

pulse

Keeping Our Finger on the Pulse

WHY THE UK MUST ADDRESS THE
PERSONAL, CLINICAL AND ECONOMIC
IMPACT OF ATRIAL FIBRILLATION

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The following organisations support this report on the impact of atrial fibrillation.



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Foreword

Failing to diagnose and treat atrial fibrillation, the most common heart rhythm disorder,¹ causes untold misery for hundreds of thousands of people and costs the NHS billions of pounds every year.² Unless we take urgent action, this situation is not going to change - in fact it will get worse. Atrial fibrillation (AF) is more common the older you become³ and the UK has an ageing population. Action is needed now.



AF is the most common heart rhythm and is one of the top ten reasons for hospital admission in the UK.⁴ However, high though this number is, it is likely to be the tip of the iceberg. Its effects can be devastating and it increases the risk of stroke five-fold.⁵

This report has analysed, for the first time, the total cost to the NHS of AF. Patients diagnosed with AF took up 5.7m bed days in 2008 at a cost of £1.8bn. In addition it is estimated that the direct cost of AF-related strokes could reach £750m a year. In a time when we are tightening the public purse strings this is a cost we simply cannot and should not afford to bear.

It is not just the financial cost that counts. The human cost of AF is also significant. The condition dramatically undermines patients' ability to perform simple everyday tasks

that most of us take for granted. The breathlessness caused by AF means sufferers find it hard to do their housework, cook, gardening or even walk up the stairs.⁶ For those who previously led active lives this can lead to mental health problems. A study in Chest found that a third of AF patients developed increased levels of depression and anxiety which often lasted for six months.⁷

This is a bleak picture, but it does not have to be this way. Some relatively straightforward measures could transform the situation, socially, medically and financially.

These are:

- Policy makers should ensure that AF is a NHS priority
- Raise awareness of AF prevention among healthcare professionals and the general public
- Encourage early identification and treatment of AF

- Establish an AF champion in every NHS trust
- Commission better services for AF
- Improve patient information and
- Encourage research and rapidly implement new treatments as they become available.

This research report outlines in detail how all these points can be achieved and I commend it to you.

**Trudie C A Lobban MBE,
Founder and Chief Executive
Officer, Atrial Fibrillation
Association**



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Executive summary

A heart rhythm disorder, atrial fibrillation (AF) is associated with an increased long-term risk of stroke, heart failure, and death, especially in women.¹ Patients with AF are up to five times more at risk of developing a stroke than people without AF.² This report examines the key issues and challenges that currently hinder optimal AF care. This report also suggests areas where policy makers could focus their attention to reduce AF's human, clinical and economic impact.

AF is one of the top 10 reasons for hospital admissions in the UK.³ The prevalence of AF roughly doubles with each advancing decade of age, from 0.5% at age 50-59 years to almost 9% at age 80-89 years.⁴ Unfortunately, for many health professionals, awareness and understanding of heart rhythm disorders is low, which can lead to some disorders being undetected.³ Furthermore, it is estimated that by 2050, 2% of the population will have AF,⁵ further underscoring the need to improve prevention, diagnosis and management.

AF exerts a considerable economic toll on the NHS. For example, patients with primary or secondary diagnoses of AF occupied an estimated 5.7 million bed days in 2008, at a cost to the NHS of £1,873 million.⁶

Statistics paint only a partial picture of the impact of AF. Behind each statistical case

lies a personal story of distress, disability and despair. AF can dramatically undermine patients' ability to perform simple everyday tasks. AF causes persistent clinical depression and anxiety in around a third of patients.⁷

Against this background, this report identifies several pressing challenges that policy makers need to meet to reduce the morbidity, mortality and economic toll associated with AF:

- The NHS needs to improve identification of people with AF. Early detection and treatment could prevent irreparable damage to the heart and reduce the risk of stroke, heart failure and other long-term complications.
- Patients and clinicians need improved treatments to establish and maintain normal rhythm. Current drugs can be unsuitable

or ineffective in many patients, commonly cause side effects and may require regular monitoring to maintain optimal blood levels.

- Every AF patient should be able to access dedicated clinics in primary and secondary care run by experienced clinicians. For example, Primary Care Trusts (PCTs) could consider funding out-reach AF, anticoagulation and dedicated secondary care clinics to ensure a clear care pathway.
- Every AF patient should be able to access specialist arrhythmia nurses who provide support and information for sufferers and their carers. Specialist arrhythmia nurses should also ensure that patients receive timely assessment and diagnosis, effective treatment and rehabilitation.

- Every person with AF should be able to access improved information to become an expert patient and, therefore, participate as fully as they wish in decisions about their care. Currently, information provision usually falls short of this ideal. Furthermore, the lack of awareness among the public probably contributes to the under-diagnosis of AF. The NHS and other stakeholders need to provide a diverse, reliable and accurate array of information sources. Patients need to have the chance to regularly discuss their disease and care with specialist nurses or other healthcare professionals.

To address these issues, this report suggests several key actions to improve AF care:

- **Policy makers should ensure that AF is an NHS priority:** AF traditionally receives scant attention from policy makers, and is under-diagnosed and under-treated by clinicians. AF should be a core public health priority, supported by measured outcomes, accurate data (especially on prevalence), standards, targets, Quality and Outcomes Framework (QOF) points and other initiatives and incentives.
- **Raise awareness of AF prevention among healthcare professionals and the public:** Policy makers need to deploy a variety of tactics to increase health professionals' awareness of AF and its risk factors as well as encouraging opportunistic screening. The DH should fund public awareness campaigns to ensure patients with possible symptoms see their GP.
- **Encourage early identification and treatment of AF:** Early diagnosis and rapid treatment is a prerequisite to reducing the morbidity and mortality associated with AF and stroke. QOF indicators should encourage active identification of AF in patients with associated risk factors, encourage referral of these patients as appropriate for treatment at the earliest opportunity and the NHS Health Check should require clinicians to check pulse rate.
- We identified several examples of 'best practice' in AF diagnosis that the DH should ensure are implemented nationwide.
- **Establish an AF champion in every Trust:** A doctor or nurse with a special interest or healthcare manager needs to take responsibility for improving AF services in every PCT and hospital Trust. This AF champion

should communicate best clinical practice, lead non-clinical initiatives - such as developing a business case for improved AF services - and represent patients' interests.

