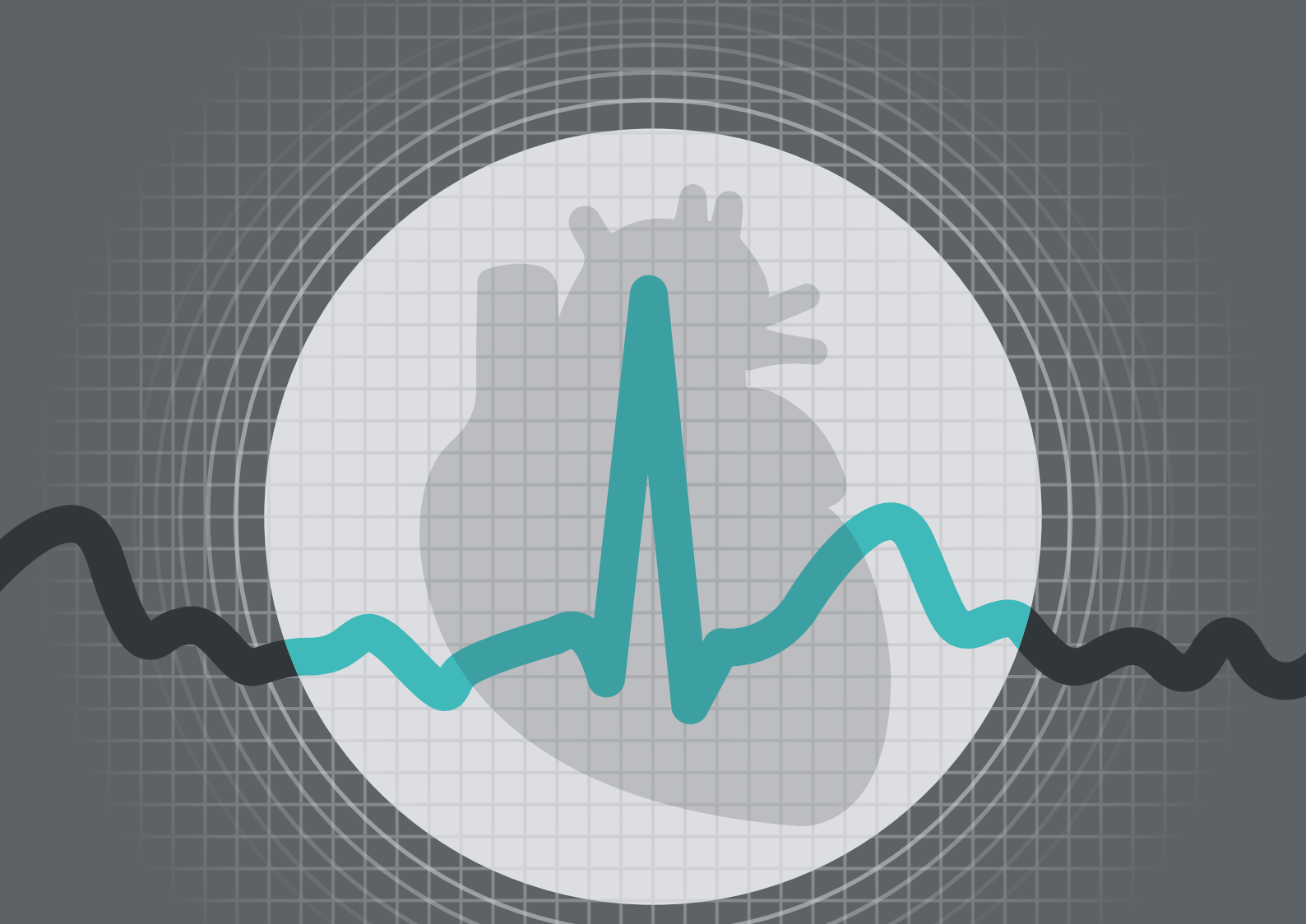


A Focus on Atrial Fibrillation in Scotland:

A report by the Cross-Party Group on Heart Disease and Stroke



This is not an official publication of the Scottish Parliament. It has not been approved by either the parliament or any of its committees. Cross-Party Groups are informal groups in the Scottish Parliament which provide an

opportunity for Members of all parties, outside organisations and members of the public to meet and discuss a shared interest in a particular cause or subject. The views expressed in this document are those of the group.

This report has been compiled and funded by the British Heart Foundation, which provides co-secretariat for the Cross-Party Group on Heart Disease and Stroke.

**CPG Heart
Disease &
Stroke**

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Foreword



The Cross-Party Group (CPG) on Heart Disease and Stroke is formed of MSPs (Members of the Scottish Parliament), clinicians, third sector organisations and individuals with an interest in heart disease or stroke.

The group meets regularly at the Scottish Parliament to debate and discuss relevant issues. Atrial fibrillation was identified as a priority area and therefore a panel was convened to produce this report. Working in such a collaborative way has allowed the report to benefit from a range of expertise and created a synergy that could be an exemplar for future policy work.

Atrial fibrillation is one of the most common types of irregular heart rhythm, with 96,000 people in Scotland diagnosed with the condition. People with atrial fibrillation are at a significantly increased risk of having a stroke, which can have a devastating personal impact for the individual and their family. The impact of stroke on health and social care system resources in Scotland is also significant, with atrial fibrillation related strokes costing significantly more than strokes from other causes.

There are many local examples of excellent care, good practice and innovation for people living with atrial fibrillation. However, many people living in Scotland have this potentially devastating condition without even being aware of it, and many more, even after their diagnosis, are not receiving the appropriate treatment and support to reduce their risk of stroke.

The CPG undertook this inquiry to better understand the key issues and how to drive forward positive change. We would like to thank all of those who took the time to contribute to the inquiry — whether that was through responding to the

consultation, by sharing the consultation with their networks or taking part in a roundtable session in Parliament. In particular we would like to extend our gratitude to those people who were kind enough to share with us their personal experiences of living with atrial fibrillation.

We would also like to draw attention to the efforts invested in this project by members of the advisory panel for this inquiry. They dedicated significant time and provided invaluable advice, which was greatly appreciated.

The recommendations in this report will drive forward change in relation to atrial fibrillation in Scotland, and act as a catalyst towards improving the outcomes and experiences of people with this condition. Creation of this report is only the first step. The CPG and the advisory panel are keen to build on the momentum created by the report and work collaboratively with the Scottish Government and NHS Scotland to make a difference to the lives of people living with atrial fibrillation, their families and carers.

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Summary of Recommendations

The Scottish Government should

- 1** Encourage targeted AF case-finding programmes for those most at risk (age over 65 years, those with previous stroke and those with existing cardiovascular risk factors).
- 2** Work with the relevant National Advisory Committees to address the shortage of cardiac physiologists working within Scotland.
- 3** Invest in the use of proven technologies within clinical practice to detect AF.
- 4** Work with stakeholders in primary and secondary care to create a clear and consistent clinical pathway for people diagnosed with AF.
- 5** Actively promote and support health boards to implement specialised AF services to facilitate accurate diagnosis; to ensure prompt, appropriate anticoagulation and to ensure patient-centred management.
- 6** Imbed consistent and effective data capture, ensuring integration across clinical boundaries of primary and secondary care and efficient processes for linking and accessing these data.
- 7** Support the development and implementation of IT software solutions to facilitate case-finding, support therapeutic decisions and allow audit within and between practices.
- 8** Ensure that all health care professionals have the necessary information about AF to support patients to take part in shared decision making, from the point of diagnosis of AF through to long term condition management.
- 9** Work with clinicians, researchers, third sector and people affected by AF to find the most effective methods to raise awareness of AF amongst the public.
- 10** Ensure that people with AF and at risk of AF receive relevant, tailored information and support, utilising robust and trusted providers such as major third sector charities.

Introduction

WHAT IS ATRIAL FIBRILLATION?

Atrial Fibrillation (AF) is one of the most common types of irregular heartbeat. In a normal heart the heart's pumping action is controlled by regular electrical messages produced by part of the heart called the sinus node.

