

# pulse

## Keeping Our Finger on the Pulse

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

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AUGUST, 2010



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



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# Foreword

Failing to diagnose and treat atrial fibrillation (AF), the most common heart rhythm disorder,<sup>1</sup> causes untold misery for thousands of people in Wales and costs NHS Wales millions of pounds every year.<sup>2</sup> Unless we take urgent action, this situation is not going to change - in fact it will get worse. AF is more common the older you become<sup>3</sup> and Wales 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.<sup>4</sup> However, high though the admission rates are, they are likely to be the tip of the iceberg.

Its effects can be devastating and it increases the risk of stroke five-fold<sup>5</sup>, as is recognised by the Cardiac Disease National Service Framework for Wales.<sup>4</sup>

This report analyses, for the first time, the total cost to Wales of AF. Patients diagnosed with AF took up almost 308,000 bed days in 2008 at a cost of more than £100 million. In addition,

the health and social care costs of AF-related strokes in Wales could reach £46.3 million 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. Nevertheless, as Dr Khalid Khan, from the Betsi Cadwaladr University Health Board, North Wales comments in this report: "AF has not been seen as a priority for resources, education or newsworthiness".

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.<sup>6</sup>

For those who previously led active lives AF can lead to mental health problems.<sup>7</sup>

A study in Chest found that a third of AF patients developed increased levels of depression and anxiety that often lasted for six months.<sup>7</sup>

1 Stewart S, Hart C, Hole D. A population-based study of the long-term risks associated with atrial fibrillation: 20-year follow-up of the Renfrew/Paisley study. *Am J Med.* 2002; 113:359-364

2 The Office of Health Economics Estimating

the direct costs of atrial fibrillation to the NHS in the constituent countries of the UK and at SHA level in England, 2008 November 2009, London

3 Wolf PA., Levy D., Kannel WB., and Benjamin EJ. Prevalence, incidence, prognosis and

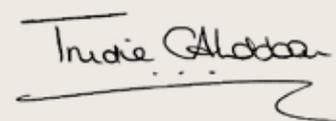
predisposing conditions for atrial fibrillation: population based estimates. *Am J Cardiol.* 1998 Oct 16; 82 (8A):2N-9N

4 National Services Framework for Coronary Heart Disease. Chapter Eight: Arrhythmia and Sudden Cardiac Death. March 2005.

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:

- NHS Wales and other Welsh policy makers should ensure that AF is a priority for health boards.
- Raise awareness of AF prevention among the general public and healthcare professionals in Wales.
- Improve public awareness and patient information to allow patients in Wales to participate as fully as they wish in decision making about their care.
- Encourage early identification , treatment and management strategies of AF, by building on the foundation laid by the NSF for Wales.
- Establish an AF specialist nurse who champions the cause in every health board in Wales.
- Plan better services for people in Wales with AF. Purchasers could base contracts on the Quality Requirements (QRs) in the Cardiac Disease NSF for Wales.
- Encourage research into AF and rapidly implement new treatments as they become available.
- Recognise the Welsh Assembly Government's Stroke Risk Reduction Action Plan is in place and ensuring it delivers.

This research report details how NHS Wales and other stakeholders in the country can achieve these improvements and I commend it to you.


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

5 Wolf PA., Dawber TR., Thomas HE Jr. et al. Epidemiologic assessment of chronic atrial fibrillation and risk of stroke: the Framingham study. *Neurology*. 1978; 28:973-77 YouGov. Qualitative research on atrial fibrillation. YouGov 2009

6 Thrall G., Lip GY., Carroll D., Lane D. Depression, anxiety and quality of life in patients with atrial fibrillation. *Chest* 2007; 132:1259-64

7 Thrall G., Lip GY., Carroll D., Lane D. Depression, anxiety and quality of life in patients with atrial fibrillation. *Chest* 2007; 132:1259-64

# Foreword

The Stroke Association in Wales welcomes this important report. Too often Atrial Fibrillation passes as an unrecognised condition, yet its potential to undermine an individuals' ability to lead an ordinary life is significant. Increasingly, we realise that it is also a major cause of stroke; one in every five strokes is directly attributable to Atrial Fibrillation. Stroke, as we know, is the third most common cause of death in the UK and the single most common cause of severe adult disability.



Effective health services that identify, recognise and treat Atrial Fibrillation are essential to promote the well-being of patients and prevent secondary conditions, such as stroke. For this reason, we believe that it is important not just to focus on treatment but also to ensure also that AF is detected early .

We want to see patients receive reliable information, to have appropriate access to services and that the condition is recognised early and so that appropriate treatment can be offered in the pursuit of maintaining good health alongside a good quality of life.

To this end, we are very pleased to have embarked

upon this partnership with the Atrial Fibrillation Association with whom we share these common concerns and with whom we can promote awareness and education of this serious condition.

We are proud to share our mutual interests to support the dissemination of this innovative report in order to bring this important public health issue to the fore of the political , health and patient agenda in Wales.

