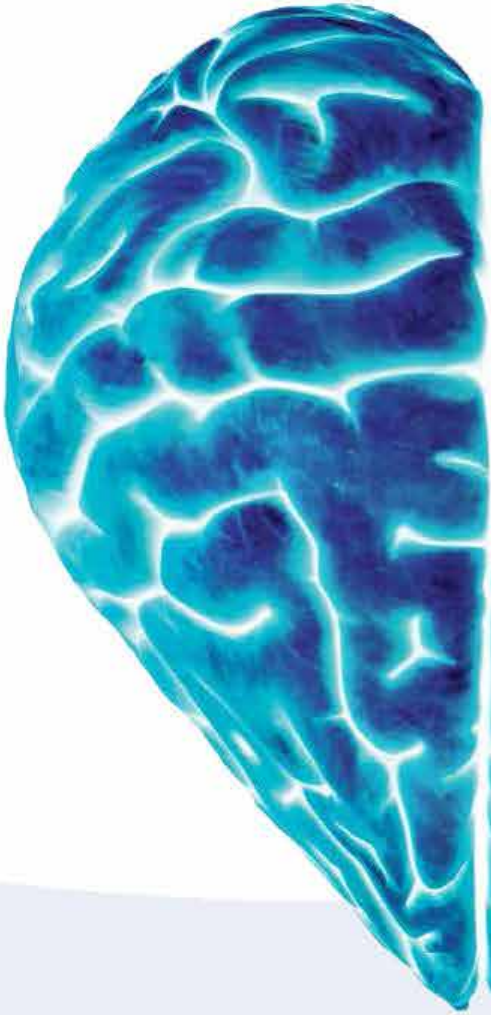
THE ROUTE MAP FOR CHANGE AND THE EUROPEAN ATLAS ON THE PREVENTION OF AF-RELATED STROKE



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II: A NOTE FROM THE STEERING COMMITTEE

AF (atrial fibrillation) is a common condition, yet few people have heard of it. What is also often not known is that AF is the second most important risk factor for stroke after blood pressure and causes one in every five strokes2 – close to 360,000 cases per year in the EU.

The good news is that effective therapies are available that help reduce the risk of stroke in people with AF. But many patients – up to 40% in many countries – are not offered these treatments – despite a strong evidence base and consistent international guidelines recommending their use.

The challenge, as ever, is one of implementation. But successful implementation requires up-to-date, reliable data to help understand what the most important unmet needs are in each country, and where efforts should be targeted to achieve the greatest returns.

Two years ago, we set out to develop a European Policy Atlas on the prevention of AF-related stroke, bringing together, for the first time, reliable evidence of what different countries are doing across Europe to help achieve effective prevention of AF-related stroke. We are grateful to the many patient organisations and clinical experts from around Europe who have contributed their thoughts and examples of best practice to help inform this document -- allowing to compare and contrast unmet needs and evidence and what has been done to tackle this important public health problem across Europe.

But data is not enough – it needs to translate into action. Accompanying the Atlas is the Route Map for Change, which draws on the findings of the Atlas to propose priority actions for policymakers to take forward in their respective countries.

These documents here to be used, and we urge you and your colleagues to draw from these documents to help impress upon policymakers the public health urgency posed by AF-related stroke. We have the means to prevent these catastrophic events, averting countless personal tragedies as a result. We hope that this document may serve as a valuable resource to bring us one step closer to achieving this goal.

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III: ABOUT THIS DOCUMENT

This document was developed to raise awareness of the need to focus attention, policies and resources towards the prevention of AF-related stroke in Europe. It presents key data documenting the burden posed by AF-related strokes across Europe, highlights key issues and challenges in implementing best practice to help prevent these strokes and provides examples of successful initiatives that have made a difference across Europe.

THE ROUTE MAP FOR CHANGE AND THE EUROPEAN ATLAS ON THE PREVENTION OF AF-RELATED STROKE

p.XX Executive Summary

p.XX-XX

3 page summary of the case for change, the situation across Europe and summary recommendations

p.XX Routemap for Change

7 priority areas:
each with background evidence, examples of good practice, and avenues for change

- p.XX **Priority 1:** Targeted policies and resources
- p.XX **Priority 2**: Greater public awareness
- p.XX **Priority 3:** Improved detection and diagnosis
- p.XX **Priority 4:** Appropriate anticoagulation therapy for all patients at risk of stroke
- p.XX **Priority 5:** Patient-centred care
- p.XX **Priority 6:** A whole-system approach to care
- p.XX **Priority 7:** Better data to guide policy

p.XX European Atlas

p.XX-XX

27 Country profiles from the EU*, Norway, Turkey and Switzerland: to compare and contrast data, policies and practice

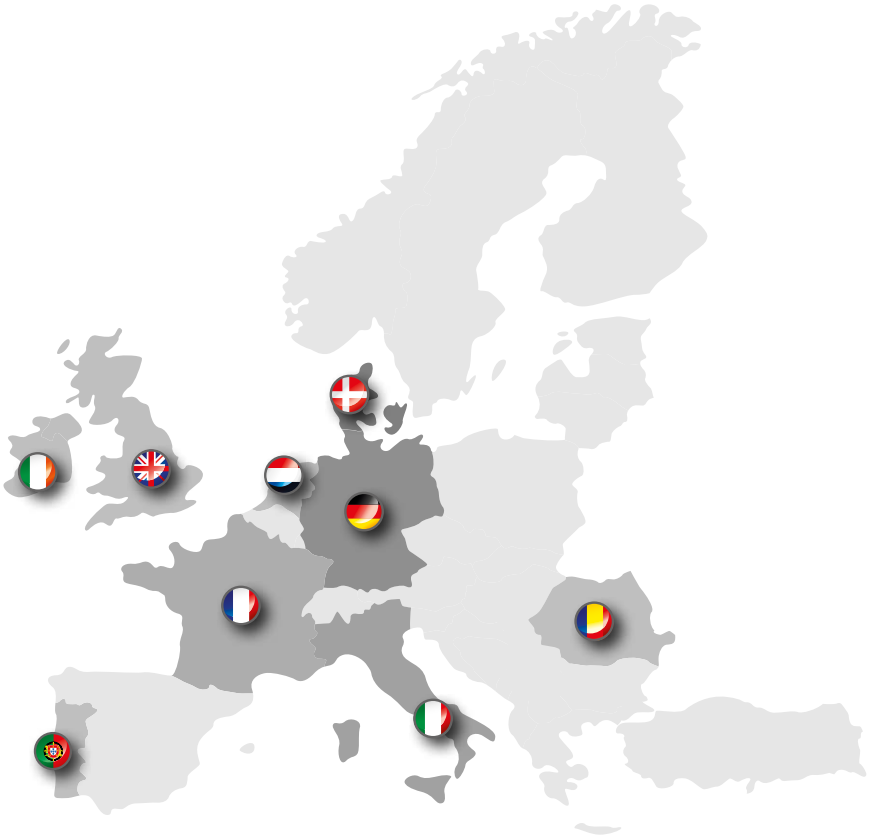
* Information was insufficient to develop country profiles for Malta, Cyprus and Luxembourg.

Case Studies:

Priority 1: Targeted policies and resources to enable the effective prevention of AF-related stroke

Priority 2: Greater public awareness and understanding of AF and the increased risk of stroke with AF

Priority 3: Improved detection of AF and integration of pulse checks into clinical practice



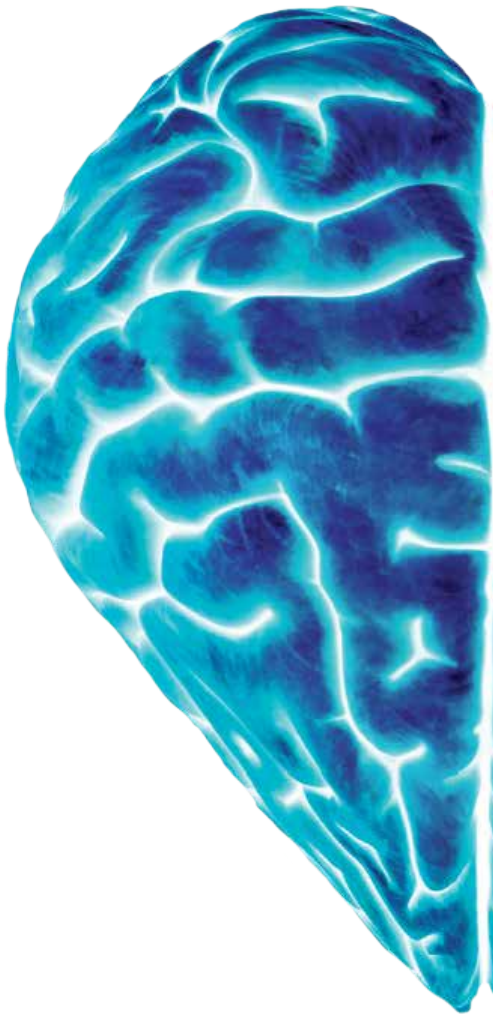
Priority 4: Appropriate anticoagulation therapy for every AF patient at risk of stroke

Priority 5: Patient-centred care and clear information to patients

Priority 6: A whole-system approach to the prevention of AF-related stroke

Priority 7: Better data to guide policy and clinical management

EXECUTIVE SUMMARY



1: THE PREVENTION OF AF-RELATED STROKE: THE CASE FOR CHANGE

*Every year in the EU, **1.8 million new cases of stroke** occur[1], each a personal tragedy, and together a huge societal burden of death, disability, and healthcare costs. One in five of these strokes[2] – close to **360,000 cases per year** -- are **due to AF** (atrial fibrillation).*

*Many AF-related strokes can be prevented through effective treatment. However, available treatments are all too often not offered to patients – leaving **millions of patients with AF at risk** of suffering a debilitating and potentially fatal stroke.*

- There are **624,000 deaths due to stroke** every year in the EU.[1]
- Stroke presents **a tremendous burden on people living with stroke, their families, healthcare systems, and society.**[3-8] The EU spends €38 billion per year on treating strokes, and the indirect costs (loss of productivity, informal care demands) are enormous.[5] In some countries, stroke patients occupy up to 20% of all acute hospital beds and 25% of long-term beds.[9]
- **AF is the most common heart rhythm abnormality** and affects close to 2% of the general population[2;10], or up to 10 million people in the EU. The incidence rises with age.[11]
- The lifetime risk of developing AF is **one in four** after the age of 40.[12]
- AF causes **one in five strokes** – one in three after the age of 80.[13;14]
- AF is the **second most important risk factor for stroke** after blood pressure and a greater risk factor than smoking, diabetes or lack of physical activity.[15]
- AF-related strokes are **the most deadly and debilitating strokes,**[16;17] lead to more permanent disability[18;19] and cost 1.5 times more than strokes not due to AF.[2]
- Today, **millions of people in Europe may be unaware they are living with AF,** and therefore are at much higher risk of stroke whilst they remain untreated. AF can often be a 'silent' condition[20] and is only diagnosed once a stroke or another serious complication strikes.[21]
- **AF is on the rise** with the ageing of the population. The numbers of people affected by AF are predicted to double by 2050,[2;22] which means the number of AF-related strokes is also likely to grow in years to come.
- Effective therapy, in the form of **oral anticoagulation therapy (OAC)**, exists to help prevent the risk of stroke in patients with AF.[20]
- The decision to use any given OAC therapy requires **a careful balance** between the potential benefits (stroke prevention) and risks (increased risk of major bleeding) of therapy for each patient -- as well as the patient's preferences and values.[23;24]
- There are two kinds of OAC therapy: vitamin K antagonists (**VKAs**), which have been the standard of care for 60 years, and non-VKA (or novel) anticoagulation therapy (often called **NOACs**), which have been made available to patients in the past few years.
- The **2012 European Society of Cardiology (ESC) guidelines** recommend that, in many patients, NOACs are broadly preferable to VKAs.[20]
- Yet in practice, **a large proportion of people with AF (up to 50-60%) do not even receive OAC therapy**[25;26] – instead, they either receive antiplatelet therapy (usually aspirin), which is ineffective at reducing the risk of AF-related stroke[27], or no treatment at all.
- This **treatment deficit** occurs for a number of reasons, including physicians' fear of bleeding caused by OAC therapy,[28] practical difficulties in using VKAs in the past,[29-33] and insufficient understanding by physicians and patients of the purpose of OAC therapy.[34;35]
- **With up-to-date guidelines and new treatment options available for the first time in 60 years, we have an unprecedented opportunity to prevent AF-related stroke.** Policy makers must lead urgent efforts to improve public awareness of AF, address system deficiencies, including poor information to patients and under-detection of AF, improve physician adherence to guidelines and encourage appropriate use of OAC therapy in all AF patients at increased risk of stroke.

2: KEY FINDINGS FROM THE EUROPEAN ATLAS

Unsatisfactory leadership by governments

- Only two countries (Ireland and the UK) have **dedicated national strategies** on the prevention of AF-related stroke, and only ten countries (Bulgaria, Czech Republic, Estonia, France, Hungary, Ireland, Poland, Portugal, Spain and the UK) have national stroke plans.
- **Funding** for stroke research pales in comparison to other conditions.[36]
- Important **gaps in acute stroke care** persist, particularly in Eastern Europe and Baltic countries, where the burden from stroke is greatest.[37]

Poor public awareness and understanding

- AF is a common condition, yet few people are aware of it.[38;41]
- Most people do not know that AF is an important risk factor for stroke.[38;41-45]

Detection gap of up to one third

- AF is likely to be **more prevalent than previously reported,** according to country-level data.[18;31;33;42;46-64]
- **Between 10-45% of cases of AF may be un-detected,** depending on the setting.[31;33;51;62;65;66]
- **Simple screening tools such as pulse checks** have yet to be integrated into general health checks. However, community screening initiatives are gaining ground in many countries.[65;67]

A treatment gap of up to 40% in many countries, with significant variation between countries and across local settings

- Across Europe, a large proportion of AF patients do not receive OAC therapy despite guideline recommendations:
  - **Up to 40% of AF patients do not receive OAC therapy** in 13 out of 20 countries where data are available.[31;52;62-64;68-90]
  - **Up to 40% of high risk patients do not receive OAC therapy** in 8 out of 15 countries where data are available.[52;57;63;72;77;82;91-98]
- There is general **over-reliance on aspirin**, despite evidence that it is ineffective at preventing AF-related stroke.[27]
- There is **under-treatment** of patients at greatest risk of stroke[52;70;91;92] as well as and **over-treatment** of patients who are not at increased risk of stroke. [52;69;70;76;98;99]
- **Older patients, particularly older women**, are most likely to be under-treated, despite being at greater risk of stroke. [75;76;92;100;101]

2: KEY FINDINGS FROM THE EUROPEAN ATLAS (CONT'D)

Better information is needed for patients, along with a patient-centred, coordinated approach to care

- Many AF patients have **a poor understanding of their condition,** their increased risk of stroke and the purpose of OAC therapy.[35;102-104] Physicians have suggested that the information available to AF patients is poor compared to other conditions.[23]
- **Health professionals other than cardiologists** (GPs[105,83], nurses, geriatricians[106], and pharmacists[107]) are likely to play a growing role in the management of AF patients in years to come.
- **Some countries are looking at nurse-led AF care** to offer patient-centred care to AF patients, with specialist nurses playing a coordinating and supportive role to patients throughout their care.[108]
- **Integrated, multidisciplinary approaches to care** have been implemented successfully in a number of countries[108] and shown to improve coordination between primary and secondary care physicians and help break down professional silos.
- In several countries, guidelines on the management of AF have been drafted by primary care professionals and **joint guidelines** between geriatricians and cardiologists exist in France.[106]

A poor evidence base and the more reliable epidemiological and economic data

- There is a general **lack of reliable data** on AF and AF-related stroke across Europe.
- Only three countries (Germany, Latvia and Estonia) have invested in dedicated registries for AF.
- Very few countries have reliable estimates of the proportion of strokes due to AF.[17;47;109-117]
- The prevalence of **AF-related stroke is increasing** due to the ageing of the population.[32]
- Stroke poses a considerable burden on our societies[3;9;118-132], but estimates of the costs of AF-related strokes are lacking in most countries, including Eastern Europe and the Baltic region, where the public health burden of stroke is greatest.
- What data do exist suggest that AF-related strokes are the most debilitating, fatal and expensive strokes.[123;124;130;133-138]

3: SUMMARY RECOMMENDATIONS

1

Targeted policies and resources to enable the prevention of AF-related stroke

- **Global, regional and national policy leaders** should consistently **recognise AF as a major risk factor for stroke** alongside other 'conventional' risk factors such as smoking, high blood pressure, poor diet and physical inactivity.
- **Governments** should create **national programmes focused on AF** (as exist for myocardial infarction, diabetes, and oncology).
- **Policymakers** should also accord AF and AF-related stroke **due priority in all relevant policy frameworks** – e.g. on chronic diseases, cardiovascular disease prevention and healthy ageing.

2

Greater public awareness and understanding of AF and the increased risk of stroke with AF

- **Patient organisations and professional societies** should be encouraged to lead **targeted, hard-hitting awareness campaigns** to improve public understanding that AF is a major risk factor for stroke and that all patients with AF should receive appropriate OAC therapy to help reduce their risk of stroke.

3

Improved detection of AF and integration of pulse checks into clinical practice

- **Primary care physicians and specialists** should **screen** all their patients over the age of 65 opportunistically for AF.
- **Governments and health insurance bodies** should integrate **manual pulse checks** into national health checks.

4

Appropriate anticoagulation therapy for every AF patient at increased risk of stroke

- **Patient organisations and professional societies should work with health professionals** to develop **educational tools and resources** to help physicians implement guidelines in practice, in terms of assessing all AF patients for their risk of stroke and offering all patients except those at very low risk of stroke the most effective OAC therapy. Tools targeting primary care physicians are particularly needed.
- **Health care system leaders** should develop **local quality improvement frameworks and centralised standards of care** to be implemented at a local level, and particularly in primary care, to reduce heterogeneity in the provision of OAC therapy to AF patients and ensure that best practice becomes embedded into local practice.

5

Patient-centred care and clear information to patients

- **All health professionals** should foster **a patient-centred approach to care**, encourage greater **patient engagement and patient education**.

