Atrial Fibrillation Association (AFA) is a registered charity.
Internationally, AFA works closely with patients, carers, medical professionals, service providers, service payers affiliated groups and allied professionals to:

- provide support and information
- advance the education of the medical professionals
- raise awareness amongst the general public
- promote research into the management of Atrial Fibrillation

In Wales, many thousands of preventable strokes occur every year leading to thousands of early deaths and a devastating burden on individuals, families and society in terms of disability, medical and social care costs, and loss of working hours and tax revenues.
Atrial fibrillation (AF) is a common heart rhythm disorder associated with deadly and debilitating consequences including heart failure, stroke, poor mental health, reduced quality of life and death.[i]

Key points of AFA evidence

1. AF patients suffer a disproportionate number of strokes which are, in turn, disproportionately fatal, debilitating, expensive and likely to recur.
2. AF detection and diagnosis is low, leaving an estimated 50% of patients undiagnosed. **Opportunistic screening**, has been shown to be both effective and cost efficient at finding AF patients, however it is not widely used.
3. **Guidance and guideline adherence** is poor and consequently leaves AF patients at risk of avoidable strokes.
4. The main current therapy option, warfarin, which can effectively prevent many of these strokes is actually effective in only 18-21% of AF patients, due to under prescribing especially in those at high risk of stroke.
5. Too often, those at most risk, frequently the elderly, are prescribed aspirin, which only reduces the risk of stroke by 22% and increases their risk of a bleed to equal that of warfarin.
6. For those who often fall out of therapeutic levels (> 60% outside of target therapeutic range), warfarin is of little or no benefit.
7. The Inquiry Committee may wish to consider seeking evidence from all relevant professionals, including heart rhythm specialists.

Supporting evidence

AFA is mindful that budgetary pressures are ever-present and inevitable, and as a result, cost effectiveness has to be a reasonable expectation when comparing guidance it is important to consider both cost and effectiveness. This difference is probably best summarised but the QIPP, Right Care programme, 'Commissioning for Value':

> *'…value must also be measured by outputs, not inputs. Hence it is patient health results that matter…'*

The AFA has amassed and documented many thousands of experiences that have been shared with us by patients, their caregivers and health care providers. These accounts are an excellent representation of the "health results" of patients suffering from AF in the UK today. In light of this amassed patient feedback and respected published data we have formulated the following response on behalf of patients suffering from AF.

1. AF is the most powerful independent risk factor for stroke and results in strokes that are more severe, more likely to disable, more likely to kill and more likely to recur.

Atrial Fibrillation (AF) is a common heart rhythm disorder associated with deadly and debilitating consequences including heart failure, stroke, poor mental health, reduced quality of life and death. [26] Today, more than 51,000 of the Welsh population have been diagnosed with AF, [28] yet experts suggest that up to half of all AF patients have not yet been detected. Among many damaging and debilitating consequences, AF increases an individual's risk of suffering a stroke by five times. [31] This effect alone results in considerable disability and death, [27,32] not to mention avoidable millions in healthcare expenditure [28] that NHS Wales cannot afford. For example, patients with primary or secondary diagnosis of AF occupied almost 308,000 bed days in 2008, at a cost to NHS Wales of £100 million [265]. Strokes kill about 1325 people in Wales each year. AF is known to be responsible for almost one quarter of these strokes, the health and social care costs of AF-related strokes in Wales are expected to reach £46.3 million per year [266]. These figures exclude the economic burden on NHS Wales and the Welsh economy.

Atrial Fibrillation is known to be responsible for 45% of all embolic strokes, resulting in more than 12,500 strokes per year in England and Wales. The strokes suffered by people with AF are also more severe, [82] they are more frequently fatal [83 84] and they are more likely to lead to disability, [83 85 86 82] increased healthcare costs [89] and extended hospital care than strokes in patients without AF. [82] Moreover, AF-related strokes are more likely to happen again [89], adding not just to the risk of future strokes, but also to the potential for increased patient anxiety and a further reduction in quality of life. AF-related strokes kill nearly twice as frequently as non-AF strokes. [82,83,84]

The medical cost of a stroke in first year is £9,500 - £14,000 per stroke. Embolic, and hence AF related, strokes are likely to be represented at the high end of this range. [93,98,100,103,104] These costs do not include continuing costs after first year, nor do they include costs associated with long term disability or the human cost, which is incalculable.

