



A Focus on Atrial Fibrillation in Northern Ireland

**An independent inquiry into the identification
and management of AF to reduce stroke risk**

Commissioned by Northern Ireland Chest Heart & Stroke and developed
in partnership with Dr Niamh Kennedy, Ulster University





**Atrial Fibrillation
or AF (irregular
heart rate)
increases your
risk of stroke
by 5 times**

without AF

supported by

CE



CONTENTS

Foreword	5
Advisory Panel	6
Summary of Key Recommendations	7
Introduction	8
What is Atrial fibrillation (AF)?	
Symptoms, risk factors & treatment of AF	
Scale of AF in Northern Ireland	
The impact of AF – Stroke	
Current Treatment and Outcomes	12
Key points	
Quality Outcome Framework (QOF)	
SSNAP Data	
Management of AF related stroke	
Direct Oral Anti-Coagulant (DOAC) Adherence	
The AF Inquiry Process	16
Key Findings	17
Public Awareness of AF	
The Questionnaire Survey Results	
Service User Survey: Engaging with people living with AF	
Healthcare Professionals survey	
8 Key Themes from the Inquiry Research	30
Theme 1: Need for targeted detection to identify undiagnosed AF	
Theme 2: Need for Good Practice or Innovation	
Theme 3: Resources and budget	
Theme 4: Awareness and Understanding	
Theme 5: Promoting self-management and medicine compliance	
Theme 6: Issues in current AF pathway	
Theme 7: Waiting Lists	
Theme 8: Technology	
Conclusions	
Recommendations	
Action Plan	40
References	42
Glossary	46
Appendix: Advisory Panel	48



Atrial Fibrillation



AF (irregular heartbeat) increases your risk of stroke by five times. It's time to talk about AF.

Did you know?

Over 40,000 people in NI have been diagnosed with AF although it is estimated that many more are living with the condition undetected. Could you be one of them?

People with AF are likely to have a much more severe stroke with:

- Almost double the death rate from stroke
- Increased disability from stroke
- Longer hospital stay
- Increased risk of a stroke happening again

What are the Symptoms of AF?

Sometimes people with AF have no symptoms and their condition is only detectable during a medical examination or by having a health check with us.

Some people may experience one or more of the following symptoms:

- Feeling very tired
- Feeling faint at times
- Being breathless
- Palpitations or fluttering or 'thumping' in the chest

Have you heard of AF?

In a recent survey we conducted of 1000 people, 700 did not know what AF is. Only 3% knew that having AF increased your risk of stroke five fold.

FOREWORD

Atrial Fibrillation (AF) is one of the most common types of irregular heart rhythm and someone with this condition could be up to five times more likely to suffer a stroke. This medical condition can have a devastating impact on the individual and their family. In addition it has consequences for the health and social care sector, the economy and our society. Whilst recognising that there are many examples of good practice, we believe that improvements can be made in the management of those who suffer from AF.

It is deeply concerning that there are an estimated 10,000 people in Northern Ireland living with AF yet undiagnosed. They will not be aware their risk of a stroke could be greatly diminished by treatment with basic medication.

By engaging directly with people in local communities, Northern Ireland Chest Heart and Stroke (NICHHS) staff witness the devastating impact of AF every day. Through our Stroke services and programmes we have met with numerous people who received their diagnosis of AF post stroke; a stroke that may very well have been prevented if their AF had been identified earlier. We are very aware of the need to do more to prevent, delay, and manage such a serious condition.

We pride ourselves on championing re-design and innovation in health services. We have been leading by example in Northern Ireland in the area of AF. In recent years NICHHS has introduced AF

testing as part of our health checks and delivered a public awareness campaign to raise the profile of the condition and the associated stroke risk.

Building on these actions, we commissioned this Independent Inquiry in March 2019 to gain a better understanding of the key issues relating to AF detection and management in Northern Ireland and to help identify solutions to address those issues. The Inquiry research ran from March 2019 to January 2020.

We would like to thank all of those who took the time to contribute to the Inquiry. We would particularly like to extend our sincere thanks and appreciation to those people who shared their personal stories and experiences of living with AF and to members of the advisory panel who provided invaluable advice, expertise, and their time.

We look forward forward to working in partnership to ensure the recommendations from this report are taken forward to improve the outcomes and experience of people living with AF. By doing this we can significantly reduce preventable strokes in Northern Ireland.



Declan Cunnane

Chief Executive
Northern Ireland
Chest Heart & Stroke

ADVISORY PANEL

Panel members:

1. **Dr John Winter** – Chairperson & GP Lead of the Ards Integrated Care Partnership
2. **Dr Brian Gallen** – Consultant Stroke Physician and Geriatrician, South West Acute Hospital and member of NICHS Governance Board
3. **Michael Jackson** – Lead Pharmacist for Cardiothoracic Services, Belfast Health and Social Care Trust
4. **Neil Johnston** – Public Affairs & Policy Manager, NICHS
5. **Dr Niamh Kennedy** – Lecturer in Psychology, Ulster University
6. **Clare Murray** – Lead GP Pharmacist, East Belfast Federation of Family Practices

The role of the panel was to ensure that the appointed researcher, Dr Niamh Kennedy, was able to regularly consult and seek advice from several healthcare professionals from across Northern Ireland with differing professional backgrounds.

Neil Johnston spoke with a wide number of people who attend our NICHS Stroke Groups to understand their experience of stroke in general and AF in particular.

Dr. Kennedy conducted one to one interviews with people living with AF about their experiences of living with this condition and over 40 people with AF responded to our patient survey.

SUMMARY OF KEY RECOMMENDATIONS

Working in partnership with key stakeholders, the Department of Health should:

- 1.** Develop an AF strategy for Northern Ireland which will:
 - drive forward service improvement in awareness, detection, support, and management
 - have a clear implementation with targets and timelines – including the appointment of an ‘AF Champion’.
- 2.** Establish a target to achieve at least 85% detected prevalence across Northern Ireland by March 2023 and have a proposed ambition of identifying 90% of expected prevalence by 2025.
- 3.** Create a holistic clinical pathway for AF in Northern Ireland involving patients and clinicians.
- 4.** Invest in the use of proven technologies within clinical practice to detect AF, monitor implementation Plan, and allow audit.
- 5.** Commission plans to increase AF detection rates by using targeted case finding based on AF risk factors.
- 6.** Take action to address the echocardiograms waiting list issue, including outlining plans to tackle any workforce issues.
- 7.** Provide information and education to people living with AF to better support understand and improve to anticoagulation medication, and to manage their condition.
- 8.** Prioritise improving treatment and review of existing AF patients to prevent future strokes. We recommend the following targets:
 - Achieve less than 20% of patients with known AF admitted with stroke who are not correctly anticoagulated by March 2023
 - Reduce individuals with a new diagnosis of AF after admission to a stroke unit from 23% to 20% by March 2023.
- 9.** Commission the Public Health Agency to identify the most effective methods to raise public awareness of AF. We recommend the following targets:
 - increase public recognition of AF from 37% of the population to 50% of the population by 2025
 - increase public awareness that AF can increase the risk of stroke by up to five times from the current base of 11% to 20% by 2025.

INTRODUCTION

Key points:

In Northern Ireland

- AF is the most common sustained irregular rhythm.
- Nearly **40,000 people (80%)** have been diagnosed with AF.
- It is estimated there are at least **10,000 people** undiagnosed.
- AF can increase the risk of stroke by **5 times** (more than any other cardiovascular risk factor).
- Between **30-40%** of people may not be aware they have AF until they have a stroke.
- Up to **25%** of ischaemic strokes due to occur because of AF.
- Approximately **2,800 people** have a stroke every year.
- Stroke is the third biggest cause of death, with over **1,000** deaths per year.
- **10%** of high-risk AF patients are not anticoagulated.
- The cost of caring for stroke in NI is projected to rise from **£484** million in 2015 to **£1.51** billion in 2035.
- Estimated potential **£4 billion** (UK) saving to societal costs of stroke by 2035 through investment in improved stroke prevention.

What is Atrial fibrillation (AF)?

Atrial fibrillation (AF) is a heart condition that causes an irregular and often abnormally fast heart rate. In a normal heart, blood is pumped through the heart by the tightening and relaxing of the muscular walls. This pumping action is controlled by part of the heart called the sinus node which sends regular electrical impulses to control the rhythm.

AF happens when irregular electronic impulses are sent to the heart's upper chambers (atria), which overrides the heart's natural pacemaker meaning it can no longer control the regular rhythm of the heart.



There are several definitions of AF and the condition can progress through these stages.

- **Paroxysmal atrial fibrillation** is AF that comes and goes. It usually lasts for less than 48 hours but can last for up to seven days. The heart reverts to normal rhythm by itself and AF is not present all the time.
- **Persistent atrial fibrillation** is when each episode lasts longer than seven days (if untreated) at a time but it is still possible for the heart rate and rhythm to return to normal.
- **Permanent or long-standing atrial fibrillation** is present all the time and the heart does not return to a normal rhythm^[30].

Symptoms, risk factors & treatment of AF

Not everyone who has AF will experience symptoms, but those who do can experience palpitations, dizziness, shortness of breath, tiredness or fatigue. Individuals who experience some of these symptoms are more likely to seek support from healthcare professionals and access treatment.

As many as 40% of people with AF do not experience symptoms (asymptomatic AF), however, their risk of stroke is unchanged^[31].

The exact cause of AF is unknown, but it's more common in men and risk increases with age. A number of risk factors are associated with AF, including:

- high blood pressure
- heart failure
- valvular heart disease
- previous heart attack
- thyroid disease
- diabetes
- chronic lung disease
- sleep apnoea
- kidney disease
- excessive alcohol consumption
- obesity
- smoking

AF is a treatable condition. Treating AF is extremely important, especially to reduce risk of stroke. Treatment can include medication to help control the heart rate or rhythm or to help reduce stroke by preventing blood clots. Traditionally Warfarin would have been prescribed but there are a range of new anticoagulants available. Other treatments include cardioversion to restore normal rhythm by delivering a controlled electric shock

or catheter ablation, during which the part of the heart causing the abnormal rhythm is destroyed by radiofrequency, after which sometimes a pacemaker is needed ^[30].

The understanding of stroke risk factors and ensuring appropriate treatment of AF allows for significant reduction in the potential impact of AF.

Scale of AF in Northern Ireland

Atrial Fibrillation (AF) is the most common sustained cardiac arrhythmia, occurring in approximately 2% of the general population^[6]. In Northern Ireland the overall prevalence is 2.0% of the population^[16] (2018 data, collected from GP practices). This has increased from 1.2% in 2008. Recent research has demonstrated that based on population data the estimated prevalence of AF is 2.5% in the UK^[29]. This would suggest in Northern Ireland, with prevalence rate of about 2.0%, that approximately 80% of people with AF are currently being detected.