6

A whole-system approach to the prevention of AF-related stroke

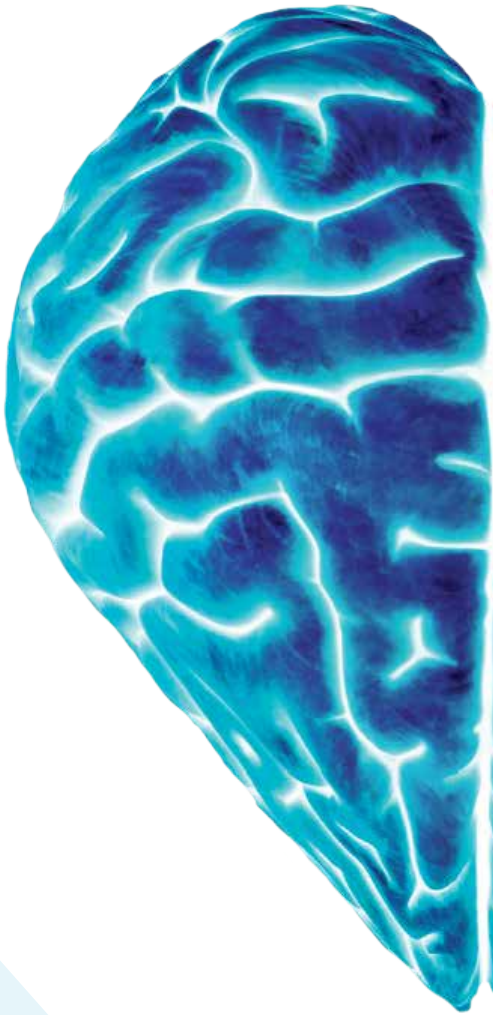
- **Health professionals** should work together and learn from other chronic diseases to identify successful models of **multidisciplinary, integrated care** that may help break down professional silos.

7

Better data to guide policy

- **Governments, research institutes and professional societies** should invest in the **systematic collection of epidemiological and economic data** on AF and AF-related stroke. This will ensure that policymakers are equipped with the most reliable and up-to-date data possible to guide policies and target resources appropriately.

THE ROUTE MAP FOR CHANGE IN THE PREVENTION OF AF-RELATED STROKE



The Routemap for Change is composed of 8 sections, a Case for Change followed by 7 priority areas for action:

The Case for Change
This section provides a brief overview of AF, how it may lead to stroke, its burden on society, the current best practice recommendations and what barriers exist to implementing these in practice. It is intended to be a useful overview and supporting brief to all of the 7 priorities for action.

The **Priorities for Action** present key avenues for change for policy makers, drawing from key findings from across Europe contained in the European Atlas, and supported by Case studies of what has worked well in different countries.

Priority 1: Targeted policies and resources to enable the effective prevention of AF-related stroke

Priority 2: Greater public awareness and understanding of AF and the increased risk of stroke with AF

Priority 3: Improved detection of AF and integration of pulse checks into clinical practice

Priority 4: Appropriate anticoagulation therapy for every AF patient at increased risk of stroke

Priority 5: Patient-centred care and clear information to patients

Priority 6: A whole-system approach to the prevention of AF-related stroke

Priority 7: Better data to guide policy and inform clinical management

The Case for Change:

THIS SECTION PROVIDES:

- A BRIEF OVERVIEW OF:
  - AF
  - HOW IT MAY LEAD TO STROKE
  - ITS BURDEN ON SOCIETY
- CURRENT BEST PRACTICE RECOMENDATIONS
- WHAT BARRIERS EXIST TO IMPLEMENTING RECOMENDATIONS IN PRACTICE.

i. What is atrial fibrillation (AF)?

Atrial fibrillation (AF) is a condition in which the heart beats irregularly. It is the most common heart rhythm disorder affecting close to 2% of the general population,[2;10] or around 10 million people in the EU.

The risk of developing AF is one in four after the age of 40.[12] Some 70% of cases of AF occur in individuals aged 65-85 years and the risk of AF increases with age.[11]

STROKE

- 1.8 million new cases per year in the EU[1]
- 624,000 deaths per year in the EU.
- 8% of deaths in men, 10% of deaths in women in the EU[140]
- A leading cause of adult disability[141]
- Cost of €38 billion per year in the EU[5]

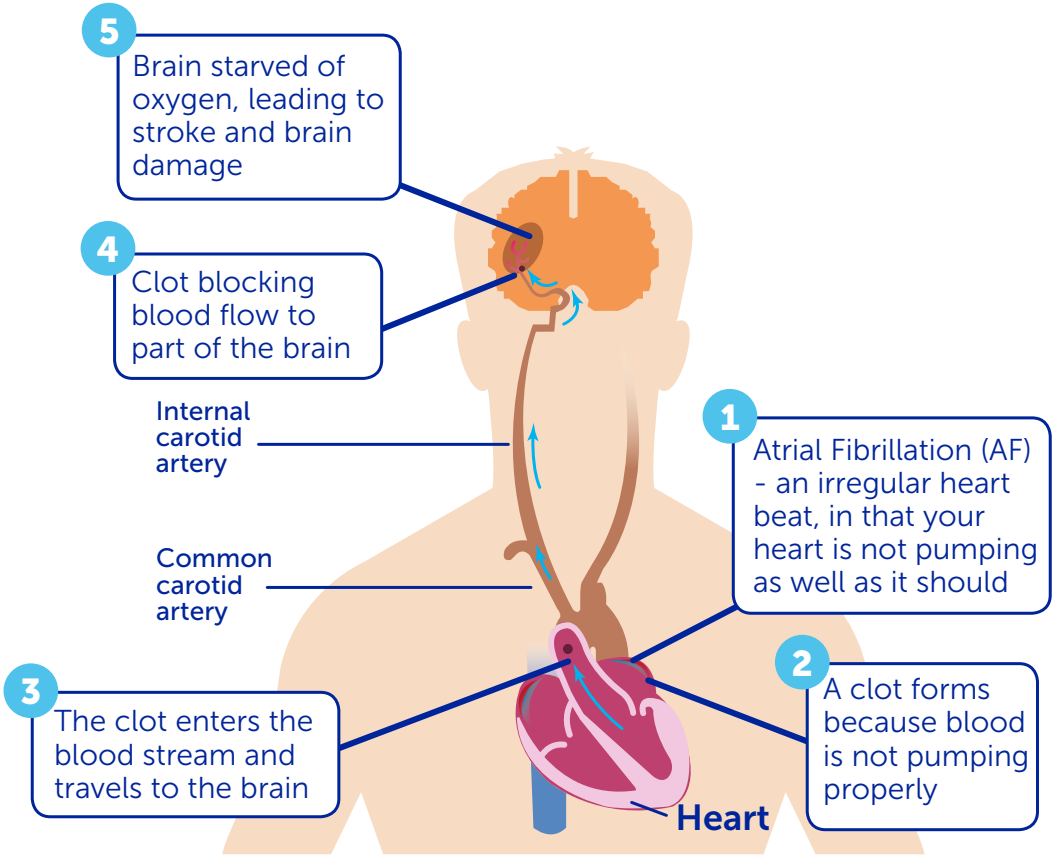
AF

- Close to 10 million people in Europe
- Affects 2% of the population[2;10]
- Prevalence set to at least double by 2050 [2;22]

AF-RELATED STROKE

- Close to 360,000 new cases per year in the EU[1;2]
- 1 in 5 strokes is due to AF[2]
- AF-related strokes are the most debilitating and expensive strokes[2;142]

Figure 1: *How AF can lead to stroke*



1 in 5 Strokes is due to AF, and AF-related strokes are the most debilitating strokes

ii. How is AF linked to stroke?

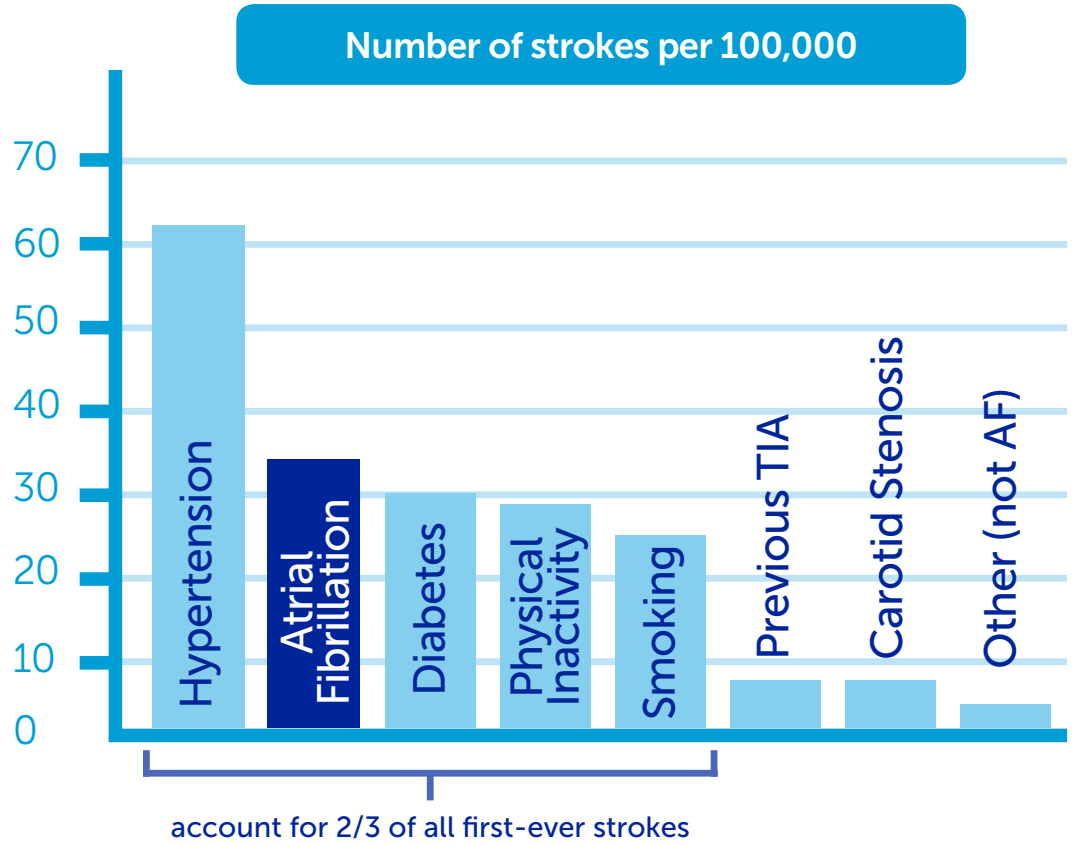
AF is the second most important risk factor for stroke after high blood pressure.[15]

Because the heart beats irregularly in AF, blood does not flow as easily through the heart's chambers, and as a result blood clots may form there, eventually travelling through the arteries to lodge in the blood vessels of the brain. In a stroke, the blood clot deprives parts of the brain of oxygen, severely damaging any affected tissue.

One in every five strokes is due to AF[2] – and this figure rises to one in three after the age of 80.[13;14]

AF increases the risk of stroke by a factor of five – more than any other cardiovascular condition.[13]

Figure 2: ***AF is one of the "big five" risk factors for stroke, along with high blood pressure, diabetes, physical inactivity and smoking:***



Adapted from Apslund 2003[15]

iii. Why should AF-related stroke be a priority for policy makers?

The clinical and economic burden posed by AF-related strokes is staggering. Stroke poses a considerable burden on people affected and their families in terms of disability, lost productivity and impact on quality of life.[3-7;143] It also imposes a huge cost to Europe's health and social care systems and to society at large, estimated as ***€38 billion*** in the EU[5] and ***€64 billion*** every year in Europe as a whole.[3]

AF-related strokes are the most deadly, debilitating and expensive strokes: they have twice the mortality rate,[16;17] have a higher chance of recurrence[16], lead to more permanent disability[118;19] and cost 1.5 times more than strokes not due to AF.[2]

AF and stroke are on the rise. The prevalence of AF is expected to at least double by 2050 due to the ageing of the population and improved survival from other heart conditions.[22;2] Also, despite falling stroke mortality in many countries, the total number of people affected by stroke (i.e. stroke survivors) will increase in years to come.[1]

As a result, the number and burden of AF-related strokes will continue to increase unless effective prevention measures are implemented across Europe.

iv. How can we prevent AF-related strokes?

The most highly regarded, up-to-date European guidelines on the management of AF are the European Society of Cardiology (ESC) 2012 guidelines.[20] Key recommendations pertaining to the prevention of AF-related stroke are:

1. **All patients over the age of 65 should be screened opportunistically** (e.g. when presenting to their doctor for care) for AF by pulse checking, with confirmation by ECG as needed.[20]
2. **All patients with AF should be assessed for their risk of stroke**, using a validated stroke risk stratification system.[20]
3. **All AF patients should be offered effective oral anticoagulation (OAC) therapy** to help reduce their risk of stroke, except those at a truly low risk of stroke.[20]
4. **The decision to prescribe any OAC therapy requires a careful balance** between the potential benefits (stroke prevention) and risks (increased risk of major bleeding) of therapy for each patient - as well as the patient's preferences and values.[23;24]
5. **In many patients, non-VKA (or novel) anticoagulation therapy (NOACs) should be considered as broadly preferable to vitamin K antagonists (VKAs),** which have been the standard of care for OAC therapy for 60 years, as a choice of OAC therapy for patients.[20]

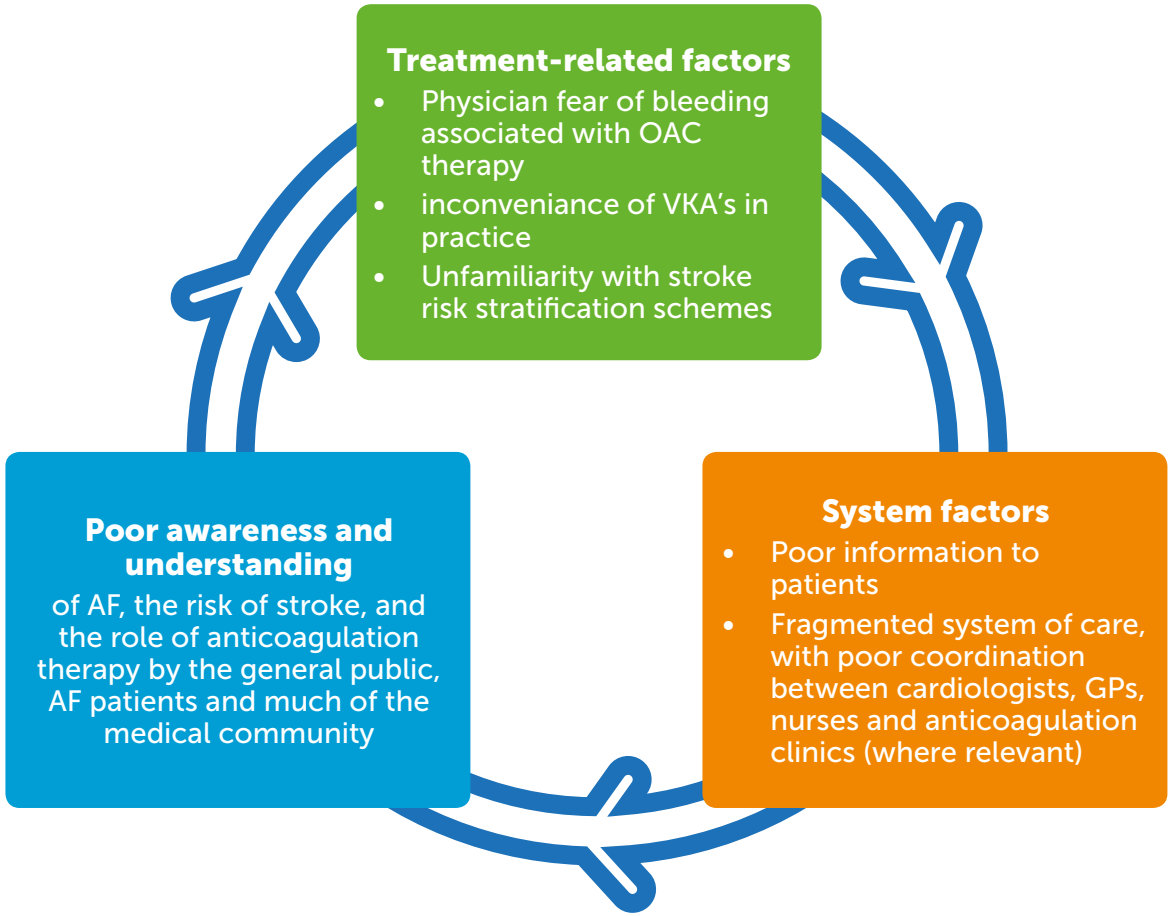
These recommendations are described in more detail in the Special Briefing section.

v. What happens in practice?

Unfortunately, there is widespread evidence that **existing guidelines are poorly implemented in practice**: AF is under-detected, AF patients are often not assessed for their risk of stroke and only about 50-60% of AF patients receive OAC therapy in accordance with clinical guidelines.[25;26]

It is important to recognise that **a number of factors contribute to the inadequate prevention of AF-related strokes.** Physicians may be reluctant to administer OAC therapy to patients due to their fear of major bleeding, or for other treatment-related factors based on their experience with VKAs.[30-33] In addition, poor awareness and understanding of AF, of the risk of stroke or the role of OAC therapy by many AF patients[35] and physicians,[34] and system-related factors such as poor coordination of care, and lack of a patient-centred approach[21] also play a role.

Figure 3: ***Factors that contribute towards inadequate prevention of AF-related stroke***



vi. *Special briefing: The ESC 2012 guideline recommendations on the prevention of AF-related stroke:*

a. Assessing the risk of stroke in AF patients:

There are two main well validated risk stratification schemes for stroke: $CHADS_2$[144] and CHA_2DS_2-VASc.[145] Both of these are scoring systems use that data that are readily available in all patients, such as age and medical history, and have been designed to be easy to use in all clinical settings.

The major international guidelines from the European Society of Cardiology and the American Heart Association/ American College of Cardiology/HRS[146] recommend the use of the CHA_2DS_2-VASc system.[145] However, its predecessor the $CHADS_2$ system is also still commonly used in clinical practice.

b. The role of OAC therapy in the prevention of AF-related stroke

There have, traditionally, been several approaches available to prevent AF-related stroke (see box below). The 2012 ESC guidelines recommend that **oral anticoagulation therapy (OAC therapy) be given to all AF patients except those at very low risk of stroke, in whom no therapy is recommended.**[20]

These recommendations differ from previous guidelines in several important respects:

- **They advocate a more inclusive approach to anticoagulation therapy**, whereas previous guidelines limited its use to patients at high risk of stroke.
- **They recommend that, in many patients NOACs are 'broadly preferable' to VKAs** if they are used as in published clinical trials.
- **They recommend limiting the use of aspirin and other anti-platelet drugs** to patients who refuse any OAC therapy, whereas previous guidelines included it as an option for lower-risk patients.

vi. *Special briefing: The ESC 2012 guideline recommendations on the prevention of AF-related stroke: (cont'd)*

Available approaches for the prevention of AF-related stroke:

1. Oral anticoagulation (OAC) therapy, which include:

- **Vitamin K antagonists (VKAs)**, such as warfarin, which has demonstrated a reduction of stroke of up to 64% in clinical trials.[147] VKAs have been the standard of care for the past 60 years. However, they have a number of limitations:[10;35;148] they are only effective within a very narrow therapeutic window, outside of which patients are either at increased risk of stroke or of bleeding, and require routine monitoring and frequent dosing adjustments. These limitations have contributed to their under-use in clinical practice.[25;26;149]
- **Non-VKAs, commonly referred to as novel oral anticoagulants (NOACs):**[1] NOACs have demonstrated promising results in terms of stroke prevention and bleeding risk compared to warfarin in clinical trials,[150-153] they offer fixed dosing and have a wide therapeutic window, precluding the need for routine monitoring.[154-156] However, these agents have only received a license for use in clinical practice in the last few years and physicians need to familiarise themselves with their use in specific clinical situations.[157]

2. Antiplatelet drugs:
The most common antiplatelet is acetylsalicylic acid (or aspirin). Aspirin is less effective than VKAs at reducing stroke and has a similar risk of bleeding,[147] therefore it is no longer considered a suitable option for preventing AF-related stroke.[20] Another commonly used antiplatelet agent is clopidogrel.[158] The combination of aspirin and clopidogrel is more effective than aspirin alone for the prevention of AF-related stroke, however it does present an increased risk of bleeding.[159]

3. Surgical or catheter-based removal or occlusion of the source of the blood clot (eg. left atrial ablation)[160]: These approaches tend to be used in a limited number of patients at high risk of thromboembolism and stroke, but for whom OAC therapy is contraindicated.