A handwritten signature in black ink that reads "Ana Palazón". The signature is written in a cursive style.

**Ana Palazón**  
**Director, The Stroke**  
**Association in Wales.**  
**September 2010.**

# 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.<sup>1</sup> For example, the NSF for Wales recognises that AF is associated with a five-fold increased risk of stroke compared to people without this common arrhythmia.<sup>3</sup> The incidence of strokes attributable to AF increases from 1.5% between the ages of 50 and 59 years to 23.5% between 80 and 89 years of age.<sup>3</sup> Demographic changes, in particular the ageing population, mean that the prevalence of AF is rising. This report examines the key issues and challenges that currently hinder optimal AF care and argues that the arrhythmia should be a priority for NHS Wales. This report also suggests areas where policy makers in Wales could focus their attention to reduce AF's human, clinical and economic impact.

AF is the most common heart rhythm disorder in Wales. AF markedly undermines patients' quality of life and imposes a heavy burden on NHS Wales.<sup>2</sup> Indeed, AF is one of the top 10 reasons for hospital admissions in the UK.<sup>3</sup> Demographic changes mean that the burden is set to rise markedly over the next few years. 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.<sup>4</sup> Unfortunately, for many health professionals, awareness and understanding of heart rhythm disorders is low, which can lead to some disorders being undetected.<sup>3</sup> Furthermore, it is estimated that by 2050, 2% of the population will have AF<sup>5</sup>, further underscoring the need to improve prevention, diagnosis and management.

AF exerts a considerable economic toll on the NHS in Wales. For example, patients with primary or secondary diagnoses of AF occupied almost 308, 000 bed days in 2008, at a cost to NHS Wales of £100 million.<sup>6</sup> Strokes kill 1325 people in Wales each year. AF is responsible for around a quarter of strokes. The health and social care costs of AF-related strokes in Wales could reach £46.3 million a year.<sup>7</sup> These figures exclude the economic burden imposed on NHS Wales and the Welsh economy associated with AF's other complications.

Statistics paint only a partial picture of the impact of AF on Wales. Behind each statistical case lies a personal story of distress, disability and despair. AF can dramatically undermine patients' ability to perform

simple everyday tasks. Indeed, AF causes persistent clinical depression and anxiety in around a third of patients.<sup>8</sup>

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

- The NHS in Wales 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. As part of this, NHS Wales must continue to ensure that health boards implement standard 5 and the associated Quality Requirements (QRs) of the NSF for Wales.

- 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, health boards could consider funding out-reach AF, anticoagulation and dedicated secondary care clinics to ensure a clear care pathway.
  - Every AF patient in Wales 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 in Wales should be able to access improved comprehensive information about AF and its treatment 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. NHS Wales and other Welsh 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 heart rhythm specialist.
- To address these issues, this report suggests several key actions to improve AF care:
- Policy makers should ensure that AF is a priority for the NHS in Wales: 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 for Wales, 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 the public and healthcare professionals in Wales:** 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. NHS Wales and the Welsh Assembly Government should fund public awareness campaigns to ensure patients with possible symptoms see their GP.

- **Improve public awareness and patient information:** NHS Wales, the Welsh Assembly Government, Health Boards, patient support organisations and other stakeholders should provide information and education about AF and its treatment that allows patients to participate as fully as they wish in their care. Patients in Wales should have regular opportunities to discuss AF and treatment options with a specialist nurse or other heart rhythm specialist.

- **Encourage early identification, treatment and management strategies of AF:** Early diagnosis and rapid treatment is a prerequisite to reducing the morbidity and mortality associated with AF and stroke. NHS Wales should encourage the active identification of AF in patients with associated risk factors and encourage referral of these patients as appropriate for treatment at the earliest opportunity. Therefore, health boards should ensure that they implement Standard 5 and the associated QRs of the NSF for Wales, including distributing guidelines for general practice on the diagnosis and management of arrhythmias. NHS Wales should also implement 'best practice' in AF diagnosis and treatment across the country.

- **Establish an AF specialist nurse who champions the cause in every Health board:** A doctor or nurse with a special interest in arrhythmias or healthcare manager needs to take responsibility for improving AF services in every health board across Wales. 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. The AF champion can drive implementation of Standard 5 and the associated QRs of the NSF for Wales.
- **Plan better services for AF in Wales:** NHS Wales should identify barriers for AF services, examine patient pathways, estimate local costs, and evaluate the

implementation of guidelines developed according to the Cardiac Disease NSF for Wales. Those responsible for planning services for AF should ensure that AF care links seamlessly with networks managing stroke, heart failure and other associated conditions. Planning 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. Health Boards should set standards and audit their performance before and after implementing improved services.

- **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, All Wales Medicines Strategy Group (AWMSG), NHS Wales and other stakeholders need to evaluate new interventions rapidly. Health boards must implement advances promptly to ensure patients with AF can benefit as soon as possible.