Nearly 40,000 people in Northern Ireland are diagnosed with AF but it could be as many as 50,000 people with the condition due to the undiagnosed proportion.

The impact of AF - Stroke

The human cost:

It is estimated that between 30-40% of individuals with AF may not be aware that they have it and the first manifestation of AF may be an ischaemic stroke^[17]. AF is a major contributor to stroke incidence and a powerful predictor of first ever ischaemic stroke^[10]. Approximately 25% of ischaemic strokes are thought to occur because of AF. It is generally accepted that these strokes tend to be more extensive, carry a higher mortality and increased

morbidity^[6]. Having untreated AF means that you may be five times more likely to suffer from a stroke than someone without AF, as well as contributing to a range of other conditions, including congested heart failure, cognitive impairment, decreased quality of life and mortality^[17,24].

Stroke is the third biggest cause of death in Northern Ireland. It is estimated that AF causes 12,500 strokes in the UK every year, that potentially 7,000 strokes and 2,000 premature deaths could be avoided every year through effective detection and protection with anticoagulant drugs that prevent blood clots forming^[1,7].

In Northern Ireland, 10% of high-risk AF patients are not anticoagulated. Evidence shows, that optimally treating high-risk AF patients over three years can avoid 210 strokes^[12].

The cost to Health & Social Care:

In Northern Ireland there are 36,000 stroke survivors, 2,800 people admitted to hospital every year with a diagnosis of stroke and approximately 1,000 stroke related deaths.

The economic cost:

In 2015, the average societal cost of stroke per person (UK) was £45,409 in the first 12 months after stroke plus up to £24,778 in subsequent years. UK leading experts have recommended that there is a potential £4 billion saving to societal costs of stroke by 2035 through investment in improved stroke prevention^[5, 15,18]. The cost of caring for stroke in Northern Ireland is projected to rise from £484 million in 2015 to £1.51 billion in 2035 with £585 million of this being health and social care.

One of the clearest ways of preventing a stroke is the detection and management of underlying conditions such as AF.

The growing problem AF and ageing population

UK population projections suggest that between 2015 and 2035 the total population aged 45 and over will rise by 22.5%^[13]. Age is a risk factor for AF, the prevalence of AF roughly doubles with each advancing decade of age^[1]. By 2030, the population in Northern Ireland aged 65-84 will rise by 37% and those over 85 by 76%.

Considering the ageing population, with people living longer it is essential that stroke prevention and management of underlying conditions such as AF is prioritised, to decrease potential stroke risk.

The Policy Context

The need for reform and innovation within the health and social care sector is well documented and numerous policy documents point to the need to focus on health promotion, prevention and early detection measures.

Transforming Your Care (TYC)

Published in December 2011 the TYC Review proposed a new model of care for Northern Ireland with the individual at the centre to improve the health and wellbeing of people by:

- promoting good health decisions;
- preventing ill health in the first place;
- achieving better outcomes when ill health does occur and;
- enabling people to live healthily and independently for as long as possible.

Health & Well-being 2026: Delivering Together

Published in October 2016 Delivering Together further reinforces the message that change is essential and that,

in particular, an ageing population presents challenges to services. It emphasises that advances in treatments, drugs, and technologies need to be adopted to counter every increasing need.

Delivering Together puts people at the forefront. The focus is on enabling people to stay well for longer.

Making Life Better – A Whole System Framework

The Northern Ireland Executive's overarching public health strategy - Making Life better, was published online in June 2014. This framework's vision is that "all people are enabled and supported in achieving their full health and wellbeing potential".

Stroke Services Review

The current review of strokes services focuses heavily on acute services and prevention is largely only considered with regard to transient ischaemic attack (TIA) or "mini stroke". NICHs believe we need a stronger focus on preventing strokes in the first place, to keep people healthy and out of hospital.



CURRENT TREATMENT AND OUTCOMES

Key points:

In Northern Ireland

- It is estimated at least **10,000 people** remain undiagnosed.
- Analysis of two years of Sentinel Stroke National Audit Programme (SSNAP) data indicates, that despite the total number of strokes falling, the number of strokes that were AF related has increased from **18.9%** to **23%**.
- From SSNAP data, there is a significant number of individuals having a stroke every year in Northern Ireland who didn't know they had AF and who, had they been on appropriate anticoagulation, may have avoided having a stroke.
- SSNAP data indicates the numbers of people with AF on appropriate medication for stroke prevention/anticoagulation and shows there has been improvements made – increasing from **60%** in Apr 2016-March 2017 to **68%**.
- Over **30%** of people with AF are not on appropriate medication.
- There are concerns about medicine management (adherence) as it is estimated that in the long term, **40-60%** of people with AF may be non-adherent to their direct oral anticoagulant (DOAC) therapy.

Quality Outcome Framework (QOF)

In Northern Ireland the overall prevalence of AF is 1.9% of the population^[16] (2018 data). This has increased from 1.2% in 2008. This suggests that detection has improved, however, it is still lower than England where QOF data has a national prevalence of 2.0 and many Clinical Commissioning Groups in the North West of England which have focused on AF detection have figures in the 2.5-2.9 range.

Recent data for England has led to an estimated prevalence figure for England of 2.5. Northern Ireland is unlikely to be hugely different, suggesting there is a considerable cohort of undetected AF. This would support the belief that there is a significant opportunity to increase detection and reduce stroke.

SSNAP Data

Sentinel Stroke National Audit Programme (SSNAP) SSNAP^[20] is the national stroke audit which measures the quality and organisation of stroke care in the NHS. There are several elements of the audit data that are directly relevant to AF including number of AF related strokes and whether they were on anticoagulants prior to their stroke. The SSNAP regularly adds new questions and in 2018 the INR (International Normalising Ratio) range for individuals on Warfarin when admitted to hospital was added.

Data from the last two years has been analysed in order to give an indication of the current effect of AF related strokes.

Total number of stroke and AF related strokes

	No. strokes	No. AF strokes	% AF related strokes	Anticoagulation prior to stroke?	
				Yes	No
2017-18	2,774	520	18.9	360	101
2018-19	2,749	639	23	324	112

This comparison shows that despite the total number of strokes falling, the number of strokes that were AF related has increased. The proportion % of strokes that were AF related has risen from 18.9% to 23% in 2018-2019.

According to data collected by SSNAP between April 2018- March 2019, 149 people had a new diagnosis of AF following their stroke. This translates to 23.3% of all AF related strokes or 5% of all strokes in that year. From the SSNAP data above, there is a significant number of individuals having

a stroke every year in Northern Ireland who didn't know they had AF and who, had they been on appropriate anticoagulation, may have avoided having a stroke.

The most recent SSNAP data (April to September 2019) continues this trend with 24% of all strokes being AF related (up 1% since the year before) in this 6-month period. Also, during this time 64 people got a new diagnosis of AF following their stroke which corresponds to 19% of all AF related strokes.

Management of AF related stroke

The SSNAP data allows us to see the numbers of people with AF on appropriate medication for stroke prevention/ anticoagulation. There appears to have been improvements made in this increasing from 60% in Apr 2016-March 2017 to 68% in Apr 2017- March 2018, but we can't be complacent as this number fell slightly to 66% in April 2018- March 2019. This trend is positive as anticoagulation is key to stroke prevention in AF patients.

However, this does leave over 30% of AF patients who may not be on appropriate medication. It is essential that patients with known AF are placed on anticoagulants where appropriate. There is a proportion of AF patients (63 patients) who are still on antiplatelet therapy only which is no longer recommended by NICE and is therefore not providing sufficient stroke prevention. This offers an opportunity to improve management of AF related stroke prevention.

It is not only critical that AF patients are put on an appropriate anticoagulation but, when they are prescribed Warfarin,

that this is managed and within range, to be of stroke prevention benefit.

From April 2018-March 2019 the INR range of all relevant AF patients could be recorded as part of the SSNAP database. This related to 140 patients, 24 did not have their INR checked. Of the patients who did, 48% (56 patients) had a value between 0-1.9; 44% (51 patients) had a value of between 2-3 and 8% (9 patients) who had a value over 3. The optimal range is an INR between 2-3, this corresponds to 56% of all patients were not in range for correct and effective anticoagulation.

This is a worrying trend and highlights issues around the management of Warfarin, which is particularly concerning as Warfarin clearly requires regular monitoring, and it is important that patients receive this.

In comparison to Warfarin, direct oral anticoagulants (DOACs) offer many treatment advantages, including fixed dosing, fewer drug and dietary interactions, rapid onset and short half-lives, which can preclude the need for peri-procedural bridging, as well as no monitoring requirement.



It is also important to be aware of potential disadvantages:

- there is no specific reversal agent (except for Idarucizumab for Dabigatran);
- there is a need for avoidance or dose reduction in renal impairment and;
- the short half-lives necessitate strict adherence.

This is of importance as the number of AF patients on DOACs in Northern Ireland is increasing. In Apr 2018 - March 2019 62% were on a DOAC compared to 36.7% of people on Warfarin.

Direct Oral Anti-Coagulant (DOAC) Adherence

Any medication regime is only as effective as the adherence to it. Warfarin prescription has an associated management regime which provides a means of adjusting dose and an opportunity to check and discuss adherence.

One of the perceived advantages of DOACs is the removal of the need for this consistent monitoring, however this may lead to an issue around adherence. It has

been suggested that in the long term 40-60% of patients may be non-adherent to their DOAC therapy^[2]. This lower adherence of DOAC is associated with increased risk of mortality and stroke^[9]. It is therefore important that adherence on DOACs is not neglected.

There have been a number of studies and some prediction modelling to identify people with AF at risk of being non-adherent. These factors include being on medication for longer, being younger, being male, having asymptomatic AF and lacking in understanding of the nature of AF.

Recent studies suggest that adherence can be increased by:

- Appropriate selection of DOAC therapy by involving the patient in the decision including dosing (daily v twice daily);
- Patient education- regarding the importance and purpose of the DOAC including perceived risks and benefits and;
- Employing some ongoing patient monitoring face to face or via phone^[21].

Warfarin:

56%

of all patients were not in range for correct and effective anticoagulation



THE AF INQUIRY PROCESS

NICHS carried out a tendering process to appoint an independent researcher to undertake the inquiry. Dr Niamh Kennedy was appointed in March 2019 and the inquiry research commenced in March 2019 and concluded in January 2020.

An independent panel was then established to advise and assist the inquiry and three roundtable meetings were held to enable a broad range of people to contribute.

NICHS invited stakeholders with relevant expertise to join an AF Inquiry Advisory Panel, together with a representative from NICHS and the independent researcher from Ulster University. We approached people living with AF to join the panel, however, they said they would prefer to share their experiences of living with AF in a more personal way.