[1]At the time of writing this report, only apixaban, dabigatran etexilate and rivaroxaban are licensed for use in patients for stroke prevention in atrial fibrillation in Europe.

Priority 1:

TARGETED POLICIES AND RESOURCES TO ENABLE THE EFFECTIVE PREVENTION OF AF-RELATED STROKE

Case studies for Priority 1

- The full integration of AF and AF-related stroke across health policy: the Irish example
- The first National Heart Day: a political call to action on heart disease from the Alliance du Coeur

Priority 1: Targeted policies and resources to enable the effective prevention of AF-related stroke

What we know:

AF has often been overlooked as a risk factor for stroke by policymakers. For example, the WHO 2011 Global Atlas on Heart Disease and Stroke fails to include AF in its list of risk factors for stroke[161] and focuses instead on 'conventional' risk factors such as high blood pressure, smoking, physical inactivity and poor diet. This is worrying, as AF increases the risk of death from stroke more than each of these other factors.[16]

Why is this important?

National and regional governments have the authority to drive the strategic, system-wide approaches needed to prevent AF-related stroke and may provide a powerful steer to healthcare systems to implement these approaches in practice.

Key findings from the European Atlas:

- Only 2 countries in the EU (Ireland and the UK) have a **national plan targeting the prevention of AF-related stroke.** Only 10 (Bulgaria, Czech Rebublic, Estonia, France, Hungary Ireland, Poland, Portugal, Spain, UK) have a national stroke strategy.
- **AF and AF-related stroke rarely feature in other policy frameworks,** such as chronic disease prevention or healthy ageing, despite their growing prevalence, particularly in the older population.
- **Funding** for stroke research is poor compared to other conditions.[36]
- **Important gaps in acute stroke care** remain, particularly in Eastern Europe and Baltic countries, which suffer from the greatest stroke burden in Europe.[37]

Avenues for change:

- Global policy reports should take the lead and **recognise AF as a major risk factor for stroke** alongside other 'conventional' risk factors such as smoking, high blood pressure, poor diet and physical inactivity.
- National governments should develop **targeted action plans** on the prevention of AF-related stroke. *(see **Case study 1:** The full integration of AF and AF-related stroke across health policy: the Irish example)*
- Greater prominence should be given to AF and AF-related stroke in **relevant health policy frameworks** (eg. on chronic disease, cardiovascular health, and healthy ageing) *(see **Case study 2:** The first National Heart Day: a political call to action on heart disease by the Alliance du Coeur - France)*.
- **Targeted funds** for more research and care for stroke are needed to reflect the burden it poses on society.

> "AF is a major risk factor for stroke, but it is simply not on the political agenda. We are focusing increasing on prevention, chronic conditions, and healthy ageing – and yet AF is conspicuously absent from these policy frameworks and it has yet to enter into the prevention dialogue."
>
> ***(Glyn Davies, Member of the All Party Political Group on AF (APPG-AF), UK***

SUMMARY FINDINGS IN MORE DEPTH:

Very few countries have national policies targeting AF-related stroke

Only 2 countries in Europe (the UK and Ireland) have a national plan targeted at the prevention of AF-related stroke. Ten countries (Bulgaria, Czech Republic, Estonia, France, Hungary, Ireland, Poland, Portugal, Spain, UK) have national stroke strategies, which in some cases include specific sections on AF-related stroke.

Table 1: *Overview of existing policies on stroke and AF-related stroke (EU27 + Norway, Switzerland and Turkey)*

Have a national stroke strategy or plan	Have a national plan on the prevention of AF-related stroke
Bulgaria, Czech Republic, Estonia, France, Hungary, Ireland, Poland, Portugal, Spain, UK	Ireland, UK

AF and AF-related stroke rarely feature in national health plans and policy frameworks

Given its growing prevalence with the ageing of the population, one would expect AF to feature as a priority health topic within policies on healthy ageing and chronic disease prevention. **Yet very few countries appear to consider AF, or AF-related stroke in their national policies.** One notable exception is Ireland. *(see Case study 1)* France also provides an interesting case study of how the prevention of AF-related stroke has been integrated into a White paper on heart disease and a political call to action on heart disease in general. *(see Case study 2)*

SUMMARY FINDINGS IN MORE DEPTH:

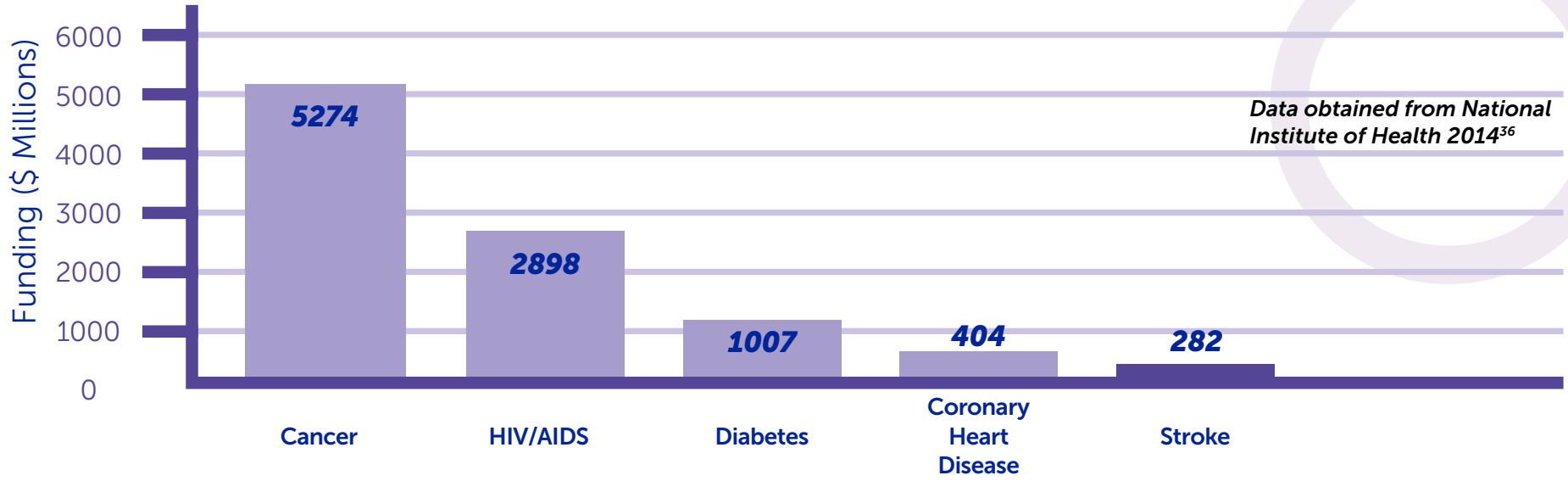
Investment in stroke research is poor compared to other conditions

Funding for research on stroke is low compared to other common conditions. For example, data from the United States suggests that research funding for stroke is about one tenth of funding for other chronic conditions (**Figure 4**).[36] Similarly, in the UK £71 of total goverment and charity research goes towards stroke research for every £1 million of health and social care costs attributable to it – as compared to £129,269 for cancer and £73,153 for coronary heart disease.[163]

Important gaps in the provision of acute stroke care remain

Persistent gaps in the provision of acute stroke services still exist in many countries, despite important improvements in recent years. This is particularly the case in Baltic and Eastern European countries, where the burden of stroke is greatest.[37;56;162] For example, only 30-40% of ischaemic stroke patients in Estonia arrive at the hospital within 3 hours, and only 5% receive intravenous thrombolysis.[56]

Figure 4: ***Relevant research funding for stroke as compared to other conditions in the United States[36]***



CASE STUDY 1: IRELAND

THE FULL INTEGRATION OF AF AND AF-RELATED STROKE ACROSS HEALTH POLICY

Overview

The Irish Government has provided for AF-related stroke prevention as a core component of its national strategy for cardiovascular health and related improvement programmes, much of which is being developed in close collaboration with the national Stroke Council led by the Irish Heart Foundation.

Timescales

- National Cardiovascular Health Policy: 2010-19[164]
- National Stroke Clinical Care Programme: ongoing
- 'Model of Care' position paper: 2012[165]

Approach

AF and AF-related stroke prevention feature prominently in several layers of Irish health policy, from national strategy to delivery and implementation.

The overarching government strategy 'Changing Cardiovascular Health: National Cardiovascular Health Policy 2010-2019' incorporates both stroke and the prevention, detection and management of AF. In particular, it outlines the need for more effective anti-coagulation therapy in AF in the primary care setting.[164] This is coupled with specific recommendations calling for the formalisation of clinical leadership and new joint care standards in anti-coagulation between GPs and hospital staff, a national screening programme for AF, and new integrated anticoagulation services spanning primary care, secondary care and community services, including new AF nurse specialists, new information systems and the collaboration with pharmacies amongst other measures.

Ireland has a National Stroke Programme led by the Irish Health Service Executive (HSE).[165] This includes a National Stroke Clinical Care Programme which aims to implement many of the stroke goals contained in the national cardiovascular health strategy, developed in close collaboration with the Irish Heart Foundation's influential Stroke Council.

✓ *TARGETED POLICIES AND RESOURCES*

What has been achieved?

- The Programme published a comprehensive '**Model of Care**' position paper in 2012,[165] setting out how stroke outcomes will be improved through the development of prevention, treatment and rehabilitation services, including anticoagulation in AF-related stroke.[71]
- Several improvement initiatives are laid out, including launching a **national 'gap analysis' of anti-coagulation in AF**, and the development of new standards of care in anti-coagulation, and efforts to promote patient-centred care, early detection of AF and patient and professional education.[165]
- Delivery and implementation efforts are supported by the creation of a **new AF Working group** spanning representatives from Primary Care, Cardiology, Haematology, Pharmacy, Drugs and Therapeutics, Neurology, Geriatric Medicine, and Public Health.
- Ireland is implementing a stroke register in each hospital admitting acute stroke patients.[165]

CASE STUDY 2: FRANCE

THE FIRST NATIONAL HEART DAY: A POLITICAL CALL TO ACTION ON HEART DISEASE FROM *THE ALLIANCE DU COEUR*

> "Cardiovascular disease is a major public health problem. In France, AF causes a stroke every 20 minutes – and this is the message that we must build into all public awareness campaigns on the prevention of heart disease to ensure that everyone is aware of the risks linked to AF and that we all take the necessary measure to reduce these risks."
>
> ***(Philippe Thébault, President, Alliance du Coeur)***

Overview

A national day devoted to heart disease, organised by the Alliance du Coeur on Valentine's Day, to call for the publication of a White Paper on heart disease (*'le Plan Coeur'*) advocating prevention of cardiovascular disease in all of its forms and supported by an ongoing awareness campaign.

Timescales

The awareness campaign will take place over several years, namely during National Heart Day (*'Journée du Coeur'*) which will take place again in 2015. The national plan (*'Plan Coeur'*) should be submitted to the government at the end of 2014.

Approach

L'Alliance du Cœur, a national alliance consisting of 16 charities and one patient organisation, has led a campaign for the past 20 years calling for better prevention and greater support for people suffering from heart disease and stroke. They had led an active campaign on prevention of AF-related stroke for several years, the key message being that a stroke due to AF occurs every 20 minutes in France.

In 2012, the Alliance partnered with the French cardiology society (*Fédération Française de Cardiologie*), to propose a national cardiovascular disease strategy (*'le Plan Coeur'*), with the aim to develop a White Paper on heart disease that will be submitted to policymakers at the end of 2014. This year, the Alliance organised the first National Heart Day (*'Journée Nationale pour le Coeur'*) on Valentine's Day. This was an interactive event in which all stakeholders involved in heart disease -- patients, health professionals, policymakers – were linked via live streaming across three cities: Paris, Bordeaux and Strasbourg. The aim of the event was to raise awareness of the wealth of ongoing local initiatives on heart disease and to demonstrate the commitment of local member organisations towards the creation of a national strategy on cardiovascular disease (*'Plan Coeur'*).

✓ *TARGETED POLICIES AND RESOURCES*

What has been achieved?

- Improved awareness of cardiovascular disease, including AF and AF-related stroke
- Integration of AF and AF-related stroke into a broader cardiovascular policy document
- A concerted call for greater political engagement on cardiovascular disease (including AF and AF-related stroke) as part of a broader commitment towards public health, prevention and chronic diseases.

Links/References

http://www.alliancecoeur.fr/
http://lajourneeducoeur.org/
http://www.fedecardio.org/plateforme-plancoeur/

Contact:
contact@alliancecoeur.fr

Priority 2:

GREATER PUBLIC AWARENESS AND UNDERSTANDING OF AF AND THE INCREASED RISK OF STROKE WITH AF

Case studies for Priority 2

- Bate Bate Coração Association
- The Irish Heart Foundation Awareness Campaign
- The Act F.A.S.T Campaign

Priority 2: Greater public awareness and understanding of AF and the increased risk of stroke with AF

What we know:

AF is a common condition, **and the lifetime risk of developing AF is one in four over the age of 40.**[12] Yet very few people have heard of AF, and poor awareness and understanding of AF and the risk of stroke with AF is a major hurdle to overcome across Europe.[29;30]

Why is this important?

AF often does not present with any symptoms – so many people may have AF without knowing it, meaning they will miss out on treatment and unnecessarily run a much higher risk of having a stroke.

Key findings from the European Atlas:

- There is **poor awareness and understanding of AF** in the general population,[38;41] especially among older people.[40]
- Most people **do not know that AF is an important risk factor for stroke.**[38;41-45]
- People are **more aware of other risk factors for stroke** than AF.[45]

Avenues for change:

- Development of **patient organisations** and professional societies as a key player in providing information *(see **Case study 3:** Bate Bate Coração-Portugal)*.
- **Targeted, hard-hitting awareness campaigns** are needed to educate the general public about AF, encourage them to regularly check their pulse, and communicate clearly the fact that AF is a major risk factor for stroke and that appropriate OAC therapy may help reduce their risk of AF-related stroke *(see **Case study 4:** the Irish Heart Foundation awareness campaign).*
- Similarly, hard-hitting campaigns to **enable people to recognise the signs of stroke** and encourage them to seek immediate treatment are needed, particularly in countries where awareness may be poorer and the burden of stroke is greatest *(see **Case study 5:** the F.A.S.T campaign).*

> "People understand high blood pressure. They understand cholesterol. They don't understand heart rate or pulse."
> ***(Mary Baker, European Brain Council)***

SUMMARY FINDINGS IN MORE DEPTH:

There is poor general awareness and understanding of AF and its role as a major risk factor for stroke

Evidence from a number of countries confirms that there is very **poor general awareness of AF,**[38-41] especially among older people.[40]

There is also **poor understanding that AF is a major risk factor for stroke**[38;41-45] – as compared, for example, to knowledge of the role played by high blood pressure.[45]

Table 2: *Evidence of poor general awareness and understanding of AF and of the increased risk of stroke with AF*

Country	Study Design/Setting	Findings
Belgium	General population survey run by Ligue Cardiologique Belge (2012)[41]	40% of the population had never heard of AF Only 11% could describe AF accurately Over half of respondents knew that stroke was the most common complication of AF.
Bulgaria	Surveys carried out amongst residents aged 45-74 in North East Bulgaria (2000-3)[44]	Knowledge of AF as a stroke risk was zero in rural and urban populations.
Estonia	Two surveys of the general population in Tartu and Tallin (2012)[45]	Just over 50% of respondents knew that cardiac arrhythmia was a risk factor for stroke, whereas 95% were aware that high blood pressure was a risk factor.[45]
France	Population survey	At least 25% of the population are poorly informed about stroke and what causes stroke[166]
Germany	General population survey conducted in adults aged 40 and over in 3 large German cities under the auspices of AFNET (2011)[38]	Over a quarter of the population over 40 had never heard of AF. Only half of the population were aware of the increased risk of stroke with AF.
Ireland	Survey conducted before the launch of an awareness campaign in 2013[40]	38% of the population were unaware of AF, and this figure reached 64% in 65-70 year olds.
Italy	Survey conducted in Northern Italy[167]	50% of people did not know much about stroke or about available anticoagulation therapy
Portugal	Survey conducted by local patient organisation[39]	40% of Portuguese are unaware of the symptoms associated with cardiac arrhythmias. 89% of Portuguese does not identify arrhythmias as a possible cause of death.
Switzerland	Survey conducted by the Swiss Heart Foundation[42]	40% of people did not know that AF could lead to stroke and only one third could identify the signs of someone having a stroke
UK	AF Association, AF week survey (2013)[43]	One in three adults is unaware of the high stroke risk caused by AF (AF)

CASE STUDY 3: PORTUGAL

BATE BATE CORAÇÃO ASSOCIATION

Overview

A range of public educational events and pulse testing in everyday settings, including major events supported by football clubs. Strong engagement of government and civil service in public debate on policy and provision for AF.

Timescales

The association was formed in 2011, following the Bata Bate Coração campaign in 2010, and has been active since.[168]

Resource Implications

The 'Sinta o seu pulso' campaign relies in part on volunteer healthcare professionals. Bate Bate Coração Association is supported by the Portuguese Association of Arrhythmology, and the Portuguese Institute and Heart Rhythm Association of Patients with pacemakers and implantable defibrillators (ICDs)[39]

Approach

The Bate Bate Coração Association has developed several key programmes to deliver on its mission of raising awareness and knowledge of cardiac arrhythmia. As part of the '*Sinta deu pulso*' (Know Your Pulse) campaign, volunteer doctors, nurses and technicians regularly teach members of the public to check their pulse in everyday settings such as shopping malls, lunch breaks in workplaces, universities, and musical events. Public seminars are also held where healthcare professionals talk about AF prevalence, co-morbidities and treatment options.

Bate Bate Coração has kept a high profile in public affairs and national policy, communicating frequently with politicians and the Health Commission in the Portuguese National Parliament. Bate Bate Coração's work has been recognised by leading healthcare commentators, receiving a first prize honour by the not-for-profit group 'Hospital do Futuro' in 2011.[339]

ASSOCIAÇÃO BATE BATE CORAÇÃO

Links/References

http://www.batebatecoracao.pt/

✓ *GREATER PUBLIC AWARENESS*

What has been achieved?