2. AF detection and diagnosis is low, leaving an estimated 50% of patients undiagnosed

Without effective detection and diagnosis of AF up to half the patients affected will never be identified. If a lack of detection and diagnosis continues, then many patients will be denied the opportunity to benefit from treatments that can dramatically reduce their risk of stroke. Existing research suggests that routine pulse screening has a role to play, as does public education on the need to investigate an irregular pulse.

Opportunistic screening, has been shown to be both effective and cost efficient at finding AF patients, however it is not widely used.

The role and value of screening programmes following the positive results of the SAFE study [266] illustrate the value of this in both finding patients with AF and reducing stroke risk, and ultimately stroke events. This has been more recently shown in Wrexham [268] where The Wrexham primary care AF model pilot launched on1st May 2007 in four general practice surgeries under the Local Health Boards and ran for six months with positive results and findings. The audit of the pilot evaluated the view of existing patients on the AF registers in the surgeries as well as those patients that were identified through the routine screening using the manual pulse check. Seven new AF patients were found during opportunistic checks as part of the pilot and 68 patients were found to be on inappropriate or no thromboprophylaxis, which prompted further review by the GPs. Four

years since the start of the pilot the team are still reaping the benefits of the work undertaken in primary care.

NICE also recommends that all patients with an irregular pulse receive an ECG to make a diagnosis. However, The SAFE study found that GP and practice nurse performance in interpreting ECGs was not encouraging, identifying another potential challenge to the effective diagnosis of AF in primary care.

The need for routine, opportunistic screening, especially amongst those at greater risk of developing AF is essential if lives are to be saved and costs due to stroke events, reduced.

3. Guidance adherence is poor and consequently leaves AF patients at risk of avoidable strokes

There remains poor adherence to authoritative and national guidelines. Even NICE's own data shows that of all those with AF who should be on warfarin, almost half are not. Yet, when asked, physicians demonstrate both awareness of the guidelines and agreement with them. One study documented the medications being taken by AF patients when they suffered an ischemic stroke. It found that only 10% of these patients had been taking an effective dose of an anticoagulant. Nearly a third were on no antithrombotic treatment at all (29%). A further 29% were on aspirin and another 29% were on a non-therapeutic dose of warfarin.

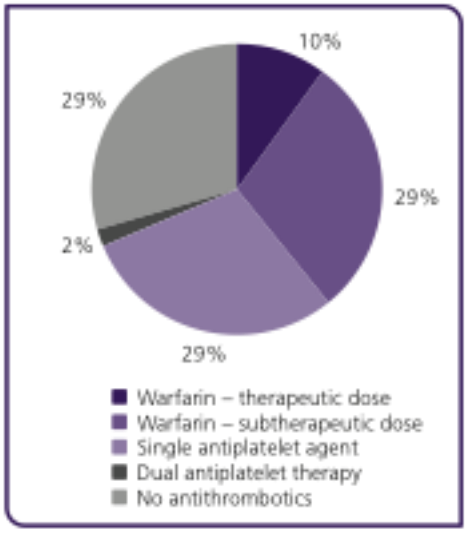

Figure 10. Medications received before admission to hospital by patients with known atrial fibrillation who suffered an acute ischaemic stroke: only 10% of patients had received warfarin at a therapeutic dose. Adapted with permission from Gladstone

Adherence to Guidelines for the prevention of stroke in patients with AF may be low for several reasons. These include difficulties in maintaining INR within the therapeutic range and physicians' concerns about bleeding risk, particularly in the elderly. [35]

Quality Outcomes Framework (QOF) was designed to reward GPs for the quality of the care that they provided, instead of for how many patients they treated. Currently, GPs can work to secure up to 1,000 QOF points by meeting predetermined performance targets in four broad areas: Clinical, Organisational, Patient Experience, and Additional Services. A total haul of 1,000 points represents an additional payment to GPs of over £13,000.

Specifically for AF, within the current QOF scheme, up to 12 points are available for GPs achieving a high percentage of 'patients with atrial fibrillation who are currently treated with anticoagulation drug therapy or antiplatelet therapy.'

