Scientist Training Programmes and Practitioner BSc Programmes are welcome, but do not go far enough in addressing the shortage in cardiac physiology in order to maintain a sustainable service.

Key stakeholders, including NES Healthcare Science Team, National Advisory Committee on Heart Disease and NHSScotland Shared Services, should be supported to work together to find the best way to provide a 'once for Scotland' approach which will address the current physiology workforce and training crisis.

Specialist Nursing

Several specialist nursing posts (such as the FH and HCM specialist nurses) were initially funded by the BHF and there is a need to develop a plan to sustain and where appropriate extend such posts beyond that initial funding. There are also staff resource capacity issues for some specialist nurse services.

For example, since 2013, all health boards in Scotland have reported an increase in the number of patients living with heart failure enrolled into heart failure nurse services, but this has not corresponded with an increase in staff resource.⁴² This has an immediate implication for the service but also limits the capacity to explore whether people with other heart conditions could benefit from similar specialist support. The development of the framework provides an opportunity for clarity on the competencies and roles of specialist nurses and their interfaces and channels of communication with the wider multidisciplinary team. This includes specialist pharmacists, psychologists, cardiologists and physiologists and those providing generalist care in the expanded primary care team outlined in the GMS contract. This should be set out in line with the *Transforming* Nursing, Midwifery and Health Professionals Roles Programme.

Clinical Psychology

At present, there are few clinical psychologists across Scotland with a remit for providing psychological support for people living with heart disease, therefore support for those providing lower level interventions and potential for referral on for more intensive interventions is limited.

The workforce sub-group should conduct a gap analysis of clinical psychology provision for people with heart disease. This should be carried out in line with the stepped care approach set out within the nationally-agreed pathways and considering the utilisation of the additional 60 clinical psychologists in training, and 800 additional mental health workers in A&E departments and GP practices, committed to in the Integrated Workforce Plan. This should be conducted in collaboration with the Mental Health Delivery Board, which is responsible for implementation of the Mental Health Strategy 2017–2027.



Training

To support the maximisation of roles identified as part of the approach to workforce planning requires a co-ordinated effort to identify appropriate training opportunities for healthcare professionals in line with the framework. Relevant partners, particularly NHS Education for Scotland, should be invited to collaborate with the workforce sub-group of the National Advisory Committee on Heart Disease to ensure that any training needs are identified and addressed.

As part of this, the following should be considered:

- The incorporation of emerging cardiac imaging techniques within radiology and cardiology training programmes.
- Training of professionals who are providing care to people with heart disease to enable them to deliver step one and two of stepped care approach to psychological intervention.
- Training and education around the delivery of telemedicine.
- Training and education across the multidisciplinary team on identification and delivery of palliative care, including device deactivation, for people with heart disease who are approaching end of life.

Research Capacity

Medical research is vital to the ability to drive improvements in care and ensure that people with heart disease have access to the best possible standard of care. While Scotland is renowned for its high-quality cardiovascular research, there are several challenges that should be addressed. One crucial factor enabling a high-quality research environment is the capacity for the clinical workforce to develop, undertake and participate in research.

Currently, those who wish to undertake research only have one block of research time to nine for clinical practise. It is important that this research time is expanded to allow health professionals to undertake vital research.

In addressing workforce issues within cardiology, the National Advisory Committee workforce sub-group should work collaboratively with the Chief Scientist's Office, NHS health boards and the medical research community to ensure that capacity for research is included as a key pillar of the cardiology workforce recommendations.

Another important factor is the ability for people with heart disease to take part in research. Giving people the opportunity to take part in research is an important part in driving improvements in care. The Cancer Patient Experience Survey measures whether opportunities to take part in research have been discussed with individuals, but there is currently no equivalent measurement of whether people with heart disease are offered the opportunity to take part in research. This could be included as part of the indicator work outlined in section 4.2.1 and findings from this should be used to support the National Research Networks to drive improvements in this area.