In addition to seeking the views of those through the survey questionnaire, Dr. Kennedy conducted one to one interviews with patients and professionals and Neil Johnston attended a number of our Stroke Group meetings across Northern Ireland to hear directly from our service users about their experiences.



The Panel advised and assisted the inquiry, developed questionnaires, invited other colleagues to roundtable discussions to feed into the inquiry and reviewed this report.

Inquiry methodology

Over nine months, this extensive, independent inquiry carried out the following:

- Significant desk research was undertaken;
- A service user and a healthcare professional questionnaire were circulated and analysed (between May and October 2019);
- 18 one to one interviews with patients and healthcare professionals were carried out between March and October 2019;
- Three roundtables (between May and October 2019). The roundtables included clinicians from across the whole clinical pathway with a range of expertise, representation from Northern Ireland Chest, Heart and Stroke (NICHS), representatives from local political parties and from pharmaceutical companies involved in providing medicines related to AF. The views and opinions collated from service users and the results of the surveys were extensively discussed at the roundtables.

The information gathered was developed into themes from which the recommendations were derived.

KEY FINDINGS

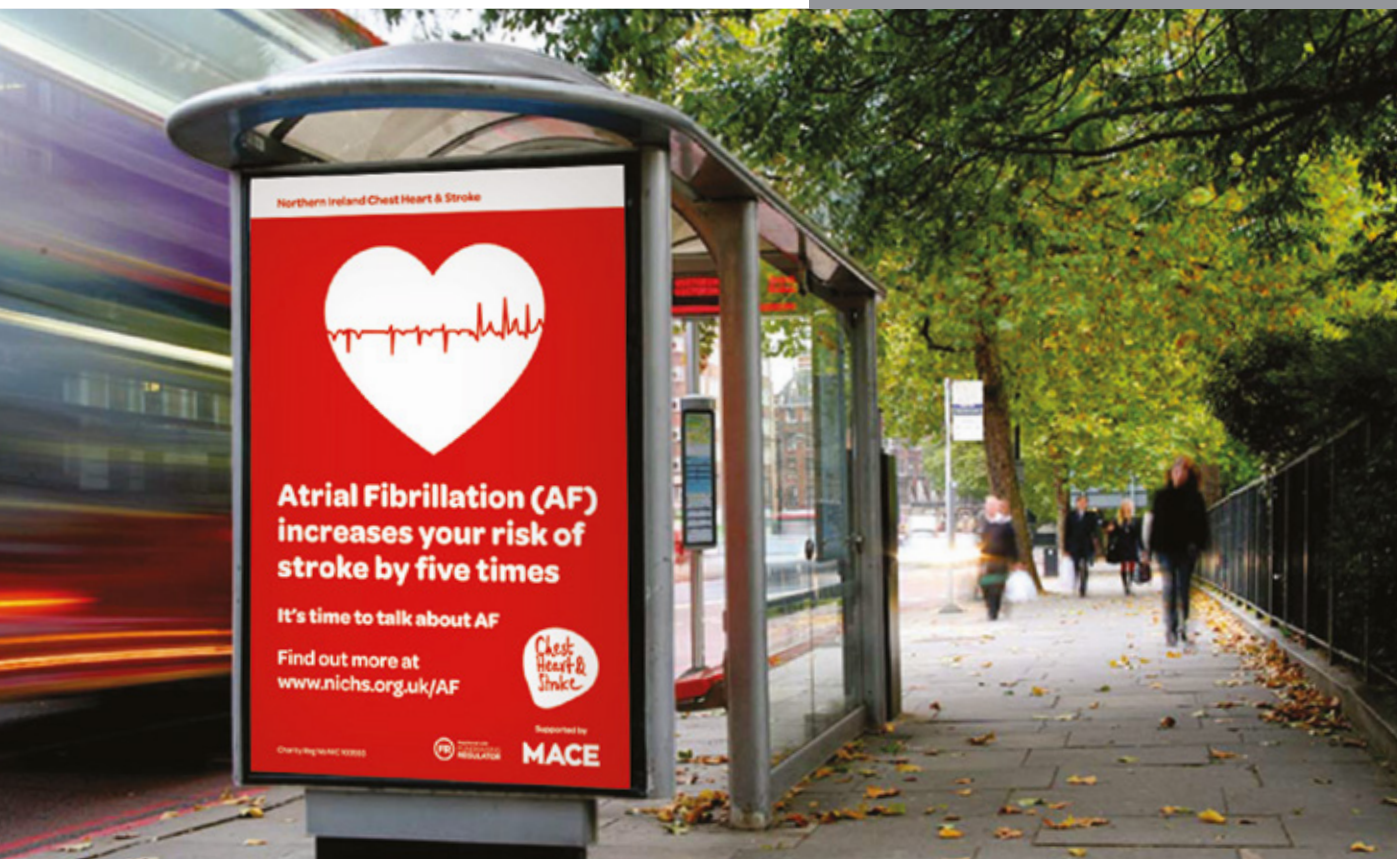
Public Awareness of AF

In parallel to the inquiry process, NICHs ran a public awareness campaign and commissioned two independent opinion surveys in October 2018 and October 2019 - one pre and one post poll to measure campaign activity and impact.

The polling was done by Cognisense (previously known as Ulster Marketing Surveys, and later Kantar Millward Brown Ulster), a well-established and respected polling company, using a representative sample of 1,000 responses from across Northern Ireland.

Key points:

- Pre-campaign public awareness – only 30% had heard of AF.
- Awareness of AF has risen markedly from 30% last year to 37% this year.
- 50-64 age category had a larger increase in awareness - 11%.



Pre-Public Awareness Campaign polling:

The pre-campaign polling took place in October 2018. The Poll identified, that only 30% of the people had heard of AF and, more worryingly, **only 30 people out of a sample of 1,000 (3%),** knew that it can increase your risk of stroke by five times.

Of the 30% who have heard of AF:

- Over a quarter didn't know about the increased risk of stroke
- Nearly 10% thought AF does not increase your risk of stroke.

It is anticipated that greater awareness could lead to better understanding of symptoms, and improved rates of AF detection in the undiagnosed population.

The Awareness campaign:

NICHS embarked on a public awareness campaign to raise awareness of AF and its link with stroke in Spring 2019 using billboards and bus shelter ads, radio ads, posters in GP surgeries, pharmacies and libraries. The campaign was supported by local retailer, Mace, who displayed posters in their stores, included AF information on the leaflets they sent out to the public, and organised AF testing for customers in selected stores. NICHS then commissioned a second opinion poll, in October 2019 to measure the impact of this awareness campaign.



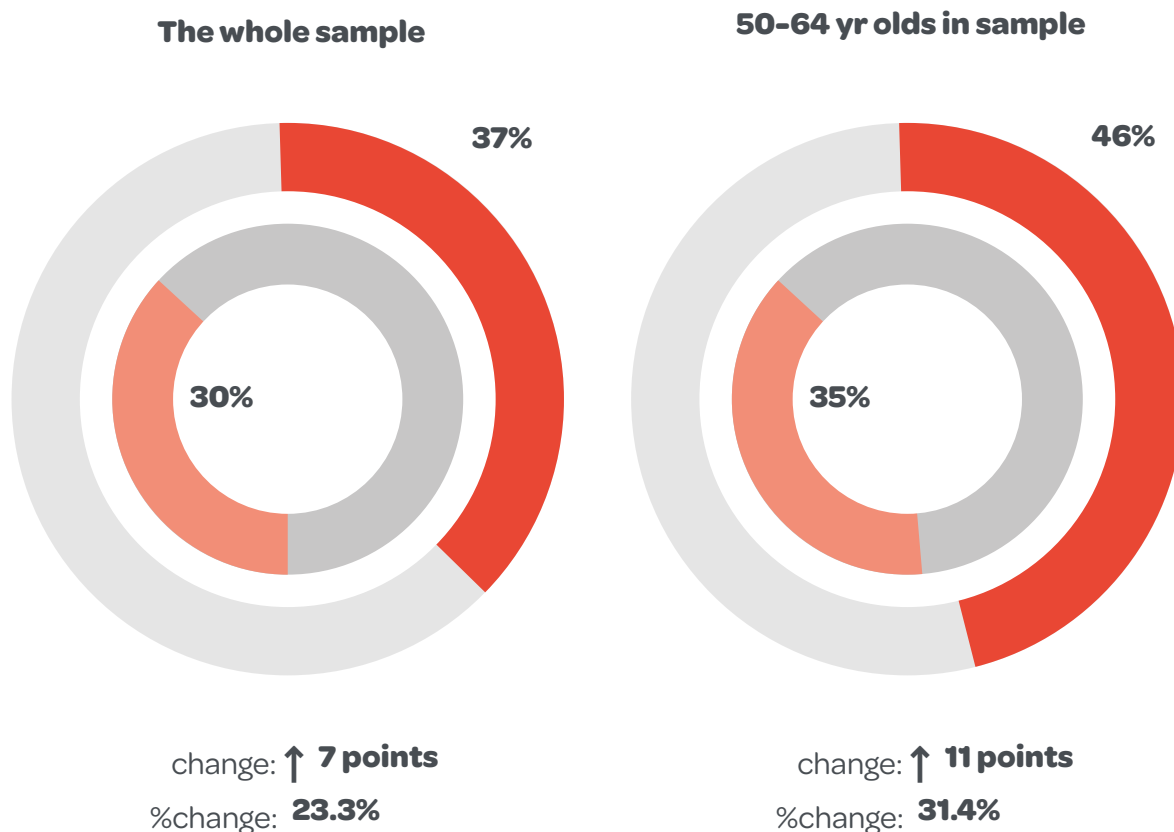
Post campaign public opinion poll results:

NICHHS commissioned a second opinion awareness poll in October 2019 after the campaign had completed.

We compared the results of the pre and post polls to identify if there had been an impact.

Have you ever heard of a common heart rhythm condition known as Atrial Fibrillation?

Percentage answered "yes"



The percentage of people who have heard of AF has risen from 30% last year to 37% this year.

The most significant increase has been in the 50-64 age category which saw a 31.4% increase in awareness. This is particularly welcome given the close relationship between the increasing prevalence of AF, age and stroke risk.

AF and risk of stroke

Subset: only people who knew what AF was.

Having the heart rhythm condition AF (Atrial Fibrillation) can...?	2018	2019	Change in % points	% Change
Double your risk of having a stroke	40%	35%	↓ 5	↓ 12.5
Triple your risk...	14%	16%	↑ 2	↑ 14.3
Increase your risk... by 5 times	11%	11%	No change	0
Does not increase your risk	8%	4%	↓ 4	↓ 50
Don't know	27%	35%	↑ 8	↑ 29.6

The results in terms of projecting the message about the fact that AF can increase the risk of stroke by 5 times are less clear cut. The numbers replying Don't Know to this proposition increased markedly.