- **Commissioning better services for AF:** Health commissioners should identify barriers for AF services, examine patient pathways, estimate local costs, and evaluate the implementation of NICE guidelines. Commissioners should ensure AF care links seamlessly with networks managing stroke, heart failure and other associated conditions. Commissioning agreements and local protocols should increase awareness of AF referral pathways among healthcare professionals. Dedicated clinics in primary and secondary care, as well as access to a specialist nurse, should be integral

elements. Trusts should set standards and audit their performance before and after implementing improved services.

- **Improve patient information:** The DH, PCTs, patient support organisations and other stakeholders should provide information and education that encourages patients to become 'experts' in AF and participate as fully as they wish in their care. Patients should have regular opportunities to discuss AF and treatment options with an appropriate healthcare professional.
- **Encourage research and rapidly implement new treatments:** AF poses diagnostic and management difficulties for health professionals. Therefore, there is a pressing need for further research into the causes and management of AF. In particular, there is

a need for innovative new treatments for AF. NICE, the SMC and other stakeholders need to evaluate new interventions rapidly and PCTs and hospital Trusts must implement advances promptly to ensure patients can benefit as soon as possible.

Demographic changes suggest that the UK faces a dramatic increase in the number of people with AF over the next few decades. However, several innovative interventions will reach the clinic over the next few years and services need to be in place to allow patients to derive the most benefit from these advances. Changes in AF service provision are clearly essential and healthcare professionals, purchasers and policy makers need to focus on AF. Educational initiatives need to increase awareness of AF. The NHS and the UK cannot - literally - afford to ignore AF any longer.

Introduction: Don't underestimate AF

This report articulates a simple central argument: the time is right for politicians, policy makers and clinicians to improve the prevention, diagnosis and management of AF.

AF is the most common heart rhythm disorder in the UK.⁸ In 2008 there were an estimated 851,095 GP visits attributable to AF in the UK.⁶ The risk of developing AF rises sharply with advancing age, roughly doubling each decade throughout life.⁴ The prevalence of AF in the UK rose from 0.78% in 1994 to 1.42% in 2006.⁹ Some estimates

predict a three-fold rise in the number of cases over the next 50 years.^{9,10}

Nevertheless, anecdotal evidence from a recent YouGov survey suggests that many clinicians under-estimate AF.

One patient commented: "I feel that medics trivialise your symptoms. I had a strong feeling of that when I was

in hospital for nine days and saw many different docs. I find it hard to believe that the enormous speed that my heart is pumping or missing beats doesn't add up to a problem over a period of 40 years!"¹¹

Improved management of AF could reduce the morbidity, mortality and expense arising from several other serious diseases associated with AF.

“ I find it hard to believe that the enormous speed that my heart is pumping or missing beats doesn't add up to a problem

Section One: What is atrial fibrillation (AF)?

AF is a condition in which the atria, the upper chambers of the heart, beat in an uncoordinated and disorganised way, resulting in an irregular heart rhythm. This can lead to serious complications including stroke and deterioration of the heart function.⁸

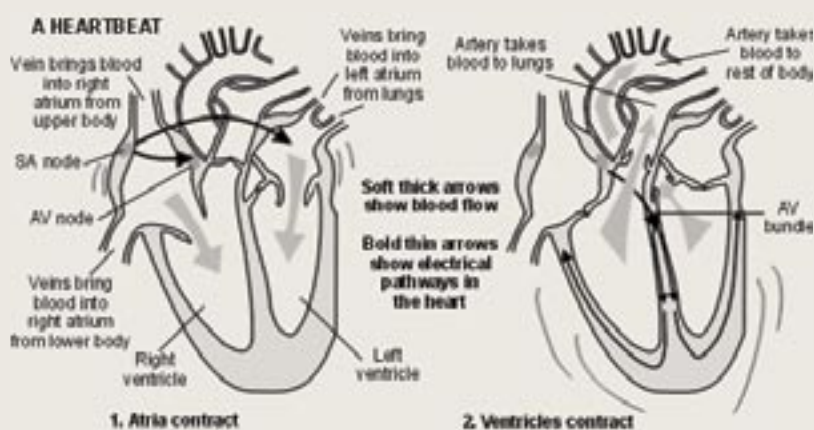


Figure 1 The heart's co-ordinated contraction

In people with AF, abnormal electrical activity in the atria disrupts the heart's normal rhythm. This causes the atria to beat extremely rapidly and irregularly, at rates of 400-600 beats per minute.¹² This leads to an increase in the rate at which the larger lower chambers of the heart (the ventricles) beat, rising to 110-180 beats a minute.¹² AF may also have serious consequences,^{1,2,13} the most important of which is stroke, with one in every six strokes caused by AF.¹⁴ This is

because the heart does not pump the blood completely out of the heart's chambers. Instead the blood pools and clots, and there is a risk that the clot will travel out of the heart and block an artery in the brain. During the past 20 years, there has been a 60% increase in the number of people with AF being admitted to hospital as a result of AF.¹⁵ This is probably due to the increasingly ageing population.

The AF Aware survey ('Close the Gap'), sponsored by a grant from sanofi-aventis, aimed to gain an insight into

the burden that AF places on patients. AF Aware enrolled 810 cardiologists and 825 patients from 11 countries: the UK, Canada, the USA, Mexico, Brazil, Germany, France, Spain, Italy, China and Australia. Overall, 56% of the patients were men and the median age was 64 years. The UK contributed 100 cardiologists and 75 patients. Of these, 33% experienced AF episodes at least once a week. A further 11% experienced AF less than once a week but more than once a month.¹⁶

types of AF

There are three main types of AF:

Paroxysmal:

Recurrent, sudden episodes each of less than seven days' duration - most paroxysmal attacks resolve within two days. In the AF Aware survey, 43% of UK patients experienced recurrent episodes that ceased in less than seven days.¹⁶

Persistent:

Episodes that last longer than seven days and that can recur after treatment. In the AF Aware survey, 33% of UK patients experienced recurrent episodes that lasted at least seven days.¹⁶

Permanent (established):

The heart does not revert fully to normal rhythm, even with treatment. In the AF Aware survey, 24% of UK patients experienced on-going, established AF.¹⁶

These types of AF are not mutually exclusive - a patient may have several paroxysmal episodes and occasional persistent AF, or vice versa. Overall, however, patients generally progress from occasional episodes to permanent AF.