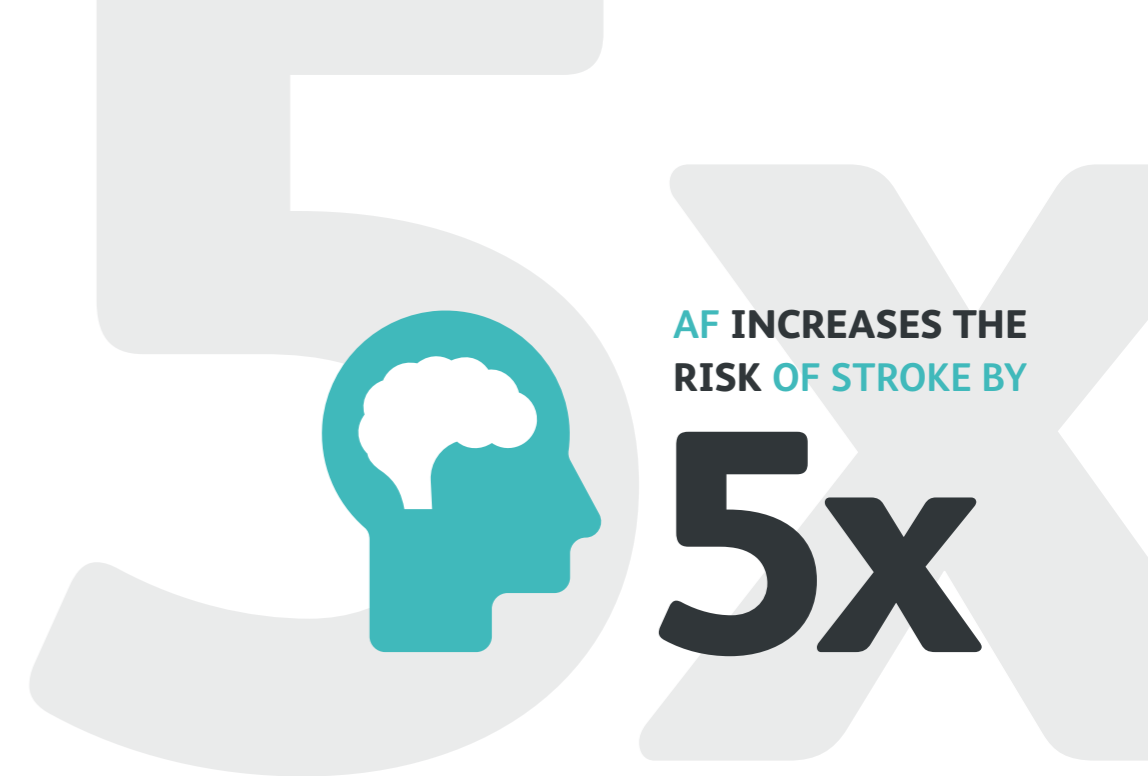
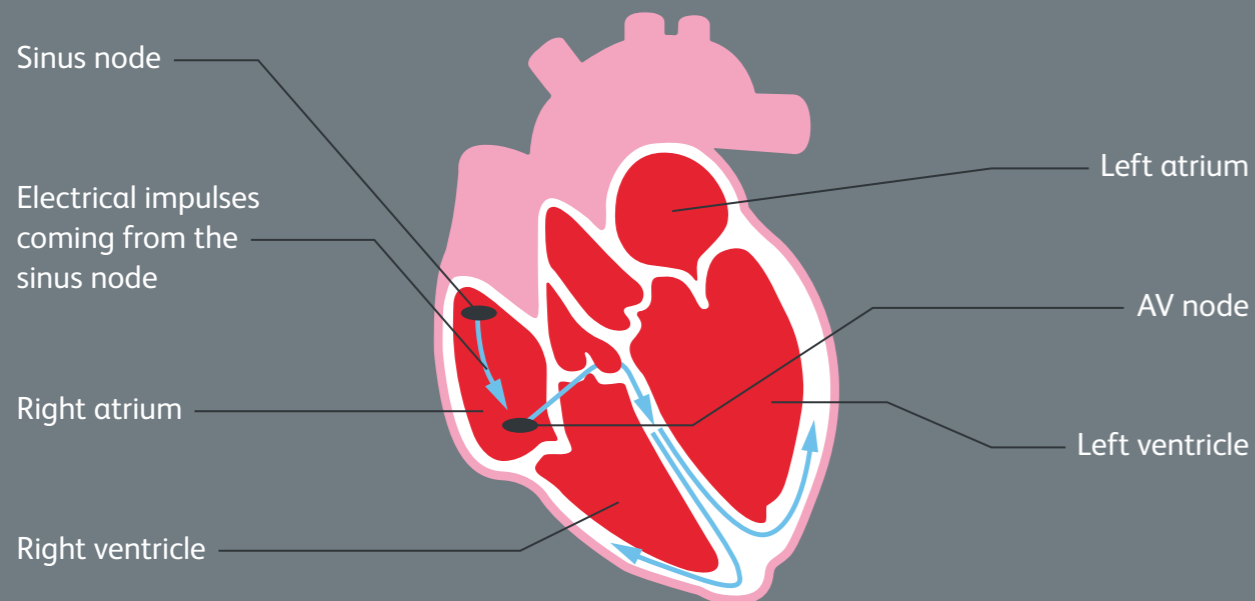
AF occurs when additional, irregular electrical messages are sent from other places in and around the atria (the upper chambers of the heart). These irregular messages make the atria quiver or twitch, which is known as fibrillation.

Some people will experience symptoms due to their AF. These can include palpitations, breathlessness, dizziness,

fainting or fatigue. People who experience symptoms are more likely to seek support from health care professionals and as a result are more likely to have access to treatment which can reduce their risk of stroke.

However, as many as 40% of people with AF do not experience any symptoms at all (this is often called asymptomatic AF).¹

NORMAL ELECTRICAL SIGNALS IN THE HEART



AF frequently progresses through the following three stages, all of which can be present without the person experiencing any symptoms and all with an increased risk of stroke;

– **Paroxysmal atrial fibrillation** is AF that comes and goes. It usually lasts for less than two days but can last for up to seven days. The heart reverts back to normal rhythm by itself and AF is not there all the time.

– **Persistent atrial fibrillation** lasts longer than seven days at a time but it is still possible for the heart rate and rhythm to return to normal.

– **Permanent atrial fibrillation** is there all the time and the heart does not return to a normal rhythm.

A significant and devastating complication of all three stages of AF is ischaemic stroke. AF increases the risk of stroke by five times.² This is because the irregular activity in the atria allows blood to pool in the heart. This blood can then form clots which might make their way to the brain, causing a stroke.

Ischaemic stroke happens when the blood supply to part of the brain is cut off. Blood carries essential nutrients and oxygen to the brain and without it, brain cells can be damaged or die. This damage can have different effects, depending on which part of the brain is affected. A stroke can affect the way someone's body functions as well as impacting how they think, feel and communicate. Strokes which occur as a result of AF are more likely to be fatal or severely disabling.³

Even if someone with AF does not experience symptoms, their AF still carries a similar risk of stroke compared to AF which presents with symptoms⁴ and so detection of

asymptomatic AF is important in order that people have the opportunity to reduce their risk of stroke through treatment.

Importantly, the risk of someone with AF having a stroke can be reduced by treatment with anticoagulation medication. Appropriate use of anticoagulation reduces stroke risk in AF by two thirds.⁵

While stroke is the most common complication, AF is associated with a number of other conditions including heart attack and dementia. Less is understood about AF and these complications, but recent studies suggest that anticoagulant medications can reduce the risk.⁶ AF is also associated with heart failure.⁷ The relationship between the two is only partially understood and is subject to ongoing research. It is thought that AF may facilitate the development or progression of heart failure in a number of ways.⁸

RISK FACTORS IN ATRIAL FIBRILLATION

A number of risk factors are associated with AF, including increasing age, high blood pressure, heart failure, valvular heart disease, previous heart attack, thyroid disease, obesity, diabetes, chronic lung disease, sleep apnoea, kidney disease, smoking and excessive alcohol consumption.⁹

The identification of these risk factors and their prevention and management is an important factor in reducing the burden of AF. Recent research has shown potential benefits for lifestyle changes and risk factor management to have a positive impact on the progression of AF.¹⁰



96,367

PEOPLE IN SCOTLAND HAVE BEEN DIAGNOSED WITH AF

THE SCALE OF ATRIAL FIBRILLATION IN SCOTLAND

AF is one of the most common irregular heart rhythms and people over the age of 40 years have a lifetime risk of one in four of developing AF.¹¹ Quality Outcome Framework (QOF) data (collected from GP practices) shows that in 2016, 96,367 people in Scotland had been diagnosed with AF.¹² However, it is estimated that 2.6% of the Scottish population, which is around 145,000 people, have AF. That would mean that nearly 50,000 people in Scotland are living with undiagnosed AF, putting them in danger of having a stroke.¹³

The condition becomes more common with age; therefore Scotland's ageing demographic means that it will likely affect higher numbers of the population in future. Indeed, it is suggested that rates of AF will more than double by the year 2060.¹⁴

THE IMPACT OF STROKE IN SCOTLAND

Stroke is the third most common cause of death and a leading cause of disability in Scotland. The Information Services Division recorded that 8,902 people in Scotland had a confirmed stroke in 2015/16.¹⁵ The Scottish Stroke Care Audit estimates 15,000 people in Scotland have a stroke each year.¹⁶ This suggests that the number of presentations to secondary care with stroke and suspected stroke may be much higher. Around 124,000 people in Scotland have survived a stroke or Transient Ischaemic Attack (TIA).¹⁷ Stroke can have a massive personal impact for an individual and their family.

At a broader level, it also has a large financial impact on health and social care services in Scotland, accounting for approximately 5% of total NHS costs.¹⁸ The economic cost of stroke to Scotland in terms of lost employment and the cost of support in the community are also significant.

A large UK study which looked at the incidence and outcome of AF related strokes showed that 24.2% of acute cerebral or peripheral vascular events were related to AF.¹⁹ International data suggests that at least a third of all ischaemic strokes are caused by AF.²⁰ However it is likely that the impact of AF with regards to stroke burden will be underestimated because, even after stroke, AF can remain undetected.

In a large study of people with known AF, including 94,474 people who had AF-related strokes, 84% of patients were not receiving adequate guideline based treatment at the time of the stroke.²¹ Therefore improved detection, diagnosis and appropriate treatment of AF present an opportunity to reduce the impact of stroke in Scotland.

POLICY CONTEXT

Many of the risk factors associated with AF are common to heart disease and stroke. These are also similar for many other long term conditions which present challenges to population health in Scotland. These population health issues are complex, persistent and underpinned by issues such as poor nutrition, obesity, physical inactivity and an ageing demographic. To tackle these issues, the policy context in Scotland is focused on the need for preventative measures. The "Christie Commission" highlighted the need for public services to shift towards prevention. Similarly the "Scottish Government's 2020 Vision for Health" also focuses on prevention.