The awareness campaign did halve (from 8% to 4%) the numbers of people who were unaware of any stroke risk - this was entirely due to a significant fall from 10% to 2% amongst women. The numbers who were correctly aware of the level of stroke risk was unchanged. Those thinking AF doubled your risk reduced while those thinking it trebled your risk increased.

It is possible that the wording of the question may have influenced the responses e.g. perhaps there were too many options, and maybe a binary choice – “does AF increase your risk of stroke?” would have been more appropriate.

In short, overall awareness of AF has increased markedly, however, amongst those who are aware of the condition, the message about the level of risk involved may not have been understood. The results do show that a relatively modest public awareness campaign can have a significant impact on public knowledge with potential public health benefits.

Overall awareness of AF increased markedly, however, amongst those who were aware of the condition, the message about the level of risk involved may not have been understood.

The Questionnaire Survey Results

Two questionnaire surveys were designed and issued: one for service users, and the other for healthcare professionals. These were sent out in May 2019 and remained open until October 2019.

Service User Survey: Engaging with people living with AF

This survey consisted of 14 questions about living with the condition of AF, including questions about diagnosis, information and knowledge about their AF, and any other comments they had.

There were 40 respondents, 52% female and 48% male with year of births between 1929 and 1973, from across Northern Ireland. Respondents were diagnosed with AF between 1995 and 2019, with 2018 being the most popular answer.

Who diagnosed you with AF?

- GP - 37.93%
- Cardiologist (heart doctor) - 34.48%
- Stroke doctor - 10.34%
- Other (A&E doctor, NICHs, thyroid doctor) - 17.24%

Key points:

- Nearly **38%** of people with AF were diagnosed by the GP.
- **Two out of five** people received a brief description to inform them of their condition.
- Lack of **equality and standardisation** in information on AF.
- Over **50%** had a good understanding of their condition.
- When diagnosed, there is great support – over **two thirds** of people felt their care and treatment was good or very good.

Feelings about diagnosis

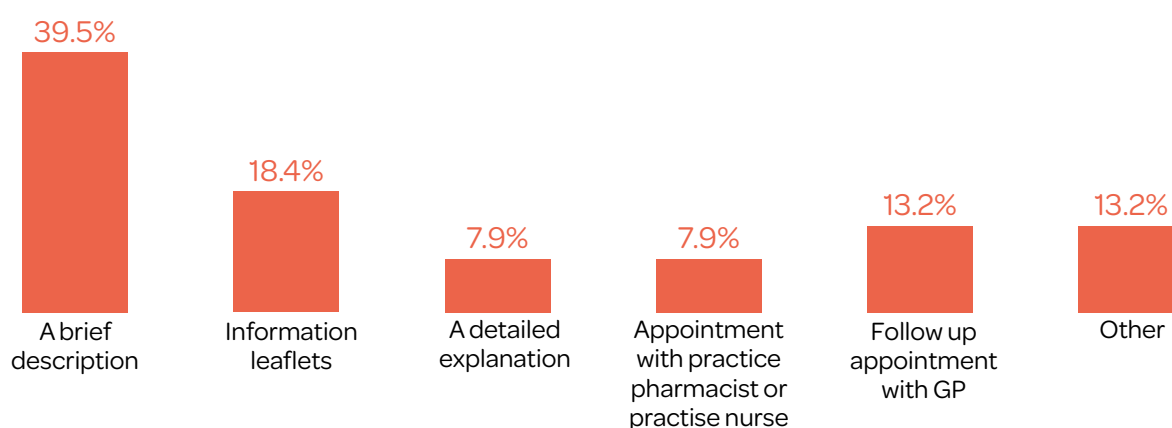
When respondents were asked if there was anything they would like to share about their experience of being diagnosed with AF, a few themes emerged.

Theme	Example quote
Shock and fear	<ul style="list-style-type: none">• “It was a horrible feeling to be told I had AF; I felt I had done everything right. I was fit and healthy, this had a big impact on my mental health”.• “It was a shock, I was young and healthy”.
Stroke	<ul style="list-style-type: none">• “I was only diagnosed after my stroke. It was a huge shock that my stroke could have been prevented”.

Theme	Example quote
Information	<ul style="list-style-type: none"> • “I would have liked more information”.
Other	<ul style="list-style-type: none"> • “I had to wait a long time for my appointment with cardiologist and for my tests- echo etc.” • “I had been unwell with a virus and then discovered I had AF”.

Information & Support

What information were you given about the condition?



The most common form of information given was “a brief description”, with two in five people stating it was the main source of information. This may not be sufficient enough detail to ensure patient understanding and adherence. The other answers included an “appointment with cardiologist” or “other consultant”.

When the respondents were asked to tell us more about the information they received, it was polarised between people who felt they received a lot of information and others who felt they didn’t get enough.

The following examples illustrate the different experiences of service users.

Sufficient information:

- “Helpful video of explanation of AF. Full explanation from nurse on diagnosis. Management of symptoms”.
- “Detailed explanation of condition. Information leaflets helpful!”

Needed more information

- “I googled it after I always felt I needed more information”.
- “Would have liked more info and support”.
- “Felt I was told in a very brief manner, lacking in detail”.

This demonstrates the lack of equality and standardisation in the information type and detail that AF patients are receiving.

Treatment and support

The findings were very positive:

- Over **50%** of respondents felt they had a good understanding of their condition.
- Over **two thirds** of people felt their care and treatment was good or very good.
- Over **95%** of respondents had a further appointment with a health care professional after their initial AF diagnosis.

In addition, the majority had ongoing care from their GP with input from practice pharmacists, practice and specialised nurses. A proportion still received input from their cardiologist, which is in keeping with the NICE guidelines.

The survey concluded by asking AF patients, if there was anything else they would like to tell us about that could have improved their diagnosis or living with AF.

- **"I had never heard of AF and now I'm left with effects from my stroke and if my AF had been detected I would never have had my stroke" (MALE, 76, Dungannon).**
- "I didn't know the condition existed before I got diagnosed" (MALE, 59, Bangor).
- "I took control of my life, health and AF. But it effected my head, I felt really shook by it" (MALE, 66, Belfast).
- "More time to understand the drugs, felt I was just scared about stroke risk" (MALE, 77, Belfast).
- "Don't like the feeling that AF caused my stroke and that it could cause another one". (FEMALE, 65, Newtownards).
- These quotes demonstrate again the shock that AF patients can feel, the lack of public understanding and the need for more information.

Healthcare Professionals survey

Key points:

- **67%** of HCPs do not believe there is an effective care pathway for AF.
- Just under one third **(31%)** of respondents stated they used a pulse check as a method to diagnose AF.
- **86%** of HCP respondents stated there should be an AF screening programme.
- Over half **(58%)** of respondents believed AF should be managed by a GP.
- **40%** of respondents identified

a lack of resources as a significant challenge to treatment and care for people living with AF.

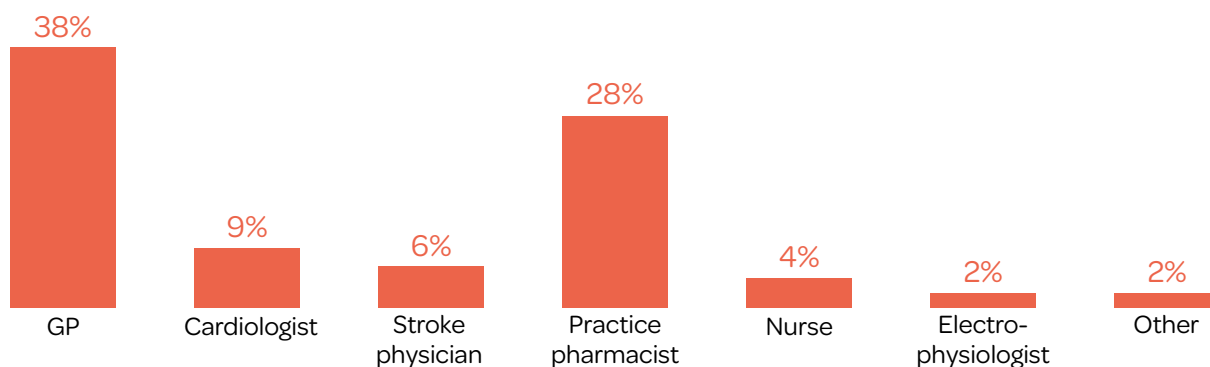
- Over one quarter **(26%)** of respondents viewed patient adherence as a challenge in the treatment and care of AF.

Background:

This survey consisted of 15 questions on AF in Northern Ireland, including the profession of the respondent and questions on methods of diagnosis, barriers to diagnosis, AF screening programme and management of AF.

Over 100 healthcare professionals (HCPs) from a range of disciplines completed the questionnaire.

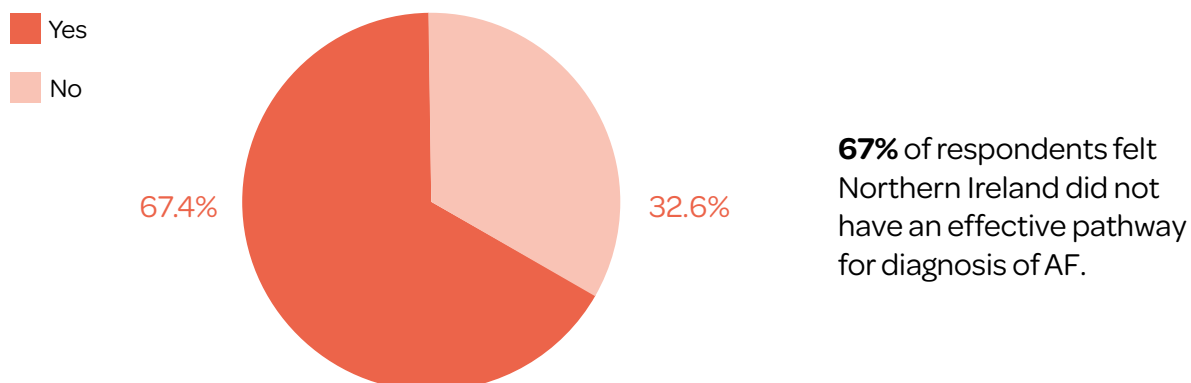
What is your profession? (%)



The other responses included GP trainee and Cardiac Physiologist.

Key findings:

Do you think Northern Ireland has effective pathways for diagnosis of AF?