Section Two: The tip of the iceberg?

By 2050, epidemiologists estimate that 2% of the general population will show AF.⁵

AF will inevitably become even more common over the next few decades due to the ageing population and increased longevity among patients with diseases that predispose to AF, such as coronary artery disease, hypertension and heart failure. The proportion of the UK population aged 65 years and over will increase from 15% in 1983 to an estimated 23% by 2033. In 1983, just over 600,000 people in the UK were aged 85 and over. By 2033, the number of people aged 85 and over could reach 3.2 million, equivalent to 5% of the UK population. Some estimates predict a three-fold rise in the number of cases over the next 50 years.^{9,10} The large and growing number of cases further underscores the need for improved prevention, diagnosis and management.

Table 1 summarises the prevalence (total number of cases) and annual incidence (number of new cases) of AF in the UK. However, the figures in table 1 probably represent considerable underestimates; AF may remain undiagnosed if symptoms are sporadic or do not markedly undermine quality of life or both. Furthermore, asymptomatic episodes of paroxysmal AF are around 12 times more common than attacks that cause symptoms. (Despite the lack of symptoms, these 'silent' attacks still increase the risk of complications.) Many patients

may also manage episodes of paroxysmal AF without resorting to medical attention. Such factors could lead to a "systematic underestimation of the incidence of AF".¹⁷ The difficulties in accurately assessing the epidemiology underscore the importance of improving clinicians' awareness of, and diagnostic acumen for, AF as well as the need to educate symptomatic patients to seek medical attention. The tables in Appendix 1 offer a regional breakdown of the epidemiology of AF across the UK.

Overall prevalence	843 708
Prevalence among people over 65 years of age	798 967
Annual incidence	90 157

Figure 1 Prevalence and incidence of AF in the UK

Section Three: A heavy economic burden

Not surprisingly, given the severe sequelae, the human, clinical and societal burdens imposed by AF translate into a considerable economic toll. The NHS Stroke Improvement Programme's own data suggests that up to 4,500 strokes and 3,000 deaths per year could be prevented through appropriate anticoagulation of all patients with AF.¹⁸ However, few studies evaluate the direct NHS or indirect costs imposed by AF. Therefore, the Office for Health Economics (OHE) has estimated the total cost of AF to the NHS based on primary or secondary diagnoses, such as AF-related stroke or heart failure.

The OHE found that patients with primary or secondary diagnoses of AF occupied 5.7 million bed days in 2008, at a cost to the NHS of £1,873million.⁶ Outpatient costs (such as electrocardiograms, monitoring anti-coagulant treatment, and post discharge attendance) accounted for £205 million.⁶ Inpatient costs other than bed days reached £124 million⁶ (figure 2). The "systematic

underestimation of the incidence of AF"¹⁷ means that these figures are likely to underestimate the economic burden. Nevertheless, these figures underscore the importance of improving diagnosis and standardising data collection.

Clearly, improved prevention, diagnosis and management of AF could result in considerable savings that the NHS could

reinvest to meet other public health priorities. The National Audit Office estimated that in 2008-2009 the direct care cost of stroke was at least £3 billion annually, within a wider economic cost of about £8 billion.¹⁹ AF causes up to a quarter of strokes. Therefore, it could be estimated that the direct cost of AF-related stroke could reach £750 million annually.

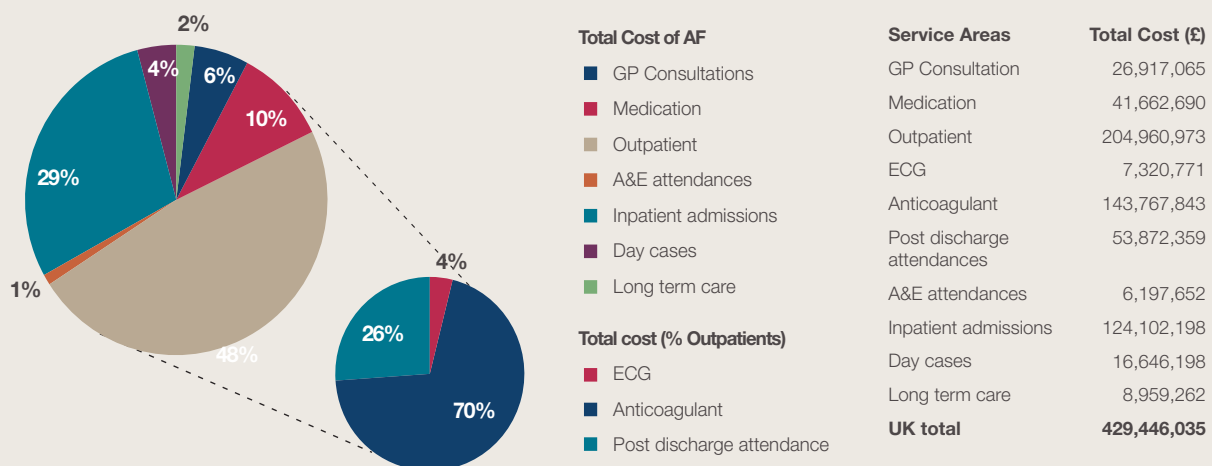


Figure 2 The breakdown of costs of AF management

Section Four: The personal impact of AF

These statistics paint only a partial picture of the problem posed by AF. Behind each statistical case lies a personal story of distress, disability and, often, despair. In the AF Aware study, 25% and 19% of UK patients suffered moderate and severe symptoms respectively.¹⁶ Only 24% were asymptomatic.¹⁶ Andrew Rankin, Professor of Medical Cardiology at the University of Glasgow and consultant cardiologist and Glasgow Royal Infirmary, explained that the symptoms and fear arising from AF effectively disables many patients. “There’s a wide spectrum with some patients totally debilitated,” he said. “The ones who suffer paroxysmal AF are more symptomatic because they suddenly switch rhythm and are very conscious of the change.”