- **Recognise the Welsh Assembly Government's Stroke Risk Reduction Action Plan is in place and ensuring it delivers.**

This 40 point action plan was announced over the

summer 2010 and its aim is to reduce the number of cases of stroke and the number of stroke related deaths. It will end in March 2012.

Demographic changes suggest that Wales 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. NHS Wales and the country generally cannot 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 across Wales to improve the prevention, diagnosis and management of AF. The Welsh Assembly Government recognises that Wales has especially high rates of coronary heart disease (CHD) and a high proportion of elderly people.<sup>9</sup> For example, the prevalence of CHD in Wales is 4.3%, compared to 3.5% in England. The prevalence of CHD in mid and west Wales is 4.6%, twice the rate in London (2.3%).<sup>7</sup> Such demographic factors will help drive an increasing number of AF cases across Wales over the next few years.

AF is the most common heart rhythm disorder in Wales.<sup>10</sup>

In 2008, an estimated 51 thousand GP visits were attributable to AF in Wales.<sup>6</sup>

The risk of developing AF rises sharply with advancing age, roughly doubling each

decade throughout life.<sup>4</sup> The prevalence of AF in the UK rose from 0.78% in 1994 to 1.42% in 2006.<sup>11</sup> Some estimates predict a three-fold rise in the number of AF cases over the next 50 years.<sup>9,12</sup>

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!"<sup>13</sup>

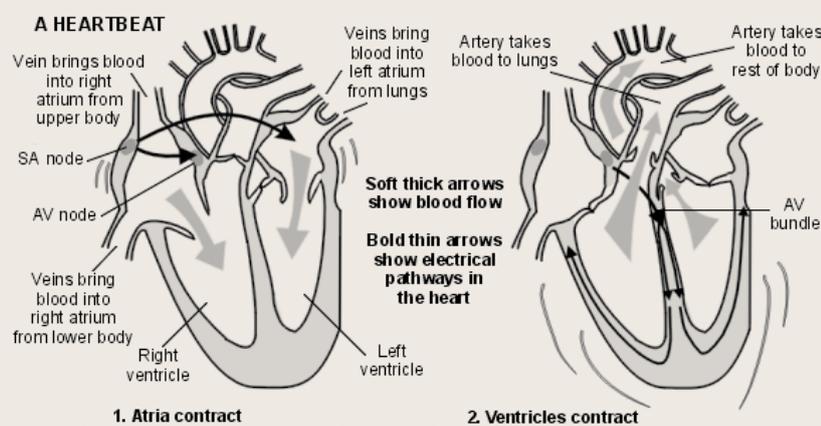
NHS Wales has made some welcome progress towards meeting the challenges posed by AF. However, health boards in Wales must continue to implement Standard 5 and the associated QRs of the NSF for Wales. Standard 5 says: "Each person with an arrhythmia has access to high quality evidence based assessment, treatment, rehabilitation and support." As part of this, patients with AF

and other arrhythmias should be able to rely on a rapid access service that offer – as a minimum - handling test results, referral for investigations and advice from a heart rhythm specialist.<sup>14</sup>

In turn, improved management could reduce the morbidity, mortality and expense arising from several other serious diseases associated with AF.

## 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.<sup>10</sup>



**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.<sup>15</sup> 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.<sup>15</sup> AF may also have serious consequences,<sup>1,2,16</sup> the most important of which is stroke, with one in every six strokes caused by AF. 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 because of AF.<sup>18</sup> 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.<sup>19</sup>

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# types of AF

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**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.<sup>19</sup>

## **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.<sup>19</sup>

## **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.<sup>19</sup>

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?

AF will inevitably become even more common in Wales over the next few decades due to the ageing population and to increased longevity among patients with diseases that predispose to AF, such as stroke and heart failure. The Welsh Assembly Government estimates that the number of dependant older people in Wales will increase by 70% between 2001 and 2031.<sup>20</sup>

Against this background, some estimates predict a three-fold increase in the number of AF cases over the next 50 years.<sup>11,10</sup> Indeed, by 2050, epidemiologists estimate that 2% of the general population will show AF.<sup>5</sup> The large and growing number of AF 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 Wales. 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.) Furthermore, 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".<sup>21</sup> 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.

Overall prevalence	50,138
Prevalence among people over 65 years of age	43,298
Annual incidence	5,368

**Table 1** Prevalence and incidence of AF in Wales

## 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 for Wales. However, few studies evaluate the direct NHS or indirect costs imposed by AF. Therefore, the Office for Health Economics (OHE) estimated the total direct cost of AF to NHS Wales based on primary diagnoses, such as AF-related stroke or heart failure was £23.2 million.

