TEN RECOMMENDATIONS FOR GOVERNMENT ON ATRIAL FIBRILLATION MANAGEMENT FROM A NATIONAL INQUIRY IN SCOTLAND

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**ABSTRACT**

Background: Understanding Atrial Fibrillation (AF) management in Scotland was identified as a key priority at the Cross Party Group (CPG) for Heart Disease and Stroke which meets regularly at the Scottish Parliament. Therefore, a national inquiry was launched to provide clear recommendations to government to improve health for people living with AF. Methods: An advisory panel was convened comprising major third sector representatives, academics, clinicians, Members of Scottish Parliament (MSPs), and people living with AF. Two questionnaires, one for clinicians; one for people living with AF were circulated through multiple channels and four roundtable events were held. Results: In total there were 262 responses to the questionnaires (n=203 clinician; n=59 people living with AF) and roundtables were attended by 35 people, including members of the advisory panel, MSPs, clinicians, academics and people living with AF. Ten key recommendations emerged relating to Detection and diagnosis of atrial fibrillation; Initial treatment and subsequent management of atrial fibrillation; The use of data to improve detection, diagnosis and treatment of atrial fibrillation in Scotland; and patient information and public awareness. Conclusions: It is hoped that the results of this inquiry will provide the blueprint for change that will improve AF management across Scotland

**KEY WORDS**

Atrial fibrillation; national inquiry; policy; patient-centred

**INTRODUCTION**

Atrial fibrillation (AF) is a major public health issue, with a high risk of frequent hospital admissions, stroke and premature death (Ball et al., 2013). Furthermore, AF is now the major cause of cardiac hospitalisation, and rates are predicted to triple by 2050 (Ball et al., 2013). AF affects at least 2 million people in the UK (Chugh et al., 2013), and data from the Framingham study suggest there is a lifetime risk of 1 in 4 for adults worldwide, and a prevalence of 5% in those over 65 years (Miyasaka et al., 2005). AF can be intermittent (paroxysmal) or permanent. For those with paroxysmal AF, nearly 2/3 will have had recurrent episode of AF at 5 years, and ¼ will have progressed to permanent AF (Kerr et al., 2005). Regardless if AF is paroxysmal or permanent, data from a large registry with over 4000 people with AF show that 11% will have an ischaemic stroke within 5 years, a five to seven-fold increase compared to stroke incidence in the general population (Gladstone et al., 2014). One in six strokes is AF-related, and these strokes are likely to be more severe, or fatal (Gladstone et al., 2009). Almost 70% of people with an AF-related stroke will die, or be left with a permanent disability, compared to 55% of people with non-AF strokes (Saposnik et al., 2013). Importantly, in a systematic review including over 75,000 participants, effective treatment with oral anticoagulant medications (OACs), such as warfarin, or non-vitamin K OACs (NOACs), reduced the stroke risk in people with AF by two-thirds (Ruff et al., 2014). Indeed it is estimated that in England alone, appropriate management of AF could prevent around 7000 strokes and save 2100 lives per year (The Stroke Association, 2016).

Despite this, AF is often inadequately managed due to low adherence to prescribed medication, and in particular to OACs (Gladstone et al., 2009). A recent cohort analysis of 64,661 AF patients prescribed OACs demonstrated that at one year only 40% of those taking warfarin had a proportion of days effectively covered >80% of the time (Yao et al., 2016). This increased slightly to 47.5% of effective cover for those prescribed NOACs (Yao et al., 2016). It has been clearly demonstrated that poor understanding of AF and appropriate management adversely affect adherence to prescribed treatments (Diamantouros et al., 2013). A survey of 500 people with AF from the American Heart Association found that AF patients have poor understanding of their condition, with only 50% of patients being aware that they are at high risk for stroke (American Heart Association, 2011). Indeed, in a recent AF screening study, including 1000 participants, it was discovered that 44% (n=23/52) of people who had a history of AF, did not know that they had AF, and did not know why they were taking warfarin (Lowres et al., 2014).