The solutions to these challenges will be beyond the scope of health care systems alone and require the influence of wider agendas, policies and programmes. Therefore bold political decisions will be needed in the coming years to provide solutions to such challenges.

Treating and preventing stroke is a national clinical priority for Scotland. In 2009 the "Better Heart Disease and Stroke Care Action Plan"²² was published, followed in 2014 by improvement plans for both Heart Disease and Stroke.^{23,24} These plans set out the priorities and actions required to deliver improved prevention, treatment and care for all people in Scotland affected by heart disease and stroke. Both highlight the need for improved identification, diagnosis and management of AF.

These specific priorities for heart disease and stroke sit within a wider Scottish framework which is focused on the provision of patient-centred, preventative and anticipatory health services, delivered by multi-disciplinary,

integrated teams. This is seen as a way of better addressing the needs of people with long term conditions, while also managing the financial pressures that NHS Scotland faces. This direction was outlined in the Scottish Government's route map to achieving sustainable quality in the delivery of healthcare services across Scotland by 2020.²⁵

The Public Bodies (Joint Working) (Scotland) Act 2014 which came into effect in April 2016 requires the integration of health and social care and created 31 integration partnerships which work across health and social care. These authorities now have responsibility for over £8bn of funding for local services which was previously managed separately by NHS Boards and Local Authorities.

A further key policy agenda of note is "The Modern Outpatient: A Collaborative Approach 2017–2020" which aims to deliver care closer to the patient's home, provide more person centred care, utilise new and emerging technologies, whilst maximising the role of clinicians across primary, secondary and community based services.

The Chief Medical Officer in Scotland encourages a concept of "Realistic Medicine". This places the person receiving health and care at the centre of decision-making and encourages a personalised approach to their care. It has core aims of reducing harm and waste, tackling unwarranted variation in care, managing clinical risk and innovating to improve.

Alongside these shifting priorities for health care there remains a need to deal with the ever present challenges of rurality and deprivation, both of which are particularly pronounced in Scotland and have a significant impact on the way in which services can be delivered.

There is also policy recognition that all of this requires a co-ordinated approach to appropriate data sharing. This means that the right digital culture, skills, processes and systems will need to be in place to achieve key health policy aims.

It is against this background and with these key policies in mind that our recommendations related to the diagnosis, initial treatment and further management of AF in Scotland have been created.

The Inquiry Process

The first step was to approach individuals with knowledge and expertise related to AF in order to form an advisory panel to guide the inquiry.

The second step was for the advisory panel to develop a consultation tool to gather initial information. This took the form of two separate questionnaires; one which was relevant to people living with AF and another which was relevant to clinicians and organisations with an interest in AF. The questions were divided into four key topics which were; prevention, diagnosis, treatment and data use relating to AF. The questions aimed to allow people to share their knowledge, so were largely qualitative in nature.

The consultation ran for 12 weeks from 20th June to 15th September 2017. There were 203 responses to the clinical consultation and 59 to the consultation for people living with AF. The consultation responses were analysed in order to identify recurrent themes.

The final step in the inquiry process was the hosting of four round table meetings in the Scottish Parliament throughout October and November 2017. The round table meetings were split into topics similar to those which shaped the consultation. These were; diagnosis, treatment, data use and a patient round table.

Around 15 people with expertise in these areas, or those who had responded to the inquiry consultation, were invited to attend each round table meeting. The discussions at these meetings explored, in more depth, the key themes that had emerged from the consultation responses and helped to further develop the recommendations in this report.



Section One:

Detection and Diagnosis of Atrial Fibrillation

“ I think the big problem is those who are undiagnosed, who perhaps don't have many symptoms, aren't aware that they've got AF and their risk of stroke, or heart failure are very, very much increased. ”

Gordon (round table participant)



BACKGROUND

AF detection and diagnosis is important in preventing stroke in the first instance (primary prevention) and also in the prevention of a further stroke (secondary prevention).

Detection of AF for primary prevention of stroke:

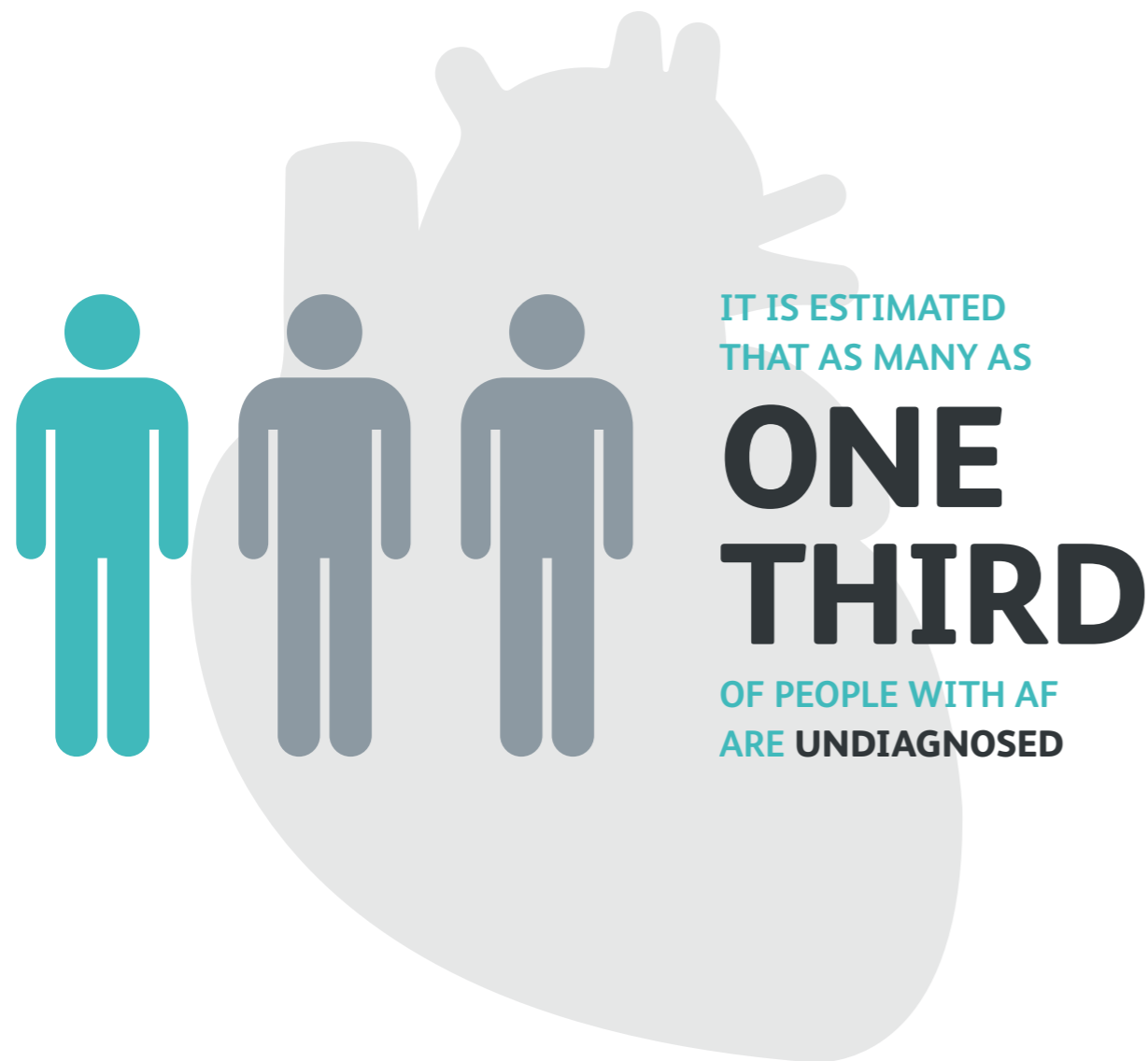
Traditionally, the most common method for detecting AF is the use of a radial pulse check for 60 seconds. If AF is present the pulse may feel irregular. This has been described as feeling like Morse code, whereas a normal pulse feels like a ticking clock.²⁶ An irregular pulse only suggests that AF may be present. Occasional extra beats of the heart can be normal and carry no risk but might be mistaken for AF when feeling a pulse.

Because pulse checking can be inaccurate, if an irregular pulse is detected then a 12 lead Electrocardiograph (ECG) needs to be carried out as soon as possible in order to confirm the diagnosis. If it is thought that the AF is paroxysmal then a longer ECG monitoring period may be required (usually 24–48 hours). Although some GP practices have ECG machines, often such diagnostic tests require

referral to a cardiac physiologist to carry out the tests and analyse the results.

There is a selection of new technologies which can be used to detect possible AF. These technologies are more accurate at detecting AF than pulse taking alone.²⁷ Therefore they reduce the likelihood of requiring unnecessary tests to exclude a diagnosis amongst people who do not have AF.

There are a number of benefits to incorporating technology in the quest to improve the detection of AF and indeed, this is highlighted in a case study later in the report. Technology in this area has advanced rapidly, perhaps more quickly than guidelines, research and clinical practice can keep up with. While increasingly sophisticated methods of diagnosis are welcome, the adoption of new technology must follow proper evaluation.