AF’s symptoms can dramatically undermine patients’ ability to perform simple everyday tasks that most people take for granted. AF reduces the flow of oxygen-rich blood to the muscles and other tissues. As a result, many AF patients experience marked breathlessness, which is often the first symptom, when they walk up stairs, carry out housework or cook.²⁰

For people who led active lives, AF leaves them feeling frustrated and can result in clinical depression. Anecdotal evidence from a recent YouGov survey included: “I worked on a cruise ship, which was my dream job, but I had to give it all up since being diagnosed,” one AF patient said. “This has led to depression.”¹¹

Another patient remarked: “On days when I don’t feel well and am unable to do much, I feel my life may be over.”¹¹ “Some patients simply give up living life,” added Dr Steve Murray, cardiologist and electro-physiologist at the Freeman

Hospital in Newcastle. “If you scratched below the surface you’d find a cohort of quite disabled patients who have stopped going on holidays or taking part in any activities.”

Furthermore, a compelling body of evidence highlights the psychological toll imposed by AF. A study from Birmingham found that around a third of AF patients have increased levels of depression and anxiety, which often persisted for six months.⁷ The rates of depression and anxiety among AF patients were similar to those in people who survived a heart attack.⁷ Not surprisingly, depression and anxiety strongly influenced patients’ quality of life.⁷

Many patients feel that clinicians do not recognise or adequately manage AF’s psychological impact. One AF patient, within the YouGov research, also commented: “The psychological aspects are all but ignored by the doctors, yet I feel these are far, far worse than the physical effects.”¹¹

Against this background, 23 people with AF were interviewed through an online forum. Fourteen patients were female and ages ranged from 37 to 80 years. Respondents said that they found living with AF frustrating, depressing and added that the disease created a feeling of helplessness. One respondent commented: “I am still relatively young, and I hate living with AF. My self-confidence has gone completely. My life is completely different to before. I now suffer anxiety attacks, and am convinced every time I feel a flutter that my time is up.”²⁰

The survey suggested that the fear of suffering a deadly or debilitating stroke imposes a particular burden on patients with AF. “I try not to think about the future, because I am still very new to this, and do not know how much I can do without giving myself a stroke. But I am quite old, and do not think I can live for years with AF,”¹¹ another respondent remarked.

Section five: The Cinderella heart condition

Despite being common, potentially fatal, and with an economic toll running into billions, AF rarely attracts the attention the severity and epidemiology warrants. Figure 3 (below) shows that clinicians do not regard AF as especially life threatening - a view at odds with the clinical evidence. However, clinicians clearly regard stroke as life threatening. This suggests that clinicians may not fully appreciate the strength of the association between stroke and AF.

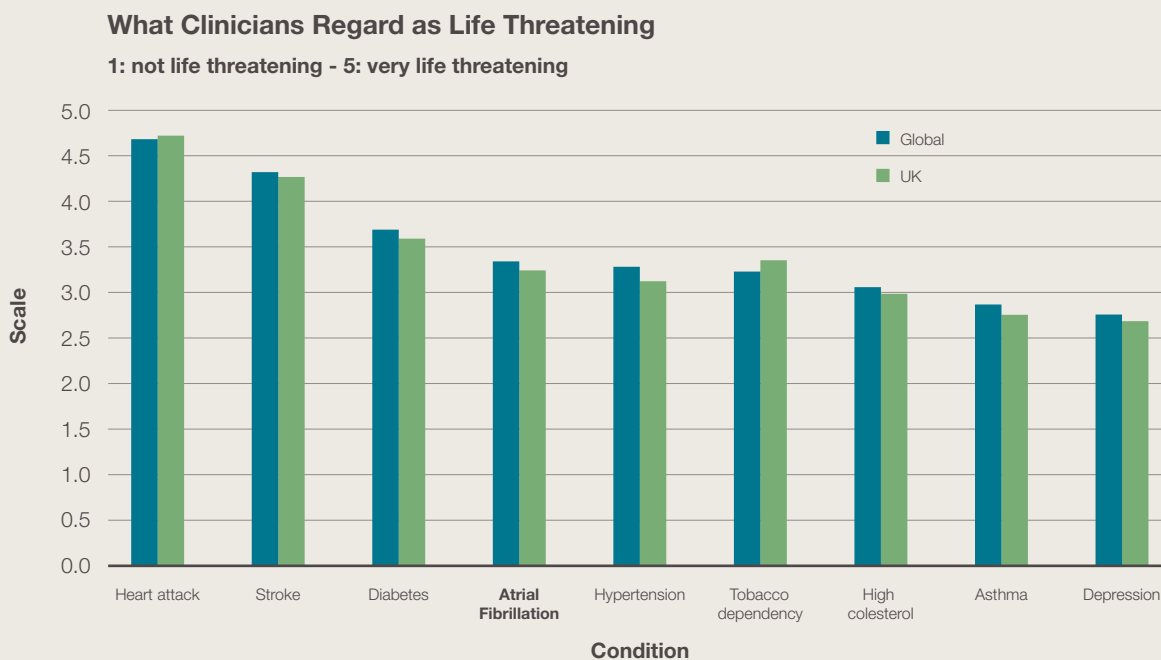


Figure 3 Clinicians' perceptions of the threat to life posed by various diseases

Dr Murray explained: “AF is a bit of a Cinderella disease because it doesn’t appear in mortality figures even though, in some cases, it causes and is associated with high levels of morbidity and mortality.” The lack of definitive economic data means that AF does not attract appropriate attention from healthcare policymakers. Meanwhile, a paucity of innovative treatments has resulted in a lack of consultant-led projects to improve best practice. “AF has not been seen as a priority for resources, education or newsworthiness,” added cardiologist, Dr Khalid

Khan, from the Betsi Cadwaladr University Health Board, North Wales. “Services are far smaller than for other cardiovascular diseases. Things have begun to improve but there has been a lack of emphasis.”