- Regular public outreach on pulse checks (see 'Approach')
- Major event held in 2010 at a key football match in the Estadio da Luz in partnership with SL Benefica.[168]
- Specialist activities for children and families provided through the 'Coração Tic Tac' project.[168]
- Website with in-depth and regularly updated information on cardiac arrhythmias and public discussion forums. Presence on Facebook.
- '*Coversas con Ritmo*' (Rhythm talks) public interactive debate launched in 2012, involving the secretary of state for health and other major public figures
- Petition launched to have November the 12th recognised as National Sudden Death Prevention Day.[168]
- Plenary session organised in national parliament in 2013 on arrhythmia

CASE STUDY 4: IRELAND

THE IRISH HEART FOUNDATION AWARENESS CAMPAIGN

> "It's our job to make people aware of the dangers of undiagnosed AF. Any impactful campaign is bound to create some public fear, because the facts are truly frightening."
>
> *(Chris Macey, Head of Advocacy, Irish Heart Foundation)*

✓ *GREATER PUBLIC AWARENESS*

Overview

A hard-hitting national awareness campaign alerting the public of the magnified risk of stroke associated with AF with a call to action to have regular pulse checks.

Timescales

The campaign was launched in November 2013 – a follow-up campaign is planned for 2014.

What has been achieved?

- Call to action to people over 50 to have regular pulse checks
- Improved awareness in people who have AF of the links between AF and stroke
- Sensitisation of the GP community to the frequency of undetected AF

A full evaluation of the impact of the campaign is forthcoming.

Resource Implications

The campaign was funded by Pfizer and Bristol-Myers Squibb.

Links/References

http://www.irishheart.ie/iopen24/atrial-fibrillation-awareness-campaign-2013-t-38_1339.html

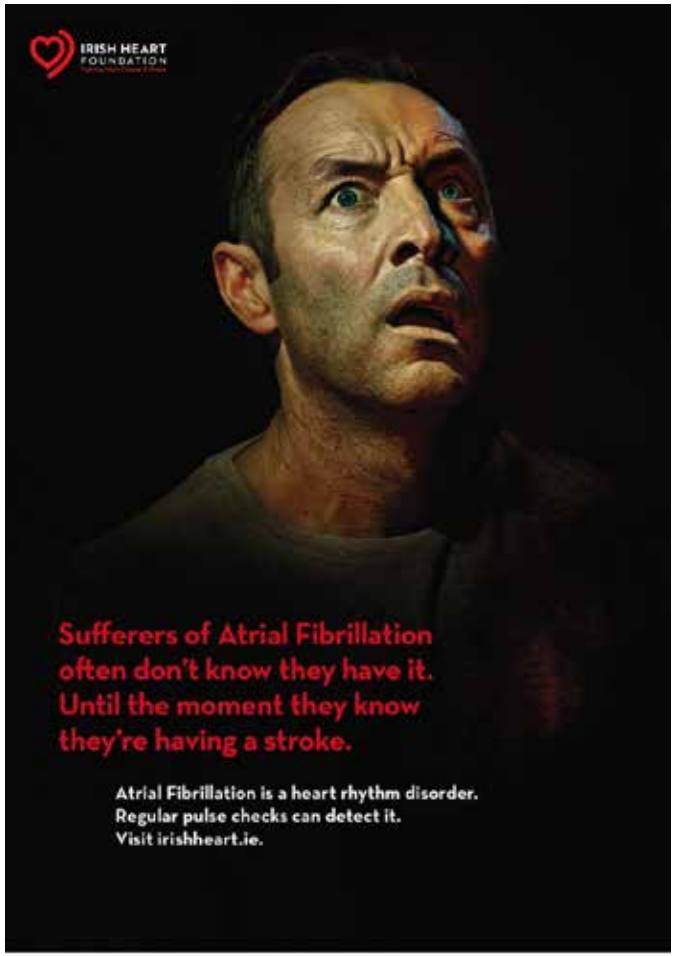
Approach

The Irish Heart Foundation has run a variety of successful stroke-related awareness campaigns in recent years, including F.A.S.T., which trebled knowledge of stroke warning signs among the Irish population.

The need for an AF awareness campaign was established through the North Dublin Stroke Registry. This suggested that 1 in 3 strokes in Ireland was due to AF, a much higher proportion than the 15-20% reported in the European Society of Cardiology guidelines. Surveys also suggested that 74% of the general population were unaware of AF, and that, amongst people who had ECG-documented AF, 38% were unaware that they had an irregular heart rhythm – and this rate was 64% in those aged 65-70.[40] This led the development of the current AF campaign by the Irish Heart Foundation, whose key message was that 'sufferers of AF often don't know they have it, until the moment they know they're having a stroke.'

The campaign urged over 50s to undergo regular pulse checks. The campaign involved an audio advertisement which was broadcast on national and regional radio over four weeks, and hard-hitting posters, flyers, and information booklets were distributed widely to GP practices, hospitals, and health centres. The next phase of the campaign will be focus on the implementation of widespread screening for AF.

Contact:
Chris Macey, Irish Heart Foundation
cmacey@irishheart.ie



Supported By: Bristol-Myers Squibb Pfizer

CASE STUDY 5: UK & OTHER

THE ACT F.A.S.T CAMPAIGN

> "What we found was that by raising awareness of stroke within the general public, this helped put pressure on the system to improve stroke services in general."
>
> *(Joe Korner, External Affairs Director, Stroke Association)*

Overview

The Act F.A.S.T campaign seeks to raise awareness of stroke warning signs amongst the general public and encourage rapid access to acute care in order to reduce the long-term impact of stroke.

Timescales

The campaign was launched in 2009 by the Department of Health in England and has been running annually since, in focused bursts of activity managed by the Department of Health, as well as independent supporting activity from organisations such as the Stroke Association and primary/secondary care organisations.

Resource Implications

In 2004, Professor Gary Ford's team at Newcastle University showed that ambulance paramedics can use the Face Arm Speech Time (F.A.S.T) test to recognise when someone is having a stroke. The study, funded by the Stroke Association, found that paramedics using the F.A.S.T test could identify a stroke just as accurately as specially trained doctors.

This research formed the basis of the national Act F.A.S.T campaign to inform emergency paramedics and the public how to identify the signs of stroke and to treat it as a medical emergency.

Approach

The Department of Health (now Public Health England), a public agency promoting information on health, social care and healthy living, launched a campaign in collaboration with the Stroke Association promoting the Act F.A.S.T acronym. The acronym stands for 'face', 'arms', 'speech', and 'time' (to call 999 and access emergency care) – a memorable 4-point action list proving clear direction for any member of the public in the event of a suspected stroke.

Act F.A.S.T. is supported by a website managed by Public Health England and NHS Choices, with further information, such as patient stories, and an invitation to get involved. It is intended as a 'viral' media campaign, providing public domain resources such as posters, adverts, and video clips for other websites and media sources to feature in support of the campaign.

In 2014, the campaign was delivered primarily through the television advertisement, with supporting campaign activity from external organisations. Further resources were available to download centrally via a public resource centre.

Links/References

http://www.nhs.uk/actfast/Pages/stroke.aspx

Stroke association

✓ *GREATER PUBLIC AWARENESS*

What has been achieved?

- Since the launch of the campaign, there has been an uplift of 54% in stroke related calls to 999, meaning that almost 24,000 people reached hospital within 3 hours of the onset of stroke symptoms
- Awareness of stroke symptoms is currently at 73% in England
- Stroke Association also see an annual uplift in enquiries to their Stroke Information Helpline and F.A.S.T campaign pages on their website

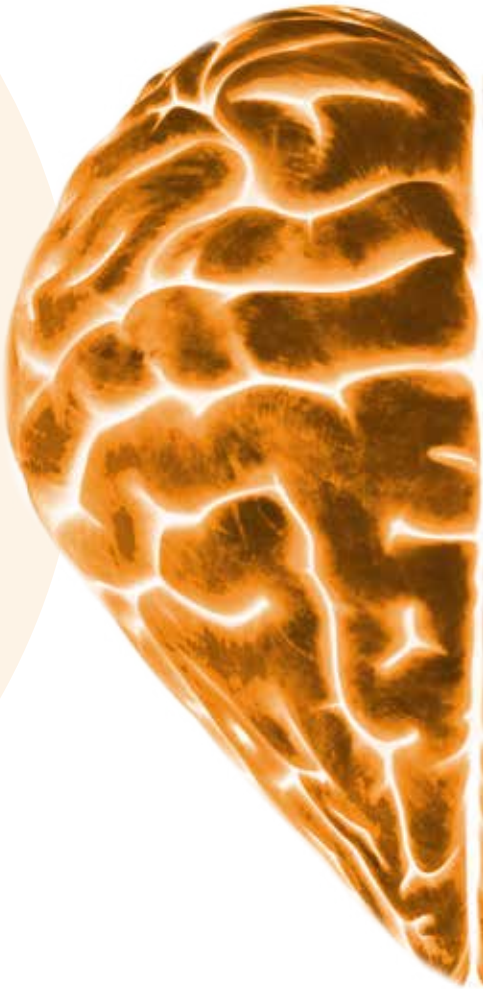
Contact:

http://www.nhs.uk/actfast/Pages/contact-information.aspx
OR stroke@dh.gsi.gov.uk

For further information on the Stroke Association's involvement with the Act F.A.S.T campaign, please contact Laura Harris, Senior Prevention Marketing Officer: *laura.harris@stroke.org.uk*

Priority 3:

IMPROVED DETECTION OF AF AND INTEGRATION OF PULSE CHECKS INTO CLINICAL PRACTICE



Case studies for Priority 3

- Pulse checks in pharmacies
- The Know Your Pulse campaign – UK, China, India, Australia, USA, Uruguay

Priority 3: Improved detection of AF and integration of pulse checks into clinical practice

What we know:

AF often does not present with any obvious symptoms,[10] therefore many cases of AF are thought to only get diagnosed once a person presents to their doctor with a serious complication such as a stroke.[21] In addition, symptoms of AF can come and go, making it sometimes difficult to diagnose. To counter this detection gap, ESC guidelines recommend that all people over the age of 65 should be screened opportunistically for AF,[20] based on clinical trial evidence.

Why is this important?

Adequate detection of AF is a first step in the prevention of AF-related strokes.

Key findings from the European Atlas:

- Country-level data on the prevalence of AF are derived from a number of sources[18;31;33;42;46-64] and are likely to vary in reliability; however, **estimates from many countries suggest that the prevalence of AF may be higher than previously estimated.**[18;31;47;48;51;52;54-56;59;61-63;57]
- There is evidence of **a detection gap of approximately 10-45%** in terms of the number of people who have AF but in whom it is undetected.[31;33;51;62;65;66]
- **Community screening** presents an important avenue for improving the detection of AF, and interesting pilot programmes have been led in many countries.[65;67]
- Yet overall **simple screening tools are being overlooked.** For example pulse checks and have yet to be integrated as part of general health checks, despite the fact that AF generally meets WHO criteria for conditions in which screenign is warranted.[169]

Avenues for change:

- **All patients aged 65 and above should be screened opportunistically** for AF in accordance with ESC guidelines. In particular, people who already present with a long-term medical condition may be good candidates for screening given the higher prevalence of AF in people with other co-morbid conditions.[30]
- **Manual pulse checks should be integrated into national health checks** sponsored by national health organisations or health insurance bodies *(see **Case study 7:** the 'Know Your Pulse' campaign)*
- **Opportunities for community screening should be explored** within each local context – for example in shopping centres, community centres, pharmacies, flu clinics *(see **Case study 6:** screening in pharmacies in Italy).*
- **Incentives to encourage proactive detection of AF** by primary care physicians should be embedded into local framework agreements and remuneration schemes where available in different countries, and supported by targeted professional education to help improve understanding of AF across the entire medical community.

> "The more you look, the more you find"
> ***(Professor John Camm, lead author of the ESC guidelines on the management of AF)***

SUMMARY FINDINGS IN MORE DEPTH:

Country-level estimates of the prevalence of AF suggest that greater numbers of people are affected by AF than previously estimated

The international literature has traditionally suggested that the prevalence of AF is between 1.5-2% of the population.[20] However, **many national estimates of AF prevalence suggest that it may be higher.**[18;31;47;48;51;52;54-56;59;61-63]

(see all available country-level estimates of AF prevalence in Priority 7).

Pulse checks have not yet been integrated into clinical practice

In order to improve the detection of AF, patient organisations and professional societies in a number of countries (eg. Germany, Denmark and UK) have lobbied governments to **include manual pulse checks in the general health checks** offered to patients over a given age. Unfortunately, decisions by governments thus far have been not to include them, despite the fact that AF generally meets the WHO established criteria for screening.[169]

A large proportion of AF cases are undetected – between 10-45% depending on the country

Existing prevalence data are likely to be underestimated as they do not include cases of AF that remain undetected. Exact figures for the number of undetected cases are difficult to obtain, however some estimates have been provided in different countries – these reveal a detection gap of between 10-45% depending on the study.[31;33;51;62;65;66] **(see Table 3)**

Table 3: *Country-level estimates of the detection gap in the prevalence of AF*

Country	Detection Gap (%)
Czech Republic	40%[66]
Norway	11%[62]
Portugal	36%[31]
Spain	10%[33]
Sweden	45% (in 75-76 year olds), 30% of all AF cases[65]
UK	18%[51]

SUMMARY FINDINGS IN MORE DEPTH:

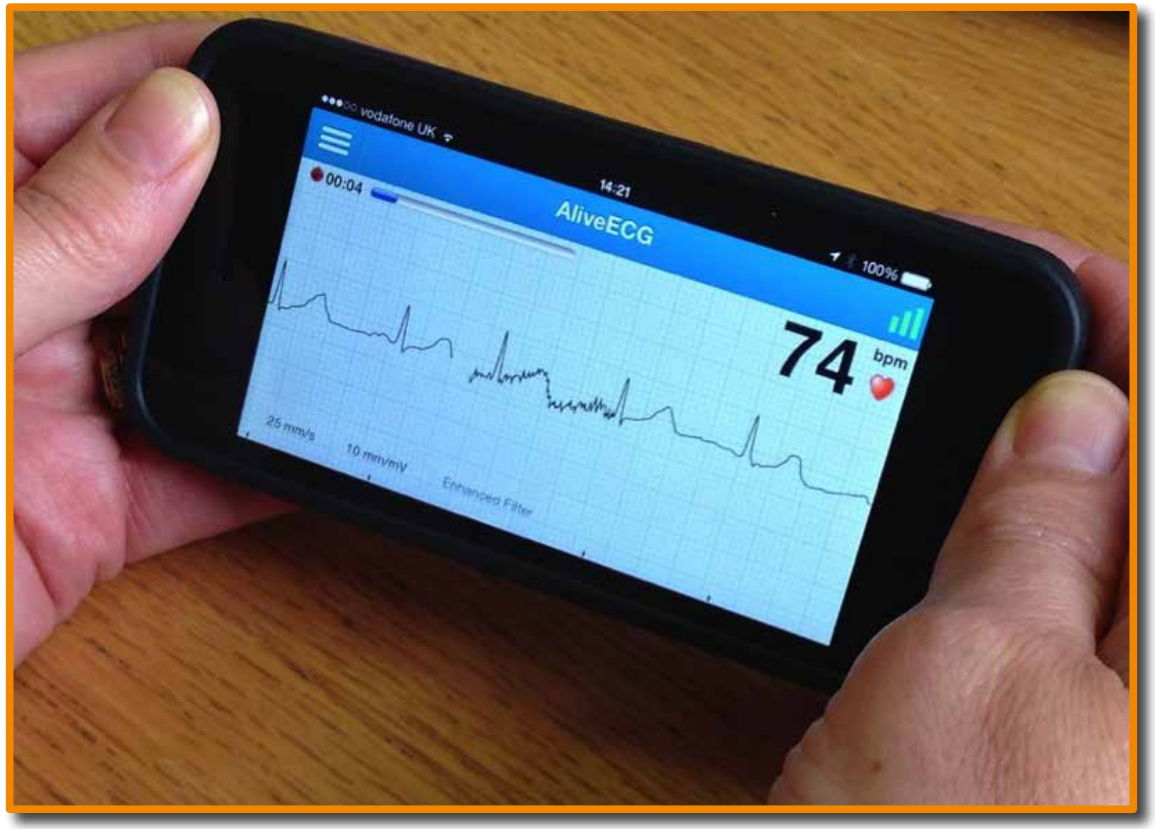
Community screening programmes for AF may help uncover undetected AF

Community screening programmes may be helpful to improve detection of AF.[170] For example in Sweden, a pilot screening study of 75-76 year olds (the STOPSTROKE study) found that **45% of AF cases were undetected.**[65] Extrapolating these findings to population-based figures, the authors suggested that the estimated prevalence rate of 3% in Sweden may be as high as 4-5%.[32;65]

Opportunities for community screening should also be explored within each local context. For example, **screening of people over the age of 65 years during seasonal flu vaccination** has been an effective and economical way of detecting AF in parts of the UK[171], and screening for AF at the same time as high blood pressure in pharmacies has done in pharmacies in Italy and France. *(see Case study 6)*

Technological advances in the form of hand-held ECG devices and iPhone apps (Figure 5) are likely to facilitate community screening in future, and have been shown to be very effective at detecting AF in primary care settings.[67] However, further research is needed into their feasibility and cost-effectiveness if implemented at scale.[170]

Figure 5: *an example of AliveECG, a portable ECG that allows to check one's heart rhythm.*



CASE STUDY 6: ITALY

PULSE CHECKS IN PHARMACIES

> "The general public is still so poorly aware that atrial fibrillation is a major risk factor for stroke. This initiative helps convey the message that people should get their pulse checked and check their blood pressure in efforts to prevent stroke."
>
> ***(Paolo Binelli, President, A.L.I.Ce. Italia)***

✓ *GREATER AWARENESS OF AF AS A RISK FACTOR FOR STROKE*

Overview

Pulse checks are offered alongside blood pressure monitoring for free to the general public in 3000 pharmacies across Italy during the week of World Stroke Day

Timescales

Every year during the week of World Stroke Day (October 29th) – run since 2011

3000 PHARMACIES ACROSS ITALY

Approach

Since 2011, Colpharma has sponsored a screening initiative across 3000 pharmacies in Italy, being the distributor in Italy of MicroLife, which provides the monitoring instruments to pharmacies. The initiative is run under the auspices of A.L.I.Ce. Italia. Individuals are encouraged to check their blood pressure as well as their pulse in order to detect possible problems of high pressure as well as whether they have AF. They are then referred, when necessary, to their family physicians.

Thousands of people participated in the initiatives since 2011, and 5-6% of people assessed were suspected to have AF. In general more than 50% of people identified with AF do not know that this a major cause of stroke.

What has been achieved?