Understanding of the current context of AF management in Scotland was identified as a key priority at the Cross Party Group (CPG) for Heart Disease and Stroke. The CPG is chaired by Members of the Scottish Parliament (MSP) and includes. clinicians, third sector organisations and individuals with an interest in heart disease or stroke. The CPG meets regularly at the Scottish Parliament to debate and discuss relevant issues. To identify national issues on AF, a panel was convened to produce a comprehensive report to Scottish Parliament. The aims of this report were to identify current practice, to define best practice, and to provide clear recommendations to government to improve health for people living with AF.

**METHODS**

The major third sector organisations with an interest in Heart and Stroke (British Heart Foundation, Chest, Heart and Stroke Scotland, and the Stroke Association) convened an advisory panel to develop the content of the inquiry, and provided the secretariat. As well as third sector representatives, the advisory panel included academics, clinicians, MSPs, and people living with AF.

The advisory panel worked together to develop a consultation tool to gather initial information. Following discussion, it was agreed that the best option was to have two separate questionnaires; one which was relevant to people living with AF; and another which was relevant to clinicians or organisations with an interest in AF. The questions were developed from common themes in the literature and related to prevention, diagnosis, treatment and data use relating to AF. The questions aimed to allow people to share their knowledge, and were mostly open-ended. Participants were invited to provide any further feedback via email, telephone, or in person. The questionnaire was shared through multiple contact lists and through social media, and ran for 12 weeks (20th June-15th September 2017).

Once the consultation closed, the responses to the questionnaires were thematically analysed and the emergent themes were used to determine four roundtable events at Scottish Parliament. Respondents to the questionnaire, or leading topic experts were invited to participate in the round tables. Each of these panels examined in more detail the results of the paper based consultation

**RESULTS**

There were 203 responses to the clinical consultation questionnaire and 59 to the consultation questionnaire for people living with AF. Emergent themes were: diagnosis of AF; treatment of AF; data use; and patient information. Each of these formed the topics for the four roundtable events held at Scottish Parliament in October and November 2017. Each roundtable was attended by around 15-20 people, including members of the advisory panel, MSPs, clinicians, academics and people living with AF. People attended based on area of expertise and personal interest, so that in total 35 individuals (29 professionals, 6 patients, not including advisory panel members) participated in the different panels, with some attending more than one panel. Each roundtable lasted approximately 90 minutes. Around 15 people with expertise in these areas, or those who had responded to the inquiry consultation were invited to attend each roundtable. The roundtable discussion on patient information was primarily comprised of people living with AF. Discussions at the roundtables elucidated findings from the consultation, provided depth, and further helped to develop the recommendations in the report. Four major themes emerged: Detection and diagnosis of AF; Initial treatment and subsequent management of AF; The use of data to improve detection, diagnosis and treatment of AF in Scotland; and, patient information and public awareness. The themes were summarised and 10 key recommendations were elucidated, which form the backbone of the report to Scottish Government (Box 1)

**Detection and diagnosis of atrial fibrillation**

The first major theme related to detection and diagnosis of AF. While respondents to the consultation highlighted the importance of this, many discussed the challenges in detecting and diagnosing AF which is asymptomatic or paroxysmal. They discussed that people without symptoms are unlikely to present to a health care professional with specific regard to their AF and those with paroxysmal AF might not be in AF at the time they are undergoing diagnostic checks. People living with AF confirmed that their paroxysmal AF made diagnosis difficult:

‘*’It was several years before it could be confirmed on ECG because it always came on at night’’*

From people living with AF, stories of late diagnosis were common:

*“I had a stroke at work and on being admitted to hospital was diagnosed as having AF by the clinical team looking after me.’’*

Therefore, both clinician respondents and those living with AF highlighted case-finding to detect asymptomatic and paroxysmal AF as a crucial opportunity to avoid AF-related strokes and the resulting personal and economic impact that these have. Clinician respondents particularly highlighted that AF case-finding could be easily carried out in primary care, pharmacies or community settings with minimally invasive tests (including pulse checks, new single lead ECG technologies, or 12 lead ECG for those with the highest probability of AF). Discussions at the inquiry roundtable meeting focusing on detection and diagnosis were broadly supportive of targeted case-finding with a focus on those most at risk. The categories for targeted case-finding should include those over 65 years of age and those with significant risk factors for AF including cardiovascular disease, diabetes or respiratory disease.

