White Paper on inequalities • and unmet needs in the detection of atrial fibrillation (AF) and use of therapies to prevent AF-related stroke in Europe

November 2018

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Authorship and expert contributions

Research, coordination, drafting and design of the White Paper were led by The Health Policy Partnership.

The following expert contributors provided strategic input and feedback through verbal consultations and written feedback on drafts, for which we are hugely grateful:

Lead expert advisor

 Professor John Camm, Professor of Clinical Cardiology, St George's University Hospitals, London; President, European Heart Rhythm Association; President and Trustee, Arrhythmia Alliance; Founder and Trustee, Atrial Fibrillation Association

Expert advisors

- Sotiris Antoniou, Chair, International Pharmacist Anticoagulation Taskforce (iPACT) and Consultant Pharmacist, Barts Health NHS Trust; member of AF Association Medical Advisory Committee
- Professor Anita Arsovska, President, Macedonian Society of Neurology; University Clinic of Neurology, Skopje, Macedonia
- Professor Valeria Caso, Past President, European Stroke Organisation (ESO); Stroke Neurologist, University of Perugia Stroke Unit
- Dr Wolfram Doehner, Chair, European Society of Cardiology Council on Stroke; Charité Universitätsmedizin Berlin
- Jean-Luc Eiselé, Chief Executive Officer, World Heart Federation
- Dr Johan Engdahl, Adjunct Senior Lecturer, Danderyd University Hospital, Karolinska Institutet
- Sue Koob, CEO, Preventive Cardiovascular Nurses Association
- Trudie Lobban MBE, Founder and CEO, Atrial Fibrillation Association and Arrhythmia Alliance
- Professor Lis Neubeck, Head of Cardiovascular Health, Edinburgh Napier University; President Elect, ESC Association of Cardiovascular Nursing and Allied Professions; member of AF Association Medical Advisory Committee
- Professor Marten Rosenqvist, Professor of Heart Diseases and Senior Consultant, Danderyd University Hospital, Karolinska Institutet
- Dr Geert Vanhooren, Head of Department (Neurology), AZ Sint-Jan Brugge Oostende AV, Ostend

The following organisations have endorsed this White Paper:









MACEDONIAN NEUROLOGY SOCIETY











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Call to action

We need to act now to prevent AF-related stroke.

A quarter of middle-aged adults will develop AF in their lifetime¹



Atrial fibrillation (AF) is the most common sustained heart rhythm disturbance (arrhythmia).² People with AF are three to five times more likely to suffer a devastating, debilitating, disabling and often fatal stroke than people without AF. Yet it is widely under-recognised by the general public and policymakers.

Preventing stroke offers policymakers the potential to lower the cost of stroke care,³ contributing to more sustainable healthcare systems.

Stroke costs an estimated €38 billion across EU countries each year⁴ - and **AF-related strokes** are more expensive to manage than non-AF-related strokes.⁵



AF-related strokes cause unacceptably high levels of death and disability, and the scale of the problem across Europe is increasing as our populations age. By 2035 the number of strokes is projected to rise by 34%, to over 800,000 events.³ At the same time, the number of people with AF is increasing and, by 2060, it is estimated that nearly 18 million adults over the age of 55 will have AF.⁶

With early detection, access to appropriate therapies and ongoing care and support, many AF-related strokes can be prevented. Appropriate stroke-prevention therapies have been shown to save lives and prevent disability in people with AF.¹ They also reduce AF-related hospital admissions, length of stay, outpatient visits⁷⁸ and healthcare costs.⁹⁻¹²

People face significant inequalities and unmet needs in AF-related stroke.

Consistent gaps and inequalities persist both in terms of rate of detection, and access and uptake of first-line therapies and ongoing care for the prevention of AF-related stroke. This White Paper highlights these inequalities and unmet needs and offers solutions to enable stakeholders at all levels to address this serious public health issue:



Recommendation 1: Build awareness and understanding of AF. Public awareness of AF as a cause of stroke is worryingly low and comes at a high price. We need population-wide information campaigns with simple, targeted messages to address this. This should cover AF as a common cardiac condition, the link between heart conditions such as AF and stroke, and the importance of effective therapy in dramatically reducing stroke risk in people with AF. People diagnosed with AF should receive therapeutic education to build their knowledge of the condition and be involved in shared decision-making with healthcare professionals.

groups. Too many cases of AF are undetected, and all too often AF is diagnosed too late, for example following a stroke. Pulse rhythm checks are recommended by European Society of Cardiology guidelines as a quick, affordable and proven method to test for AF when followed by an electrocardiogram for confirmation. Pulse rhythm checks can be performed opportunistically (e.g. during a routine health check), as well as in almost any community or social setting. Yet is it rare for them to be recommended by national guidelines, and adoption in everyday practice is highly variable.

Awareness of AF as a stroke risk factor and effective knowledge of first-line therapies for stroke prevention in AF are often inadequate outside of specialist cardiology settings. A wider range of healthcare professionals (e.g. GPs) must therefore be ready to play a key role in identifying AF and overseeing AF-related stroke prevention. To help achieve this, we must develop tailored guidelines for non-specialists, such as GPs, internists and nurses, and embed simple practices in everyday care.