Detection of AF for secondary prevention of stroke:

Diagnosis of permanent or persistent AF following stroke is fairly straightforward since detection of AF can be guided with a 12 lead ECG which should be routinely performed in patients with stroke or TIA.²⁸

However, detection of paroxysmal AF for those who have already had a stroke requires longer ECG monitoring to detect AF. Current National Institute for Health and Care Excellence (NICE) and European Society of Cardiology (ESC) guidelines, recommend at least 24 hour ECG monitoring for people who are suspected to have paroxysmal AF.²⁹ ESC guidelines also highlight that there is good evidence that prolonged ECG monitoring enhances the detection of undiagnosed AF, e.g. monitoring for 72 hours after a stroke.³⁰ It has been shown that even longer durations of monitoring (for a target of 30 days) can significantly improve the detection of AF among patients who have presented with a stroke, compared to 24 hour monitoring.³¹

The 2017 Stroke Improvement Programme Report introduced national standards for the detection of AF in patients who have had a stroke or TIA. All NHS Health

Boards should have agreed criteria for offering prolonged ECG monitoring to patients with ischaemic stroke and TIA. Prolonged monitoring should be available to patients meeting these local criteria and the results should be available within two weeks of the request for prolonged monitoring. It was highlighted throughout the inquiry that adherence to these criteria was variable across Scotland and it would be pertinent for the Scottish Government to ensure that all Health Boards adhere to these criteria. This is monitored through the Scottish Stroke Improvement Plan.

It is estimated that as many as one third of people with AF are undiagnosed.³² Prompt diagnosis allows people to receive anticoagulation treatment which can reduce their risk of having a stroke by around two thirds.

Given the risks associated with AF it is important that we consider ways in which we might improve and increase detection and diagnosis of this condition. This inquiry sought to understand the barriers to doing so which exist in Scotland, and identify solutions to overcoming these.

INQUIRY FINDINGS — DIFFICULTY IN DETECTING AND DIAGNOSING ASYMPTOMATIC OR PAROXYSMAL ATRIAL FIBRILLATION

Respondents to the consultation shared that it is difficult to detect and diagnose AF which is asymptomatic or paroxysmal. This is because people without symptoms are unlikely to present to a health care professional with specific regard to their AF and those with paroxysmal AF might not be in AF at the time they are undergoing diagnostic checks. Asymptomatic AF still carries a similar risk of stroke compared to AF which presents with symptoms³³ while the risk of stroke related to paroxysmal AF is only slightly lower than that of permanent AF.³⁴ Both types of AF often require anticoagulation.

Devastatingly, the first time many people with asymptomatic AF have their AF detected is when they present with a stroke.

“I had a stroke at work and on being admitted to hospital was diagnosed as having AF by the clinical team looking after me.”

We heard from a number of people about how their paroxysmal AF made their diagnosis difficult.

“It was several years before it could be confirmed on ECG because it always came on at night.”

Case-finding to detect asymptomatic and paroxysmal AF presents itself as a crucial opportunity to avoid AF related strokes and the resulting personal and economic impact that these have.

AF case-finding could be easily carried out in primary care, pharmacies or community settings with minimally invasive tests (including pulse checks, new single lead ECG technologies, or 12 lead ECG for those with the highest probability of AF). This would mean that many of the harms typically associated with case-finding; such as patient discomfort, long waiting times and considerable anxiety about the results would be minimal.³⁵

In particular, the new, single lead ECG devices are much more accurate than pulse checks. This means that using such technology could reduce the amount of ECGs required for people who will not end up with an AF diagnosis. Therefore case-finding using these tools could be particularly effective and indeed, a number of studies have demonstrated that such programmes could be cost effective.^{36,37}

Opportunistic case-finding is advocated for people aged over 65 years in European AF management guidelines.³⁸ Discussions at the inquiry round table meeting focusing on detection and diagnosis were broadly supportive of targeted case-finding with a focus on those people most at risk. The categories for targeted case-finding should include those over 65 years of age and those with significant risk factors for AF including cardiovascular disease, diabetes or respiratory disease.

Responses to the inquiry consultation highlighted a recent study in Scotland which focused on AF case-finding in primary care, using a single lead ECG device. These technologies can be hand-held and record an ECG reading.

“I had a stroke at work and on being admitted to hospital was diagnosed as having AF by the clinical team looking after me.”

CASE STUDY

AF CASE-FINDING IN PRIMARY CARE

A collaborative project involving NHS Lothian, Digital Health Institute (DHI), and Kardia evaluated the use of a hand-held single lead ECG device at scale in primary care. The study aimed to assess the potential benefits and cost-effectiveness of targeted, opportunistic case-finding for AF in a high risk population using a hand-held single lead ECG device, compared with usual care.

People with certain long-term conditions, including heart failure, diabetes and kidney disease were tested using the hand-held single lead ECG device when attending their practice for their annual long-term condition review. Five practices from each of five Scottish regions (Lothian, Greater Glasgow and Clyde, Tayside, Grampian, and Fife) took part in the study.

Although the device was able to detect AF effectively, the results were sent securely to local cardiology teams, who also verified diagnosis.

The study hoped to identify the yield of patients who might otherwise not be diagnosed using current methods and to propose a proven scalable solution for assessment of AF in Scotland.



Image: Hand-held ECG device, image provided by AliveCor

The DHI funded a full economic review to identify savings from strokes avoided as well as required medication costs to prevent stroke. It was found that case-finding with the hand-held single lead ECG device cost £22.02 per patient, which was more cost effective than the base case analysis of usual care with no case-finding over a 30 year time horizon.

Preliminary results from the simulation model involved in this project indicate that a move to case-finding for AF in a high risk population using a hand-held single lead ECG device has the potential to be cost effective.³⁹

“Delays in obtaining diagnostic monitoring such as Holter (24 hour ECG) monitoring for those patients with suspected paroxysmal atrial fibrillation.”

This is particularly important when we consider that longer term monitoring can pick up AF in people who might not have it detected with shorter term monitoring. Access to these types of services is particularly crucial in secondary prevention of strokes related to AF.

Discussions at the round table meeting indicated that the two key issues underpinning this difficulty in accessing diagnostic services were a lack of financial resources within the NHS and a particular issue around staff resources.

It was felt that the lack of financial resources presented a “catch-22 situation” as it inevitably has an impact on the staff resource, but also on the ability of the NHS to purchase newer, less time consuming technology which could reduce pressure on these services, and thus minimise the burden of these services on staff time.

The specific staff resource issue highlighted during the round table discussion was that of a shortage of cardiac physiologists. These health care professionals are pivotal to the care of people with AF as they carry out and analyse cardiac tests, such as echocardiograms, 12 lead ECGs, 24-hour ECGs etc. This issue was highlighted by the British Cardiovascular Society as far back as 2007.⁴⁰ While this report focused on the UK workforce more broadly, it is clear from the feedback to the inquiry that this is an issue which is still relevant and has an important impact on services in Scotland.

Consideration must be given to ways to overcome this issue. Examples of how to achieve this could be through workforce planning, developing appropriate training and ensuring multi-skilled health care staff. Furthermore, the utilisation of appropriate technology in order to relieve pressure on staff resources is another potential area for development. Finally, some respondents highlighted the importance of ensuring the application of Realistic Medicine principles in determining which patients are referred for services. These services should be utilised for patients at highest risk and who are likely to benefit from a change in management of their condition.

INQUIRY FINDINGS — DIFFICULTY ACCESSING DIAGNOSTIC SERVICES

Another issue that was highlighted by the consultation responses was the variance of access to diagnostic services that exists across Scotland.

“Not all areas have easy access to 12-lead ECG — e.g. in Tayside all GP practices have a machine, but in Lothian some patients have to attend hospital for an ECG, which can be a significant barrier. In Wishaw, patients attend hospital for their ECG and it isn’t a barrier because the District General Hospital is in the town, so there is a very varied picture across Scotland.”

This issue was discussed in more detail at the inquiry round table meeting focusing on AF detection and diagnosis. Discussions indicated that waiting times for access to diagnostic services in some areas could be up to eight or nine weeks. This is very problematic for patients who are at a very high risk of stroke and cannot commence anticoagulation to reduce that risk until their AF has been confirmed on a 12 lead ECG.

Furthermore, consultation responses pointed out that longer term monitoring to detect paroxysmal AF could be particularly difficult to access.

RECOMMENDATIONS

The Scottish Government should

1

Encourage targeted AF case-finding programmes for those most at risk (age over 65 years, those with previous stroke and those with existing cardiovascular risk factors).

2

Work with the relevant National Advisory Committees to address the shortage of cardiac physiologists working within Scotland.

3

Invest in the use of proven technologies within clinical practice to detect AF.

Section Two:

Initial Treatment and Subsequent Management of Atrial Fibrillation

“ I think atrial fibrillation is unique to the individual so each case must be carefully considered to determine the correct course of treatment. It would be good if someone could give an idea of what treatments are available, and which are likely to work in each particular situation. ”

Richard (round table participant)



BACKGROUND

As important as it is to improve detection and diagnosis of AF, it is vital that this coincides with appropriate post diagnosis pathways. Post diagnostic support involves appropriate education, treatment and follow-up.

There is currently no cure for most cases of AF. Guidelines from professional societies recommend that the first consideration when treating AF should be a decision on the need for anticoagulation medication to reduce the person’s risk of stroke.

Anticoagulation

Anti-coagulation medication is a well evidenced way to reduce the risk of AF related strokes.

Not everyone with AF has the same risk of stroke. The presence of certain factors increases the risk of an AF related stroke and this risk can be assessed using checklist scoring systems. The risk estimation tool that is recommended in Scotland is the CHA₂DS₂-VASc points system. Points are given if the person has any of the risk factors highlighted by the scoring tool shown to the right.