Respondents further explored that AF detection and diagnosis is important in preventing stroke in the first instance (primary prevention) and also in the prevention of a further stroke (secondary prevention). There was a concern that technology in this area has advanced rapidly, perhaps more quickly than guidelines, research, and clinical practice can keep pace with. Increasingly sophisticated methods of diagnosis were welcomed but the respondents urged caution to ensure that only technology that has been appropriately validated is utilised.

Another major barrier to effective care was the variance of access to diagnostic services across Scotland. Some respondents indicated that there could be delays of eight or nine weeks in obtaining diagnostic services (e.g. 12-lead ECG) and commented of the high risk of stroke in the intervening weeks. Furthermore, there was even more delay in obtaining access to longer term monitoring such as Holter monitors for people with suspected paroxysmal AF. Key identified barriers included limited access to newer technology which could improve diagnosis and reduce staff time. There were also specific barriers around cardiac physiology staffing and training, which has become a significant issue nationally. Examples of how to improve this were better workforce planning, development of appropriate training and ensuring multi-skilled health care staff. Furthermore, the utilisation of appropriate technology in order to relieve pressure on staff resources is another potential area for development. It was also suggested that ensuring the application of Realistic Medicine principles would be valuable determining which patients are referred for services. These services should be utilised for patients at highest risk and who are likely to benefit from a change in management of their condition.

**Initial treatment and subsequent management of AF**

The second major theme emerging from the consultation was the need for appropriate post diagnostic pathways. This was considered to include post-diagnostic support, appropriate education, treatment and follow-up. A number of respondents to the consultation identified difficulty in referral for specialist assessment to identify those appropriate for cardioversion or ablation due to the availability of these services. Respondents also highlighted that anti-coagulation use for AF in Scotland is sub optimal. They suggested that concern amongst clinicians about the risks of bleeding associated with oral anticoagulants was a barrier to effective care, with one clinician respondent stating:

*‘’Fear amongst professionals of causing bleeding. Need to better inform doctors of the actual risks of bleeding on anticoagulants versus risks of ischaemic stroke.’’*

A major theme which emerged from the consultation responses and discussions at the roundtable meetings was that bleeding risk was often used as a reason not to prescribe anticoagulant medication when, in a number of cases, it should be used as a tool to modify risk factors (such as hypertension or alcohol consumption). A number of respondents mentioned that the risk of bleeding associated with falls was greatly over-estimated in clinical practice. Other respondents to the consultation highlighted that rapid changes in evidence for the newer oral anti-anticoagulants made it difficult to remain professionally up-to-date. This was further elucidated during the round table discussions, with respondents suggesting making appropriate choices could be time consuming and had the potential to increase prescriber anxiety. Thus, it was suggested by many that there is a need for better clinician education about guideline based therapy.

One further issue emerged around the use of the NOACs. These medications are substantially more expensive than warfarin, and there is variation in guidance between Health Boards regarding their use. There were also bureaucratic processes which added complexity to prescribing of NOACs. Furthermore, there were concerns that patients did not receive adequate information to make informed choices about NOACs, nor sufficient information to support their continued use, and it was recommended that people prescribed these medications for AF should have ongoing care from appropriately trained health care professionals. Exemplars of good practice for AF management across Scotland were shared, highlighting the improvements that resulted from nurse-led integrated care.