It is reasonable to expect that many patients diagnosed with AF will already be taking aspirin for another condition. It is also relatively simple to start and manage a patient on aspirin (antiplatelet

therapy) compared to warfarin (anticoagulation therapy). Consequently, the way the target is written enables GPs to receive the maximum QOF reward just by having AF patients on aspirin, even if none of them is on warfarin.
Consequently, QOF today provides virtually no incentive for GPs to put patients on warfarin in accordance with the NICE 2006 or the ESC 2010 guidelines.
AFA would suggest that guidelines and rewards encourage

- An increase in the percentage of patients with Atrial Fibrillation in whom stroke risk has been assessed using the $CHADS_2$ risk stratification scoring system in the previous 15 months
- In those patients with Atrial Fibrillation in whom there is a record of a $CHADS_2$ score of ≥1, an increase the percentage of patients who are receiving anticoagulants

Adherence to agreed guidance is essential if AF patients are to be properly assessed and treated to reduce stroke.

4. Aversion to warfarin leaves thousands of patients at unnecessarily high risk of stroke

In clinical trials warfarin has been associated with a stroke risk reduction in AF patients of 50%-70%. However, this potential is not being realised in routine clinical practice, leaving thousands at risk of preventable strokes.
Warfarin is currently recommended in UK and European guidelines as first-line therapy in patients with AF and a moderate or high risk of developing stroke. [138 139] Despite evidence that following the guidelines results in improved patient outcomes, [166] there is significant under-use of warfarin. Thus, many patients with AF and a moderate-to- high risk of stroke do not receive anticoagulant therapy and therefore remain at high risk for stroke. [156 153]
NICE data shows that of all those with AF who should be on warfarin, almost half are not. [179]. In a study conducted in seven European countries, it was found that only 8.4% of patients with AF who had a stroke were receiving anticoagulants at the time of their stroke, and the proportion decreased by 4% per year with increasing age. [181] A review of the scientific literature from 2000 indicated that only 15–44% of eligible patients with AF were receiving warfarin.[180] Yet, when asked, physicians demonstrate both awareness of the guidelines and agreement with them, despite not treating patient in accordance with those guidelines. [182] This further highlights the discrepancy that is often found between trial results and what happens in clinical practice. Another study documented the medications being taken by AF patients when they suffered an ischemic stroke. It found that only 10% of these patients had been taking an effective dose of an anticoagulant. Nearly a third were on no antithrombotic treatment at all (29%). A further 29% were on aspirin and another 29% were on a non-therapeutic dose of warfarin. According to recent surveys in different parts of Europe, the proportion of patients with AF at high risk of stroke who are receiving adequate anticoagulation is most commonly around 54–61% [185,172]
Warfarin is under-prescribed for many reasons including the complexity of dosing and patient management as well as fear of the associated bleeding risks. Consequently, almost half the AF patients for whom warfarin is indicated are not on warfarin and remain at extremely high risk of severe, debilitating and expensive strokes.
Management of warfarin is complex and time-consuming for primary care physicians. It is also recognised that those at greatest risk, the elderly, are less likely to be given warfarin because of perceived fear of complications.

In centres where clinicians with a special interest in AF have set up clinics and outreach support, such as Prince Philip Hospital, Llanelli, commitment of a truly multidisciplinary team, has led to a

successful "one-stop service" service for those referred with AF. When started, only 22% of the patients referred to Dr Izzat with a CHADS2 of more than 1 were adequately anti-coagulated with warfarin, this has now improved to just over 40% and plans to improve this further are in hand. Knowledge of and adherence to current guidance, effective use of validated risk assessment schema and appropriate use of anticoagulation has lead to successful stroke prevention – and with no extra finance.

5. Too often, those at most risk, frequently the elderly, are prescribed aspirin, which only reduces the risk of stroke by 22% and increases their risk of bleed to equal that of warfarin.