Recommendation 4: Ensure policy leadership to drive equitable access to best practice. We must ensure local and national policies are in place to tackle the structural barriers behind persistent inequalities in the detection of AF and access to first-line therapies for AF-related stroke. To achieve this, we must also raise awareness and understanding of AF among decision-makers at all levels of the health system including administrators, managers and payers.

We therefore call on central governments to express a formal strategy or position on AF-related stroke.

AF-related stroke is a clear challenge to the future sustainability of healthcare systems and demands high-level attention in every nation in Europe. This should align to the Action Plan for Stroke in Europe 2018–2030 and should include, at a minimum:

- an assessment of the current human and economic burden of AF as a cause of stroke
- an estimate of undiagnosed AF in the general population; and, for those with a diagnosis, an estimate of the current access to and uptake of first-line therapy to prevent AF-related stroke
- an assessment of systemic and structural strengths and weaknesses to explain current performance
- future projections of AF prevalence and their implications for the burden of stroke, with scenario modelling for guideline-based efforts to reduce AF-related stroke
- clear and measurable targets to prevent AF-related stroke, and the identification of best-value investments to achieve them
- adequate resources to ensure key actions can be implemented effectively.

This call to action is endorsed by: Professor John Camm; Sotiris Antoniou; Professor Anita Arsovska; Professor Valeria Caso; Dr Wolfram Doehner; Jean-Luc Eiselé; Dr Johan Engdahl; Sue Koob; Trudie Lobban MBE; Professor Lis Neubeck; Professor Marten Rosenqvist; Dr Geert Vanhooren.

Recommendation 2: Increase opportunistic detection of AF among high-risk

Recommendation 3: Increase knowledge and skills of healthcare professionals.

About this White Paper: Why AF, and why now

This White Paper is the culmination of a consultative and consensus-driven process. It begins by placing AF and AF-related stroke within the policy context, then focuses on four areas that are recognised by experts as critical to driving meaningful change for patients. In each of these areas, recommendations are made for how AF can be prioritised to improve outcomes and maximise benefits for both patients and the wider healthcare system.

This White Paper arrives at a critical moment for strategic health policymaking.

Non-communicable diseases (NCDs) are currently a major focus at the European level, with increasing attention being given to stroke. Recent developments include a European Union Joint Action on chronic diseases¹³ and a World Health Organization (WHO) European Region action plan for NCDs.¹⁴ This has created an opportunity to advance AF-related stroke prevention at all levels. However, AF – and the link between AF and stroke – has so far been absent from these European-level discussions.

Gaining a deeper understanding of inequalities in access to AF detection, care and management presents a significant opportunity to reduce the burden of AF-related stroke in Europe. As such, an evidence-based consensus on the current

state of play, leading implementation models, and key system barriers and opportunities faced by decision-makers as they seek to drive improvements into mainstream healthcare is vital.

With this aim in mind, Bristol-Myers Squibb (BMS) and Pfizer (the BMS–Pfizer Alliance) commissioned a programme of work starting in 2017 with a literature review to provide greater insight into the inequalities in AF detection and stroke-prevention therapies. This was followed by two expert meetings where leading figures working in AF and stroke were convened to better understand these inequalities, the underlying system and policy drivers responsible for them, and the possible actions that could be taken to address them. The Health Policy Partnership has been working with the BMS-Pfizer Alliance to coordinate research and drafting of the White Paper under the guidance of expert contributors.

This White Paper sets out a clear call to action, highlighting areas where gaps exist and the changes that we need to put in place to address them. There are four key areas where action is required:



This report will consider the current situation in each of these areas, and recommend actions for advocates, healthcare professionals and decision-makers to improve outcomes in the management of AF and prevention of AF-related stroke.





Introduction: What AF is, and why it matters

AF is a major risk factor for stroke

AF is a heart rhythm disorder that is an important risk factor for stroke,¹ being associated with at least one in every five strokes² (see *Box 1*). AF-related strokes have also been found to have twice the mortality rate,⁵ cause more severe symptoms,¹⁵ have a higher chance of recurrence,¹⁶ lead to longer hospital stays¹⁵ and lead to more permanent disability than non-AF related strokes.^{15 17} Evidence is also accumulating that AF increases the risk for dementia.¹⁸

Effective therapies reduce the risk of AF-related stroke. There are, however, significant inequalities both in their use and in the successful detection of AF.¹⁹

Box 1 What is AF, why does it occur, and how does it cause strokes?

• AF is the most common sustained heart rhythm disturbance (arrhythmia).² AF occurs when abnormal electrical impulses take place in the upper chambers of the heart (atria), resulting in a highly irregular pulse rhythm.²⁰

One in four middle-aged adults in Europe

will develop AF in their lifetime.¹

- While the cause of AF is not fully understood, it is more common in older people and in people with other conditions including high blood pressure (hypertension), coronary artery disease, obesity, diabetes, chronic kidney disease or heart failure, which is the most common cause of death and hospital readmission among patients with AF.²¹
- By disrupting blood flow through the heart, AF increases the risk of blood clots forming,²⁰ making people with AF three to five times³ more likely to suffer a devastating, debilitating and often fatal stroke than people without AF.⁵

There has been a shift in understanding of AF as a cause of strokes and in therapies to address risk.