**The use of data to improve detection, diagnosis and treatment of atrial fibrillation in Scotland.**

The third theme was the use of data to improve AF detection and management. A number of respondents to the consultation highlighted the need for software that allowed practice staff to better assess the needs of the practice population. Once again respondents described exemplar projects where the use of data had transformed healthcare outcomes for people living with AF. In particular, they referred to a practice software tool called GRASP-AF. This is an electronic tool which runs a set of queries on the practice database building a list of every patient with a diagnosis of AF, the drugs associated with AF and any contraindications for anticoagulation. GRASP-AF is funded by the Department of Health England and therefore is freely available to practices within NHS England. Discussions at the inquiry roundtable meeting on the use of data were very supportive of a similar tool being developed for Scotland. It was felt that this would be a crucial intervention which could have a significant impact on the prevention of AF related strokes.

Throughout the course of the inquiry some general barriers were highlighted which might explain the barriers to use of data to improve health of people living with AF. These included the time necessary to input data fully, concerns about confidentiality, ensuring accurate coding and disparate IT systems. In particular, attention was drawn to the disparity between systems at primary and secondary care levels. It was highlighted that creating a cohort of AF patients for big data research projects has to use data from various records (hospitalisation, community prescribing records or Scottish Stroke Care Audit). These data sources do not allow for an identification of AF patients who are not anticoagulated, and who have not been hospitalised with either AF or a stroke. This is a major limitation for potential research into this condition.

Discussions at the roundtable meeting also highlighted that working with routine administrative data sources can be difficult due to long waiting times as several data custodians are involved to grant permission for data access. Linking the different data sources requires separate applications for data access. Individuals who were involved in data usage expressed that their hope was for a more streamlined process to facilitate improved use of data.

**Patient information and public awareness**

The final, and arguably most important area that emerged from the consultation, were the barriers that existed to patients finding information about their condition. Of the 59 respondents to the patient questionnaire, 15% stated that they received no information at all about their condition while only 33% felt that they received a detailed explanation.

In particular, respondents highlighted a gap in information sharing with regards to whether they should have been given rate or rhythm control interventions such as cardioversion or ablation, and a lack of information about why these procedures may not be suitable for them.

*“I was advised by my GP that I was not a candidate for cardioversion or ablation, but he did not explain why.”*

*“I am angry that I was not told about a procedure called Ablation (I think) until it was too late”*

People living with AF were clear that receiving more information about the condition and their treatment options would have greatly improved their experience. Those who were happy with the care they received pointed to the flow of information and communication with their health care professionals as a factor crucial to their satisfaction.

Clinician respondents to the survey noted that, although anticoagulation for AF is usually a long-term medication, many patients were not taking their prescribed anticoagulant a few years after diagnosis. At a clinical level, they suggest this highlights the importance of exploring the patient’s perspective and sharing information in a way that the patient can make informed decisions. They further suggested that there is much greater scope for thinking about how patient centred care and shared decision making principles can be applied in the context of AF. Clinician respondents identified leaflets as a useful tool for sharing information with patients, but only a minority of those living with AF recalled receiving anything like this.

In our roundtable discussion with people with AF, it was felt that leaflets had been helpful and played an important role. In particular, a need to ensure that information was reliable was expressed and many people pointed to publications from respected third sector organisations or NHS websites as sources of good information. The discussions highlighted that further to receiving leaflets, the critical aspect for most people was having contact with a health care professional who could answer any questions and tailor information to the person’s individual situation.

It was clear from the responses that review processes for people with AF are variable throughout Scotland. In some areas people with AF are reviewed regularly, while in other areas this does not seem to be the case. People living with AF indicated that a more regular review process would have improved many of their experiences. Clinicians highlighted that community pharmacy could have a particular role to play with regards to regular medication review of people with AF.

Both clinicians and people living with AF commented strongly on the lack of public awareness of AF. At the roundtable discussion on detection and diagnosis the merits of raising public awareness were discussed. It was thought to be helpful generally to raise awareness of the condition and its links to stroke amongst a general population, although it was felt that more detailed information such as how to check a pulse for example, was better shared through more targeted awareness raising to high risk groups. One of the key areas that emerged was that not all health care professionals were aware of AF and that professional education could play a major role in improving the experience of people living with AF.

**DISCUSSION**

This national inquiry into AF management is, to the best of our knowledge, the first time a range of stakeholders have come together at a national level to deliver clear recommendations to government on the diagnosis, management and support required for people living with AF. From the findings of the inquiry, ten clear recommendations have been made to Scottish Government.