- 3000 pharmacies participated
- Thousands of people over a 1-week period had their pulse checked, and more than 5% of new cases of AF were referred to physicians.
- Increased awareness of AF as an important risk factor for stroke, alongside high blood pressure, has been achieved
- Initiative also replicated in France, in a collaboration with France-AVC (the national stroke patient organisation)

Resource Implications

Funding for the initiative from Colpharma. Provision of blood pressure and pulse check monitoring instruments by MicroLife. Promotion and dissemination of the initiative by A.L.I.Ce. Italia with support.

Links/References

www.aliceitalia.org

A.L.I.Ce. Italia Onlus

Associazione per la Lotta all'Ictus Cerebrale

www.aliceitalia.org

Contact:

Paolo Binelli, Associazione per la Lotta all'Ictus Cerebrale (A.L.I.Ce. Italia)

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CASE STUDY 7: UK & WORLD

THE 'KNOW YOUR PULSE' CAMPAIGN

> "We all know to check our weight, blood pressure, cholesterol, any lumps in case of cancer – yet few of us think to check our pulse. A simple pulse check can identify an irregular heart rhythm – the first signs of diagnosing potential AF. Having a record of your pulse will help your doctor determine whether or not you have AF and put you on effective therapy to help reduce your risk of an AF-related stroke."
>
> ***(Trudie Lobban, MBE, Atrial Fibrillation Association)***

Overview

A broad campaign to encourage people to check their pulse and to promote the inclusion of routine manual pulse checks in clinical practice.

Timescales

Launched in 2009, still running today.

Resource Implications

The campaign has been run by the Atrial Fibrillation Association in the UK and other AF associations in different countries. The campaign has benefited from educational grants from Bayer Healthcare and other private companies.

What has been achieved?

- Improved awareness and understanding amongst the general public of the importance of taking one's pulse as a first step to detecting AF
- Campaign endorsed by the Department of Health in the UK and by leading cardiology societies in other countries
- A powerful political campaign focused on AF, with public events hosted in national parliaments, schools, and other public arena in participating countries

Approach

The Know Your Pulse (KYP) campaign was first launched jointly by the AF Association and Arrhythmia Alliance during Heart Rhythm Week in 2009. Its aim is to raise public and medical awareness of the pulse as one of the most effective ways of identifying potential cardiac arrhythmias. Founded in UK, it now is an ongoing campaign in the UK, Australia, USA, Uruguay, China and India, promoting the need for us all to be aware of our pulse, and encouraging governments to include routine manual pulse checks in clinical practice.

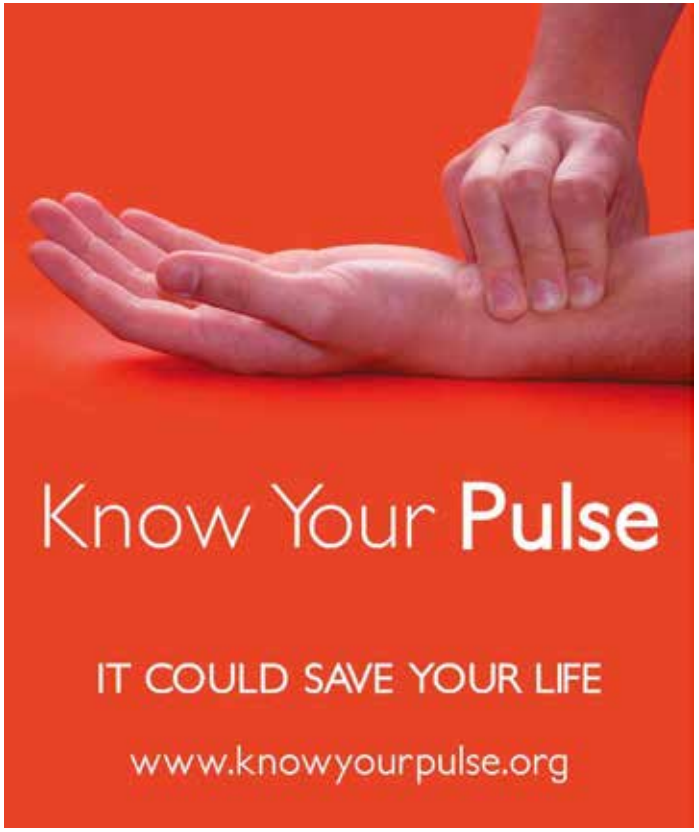
The campaign has involved thousands of events and social media. The campaign website features a dedicated app, 'Know Your Heart Rhythm' and tools (eg. letters to MPs) for individuals to lobby their local politicians to introduce pulse checks to screen for AF in the general health checks and flu vaccination clinics.

Links/References

http://pulse.knowyourpulse.org/

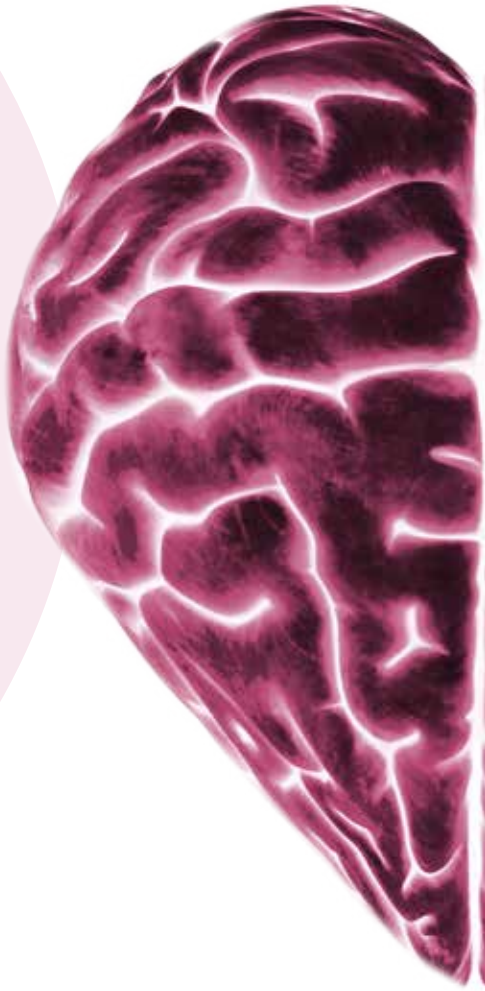
Contact:

kyp@heartrhythmcharity.org.uk



Priority 4:

APPROPRIATE ANTICOAGULATION THERAPY FOR EVERY AF PATIENT AT INCREASED RISK OF STROKE



Case studies for Priority 4

- The Heart of AF programme
- EHRA practical guide to the use of new anticoagulants
- Primary care leadership driving best practice in Bradford

Priority 4: Appropriate anticoagulation therapy for every AF patient at increased risk of stroke

What we know:

The decision to prescribe any given OAC therapy requires **a careful balance** between the potential benefits (stroke prevention) and risks (increased risk of major bleeding) of therapy for each patient - as well as the patient's preferences and values.[23;24]

Evidence suggests that **physicians often overestimate the risk of bleeding** but underestimate the risk of stroke with OAC therapy,[28] and therefore do not offer appropriate OAC therapy to their AF patients.

Why is this important?

The ESC guidelines recommend that **all AF patients except those at very low risk of stroke** be offered the most appropriate anticoagulation medicine to meet their individual needs.[20]

Key findings from across Europe:

- Country-level estimates of OAC therapy use suggest that a large proportion of AF patients do not receive OAC therapy in accordance with clinical guidelines and that the treatment gap is larger than reported in recent international registry studies:
  - **Up to 40% of AF patients do not receive OAC therapy** in 13 out of 20 countries where data are available.[31;52;62-64;68-90;97]
  - **Up to 40% of high risk patients do not receive OAC therapy** in 8 out of 15 countries where data are available.[52;57;63;72;77;82;91-98]
  - **Generally, physicians still over-rely on aspirin,** despite evidence that it is ineffective at preventing AF-related stroke.[27]
- There is considerable variation in the use of OAC between local settings even in countries where national guidelines recommend its use -- pointing to the need for localised quality improvement schemes..
- There are also important deficiencies in practice, including:
  - **under-treatment** of patients at greatest risk of stroke[52;70;91;92,] and **over-treatment** of patients who are not at risk of stroke.[52;69;76;98;99;70]
  - **under-treatment of older patients,** particularly older women, who are at greater risk of stroke.[75;76;92;100;101]

Avenues for change:

- **Local quality improvement frameworks** should be developed to ensure that inequalities in access are redressed between local settings and that good practice is embedded in local care pathways. *(see **Case study 10:** Primary care leadership driving best practice in Bradford)*
- **Where possible, these should be supported by financial incentives for GPs** to encourage them to adhere to existing guidelines.
- **Physician education tools and resources** are also needed on the importance of assessing all AF patients for their risk of stroke, and of offering each patient the most appropriate OAC therapy to meet their individual needs, particularly in primary care. *(see **Case study 8:** The Heart of AF).*
- **Information on all OAC therapy alternatives** should be provided to physicians and patients to ensure that these medicines are used appropriately and safely and that an individualised approach to therapy is offered to patients.[157;172] *(see **Case study 9:** the EHRA practical guide to the use of new anticoagulants)*

> "There are approximately 360,000 new cases of AF-related stroke every year in the EU[1] – and many of these can be prevented through appropriate anticoagulation therapy, thereby avoiding considerable morbidity, death and costs to society."
>
> ***(Eve Knight, President of AntiCoagulation Europe)***

SUMMARY FINDINGS IN MORE DEPTH:

In many countries, a significant proportion of patients are not treated with OAC therapy, and are offered aspirin instead, despite its use not being supported by recent clinical evidence or ESC guidelines.

Data on OAC therapy use were available for 22 countries, and are shown in **Table 4**. **These rates are often much lower** than those found in recent publications of international registries[173-175] – probably reflecting the fact that most of these national studies have more recruitment of patients from non-specialist centres, including primary care – where under-use of OAC therapy is known to be more common.[176] Key findings are:

- **Up to 40% of AF patients do not receive OAC therapy** in 13 out of 20 countries where data are available.[31;52;62-64;68-90;97]
- **Up to 40% of high risk patients do not receive OAC therapy** in 8 out of 15 countries where data are available.[52;57;63;72;77;82;91-98]
- **In most countries, there is still over-reliance on aspirin**, although it is no longer recommended by ESC guidelines on the basis that it is less effective at preventing stroke and does not carry a lower risk of bleeding compared to OAC therapy.[20;27]

Table 4: *Use of OAC therapy in different countries (data restricted to studies > 2006)*

Country	% of all AF patients receiving OAC therapy	% high risk patients receiving OAC therapy
Czech Republic	75%[73]	
Denmark	32-66%[72;79]	69%[72]
Estonia	66%[88]	
Finland	60%[82]	71%[82]
France	51%[89]	
Germany	60-83%[63;71;84]	70%[63]
Greece	39%[85]	33%[59]
Hungary	50-60%[78,68]	
Ireland	47%*[52]	59%[52]
Italy	46-69%[64;76;98]	69%[98]
Lithuania		39.4%***[97]
Netherlands	69%[70]	87%[70]
Norway	94%[62]	
Poland	50%[86]	15%[57]
Portugal	34-41% [31;80;87]	
Romania		71%**[96]
Slovakia	67%[77]	58%**[77]
Spain	52-84%[74;83;94]	57%-59%[91;94]
Sweden	42[177]-64%[69]	50%[92]
Switzerland	51%[90]	80%****
Turkey	44%[81]	
UK	56%[75]	51%[95,93]

* Percentage of patients eligible for OAC therapy who are receiving it.

** Defined as patients with a previous TIA or stroke.

*** Defined as OAC rates in patients discharged from hospital for stroke.

**** Expert opinion, unpublished data.

No data are available for: Austria, Belgium, Bulgaria, Latvia, or Slovenia.

SUMMARY FINDINGS IN MORE DEPTH:

Even in countries where national guidelines recommend broad use of OAC therapy, there is large variation in local practice.

Decentralisation of health care across many European countries has resulted in **significant heterogeneity in practices** surrounding the prevention of AF-related stroke – and this heterogeneity often exists despite national standards or guidelines.

For example in Sweden, the National Board of Health and Welfare (NBHW) has recently introduced as one of its KPIs for reducing the disease burden that at least 80% of all AF-patients with one additional risk factor for stroke should receive anticoagulant therapy. In theory, these KPIs are meant to lead focus and investment at a local level. However in practice to date: none of Sweden's 21 county councils reaches that target.

Local quality improvement initiatives, particularly in primary care, may help reduce discrepancies between localities and encourage the local implementation of guidelines. However, very few countries reported such initiatives taking place. *(see Case study 10)*

SUMMARY FINDINGS IN MORE DEPTH:

Under-treatment as well as over-treatment are common

Findings from several countries also suggest that physicians do not necessarily base their decisions to prescribe OAC therapy on stroke risk and that their understanding and use of stroke risk classification schemes is limited. These findings confirm those of previous reports.[35] Specifically:

- **Under-treatment:** i.e. patients at the highest risk of stroke are often not offered OAC therapy,[52;70;91;92] and
- **Over-treatment:** patients with no known risk factors for stroke are being offered OAC therapy.[52;69;70;76;98;99]
- Under-treatment is a particular problem in non-specialist settings such as primary care – which may be reflective of the tendency of **multi-morbid patients** to present to internal medicine departments compared to cardiology, for example.[76]

Older people, particularly older women, are at greatest risk of under-treatment despite being at greatest risk of stroke

In many countries, under-use of OAC therapy is greatest in older people even if they are otherwise healthy.[75;76;92;100;101]

This is a worrying trend, as older people are at greatest risk of AF and of stroke.[13] Older women in particular are at greatest risk of under-treatment[81;178], despite evidence that OAC therapy may be of greatest benefit in this population of patients.[179] Unfortunately, this finding mirrors a number of reports that women with heart disease tend to be under-treated compared to men.[180]

CASE STUDY 8: ONLINE TOOL

THE HEART OF AF PROGRAMME

> "Although initially designed to provide physicians with information, we found that non-specialists in AF welcomed the website as a forum in which they can exchange good practice with their peers."
>
> *(Jo Jerrome, Atrial Fibrillation Association)*

✓ *APPROPRIATE ANTICOAGULATION THERAPY*

Overview

A web-based resource which provides healthcare professionals with state the art resources to better equip them with the skills and knowledge to better diagnose, treat and manage AF patients.

Timescales

The site was launched in June 2013 and has run continuously since

Resource Implications

Resource created and managed entirely by Atrial Fibrillation Association (patient organisation) with financial support from various private and commercial sources

Links/References

http://www.heartofaf.org/

Approach

The site functions as an online information platform and is targeted at all health professionals who may be involved in the care of a person with AF. The site is used by a wide range of health professionals working in different settings (e.g., GPs, emergency physicians, commissioners and medical students) and materials are appropriate for a wide range of professionals.

Resources provided include: guidelines, information on AF as a condition, treatment options, information on commissioning, real life examples, and training resources, including signposting to relevant courses. Users also use it as a network and forum for exchange on good practice.

THE HEART OF AF

What has been achieved?

- 1293 new health care professionals joining, and 4973 visits to the website in its first 12 months, with the number of visits continuing to increase month on month
- Increasing number of centres approaching AF Association to share information on the site, as well as good feedback from others who have gone to the site to look for information.
- Contributes towards better information of non-specialists about AF and its management
- Forum for exchange of information and sharing of best practice among non-specialist physicians on all aspects of AF management

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CASE STUDY 9: EUROPE

EHRA PRACTICAL GUIDE TO THE USE OF NEW ANTICOAGULANTS

> "We have brought together information on all the NOACs in one document so it's clear for physicians what the similarities and differences are. We worked closely with the drug companies to make sure that all of the information in the SmPCs [patient information leaflets] is also in our document."
>
> ***(Professor Hein Heidbuchel – lead author)***[181]

Overview

A practical guide, meant as a complement to the ESC 2012 guidelines, to help physicians in their use of the different NOACs with their patients.

Timescales

Published in 2013,[157] due to be updated

Resource Implications

The EHRA Practical Guide and all supporting educational material was produced solely by the European Heart Rhythm Association, and was funded through unrestricted and educational grants from Boeringher Ingelheim, Bayer, Daiichi-Sankyo and Pfizer and Bristol-Myers Squibb.

Links/References

Heidbuchel H, *et al*. European Heart Rhythm Association Practical Guide on the use of new oral anticoagulants in patients with non-valvular atrial fibrillation. Europace 2013; 15(5):625-651.[157]

www.NOACforAF.eu

Approach

The ESC 2012 guidelines recommend NOACs as an alternative to VKAs for the prevention of AF-related stroke; given their novelty, patients and physicians will need to learn how to use NOACs safely and effectively. Thus the European Heart Rhythm Association (EHRA) developed a single comprehensive guide to support clinicians in the practical use of NOACs, providing them a practical guide to the use of individual NOACs which may serve as a complement to the ESC guidelines. The guide summarises existing evidence of best practice, and gives practical directions for 15 concrete clinical scenarios. They cover practical start up and follow up schemes for patients on NOACs, how to measure the anti-coagulation benefits of NOACs, drug-drug interactions and pharmacokinetics of NOACs, switching between anticoagulant regimes, the management of co-morbidities and complications, and various other important 'what if' scenarios.

The guide comes with various embedded resources to assist clinical practice, including a proposed patient information card on NOACs, a card to record all planned or unplanned visits and a template to list any concomitant medication. In recognition of the rapid development of new information and evidence, EHRA has provided a supporting website **www.NOACforAF.eu** and a pocket sized booklet with key messages.

The EHRA practical guide was co-authored by leading cardiologists from 5 different countries across Europe.

What has been achieved?

- Practical information to physicians to help them implement ESC guidelines in different clinical situations
- Helpful information to physicians on the characteristics, risks and benefits of individual NOACs
- Useful, adaptable patient information cards that may keep track of patients' medication, educate them about how to optimise therapy (e.g., by listing concomitant medications, in the hope of minimising drug-drug interactions,) and ensure continuity of care across different providers.

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CASE STUDY 10: UK

THE AF QUALITY IMPROVEMENT PROJECT (AFQIF) - PRIMARY CARE LEADERSHIP IN BRADFORD

> "Guidelines are important, but to really make things change, you have to have clinical leaders within each local health care setting who can drive best practice amongst their peers and reinforce existing policy levers."
>
> ***(Dr Matthew Fay, GP Executive Member, Bradford Districts Clinical Commissioning Group Westcliffe Medical Centre)***

✓ *APPROPRIATE ANTICOAGULATION THERAPY*

Overview

A quality improvement project, led in a collaborative approach between local commissioning bodies and GPs, which aimed to improve anticoagulation rates in AF patients.

Timescales

The initial initiative was run in 2012 with a follow up of 18 months , but the quality improvement model has since become embedded within participating practices.

Resource Implications

The programme was funded using existing resources and volunteer GP time. A preliminary economic analysis suggested that the overall cost of implementation was offset considerably by the reduced costs associated with the prevention of AF-related stroke.