The medical understanding of the risks associated with AF is a relatively recent development. As recently as the 1970s, AF was thought to be a benign condition, and it was not until the 1980s that attempts were made to fully understand the association between AF and stroke.²²

Over the past decade, there has been a rapid development of evidence regarding the role of therapies to prevent AF-related stroke. This is reflected in frequent updates in European Society of Cardiology (ESC) guidelines for the management of AF. The most recent edition, published in 2016, provides an update on AF-related stroke prevention in the era of non-vitamin K antagonist oral anticoagulant (NOAC) therapy; it recommends NOACs as a first-line therapy for people with AF who are at a medium or high risk of stroke, and puts greater emphasis on the early detection of AF before an AF-related stroke occurs.¹

Stroke is a major contributor to non-communicable diseases.

Europe's healthcare systems are under increasing pressure from ageing populations and a rise in non-communicable diseases (NCDs). Data suggest the number of people over the age of 65 is expected to rise from around 97 million in 2015 to more than 125 million by 2030.²³⁻²⁵

Stroke is an important contributor to the NCD burden. In 2013, stroke was responsible for 433,000 deaths in Europe (9% of all deaths), and was the cause of a significant proportion of disability.²⁶

The number of strokes across Europe – and the number of people living with the long-term effects of stroke – is predicted to rise. Stroke Alliance for Europe (SAFE) estimates that between 2015 and 2035, the number of new strokes will increase by 34%.³



Action focus 1: Supporting patient education

Key messages

- Poor understanding of AF among newly diagnosed AF patients is common, and may affect their care and increase their risk of AF-related stroke.
- Healthcare professionals and patient organisations are best placed to educate patients.
- Simple messages targeting different patient groups should be available across clinical settings.

What is the issue?

AF patients have been found to have gaps in knowledge of their condition, impacting both their health and their experience of care.

This is, in part, a reflection of low levels of awareness and knowledge of AF across society more broadly.²⁷ Some key areas where knowledge gaps exist include understanding of AF and the increased risk of stroke that AF brings (see *Box 2*). This lack of understanding is likely to be important in explaining low persistence with anticoagulants.²⁸

Why is this happening?

Gaps in access to helpful information exist in some countries.

There are compelling models which provide information and support, including online tools, patient discussion forums and helplines for AF patients through patient advocacy groups and foundations in some countries.³⁰⁻³² However, these resources and activities are not consistently available across Europe.

Healthcare professionals often underuse educational tools.

A range of educational materials has been developed by patient organisations and professional societies. However, healthcare professionals often do not pass these on to patients, creating significant information gaps. For example:

- A recent study by the ESC found that, when discussing therapies with patients, only one third of clinicians used informational brochures and even fewer referred patients to educational websites.³³
- In another study, only an average 14% of AF patients reported being informed of the potential side effects of their medication.³⁴

Box 2 Low patient understanding of AF²⁹

A survey conducted in 11 countries found that at least one in four patients felt unable to explain AF to another person. Only 57% of patients surveyed felt that the information provided by their doctor was easy to understand. Furthermore, more than one third of patients reported being worried or fearful about AF.

Messages about AF and the risk of AF-related stroke may be difficult for patients to digest – particularly if they are being treated for multiple chronic conditions or if they are only diagnosed after they have had a stroke.

Many patients with AF have multiple chronic conditions which are managed by a range of specialists.¹³⁵ Clinical guidelines are often disease-specific and do not adequately support healthcare professionals who manage complex patients with multiple conditions.³⁶ Patients may be overwhelmed by the amount of advice they receive on their conditions,³⁷ and find it difficult to understand the association between AF, AF-related stroke and their other conditions.

Crucially, AF is often diagnosed only after a person has had a serious complication such as an AF-related stroke.³⁸ This means patients are often trying to learn about the condition, and the complexities of its management, at a difficult time when they are simultaneously dealing with many other challenges.

How can patient education be better supported?

Recommendation 1

• **Build awareness and understanding of AF** among patients and the wider population, through campaigns with simple, tailored messages implemented in a way that builds knowledge and supports shared decision-making between patients and healthcare professionals.

We can do this by...

Developing simple, targeted messages for patients in a range of clinical settings

Accessible information about AF is urgently needed in a range of clinical settings. These materials should be available in local languages and be easily understandable to people with different levels of health literacy. Simple, targeted messages are needed to address the priorities of different groups, including patients, covering key elements of AF:

- AF as a condition to encourage those at risk to get detected
- AF's role as a risk factor for stroke
- Benefits and risks associated with anticoagulation to prevent AF-related stroke
- The importance of continuing with the medication.

Embedding shared decision-making across all settings of care

Healthcare professionals can play a key role in empowering patients and supporting them to take a more active role in their own care, through shared decision-making.^{3 39} This can be achieved through:

- close collaboration between patient organisations and healthcare professionals in developing accurate information and resources that address patients' needs
- active healthcare professional engagement to help build patients' skills, confidence and ultimate engagement in their care
- fostering development of tools to aid patient-clinician communication (see Box 3).

Box 3 AF stroke risk calculators⁴⁰

AF stroke risk calculators were developed to help physicians calculate their patients' risk of AF-related stroke – but they also provide patients with a comprehensive assessment of their risk of stroke, coupled with critical information. The calculators run through a series of questions aligned with ESC guidelines to determine stroke risk. They provide patients with printable results and information on therapy options, which they can use to initiate discussion with their GP, cardiologist or neurologist. A number of AF stroke risk calculators are available, including one from the AF Association: http://www.preventaf-strokecrisis.org/calculator

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Action focus 2: Adapting clinical practice to enhance AF detection

Key messages

- AF is often detected only after the person has had an AF-related stroke.
- Opportunistic screening for AF is recommended by the ESC, but many national guidelines do not include this recommendation.
- Opportunistic pulse rhythm checks are a simple way of detecting AF and should be introduced as standard practice across a range of care settings.