Physicians surveyed for AF Aware identified five challenges that policy makers need to meet to reduce the morbidity and mortality associated with AF:

- The NHS needs to improve identification of people with AF and then stratify patients based on their risk of developing strokes and other complications.
- Patients and clinicians need improved treatments to establish and maintain normal rhythm.
- Every AF patient should be able to access dedicated clinics and electrophysiological services.
- Every AF patient should be able to access specialist nurses.
- The NHS and other stakeholders need to offer improved information to allow patients to participate as fully as they wish in treatment decisions.

“ AF is not being seen as a priority for resources, education or newsworthiness

Dr Khalid Khan

Cardiologist, Betsi Cadwaladr University Health Board, North Wales

Section six: The importance of early diagnosis

AF offers a classic example of a biological vicious cycle. AF usually progresses from occasional paroxysmal symptoms, to persistent episodes and, eventually permanent arrhythmia. When AF lasts minutes to hours, restoring normal rhythm reverses any damage to the heart. However, persistent arrhythmia results in irreversible atrial damage. Early detection and treatment could prevent this.²¹

However, the AF Aware international survey reported an average delay of 2.6 years between the onset of symptoms and the diagnosis of AF¹⁶, increasing the risk of stroke and other serious sequelae. In the UK, the delay averaged 1.1 years.¹⁶ In 15% of cases, doctors diagnosed AF during a routine check up and in 44% during a consultation for another condition.¹⁶

Furthermore, several conditions other than AF can cause symptoms such as breathlessness, palpitations and dizziness. Partly as a result, Dr Khan notes, AF is often more difficult to diagnose and manage than other cardiovascular diseases. "We need efficient ways of detecting AF. Currently, many people are only picked up when they're in crisis; they are the tip of the hidden iceberg," he says. Indeed, NICE guidelines

state that identification of AF is a key priority and advocate performing ECGs in all patients with an irregular pulse, whether they experience AF symptoms or not.²²

The Quality and Outcomes Framework (QOF) rewards practices for producing a register of AF patients and for the percentages, firstly, diagnosed by ECG or a specialist and, secondly, treated with anticoagulants or anti-platelet therapy. However, the QOF indicators do not encourage active identification of AF in patients with associated risk factors, such as age or obesity, who may benefit from additional treatment to anticoagulation alone. Additionally, the NHS Health Check for adults aged 40 to 74 years does not require clinicians to check pulse rate. The DH should consider revising the QOF and NHS

Health Check protocol to address these deficiencies.

The NHS's *Commissioning for Stroke Prevention in Primary Care - the Role of Atrial Fibrillation*²³ suggests several methods that potentially increase the number of AF cases detected. For example, the SAFE study, conducted in Birmingham, found that opportunistic screening for AF was more cost-effective than population screening. The Bedfordshire and Hertfordshire Heart and Stroke Network measured pulse rates when patients attend a flu vaccination clinic (see case study). The groups of patients that the DH recommends should receive flu jabs has a high overlap with those at high risk of developing AF. However, while these and other initiatives are encouraging, the NHS, policy makers and clinicians need to ascribe AF diagnosis a higher priority.

case study

Screening for AF at flu clinics

At Pemberley Surgery in Bedford, two nurses measured pulse rates of every attendee over 65 years of age who was not already on the AF register when they attended for their flu jab. The PCT agreed to pay the practice for performing screening ECGs on all patients with an irregular pulse. Patients also received information leaflets. The nurses screened 345 patients. They found 21 patients with irregular pulses, 14 of whom attended for follow-up ECG. As a result, the practice included seven new cases on their AF register, giving a prevalence of 1.9%.

Section seven: The urgent need for more treatment options

New AF treatments will give extra impetus to initiatives to improve early diagnosis. Currently, the British physicians surveyed by AF Aware considered AF management to be particularly demanding and difficult (figure 4). “Atrial fibrillation is a difficult condition to manage because it’s not a single condition and its symptoms and impact vary from patient to patient,” Professor Rankin remarks.

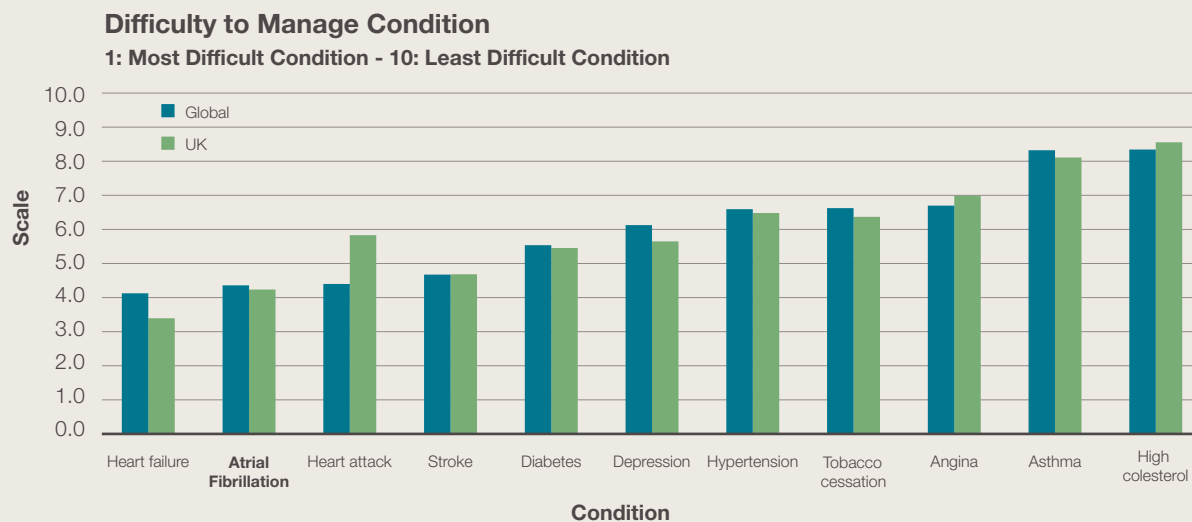


Figure 4 Clinicians regard AF as especially difficult to manage

Doctors treat AF by restoring and maintaining a normal heartbeat (cardioversion) and preventing blood clots forming by using anticoagulants or antiplatelet agents. Drugs are usually the first-line treatment. According to the AF Aware survey, 93% of UK AF patients take medication: 86% take anticoagulants or antiplatelet agents, 64% and 69% take

drugs to manage heart rhythm and heart rate respectively,¹⁶ although according to other data sources, fewer than 20% of AF patients are offered anti-arrhythmic agents.²⁴