Approach

A quality improvement initiative was established as a complement to the national incentive framework for GPs (the Quality Outcomes Framework) to improve the use and quality of anticoagulation therapy in AF patients in Bradford. Sixty-four out of 80 local practices participated. Participating practices were offered 10 simple, evidence-based strategies to encourage improvement. The programme achieved a significant increase in the number of AF patients receiving OAC therapy, with the greatest improvement of practice in patients at highest stroke risk. Success factors included:

- Clear measurable indicators that were evaluated across all participating practices and fed back to encourage improvement
- Leadership from local GPs, working in collaboration with local commissioners, public health, and local hospitals
- A clear approach to peer facilitation, recognising that practices have as much to learn from each other as 'experts' had to teach them
- Constant availability of advice and support in the form of Q&A, expert events, training, practice visits and IT support tools.

What has been achieved?

- 31% relative increase in patients put on OAC therapy vs. 4% increase in non-participating practices over 18 months
- Stroke reduction rate of 10% in one year
- 25 strokes and 17 deaths estimated to have been prevented.

Contact:

Dr Matthew Fay

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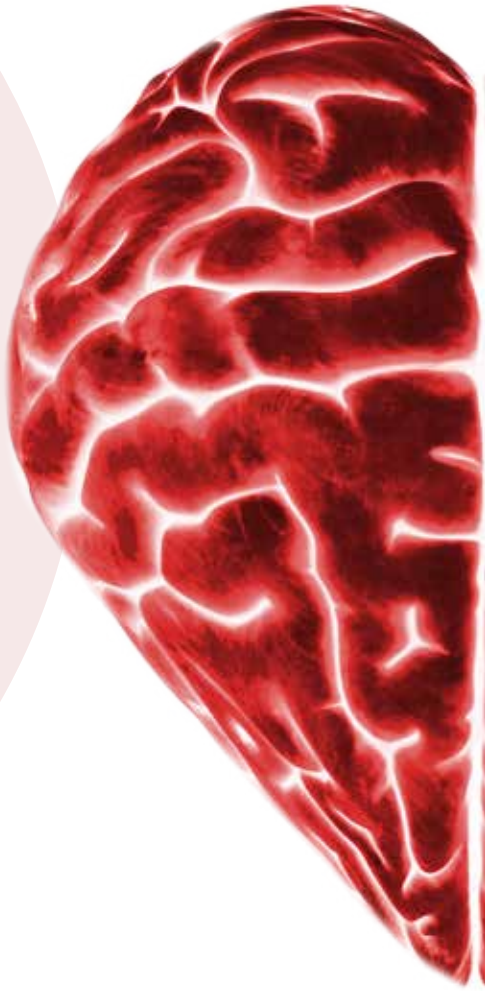
matthew.fay@bradford.nhs.uk

Priority 5:

PATIENT-CENTRED CARE AND CLEAR INFORMATION TO PATIENTS



Case studies for Priority 5

- The AF risk stroke calculator
- Nurse-led integrated chronic care model for AF management

Priority 5: Patient-centred care and clear information to patients

What we know:

Physicians and patients are known to differ in how they view the **relative risks and benefits of OAC therapy:** physicians tend to overestimate the risk of bleeding and underestimate the risk of stroke compared to their patients,[28] whereas patients tend to place more value on reducing the risk of stroke.[24;182]

Why is this important?

Persistence with OAC therapy is low,[183] with **up to 60% of AF patients on OAC therapy discontinuing medication** within the first year.[184]

Key findings from the European Atlas:

- AF patients often have a poor understanding of their condition, their increased risk of stroke and the purpose of OAC therapy.[35;102-104]
- According to physicians, the amount and quality of information available for AF patients is poor compared to other cardiac conditions.[23]
- Some countries are beginning to look at nurse-led AF care as an approach offering patient-centred care to AF patients, with specialist nurses playing a coordinating and supportive role to patients throughout their care.[108]

> "All too often patients do not understand or are not told why they have been prescribed oral anticoagulation. Symptoms of AF do not go away by taking anticoagulation drugs so often patients stop taking them as they feel no difference. If you were given paracetamol and your headache did not go away, you would stop taking it. If we want to achieve good adherence to OAC therapy, we must improve the information we provide to patients about the purpose of treatment and stress the critical importance of adhering to the treatment prescribed"
>
> ***(Trudie Lobban MBE, Arrhythmia Alliance and AF Association)***

Avenues for change:

- **Easy-to-access information** about AF, the risk of AF-related stroke and the importance of OAC therapy is urgently needed to help improve patients' understanding of the purpose of OAC treatment and encourage greater adherence to therapy.
- **Resources to support the development of patient organisations** are critical to provide AF patients and their families with a local community of support as well as the information, coping skills and support they need to learn to live with their condition, make the right treatment choices and find ways to improve their quality of life.
- **The development of tools to help patient-physician communication and shared decision-making approaches** between the patient and his/her physician should also be encouraged. *(see **Case study 11:** The AF stroke risk calculator).*
- **Health care systems should explore the feasibility of nurse-led AF clinics as a model of care** and should invest in the development of specialist nurses who may offer AF patients continuous case management, support and information in community and hospital settings. *(see **Case study 12:** A nurse-led, integrated chronic model for AF care in Maastricht).*

SUMMARY FINDINGS IN MORE DEPTH:

AF patients often have a poor understanding of their condition, their increased risk of stroke, and the purpose of OAC therapy

Findings from a number of countries suggest that **many AF patients are poorly informed** about their condition, the risk of AF and the role of OAC therapy. For example:

- An international patient survey found that up to 25% of AF patients were unable to explain their condition to someone else.[102]
- In a UK study, 56% of patients with AF did not know AF could lead to stroke.[103]
- Many patients do not know why they are on OAC therapy to begin with.[35]
- Even stroke survivors more widely have been found to have a poor understanding of risk factors for stroke – particularly older patients and those with excellent recovery.[104]

There is a general lack of high-quality information and support available to AF patients, leading to poor engagement in their care

Patient organisations focused on AF, anticoagulation and stroke exist in many European countries. However, important gaps in information and support still exist, particularly in Eastern European and Baltic countries.

In a survey of patients and physicians from five EU countries, physicians suggested that **the amount and availability of patient information on AF compares poorly** to that available for other cardiac conditions and AF patients stated that poor engagement in clinical decisions and lack of support were an important concern.[23] In the same study, on average only 14% of AF patients reported having been informed of the potential side-effects of their medication (range across five countries: 9-30%).[23]

Similarly, an Italian study found that fewer than 20% of AF patients received information on the side-effects of OAC therapy and only 24% received information about interactions with other drugs.[98]

Nurse-led models of care should be explored as a means to offer a truly patient-centred approach to patients

Physicians often lack the time to provide information to their AF patients.[102] Lessons can be learnt from other chronic conditions such as diabetes or cardiac failure, where the role of **specialist nurses** has been developed to provide patients with the information, support and continuity of care they need throughout the course of their condition and disease management programmes have been implemented successfully.[185]

Some countries are beginning to invest in specialist arrhythmia nurses, and successful **models of integrated, nurse-led chronic care** for AF have been implemented and have led to greater patient satisfaction and patient outcomes.[108;186;187] *(see **Case study 12**).*

CASE STUDY 11: ONLINE TOOL

THE AF STROKE RISK CALCULATOR

> "This user-friendly tool not only enables physicians in any setting of care to assess their patients for their risk of stroke according to guidelines, it also gives AF patients at risk of stroke a record of this assessment, which they can then take with them to any other health provider they may be seeing, therefore avoiding that any critical information gets lost along the care pathway."
>
> ***(Jo Jerrome, Atrial Fibrillation Association)***

✓ *PATIENT-CENTRED CARE*

Overview

An online tool that provides AF patients with an individual assessment of their risk of stroke using the CHA_2DS_2-VASc risk scoring system.

Timescales

The risk calculator was launched in 2012 and is available online.

Resource Implications

The risk calculator was developed by Atrial Fibrillation Association (AFA) and Anticoagulation Europe. Funding for the project is provided by Bayer Healthcare.

Links/References

http://www.preventaf-strokecrisis.org/calculator

Approach

This is an easy-to-use online tool that is aimed at AF patients to improve their awareness of their risk of stroke, but is also professional-looking so that it is viewed as credible by GPs and other physicians.

It can be used both in primary or secondary care settings. The tool runs through a series of questions that mimic the sequence of questions in the CHA_2DS_2-VASc score, and ensures that no step is skipped so that the patient receives a comprehensive assessment of their risk of stroke. The tool provides each patient with printable information which can serve as a record of results – this can also be emailed to the patient and his or her doctor.

The risk calculator also provides information on anticoagulant treatment options based on the most recent guidelines.

What has been achieved?

- User friendly, simple tool which appeals to patients as well as physicians
- Improved understanding by AF patients of their risk of stroke
- Helps ensure each patient receives a thorough assessment of their stroke risk in accordance with clinical guidelines
- Starting point for discussion between patient and all treating physicians about AF and risks of stroke with AF, helping improve continuity of care throughout the care pathway
- Positive feedback received to date from physicians and AF patients

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CASE STUDY 12: NETHERLANDS

A NURSE-LED INTEGRATED CHRONIC CARE MODEL FOR AF MANAGEMENT IN MAASTRICHT

> "We were able to convey to patients that responsibility comes hand-in-hand with involvement – and to convince cardiologists that if patients were involved in their care, they would achieve better outcomes."
>
> ***(Dr Jeroen Hendriks, Maastricht University medical centre and Dutch Society for Cardiovascular Nursing)***

✓ *PATIENT-CENTRED CARE*

Overview

A multidisciplinary, nurse-led AF clinic offering integrated, long-term support and care to AF patients.[108]

Timescales

The nurse-led clinic model was evaluated in a clinical trial in 2007-8[108] and has been established in the outpatient setting ever since.

Resource Implications

The initial trial comparing nurse-led care to usual care was supported by the University Hospital Maastricht as well as by unrestricted educational grants from Boehringer Ingelheim and Medtronic Bakken Research Centre. The clinic is now funded through the general University Medical Centre budget.

Links/References

Hendriks JML. Nurse-led vs. usual care for patients with AF: results of a randomized trial of integrated chronic care vs. routine clinical care in ambulatory patients with AF. ***Eur Heart J 2012;*** *33: 2692-6.* [108]

Approach

In 2007, Maastricht University Medical Centre set out a randomised clinical trial to compare nurse-led integrated chronic care for AF patients versus usual care by a cardiologist. The integrated care model was based on the Chronic Care Model[188], and involved nurse-led outpatient care steered by decision-support software based on the ESC guidelines and supervised by a cardiologist.[108] Usual care consisted of care provided by cardiologists in the regular outpatient setting.

The clinic model was based on a shared decision-making approach: patients are provided with information about their disease, care and treatment options from the onset and are encouraged to remain engaged in decisions throughout their care. They are also encouraged to undertake self-management activities and to contact the nurse in between visits should they require additional support or information.

The model is based on a multidisciplinary approach in which nurses provide the mainstay of care, guided by a cardiologist who has medical oversight. The use of a common electronic record and decision-making tool requires specialist nurses and cardiologists to justify reciprocally any deviations from clinical guidelines, thereby improving adherence to guidelines. Finally, the use of electronic medical records ensures better information transfer between treating clinicians.[108]

What has been achieved?

As compared to usual care, nurse-led care led to:

- Greater adherence to stroke prevention guidelines (99% vs. 83%)
- Overall, prevention of incomplete diagnostics and therapeutics
- Lower rate of cardiovascular death (1.1% vs. 3.9%)
- Better information of patients about AF and their treatment, as measured by a validated scale (the AF Knowledge Scale)[186]
- 35% relative risk reduction of cardiovascular hospitalization or death[108]
- Lower overall costs compare with usual care and more life-years gained, therefore a highly cost-effective (dominant) option from an economic point of view.

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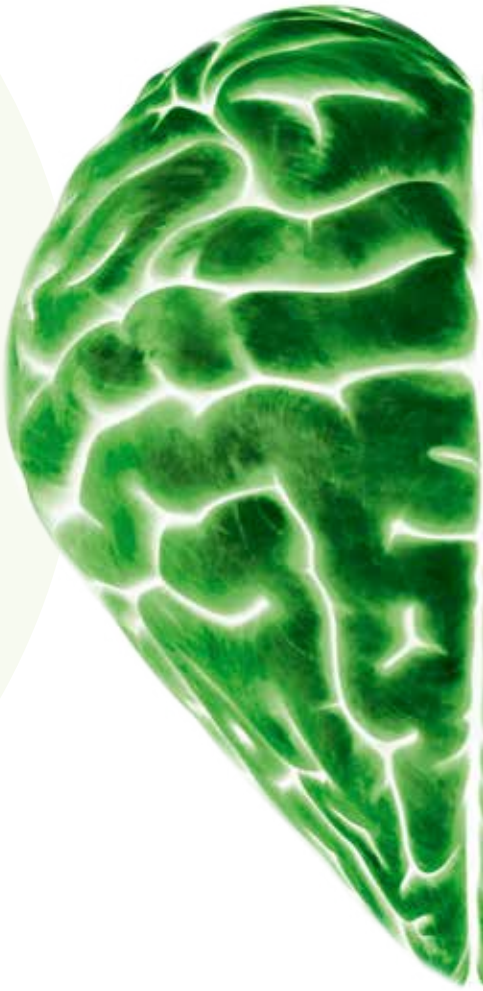
Priority 6:

A WHOLE-SYSTEM APPROACH TO THE PREVENTION OF AF-RELATED STROKE



Case studies for Priority 6

- A 'one stop shop' AF clinic
- Collaboration between neurologists and cardiologists in Odense

Priority 6: A whole-system approach to the prevention of AF-related stroke

What we know:

Poor coordination of care is a key concern for AF patients[23], who often find themselves caught between numerous physicians - cardiologists, general practitioners, neurologists, and other professionals – who do not systematically share information about their patients. Thus any strategy to improve the prevention of AF-related stroke must look at system changes and tools that may foster greater communication between physicians and encourage more efficient use to resources and better quality of care for patients.[102;185]

Why is this important?

Lack of coordination of care is one of the main concerns of AF patients, and may lead to important **information about the patients getting lost** between treating physicians.[23]

Key findings from the European Atlas:

- **Health care professionals other than cardiologists** (particularly general practitioners, nurses, geriatricians[106] and pharmacists[107]) are likely to play a growing role in the management of AF in years to come.
- In many countries, **primary care clinicians** have called for greater involvement in anticoagulation decisions for AF patients.[105;83]
- **Integrated, multidisciplinary approaches** to care may encourage greater coordination between physicians and help break down professional silos
- **Harmonised standards of care** for anticoagulation practice may help reduce heterogeneity across care settings.

Avenues for change:

- **Policymakers should learn from other conditions** and explore the development and implementation of multidisciplinary models of care to improve coordination of care for AF patients and improve collaboration between all relevant professionals.
- **Ways to achieve greater collaboration** between cardiologists, neurologists, and other health professionals (including GPs, nurses, pharmacists and geriatricians) should be explored within the context of each particular health care setting. *(see **Case study 13:** A 'one stop shop' clinic in Llanelli and **Case study 14:** Coordination between cardiologists and neurologists in Odense).*
- **Cardiology professional societies should work with other disciplines** (geriatrics, neurology, primary care) to develop joint guidance that may help practising physicians place the requirements for prevention of AF-related stroke within the broader context of each patient's individual health needs.

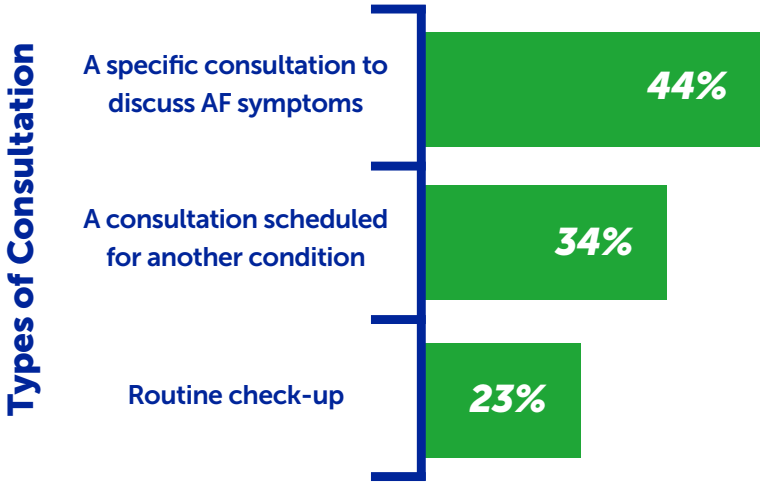
> "Achieving better prevention of AF-related stroke is not just the responsibility of cardiologists. With the rising prevalence of AF and the ageing of the population, it will be critical that all involved professionals raise awareness among their patients of the risks of AF-related stroke and work together to make best use of available resources to offer patients the highest standard of care across the whole health care system."
>
> ***(Dr Thomas Fåhraeus, Chairman of Arrhythmia Alliance, Sweden)***

SUMMARY FINDINGS IN MORE DEPTH:

The growing prevalence of AF is likely to mean that GPs and other primary care physicians will play a growing role in the management of AF in years to come.

Increasing numbers of AF patients are likely to put unsustainable pressures on hospital-based cardiology clinics, and a gradual shift of care into primary care settings is likely to occur. In addition, the fact that most diagnoses of AF are made 'by accident' **(see Figure 6 below)** underscores the need for all primary care clinicians to have a good understanding of clinical guidelines and OAC therapy in order to guide their patients towards appropriate care.[34;102]

Figure 6: *Type of consultation at which AF diagnosis was made*



Adapted from Aliot et al 2010[102]

In many countries, general practitioners, pharmacists and family physicians have called for greater recognition of their critical role in OAC management decisions.