What is the issue?

The timely detection and diagnosis of AF is critical in the prevention of AF-related stroke, but many patients are diagnosed only after they have had an AF-related stroke. There is a detection gap (in terms of the number of people who have AF but in whom it is undetected) of approximately 10–45%, depending on the setting.¹⁹⁴¹⁻⁴⁴

In **England**, around 425,000 people – or 30% of those with AF – are thought to have undiagnosed AF.⁴²



In **Spain**, 31% of people with AF who are over 60 years old have not had a diagnosis.⁴⁵



Detection of AF can be challenging as it often does not present with any obvious symptoms.⁴⁶ In some patients, AF may have intermittent or even no symptoms, making detection difficult.

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The 2016 ESC guidelines recommend opportunistic pulse checks in people over 65 and an electrocardiogram (ECG) for confirmation of AF. These guidelines also recommend the systematic screening of high-risk patients (who have had an ischaemic stroke or transient ischaemic attack (TIA)), as well as the consideration of systematic ECG screening in patients aged 75 and over, or those at high risk of stroke.¹

Regular checks for AF, however, are not common practice. A survey of 550 GPs in 11 European countries found that, in 10 of the countries, fewer than 20% of patients over 65 were checked for AF during routine GP appointments, despite this age group being at increased risk of AF (see *Table 1*).⁴⁷

Table 1. Percentage of GPswho check patients for AFduring routine appointments47

Country	Percentage
Belgium	12%
France	15%
Germany	13%
Italy	17%
Netherlands	5%
Norway	18%
Russia	42%
Spain	12%
Sweden	19%
Turkey	13%
United Kingdom	8%

Why is this happening?

The evidence base on AF detection is evolving rapidly.

The case for opportunistic screening is well articulated in ESC guidelines, but the evidence on whether opportunistic and systematic screening for AF leads to reductions in AF-related stroke is still evolving. This evidence gap has influenced decisions by policymakers against the introduction of AF screening programmes in the UK⁴⁸ and Sweden.⁴⁹ Research is currently underway in both of these countries, however, to determine whether systematically screening patients for AF can reduce rates of AF-related stroke.^{50 51}

Access to diagnostic services for AF is inconsistent.

Variable access to diagnostic services restricts the ability of healthcare professionals to identify people with AF.

In **Scotland**, there is variation in access to 12-lead ECGs; some National Health Service regions provide machines in all GP practices, while in others they are only available in hospitals. Waiting times of up to nine weeks for access to diagnostic services have been highlighted, which is problematic for patients who are unable to begin anticoagulation until their AF has been confirmed.⁵²

Even where opportunities for detection do exist, they may not be accessible by people who do not utilise health services due to cultural and linguistic barriers.⁵³

Uptake of new screening tools has been limited.

Innovative screening tools that facilitate AF detection are a key aspect of the growing evidence base, but their adoption into routine medical practice has been limited. Handheld single-lead ECG devices, for example, can provide a simplified, accurate and potentially cost-effective way of screening for AF in high-risk populations.^{54 55} However, expert commentators have highlighted how financial constraints on healthcare systems may affect the uptake of this technology in medical practice.⁵²

National guidelines often do not include recommendations for opportunistic screening of over-65s.

Few national guidelines recommend opportunistic checks for AF. This is despite national cardiac society endorsement of the 2016 ESC guidelines in many countries,¹ and evidence that opportunistic screening leads to a statistically significant absolute increase in the proportion of people diagnosed with AF.⁵⁶

National guidelines in England⁵⁷ and France⁵⁸ do not include opportunistic tests for AF.

Pulse rhythm checks are not integrated into routine care in many settings. Despite lobbying by patient organisations and professional societies in a number of countries - and the fact that pulse checks are a simple, quick and affordable tool to detect AF - decision-makers have seldom chosen to include pulse rhythm checks as part of routine practice.

How can clinical practice be adapted to improve AF detection?

Recommendation 2

• Introduce opportunistic detection of AF among high-risk groups through pulse rhythm checks across a range of clinical and non-clinical settings.

We can do this by...

Introducing opportunistic pulse rhythm checks as standard practice

Opportunistic pulse rhythm checks are appropriate for a range of care settings. Annual flu clinics in primary care using traditional⁵⁹ or handheld ECGs,⁶⁰ routine GP consultations^{61 62} and specialist clinics (such as for podiatry)⁶³ have all been used to successfully detect AF.

In **Italy**, GP guidelines recommend the opportunistic testing of patients for AF using pulse rhythm checks followed by an ECG confirmation.64



Routine hospital care can be adapted to include opportunistic checks for AF. Simple adaptations could be made to routine checks in the hospital, such as bedside checks on vital signs conducted by nurses or healthcare assistants. Training staff to record arrhythmia during these checks could provide a relatively low-cost addition to normal care.