“We’re on the horns of a dilemma”, Dr Murray told us. Many patients and doctors, in my experience, do not like the current therapies (figure 5) but, as Dr Murray continued, “aspirin

is a poor second best to warfarin for the prevention of stroke and thromboembolism in AF” and may reduce risk by affecting concurrent vascular disease rather than modulating AF.²⁵

Anti-arrhythmic drugs can help restore normal rhythm during a sudden-onset sustained attack, prevent or reduce the risk of recurrence, establish

a normal rhythm and offer long-term suppression of AF.^{21,5} However, conventional anti-arrhythmic drugs show sub-optimal efficacy in at least some groups of patients and especially during long-term treatment. Furthermore, clinicians cannot always accurately predict the risk of inducing arrhythmias and toxicity in individual patients taking anti-arrhythmic drugs.⁵

Currently, the OHE estimates that medications account for only 10% of the costs of managing AF - around £41.7 million in 2008 across the UK.⁶ In contrast, anticoagulant monitoring costs an estimated £143.8 million in 2008.⁶ Furthermore, the OHE estimated that in-patient admissions accounted for 29% of the cost

offset much, if not all, of the costs of new pharmaceuticals. This needs confirmation in formal health economic evaluations. Nevertheless, NICE, the SMC and other stakeholders need to evaluate new interventions rapidly, and PCTs and hospital Trusts must implement advances promptly to ensure patients can benefit as soon as possible.

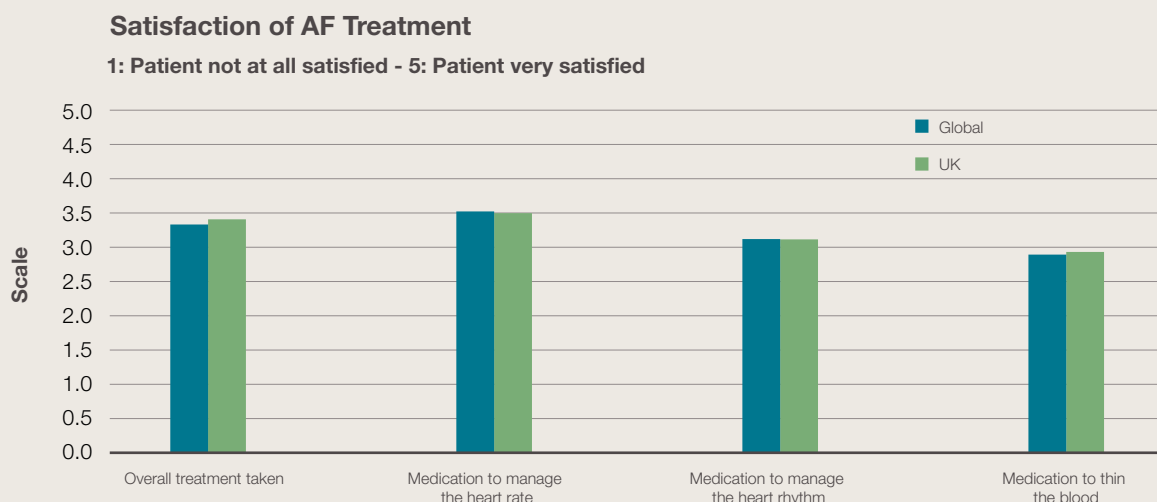


Figure 5 Clinicians' perceptions of patients' satisfaction with AF treatment

"There does seem to be an attitude of put up and shut up," Dr Murray remarks. Rate control drugs, however, are able to reduce symptoms by controlling the heart rate, particularly in patients with permanent AF. The rate control agent digoxin, for example, slows the heart rate by decreasing conduction of electrical impulses between the atria and ventricles.

associated with AF. Considerable uncertainty surrounds these costs – underscored by the discordance between the total cost (£429 million) and the expenditure on beds alone (£1.7 billion).⁶ Nevertheless, the proportions suggest that investing more in current and improved drugs that prevent in-patient admissions could

Clearly, there is a need for better AF treatments. "We would like a medication that can maintain rhythm without side effects, that can be used with other therapies, that is effective and remains so in the long term with a low set of contraindications," Dr Murray said. "That would make a big difference."

Section eight: Structure and delivery of AF care

Dedicated clinics

As mentioned above, AF diagnosis and management often proves difficult. In the AF Aware survey, 31% of UK patients with AF had never seen a cardiologist.¹⁶ A further 24% saw their cardiologist less than once a year.¹⁶ Indeed, 35% of patients with this potentially debilitating condition only saw their GP once a year or less.¹⁶ It seems unlikely that, in many cases, this level of engagement with primary and secondary care is sufficient to ensure optimal management.

Patients need to be able to access dedicated clinics in primary and secondary care run by experienced clinicians. According to Professor Rankin, diagnosis is relatively straightforward after a patient's admission to hospital. However, as AF is now included in the QOF, the community healthcare teams need to diagnose and manage more patients. Diagnostic initiatives

such as those mentioned above will help. PCTs could consider funding outreach AF or anticoagulation clinics in primary care. Furthermore, PCTs could consider commissioning dedicated secondary care clinics to ensure a clear care pathway that will aid the diagnosis, treatment and rehabilitation of AF patients.

Specialist nurses

Specialist nurses are key members of the clinical teams caring for conditions as diverse as cancer, Parkinson's disease, asthma and diabetes. Specialist nurses perform much of the routine management of, and screening for, serious diseases, helping GPs and specialists meet their other commitments or deal with more complex cases.