There are a number of examples across Europe of professionals working in primary care having a growing role – or calling for a greater role - in the management of AF patients. For example:

- In Austria, the national professional society of general practice and family medicine has drafted its own **guidelines** on the prevention of AF-related stroke, in collaboration with the cardiology professional societies. [189]
- In Spain, primary care physicians have called for **greater involvement in the management of AF patients** and better coordination between primary and secondary care.[105]
- In Spain and Italy, primary care physicians have asked to receive **appropriate training on NOACs** and to have the right to prescribe NOACs to their patients (currently prescription is only allowed by specialists).[83]
- In France, the main Sickness Fund granted **pharmacists specific remuneration,** as of 2013, for their role in providing follow up to patients on OAC therapy.[107]

Joint guidelines between cardiology and geriatrics may offer useful guidance for the care of older patients with AF

Seventy percent of AF patients are over the age of 65[11], and patients with AF often present with significant co-morbidities, each of which needs requires a particular care pathway. Yet surprisingly, **the only example of joint guidelines between national geriatrics and cardiology societies was found in France.**[106] The authors provide useful guidance on how to place the requirements for OAC therapy within the broader context of older patients' competing health needs, and highlight the need to perform a comprehensive geriatric assessment in all patients. It should be mentioned, however, that joint guidelines between different specialties including internal medicine, haematology and others also do exist, for example in Switzerland.[190]

SUMMARY FINDINGS IN MORE DEPTH:

Integrated, multidisciplinary approaches to care may encourage greater coordination and help break down professional silos

Multidisciplinary, integrated models of care have been applied successfully to other conditions such as cardiac failure[191] and may offer a promising model of care for the organisation of AF management as well.[108] *(see Case study 12)*

Key components of such integrated models of care include:

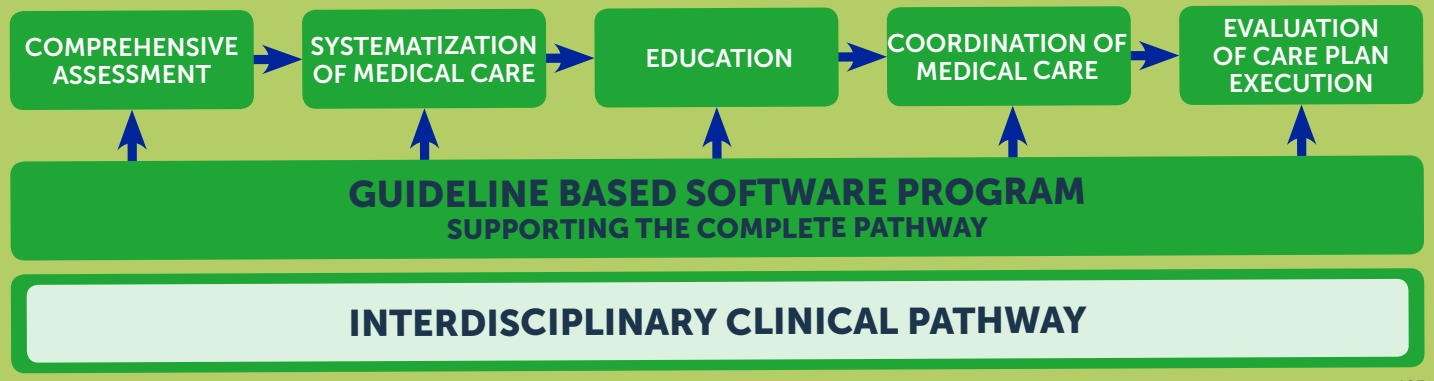
- A **multidisciplinary approach to care**, with clear delineation of roles between professionals
- The **use of decision-supporting software,** which prompts a dialogue between clinicians to explain their therapeutic decisions, and helps engage patients in therapeutic decisions[108]
- **Centralised records of information** on patients, facilitating dialogue between GPs and cardiologists[185] *(see Case study 13 and Case study 14).*

Harmonised standards of care for anticoagulation practice may help reduce heterogeneity across care settings

Harmonised standards of care that work across primary and secondary care may also play an important role in improving overall standards of care.

For example in Tuscany, a regional law was passed to ensure that all AF patients on OAC therapy receive the same level of information and follow-up care, regardless of whether they were treated in a primary care or hospital setting. A specific training programme was developed for all professionals, with the underlying slogan **'written is better'** to ensure that a continuous and complete record of information was maintained and communicated across the entire chain of care for each patient.[192]

Figure 7: *Cornerstones of a multidisciplinary approach to AF care*



Adapted from Berti et al 2013[185]

CASE STUDY 13: UK

A 'ONE STOP SHOP' CLINIC IN WALES

> "AF is often the entry point into a host of other cardiac problems –for example today I saw a patient who was coming to see me for his AF, but I also found that he had ischemic heart disease. Because we are all under one roof, I was able to refer him immediately for bypass surgery."
>
> ***(Dr Lena Marie Izzat, Prince Philip Hospital, Wales)***

✓ *A WHOLE-SYSTEM APPROACH*

Overview

A multidisciplinary "one stop shop" AF clinic was established within the local hospital to offer patients with AF a comprehensive, integrated service and achieve greater stroke prevention in the area.

Timescales

Commenced in January 2009, currently running 2-3 clinics per week.

Resource Implications

The service is entirely self-funded. Additional funding was received recently from a private company to fund a third session.

Links/References

http://www.atrialfibrillation.org.uk/files/file/Events/120501-1-1125%20Carmarthen%20Audit%20Report%20on%20AF.pdf

Approach

The centre is located in Carmarthenshire, a rural part of Wales prone to high rates of AF (population: 200,000).

The centre accepts all referrals from GPs or other providers (emergency department, other hospital clinicians,...), but not self-referrals. Referring clinicians are asked to assess all AF patients for their risk of stroke using CHA_2DS_2-VASc and provide a clear treatment plan.

Patients are then seen at the clinic first by a cardiovascular nurse who begins/confirms OAC treatment according to ESC 2012 guidelines, and then by the cardiologist consultant who does a thorough cardiac assessment of the patient and recommends future management.

Patients have access to everything under one roof – all patients can have an ECG, receive their anticoagulation therapy and echocardiography on the same day and receive cardioversion or other specialist interventions very promptly. The clinic has close links with the stroke unit and tertiary centre in Swansea, helping to reduce waiting times for procedures.

What has been achieved?

- More local GPs are checking for AF
- General reduction in disabling stroke incidence in the region
- Decreased waiting times for general cardiology
- Identification of other cardiac problems that would have gone unnoticed in AF patients

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CASE STUDY 14: DENMARK

COLLABORATION BETWEEN NEUROLOGISTS AND CARDIOLOGISTS IN ODENSE

> "A key success factor in our region has been that many neurologists have championed the need for greater collaboration between all those who treat AF patients in order to ensure more effective stroke prevention in this patient population."
>
> ***(Dr Axel Brandes, Odense University Hospital and President of the Atrial Fibrillation Association, Denmark)***

Overview

A collaborative approach between neurology and cardiology departments ensures that all patients admitted for a TIA or stroke are monitored for AF, especially if they are in sinus rhythm. If AF is detected during the hospital stay, this data is included in the national stroke registry. In addition, a standardised web based tool is applied across all primary care centres where AF patients may receive OAC therapy.

Timescales

Currently ongoing.

Resource Implications

No resource implications.

Links/References

Brandes A, Overgarrd, M, Plauborg L, et al. Guideline adherence of antithrombotic treatment initiated by general practitioners in patients with nonvalvular atrial fibrillation: a Danish study. Clin Cardiol 2013; 36: 427-432.[72]

Approach

Cardiology and neurology departments work together in Odense to ensure that all patients admitted for suspected TIA or stroke to the neurology department are monitored for AF, and referred for OAC therapy as appropriate. It is aimed that the results of this prolonged monitoring will also be included in the standardised dataset for the stroke registry in the future.

In an effort to harmonise practices across all physicians, a practical guide is also being developed as part of the National Cardiology Treatment Guidelines by the Danish Society of Cardiology to ensure that all patients follow the same pathway from detection of AF to stroke risk assessment to OAC treatment, regardless of where they are seen.

In addition, it is intended that all hospitals or GPs must report their INR results centrally in the future, and any patient whose results are not within the TTR at least 70% of the time is referred to a specialist department for treatment.

What has been achieved?

- Routine monitoring for AF is now done for all stroke and TIA patients
- Standardisation of the quality of care in OAC therapy across the whole treatment pathway
- High adherence to clinical guidelines for OAC therapy across primary care (>75%)[72]

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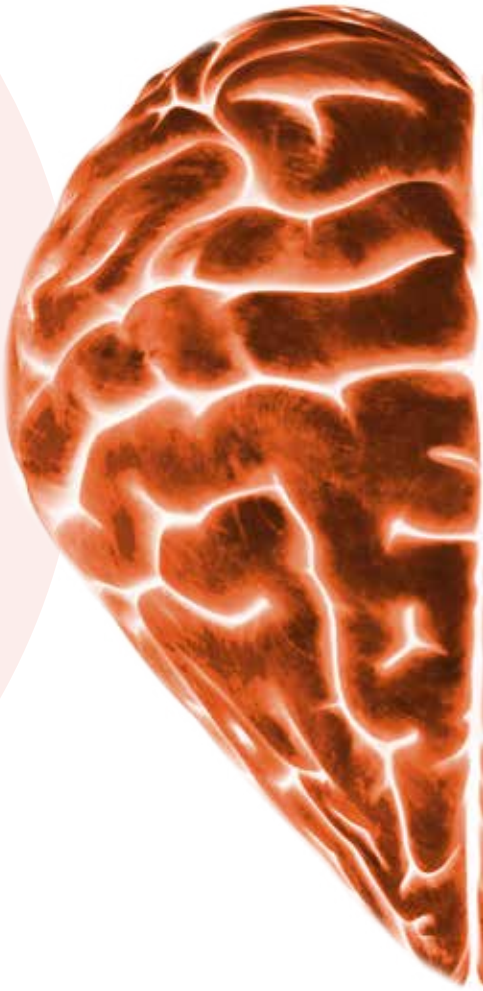
Priority 7:

BETTER DATA TO GUIDE POLICY AND INFORM CLINICAL MANAGEMENT



Case studies for Priority 7

- The German Competence Network on Atrial Fibrillation (AFNET)
- The FACTS spot registry

Priority 7: Better data to guide policy and inform clinical management

What we know:

In 2010, the World Health Organisation included AF for the first time as one of the conditions it investigated in its influential **Global Burden of Disease study,** recognising its growing prevalence worldwide.[193] This was a welcome milestone, as several expert reports have commented on the poor level of evidence available and the need for greater research on AF as well as AF-related stroke.[29;194]

The purpose of the **European Atlas** developed as part of this report, was to uncover what data and evidence exists within each country of the EU, as well as in Norway, Switzerland and Turkey. We have summarised key findings below.

Why is this important?

Policymakers need **accurate estimates** of the number of people affected by AF-related stroke to ensure that health care systems are resourced appropriately to meet patient needs.

Key findings from the European Atlas:

- Country-level data on the prevalence of AF suggest that **the true prevalence of AF may be higher than previously estimated.**[18;31;33;42;46-64]
- Very few countries have dedicated AF **registries**.
- Estimates of the proportion of strokes due to AF are rare but suggest that **at least 20% of strokes are due to AF** and that this proportion is increasing with the ageing of the population.[17;47;109-117]
- Available economic data confirm the **high burden posed by stroke,**[3;9;118-132] but estimates are lacking in most Eastern European and Baltic countries, even though the burden posed by stroke is greatest in these countries.
- Data on the economic burden of AF-related stroke are rare, however existing figures support previous reports that **AF-related strokes are the most debilitating and costly strokes.**[123;124;130;133-138]

Avenues for change:

- Governments should invest in the **systematic collection of epidemiological and economic data** on AF, stroke and AF-related stroke, to ensure that policies are guided by the best possible evidence.
- **Professional societies** have an important role to play in strengthening this evidence base and to communicating these data to policymakers.
- **Investment in stroke registries,** and inclusion of 'AF diagnosis' within existing stroke registries is needed to be able to quantify with accuracy the percentage of strokes due to AF.
- **EU-level funds** should be devolved to research that may provide reliable figures on the burden of stroke and AF-related stroke in countries where prevalence is greatest – Eastern European and the Baltic region in particular.

> "There are different ways to obtain reliable information on AF and AF-related stroke – and different sources (registries, observational studies, large claims databases) should be explored based on what is most feasible in each country. Obtaining this data is essential if we are to understand existing differences in practice and find ways to remedy them, with the ultimate goal of improving patient outcomes across all settings of care."
>
> ***(Professor Paulus Kirchhof, founding member and current board member, AFNET)***

SUMMARY FINDINGS IN MORE DEPTH:

Estimates of the prevalence of AF come from a variety of sources and suggest that the prevalence of AF is greater than previously estimated

Available country-level estimates of the prevalence of AF are presented in **Table 5.** Data are derived from a number of sources and it is likely that some data is more reliable than others, therefore any comparisons should be made with caution.

No recent (>2005) prevalence data were found in Austria, Bulgaria, Czech Republic, Finland, Latvia, Lithuania, or Slovakia.

Table 5: Most recent country-level estimates of AF prevalence*

Country	Estimated prevalence (%)	Age group	Study Design
Belgium[48]	2.2%	>40	voluntary screening programme
Denmark[18]	2%	all	Copenhagen Stroke Study
Estonia[56]	2%	all	
France[53]	1-2%	all	Official government figure (estimate)
Germany[63]	2.1%	all	Claims database of 2 large statutory insurance funds
Greece[59]	3.9%	all	Community screening study
Hungary[61]	2.9%	all	Analysis of National Health Insurance Fund database
Ireland[52]	3%	>50	The Irish Longitudinal Study on Ageing (TILDA)
Italy[64]	1.85%	all	ISAF (Italian Survey of AF Management Study)
Latvia[55]	3.0 – 3.5%		Riga Stradins University pilot project
Netherlands[54]	5.5%	>55	Rotterdam Study
Norway[62]	10%	Age 75	Population-based study in 2 municipalities
Poland[57]	18%	>65	Self-reported survey
Portugal[31]	2.5%	>40	FAMA study, a cross-sectional observational study
Romania[49]	2-3%	All	Expert opinion
Slovenia[58]	1-2%	All	Expert opinion
Spain[33]	4.4%	>40	OFRECE cross-sectional, population-based study
Sweden[47]	3.2%	>20	Population-based study
Switzerland[42]	1.25%	all	Swiss Heart Foundation estimate
Turkey[60 50]	0.8-1.25%	all	TRAF hospital database on AF; TEKHARF (Cardiac Disease and Risk Factors in Adults in Turkey), cross-sectional prospective study
UK[46]	1.4%	all	GARFIELD registry (UK arm)
UK[51]	6.9-7.9%	>65	SAFE study

* In order to have a current estimate of prevalence, we limited figures to those obtained after 2005.

Priority 7: Better data to guide policy and inform clinical management

SUMMARY FINDINGS IN MORE DEPTH:

Very few countries have established registries for AF or stroke

Across Europe, Germany is the only country with established AF registry *(see Case study 12)*, although AF registries are in development in Estonia and Latvia. Registries are also being considered in a number of other countries. Denmark and Sweden have national patient registries which cover all conditions and from which data on AF may be extracted and Norway has a national prescription database which similarly collects information on AF.[195] Romania has a spot registry on AF *(see Case study 14)*. Both the German and Romanian registries have been incorporated into the European-wide EORP-AF registry, with Germany providing an extended contribution.[175] Many other countries have conducted longitudinal cohort studies on AF, which are not registries as such – for example Turkey has a hospital-based database called TRAF which is focused on AF.[60]

Stroke registries are available in a few more countries.

NO AF REGISTRY

AUS, BEL, BUL, CZR, EST, FIN, FRA, GRE, HUN, IRE, ITA, LIT, NET, POL, POR, SVK, SLO, SWZ, TUR, UK

NO STROKE REGISTRY

BEL, BUL, CZR, FIN, FRA, GER, GRE, HUN, ITA, LIT, NET, POR, ROM, SVK, SPA, SWZ, TUR

COUNTRY	AF REGISTRY	STROKE REGISTRY
Austria	X	√ Austrian stroke registry
Czech Republic	X	√ IKTA – National Stroke Registry
Denmark	No, but Danish National Patient Register collects data on AF	√ Danish Stroke Registry
Estonia	X	√ In preparation
Germany	√ The AF-NET registry	X
Ireland	X	√ National Stroke Registry
Latvia	√ Latvian AF Registry in development	√ Latvian National Stroke Registry
Norway	No, but Norwegian Prescription Database (NorPD) collects data on AF	√ Norwegian Stroke Registry
Poland	X	√ Polish National Stroke Prevention and Treatment Registry
Romania	√ FACTS spot registry, (recruitment has stopped)	X
Slovenia	X	√ Slovenian Stroke Registry*
Spain	No, but FANTASIIA registry of AF patients on OAC therapy run by Spanish Society of Cardiology	X
Sweden	√ Swedish Population Register records diagnosis of AF, AuriculA is the national quality registry of patients with AF	√ The Riks-Stroke registry
Turkey	X	X
UK	X	No, but Sentinel Stroke National Audit Programme

* although commentators suggest it is not updated or comprehensive.[196]

SUMMARY FINDINGS IN MORE DEPTH:

There are several Ongoing European and global registries (which include EU countries) on AF

Several European-wide and international registries on AF have been developed in recent years, although they tend to recruit patients predominantly from hospital cardiology departments. (see **Table 6**)

Table 6: Ongoing European and global registries on AF*

EORP-AF[175]	GARFIELD[173]	PREFER in AF[174]	Realise-AF[197]
Hospital + outpatient	Hospital-based cardiologists	53% hospital-based, 42% office-based, 70% enrolled by cardiologists	83% cardiologists, 17% internists, hospital- and office-based
BEL, DEN, GER, GRE, ITA, NET, NOR, POL, POR, ROM, UK	AUS, DEN, FIN, FRA, GER, ITA, NET, NOR, POL, SPA, SWE, UK	AUS, FRA, GER, ITA, SPA, SWZ, UK	BEL, BUL, CZR, GER, HUN, IRE, ITA, LIT, POR, SVK, SPA, SWE, SWZ, TUR

SUMMARY FINDINGS IN MORE DEPTH:

There is very little information available which allows to understand the full clinical and economic burden of AF-related stroke in individual countries

A striking finding across Europe is the **lack of accurate data on the number of AF-related strokes** in many countries.

For example, the ESC guidelines suggest that 1 in 5 strokes is due to AF. Yet **precise estimates of the proportion of strokes due to AF are rare across Europe.** Expert opinion[198] as well as data from several countries suggest that this proportion may in fact be higher than 20%. This may be explained in part by the ageing of the population and the increased risk of AF in older people. (see **Table 7**) These findings have important implications for policymakers and reinforce the importance of recognising the key role of AF as a major risk factor for stroke in existing policy platforms (see **Priority 1**).

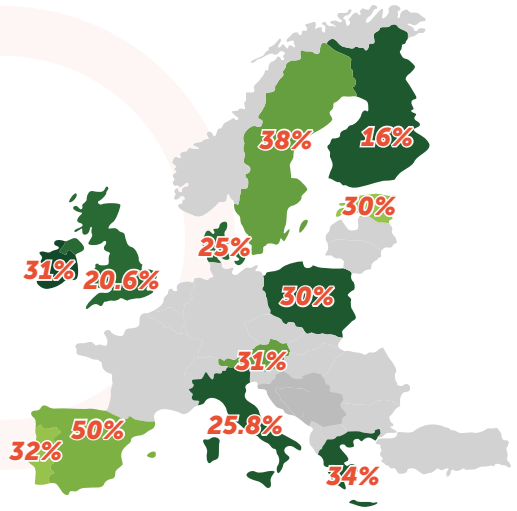


***Table 7:** Country-level estimates of the proportion of strokes due to AF*

Country	% strokes due to AF	Study details/source
Austria	31	Austrian Stroke registry[17]
Denmark	25	The Danish Heart Foundation and Danish Society of Cardiology estimates[109;113]
Estonia	30	Expert report[56]
Finland	16	National hospital discharge register (1999-2006)[114]
Greece	34	Arcadia Stroke Registry[117]
Ireland	31	The North Dublin Population Stroke Study[112]
Italy	25.8	Prospective study of consecutive stroke patients admitted to a comprehensive stroke unit[111]
Poland	30	Polish National Stroke Prevention and Treatment Registry[115]
Portugal	32	Retrospective study of stroke patients admitted to one hospital[116]
Spain	50% of cardioembolic strokes	Diaz Guzman 2013[110]
Sweden	38	Population-based study in one Swedish region[47]
UK	20.6	National stroke audit[199]

SUMMARY FINDINGS IN MORE DEPTH:

Country-level estimates of the cost of stroke confirm the high burden posed by stroke, however estimates are lacking in Eastern Europe and the Baltic region, where the burden posed by stroke is greatest.