For this practice to be effective, patient-focused pathways must be in place and health systems must be ready and resourced to manage higher numbers of AF patients. The development of programmes for opportunistic screening will likely lead to more cases of AF being identified. Robust referral pathways are essential to ensure patients are supported along the whole pathway, from detection to initiation of anticoagulation therapies, and access to therapies and ongoing care.65

Improving efforts to detect AF in non-clinical and community settings

Pulse rhythm checks in the community could be expanded to meet the needs of patient groups who may not access traditional health services. Innovative approaches are needed to identify 'missing' groups and develop appropriate activities to engage them. Community-based screening – led by pharmacists who are able to speak the communities' languages, for example - has been shown to be successful (see Box 4).66

Robust referral pathways and access to ECG confirmation, therapies and ongoing care must be available, regardless of the setting in which the suspected AF is detected. Clear referral pathways ensure people with suspected AF identified in the community have timely access to an ECG for accurate confirmation.65

In **England**, a pathway is being trialled which allows community pharmacists in London to refer people with an abnormal heart rhythm to a one-stop AF clinic, after first testing them using a handheld device.⁶⁷ This has resulted in quick diagnosis of AF and access to appropriate anticoagulant therapy within two to three weeks, compared with the national average of 12 weeks.

Detecting AF Box 4 in community pharmacies⁶⁶

The International Pharmacist for Anticoagulation Care Taskforce (iPACT) partnered with the Atrial Fibrillation Association (AF Association) to set up an initiative in 10 countries to actively involve community pharmacists in opportunistic screening for AF. Pharmacists took people's pulse manually, and assessed symptoms and risk factors. People with an abnormal heart rate or rhythm were referred to a physician and, in some countries, pharmacists additionally confirmed the manual pulse check using a mobile single-lead ECG. A total of 2,573 patients were included in the final analysis, with an irregular pulse detected in 212 patients (8.3%) and AF confirmed in 35 individuals, corresponding to a detection rate of 1.4%.

Expanding training in the use of mobile ECG devices broadens access to accurate AF detection in the community.

Professionals outside of healthcare could be trained to check 'hard-to-reach' groups for AF; for example, training fire and rescue personnel to use mobile ECG devices during Health and Safety Assessment visits with people over 65 has been shown to effectively target this high-risk group.68

Supporting stronger collaboration and communication between healthcare professionals

Improving communication channels between healthcare professionals is crucial to the successful adaptation of clinical practice for AF detection. Poor coordination of care has been highlighted as a key concern for AF patients, with clinicians and other healthcare professionals not systematically sharing information.¹⁹ Centralised records of patient information can facilitate dialogue between different healthcare professionals, and should be investigated further. Building a shared understanding of diagnosis and clinical decision-making among specialisms is also needed. This can be achieved through stronger interdisciplinary collaboration among healthcare professional societies, an area which is explored further in Action focus 4.

Improving screening for AF by optimising the use of new technology

Innovations in technology may offer opportunities to make AF screening more comprehensive and cost-effective. Increased availability of mobile, single-lead ECGs may mitigate many of the issues associated with identifying AF, such as patient discomfort and long waiting times.⁶⁹

Technologies such as ECG patches can significantly improve the detection

of AF. A study in the United States found that immediate monitoring using self-applied continuous ECG monitoring patches at home for up to four weeks - compared with delaying ECG monitoring for four months - led to a significantly higher rate of AF diagnosis at four months, and greater initiation of anticoagulants in monitored individuals compared with those who were not monitored.⁷⁰

Smartphone apps and smart watches can facilitate population screening and help uncover asymptomatic AF. A major study examining the feasibility of mass screening for AF has found promising results, although more evidence is needed to enable these technological solutions to be implemented on a mass scale (see Box 5).



into the care pathway in the same way that AF is detected in clinical or community settings, to ensure that people with suspected AF receive adequate follow-up care. In the case of smartphone apps, for example, key aspects of the pathway would include prescription of the app, effective monitoring and analysis of the data,

referral for ECG testing if appropriate, and access to anticoagulation.

Action focus 3: Strengthening clinical and professional training in AF

Key messages

- Limited professional understanding of AF has a negative impact on patient care.
- Appropriate training materials are required to support the different needs of healthcare professionals along the whole patient pathway.

What is the issue?

Many healthcare professionals lack adequate awareness and understanding of AF.³³ A recent ESC educational needs assessment of European clinicians treating patients with AF highlighted a range of gaps, including:³³

- uncertainty over how to deal with anticoagulant therapy, particularly in complex patients
- problems in using and interpreting risk assessment scores
- difficulties in AF detection associated with the complexity of symptoms.

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These gaps lead to suboptimal management

of patients with AF. Evidence suggests that clinicians often underestimate the risk of AF-related stroke and overestimate the risk of bleeding, resulting in patients not receiving appropriate anticoagulation therapy.⁷³ Patients who do receive anticoagulation therapy are not always given adequate information on its benefits or the risks of discontinuing therapies, which likely contributes to low adherence.⁷⁴

Why is this happening?

Management of AF is complex owing to variable symptoms and the presence of other chronic conditions.

Symptoms vary not only from one patient to another, but also for the same individual at different time points.⁴⁶ AF is more common in people with conditions such as diabetes and has a close association with heart failure,^{1 35} which further complicates care. Primary care professionals, who may lack knowledge of AF, often deal with high numbers of patients with a wide range of conditions. Given their limited contact time with patients, professionals may, understandably, prioritise managing AF's more immediate symptoms such as heart palpitations, dizziness, syncope (temporary loss of consciousness) and fatigue.