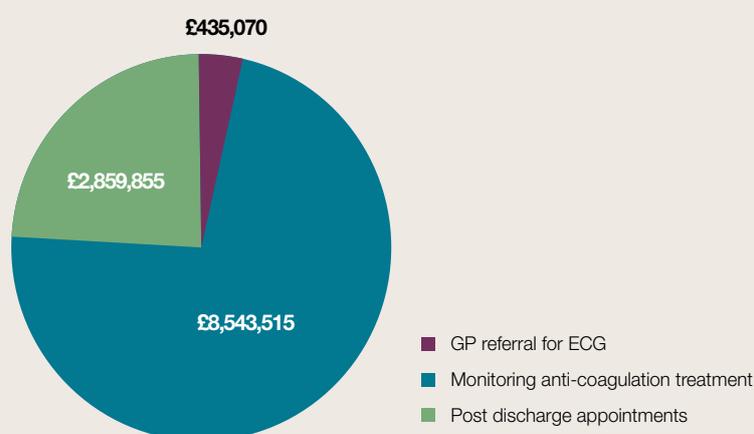
The OHE found that patients in Wales with primary or secondary diagnoses of AF occupied 308,000 bed days in 2008, at a cost to NHS Wales of £100.7 million. Outpatient costs (such as electrocardiograms, monitoring anti-coagulant treatment and post discharge attendance) accounted for £11.9 million (see figure 2). Monitoring anticoagulant treatment (see section 7) accounting for almost three-quarters of the total cost.<sup>6</sup> Patients with AF made over 50,000 GP consultations in Wales,

which cost £1.6 million. The “systematic underestimation of the incidence of AF”<sup>21</sup> means that these figures are likely to underestimate the economic burden. Nevertheless, these figures underscore the importance of improving diagnosis and treatment of AF, and standardising data collection, in Wales.

Clearly, improved prevention, diagnosis and management of AF could result in considerable savings that NHS Wales could reinvest to meet other public health

priorities. Stroke exemplifies this principle. The NSF for Wales on CHD recognises that AF is associated with a five-fold increased risk of stroke compared to people without the arrhythmia. The incidence of strokes attributable to AF increases from 1.5% at between the ages of 50 and 59 years to 23.5% between 80 and 89 years of age.<sup>1</sup>

Against this background, the prevalence of stroke in Wales is 2.0%, compared to 1.6% in England.<sup>7</sup> According to the British Heart Foundation, the health and social care costs arising from transient ischemic attacks (TIA) and strokes in Wales in 2006-7 were £22.5 million and £185.4 million respectively. The per capita costs in Wales are higher than in England: £62 and £39 for stroke alone.<sup>7</sup> Overall, AF causes up to a quarter of strokes. Therefore, it could be estimated that the health and social care costs AF-related stroke and TIA in Wales could reach approximately £46.3 million annually.



**Figure 2** The breakdown of outpatient costs of AF management in Wales

## Section Four: The personal impact of AF

These statistics paint only a partial picture of the problem posed by AF for Wales. 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.<sup>19</sup> Only 24% were asymptomatic.<sup>19</sup> 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.<sup>22</sup> 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.”<sup>13</sup>

Another patient remarked: “On days when I don’t feel well and am unable to do much, I feel my life may be over.”<sup>13</sup> “Some patients simply give up living life,” added 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.<sup>8</sup> The rates of depression and anxiety among AF patients were similar to those in people who survived a heart attack.<sup>8</sup> Not surprisingly, depression and anxiety strongly influenced patients’ quality of life.<sup>8</sup>

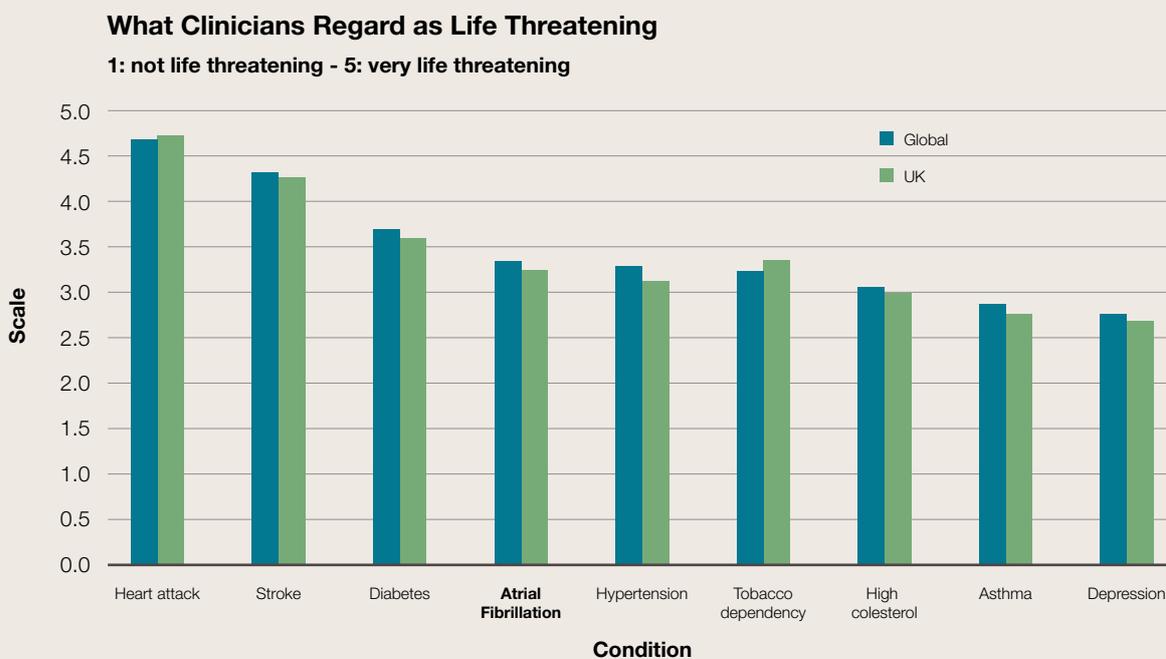
Many patients feel that clinicians do not recognise or adequately manage AF’s psychological impact. One AF patient, who participated in the YouGov research, also commented: “The psychological aspects are all but ignored by the doctors, yet I feel these are far, far worse than the physical effects.”<sup>13</sup>