3.5 Recommended Actions for Scottish Government

- 5. The National Advisory Committee on Heart Disease should develop standardised evidence-based national pathways for heart conditions which set out key interventions, timeframes, milestones and outcomes and take a whole systems approach including primary care, acute and specialist care, cardiac rehabilitation, psychological support and palliative care. These should be used to improve equity and reduce unwarranted variation in local pathways.
- 6. A framework to provide practical guidance and resource to support health boards and health and social care partnerships in implementing and evaluating new models of care in line with the agreed pathways should be published and resourced. This must consider the integrated nature of pathways, set out a clear governance for their implementation, identify services best planned at regional or national level, address key workforce issues and identify training and education opportunities.
- 7. A sub-group of the National Advisory Committee on Heart Disease should be established to address the workforce requirements of the framework. This group should work closely with key stakeholders to improve the data held by Public Health Scotland on the cardiology workforce. The group should also carry out a gap analysis and make recommendations to the Scottish Government Health Workforce, Leadership and Service Reform Directorate on the workforce requirements of the framework, including training needs and capacity for clinical research.
- 8. A nationally co-ordinated approach to addressing workforce and training issues for physiology services should be taken.



4. Priority Three:

Effective collection and use of health data

4.1 Overall Ambition

We want to ensure that high-quality data is used effectively for high-quality research, to support clinical decision-making, understand patient outcomes and enable better service-planning, such that people experience better quality of care, improved outcomes, and a reduction in unwarranted variation.

Recommended Actions for Scottish Government

- Ensure that access to timely, high-quality data
 for research and quality improvement for heart
 disease is financially resourced equivalent to work
 carried out to improve cancer data in Scotland
 and to enable the achievement of the following
 recommended actions.
- 10. Establish and resource a sub-committee of the National Advisory Committee on Heart Disease tasked with supporting a national focus on quality improvement for heart disease through the development of a set of heart disease quality indicators for inclusion with the Atlas of Variation. These should be based on the nationally-agreed pathways.
- Map, streamline and standardise data currently collected relevant to heart disease in Scotland, and identify and address gaps in data collection based on the indicator requirements and secondary care audits including the National Institute for Cardiovascular Outcomes Research (NICOR).
- 12. Establish a National Heart Disease Intelligence
 Platform that enables healthcare professionals
 and researchers to more easily access heart
 disease-related information and intelligence,
 similar to the National Cancer Intelligence
 Platform

4.2 Context

To support all the ambitions and actions in this plan it is necessary for healthcare professionals to have access to a range of information and intelligence to support services and enable improvements in patient outcomes. Improved access to data supports high-quality research and quality improvement.

Providing national leadership and support on this area is crucial. A sub-group of the National Advisory Committee on Heart Disease should be established. This should have a remit for the development of quality indicators based on the nationally-agreed pathways, the identification of appropriate targets or aims that will drive improvements in patient care and outcomes,

the implementation of a governance framework on reporting against these indicators, working with key stakeholders to standardise and collect data relevant to the indicators and ensuring the overall sustainability of quality improvement programmes for heart disease across Scotland.



4.2.1 Quality Indicators

It is important to be able to identify and reduce unwarranted variation to help drive improvements in safe, effective and patient-centred care for people with heart disease across the country. Having a clear and agreed understanding and operational definitions of outcomes-focused, systemwide quality indicators based on nationally-agreed pathways and clinical guidelines supports better understanding of what works well, provides an opportunity for sharing learning and enables evaluation of new models of care. A national approach to collating, analysing and disseminating appropriate information and support for local areas to undertake improvement, in partnership with people with lived experience of heart disease, is also a critical element.