Healthcare Professionals recommend:

When asked to provide additional comments, the following key themes and comments were identified by HCP respondents:

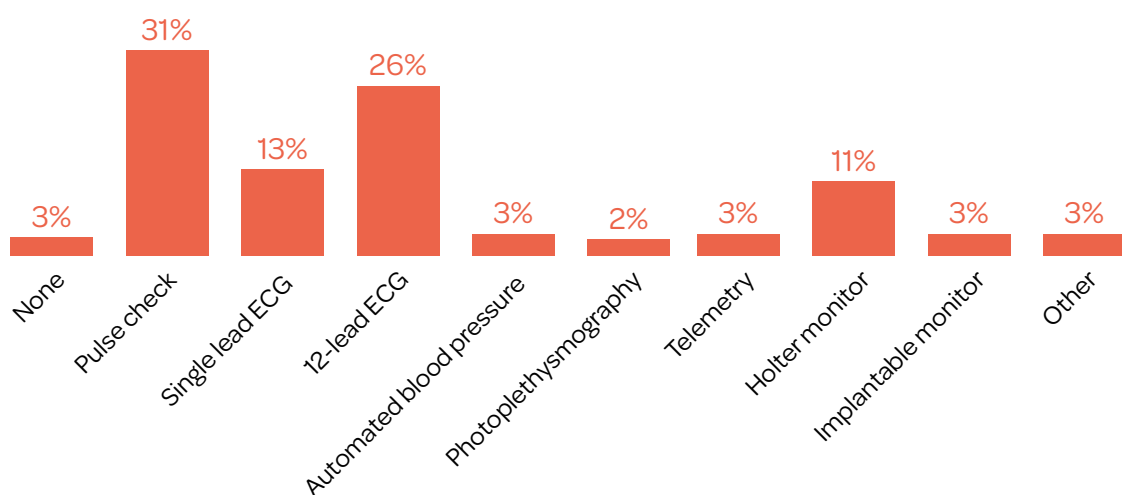
Theme	Example quote
Need for screening	"Opportunistic screening programme- target over a certain age or at other clinics" "Could use existing clinics to screen" "insufficient opportunistic screening and poor searching for AF"
Monitoring	"Should monitor high risk patients" "People get lost, monitoring needs to get better"

Current issues	<p>“Currently leaves too much to chance”</p> <p>“Works in part but still needs improvement”</p>
Resources	<p>“Could be catching more AF if had the resources”</p> <p>“Not enough investment so pathway is slow”</p>
Stroke	<p>“Still a major contributing factor I see on admission to the stroke ward”</p> <p>“Still too many people finding out about their AF when they have a stroke”</p>

Diagnosing AF:

Respondents were asked a number of questions regarding diagnosing AF. The following was identified:

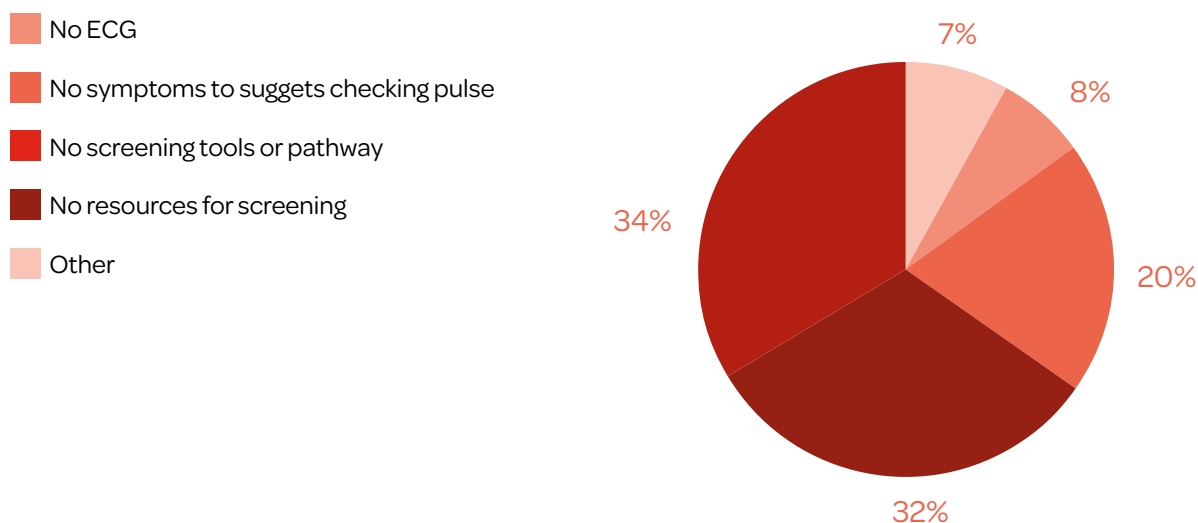
What methods do you use to diagnosis AF? (%)



All GPs reported using pulse checks, in combination with additional measures. The most common of which was 12 Lead ECG which 66% (25 GPs) used while 42% (16 GPs) used single lead ECG. Holter monitors were also common with 32% (12 GPs) using them,

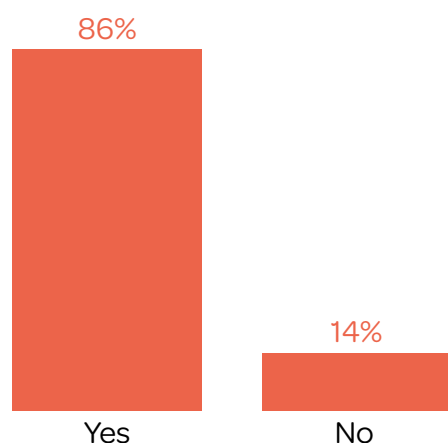
and 2 GPs mentioned the use of Kardia devices. Highlighting although GPs primarily appear to use pulse checks all of them apart from one used ECG (either single lead or 12 lead) as well, suggesting access to ECG is high in this GP sample.

What are the practical barriers to diagnosing Atrial Fibrillation?



- Just over a third (34%) of respondents stated the barrier to diagnosing AF was the lack of resources, this was followed by 32% stating there was no screening tools or pathway for AF
- Answers for others include time, high workload, public understanding, ECGs are time consuming for treatment rooms, not part of GP contract, improper GP referral.

Do you think there should be Atrial Fibrillation Screening programme?

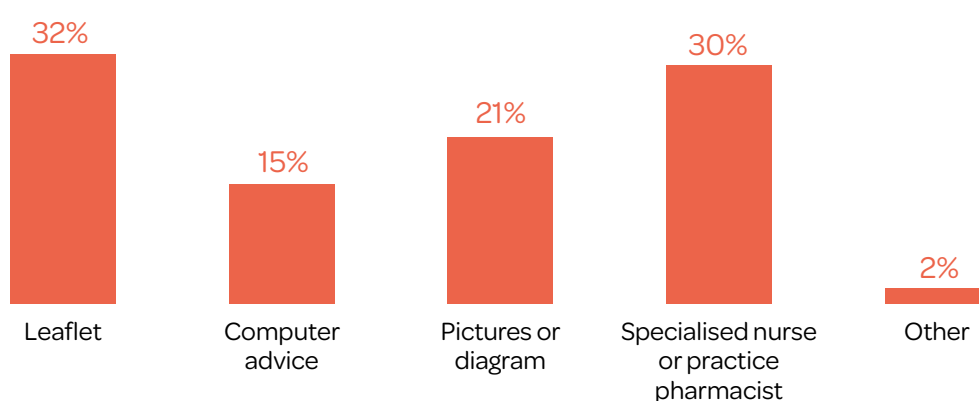


- 86% of Healthcare Professionals respondents stated there should be some type of AF targeted detection programme.
- When asked to identify possible actions to address key issues concerning diagnosis, HCPs suggested the following (see table):

Theme	Example quote/detail
Pulse Checks	Pulse checks (annual for those over 55; annual reviews, target individuals)
Technology	Use of technology (iPhone, handheld devices)
Outside GP	Pharmacies offer pulse check as well as BP testing. Use practice pharmacists and nurses to detect and manage AF patients

Risk Factors	Target people with known risk factors. Monitor high risk patients Opportunistic screening for over 65s Use patient database to identify potential sufferers
Public Education	Using apple watches etc. for people to gain understanding of AF More understanding of AF as a condition
Resources	Include in the GP contract. Could be GP LES where patients have annual pulse and BP check

What resources are useful in explaining the condition at diagnosis?

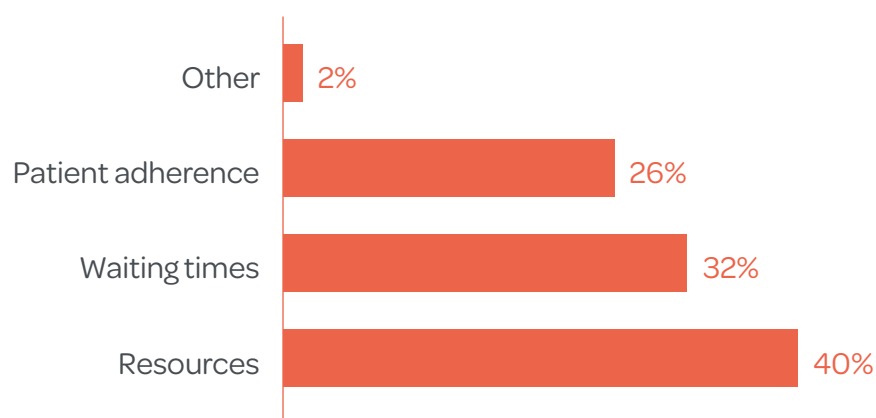


When asked what resources would be useful in explaining the condition at diagnosis:

- 32% recommended using a leaflet to help explain AF at the point of diagnosis
- 30% recommended a specialist nurse or practice pharmacist as a key source for information at the point of diagnosis

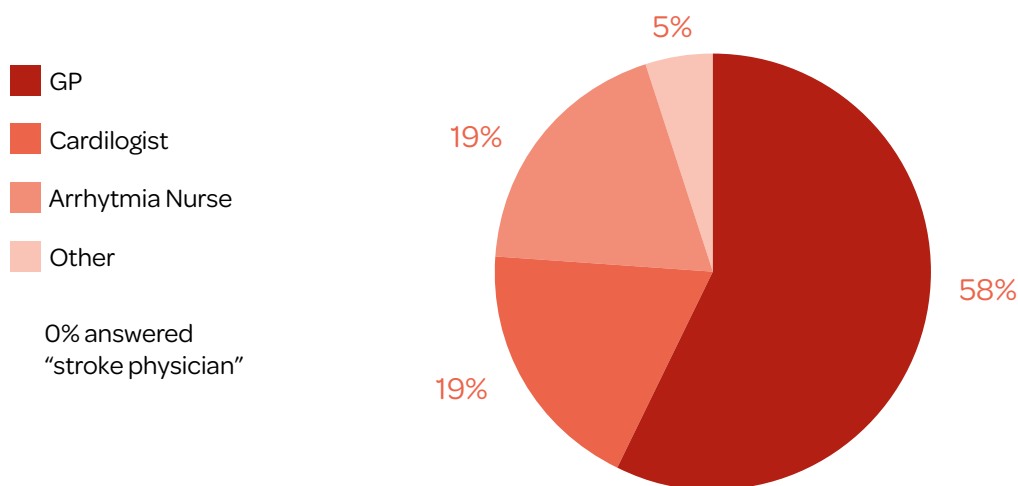
Treatment and management of AF

What are the key challenges around treatment and care of people living with AF?