Against this background, 23 people with AF were interviewed through an on-line 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.”<sup>22</sup>

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,”<sup>22</sup> another respondent remarked.

## Section Five: The Cinderella heart condition

Despite being common, potentially fatal, and with an economic toll running into millions, AF rarely attracts the attention the severity and epidemiology warrants. Figure 3 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 for AF 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 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. These challenges have several implications for healthcare in Wales:

- NHS Wales 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 in Wales should be able to access dedicated clinics and electrophysiological services.
- Every AF patient in Wales should be able to access specialist nurses.
- NHS Wales, the Welsh Assembly Government and other stakeholders need to offer improved information to allow patients to participate as fully as they wish in treatment decisions.

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

**Dr Khalid Khan**

Cardiologist, Betsi Cadwaladr University Health Board, North Wales

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## 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.<sup>23</sup>

However, the international AF Aware survey reported an average delay of 2.6 years between the onset of symptoms and the diagnosis of AF<sup>19</sup>, increasing the risk of stroke and other serious sequelae. In the UK, the survey suggested that the delay averaged 1.1 years.<sup>19</sup> In 15% of cases, doctors diagnosed AF during a routine check up and in 44% during a consultation for another condition.<sup>19</sup> Such figures underscore the importance of improving diagnostic services and acumen.

Furthermore, several conditions other than AF can cause symptoms such as breathlessness, palpitations and dizziness. Partly as a result, notes Welsh cardiologist Dr Khan, 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.<sup>24</sup>

The Quality and Outcomes Framework (QOF) in England and Wales 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.

The NSF for Wales on CHD proves extra impetus for improving diagnosis and management of arrhythmias in general and AF in particular. To meet the vision articulated in the NSF, NHS Wales must continue to ensure that health boards implement standard 5

and the associated QRs of the NSF for Wales on CHD. For example, health boards should agree and distribute guidelines (agreed with representatives of local practices and the hospital to which patients are usually referred) to general practice covering the diagnosis and management of arrhythmias. These guidelines should include giving the patient a copy of any ECG taken during typical symptoms.

Furthermore, according to the NSF for Wales, ambulance crews should followed agreed clinical guidelines covering the assessment and initial management of patients with suspected AF or another arrhythmia. Furthermore, patients should be able to rely on a rapid access arrhythmia service, available at least weekly, that covers – as a minimum - handling test results, referral for investigations (eg ECG recording, 24 hour ECG testing, echocardiography and patient activated monitoring) as well as advice from a heart rhythm specialist.

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# case study

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## Llanelli AF clinic

The Llanelli AF clinic opened in January 2009, invitations to use the service were sent to General Practitioners in the catchment area along with physicians and A&E departments. The majority of patients at the clinic are referred from general practice. The clinic provides prompt and thorough assessment of patients, 87% are referred for an ECG on the day they attend the clinic. Investigations and anticoagulation decided and often initiated in once place, which is more convenient for patients and it enables continuity of care.

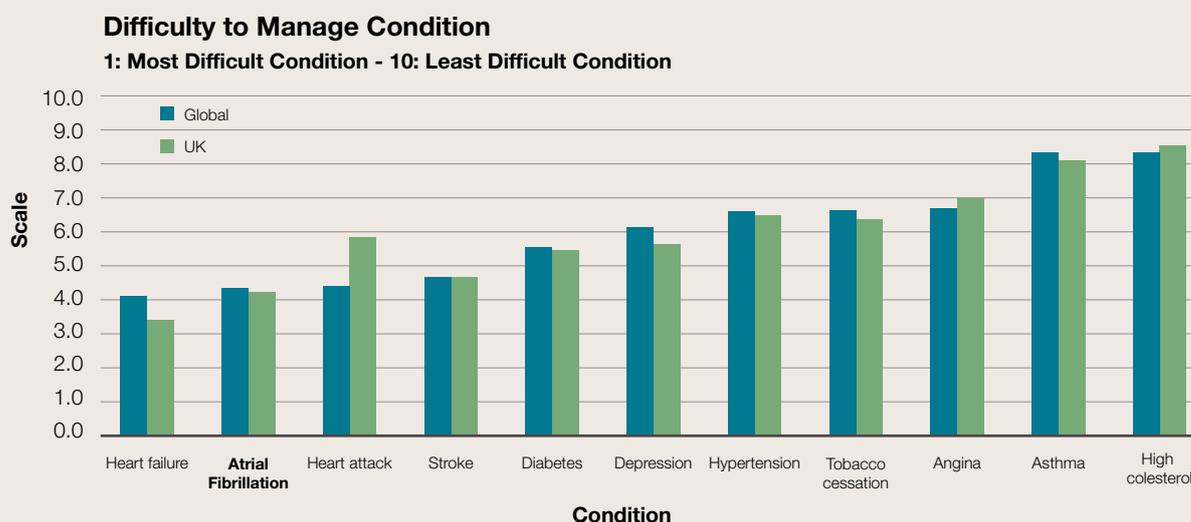
### **Example of good practice in North Wales**