CHA ₂ DS ₂ -VASc SCORE		
		SCORE
C	Congestive Heart Failure / LV Dysfunction	1
H	Hypertension	1
A	Age ≥ 75 years	2
D	Diabetes Mellitus	1
S	Stroke (TIA / TE)	2
V	Vascular Disease ^(a)	1
A	Age 65–74 years	1
S	Sex (female)	1

a. Prior myocardial infarction, peripheral arterial disease, aortic plaque.
LV = left ventricular, TE = thromboembolism, TIA = transient ischemic attack

SIGN Guidelines recommend that patients with AF who have a CHA₂DS₂-VASc score of 1 or above should be considered for anticoagulation.⁴¹ All patients with AF who have already had a stroke or TIA would have a high enough score to justify anticoagulation.

Anticoagulants work by increasing the time that the blood takes to clot, thus helping to reduce the risk of strokes caused by AF. Due to their effects on blood clotting, anticoagulants can cause bleeding complications. Decisions to start an anticoagulant need to balance the risk of stroke and the risk of bleeding. In the same way that clinical factors such as age and heart disease can be used to predict risk of stroke in AF, clinical factors can also be used to assess the risk of bleeding with anticoagulation. However, many of the things that can put someone at risk of bleeding with anticoagulation, for example high blood pressure and alcohol consumption, can be modified.

Warfarin is the most commonly prescribed anticoagulant and, when used appropriately, it's an effective way of significantly reducing the risk of AF-related strokes, but it requires frequent blood tests and the dose often needs to be adjusted to ensure the medication is working as required.

The direct oral anticoagulants (DOACs) are a new class of anticoagulant drug. They are sometimes referred to as NOACs or non-vitamin K oral anticoagulants. They can be used in the prevention of stroke for people with AF, when the AF is not associated with certain heart valve problems. There are now four DOACs approved for use in NHS Scotland by the Scottish Medicines Consortium; Dabigatran, Rivaroxaban, Apixaban and Edoxaban.

Large clinical trials have shown the DOACs to be similarly effective at preventing strokes as Warfarin.⁴²⁻⁴⁵ The main difference is that they are less influenced by diet and other medications. This means that a set dose can be prescribed and the doctor will know that the patient's risk of stroke is reduced as long as the drug is taken. Patients do not require regular blood tests to check whether these drugs are working, as they do when on Warfarin, but they are required to be taken at the same time daily. A potential downside of this is that the process of monitoring can be a useful way to encourage medication compliance and present an opportunity for people taking an anticoagulant to get information about the drug from health care professionals.

DOACs do have some limitations. For example, they have variable effects on routine coagulation tests which mean that if a person taking a DOAC has a major bleed or emergency surgery, then the amount of anticoagulant in their system is not easy to determine. Similarly, only

one DOAC (Dabigatran) currently has a reversal agent available.⁴⁶ Reversal agents for anticoagulation are used to reverse their effects on the blood in the case of serious bleeding or emergency surgery.

The introduction of DOACs has created space for patients to have more choice in the medication which best suits their needs.

Heart rate and rhythm treatments

Some of the symptoms of AF, particularly palpitations, can be reduced through the use of medications to slow the heart rate. In some people with AF, medication, cardioversion (controlled electric shocks to the heart), or radiofrequency ablation (where energy is used to destroy the affected area of the heart causing the abnormal rhythm) can sometimes restore a normal heart rhythm in the short term. However, for older adults with other medical problems the AF often returns. These options are only suitable for those who have symptoms caused by AF.

It is important to note that, while these interventions can improve symptoms and help people with AF feel better, anticoagulation remains the key intervention in reducing the risk of stroke.

A number of respondents to the consultation highlighted that in Scotland there was a difficulty in referral for specialist assessment to identify those appropriate for cardioversion or ablation due to the availability of these services. Some respondents highlighted locally agreed protocols for referral to these services and suggested that perhaps a national protocol could be helpful.

INQUIRY FINDINGS — SUB OPTIMAL ANTICOAGULATION

Anticoagulation use for AF in Scotland is sub optimal.^{47,48}

“Of the 284 patients seen in clinics with TIA or stroke with AF, only, 141 (50%) were on oral anticoagulants at the time of their event in 2016. Although, in many cases the AF may have been new, in many others this represents either a continued failure to identify patients with AF, or a failure to start patients on anticoagulants.”
— Scottish Stroke Care Audit⁴⁹

Responses to the consultation questionnaire suggested that one of the key reasons for this was concern among clinicians about the risks associated with these medicines.

“Fear among professionals of causing bleeding. Need to better inform doctors of the actual risks of bleeding on anticoagulants versus risks of ischaemic stroke.”

Navigating this risk decision is understandably difficult but a theme which emerged from the consultation responses and discussions at the round table meetings was that bleeding risk was often used as a reason not to prescribe anticoagulant medication when, in a number of cases, it should be used as a tool to modify risk factors (such as hypertension or alcohol consumption). A number of respondents mentioned that the risk of bleeding associated with falls was greatly over-estimated in clinical practice.

INQUIRY FINDINGS — ISSUES AROUND THE USE OF DIRECT ORAL ANTICOAGULANTS (DOACS)

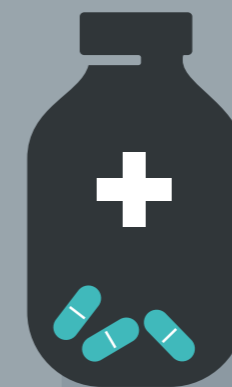
Some responses to the consultation indicated that there could be a lack of awareness and confidence amongst some clinicians with regards to prescribing DOACs.

“Variation in where DOACs come in recommended treatment. Many GPs only offer Warfarin which the patient turns down, without realising that DOACs are available.”

Other respondents to the consultation highlighted that it could be difficult to keep up with the evidence around these drugs. During the round table discussion on treatment and management of AF this was discussed in more detail with an agreement that, particularly in primary care, the option of choosing between five drugs (Warfarin and four DOACs) could be time consuming and had the potential to increase prescriber anxiety. It was suggested that support and education for health care professionals with regards to anticoagulants could be helpful in this regard.

Finally, a crucial barrier to the use of DOACs is financial limitations. Currently, DOACs are more expensive than Warfarin. There are variations in the guidance produced by different Health Boards with respect to which patients should be offered the new, and more expensive, oral anticoagulants. The round table discussions highlighted that this resulted in geographical variation in the availability of these medications. It was also highlighted at the round table discussion that there were often significant bureaucratic systems to adhere to in order to prescribe DOACs for patients.

The purpose of the Scottish Medicines Consortium (SMC) is to accept for use those newly licensed medicines that clearly represent good value for money to NHS Scotland. The four DOACs mentioned above have been approved by the SMC.⁵⁰⁻⁵³ Discussions at the inquiry round table suggested that it seemed that NHS Scotland national policy and the policies of local Health Boards were disconnected.



APPROPRIATE USE OF ANTICOAGULATION REDUCES STROKE RISK IN AF BY

TWO THIRDS

One concern raised at the round table meetings with regards to a move away from Warfarin towards DOACs was the patient information and support given along with these drugs. Fairly robust pathways and patient information exists for Warfarin, and patients are recalled regularly for monitoring. It is important that patients continue to receive appropriate information and engage with appropriate health care professionals when they are prescribed DOACs.

INQUIRY FINDINGS — NEED FOR INTEGRATED CARE FOR PEOPLE WITH ATRIAL FIBRILLATION

In response to a question on the co-ordination of care for people with AF, many professional responses to the inquiry consultation highlighted that either a GP or a specialist AF nurse should be responsible for this, with the best standard of care probably achieved by the two working together in an integrated way.

CASE STUDY

NURSE LED INTEGRATED CARE FOR AF — NHS LANARKSHIRE

In NHS Lanarkshire a nurse led atrial fibrillation clinic was set up in 2010. This clinic aimed to assess, investigate and manage patients with new onset AF, quickly and efficiently and ensure involvement in all decisions by patients and their families.

The clinic was established utilising pre-existing resources within cardiology to streamline the pathway for existing patients. Crucially, the clinic received support from the cardiology department for investigations.

The first key goal was to address the need for anticoagulation to reduce patients' risk of stroke by utilising the scoring system highlighted earlier in the document. The second was to improve the patients' quality of life: by ensuring prompt initiation of medication, tailored to the patients' symptoms and lifestyle.

“Few boards recruit arrhythmia nurses and I think this would improve the long term management of AF. If there was a dedicated specialist nurse they would have more time to develop pathways and local guidance documents to ensure regular follow up for AF patients.”

AF requires long term condition management in a large population of patients. Therefore integrated care models that provide patient centred care while maintaining access to specialist treatment options are an appropriate approach to delivery of health care services to people with this condition. Such integrated care can be provided by multi-disciplinary health care teams including pharmacists, nurses, GPs and cardiologists.

Given the policy background of integration and multi-disciplinary working discussed in the introduction to this report, such a pathway seems highly relevant.

Two examples of integrated care were highlighted by a number of respondents to the inquiry consultation as examples of good practice.

The clinic operated in a 'one stop shop' style where patients would have access to necessary assessment and treatment at the one appointment. An audit of patients' experiences showed that 80% felt their results were explained in a way they could understand and 95% felt the standard of care received was excellent (65%) or very good (30%).

The clinic also had an impact on anticoagulation rates, with an audit showing that the 66% of the clinic's patients were anticoagulated (at only two weeks post diagnosis) in comparison to a national audit at the time which placed anticoagulation rates at 41%.