40% of respondents identified the lack of resources as significant challenge to treatment and care for people living with AF, followed by 32% recognised waiting times as a challenge.

Who should be responsible for co-ordinating care of people living with AF?



Over half (58%) of respondents believed AF should be managed by a GP.

The survey finished by asking if there were any other comments about the diagnosis and treatment of AF in Northern Ireland they would like to add.

Additional comments included:

- "Requires innovative digital solutions integrated into the clinical pathway for diagnosis and monitoring." (Cardiologist)
- "Large number of patients on stroke wards have undiagnosed AF, this is an important and relatively easy way of potentially reducing stroke incidence and cost." (Stroke Physician)
- "Need to improve patient understanding and public awareness to ensure individuals realise how serious this condition is and therefore improve adherence." (Practice Pharmacist)
- "Patient understanding and adherence to NOACs problematic, people were more scared of Warfarin and its consequences." (Practice Pharmacist)
- "Pharmacists have a key role in identifying patients who are poorly controlled on Warfarin who should be switched to a NOAC and we should be taking a proactive role in this. This should help reduce the devastation strokes can cause to patients and their families by this condition." (Practice Pharmacist)
- "Need more joined up working between GP and cardiology." (GP)
- "Long waiting lists to be seen." (GP and cardiologist)

Key Recommendation from Healthcare Professionals

The need for **effective pathway for diagnosis** was overwhelming supported by the clinicians. Equally there was strong support for some form of targeted screening or process for identifying AF amongst at risk cohorts of the population.

Key Findings:

- Panel members, health care professionals and patients agreed that not enough is currently being done to identify the large number of people with AF who are undiagnosed.
- Widespread, whole population screening programme was not cost effective or practical. However, it was felt AF has clear risk factors (assessed by CHADSVASC) and that targeting those individuals would be beneficial.
- There needs to be a more systematic way of detecting AF, using opportunities to identify at-risk patients, for example at flu clinics, diabetic reviews, hypertension, COPD clinic and health checks or medication reviews.
- Need to share best practice and innovation within a pathway.
- Need to provide education and upskilling to GPs (and others in primary care) about AF and AF pathway.
- Service users living with an AF diagnosis may not fully understand their condition which has an influence on how they manage their condition.
- Waiting lists for echocardiograms have doubled from approximately 10,000 in 2016 to 20,000 in 2019.
- With a 16 fold increase (1570% over the three year period (Sept 2016-Sept 2019) of patients waiting over 26 weeks for an echocardiogram there is potential for delays in diagnosis and treatment to impact negatively on patient outcomes.

Three roundtables were held between May and October 2019 in NICHHS Head Office in Belfast. Attempts were made to ensure as many HCPs and participants could attend by varying the day it was held on to account for outpatient clinics, etc.

There were approximately ten participants at each of the roundtables these included cardiologist, General Practitioners, pharmacists (both practice and hospital based), Assistant Director of Promoting Health & Wellbeing, a cardiac nurse, representation from local political parties, representation from pharmacological companies involved in AF medication, representation from a local medical auditing company, representation from NICHHS (who ensured the service user perspective was part of the discussions) and the lead researcher.

KEY THEMES FROM THE INQUIRY RESEARCH

The Roundtable meetings discussed, and analysed information and data collected from the engagement phase. This included feedback from service users, patient and healthcare survey results. They also raised issues and solutions from their perspective. All of this information was grouped by the researcher thematically.

Theme 1: Need for targeted detection to identify undiagnosed AF

The most common theme to be discussed during the roundtables was detection. Participants discussed the advantages and pitfalls of targeted testing programmes, how we might identify the large number of undiagnosed patients, and specific examples of detection. It was widely agreed that not enough is currently being done to

identify the large number of people with AF who are undiagnosed but it was felt that a whole population screening programme was not cost effective or practical.

However, it was felt AF has clear risk factors (assessed by CHADSVASC), that targeting of those individuals would be beneficial. It was felt that using the term detection as opposed to screening was useful, as not only is screening not advised in the current NICE guidelines but it also more accurately represents the identification of these patients.

It was also felt that all potential opportunities should be used to identify these at-risk patients, including Flu clinics, Diabetic reviews, Hypertension, COPD clinic and health checks or medication reviews. This is an effective way of reaching patients and due to technology (AF detection devices) it can be tested in a time efficient way.



Theme 2: Need for Good Practice and Innovation

The second most common theme to be discussed during the roundtables was good practice and innovation. Members shared good practice either within current services or from elsewhere.

An overview of different types of innovation and good practice are provided in the case studies below:

Example1: South Eastern Health & Social Care Trust - Pilot Community Pharmacy Offer

In the SEHSCT area, a pilot Community Pharmacy Hypertension Detection Service was developed by the SE Integrated Care Partnership. Patients can have a robust high blood pressure (HBP) test (including a week's testing via a home monitor), be given lifestyle advice, and be signposted to community services by their local Community Pharmacy. This potentially achieves improved detection rates while reducing 'false' high readings due to white coat syndrome.



In the context of the new ICP / Community Pharmacy pilot, a complimentary initial detection pilot was undertaken, alongside the Pharmacy pilot in one geographical locality within the SE area (Lisburn). This initial pilot was intended to drive additional

high-risk individuals to their local pharmacy, who otherwise would not visit either their local Pharmacy or GP on a regular basis. This initial detection pilot was delivered by NI Chest, Heart and Stroke (CHS).

The initial detection pilot involved a rolling programme of pop-up testing over a 6-month period building on NICHs's innovative Health Checks Pop Up service across NI. Both HBP and AF testing were offered. These pop-up tests took place at community locations where there are large numbers of people across Lisburn over two days per week.

These included:

- Large workplaces in Lisburn including Lisburn Health Centre, Lagan Valley Hospital, PSNI, NIFRS HQ and Lisburn Castlereagh City Council e.g. canteens
- Shopping Centres including Bow Street Mall and Sprucefield
- Transport Hubs, including Bus and Train stations
- Parks, such as Wallace Park and local events such as Park Runs

The tests were intended to be focused on the over 45 population and were carried out using 'pop-up' cubicles, which individuals were able to either drop-in or pre-book on-line. Community groups were also able to request 'group testing' at community clubs and events. A key role for the staff delivering the checks was to engage with the passing public, to encourage them to get tested, and to identify the other potential locations and times to engage with the target population.

Between July and December 2019, a total of 1,826 checks were carried out, this resulted in 51 patients being identified with AF – of who, 28 were new referrals. This is 28 individuals who potentially may need anticoagulation and can work with their GP to hopefully prevent stroke.

AF Referral Age Breakdown SET Project

18-44 years old - 15

45-59 years old - 11

60+ - 25

In addition, 441 people were referred to their GP and 58 to their pharmacist regarding high blood pressure. 220 were new referrals. (10 individuals were referred for both AF and high blood pressure).

It is an important to consider two potential limitations to this. Firstly, that it is up to the individual what they do with the information provided by this check, not all patients may act upon it and see their GP. Secondly, there is potential to increase strain on GP practices by sending more patients to see them. But the numbers identified are not huge and are spread throughout the South East region.

As outlined within the case studies, the possibilities to prevent strokes through combined AF and blood pressure checking are obviously substantial and are worth further exploration.

Example 2: Well Check

NICHS Well Check

NICHS runs health checks throughout Northern Ireland in places of work, at public places or events. Our health checks aim to detect the early warning signs associated with developing chest, heart and stroke conditions.



Our health promotion team offer a range of health checks that assess lifestyle, blood pressure (B), cholesterol (C), BMI and others. Last year, NICHS introduced AF (A) testing to the well check measured via Alivecor NICE approved technology, which is a simple test that only takes five minutes yet can help prevent AF related strokes.

If someone is classified as having AF, they are advised to go to their GP, given an NICHS client leaflet about AF and are emailed their ECG results from the Alivecor with a further reminder to go to their GP. The following week they are sent their full health report with a further reminder to see their GP if AF was detected and to contact the NICHS health promotion team for advice and support. Clients are also informed about, and encouraged to attend, NICHS Support Services, including our Taking Control Self-Management 6 week programme.

NICHS is the only local charity offering a comprehensive 'ABC' Health Check in Northern Ireland.

We offer a range of health checks that are based on NICE approved guidelines with same day results provided, these include our:

- AF and BP check
- ABC Health Check
- Full Health Check that assesses ABC, Body Composition, Blood Sugar, Lung Capacity, Lifestyle with advice and goal setting.

At the Balmoral Show in 2019, 1,061 AF checks were carried out and 23 individuals were signposted to their GP

In addition, from January - December 2019, 4,660 AF checks were carried out and 148 individuals were signposted to their GP

Well Check participants say:

“Very thorough examination, good explanation of results and follow up actions.”

“I was grateful for the health check because, unknown to me, I had high blood pressure and had no idea. So as a result of that, I have had to be monitored at the doctor for about 3 months.”

Example 3: Cardiac Nurse Led AF Clinic AF Clinic

An innovation developed in SEHSCT has been the development of an AF specific clinic run by a specialised cardiac nurse. People newly diagnosed with AF are referred direct from local hospital (emergency department or elderly care) or from cardiologist. The service involves an extended appointment time (45 minutes) to provide enhanced patient education and counselling.

This appointment time is substantially higher than the average GP appointment (10 minutes) or practice pharmacist (15-20 minutes). This longer appointment time allows for more detailed discussion of anticoagulation options, counselling around these options and patient education of the risks of AF.

Service users will also be reviewed for their suitability for cardioversion. In addition, service users are then reviewed 4 weeks later to answer any further questions and are given a patient education ‘top-up’. They are then referred back to their GP to be reviewed annually.

It is hoped that this initiative helps improve adherence due to additional time for patient education/counselling and will practically help to address long waiting lists in cardiology.

Theme 3: Resources and budget

In the current economic climate and with the associated funding restrictions on Health & Social Care, the ongoing issue of cost and resource was raised. Several participants gave examples of how external money (from outside NHS) for example, from pharmaceutical company medical education grants, were used to audit GP registers to identify patients with key risk factors of AF and to call them in for review. Funding for an independent company to carry out targeted detection was regarded as worthy of consideration, as this addressed both a funding and capacity issue within GP practices.