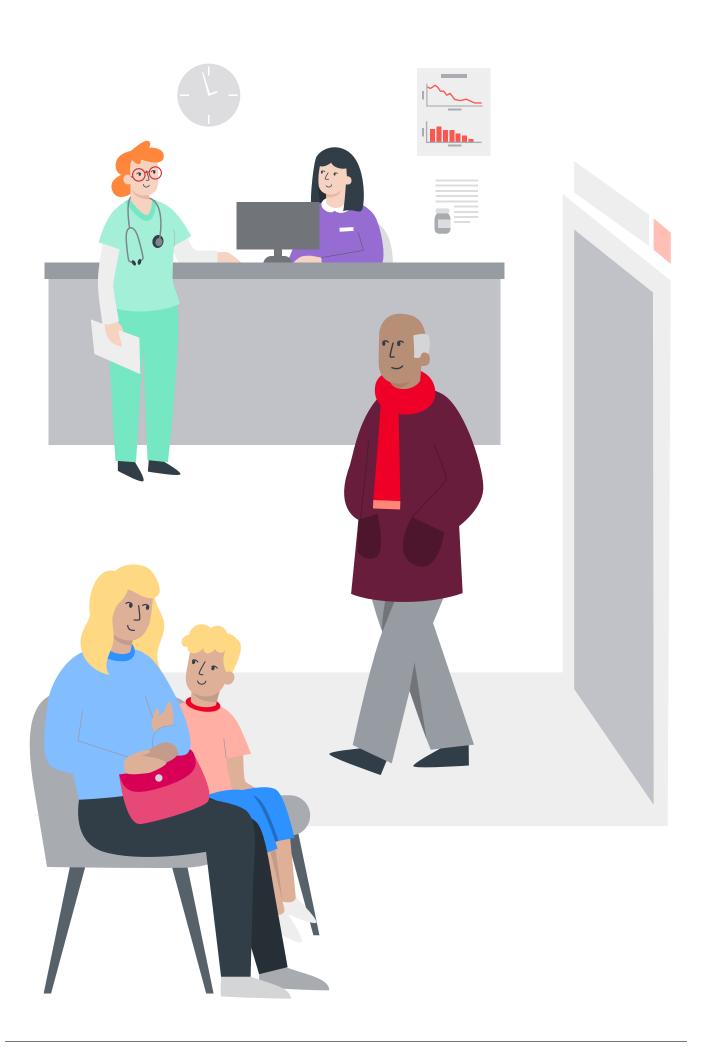
The development of nationally-agreed pathways advocated in Priority Two supports the identification of key timescales, interventions and outcomes which can be measured against to support learning and service development. Such indicator development must be based upon those agreed pathways, should be co-produced with healthcare professionals, people with lived experience of heart disease, GP clusters, health boards or health and social care partnerships to ensure that they are pragmatic and deliverable.

The delivery of truly person-centred care requires careful consideration of any unintended consequences that may widen inequalities and so indicator development, and data collection based on them, must consider this to ensure that addressing inequalities forms a core part of the learning and development of services.

Several cardiac services contribute to UK-wide audits, and it is important that these audits are referenced, and included in the work to develop indicators to avoid duplication and to support wider audit participation where appropriate.



Scotland needs better collection, dissemination and use of data to really drive service improvement.



4.2.2 Data

The ability to measure against those quality indicators, to support learning about services and to participate in wider audit is dependent upon effective use of data from a wide range of sources, including important data collected in primary care and community settings, secondary and tertiary care. There must also be consideration given as to how to incorporate patient experience and input. Linking all this data together where appropriate provides a deeper view of quality across the pathways and provides a perspective of care closer to the patient.

The ability to access high-quality, linked data also provides important opportunities for research which will drive improvements in cardiovascular health. The BHF Data Science Centre was established in 2019 and aims to deliver the data and data science needed to address some of the most pressing challenges in heart and circulatory health research. Utilising data for research helps to uncover improved strategies for prevention, innovative new therapies and medical breakthroughs that will ultimately improve the lives of people affected by cardiovascular disease.

There is an abundance of data relevant to heart disease in Scotland that is routinely collected within the healthcare system. However, it is not always recorded, coded or used consistently and this has significantly limited the ability to identify variation and support learning. Accessibility of data for researchers and healthcare professionals is another often cited barrier. It is crucial to take a national approach to mapping, streamlining and standardising the data currently collected, improving the interoperability of systems in different care systems or across geographical areas and identifying and addressing gaps in data collection based on the indicator requirements.

Similar work has already taken place at national level for data relating to cancer. The Innovative Healthcare Delivery Programme (IHDP) and National Services Scotland (NSS) collaborated to create the Scottish Cancer Registry and Intelligence Service (SCRIS). This work has close links with the Scottish Cancer Quality Steering Group and has supported the ability to effectively use data to measure against cancer quality performance indicators (QPIs).

A key remit of this programme was to develop a National Cancer Intelligence Platform that enables healthcare professionals to access cancer-related information and intelligence. The Scottish Cancer Registry and Intelligence Service Dashboard went live for NHS users in May 2019. It provides a single point of entry to national cancer data, bringing together a range of cancer indicators presented at Scotland, NHS Board and Regional Cancer Network level.