Specialist arrhythmia nurses offer a dedicated point of contact and advocate for patients with heart rhythm

problems. Specialist nurses can provide support and information for patients presenting with arrhythmias such as AF and ensure that patients receive timely assessment and diagnosis, effective treatment and rehabilitation. "If you have a key member of staff who can concentrate on patients it impacts the care given, focuses healthcare more effectively and gives people a point of contact," comments Dr Faizel Osman, consultant cardiologist and electrophysiologist at University Hospital Coventry.

In North Wales, the British Heart Foundation funded two specialist nurses who worked across the NHS supporting AF patients. Dr Khan reported that benefit was so clear that the health board now funds the nurses. However, all patients should be able to access specialist nurses and the DH should ensure that best practice, established in places such as Coventry and North Wales, extends nationwide.

Section nine: The need for improved access to information about AF

Expert patient programmes, run by the DH and PCTs, increase patients' confidence that they can manage their disease, improve quality of life and optimise clinical outcomes. In many cases, expert patient programmes decrease the perceived intensity of several symptoms, such as pain, tiredness, depression and breathlessness.

The AF Aware survey shows the extent to which patients are unable to manage their condition optimally due to their clinicians not providing them with enough information (figure 6). Everyone with AF should have the opportunity to become an expert patient and be able to participate as fully as they wish in decisions about their care. The survey suggested that physicians considered that

patients did not have access to easy-to-understand information. They also suggested that there was insufficient information available to patients and patients and their carers often did not know where to look for information (figure 7).

The lack of awareness about AF among the general public probably contributes to the pervasive under-diagnosis.

Dr Osman says many people never ask their GPs about palpitations. "There's nothing we pass on to patients," Professor Rankin commented. "There's an option to get information from other sources like the Atrial Fibrillation Association or the British Heart Foundation but the NHS hasn't been all that good at producing documents."

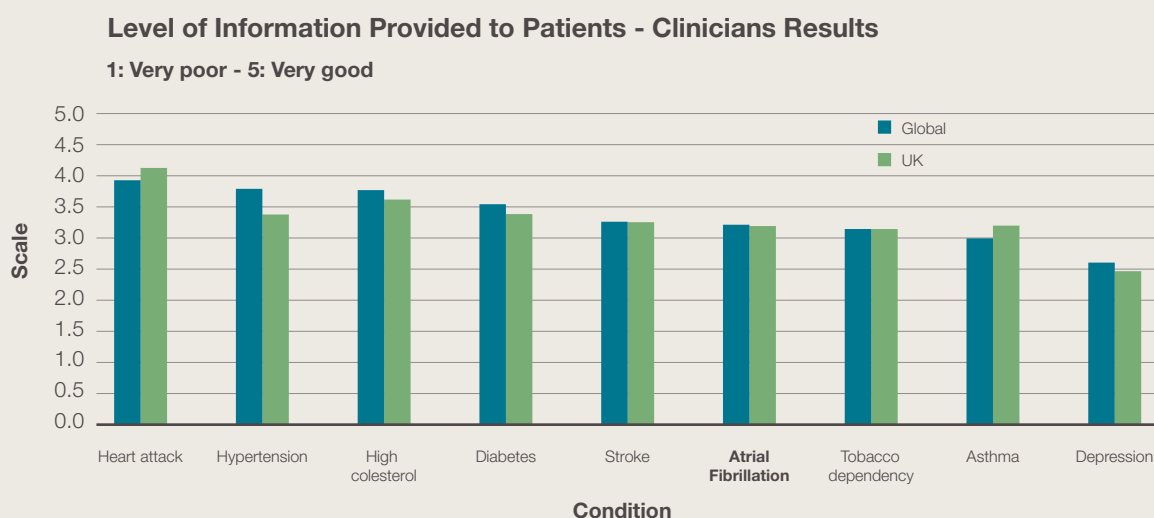


Figure 6 Clinicians' perception of the quality of information provided to patients

Patients also condemned the lack of information (see case study). One patient, surveyed by YouGov, described “being sent home with tablets for ‘chronic heart failure’ without time to talk to anyone”.¹¹ The importance of talking to a health professional and getting reassurance is particularly important for AF,

which commonly engenders considerable fear and anxiety. The NHS and other stakeholders need to provide a diverse, reliable and accurate array of information sources to hone patients’ ability to participate as fully as they wish in decisions about their healthcare. As the AF Aware study showed (figure 8),

clinicians highlighted patients’ relative ignorance around key areas of their treatment. Specialist nurses could also educate, inform and reassure patients. Written information alone is insufficient. All AF patients should have the opportunity to discuss their disease and treatment with a healthcare professional.

Level of Information Provided - Clinicians results

1: Strongly disagree - 5: Strongly agree

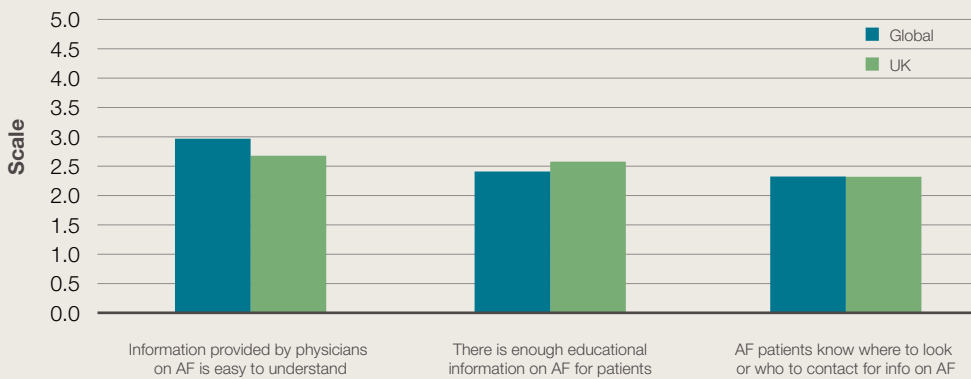


Figure 7 Clinicians’ perceptions of deficiencies in the information provided to patients