There was also discussion regarding the cost of various treatments, specifically anticoagulants and the relative cost savings that may be generated by switching. The cheaper up front/daily dose of Warfarin compared to direct oral anticoagulants (DOACs) versus the ongoing monitoring costs associated with Warfarin was noted.

Theme 4: Awareness and Understanding

In terms of awareness, many participants discussed the lack of public information and awareness on AF – specifically understanding what the condition is; what are the risk factors and what are the potential complications and consequences of AF. It was felt there was a body of work to be done raising public awareness of this condition and related complications. Various examples were discussed of similar conditions which have successfully seen an increase in awareness amongst the public were discussed - such as diabetes, and hypertension and blood pressure.

As highlighted within research carried out both before and after the public awareness campaign, even when people knew what AF is, the message about being at greater risk of developing a stroke is lost as many felt it is something that only affects older people and is therefore not relevant to them. It is imperative that people are provided with similar information and education as people living with diabetes have access to. Those living with diabetes are at a similar risk of stroke as people living with AF.

Theme 5: Promoting self-management and medicine compliance

In terms of secondary prevention / self-management and education, roundtable participants discussed how service users already diagnosed with AF needed additional support, education and self-management. Earlier detection and diagnosis combined with education and support will aid medicine management and ultimately reduce the risk of a major stroke.

Adherence to medication was identified as a major concern. Evidence suggests a crucial part of managing AF is compliance, as failure of the patient to take their prescribed medication will reduce the effectiveness in stroke prevention^[4]. This issue was raised in roundtable discussions.

Pharmacists highlighted how enhanced patient understanding and education (possible through longer appointment time, increased education/counselling) could improve compliance. It was recommended that there should be a more co-ordinated approach to management and education.

In addition, several AF patients mentioned how isolating it was, citing the impact of lack of information of their condition. Service users highlighted how valuable peer support from fellow AF patients could be. It was suggested at the roundtables that patient support networks could also improve medicine management.

Theme 6: Issues in current AF pathway

There were several key areas highlighted within the current pathway that are affecting current AF care and management. This was further supported by feedback from the Healthcare Professional questionnaire findings, which also identified lack of resources (cost, staff and capacity) as creating barriers and challenges to providing a more consistent approach to the effective management of AF in Northern Ireland. This was specifically evident with responses from GPs, who stated they did not have sufficient time with patients to explain the condition and treatment options.

This was further supported by service users who outlined that they didn't have enough time in appointments to understand their condition and treatment.

Theme 7: Waiting Lists

Waiting lists for echocardiograms have doubled from approximately 10,000 in 2016 to 20,000 in 2019.

This is a problem that has been building for a considerable period. Some may argue that it has been driven by increased demand due to both increased awareness of AF and the rapidly increasing elderly population. It should be noted, however, that the increase in elderly population has been long predicted and it should have been possible to prepare to meet this demand through additional recruitment of relevant staff.

Funds were put in place to recruit 5 additional WTE clinical physiologists in 2018. Regardless of whether this individual initiative was successful or not it is clear that it has little to no impact on the waiting list situation.

The number of patients waiting over 26 weeks for an echocardiogram has gone from 540 in September 2016 to 9,019 in September 2019. This represents a sixteen-fold (1570%) increase over the three-year period. Clearly there is potential for delays in diagnosis and treatment to impact negatively on patient outcomes.

	Sep 16	Mar 17	Jun 17	Sep 17	Dec 17	Mar 18	Jun 18	Sep 18	Dec 18	Mar 19	Jun 19	Sep 19
Echocardiography	9968	12,323	12,886	13,288	12,648	13,154	15,929	17,131	17,114	17,296	19,363	20,042
(Over 26 weeks)	540	1,466	2,447	3,406	3,338	3,869	5,686	7,073	6,997	6,810	8,721	9,019

First Inpatient Appt (admission)												
Cardiology	2,833	2,704	2,600	2,592	2,587	2,493	2,285	2,354	2,196	2,122	2,199	2,119
Over 52 weeks	8	57	130	243	349	237	90	82	73	74	124	70
26-52 weeks	452	576	606	616	482	380	323	456	330	328	310	279

Outpatient												
First consultant led appt	7,906	8,074	8,519	8,394	8,770	7,772	8,240	9,104	9,767	10,304	10,531	10,832
Over 52 weeks	236	522	710	938	1,146	232	221	319	263	351	651	834
18-52 weeks	2,387	1,903	2,104	2,339	2,418	1,934	1,749	2,436	2,603	2,582	2,835	3,206

Theme 8: Technology

Both the HCP Questionnaire and the roundtable discussed and viewed the variety and ease of AF detection devices as a widely positive development.

1. Technology which is used by healthcare professionals for example NICE approved devices such as the AliveCor.
2. Technology which is used by service users – for example widely used devices for smart phones or fitness trackers.

The implementation of these handheld devices into GP practices has allowed for other healthcare professionals to conduct screening and is seen as a quick tool.

Discussions recommended further investment in the use of proven technologies within clinical practice to detect AF.

Conclusions

To summarise, the collective information gathered from extensive engagement with service users and healthcare professionals, indicates that there are clear gaps in understanding, detection and management of AF in Northern Ireland. It can be seen from the SSNAP and other data that there are still a significant number of individuals who are only being diagnosed with AF following their stroke and others who have had a stroke, and were not receiving anti coagulation, despite have been previously diagnosed with AF.

The recommendations suggested in the next section of this report will help shape discussions on the way forward in helping provide a high-quality service for people living with AF in Northern Ireland.



Meet Rosaleen Fearon from Newry. Rosaleen was lucky as her atrial fibrillation (AF) was diagnosed when she was admitted to hospital to receive treatment for a fractured back.

“I didn’t know it was possible I could have a stroke”

“I didn’t understand at the time. I remember the nurse taking my pulse and saying the doctor will probably want to have a chat with you about your heart. I didn’t take this diagnosis serious at all and just continued life as normal thinking I was healthy.”

“I was put on medication and was told to take 2 Apixaban tablets per day. Unfortunately, a friend told me she didn’t bother with the two tablets and I had heard others saying this too, so I just took one of them instead of both.”

Rosaleen didn’t understand the seriousness of the condition and didn’t understand the importance of taking her blood thinning medication. Then tragedy struck in June 2018.

“I don’t remember very much about the day I took my stroke. I was making the bed and thought I’d tripped over the pillowcases, but I’d collapsed. The next thing I remember is waking up in the Royal Victoria Hospital and being told I’d had clot retrieval surgery.”

“I didn’t know it was possible I could have a stroke because of AF but I remember the GP telling me quite firmly that the second tablet would have helped prevent the stroke.”

Rosaleen believes strongly in playing an important role in her care and is a great champion for awareness and education. Since her stroke, she has completed NICHHS’ Post Rehabilitation Exercise Programme (PREP).

“Talking to others with the same problems has really helped me. It has boosted my confidence and my self-esteem and motivated me to take more control of my life and play an important role in decisions about my healthcare.”

Recomendations

Working in partnership with key stakeholders, the Department of Health should:

- 1.** Develop an **AF strategy** for Northern Ireland which will:
 - drive forward service improvement in awareness, detection, support and management.
 - have a clear implementation with targets and timelines – including the appointment of an ‘AF Champion’.
- 2.** Establish a target to achieve at least **85%** detected prevalence across Northern Ireland by March 2023 and have a proposed ambition of identifying **90%** of expected prevalence by 2025.
- 3.** Create a **holistic clinical pathway** for AF in Northern Ireland involving patients and clinicians.
- 4.** Invest in the **use of proven technologies** within clinical practice to detect AF, monitor implementation and allow audit.
- 5.** Commission plans to **increase AF detection rates** by using targeted case findings based on AF risk factors.
- 6.** Take action to **address the echocardiograms waiting list issue** including outlining plans to tackle any workforce issues.



- 7. Provide information and education** to people living with AF to better support understanding, improve adherence to anticoagulation medication, and to manage their condition.
- 8. Prioritise improving treatment and review** of existing AF patients to prevent future strokes. We recommend the following targets:
 - Achieve less than **20%** of patients with known AF admitted with stroke not correctly anticoagulated by March 2023
 - Reduce individuals with a new diagnosis of AF after admission to a stroke unit from 23% to **20%** by March 2023.
- 9. Commission the Public Health Agency to identify the most effective methods** to raise public awareness of AF. We recommend the following targets:
 - increase public recognition of AF from **37%** of the population to **50%** of the population by 2025
 - increase public awareness that AF can increase the risk of stroke by up to five times from the current base of **11%** to **20%** by 2025.

ACTION PLAN

In order to implement the recommendations, the Inquiry identified a range of actions to that could be taken forward – as part of a system wide strategic approach.

Key issues	Key actions
<p>Support</p> <p>Both healthcare professionals and people living with AF feel that understanding, management and adherence of AF could be improved with better information, education and support. A range of support mechanisms could be in-troduced to facilitate this.</p>	<ul style="list-style-type: none"> • NICHHS to support patients by providing education, peer support and information to AF patients • AF information evening held across each Trust on a quarterly basis • NICHHS to help develop an AF information pack/video for use by Healthcare professionals when describing/educating new patients about AF • Development of a Counselling template, with key information and signposting to additional information/support • Develop a referral system to an AF clinic for those more complex cases or in need of enhanced time
<p>Detection</p> <p>It is known that there is a proportion of undiagnosed AF patients in Northern Ireland. Every year a substantial number of people only discover they have an AF following a stroke. Increased detection provides an opportunity to medicate to help prevent stroke.</p>	<ul style="list-style-type: none"> • Encourage targeted AF case finding programmes for those most at risk • Use existing clinics/contact time with individuals with AF risk factors (hypertension, diabetes, Flu jab) to test for AF (use technology to help enable this). Opportunistic testing of those aged over 65. • Follow up patients who are identified with AF but are below the level for anticoagulants – flag them so that when they reach 65 they will be called back for a review. • Use risk factors to target populations • Use resources outside GP to detect such as pharmacies • NICHHS Wellness checks