In common with previous work, the inquiry highlighted areas of low knowledge and variability in AF management across the country (Oldgren et al., 2014). It was clear that clinicians and people living with AF believed that clearer care pathways from identification through to lifelong management with a patient-centred approach would improve the experience of living with AF in Scotland. It has previously been demonstrated that AF patients do not receive counselling regarding the nature of AF, appropriate treatment, self-management, and healthy lifestyle (Steg and investigators, 2010) and this was supported by the findings of this inquiry.

While some patients in the report were able to access health information, many reported having to seek out information themselves, or being dependent on an individual clinician with an interest. There are a number of other barriers like language barriers, medical jargon and health literacy to information provision, which have been clearly identified in the literature (Aronis et al., 2017). Any efforts to improve information dissemination in Scotland must take these into account.

One clear theme was the need for integrated care involving the whole health care team. In a systematic review of three studies of integrated care involving 1383 participants with AF, it was demonstrated that there were significant reductions in hospitalisation (0.58 (95% confidence interval (CI) 0.44-0.77), p=0.0002) and in the two studies that reported all-cause mortality there was a significant reduction in death (0.51 (95% CI) 0.32-0.80), p=0.003) (Gallagher et al., 2017). Of note, the trial with the most striking differences in this review was supported by an electronic decision support tool. Respondents to the inquiry also stated their preference for the use of electronic tools and data to support management of AF, and thus this is included as one of the ten recommendations.

***Limitations***

This national inquiry may be under-representing the problem of AF in Scotland, as the respondents were self-selected and therefore had greater interest in the key issues. In particular, people living with AF may have been those who had higher levels of literacy and who had been able to source relevant information via other mechanisms than the usual care pathways e.g. by contacting major third sector charities and by researching on the Internet.

**CONCLUSION**

Working together in this collaborative way has allowed the report to benefit from a range of expertise and created a synergy that could be an exemplar for future policy work. The major findings of the inquiry suggest that there are pockets of excellence, but there are substantial areas for improvement. It is hoped that the results of this inquiry will provide the blueprint for change that will improve AF management across Scotland.

Full details of the AF inquiry can be found at

<https://www.bhf.org.uk/get-involved/heart-voices/updates-on-our-current-projects/cross-party-group-inquiry-into-atrial-fibrillation-in-scotland>

<https://www.stroke.org.uk/Scotland>

**Box 1: RECOMMENDATIONS FOR SCOTTISH GOVERNMENT**

***Detection and diagnosis of atrial fibrillation***

1. Encourage targeted AF case finding programmes for those most at risk (age over 65 years, those with previous stroke and those with existing cardiovascular risk factors).
2. Work with the relevant National Advisory Committees to address the shortage of cardiac physiologists working within Scotland.
3. Invest in the use of proven technologies within clinical practice to detect AF.

***Initial treatment and subsequent management of atrial fibrillation***

1. Work with stakeholders in primary and secondary care to create a clear and consistent clinical pathway for people diagnosed with AF.
2. Actively promote and support health boards to implement specialised AF services to facilitate accurate diagnosis; to ensure prompt, appropriate anticoagulation and to ensure patient-centred management.

***The use of data to improve detection, diagnosis and treatment of atrial fibrillation in Scotland.***

1. Imbed consistent and effective data capture, ensuring integration across clinical boundaries of primary and secondary care and efficient processes for linking and accessing these data.
2. Support the development and implementation of IT software solutions to facilitate case finding, support therapeutic decisions and allow audit within and between practices.

***Patient information and public awareness***

1. Ensure that all health care professionals have the necessary information about AF to support patients to take part in shared decision making, from the point of diagnosis of AF through to long term condition management.
2. Work with clinicians, researchers, third sector and people affected by AF to find the most effective methods to raise awareness of AF amongst the public.
3. Ensure that people with AF and at risk of AF receive relevant, tailored information and support, utilising robust and trusted providers such as major third sector charities.

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