The SAFE study identified that when GP's record manual pulses during routine consultations the incidences of AF diagnosis is significantly increased annually, ultimately leading to the reduction in the incidence of stroke.<sup>1</sup>

A pilot study conducted by two arrhythmia nurse specialists in North Wales looked at integrating manual pulse checks into routine chronic disease management appointments and consultations within the general practice setting whilst incorporating the revised quality and outcome framework (QOF) which came into effect in April 2006 and extended the clinical disease areas covered to include atrial fibrillation. This is a very simplistic idea however, none the less effective and requires no extra funding.

## 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 for AF. 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.<sup>19</sup> However, according to other data sources, fewer than 20% of AF patients are offered anti-arrhythmic agents.<sup>25</sup>

“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,

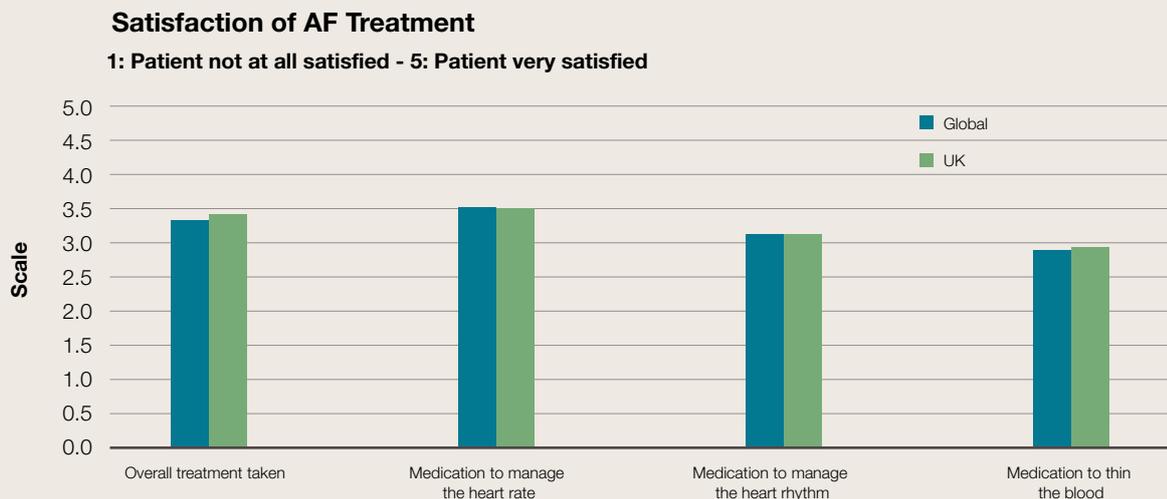
“aspirin is a poor second best to warfarin for the prevention of stroke and thromboembolism in AF” and may reduce risk by affecting concurrent vascular disease rather than modulating AF.<sup>26</sup>

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.<sup>23,5</sup> 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.<sup>5</sup>

“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.

Currently, the OHE estimates that medications account for only 10% of the costs of managing AF.<sup>6</sup> The OHE found that patients in Wales with primary or secondary diagnoses of AF occupied 307,946 bed days in 2008, at a cost of £100.7 million.<sup>6</sup> Monitoring anticoagulant treatment accounted for almost three-quarters of total outpatient costs of £11.9 million.<sup>6</sup>



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

Patients with AF made 50 577 GP consultations in Wales, which cost £1.6 million. Considerable uncertainty surrounds these costs nevertheless, the proportions suggest that investing more in current and improved drugs that prevent in-patient admissions could offset much, if not all, of the costs of new pharmaceuticals.

This needs confirmation in formal health economic evaluations. Nevertheless, NICE, AWMSG, NHS Wales, the Welsh Assembly Government and other stakeholders need to evaluate new interventions rapidly, and health boards must implement advances promptly to ensure patients can benefit as soon as possible.

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.”

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## Section Eight: Structure and delivery of AF care

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### 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.<sup>19</sup> A further 24% saw their cardiologist less than once a year.<sup>19</sup> Indeed, 35% of patients with this potentially debilitating condition only saw their GP once a year or less.<sup>19</sup> It seems unlikely that, in many cases, this level of engagement with primary and secondary care is sufficient to ensure optimal management.