Given the size and scale of the impact of heart disease in Scotland, and the current dearth of accessible data to support learning, a similar approach should be taken based on the existing infrastructure and expertise developed as part of work relating to cancer. Key stakeholders for this work include IHDP and wider data science partners, including the British Heart Foundation data and data science centre.



4.3 Recommended Actions for Scottish Government

- 9. Ensure that access to timely, high-quality data for research and quality improvement for heart disease is financially resourced equivalent to work carried out to improve cancer data in Scotland and to enable the achievement of the following recommended actions.
- 10. Establish and resource a sub-committee of the National Advisory Committee on Heart Disease tasked with supporting a national focus on quality improvement for heart disease through the development of a set of heart disease quality indicators for inclusion with the Atlas of Variation. These should be based on the nationally-agreed pathways.
- 11. Map, streamline and standardise data currently collected relevant to heart disease in Scotland, and identify and address gaps in data collection based on the indicator requirements and secondary care audits including the National Institute for Cardiovascular Outcomes Research (NICOR).
- 12. Establish a National Heart Disease Intelligence Platform that enables healthcare professionals and researchers to more easily access heart disease-related information and intelligence, similar to the National Cancer Intelligence Platform.



Appendix

Appendix

Between 2018 and 2020, BHF Scotland undertook significant evidence gathering and wider clinical and patient engagement in order to gain a deeper understanding of how to overcome the issues faced in heart disease care in Scotland. This process aimed to explore thought on improving patient outcomes, uncover clinical experiences and consider potential solutions.

Clinical and Patient Engagement Workshops

To gather the views of clinicians, we held a series of five clinical consultation roundtables in July and August 2019. These roundtables consulted the views of more than 30 clinicians from a range of roles on a number of topics including:

- Workforce
- Long-term management of disease
- Data
- Detection and diagnostics
- Improving treatment

Additionally, we gathered the views of patients at a patient engagement day in August 2019, which was attended by 11 people affected by heart disease. In addition to those who could not attend the patient engagement day we received additional written responses from seven and held 1-to-1 meetings with three other people affected by heart disease.

Clinical Development Group

The Clinical Development Group, chaired by Professor Stuart Pringle, was comprised of 14 members from across the clinical community. The group met between May 2019 and September 2020 and performed a key role in driving the focus of the paper.

The members of the group were:

Professor Stuart Pringle (Chair)
Chris MacNamee
Dr Catherine Labinjoh
Dr David Murdoch
Professor Lis Neubeck
Paul Forsyth
Lynne Innes
Professor David Newby
Catrina MacGregor
Dennis Sandeman
Dr Gordon Black
Dr John Sharp
Dr Renzo Pessotto
Richard Meade

Public Consultation

In Summer 2020, BHF Scotland ran an online consultation with questions aimed at a clinical and a patient audience. The clinical consultation received 27 responses and the patient consultation 15 responses. In addition to the online consultation, a focus group session was also performed with a panel of 10 participants.

Additionally, the draft strategy was also presented at the Scottish Parliament's Cross Party Group on Heart Disease and Stroke on 1st September 2020, gathering the views and feedback of the wide membership of the group.