Decisions over appropriate therapies to prevent AF-related stroke add further

complexity. The decision to use any given oral anticoagulant therapy, for example, requires a careful balance of the potential benefits (stroke prevention) and risks (increased risk of bleeding) for each patient, as well as taking into account the patient's preferences and values.^{34 75 76}

Healthcare professionals' educational needs are not well supported.

Professional educational needs relating to AF-related stroke prevention in non-cardiac settings are not well supported, despite many AF patients being cared for in primary care, emergency medicine and geriatrics. There is a lack of AF-related stroke prevention guidelines for non-cardiac specialists, despite notable exceptions such as for GPs in Ireland⁷⁷ and Italy.⁶⁴ Usually, the only available guidelines on the prevention of AF-related stroke are for cardiologists, which may be too detailed and complex for non-cardiac settings. This is compounded by the continuing historical misconception of AF as benign.78

It is not clear whether the educational tools that do exist are being optimally

used. Tools currently available include online decision-support tools,⁷⁹ the GRASP-AF tool developed to support GPs in the UK,⁸⁰ and the ESC's 'pocket guidelines' and CATCH ME mobile app.⁸¹ It is not clear, however, whether these tools are being used by healthcare professionals to support optimal patient care.

Language barriers may inhibit the uptake of guideline recommendations.

ESC guidelines are available in a limited number of languages,⁸² which may hinder their effective use by cardiologists across Europe, especially in areas where English is less widely understood.

There is a lack of guidance on referral pathways. The 2016 ESC guidelines, for example, do not include information on where and when AF patients should be referred, although they stress the need for a team approach to the management of AF patients.¹

How can clinical and professional training in AF be strengthened?

Recommendation 3

• Increase knowledge and skills of healthcare professionals by developing tailored guidelines and tools, and ensuring existing tools are more widely used, where available.

We can do this by...

Developing user-friendly guidelines and practical decision-making tools for healthcare professionals

Accessible, tailored guidelines that include recommendations on referral pathways would support comprehensive implementation of ESC recommendations. GPs, for example, should be helped to define what care they should provide and for which patients, while also identifying patients with complex needs who should be referred to specialist care. Bespoke guidelines for pharmacists could help to carve a broader role for these professionals in both the detection of AF and anticoagulation medication management, taking advantage of their unique position in the health system.

Existing guidelines, such as those for stroke, could be updated to include information on AF and anticoagulation therapy. The ESC, along with national cardiology organisations, should take a leading role in developing subsets of guidelines, and reaching out to national organisations for other disciplines to develop guidelines collaboratively.

- **Decision-making tools would support** the management of patients with AF.
- Educational tools to support the assessment of AF-related stroke risk, and aid in the selection of the most appropriate anticoagulation therapy for each patient, could be particularly beneficial. The CHA₂DS₂-VASc risk assessment tool has led to more accurate and appropriate assessment of risk and decisions on anticoagulation by cardiologists,⁸³ and this needs to be incorporated into primary care IT systems to enable seamless implementation and support GPs in the decision-making process.⁸⁴
- Guidelines and decision-making tools must be made available in multiple languages to ensure access across Europe. The ESC could take the lead in working with national cardiology societies to ensure that at least the basic recommendations from the guidelines are translated into all European languages.
- Better use must also be made of existing tools. Stronger collaboration between national cardiology societies and other professional medical organisations, as well as with healthcare providers and patient organisations, could help to raise the profile of these tools and aid in their incorporation into clinical practice.85

Maximising peer-learning opportunities and training courses

AF should be integrated into professional development programmes that meet healthcare professionals' continuing professional development (CPD)

responsibilities. Practical, short courses on AF care should be developed and tailored to the specific needs of different professionals and care settings, addressing common problems at various points of AF care. Training courses could also facilitate innovative changes to normal care, such as the adaptations to clinical practice described in **Action focus 2**. Collaboration among all stakeholders including healthcare professionals, patient organisations and policymakers is needed to develop and effectively roll-out training courses.

Publication in national clinical journals can also support professional learning. As such journals are usually written in local languages, they may be more accessible to clinicians than international scientific journals published in English.

Web-based platforms offer further learning opportunities. For example, the Heart of AF programme, developed by the AF Association,⁸⁷ provides healthcare professionals globally with resources to develop the skills and knowledge to better diagnose, treat and manage AF patients.

In the UK, local cardiac and stroke networks that link patients, GPs, commissioners and providers for improved patient outcomes have been used to provide targeted training to non-cardiac specialists.⁸⁶ This has included training for primary care staff who run INR (international normalised ratio) clinics, where awareness of opportunistic pulse checks has been raised.

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Action focus 4:

Promoting awareness and accountability among decision-makers for effective AF-related stroke policies

Key messages

- AF-related stroke is under-represented in policy, which contributes to inequalities in access to AF detection and first-line therapies to prevent AF-related stroke.
- Better articulation of the case for investment is needed, emphasising the cost of inaction.
- Population-based registries and national health databases related to AF are necessary to increase the level of nationally and regionally relevant data.
- Decision-makers must be accountable for implementing changes to prevent AF-related stroke; the Action Plan for Stroke in Europe 2018–2030 presents an opportunity to achieve this.
- Strong collaboration between a range of disciplines
 is needed to advocate for change.

What is the issue?

AF-related stroke is severely under-represented in policy, performance and improvement efforts.