Patients with AF in Wales 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, community healthcare teams in Wales need to diagnose and manage more patients. Diagnostic initiatives such as those mentioned above will help. Health boards in Wales could consider funding outreach AF or anticoagulation clinics in primary care. Furthermore, health boards in Wales could consider planning dedicated secondary care clinics to ensure a clear care pathway that will aid the diagnosis, treatment and rehabilitation of AF patients.

In particular, NHS Wales must continue to ensure that health boards implement Standard 5 and the associated QRs of the NSF for Wales on CHD. For example, the QR framework states that health boards should assess distribute guidelines for general practice on referral to rapid access arrhythmia services, assessment by a consultant cardiologist and by a heart rhythm specialist. Research from Dr Leena Izzat on the AF clinic in Llanelli found that 87% of patients were referred for echocardiogram on the day of clinic. Furthermore, 59% of patients referred to anticoagulation on the same day as the clinic.<sup>27</sup>

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## 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 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 NHS Wales should ensure that best practice, established in places such as North Wales, extends nationwide.

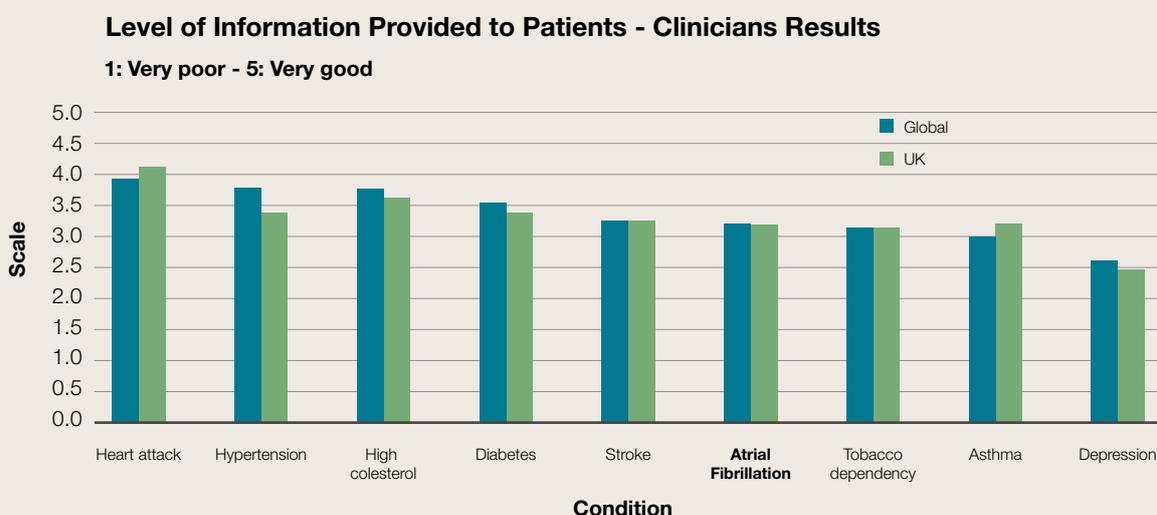
## Section Nine: The need for improved access to information about AF

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 in Wales with AF should have the opportunity to be comprehensively informed about their disease and its treatment, and be able to participate as fully as they wish in decisions about their care. The AF Aware survey suggested that physicians considered that patients did not have access to easy-to-understand information. The survey 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). Based on the QR for the NSF the minimum information should cover the procedure or treatment; care following the procedure, including self-care; and possible complications.

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."

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".<sup>11</sup>



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

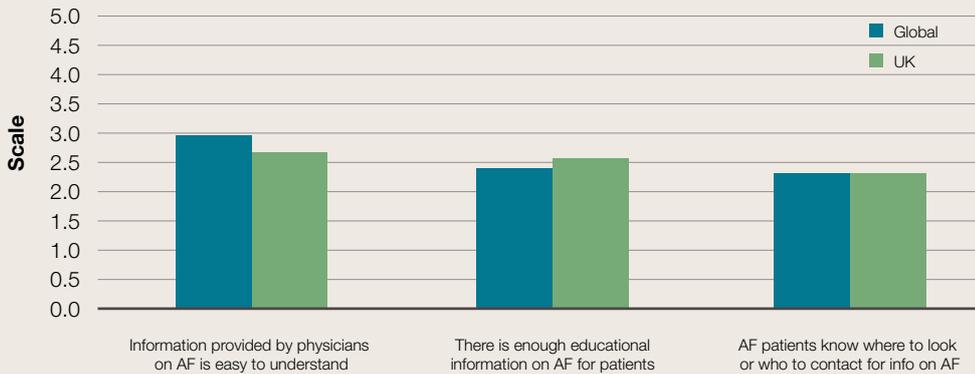
The importance of talking to a health professional and getting reassurance is particularly important for AF, which commonly engenders considerable fear and anxiety. Therefore, NHS Wales and other stakeholders need to provide a diverse, reliable and

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 in Wales should have the opportunity to discuss their disease and treatment with a healthcare professional.