Many physicians resist the use of warfarin in the elderly, largely on grounds of safety. Research has demonstrated repeatedly that physicians over-estimate the risk of bleeding associated with the use of warfarin and under-estimate its benefits in preventing thromboembolism and stroke; conversely, they have been shown to under-estimate the bleeding risk of aspirin therapy and over-estimate its benefits. [196,188,201] As a result, eligible patients are not receiving therapy that could prevent strokes. [18] For many physicians, bleeding risk is a particular concern in the elderly, who are more prone to falls, more likely to have suffered previous major bleeds, and who are subject to many additional problematic factors associated with old age. [202,204] While the bleeding risk with warfarin is no worse than that with aspirin, physician experience of major bleeding events associated with warfarin can profoundly reduce prescription of warfarin. [205] A study investigated the behaviour of physicians treating AF patients who had bleeds while on warfarin. Patients treated in the 90 days after the physician had encountered a bleeding event were significantly less likely to receive a prescription for warfarin than patients treated before the bleed. [205] In contrast, having a patient who experienced a Stroke while not receiving warfarin did not influence prescribing behaviour with subsequent patients. [205] In other words, a bleeding event may make a physician less likely to prescribe an anticoagulant but a stroke does not increase the likelihood that a physician will prescribe and anticoagulant.There are large numbers of younger patients who according guidance should be prescribed anticoagulants including 'those with a history of stroke and those aged 65 years or over with one of the following: diabetes, coronary artery disease, or hypertension', but who simply are not receiving it, whether this be through their choice or physician assessment. AFA would propose that guidelines recommending that patients be assessed for risk using the $CHADS_2$ and the $CHADS_2VASc_2$ system should be adopted.

6. For those patients on warfarin large numbers of patients are difficult to control and spend >60% outside the target therapeutic range – rendering warfarin of no benefit.

Research has shown that AF patients in routine clinical care were able to maintain a target INR for over half the time (56%). Of the considerable remaining time, patients were above the target range for 30%, and below the target range for 14%. [184]. If around half of all patients in need of anticoagulation aren't prescribed warfarin [179] and if those who are have either ineffective or unsafe blood levels of warfarin for nearly half of the time, [184] then perhaps only a quarter of patients at any one time receive the therapy they need to safely lower their risk of stroke. This becomes ever more worrisome when considering experts' estimates that only about half of all AF patients are actually diagnosed. The vast majority of these undiagnosed patients would be expected to be at moderate or high risk of stroke, [190] and, hence, in need of warfarin therapy according to

the ESC 2010 guidelines. Yet perhaps only a fifth of patients in need of warfarin to reduce risk of stroke are actually receiving safe and effective anticoagulation treatment at any time.

-Effective monitoring is essential if at risk AF patients are to be protected.

-An education programme, in line with recommended guidance is required to increase awareness and understanding of the importance of appropriate anticoagulation therapy in AF patients.

7. **The Inquiry Committee may wish to consider seeking evidence from all relevant professionals, including heart rhythm arrhythmia specialists.**

AF is largely managed in primary care, but cardiologist who are arrhythmia specialists also play a key role in local training, referrals and care of more challenging AF patients. Cardiac Networks and cardiology arrhythmia specialists are also instrumental in informing and supporting local guideline adherence in order to PREVENT stroke in AF patients.

AFA has worked with the Cardiac Networks and Arrhythmia specialist in Wales, and suggests that the Inquiry would benefit from seeking expert advice from these sources. AFA would be very happy to highlight Welsh centres where specialist clinicians are working to reduce both the burden of AF and the risk of stroke amongst the AF population.

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Atrial fibrillation—so what? Changing clinical practice

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The arrhythmia nurse practitioner's role has many different titles, from specialist nurse to arrhythmia care co coordinator, with the different titles comes the diverse yet rewarding workload. The role of the British Heart Foundation (BHF) arrhythmia nurse is underpinned with three key elements

- Ensuring that all patients with arrhythmias receive an effective and holistic assessment and a package of care, to ensure that all the patients' medical and emotional needs are discussed.
- All those who are included in the care pathways including patients, families and carers receive education and support as needed.
- Ongoing monitoring and auditing of the arrhythmia service takes place. These elements ensure that the quality requirements of chapter 8 of the National Service Framework (NSF) for Coronary Heart Disease (CHD) (Department of Health, 2005) and the Welsh equivalent standard 5 of the Welsh NSF (Welsh Assembly Government, 2008) are met.

Arrhythmia nurse practitioners service

In October 2006 two experienced cardiac nurses were appointed to the arrhythmia nurse practitioners (ANPs) service based in a district general hospital, one with additional experience in primary care with knowledge of the local area. These roles had been created to develop a service that would bridge the gap between primary, secondary and tertiary care for patients who suffer from arrhythmias.