References

- National Records of Scotland, (2018), Scotland's Population: The Registrar General's Annual Review of Demographic Trends, available at https://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/registrar-generals-annual-review/2018, accessed 4th March 2020.
- 2. Scottish Government, (2020), Long Term Monitoring of Health Inequalities: January 2020 report, available at https://www.gov.scot/publications/long-term-monitoring-health-inequalities-january-2020-report/, accessed 28th May 2020.
- 3. Docherty et al. (2020), Features of 16,749 hospitalised UK patients with COVID-19 using the ISARIC WHO Clinical Characterisation Protocol, (pre-print).
- National Records of Scotland, (2020), Deaths involving Coronavirus (COVID-19) in Scotland, week 19 (4 to 10 May 2020), available at https://www.nrscotland.gov.uk/files/statistics/covid19/covid-deaths-report-week-19.pdf, accessed 4th June 2020.
- National Records of Scotland, (2020), Deaths involving Coronavirus (COVID-19) in Scotland, week 24 (8 to 14 June 2020), available at https://www.nrscotland.gov.uk/news/2020/deaths-involving-covid-19-week-24-8th-to-14th-june, accessed 2nd July 2020.
- National Records of Scotland, (2020), Deaths involving Coronavirus (COVID-19) in Scotland, week 19 (4 to 10 May 2020), available at https://www.nrscotland.gov.uk/files/statistics/covid19/covid-deaths-report-week-19.pdf, accessed 4th June 2020.
- National Records of Scotland, (2018), Vital Events
 Reference Tables (Table 6.04), available at <a href="https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2018/section-6-death-causes, accessed 3rd July 2020.
- National Records of Scotland, (2018), Scotland's Population: The Registrar General's Annual Review of Demographic Trends - 2018, available at https://www.nrscotland.gov.uk/statistics-and-data/statistics/stats-at-a-glance/registrar-generals-annual-review/2018, accessed 20th October 2019.
- National Records of Scotland (2018) Leading causes of death in Scotland, available at: https://www.nrscotland.gov.uk/statistics-and-data/statistics/scotlands-facts/leading-causes-of-death-in-scotland, accessed 3rd July 2020.
- Information Services Division Scotland (2020) Main diagnosis discharges from hospital 2018/19. Personal correspondence.
- Public Health Scotland, (2019), Scottish Heart Disease Statistics - Year Ending 31 March 2018, IC3 - Heart failure incidence by health board, age group and sex, available at https://www.isdscotland.org/Health-Topics/Heart-Disease/Publications/data-tables2017.asp?id=2338#2338, accessed 13th January 2020.

- Global Burden of Disease Study Data Resources (2017), Scotland Heart Valve Disease Incidence, 1990-2017.
- 13. Public Health Scotland, General practice: disease prevalence data visualisation, available at https://beta.isdscotland.org/find-publications-and-data/health-services/primary-care/general-practice-disease-prevalence-data-visualisation/, accessed 22nd January 2021.
- Global Burden of Disease Study Data Resources (2017), Scotland Heart Valve Disease Incidence, 1990-2017.
- 15. Public Health Scotland, General practice: disease prevalence data visualisation, available at https://beta.isdscotland.org/find-publications-and-data/health-services/primary-care/general-practice-disease-prevalence-data-visualisation/, accessed 22nd January 2021.
- **16.** BHF estimate based on latest prevalence estimates.
- Public Health Scotland, Congenital anomalies in Scotland, available at https://beta.isdscotland.org/find-publications-and-data/population-health/births-and-maternity/congenital-anomalies-in-scotland/, accessed 22nd January 2021.
- National Statistics for Scotland, (2020), A&E activity and waiting times, 2015-2020, available at https://beta.isdscotland.org/find-publications-and-data/health-services/hospital-care/ae-activity-and-waiting-times/, accessed 20th June 2020.
- 19. Public Health Scotland (2020), Covid-19 wider impacts on the healthcare system, summary trends, hospital admissions data, available at https://scotland.shinyapps.io/phs-covid-wider-impact/, accessed 20th June 2020.
- Healthcare Improvement Scotland, (2017), SIGN 149: Risk estimation and the prevention of cardiovascular disease, a national clinical guideline, available at https://www.sign.ac.uk/assets/sign149.pdf, accessed 21st October 2020.
- Scottish Government, (2018) The Scottish Health Survey, 2017 edition: Volume 1: main report, A National Statistics Publication for Scotland, 2018, available at https://www2.gov.scot/Resource/0054/00540654.pdf, accessed 21st October 2020.
- **22.** Imperial College Health Partners analysis for the BHF based on Schiffrin EL, Campbell NR, Feldman RD, et al, (2016), Hypertension in Canada: Past, Present and Future, *Annals of Global Health*, 82(2), pp288–299.
- 23. Imperial College Health Partners analysis for the BHF using Sheffield/Public Health England CVD Return on Investment tool.
- 24. Schiffrin EL, Campbell NR, Feldman RD, et al. (2016), Hypertension in Canada: Past, Present and Future, Annals of Global Health, 82(2), pp288–299.