NURSE LED INTEGRATED CARE FOR AF — NHS TAYSIDE

One strand of an integrated care project, initially funded by the British Heart Foundation, included reviewing current care provision for AF patients and setting up a rapid access nurse-led clinic for these patients in NHS Tayside.

The programme also provided education and developed knowledge and skills in arrhythmia management for members of the wider health care teams within primary and secondary care. These education events were evaluated positively with most participants saying that they would recommend the event and that their post-course knowledge was substantially higher than pre-course.

The impact of the project locally, and its potential transferability were robustly evaluated. Patients reported many positive outcomes relating to their experience, the ease of access to the service, the degree to which they could manage their condition and the impact that this care had



Image: NHS Tayside nurses receiving an award from BHF

on their quality of life. In an evaluation of the service, 98% of respondents reported satisfaction with care provided by a nurse as opposed to another medical professional and 94% of respondents reported that the nurse had helped them understand their condition. This project has successfully been implemented, operating at full capacity and now sustained by the NHS Health Board.⁵⁴

KEY OUTCOMES WERE;

- Better working and sharing of information/skills across teams e.g. between nursing, medical staff and the physiologists; and integration between primary and secondary care teams.
- Shorter waiting times, fewer cancellations and timely follow up allowing further intervention if required.
- Improved patient experience.

Nurse-led care has been shown to be very effective in the management of patients with AF, improving appropriate prescribing of anticoagulation treatment, appropriate application of rate and rhythm control therapies and

patient understanding of the condition, all of which have been identified as issues by this inquiry. Cardiovascular hospitalisation rates and mortality were also shown to be lower in a nurse-led care model.⁵⁵

RECOMMENDATIONS

The Scottish Government should

4 Work with stakeholders in primary and secondary care to create a clear and consistent clinical pathway for people diagnosed with AF.

5 Actively promote and support Health Boards to implement specialised AF services to facilitate accurate diagnosis; to ensure prompt, appropriate anticoagulation and to ensure patient-centred management.

Section Three:

The Use of Data to Improve Detection, Diagnosis and Treatment of Atrial Fibrillation

BACKGROUND

Health care professionals collect a variety of information during patient consultations. Information such as whether the patient smokes, any medicines prescribed and other tests or treatments the patient has had, are recorded and can be shared with other parts of the NHS to make sure that the person receives the appropriate treatment.

These data are also very useful for purposes beyond individual treatment. In Scotland every patient has a unique identifier, the Community Health Index (CHI) number, which is used to label every interaction they have with health care. The use of CHI numbers allows national records (births, deaths etc.) hospital, primary and social care information to be integrated for an individual across their lifetime. Some of this information is brought together and stored in national databases which are managed by the Information Services Division (ISD) Scotland on behalf of NHS Scotland.

The Quality & Outcomes Framework (QOF) was an important source of data to estimate the prevalence of

particular chronic conditions. It measured achievement by general practices against a range of evidence-based indicators. Participation by general practices in the QOF was voluntary and payments were made to each participating practice on the basis of points achieved against indicators.

QOF is being decommissioned in Scotland, and funding transferred to practice core funding. QOF data will no longer be extracted for payment purposes, although 2016–17 QOF data was extracted to support the peer led GP Cluster Continuous Quality Improvement process as part of the latest General Medical Services contract agreement. Some respondents to the survey highlighted concerns about the effectiveness of data collection in the absence of the incentivisation from QOF.

Scottish Primary Care Information Resource (SPIRE) is the Scottish Government's move to improve the way it uses information from patient records. It has been developed to help GPs, the NHS in Scotland and researchers learn from information held at GP practices and will be used to plan for Scotland's health and care needs. The system allows information from GP patient records to be transferred electronically and held securely at NHS National Services Scotland.

At the outset of this inquiry the members of the advisory panel were clear about the potential for data to have an impact on AF detection, diagnosis and treatment in Scotland. The inquiry consultation and subsequent round table meeting sought to identify areas of good practice and also the barriers to utilising data which exist in Scotland.

INQUIRY FINDINGS — IMPROVEMENTS AT PRACTICE LEVEL NEEDED

A number of respondents to the consultation highlighted the need for software that allowed practice staff to better assess the needs of the practice population. This is important because practice level is where immediate changes and interventions can be made for people with AF, thus having a substantial impact.

A number of responses to the consultation highlighted two similar projects as examples of best practice in relation to data use to improve AF treatment.

Both projects utilised a practice software tool called GRASP-AF. This is an electronic tool which runs a set of queries on the practice database building a list of every patient with a diagnosis of AF, the drugs associated with AF and any contraindications for anticoagulation.

“

There are massive opportunities for using national datasets but also many barriers to accessing these data.

Dr Terry Quinn (advisory panel)

”



CASE STUDY

THE USE OF GRASP-AF IN PRIMARY CARE — NHS LANARKSHIRE

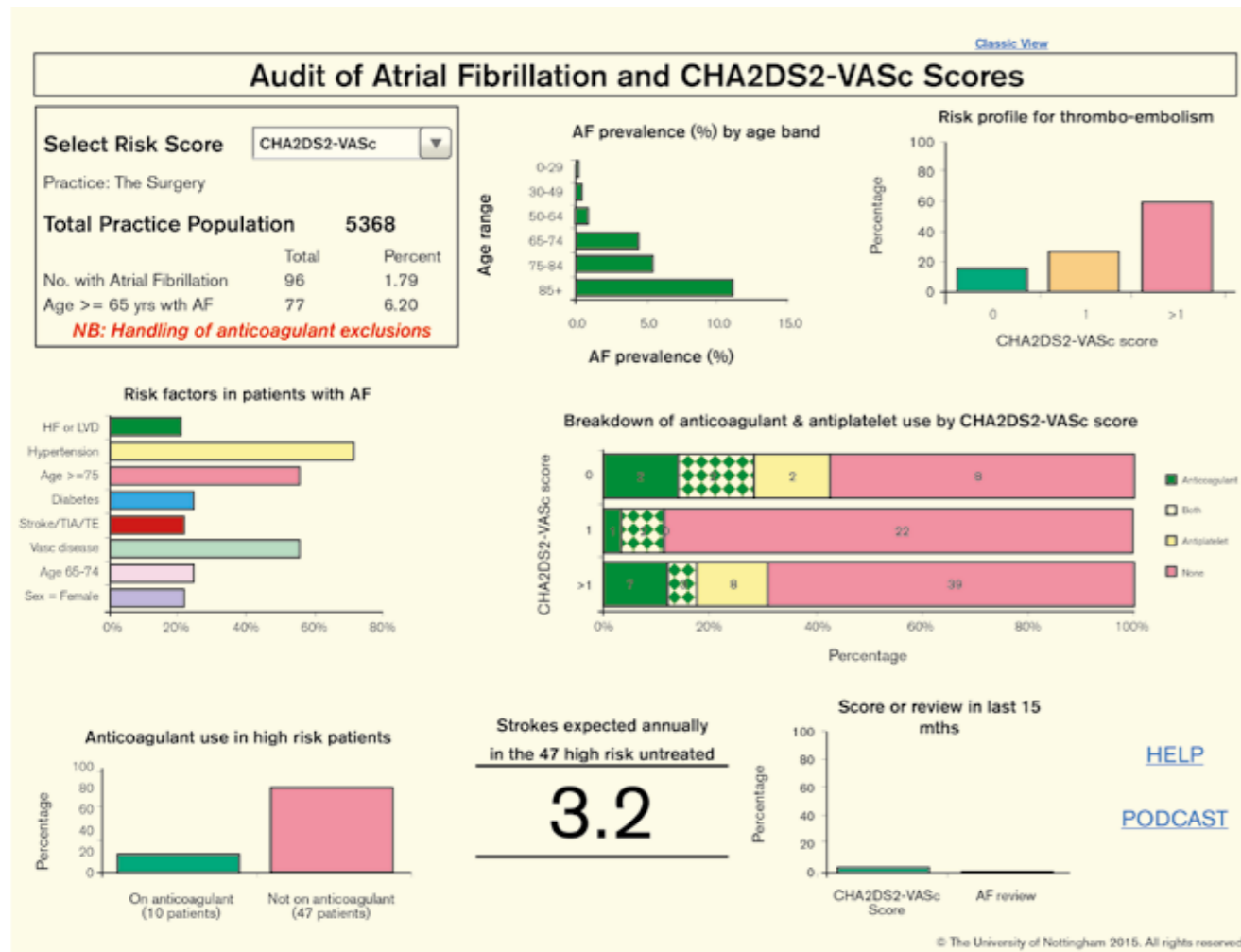


Image: GRASP-AF summary dashboard example, image provided by PRIMIS

This project ran from 2012 until 2014 and was fully funded by the British Heart Foundation. Its primary aim was to improve the capability of staff in primary care settings to manage patients with AF. To achieve this, an audit of activity was conducted using the GRASP-AF tool.

GRASP-AF ALLOWS THE PRACTICE TO;

- Calculate the risk of stroke in patients with AF using CHA₂DS₂-VASc scoring.
- Identify patients at high risk of having a stroke who are not receiving anticoagulation.

- Calculate the number of strokes that a practice can expect in the next 12 months, given current levels of anticoagulation.
- Help practices manage their patients with AF and highlight patients of concern or interest.
- Provide a dashboard view that is easy to read and gives a graphical representation and 'snapshot' of patient care.

On completion of the audit, practices were provided with a summary of the findings, and the health care professionals involved in the project made recommendations and provided

THE USE OF GRASP-AF IN PRIMARY CARE — NHS LANARKSHIRE CONTINUED

tailored training for staff based on the findings. The project's design involved the use of an "audit and education" approach focused on increasing the skills, knowledge and confidence of primary care staff to identify patients with AF, and to optimise their on-going management. The project team worked with 55 out of 96 GP practices in Lanarkshire, exceeding their original target.