The day-to-day work load now is very varied and can include answering telephone enquires from the advice line, pre-assessing patients for procedures such as elective direct current cardioversion, permanent pacemaker implants, educating other health professionals about the management of patients with arrhythmias, visiting patients, families or carers at home or in hospital to discuss arrhythmias and their management, liaising with other health professionals to improve patient care, audit, and developing patient pathways to improve access to services. Nevertheless the majority of our work load centres around the management of patients with atrial fibrillation (AF).

Atrial fibrillation

Atrial fibrillation (AF) is the most common sustained cardiac arrhythmia, if left untreated it is a significant risk factor for stroke and other morbidities (National Collaborating Centre for Chronic Conditions (NCC-CC), 2006). The annual risk of stroke increases by around 4-5% for patients with atrial fibrillation, however this is not relative and the risk increases with age and other co-morbidities. This risk can be reduced with appropriate and timely thromboprophylaxis (NCC-CC, 2006). The effects of AF on the patient can range from none to many side effects such as reduced quality of life, breathlessness, fatigue, palpitations, and angina. The screening for atrial fibrillation in the elderly (SAFE) study (Hobbs et al, 2005) identified that when GPs record manual pulses during routine consultations the incidence of AF diagnosis is significantly increased, ultimately leading to a reduction in the incidence of stroke.

Based on experience as a practice nurse prior to taking the post as an arrhythmia nurse practitioner, it was felt that GP surgeries and practice nurses play a vital role in the care of patients with chronic diseases and are therefore

ABSTRACT

Atrial fibrillation (AF) is the most common sustained cardiac arrhythmia, if left untreated it is a significant risk factor for stroke and other morbidities. Approximately 12 500 strokes each year are sttributable to AF and the annual cost to the NHS and personal social services budget is estimated to be around £148 million. The SAFE study identified that when GPs record manual pulses during routine consultations the incidence of AF diagnosis is significantly increased, ultimately leading to a reduction in the incidence of stroke.

On 1 May 2007 the Wrexham primary care AF model pilot was launched. Working in partnership across organizational boundaries, changes were made to existing templates in some GP surgeries. A manual pulse check was added to all chronic disease management templates, and a stroke risk stratification tool was added to AF templates to ensure patients are correctly stratified for appropriate use of a thromboprophylactic agent, which in turn would reduce the incidence of stroke. Seven new AF patients were found by opportunistic checks during the pilot and 68 patients found to be on inappropriate or no thromboprophylaxis, which prompted further review by the GPs.

KEY WORDS

- Manual pulse checks
- Atrial fibrillation
- Screening
- Stroke risk assessment

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ideally situated to initiate a screening service for atrial fibrillation within local primary care settings.

The hospital is based on the borders of Wales and England, serving patients from both countries, and the same region is also served by two other hospitals. To reduce inequalities in services between the different hospital that serve the local area, we chose to facilitate other health care professionals in the community to undertake screening for AF by integrating manual pulse checks into routine clinical assessments i.e. chronic disease management in GP surgeries, district nurse assessments, community matron or long-term condition nurse assessments.

Facilitating AF screening in GP surgeries

The model for screening is not complex, nor ingenious, quite the opposite. It is simple, requires no funding, and can be adapted into any general practice setting that conducts chronic disease management reviews. The model aims for each individual to be assessed, to create a treatment plan that is centred on their own exclusive needs.

Before piloting the model we delivered several educational workshops for local practitioners (including GPs, practice nurses and district nurses) to reach as many health professionals in primary care as possible in order to highlight the implications of AF. Emphasis was placed on the need for manual pulse and blood pressures monitoring, as the use of automated machines can give inaccurate readings for patients with irregular pulses.

The arrhythmia nurse practitioner service worked in partnership across organizational boundaries and made changes to existing templates in some GP surgeries (who volunteered to take part). These included the addition of a manual pulse check to all chronic disease management templates, which instigates opportunistic and routine screening not only for those who are at high risk for AF but also for the wider population.

In addition, the model used a stroke risk stratification tool—CHADS2 (Valentin et al, 2006)—and recorded the results using the read code 388I in an AF template to ensure patients were correctly stratified for the appropriate thromboprophylactic agent, which in turn would reduce the incidence of stroke.