There seems to be a lack of awareness among decision-makers as to how AF links to wider policy goals such as the prevention of NCDs, healthy ageing and healthcare sustainability. Very few countries in Europe have a national plan targeting the prevention of AF-related stroke.¹⁹

This situation has allowed significant inequalities to endure unchallenged.

There is, for example, variation across Europe in access to AF detection services: between 10% and 45% of people with AF remain undetected, depending on the setting.^{19 41} In addition, despite evidence on the cost-effectiveness of using NOACs to prevent AF-related stroke, access varies greatly from country to country.⁴²⁻⁴⁴ For example, in many Eastern European countries, health service budget constraints mean NOACs are often limited to patients who have had a previous stroke or those with poor control on other therapies.⁸⁸⁻⁹¹ This means many patients can access NOACS only if they cover the cost themselves, potentially limiting the use and duration of these therapies.

Unlike other countries in Western Europe, **Spanish** guidelines do not align to the 2016 ESC guidelines and restrict the use of NOACs to a second-line therapy in most cases.⁹² This is despite the fact that 40% of people with AF⁹³ – which amounts to over 300,000⁴¹ patients – are inadequately controlled using vitamin K antagonists (VKAs).

In **Italy**, NOACs can be prescribed only if monitoring on other therapies is difficult, and only by authorised specialists.^{94 95}

Why is this happening?

Awareness and understanding of AF is low.

Although AF is widespread, poor public awareness of the condition and its associated stroke risk continues to be a major hurdle,²⁷ and is reflected in low knowledge among policymakers and decision-makers at all levels. In a series of interviews with different stakeholders from across Europe, respondents reported that policymakers' understanding of AF is low, and that AF is often viewed as a medical issue rather than a public health issue.78

The risk of AF-related stroke has not been well articulated.

The significant stroke risk resulting from AF has not been well articulated either at the public or policy level, which has led to AF being neglected in stroke policy. AF is not mentioned, for example, in the WHO's Atlas of Heart Disease and Stroke, even though this resource aims to guide the development and implementation of appropriate policies on stroke, and despite AF fitting its three criteria for a major established risk factor for stroke.⁹⁶

Implementation of national strategies at the regional or local level is variable.

Even where national AF and AF-related stroke strategies exist, the differing priorities of sub-national decision-makers result in regional differences in their implementation.

In **Spain**, different policies are in place at the level of the autonomous regions, leading to wide variation in access to NOACs for the prevention of AF-related stroke. In fact, in 2015, only 10 of the 18 autonomous regions applied national recommendations on access to NOACs, with the remaining eight applying additional access barriers.93

In **England**, National Institute for Health and Care Excellence (NICE) guidelines recommend NOACs as an equal first-line option to VKAs.⁹⁰ Some local clinical commissioning groups, however, appear to interpret this as meaning NOACs are a second-line option, with VKAs as first-line.⁹⁰ This may contribute to considerable variation in NOAC uptake between regions, ranging from approximately 4% to nearly 70% of all oral anticoagulant use in a 2015 survey.97

National collaboration among key AF stakeholders is inadequate.

A lack of collaboration between key stakeholders contributes to AF's low visibility on the policy agenda. There is, for example, not usually a strong relationship between cardiology and neurology at the national level in most countries. The absence of collaboration may reduce the efficacy of key messages on AF and AF-related stroke, and the impact of advocacy efforts.

How can we promote awareness and greater accountability among decision-makers?

Recommendation 4

• Ensure policy leadership to drive equitable access to best practice. This can be achieved by building awareness and understanding of AF among policymakers and decision-makers at all levels of the health system.

We can do this by...

Better articulating the case for investment at national and sub-national levels

Policymakers and payers may be receptive to arguments focusing on the cost of inaction (e.g. the opportunity cost associated with not using NOACs) and return on **investment.** There is, for example, a growing body of 'real-world' evidence on the benefits of anticoagulation for reducing stroke (see Box 6). There is also a growing evidence base on the cost-effectiveness of NOACs compared with VKAs, despite their higher cost, which is at least in part due to the fact that, unlike VKAs, they do not require regular monitoring.⁹¹¹¹² In addition, there is increasing evidence on the case for investment in opportunistic screening, with research suggesting that screening of people aged 65 and over is likely to be cost-effective.⁶¹

However, arguments aimed at the sub-national level must take into account the complexities and pressures affecting local decision-makers. The potential impact of economic evaluation will depend on whether cost-effectiveness has become an explicit criterion to set health priorities at the local level.⁹⁹ In Spain, this has occurred for some regions to guide recommendations on the use of new pharmaceuticals,⁹⁹ while local-level decisions in the UK are usually based on broader criteria, such as evidence of clinical benefit and budget impact.¹⁰⁰

These messages should be articulated via innovative methods. Educational events aimed at politicians, for example, have been shown to be an effective way of engaging with high-level decision-makers on AF (see Box 7).

UK data highlight Box 6 a strong association between anticoagulation and stroke prevention⁹⁸

Data from the UK found that changes in clinical practice between 2006 and 2016 led to higher rates of anticoagulation and that this was associated with a decrease in the number of strokes. The study estimates that a 1% increase in the use of anticoagulant therapy was associated with a decrease of 0.8% in the number of AF-related strokes per week. The authors of this study estimate that more than 4,000 AF-related strokes were prevented in 2015–16 due to higher rates of anticoagulation compared with 2009.