No country-level estimates of the cost of stroke were available for: Austria, Belgium, Bulgaria, Czech Republic, Denmark, Estonia, Greece, Latvia, Lithuania, Portugal, Romania or Slovakia

Table 8: Country-level estimates of the cost of stroke

Country	Direct Medical Costs	Indirect Costs	Data
Finland	√		Average lifetime healthcare costs after a stroke are 86,300 Euros per patient, for a total of €1.1 billion per year, or 7% of total healthcare costs.[127;137]
France	√	√	Total direct costs of €5.3 billion per year; nursing home costs: €2.4 billion; lost productivity for those under 65: €255.9 million per year. [121]
Germany	√	√	Direct medical costs of a first-occurring stroke are €18,517 in the first year, and €5,479 for each of the four years following stroke.[125]
Hungary			€38.8m (12.1 billion HUF) incremental cost due to stroke (direct healthcare costs)[124]
Ireland	√	√	Total costs of stroke were estimated at €489 million (2007 data), which comprises €345-557 million in direct healthcare costs and 143-248 million in indirect costs.[131]
Italy	√		Between €20,000[200] and €30,000[129] per person
Netherlands	√		Total direct healthcare cost of €1.5bn (2005 data)[119]
Norway	√	√	Total costs per year of €874 million (direct + indirect costs) [3]
Poland	√		704 million PLN (€168 million), of which 159 million PLN are for rehabilitation and 545 million PLN for acute stroke care. [120]
Slovenia	√	√	€87.4 million direct costs, €24.7 million indirect costs[132]
Spain	√	√	Total direct costs of cerebrovascular disease are €6 billion per year, of which hospital costs account for €1.5 billion.[126] Informal care for stroke costs €6.5-10.8 billion per year, or €27,314 Euros per stroke survivor.[130]
Sweden	√		Stroke hospitalisations in the first year cost around €10,000. [123]
Switzerland	√	√	Healthcare and social costs of 21,203-43,821 CHF per stroke depending on severity[118]
Turkey	√		Direct healthcare cost of stroke in the first year was TL 5,719 of which TL 2,432 were within the first month and TL 3.257 within the next 11 months. [122]
United Kingdom	√	√	Annual direct healthcare cost of stroke in UK between £2.8[9]-3.0 billion[128], indirect societal costs £4.2[9]-5.0 billion[128]

SUMMARY FINDINGS IN MORE DEPTH:

Data on the economic burden of AF-related stroke are still too rare

There are very limited estimates of the costs associated with AF-related stroke, however those available confirm that **AF-related strokes are more debilitating and costly than strokes not due to AF.**

No recent country-level estimates of the cost of AF-related stroke were available for: Austria, Belgium, Bulgaria, Czech Republic, Denmark, Estonia, Germany, Greece, Italy, Latvia, Lithuania, the Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Switzerland, or Turkey.

Table 9: Country-level estimates of the costs of AF-related stroke

Country	Data
Finland	AF-related strokes cost approximately €23,500 in direct healthcare costs in the first year, as compared to an average cost for all patients with first-ever ischemic stroke of €21,900.[137]
France	Mean direct medical costs of AF-related strokes range from €4,848 (mild) - €29,700 (severe case) over 2 years.[134]
Hungary	$8 million (2.5 billion HUF) incremental cost due to AF-related stroke (direct healthcare costs).[124]
Ireland	Two-year median costs of AF-related stroke are €25,150 – compared to an average of €12,751 for strokes not due to AF.[135]
Spain	AF-related strokes have a longer length of stay in hospital than strokes not due to AF, and are less likely to be discharged home than non-AF related strokes (38% vs. 63%).[138] Patients hospitalised for AF-related strokes are also older, require more intravenous treatments, have more intense neurological deficits and more systemic complications compared to stroke patients without AF, although costs of care are similar.[130;133]
Sweden	In-patient costs for patients amounted to €9,300 for AF-related stroke and €8,900 for strokes not due to AF. The presence of AF in stroke patients under 65 increased costs by 46% compared to stroke patients without AF.[123]
United Kingdom	Average costs of stroke amongst patients with AF were £10,413.[136] The 10% of stroke patients who survived acute stroke phase incurred annual long-term care costs of €6880 annually.[136]

CASE STUDY 15: GERMANY

THE GERMAN COMPETENCE NETWORK REGISTRY (AFNET)

> "The creation of the registry allowed to bring together physicians of all disciplines and care settings and the data collected provided a starting point for engaging with policymakers, the media and patient groups as well as providing a starting point to plan clinical trials. We are delighted to be able to report long-term follow-up data of the AFNET registry patients soon."
>
> ***(Professor Paulus Kirchhof, founding member and current board member, AFNET)***

✓ *BETTER DATA TO GUIDE POLICY*

Overview

AFNET is an interdisciplinary translational collaborative research organization that started off with 200 German centres and now conducts international clinical studies in AF. Part of AF is a national patient registry intended to help improve the treatment of atrial fibrillation (AF).

Timescales

AFNET was established in 2003 and is still operating today with a focus on the conduct of observational and investigator-initiated interventional multi-centre studies in Germany and Europe.

Resource Implications

AFNET was funded by the German Federal Ministry of Research and Education for 10 years. Today, AFNET is an independent association and is expected to become an associated partner of the newly-created German research centre on cardiovascular disease as of 2015.

Links/References

http://www.kompetenznetz-vorhofflimmern.de/en/

Nabauer et al. 2009[116]; Kirchhof, et al. 2011[81]

Approach

AFNET was established as one of 17 competence networks funded by the German government. From its onset, it has had three aims: i) establish a registry to provide information on AF and its management in Germany; ii) provide a platform for investigator-initiated trials, and iii) help improve understanding of the mechanisms and pathology of AF.

The Basis-AF registry is a prospective, nationwide registry that enrolled a total of 9,577 patients from 2004 to 2006 from 191 German centres drawn from primary care, office- and hospital-based cardiologists, and internal medicine. The registry included data on patient characteristics, medical history, presence of co-morbidities, risk factors and treatments. Patients were followed up for an average of 5.1 years after enrolment, and an updated publication on follow-up data is currently being prepared. In 2012, AFNET was nominated as the official German partner of the EURObservational Research Programme AF General Registry (EORP-AF Registry) and provides an extended contribution of 3500 patients (EORP-AF Registry Germany).

Today, AFNET is recognised as a unique centre of excellence on AF, particularly on the development of investigator-led trials. It runs a series of consensus conferences in partnership with the European Heart Rhythm Association (EHRA), the latest one focused on individualised management of AF.[172]

What has been achieved?

- Around 20 clinical trials, registries, and basic research projects completed to date, including three large completed multicentre clinical trials
- Setup of a platform for the planning, conduct, and analysis of investigator-initiated trials in Europe, where AFNET functions as an academic research organization
- Significant contribution to improving knowledge about AF through a strong media presence, multiple publications and broad, interdisciplinary membership.
- A powerful platform for engagement with the media, the German Parliament, patient groups and other stakeholders about new ways to combat AF.

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CASE STUDY 16: ROMANIA

THE FACTS SPOT REGISTRY

> "We need to convince GPs to move away from passive to active recognition of AF. Having a national registry for AF was an important first step in raising awareness of AF and the risk of stroke among the medical community."
>
> ***(Prof. Gheorghe Andrei Dan, University Clinical Hospital 'Colentina', Bucharest)***

Overview

A spot registry, run as part of a broader programme aimed at improving awareness of AF and AF-related stroke in Romania (AF-Awareness, Consciousness and Therapeutic Strategy)

Timescales

The FACTS programme began in 2010. 3800 patients were screened and 3,644 were included in the registry between 2011-2012, with a follow up of 1 year. Full results to be published in 2014.

Resource Implications

The FACTS programme is an academic initiative funded through an unrestricted grant for the registry from Sanofi Aventis. The APA 1 Euro 1 Patient project was sponsored by Boehringer Ingelheim through the "1 Mission 1 Million" project.

Links/References

Popescu R, Dan, GA, Buzea A. Secondary prevention in patients with atrial fibrillation and stroke or transient ischemic attack – an insight from the FACTS programme. Romanian J Neurology 2013; 12: 130-135. *http://www.medica.ro/reviste_med/download/neurologie/2013.3/Neuro_Nr-3_2013_Art-5.pdf*

Approach

The FACTS spot registry included patients with AF or atrial flutter identified in 27 cardiology units located throughout Romania between 2011 and 2012. It was initiated as part of the FACTS programme, which aimed to raise awareness of AF in an effort to improve adherence to guidelines on the prevention of AF-related stroke. The FACTS programme had an important educational component, and one of the central aims was to raise awareness and understanding of AF and AF-related stroke amongst GPs, as the country has relatively few cardiologists and GPs will invariably need to play a greater role in detecting AF in the future.

Collecting data through the registry has helped quantify the problem of AF and AF-related stroke and raise awareness of treatment gaps in particular groups of patients, for example those with a prior stroke or other thrombotic event. A major challenge in the future will be to improve detection of AF in general practice and convince doctors to move away from antiplatelet therapy and provide appropriate anticoagulation therapy.

The registry was created before the creation of the ESC-supported EORP pilot registry on AF (results published in 2013, 2014), and participating centres are now part of the EORP long term registry.

What has been achieved?

- Greater awareness of AF and what is happening at the local level in terms of prevention of AF-related stroke
- National data now available to help gain political support for greater resources to be spent on AF and stroke
- Greater knowledge of treatment patterns in given subgroups of patients (eg. those with prior stroke or TIA), with further analyses planned.
- Arrhythmia Patients' Association (APA) was founded based on FACTS programme

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2: CONCLUSIONS AND KEY RECOMMENDATIONS

AF-related strokes are the most deadly, debilitating and expensive strokes and are likely to increase in years to come, leading to significant morbidity and mortality across Europe. With recent guidelines and the advent of new therapeutic options offering effective stroke prevention to AF patients, there is **an unprecedented opportunity to prevent the most debilitating of strokes and save thousands of lives in Europe.**

The key to achieving this is **greater implementation of clinical guidelines**, but this will not happen without greater public, patient and professional understanding of AF and the increased risk of stroke with AF; more integrated, patient-centred; effective care pathways which foster greater coordination and a multidisciplinary approach to care; and the investment in reliable data to drive policies and target resources towards the effective prevention of AF-related stroke.

Finally, the fact that **AF is one of the major risk factors for stroke** must be communicated loud and clear to policymakers and all decision-makers, to ensure that better detection of AF and provision of effective anticoagulation therapy be considered as integral parts of the prevention of AF-related stroke and cardiovascular prevention strategies more generally.

In summary, we make the following key recommendations to improve the prevention of AF-related stroke in Europe:

1

Targeted policies and resources to enable the effective prevention of AF-related stroke

- **Global, regional and national policy leaders should consistently recognise AF as a major risk factor for stroke** alongside other 'conventional' risk factors such as smoking, high blood pressure, poor diet and physical inactivity.
- **Policymakers should also accord AF and AF-related stroke due priority in all relevant policy frameworks** – e.g. on chronic diseases, cardiovascular disease prevention and healthy ageing.
- **Governments should create national programmes** focused on AF (as exist for myocardial infarction, diabetes, and oncology).

2

Greater public awareness and understanding of AF and the increased risk of stroke with AF

- **Patient organisations and professional societies should be encouraged to lead targeted, hard-hitting awareness campaigns** to improve public understanding that AF is a major risk factor for stroke and that all patients with AF should receive appropriate OAC therapy to help reduce their risk of stroke.

3

Improved detection of AF and integration of pulse checks into clinical practice

- **Primary care physicians and specialists should screen** all their patients over the age of 65 opportunistically for AF.
- **Governments and health insurance bodies** should **integrate manual pulse checks** into national health checks.

Recommendations 4-7 on the next page.

2: CONCLUSIONS AND KEY RECOMMENDATIONS

4

Appropriate anticoagulation therapy for every AF patient at increased risk of stroke

- **Patient organisations and professional societies should work with health professionals** to develop **educational tools and resources** that may help physicians implement guidelines in practice, in terms of assessing all AF patients for their risk of stroke and offering all patients except those at very low risk of stroke the most effective OAC therapy. Tools targeting primary care physicians are particularly needed.
- **Health care system leaders** should develop **local quality improvement frameworks and centralised standards of care** to be implemented at a local level, and particularly in primary care, to reduce heterogeneity in the provision of OAC therapy to AF patients and ensure that best practice becomes embedded into local practice.

5

Patient-centred care and clear information to patients

- **All health professionals should foster a patient-centred approach to care, encourage greater patient engagement and patient education.**

6

A whole-system approach to the prevention of AF-related stroke

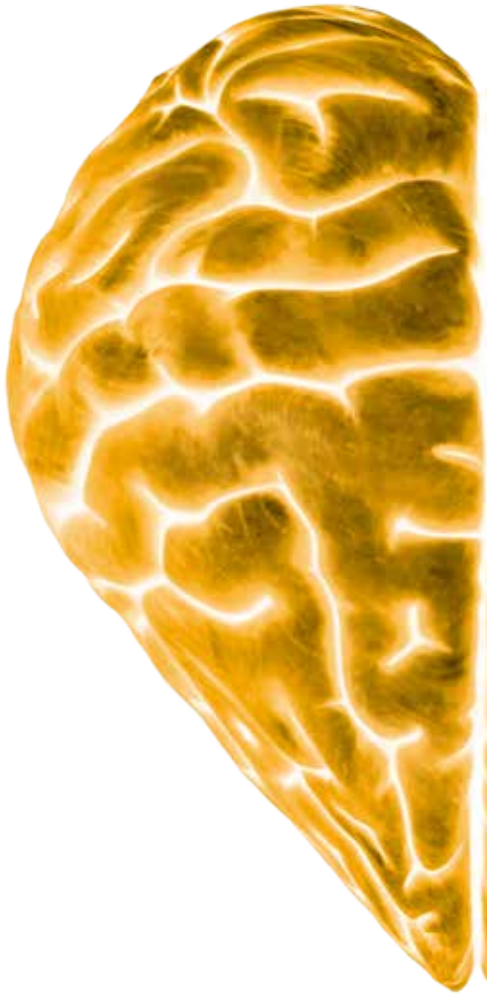
- **Health professionals should work together** and learn from other chronic diseases to identify successful models of multidisciplinary, integrated care that may help break down professional silos.

7

Better data to guide policy and clinical management

- **Governments, research institutes and professional societies** should invest in the **systematic collection of epidemiological and economic data** on AF and AF-related stroke. This will ensure that policymakers are equipped with the most reliable and up-to-date data possible to guide policies and target resources appropriately.

CASE STUDIES FOR THE ROUTE MAP FOR CHANGE



Case Studies:

Priority 1: Targeted policies and resources to enable the effective prevention of AF-related stroke

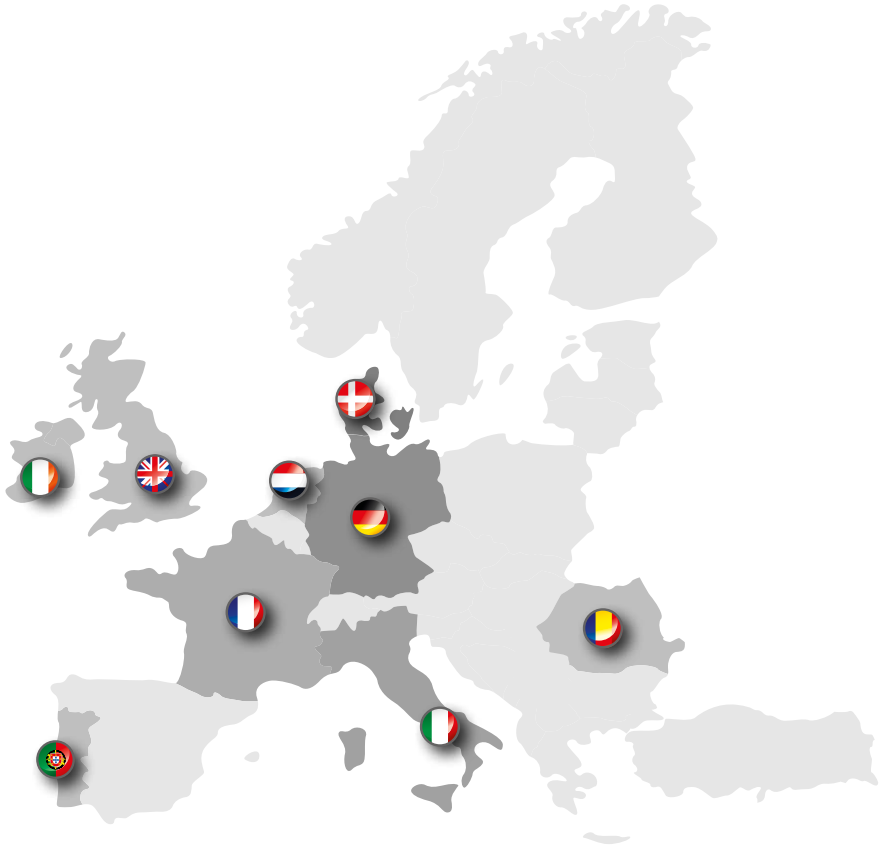
- The full integration of AF and AF-related stroke across health policy: the Irish example
- The first National Heart Day: a political call to action on heart disease from the Alliance du Coeur

Priority 2: Greater public awareness and understanding of AF and the increased risk of stroke with AF

- Bate Bate Coração Association
- The Irish Heart Foundation Awareness Campaign
- The Act F.A.S.T Campaign

Priority 3: Improved detection of AF and integration of pulse checks into clinical practice

- Pulse checks in pharmacies
- The Know Your Pulse campaign – UK, China, India, Australia, USA, Uruguay



Priority 4: Appropriate anticoagulation therapy for every AF patient at risk of stroke

- The Heart of AF programme
- EHRA practical guide to the use of new anticoagulants
- Primary care leadership driving best practice in Bradford

Priority 5: Patient-centred care and clear information to patients

- The AF risk stroke calculator
- Nurse-led integrated chronic care model for AF management

Priority 6: A whole-system approach to the prevention of AF-related stroke

- A 'One stop shop AF' clinic
- Collaboration between neurologists and cardiologists in Odense

Priority 7: Better data to guide policy and clinical management

- The German Competence Network on Atrial Fibrillation (AFNET)
- The FACTS spot registry

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