The $CHADS_2$ stroke risk stratification is a clinical prediction tool used for estimating the risk of stroke in patients with nonrheumatic, or nonvalvular, AF. Points are assigned for chronic heart failure (C), hypertension (H), age 75 years or over (A), diabetes mellitus (D) and history of stroke or transient ischaemic attack (S—2 points). The higher a person's $CHADS_2$ score, the greater the risk of stroke.

An annual diary date was created to prompt annual review, which is a component missing from the clinical indicators of the quality outcome framework (QOF) for atrial fibrillation (British Medical Association/NHS Employers 2006).

Implementing the tool and annual check was supported by the development of internet-based guidelines and cardiac network guidelines that GPs can access.

AF primary care pilot

The Wrexham primary care AF model pilot launched on 1st May 2007 in four general practice surgeries under the local health boards, and ran for six months with positive results and findings. The audit of the pilot evaluated the review of existing patient on the AF registers in the surgeries as well as those patients that where identified through the routine screening using the manual pulse check. Seven new AF patients were found during opportunistic checks as part of the pilot and 68 patients were found to be on inappropriate or no thromboprophylaxis, which prompted further review by the GPs.

Nearly two years since the start of the pilot the team are still reaping the benefits of the work undertaken in primary care. Although four practices were initially recruited into the pilot, the arrhythmia nurse practioners wrote to every practice in the catchment area and asked to set up a meeting to discuss the basis of the pilot.

It seems a key reason that practices were not keen to take part in the pilot was that the pilot scheme used paper audit forms, whereas most GP surgeries operate a paperless policy. This appeared to be an obstacle that could not be overcome at the time, and the additional time needed to complete the form was seen to be problematic.

In one surgery one of the ANPs personally performed an audit of all the patients on the AF register, highlighting any patients that appeared to be on inappropriate therapy or thromboprophylaxis. This allowed her to gain a better understanding of the extent of problems that could be discovered, and appreciate the time it took to perform this audit and the impact it would have on GP and practice nurses' workload. This method of auditing patients was also used in other surgeries by GPs and practice nurses, whereas some practices chose to invite all patients on the AF register in for a review.

The ANP service now see on many referral letters that the patient was found to be in AF during a routine blood pressure check or during an annual chronic disease management review. Hopefully, this is a direct effect of the educational events the service continues to provide and also a result of those surgeries that made the changes to their chronic disease management templates.

Award winning service.

In April 2008 the team's work in this area was recognized nationally with an award at the Cardiac Nursing Awards in London for 'Excellence or innovation in arrhythmia management'. This award would not have been possible if it were not for the continued support of our manager, consultants, GPs, practice nurses, cardiac lead nurses in the community and last but not least the BHF. Our idea was simple but has proved to be effective.

The future

Other initiatives undertaken by the team include a collaboration with the local health board lead nurse for cardiovascular disease on developing part of a cardiology local enhanced service (LES) for GPs (DH, 2008)).

The option in the LES relating to AF included raising awareness of AF, the significance of taking a manual pulse and the importance of using the stroke risk stratification tool to identify those who needed interventions to reduce the risk of stroke. GP practices agreeing to take part in this option were asked to attend an ECG study day on arrhythmias and an AF study session provided by the two ANPs. The session included the importance of the stroke risk stratification tool and thromboprophylaxis. Following this, the practices involved were encouraged to adapt all their chronic disease management computer templates to include taking a manual pulse.

It is recognized that ongoing education is required in primary care and working closely with local health boards the ANP service aims to provide further education.

In addition, the service is in the process of organizing a 'Know your Pulse' educational event for Arrhythmia Awareness Week 2009. The event is to be hosted with the support of the occupational health department of a large local employer who has approximately 8500 permanent and contract staff. The event will start with an internal television campaign highlighting the importance of 'know your pulse' followed by site tours educating staff on how to check their own pulse and the importance of seeking medical advice if an abnormal pulse is found. Due to the enormity of the site three days have been scheduled for this event over the summer months, alongside night visits to ensure night staff benefit from this event.

Key Points

- Atrial fibrillation is the most common arrhythmia and if left untreated can lead to an increased risk of stroke
- Undetected AF cannot be treated, making screening important
- Studies have shown that when GPs record manual pulses during routine consultations the incidence of AF diagnosis is significantly increased
- By providing education and support to primary care colleagues to assist them in identifying and appropriately treating patients with AF, future complications may be reduced

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