- **25.** Tucker KL, Sheppard JP, Stevens R, et al, 2017. Self-monitoring of blood pressure in high blood pressure: A systematic review and individual patient data meta-analysis. *PLoS Medicine*, 14(9).
- **26.** Villa G, et al, (2017), Prediction of cardiovascular risk in patients with familial hypercholesterolaemia, *European Heart Journal Quality of Care and Clinical Outcomes*, Volume 3, Issue 4, pp274–280.
- NICE (2017) Familial hypercholesterolaemia: identification and management (CG71), available at, https://www.nice.org.uk/guidance/cg71/chapter/Recommendations, accessed 19th June 2020.
- 28. British Society of Cardiovascular Imaging, (2016), The challenge of national CT Coronary Angiography (CTCA) provision in response to NICE CG95 update 2016, available at https://bsci.org.uk/standards-and-guidelines/nice-cg95-update-2016/, accessed 2nd July 2020.
- NHS Education for Scotland, (2020), NES Healthcare Science Annual Report 2019-20, available at https://www.nes.scot.nhs.uk/education-and-training/by-discipline/healthcare-science/all-healthcare-science/publications/annualreport2019-20.aspx, accessed 3rd June 2020.
- Public Health Scotland, (2019), Summary inpatient/ day case activity by NHS Board of residence, 2009/10 – 2018/19, available at https://www.isdscotland.org/Health-Topics/Hospital-Care/Inpatient-and-Day-Case-Activity/, accessed 2nd June 2020.
- **31.** Healthcare Improvement Scotland, (2016), SIGN 147: Management of chronic heart failure, A national clinical guideline, available at https://www.sign.ac.uk/assets/sign147.pdf, accessed 4th June 2020.
- **32.** Healthcare Improvement Scotland, (2018), SIGN 151: Management of stable angina, A national clinical guideline, available at https://www.sign.ac.uk/assets/sign151.pdf, accessed 4th June 2020.
- 33. British Heart Foundation, The National Audit of Cardiac Rehabilitation | Quality and Outcomes Report 2018, available at https://www.bhf.org.uk/informationsupport/publications/statistics/national-audit-of-cardiac-rehabilitation-quality-and-outcomes-report-2018, accessed 3rd July 2020.
- **34.** Healthcare Improvement Scotland, (2017), SIGN 150: Cardiac rehabilitation, A national clinical guideline, available at https://www.sign.ac.uk/assets/sign150.pdf, accessed 4th June 2020.
- 35. Jha MK, Qamar A, et al, (2019), Screening and Management of Depression in Patients with Cardiovascular Disease JACC State-of-the-Art Review, Journal of the American College of Cardiology, VOL. 73, NO. 14, pp1829-1845.

- 36. Healthcare Improvement Scotland, (2016), SIGN 147: Management of chronic heart failure, A national clinical guideline, available at https://www.sign.ac.uk/assets/sign147.pdf, accessed 4th June 2020.
- Healthcare Improvement Scotland, (2017), SIGN 150: Cardiac rehabilitation, A national clinical guideline, available at https://www.sign.ac.uk/assets/sign150.pdf, accessed 4th June 2020.
- **38.** Gibbs JSR, McCoy ASM, et al, (2002), Living with and dying from heart failure: the role of palliative care, *Heart*, 88 (II), pp36–39.
- **39.** Finucane AM, Davydaitis D, et al, (2020), Electronic care coordination systems for people with advanced progressive illness: a mixed-methods evaluation in Scottish primary care, *British Journal of General Practice*, 70 (690): pp20-28.
- **40.** Finucane AM, Davydaitis D, et al, (2020), Electronic care coordination systems for people with advanced progressive illness: a mixed-methods evaluation in Scottish primary care, *British Journal of General Practice*, 70 (690): pp20-28.
- 41. Marie Curie, British Heart Foundation and NHS Greater Glasgow and Clyde, Better palliative and end of life care for patients with advanced heart failure: The caring together programme, available at https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/current-partnerships/caring-together/caring-together-summary-report-2017.pdf, accessed 1st July 2020.
- **42.** The Scottish Heart Failure Nurse Forum, (2018), *Review of Specialist Heart Failure Nurse Services*, available at https://www.shfnf.co.uk/shfnf-2018-report/, accessed 21st October 2019.

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