Box 7

Engaging and educating policymakers on AF

The Arrhythmia Alliance and AF Association regularly host 'Know Your Pulse' events in parliaments in locations including England,¹⁰¹ Scotland,¹⁰² Australia¹⁰³ and at the European Parliament in Brussels,¹⁰⁴ among others. During these events, politicians are offered a simple pulse rhythm check. Engaging with politicians – and identifying those with previously unknown AF – raises awareness while helping to influence policymakers and leading to action at the highest level.

Collecting relevant data to aid national and regional decision-making

Population-based AF registries and national health databases provide the data needed to understand inequalities and gaps in care, and missed opportunities to prevent strokes. These, however, do not exist in many countries. Currently, only Germany, Estonia and Latvia have invested in dedicated registries for AF, and only Denmark and Sweden have national patient registries that cover all conditions from which data on AF may be extracted.¹⁹ The value of these data can be seen in Denmark, for example, where the establishment of the Danish Stroke Registry has correlated with improved anticoagulation rates.¹⁰⁵

The **Danish** Stroke Registry was established to monitor and improve the quality of care among all patients with acute stroke and TIA treated at Danish hospitals.¹⁰⁵ Reporting is mandatory and an audit of the data is published annually and includes recommendations on improving quality of care.¹⁰⁵

Since the publication of data on the percentage of stroke patients with AF who are receiving anticoagulation therapy within 14 days of a stroke, anticoagulation rates have increased and the gap between anticoagulation rates in the capital and the rest of the country has closed.¹⁰⁶

Regional-level data should be made available to local decision-makers. This would enable them to monitor performance and facilitate service development.

The Sentinel Stroke National Audit Programme (SSNAP) is the single source of stroke data in **England**, **Wales** and Northern Ireland. The SSNAP aids commissioners by providing them with region-specific data every four months on a number of measures, such as the proportion of patients with AF on anticoagulation admitted to hospital for stroke. The programme also provides consistent benchmarking and regional breakdowns, allowing decision-makers to compare their service performance with other regions.¹⁰⁷



Harnessing data to hardwire accountability at the policy level

Policymakers must be accountable for implementing changes to prevent AF-related stroke and ensuring that sufficient resources are committed to address inequalities in care. Accountability mechanisms should be developed to monitor, review and propose remedial action to ensure progress towards the agreed goals and targets.¹⁰⁸ Impact assessments, for example, could contribute to the transparency of decision-making, and allow the participation of stakeholders in public health, civil society groups and communities to increase accountability.¹⁰⁹ Dashboards charting the progress made in implementing agreed policies and actions could be a useful tool to ensure commitment and accountability.¹⁰⁰

Leveraging European and international work to gain momentum

The Action Plan for Stroke in Europe 2018–2030¹¹⁰ presents a tangible opportunity to engage decision-makers and advance accountability around AF-related stroke prevention (see Box 8). At the national and regional level, the Action Plan can serve as a model for countries to develop their own AF policies and update their national NCD action plans. The World Heart Federation's Roadmap for Nonvalvular Atrial Fibrillation is another such opportunity, as it focuses on topics aligned with WHO's Global Action Plan targets for NCDs.¹¹¹



Fostering strong cross-stakeholder collaboration

Effective collaboration between healthcare professionals is crucial, such as that facilitated at the European level by the ESC Council on Stroke. The Council establishes links with 'sister' societies which aim to support and encourage collaboration and dialogue between disciplines. The Council helps contribute to the development and implementation of ESC Clinical Practice Guidelines, along with position papers and consensus documents. It also brings together its varied membership of healthcare professionals for interdisciplinary workshops and educational activities.¹¹² The ESO also supports multidisciplinary collaboration through its range of committees.¹¹³

This collaboration needs to be replicated with similar efforts at the national level, bringing clarity and consensus to political decision-making. Better collaboration between professional societies could help drive the changes outlined in the Action Plan for Stroke in Europe 2018–2030 by facilitating interdisciplinary dialogue and a stronger shared understanding of patient needs.

Patient organisations' potential to achieve recognition and policy commitment may be enhanced through multidisciplinary collaboration, such as with scientific professional and public health organisations. For example, the AF Association, Arrhythmia Alliance, AntiCoagulation Europe and SAFE have released a joint action plan on supporting the prevention of AF-related stroke.¹¹⁴ In the UK, an All-Party Parliamentary Group on AF has been established to provide a constructive forum for patient organisations to collaborate alongside healthcare professionals and members of parliament.¹⁰¹

Conclusion

AF-related strokes are not only devastating for individuals and their families, they also place significant pressure on health services. Populations across Europe are ageing and, unless we take urgent action, the number of AF-related strokes will rise significantly, impacting on the sustainability of our health systems.

We already have the tools we need to deliver effective care for patients with AF, but unacceptable inequalities exist in access, meaning huge opportunities to prevent AF-related stroke are being missed. The proportion of AF patients who are undiagnosed and therefore missing out on essential care for the prevention of AF-related stroke varies greatly between countries. Similarly, barriers to accessing cost-effective, first-line therapies for the prevention of AF-related stroke among already-diagnosed patients is highly uneven between – and even within – countries.

This White Paper has outlined four critical areas where change is urgently required. By working together, patient organisations, healthcare professionals and policymakers can drive these changes and ensure that all patients have access to the care they need.

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