Patient Knowledge of AF - Clinicians Results

1: Patient not at all familiar - 5: Patient very familiar

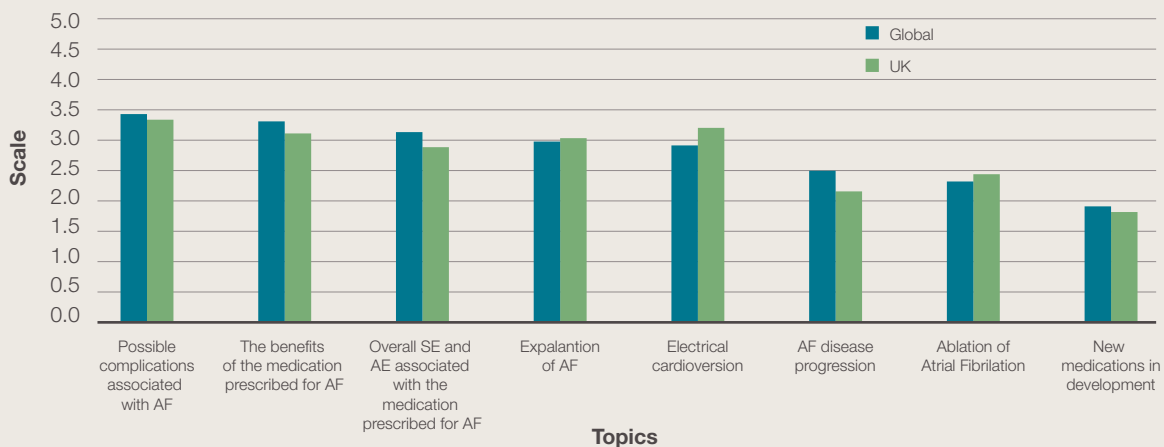


Figure 8 Clinicians’ perceptions of the extent of patients’ knowledge about AF and its treatment

case study

A patient's story

After my admission to casualty, I was given an ECG, wired up to monitor and placed on a drip. After some time, I was told that I would need to be admitted to a cardiac ward. I was placed on a heart monitor and continued with the drip. Later, I was told I would need to have shock treatment, but after several hours without food or drink I was told that a medical reversal was to be attempted. I was put on another drip, and observed continuously until the heart pattern became normal. Immediately after this, I was told I could get dressed and go home. I found this a bit disconcerting. One minute, I was wired up to heart monitors, the next I was out on my own. I was given a letter for my doctor and an appointment for four months later at outpatients. When my stay in the cardiac ward ended after the reversal, I felt none of the staff were interested in me any longer. It would have been nice to have five minutes with a cardiac nurse just to talk over what had happened and what might happen again.

Conclusion: A call to action

One in 25 adults over 60 and one in 10 adults over 80 has AF. Inexorable epidemiological changes suggest that the number of AF cases will rise markedly over the next few decades. Implementing several key actions would dramatically improve AF care.

1 Make AF an NHS priority: AF traditionally received very little attention from policy makers and is under-diagnosed and under-treated by clinicians. That needs to change. AF should be a public health priority, supported by measured outcomes, standards, targets, QOF points and other initiatives and incentives.

2 Raise awareness of AF prevention among healthcare professionals and the public: Several factors including age, obesity, hypertension, congestive heart failure increase the risk of developing AF. Educational initiatives, Health Check Protocols, local commissioning agreements and QOF points need to increase health professionals' awareness of AF and its risk factors as well as encouraging opportunistic screening. The DH should fund public awareness campaigns to ensure patients with possible symptoms (such as palpitations and excessive breathlessness) see their GP.

3 Encourage early identification and treatment of AF: Early diagnosis and rapid treatment is a prerequisite to reducing the morbidity and mortality associated with AF and its complications, such as stroke. Therefore, commissioners and health professionals should develop local opportunistic screening programmes for AF. Moreover, QOF indicators should encourage routine opportunistic screening, appropriate referral to secondary care for treatment initiation and the NHS Health Check programme should include pulse rate.

4 Establish an AF champion in every trust: A doctor, nurse with a special interest or healthcare manager needs to take responsibility for improving AF services in every PCT and secondary care trust. This AF champion should communicate best clinical practice, lead non-clinical initiatives - such as developing a business case for improved AF services - and represent patients' interests.

- 5 Commission better services for AF:** Health commissioners should identify barriers for AF services, examine patient pathways, estimate local costs, and evaluate the implementation of NICE guidelines. Commissioners should ensure AF care links seamlessly with networks managing stroke, heart failure, dementia and the other serious conditions associated with AF. Commissioning agreements and local protocols should increase awareness of AF referral pathways among healthcare professionals. Dedicated clinics in primary and secondary care, as well as access to a specialist nurse should be integral elements in commissioning. Trusts should set standards and audit their performance before and after implementing improved services.
- 6 Improve patient information:** The DH, PCTs, patient support organisations and other stakeholders should provide information and education that encourage patients to become 'experts' in AF and participate as fully as they wish in their care. Written information alone is inadequate. Patients must have the opportunity to discuss AF and treatment options with a specialist nurse or another healthcare professional.
- 7 Encourage research and rapidly implement new treatments:** AF poses diagnostic dilemmas and management difficulties for health professionals. Therefore, there is a pressing need for further research into the causes and management of AF. In particular, there is a need for innovative new treatments for AF. NICE, the SMC and other stakeholders need to evaluate new interventions rapidly, and PCTs and secondary care trusts must implement advances promptly to ensure patients are appropriately referred and can benefit as soon as possible.

The UK faces a dramatic increase in the number of people with AF over the next few decades. Unless the NHS takes urgent action, the number of strokes and other serious complications arising from AF will rise markedly.

Several innovative therapies will reach the clinic over the next few years and services need to be in place to allow patients to derive the most benefit from these advances. Changes in AF service provision are clearly essential and healthcare professionals, purchasers and policy makers need to focus on AF. Educational initiatives need to increase awareness of AF. The NHS and the UK cannot – literally – afford to ignore AF any longer.

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