THE OUTCOMES WERE;

- The prevalence of AF increased: up to 1.68% of patients in the Health Board area from a 1.4% baseline;
- More high risk patients were on anticoagulation medication: 62.2% of high risk patients which is an increase of 4.2% from baseline; and,
- The stroke risk reduced by 14% from baseline which meant 13 strokes saved in the first year.⁵⁶

THE USE OF GRASP-AF IN PRIMARY CARE — NHS GREATER GLASGOW & CLYDE

Based on the success of that project NHS Greater Glasgow and Clyde (NHSGGC) developed a similar model led by their Managed Clinical Network and supported by the British Heart Foundation.

Starting in 2014, three quarters of GP practices in NHSGGC ran GRASP-AF software in order to undertake localised audit in each participating practice.

Each practice was provided with a GRASP-AF summary dashboard which clearly showed their AF prevalence. The dashboard showed the CHA₂DS₂-VASc score including a percentage and actual patient numbers of people with AF according to their current medical management — prescribed an anticoagulant, antiplatelet, both or neither.

In addition to the audit tool, all practices involved were offered education sessions provided by a Clinical Development Coordinator employed by the British Heart Foundation.

This work resulted in significant improvements in the management of patients with AF. Anticoagulation rates in high risk individuals rose from 57% to 71% over two years which is conservatively estimated to have saved 30 strokes per year across NHSGGC.

A crucial part of this process was the help received from primary care pharmacists and pharmacy support technicians to run the software in practices and produce the patient level detail for the GP. Without such support from pharmacy colleagues, the software was often not utilised to its full potential.

GRASP-AF is funded by the Department of Health England and therefore is freely available to practices within NHS England. Discussions at the inquiry round table meeting on the use of data were very supportive of a similar tool

being developed as part of the SPIRE roll out. It was felt that this would be a crucial intervention which could have a significant impact on the prevention of AF related strokes.



INQUIRY FINDINGS — BARRIERS TO THE USE OF 'BIG DATA'

Traditionally, AF research has been based on recruiting large numbers of participants into research studies and collecting information over several years. Improvements in Information Technology (IT) and the availability of large databases of clinical information potentially allow information to be collected for research at a national level.

The unique CHI identifier makes Scotland ideally placed for such 'big data' research. Combined patient data could be used to plan health care policy, monitor safety, ensure that drugs aren't causing unexpected side effects, and improve the quality of health care by analysing how the health service is being run.

Although there have been exemplars of using routinely collected data to look at important questions in AF, such as the anticoagulation prescribing patterns in stroke survivors with AF, with particular emphasis on sociodemographic associations,⁵⁷ such routinely collected data have not been used as often or as well as many would have hoped for.

Throughout the course of the inquiry some general barriers were highlighted which might explain why this is the case. These included the time necessary to input data fully, concerns about confidentiality, the difficulty in ensuring accurate coding and disparate IT systems. In particular, attention was drawn to the disparity between systems at primary and secondary care levels.

At the round table discussion on this topic it was highlighted that creating a cohort of AF patients for big data research projects requires using data from various records (hospitalisation, community prescribing records or Scottish Stroke Care Audit). These data sources do not allow for an identification of AF patients who are not anticoagulated, and who have not been hospitalised with either AF or a stroke. This is a major limitation for potential research into this condition.

Discussions at the round table meeting also highlighted that working with routine administrative data sources can be difficult due to long waiting times as several data custodians are involved to grant permission for data access. Linking the different data sources requires separate applications for data access. Those involved in such data usage expressed that their hope was for a more streamlined process available in the future.

Decisions and policy around AF should be based on the best available evidence and researchers have been using routinely recorded data in Scotland to look at effectiveness and cost effectiveness of various anticoagulant medications. One team, who had a lot of experience working in this area, appreciated the possibilities of using routine data for AF research but also noted challenges. For example, it was a struggle for them to include patients who had not been in contact with secondary care services.

A more streamlined process, that still maintained data governance, would be a major step forward for AF research in Scotland.

RECOMMENDATIONS

The Scottish Government should

6 Imbed consistent and effective data capture, ensuring integration across clinical boundaries of primary and secondary care and efficient processes for linking and accessing these data.

7 Support the development and implementation of IT software solutions to facilitate case-finding, support therapeutic decisions and allow audit within and between practices.

Section Four:

The Views of People Living with Atrial Fibrillation

BACKGROUND

Cultural attitudes and policy direction in Scotland are increasingly focused on the need for patients and their carers to be involved in shared decision making around their healthcare.

In 2012 the Scottish Government published the Charter of Patient Rights and Responsibilities.⁵⁸ A key theme in this document was around communication and participation in health care decisions. Furthermore, the Chief Medical Officer in Scotland is supportive of a cultural change towards “Realistic Medicine” which aims to build a personalised approach to care and a culture of shared decision making.

“When people are more involved in decisions, they are more likely to adhere to treatment, less likely to suffer the consequences of over-investigation and over-treatment and be more satisfied with their outcomes and relationship with their professionals.”
— *Realistic Medicine*, p17⁵⁹

With this in mind, the inquiry process set out to hear from people living with AF about their experiences and get their suggestions as to what worked well and what could have been better for them. These findings have been kept in mind throughout the development of all of the recommendations.

INQUIRY FINDINGS — INFORMATION PROVISION TO PEOPLE LIVING WITH ATRIAL FIBRILLATION

Living with a long-term condition such as AF can have a significant impact on those affected, including on the social, economic, psychological and physical aspects of their lives. In order to deal with this impact as best as possible, people need to have the information and skills to develop appropriate self-management strategies. Being able to access reliable information and support can empower people to learn about their condition and identify where changes could be made, or where they might need extra support.

The people living with AF who responded to our consultation highlighted accessing information about the condition and potential treatments as an area where they felt

“ I probably had AF for a long time but didn’t know what it was. To me, the condition was unknown. ”

Ivan (round table participant)



improvements could be made. Of the 59 respondents to the patient questionnaire, 15% stated that they received no information at all about their condition while only 33% felt that they received a detailed explanation.

In particular, respondents highlighted a gap in information sharing with regards to whether they should have been given rate or rhythm control interventions such as cardioversion or ablation.

“I was advised by my GP that I was not a candidate for cardioversion or ablation, but he did not explain why.”

“I am angry that I was not told about a procedure called ablation (I think) until it was too late.”

“I would have been happier if it had been explained to me why other treatments were not for me.”

People living with AF who responded to the consultation were clear that receiving more information about the condition and their treatment options would have greatly improved their experience. Discussions at the round table confirmed this. Those who were happy with the care they received pointed to the flow of information and communication with their health care professionals as a factor crucial to their satisfaction.

Clinician respondents to the consultation noted that, although anticoagulation for AF is usually a long-term medication, many patients were not taking their prescribed anticoagulant a few years after diagnosis.

NICE guidelines highlight that non-adherence to medication should not be seen as the patient’s problem but that it represents a limitation in the delivery of healthcare, perhaps due to a failure to fully agree the prescription, provide the appropriate information or identify the support that patients require.⁶⁰

Addressing this requires more work to understand the patient experience and their reasons for continuing or stopping AF medications. At a clinical level, this highlights the importance of exploring the patient’s perspective and sharing information in a way that allows the patient to make informed decisions.

It is clear that there is scope for thinking about how patient centred care and shared decision making principles can be applied in the context of AF. Specialist AF clinics, as highlighted earlier in this report, are one way to achieve the provision of personalised information and care for people with AF, and promote appropriate self-management strategies.

Many clinicians who responded to the consultation identified leaflets as a useful tool for sharing information with patients but only a small number of those living with AF who responded to the consultation (17%) recalled receiving anything like this.

In our round table discussion with people with AF, it was felt that leaflets had been helpful and played an important role. In particular, a need to ensure that information was reliable was expressed and many people pointed to publications from respected third sector organisations or NHS websites as sources of good information. The discussions highlighted that further to receiving leaflets, the critical aspect for most people was having contact with a health care professional who could answer any questions and tailor information to the person’s individual situation.

There are a number of other barriers to information provision such as language barriers, medical jargon and poor health literacy. Any efforts to improve information dissemination must take these into account.

INQUIRY FINDINGS — PEOPLE WITH ATRIAL FIBRILLATION FELT THAT THEY COULD BENEFIT FROM A REGULAR REVIEW OF THEIR CONDITION

A number of responses to the consultation indicated that review processes for people with AF are variable throughout Scotland. In some areas people with AF are reviewed regularly, while in other areas this does not seem to be the case.

Responses from people living with AF indicated that a more regular review process would have improved many of their experiences.

“I would have liked a check-up programme, perhaps six monthly. I have had little success in asking about drug changes and risks of current drugs.”

SIGN guideline 129 states that,

“The balance of risks and benefits of anticoagulant therapy should be assessed and discussed annually with the patient, with consideration given to patient preference.”⁶¹

The provision of integrated multi-disciplinary care can allow opportunities for patients to receive appropriate review of their condition. This could be provided by a variety of health care professionals depending on local staffing provision. This may involve nurses, pharmacists or cardiac physiologists.

Discussions at our round table meeting on treatment of AF highlighted that community pharmacy could have a particular role to play with regards to regular medication review of people with AF.