Key issues	Key actions
<p>Innovation / Best Practice</p>	<ul style="list-style-type: none"> • Monitor success of AF clinic • Possibility of an implementation group to discuss initiatives throughout Northern Ireland • Work with relevant NHS/government organisations to address long waiting times especially for echos- increased number of cardiac physiologists. • Engage with HIRANI and other key networks to identify an innovation pipeline to support future AF service delivery and transformation
<p>Practicalities</p> <p>Software or technology in-vestment/ development to better detect and monitor people living with AF.</p>	<ul style="list-style-type: none"> • The possibility of SSNAP to include a measure of DOAC adherence • Software to identify potential non-adhering patients based on risk factors • Software to identify people once they turn 65 who already presented with AF • Update to Q-risk 3 to help prompt relevant questions
<p>Adherence (Perfect)</p> <p>These are individuals who have already been identified as having AF and are generally on medication. However, we know from the SSNAP data the medication may not be appropriate or may not be taken consistently.</p>	<ul style="list-style-type: none"> • Adherence assessment; Review of DOAC patients to review adherence: existing patients reviewed. Direct questioning about adherence, followed by patient education and adherence strategies discussion. • Practice pharmacists: review of current AF patients in the practice. Identification of patients who may be suitable for a change to DOAC or patients who have not been reviewed. • Standardised information given to all patients regarding anticoagulation medicine • Education of clinicians of appropriate anticoagulant medication • Regular or annual reviews of all AF patients
<p>Public awareness</p> <p>Both patients and clinicians identified the lack of knowledge or understanding about what AF is, its risk factors or consequences. Patients felt that the acceptance and life with AF would be improved with better public awareness. Clinicians also felt this may improve detection and adherence.</p>	<ul style="list-style-type: none"> • Public awareness campaign to highlight what AF is, risk factors, and consequences. • Educating people to monitor their own pulse rhythm

REFERENCES

1. Atrial Fibrillation Association. Atrial Fibrillation: Preventing a Stroke Crisis, 2011. Available at: <http://atrialfibrillationassociation.org.uk/app/webroot/files/file/140508-cw-FINAL-The%20AF%20Report.pdf>. Accessed August 2019.
2. Abdou, J. K., Auyeung, V., Patel, J. P., & Arya, R. (2016). Adherence to long-term anticoagulation treatment, what is known and what the future might hold. *British journal of haematology*, 174(1), 30-42.
3. Borne, R. T., O'Donnell, C., Turakhia, M. P., Varosy, P. D., Jackevicius, C. A., Marzec, L. N., ... & Ho, P. M. (2017). Adherence and outcomes to direct oral anticoagulants among patients with atrial fibrillation: findings from the veterans health administration. *BMC cardiovascular disorders*, 17(1), 236.
4. Castellucci, L. A., Shaw, J., Van Der Salm, K., Erkens, P., Le Gal, G., Petrcich, W., & Carrier, M. (2015). Self-reported adherence to anticoagulation and its determinants using the Morisky medication adherence scale. *Thrombosis research*, 136(4), 727-731.
5. Costing Report: atrial fibrillation Implementing the NICE guideline on atrial fibrillation (CG180) 2014
6. Cromie, N. (2013) Atrial Fibrillation. *Ulster Medical Society*, 82(3):135-140
7. Department of Health. Cardiovascular Disease Outcomes Strategy, 2013).
8. London Clinical Networks. AF Toolkit: Detect, Protect, Perfect. Available at: www.londonscn.nhs.uk/wp-content/uploads/2017/06/detect-protect-perfect-london-af-toolkit-062017.pdf. Accessed August 2019.
9. Manzoor, B. S., Lee, T. A., Sharp, L. K., Walton, S. M., Galanter, W. L., & Nutescu, E. A. (2017). Real-world adherence and persistence with direct oral anticoagulants in adults with atrial fibrillation. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, 37(10), 1221-1230.
10. Marini, C., De Santis, F., Sacco, S., Russo, T., Olivieri, L., Totaro, R., & Carolei, A. (2005). Contribution of atrial fibrillation to incidence and outcome of ischemic stroke: results from a population-based study. *Stroke*, 36(6), 1115-1119.
11. Hart, R. G., & Halperin, J. L. (2001). Atrial fibrillation and stroke: concepts and controversies. *Stroke*, 32(3), 803-808.
12. (BHF analysis (2018) based on NHS England/Public Health England (2017) The Size of the Prize in Cardiovascular Disease (CVD) Prevention) NHS England/Public Health England (2017) The Size of the Prize in Cardiovascular Disease (CVD) Prevention
13. Office of National Statistics, 2015
14. Patel A, Berdunov V, King D, Quayyum Z, Wittenberg R, Knapp M (2018). Current, future and avoidable costs of stroke in the UK: technical report. London: Stroke Association.

15. Patel A, Berdunov V, King D, Quayyum Z, Wittenberg R, Knapp M, (2017). Executive summary Part 2: Burden of Stroke In the next 20 years and potential returns from increased spending on research. Stroke Association.
16. Quality Outcome Framework (QOF) 2018
17. Quinn, F. R., & Gladstone, D. (2014). Screening for undiagnosed atrial fibrillation in the community. *Current opinion in cardiology*, 29(1), 28-35.
18. Senoo, K., Lau, Y. C., & Lip, G. Y. (2014). Updated NICE guideline: management of atrial fibrillation (2014).
19. Stevens et al, 2017 Burden of Stroke in Europe Report; Stroke Alliance for Europe
20. Sentinel Stroke National Audit Programme (SSNAP) 2016-2019
21. Shore, S., Ho, P. M., Lambert-Kerzner, A., Glorioso, T. J., Carey, E. P., Cunningham, F., ... & Turakhia, M. P. (2015). Site-level variation in and practices associated with dabigatran adherence. *Jama*, 313(14), 1443-1450.
22. Smith, L. N., Lawrence, M., Kerr, S. M., Langhorne, P., & Lees, K. R. (2004). Informal carers' experience of caring for stroke survivors. *Journal of advanced nursing*, 46(3), 235-244.
23. State of the Nation(2018) Stroke Association Report
24. Thrall, G., Lane, D., Carroll, D., & Lip, G. Y. (2006). Quality of life in patients with atrial fibrillation: a systematic review. *The American journal of medicine*, 119(5), 448-e1.
25. Xu, X. M., Vestesson, E., Paley, L., Desikan, A., Wonderling, D., Hoffman, A., ... & Bray, B. D. (2018). The economic burden of stroke care in England, Wales and Northern Ireland: Using a national stroke register to estimate and report patient-level health economic outcomes in stroke. *European stroke journal*, 3(1), 82-91.
26. Xiong, Q., Proietti, M., Senoo, K., & Lip, G. Y. (2015). Asymptomatic versus symptomatic atrial fibrillation: a systematic review of age/gender differences and cardiovascular outcomes. *International journal of cardiology*, 191, 172-177.
27. Zoni-Berisso, M., Lercari, F., Carazza, T., & Domenicucci, S. (2014). Epidemiology of atrial fibrillation: European perspective. *Clinical epidemiology*, 6, 213.
28. Zathar, Z., Karunatileke, A. S., Fawzy, A. M., & Lip, G. (2019). Atrial Fibrillation in the Elderly: Concepts and Controversies. *Frontiers in medicine*, 6, 175.
29. Public Health England. 2017. Atrial fibrillation prevalence estimates in England: Application of recent population estimates of AF in Sweden. London: Public Health England
30. Atrial Fibrillation and overview: NHS England website <https://www.nhs.uk/conditions/atrial-fibrillation/>
31. Boriani G et al, (2015) Asymptomatic Atrial fibrillation clinical correlates management and outcomes in the EIRP-AF Pilot General Registry, *the American Journal of Medicine*, 128 (5): m 509-18.

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 return the heart rhythm to normal

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

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

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

D

Demographic – characteristics of a given population.

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

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

INR The international normalised ratio (INR) is a laboratory measurement of how long it takes blood to form a clot. It is used to determine the effects of oral anticoagulants on the clotting system

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

L

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

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.

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.

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

APPENDIX



Dr John Winter is Chairperson and GP lead of the Ards ICP. He qualified from Queen's University Belfast in 1978 and practiced in Ards hospital for 3 years. Subsequently, he combined working in church and counselling organisations with part time sessional general practice. From 1996-2000, he undertook full time medical work in the City, Holywell and Ulster hospitals, gaining membership of the Royal College of General Practitioners and diplomas in Mental Health, Child Health and Geriatric Medicine.

Dr Winter recently retired having been in a GP Practice in Newtownards since 2000. He became a GP Trainer in 2003, and subsequently, senior partner in the practice.



Michael Jackson is Lead Pharmacist for Cardiothoracic Services at Belfast Health & Social Care Trust. He has over 25 years hospital experience in England and Northern Ireland. Michael leads a pharmacy team, delivering services to regional Cardiology, Cardiothoracic, Pulmonary Hypertension teams as well as providing anticoagulation services.

His role is split between managing the pharmacy team and leading adult and paediatric pharmacist clinics (pulmonary hypertension and anticoagulation).



Clare Murray is the Lead General Practice Pharmacist for East Belfast Federation of Family Practices. She has been a practice pharmacist for the past three years having previously been employed in Boots Pharmacy for over seven years.

In addition to holding a Master's in Pharmacy, Clare holds a Post Graduate Certificate in Independent Prescribing.



Dr Brian Gallen has been a Consultant Stroke Physician and Geriatrician in the South West Acute Hospital in Enniskillen since 2015.

He has a particular interest in clinical education, a subject in which he has a Postgraduate Certificate.

He has a wide range of clinical experience throughout Northern Ireland having worked for all 5 of Northern Ireland's Health and Social Care Trusts. He has developed a keen interest in development of stroke services for different populations and equitability of access to stroke services such as TIA, stroke thrombolysis, rehabilitation and mechanical thrombectomy.



Dr Niamh Kennedy, is a Lecturer in Psychology at the Ulster University and has been commissioned by NICHs to oversee the AF Inquiry.

Niamh was previously a Lecturer in Rehabilitation Neuroscience at the University of East Anglia. Her research area concentrates on improving outcomes for stroke survivors.

In 2018 she carried out the research that led to the 'Struggling to recover' Report about life after stroke in Northern Ireland.



Neil Johnston is the Public Affairs and Policy Manager at Northern Ireland Chest Heart and Stroke.

Neil has worked for NI Chest Heart and Stroke for 10 years. He develops the charity's policy positions, responses to government consultations and seeks opportunities to promote improved health and social care across chest, heart and stroke conditions.

Chest
Heart &
Stroke

Nearly 90%

of our work relies on donations from the public.

Without your support we couldn't be here making a difference.

Belfast Office

21 Dublin Road

Belfast

BT2 7HB

Tel: 028 9032 0184

Email: mail@nichs.org.uk

www.nichs.org.uk

Follow us on social media!

 [@Belfast.NICHs](https://www.facebook.com/Belfast.NICHs)

 [@nichstweet](https://twitter.com/nichstweet)

 [@ni_chest_heart_and_stroke](https://www.instagram.com/ni_chest_heart_and_stroke)

 [linkedin.com/company/northern-ireland-chest-heart-and-stroke](https://www.linkedin.com/company/northern-ireland-chest-heart-and-stroke)



Registered with
**FUNDRAISING
REGULATOR**

INVESTORS IN PEOPLE™
We invest in people Silver