

Take Action Now:

Supporting the prevention
of AF-related stroke



TAKE ACTION NOW: Supporting the prevention of AF-related stroke

Contents



Introduction

On behalf of the Atrial Fibrillation Association (AFA), Arrhythmia Alliance (A-A), AntiCoagulation Europe (ACE) and the Stroke Alliance for Europe (SAFE), we would like to introduce the **Take Action Now: Supporting the prevention of AF-related stroke** Action Plan.

The AFA, ACE, SAFE and A-A were solely responsible for both the development of, and resources contained, within the Take Action Now Toolkit.

Boehringer Ingelheim provided an independent educational grant for this initiative. BI has no influence over its contents.

This Action Plan has been developed as a practical resource, outlining simple steps to help us, and other patient advocacy groups throughout the world, address under-treatment for stroke prevention among atrial fibrillation (AF) patients.

We believe such action is vital. AF, the most common sustained heart rhythm disorder, is the single most powerful independent risk factor for stroke and its prevalence is increasing.¹ Those with AF are five times more likely to have a stroke than those without. Their strokes will be more severe leading to greater disability and death than non-AF strokes. As well as being more deadly and disabling, AF-related strokes are also more expensive; putting a disproportionately high burden both on healthcare budgets and on those providing care either formally or informally.

However, through under-detection and under-treatment, it is estimated that only 18% of all AF patients are currently receiving treatment that safely and effectively reduces this risk of stroke.^{1,2} Consequently, there is urgent need for the improved diagnosis and management of AF to prevent thousands suffering avoidable strokes, disability and death.

Warfarin, the most commonly used anticoagulant drug, is a safe and effective treatment option for many patients. However, the important contribution of warfarin to stroke prevention in AF has been limited both by the need for close monitoring and by safety concerns among prescribers.² Consequently, many thousands of patients are receiving vastly sub-optimal treatment with aspirin instead of with an anticoagulant. Efforts that increase the rate of anticoagulation among AF patients are to be applauded, including the introduction of alternatives to warfarin that are not associated with the traditional barriers to the use of anticoagulation.²

Despite recently published international clinical guidelines that recommend anticoagulation in all AF patients at moderate or high risk of stroke, adherence to these guidelines is poor.² Furthermore, patients' lack of understanding of AF, and the associated risk of stroke, prevents them from engaging appropriately with their clinicians on decisions about their treatment.² This lack of awareness limits patient understanding of the importance of their treatment.

We call for all patient advocacy groups to **'take action now'** to help address these barriers to optimal prevention of AF-related stroke. Through improved awareness and education, patient advocacy groups can engage with key stakeholders to change health systems and to ensure that patients receive access to the most appropriate treatment.

The **Take Action Now** Action Plan outlines five areas of recommended actions for your consideration. These areas have been chosen based on input and recommendations received from 13 patient advocacy organisations from Canada and Europe who participated in the **Take Action Now** advocacy group workshop in London earlier this year.

We have specifically designed the Action Plan to accommodate the needs of patient groups at varying stages of development – from larger, long-established groups to smaller groups in earlier stages of development. While the Action Plan includes best-practice examples of effective, large-scale campaigns to drive awareness and change, each area of the Action Plan also includes at least one simple, cost-effective activity that can be implemented with limited resource while delivering maximum impact.

In summary, we've aimed to develop a comprehensive resource that can be utilised by any patient advocacy organisation or individual who wants to drive change, ensuring healthcare systems prioritise stroke prevention for patients with AF and that patients with AF have access to the most appropriate treatments to prevent stroke.

Through our combined efforts and commitment to 'take action now', we believe that we can help reduce the number of preventable AF-related strokes and significantly improve the lives of thousands of people with AF.

Trudie C A Lobban MBE

Founder & Trustee, Arrhythmia Alliance; Founder & Chief Executive Officer, Atrial Fibrillation Association

Eve Knight

Co-Founder and Chief Executive, AntiCoagulation Europe

Maria Caporaso

Corporate Partnerships, Stroke Alliance for Europe



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How can we support the uptake of, and adherence to, clinical guidelines?

Introduction

There is considerable evidence that adherence to internationally agreed guidelines on AF management is associated with fewer strokes and improved patient care. Despite this evidence there is significant deviation from the guidelines throughout Europe, resulting in widespread sub-optimal care. Research has demonstrated the impact of non adherence to international guidelines, particularly highlighting the underuse of anticoagulants in patients with AF. Several countries also have differing regional guidelines, resulting in further deviation from the international consensus.

In addition, many family doctors do not have enough knowledge to be aware of and/or follow guidelines with confidence, primarily attributed to a lack of education around the benefit-to-risk ratio of existing therapies.² To ensure patients with AF at increased risk of stroke are receiving the best, most appropriate treatment for them as individuals, family doctors need to be made aware of the guidelines and follow them to ensure the optimal management of their AF patients.