“Achieving Excellence in Pharmaceutical Care: A Strategy for Scotland”⁶² highlights the importance of the pharmaceutical workforce in delivering integrated, person centred care in Scotland.

The strategy draws attention to the fact that work is ongoing to enhance the Pharmacy Care Record (PCR) in order to introduce an annual pharmacist-led medication review traditionally carried out by GPs. So perhaps there is scope to consider how AF would fit within this framework, as it was clear throughout the inquiry that this would be of great value to people with AF.

INQUIRY FINDINGS — RAISING PUBLIC AWARENESS OF ATRIAL FIBRILLATION

A public health awareness campaign around AF was a common theme which arose from the consultation responses, both from clinicians and people living with AF.

“I think there needs to be more public awareness. So that people are aware of what it is.”

At the round table discussion on detection and diagnosis the merits of raising public awareness were discussed. It was thought to be helpful generally to raise awareness of the condition and its links to stroke amongst a general population, although it was felt that more detailed information such as how to check a pulse for example, was better shared through more targeted awareness raising to high risk groups. Some examples of projects which did this were shared with the group, including a project carried out in NHS Fife⁶³ and one carried out in NHS Grampian which aimed to provide people attending cardiac rehabilitation with the skill to take their own pulse.⁶⁴

It was also suggested that, just as important as raising public awareness, was raising awareness of AF among health care professionals.

RECOMMENDATIONS

The Scottish Government should

8 Ensure that all health care professionals have the necessary information about AF to support patients to take part in shared decision making, from the point of diagnosis of AF through to long term condition management.

9 Work with clinicians, researchers, third sector and people affected by AF to find the most effective methods to raise awareness of AF among the public.

10 Ensure that people with AF, and at risk of AF, receive relevant, tailored information and support, utilising robust and trusted providers such as major third sector charities.

Glossary

A

Ablation — a treatment that aims to control or correct certain types of abnormal heart rhythms.

Anti-arrhythmic medications — medicines which aim to return the heart rhythm back to normal.

Anticoagulants — a group of medicines used to prevent harmful blood clots from forming.

Antithrombotic medication — drugs which reduce the formation of blood clots. There are two classes of antithrombotic drugs: anticoagulants and antiplatelets (such as aspirin). Aspirin is no longer recommended in the prevention of strokes associated with AF.

Arrhythmia — an abnormal heart rhythm.

Atria — the upper chambers of the heart.

Atrial Fibrillation — an irregular heart rate that increases the risk of stroke.

C

Cardiac physiologist — health care professional who carries out cardiac tests, such as echocardiograms, ECGs, Holter monitors (24-hour ECG) etc.

Cardiology — medical speciality relating to the diagnosis and treatment of heart disease.

Cardiovascular disease — includes all the diseases of the heart and circulation.

Cardioversion — involves using a defibrillator to give a controlled electric shock to get return the heart rhythm to normal.

Case-finding — a strategy used to identify patients with a certain condition.

Chronic kidney disease — a disease where the kidneys don't work as well as they should.

Chronic respiratory diseases — diseases of the airways and other structures of the lung.

Coagulation tests — measurement of how long a person's blood takes to clot.

Cohort — a group of subjects with a common defining characteristic.

Community Health Index — a population register which is used in Scotland for health care purposes.

Contraindication — a condition or factor that serves as a reason to withhold a certain medical treatment due to the harm that it would cause the patient.

Coronary artery disease — a condition where the inside of the coronary arteries becomes narrowed because fatty deposits have built up within the artery walls.

D

Dementia — an umbrella term for a group of conditions that affect how well the brain can function.

Demographic — characteristics of a given population.

Diabetes — a condition where the level of glucose (sugar) in the blood is too high.

Direct oral anticoagulant — a newer class of anticoagulation medications.

E

Electrocardiograph — a test that gives information about the electrical activity of your heart. The ECG helps to identify the source of the abnormal rhythm.

F

Fatigue — persistent feeling of tiredness.

G

GP — a primary care doctor.

H

Health boards — NHS Scotland consists of 14 regional NHS Boards which are responsible for the protection and the improvement of their population's health and for the delivery of frontline healthcare services and 7 Special NHS Boards and one public health body who support the regional NHS Boards by providing a range of important specialist and national services.

Heart attack — damage to a part of the heart muscle caused by a sudden loss of blood flow to a part of the heart.

Heart failure — when the heart becomes less effective at pumping blood around the body.

Heart rate — how quickly the heart beats.

Heart rhythm — how regular or irregular the beats are.

High blood pressure — when the pressure of blood running through the arteries is too high (consistently over 140/90mmHg) it can have negative effects on the cardiovascular system.

Holter monitoring — a technique involving continuous recording on an electrocardiogram (ECG) over 24 hours, or longer. The patient wears the device on a belt with electrodes attached to their chest.

I

Ischaemic stroke — a stroke caused by a blockage cutting off the blood supply to the brain.

L

Left ventricular dysfunction — heart condition in which the heart is unable maintain normal function due to a problem in the left ventricle.

Long term condition — conditions for which there is currently no cure and which are managed with drugs and other treatment.

M

Mortality — another word for death, when considered on a large scale.

O

Obesity — the term "obese" describes a person who's very overweight, with a lot of body fat.

P

Palpitations — the sensation of feeling your heartbeat sometimes described as a thumping or fluttering in the chest.

Prevalence — a statistical concept referring to the number of cases of a disease that are present in a particular population at a given time.

Primary care — health care provided in the community. It is usually the first point of contact for patients and involves providing care for common illnesses and long term conditions.

R

Radial pulse check — is the measurement of the pulse through the radial artery in the wrist.

Rate control — giving treatment to control the rate of the heartbeat, so that the heart beats more slowly, even if the heartbeat remains irregular.

Risk factor — something that increases your risk of developing a disease or condition.

Rhythm control — giving treatment to try to get the heart back to a normal rhythm.

S

Secondary care — medical care provided by a specialist, usually upon referral by primary care.

SIGN guidelines — Scottish Clinical guidelines which are developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances by making recommendations for effective practice based on current evidence.

Sinus node — the heart's natural pacemaker. Electrical impulses originate here and travel through the heart, causing it to beat.

Sleep apnoea — a condition where the walls of the throat relax and narrow during sleep, interrupting normal breathing.

Stroke — a stroke is a brain attack which happens when the blood supply to part of your brain is cut off.

T

Thrombectomy — a treatment that removes a blood clot with a mechanical device.

Thromboembolism — an obstruction to blood flow due to a blood clot in a deep vein, usually the legs (DVT) or the lungs (PE).

Thrombolysis — a process to that uses medication to dissolve a blood clot in the coronary arteries or in the arteries leading to the brain.

Thyroid disease — a medical condition affecting the function of the thyroid gland.

Transient Ischaemic Attack — is the same as a stroke, except that the symptoms only last for a short amount of time because the blockage that stops the blood getting to the brain is temporary.

V

Valvular heart disease — disease of the heart valves, which can affect the flow of blood, putting extra strain on the heart.

Vascular disease — disease of the blood vessels.

W

Warfarin — the most widely prescribed anticoagulant. It decreases the clotting ability of the blood, and so reduces the risk of blood clots forming.

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Appendix

Patient representatives

Mr Jim Bruce

Jim engages regularly with Chest, Heart & Stroke Scotland and has an interest in atrial fibrillation which led to him joining the advisory panel.

Mr Paul Hodson

Paul regularly volunteers for Chest, Heart & Stroke Scotland, sharing his lived experience of aphasia with health care professionals and other volunteers. He also sits on the Stroke Association UK Stroke Assembly Panel. His interest in atrial fibrillation led him to joining this advisory panel.

Third sector organisations

Ms Wendy Armitage

Community Engagement Manager,
Chest Heart & Stroke Scotland

Wendy Armitage is a nurse with over 20 years' experience working within the NHS across primary and secondary care before moving into the Third sector. She has a special interest in the field of cardiology and community-based support.

Ms Morven Dunn

CVD Clinical Development Coordinator,
British Heart Foundation Scotland

Morven Dunn has over 20 years of cardiovascular nursing experience, including developing the first Scottish specialist AF clinic. For the last 4 years she has worked as part of the Health Services Engagement team at the British Heart Foundation.

Mr Colin Oliver

Head of Information and Awareness,
Stroke Association

Colin Oliver is responsible for information on stroke and stroke-related matters for the Stroke Association in Scotland.

Academic and clinical advisors

Dr Neil Grubb

Consultant in Cardiology and Cardiac
Electrophysiology, NHS Lothian

Dr Neil Grubb is a Consultant in Cardiology and Cardiac Electrophysiology in NHS Lothian. He was the Principal Investigator for a Scottish national pilot screening for atrial fibrillation in primary care.

Professor Lis Neubeck

Professor and Head of Theme of the
Long Term Conditions theme in the
School of Health and Social Care at
Edinburgh Napier University

Professor Lis Neubeck is a cardiovascular nurse with more than 20 years of clinical experience. Her research interests are in detection and patient-facing management of AF. She has led numerous research projects and published extensively on these topics.

Dr Terry Quinn

Stroke Association and Chief Scientist
Office Senior Clinical Lecturer,
Cardiovascular and Medical Sciences,
University of Glasgow

Dr Terry Quinn holds the post of joint Chief Scientist and Stroke Association Senior Clinical Lecturer. He combines his program of research into stroke with his clinical and teaching work in the stroke units of Glasgow.

The Secretariat for the Cross-Party Group on Heart Disease and Stroke is provided by British Heart Foundation Scotland, Chest, Heart & Stroke Scotland and Stroke Association.