**Level of Information Provided - Clinicians results**

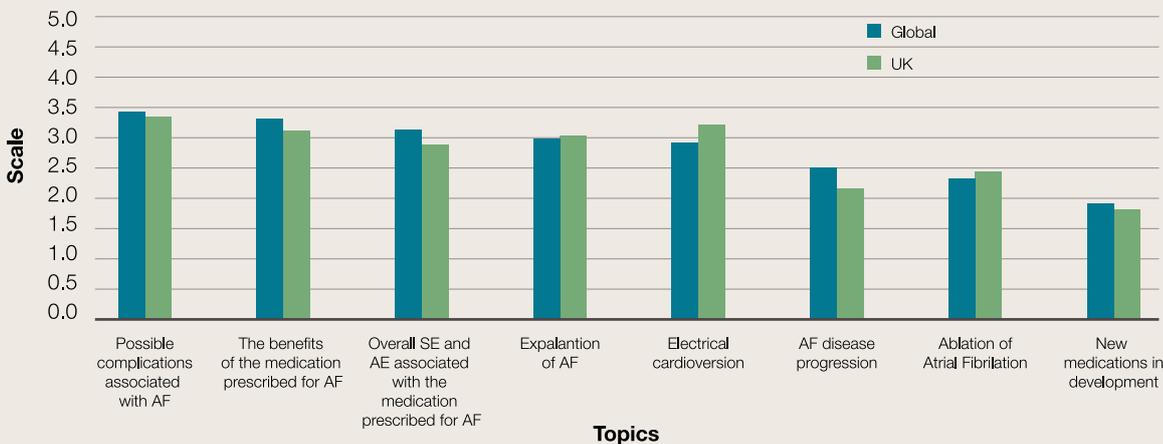
1: Strongly disagree - 5: Strongly agree



**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

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# case study

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## A patient's story

After my admission to casualty, I was given an ECG, wired up to a 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.

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## 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 in Wales will rise markedly over the next few decades. Implementing several key actions would dramatically improve AF care.

**1 Make AF a priority for NHS Wales:** 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 for Wales, supported by measured outcomes, standards, targets, QOF points and other initiatives and incentives. In particular, NHS Wales must continue to ensure that health boards implement standard 5 and the associated QRs of the NSF for Wales on CHD.

**2 Raise awareness of AF prevention among the general public and healthcare professionals:** Several factors including age, obesity, hypertension, congestive heart failure increase the risk of developing AF. Indeed, the Welsh Assembly Government recognises that Wales has especially high rates of heart disease and a high proportion of elderly people. Educational initiatives, local planning agreements and QOF points need to increase health professionals' awareness of AF and its risk factors as well as encouraging opportunistic screening. NHS Wales and the Welsh Assembly Government should fund public awareness campaigns to ensure patients with possible symptoms (such as palpitations and excessive breathlessness) see their GP.

**3 Improve public awareness and patient information:** NHS Wales, the Welsh Assembly Government, patient support organisations and other stakeholders should provide information and education that allows patients to participate as fully as they wish in their care. Written information alone is inadequate. Patients with AF in Wales must have the opportunity to discuss AF and treatment options with a specialist nurse or another specialist in health rhythm abnormalities.

**4 Encourage early identification, treatment and management strategies 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, policy makers, those responsible for planning care for AF and health professionals in Wales should develop local opportunistic screening programmes for AF. Moreover, QOF indicators should encourage routine opportunistic screening and appropriate referral to secondary care for treatment initiation. Therefore, health boards need to ensure effective implementation of standard 5 and the associated QRs of the NSF for Wales.

**5 Establish an AF specialist nurse who champions the cause in every health board:** A doctor, nurse with a special interest or healthcare manager needs to take responsibility for improving AF services in every health board. 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. The champion can drive implementation of standard 5 and the associated QRs of the NSF for Wales on CHD.

**6 Plan better services for AF patients in Wales:** Health planners should identify barriers for AF services, examine patient pathways, estimate local costs, and evaluate the implementation of NICE guidelines. They should ensure AF care links seamlessly with networks managing stroke, heart failure, dementia and the other serious conditions associated with AF. Planning 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 the planning of AF services. Health boards should set standards and audit their performance before and after implementing improved services.

**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, NHS Wales, the Welsh Assembly Government and other stakeholders need to evaluate new interventions rapidly. LHB must implement advances promptly to ensure patients in Wales with suspected AF are appropriately referred and can benefit as soon as possible.

**8 Recognise the Welsh Assembly Government's Stroke Risk Reduction Action Plan:** This 40 point action plan was announced over the summer 2010 and its aim is to reduce the number of cases of stroke and the number of stroke related deaths. It will end in March 2012.

Wales faces a dramatic increase in the number of people with AF over the next few decades. Unless, NHS Wales 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 Wales cannot afford to ignore AF any longer.

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