We feel that advocacy can play an important role in raising awareness of the need for improved adherence to relevant, up-to-date guidelines. It is important that physicians and patients are aware of international recommendations, as examples of best practice for adoption at local level, in-particular in regions where no national, or conflicting national guidelines exist.

The most recent international guidelines relating to the treatment of people with AF at increased risk of stroke are those produced in 2010 by the European Society of Cardiology (ESC) for the management of atrial fibrillation and updated in 2012.³

How can we help improve awareness of international clinical guidelines?

Goal: All primary care professionals and AF patients have access to and are aware of the ESC Guidelines, as updated in 2012, for the management of atrial fibrillation.

	Recommended actions	Useful tips / resources	Action Plan links
1	Provide summaries of the ESC Guidelines on your group's website for healthcare professional and patient use, along with a link to the full version of the guidelines for downloading	A summary of the guidelines for distribution to physicians can be found on the Atrial Fibrillation Association website	Refer to section 4 for further guidance on simple methods of awareness raising and channels of distribution
2	Distribute the ESC Guidelines summaries to all members of your group, encouraging them to take them to their family doctor appointment to support discussion around the most appropriate treatment for them	A simple e-communication can be an effective method for distributing material cost effectively to a wide audience	Refer to section 3 for guidance on establishing partnerships
3	Distribute the ESC Guidelines summaries to national / regional family doctor surgeries, for placement in waiting rooms and for family doctors to provide to patients during appointments	You may wish to contact a local industry partner who can support you in identifying the appropriate contacts	
4	Print hard-copy versions of the ESC Guidelines summaries for distribution at your group's healthcare professional / patient events and meetings	Consider additional channels for distribution via partnerships with other stakeholder groups, such as professional organisations and other patient groups	

How can we help increase understanding of international clinical guidelines and ensure physicians are adhering to their recommendations?

Goal: All primary care professionals have a greater understanding of the content of clinical guidelines and adhere to guidelines' recommendations regarding the appropriate management of AF patients at increased risk of stroke.

	Recommended actions	Useful tips / resources	Action Plan links
1	<p>Coordinate a series of educational workshops / meetings aimed at local primary care professionals, to discuss:</p> <ul style="list-style-type: none"> • An overview of ESC Guidelines • Key existing research data highlighting the current lack of adherence to guidelines globally / in your country • The importance of adhering to guidelines • Introduction to the AF Stroke Risk Calculator 	<p>Refer to the following materials as useful sources of information / content:</p> <p>AFA medical professional toolkit</p> <p>‘Atrial Fibrillation – Preventing a Stroke Crisis’ report</p> <p>‘How Can We Avoid a Stroke Crisis?’ Report</p> <p>The Take Action Now Project Manager will be able to assist you in planning and implementing your workshops</p> <p>Please refer to Case Study 1 in Section 6 for an example of activity in Belgium</p>	<p>Consider partnering with other stakeholders to coordinate your workshops – (refer to section 3)</p>
2	<p>Provide primary care professionals with a practical resource to support identification, diagnosis and optimal management of AF patients at increased risk</p>	<p>The AFA / ACE Stroke Risk Calculator is available for local translation and use in your country</p> <p>In addition, audit tools, such as GRASP AF, are a useful model to refer to when considering the development of similar resources. Refer to chapters 5 and 6 of the ‘Atrial Fibrillation – Preventing a Stroke Crisis’ report for further information</p>	<p>Refer to section 4 for further guidance on simple methods of awareness raising and channels of distribution</p>
3	<p>Ensure your group takes a more active role in decision-making by engaging with bodies responsible for making recommendations on treatment and access to funding, such as clinical guidelines and Health Technology Assessments (HTAs). Send a letter requesting a meeting to discuss how your group / individual patients can participate in the HTA process</p>	<p>Examples of how this has worked effectively within the UK and Spain are included within Case Study 2 and Case Study 3 in Section 6</p>	

2



How can we participate in political / health service engagement to effect change in anticoagulation services?

Introduction

Economic variation and large differences in healthcare budgets have contributed to high levels of inequities in AF service provision, both between countries and within specific country regions. Further information on these regional differences is included within the 2009 'How Can We Avoid a Stroke Crisis?' Report which outlines the high economic costs associated with stroke, inequities in access to healthcare services and the need for more consistent strategies for AF-related stroke prevention.¹

While cardiovascular disease management and prevention is a priority, AF and AF-related stroke prevention specifically is often not recognised as a priority on the health policy agenda. We believe that healthcare systems should prioritise best-practice diagnosis and treatment for AF, to avoid every 'preventable' stroke.

How can we communicate with policy makers to increase their understanding of the need for more consistent health service provision in AF-related stroke prevention?

Goal: AF and AF-related stroke prevention is recognised as a priority on the health policy agenda. More consistent health service provision enables patients' access to the most appropriate treatments for them, regardless of the region they live in.

	Recommended actions	Useful tips / resources	Action Plan links
1	<p>Host an 'online patient petition' on your group's website, calling for policy makers to recognise AF-related stroke prevention as a health priority in your country</p> <p>Communicate the results of the petition to local policy makers via a simple letter mailing (see action 2 below)</p>	<p>You could help generate signatures for the petition by distributing flyers / posters announcing the initiative at local events / meetings</p> <p>Visit www.heartofstroke.com for an example of a global petition</p> <p>Consider announcing the results of the petition to the media to generate wider awareness</p>	<p>Consider partnering with other stakeholders to drive your petition and communicate the results (refer to section 3)</p> <p>Include the results of the petition as part of a larger awareness raising activity (refer to section 4)</p>
2	<p>Conduct a simple letter mailing to local policy makers, outlining a call-to-action for:</p> <ul style="list-style-type: none"> • More consistent health service provision • AF and AF-related stroke prevention to be recognised as a health priority in your country <p>If you have conducted an online petition (see action 1 above) you should highlight the results of the petition within your letter</p>	<p>A template email for you to adapt and translate can be found on the Know Your Pulse website</p> <p>Refer to the 'Atrial Fibrillation – Preventing a Stroke Crisis' report for an overview of the global burden of AF, including data and statistics on quality of life impact, burden on families, carers and society, and demand on health and social services and economic cost</p> <p>National / local government websites are a useful source for identifying relevant health policy contacts, for example http://findyourmp.parliament.uk/</p>	
3	<p>Organise one-to-one meetings with local policy makers to present an overview of the specific challenges in your country regarding AF-related stroke prevention</p> <p>Identify examples of 'innovative best practice' where national/regional activities have resulted in positive healthcare system change. Share these during your meetings with policy makers to encourage quality and consistent standards of care and access to the most appropriate treatment for individual patients</p>	<p>An example meeting agenda is included within Section 6 of the Action Plan</p> <p>Refer to AFA's 'Healthcare Pioneers – Showcasing innovative practice in Atrial Fibrillation' booklet for some best practice examples from the UK</p>	

How can we help improve AF diagnosis and education around recognising the symptoms of AF?

Goal: Simple detection initiatives are adopted and recognised by primary care professionals as one of the most cost effective ways of detecting AF and preventing AF-related strokes. Patients who are concerned that they might have AF, or are at risk of AF-related stroke, are encouraged and motivated to ask for a routine check.

	Recommended actions	Useful tips / resources	Action Plan links
1	<p>Conduct a national 'Know Your Pulse' campaign to promote routine pulse checks for people visiting their family doctor surgery and help raise public and medical awareness of how a simple pulse check could help detect cardiac arrhythmias</p> <p>Distribute Pulse Check Guides to national / regional family doctor surgeries for placement in waiting rooms and as handouts to patients, or at local events and meetings</p>	<p>Visit the Arrhythmia Alliance website for tips and ideas on conducting your local campaign</p> <p>Download and translate A-A's Pulse Check Guide for local distribution</p>	<p>Refer to section 4 for further guidance on simple methods of awareness raising and channels of distribution</p>
2	<p>Organise a series of national / regional 'booth' testing initiatives to encourage people to take a pulse check</p>	<p>You may wish to align your activity with global / national awareness days / weeks, for example World Heart Rhythm Week or World Stroke Day</p> <p>Consider collaborating with local hospitals or pharmacies to host your 'booths' and encourage participation by distributing flyers and posters (for example at community health centres, pharmacies, supermarkets). Promotional material should include educational information on recognising the symptoms of AF, so that potential AF patients are encouraged to visit a booth</p> <p>Please refer to Case Studies 4 and 6 in Section 6 to read how this has been successfully rolled out in Belgium and Italy</p> <p>Activity can be used to generate media coverage to help raise awareness of the importance of early AF detection, the risk of AF-related stroke and appropriate management</p>	<p>Refer to sections 3 and 4 for further guidance on establishing partnerships and simple methods of awareness raising</p>

3



How can we develop and maximise partnerships with other stakeholder groups, such as professional organisations and other patient groups?

Collaboration between patient organisations and other stakeholders / stakeholder groups can help provide you with access to a wider range of resources, clinical expertise, added credibility for your activities and opportunities to access further funding, all of which will support you in helping to impact system change and ensure AF patients are gaining access to the best, most appropriate treatments for them. There are various partnerships you can consider, including partnering with professional societies / organisations, individual physicians, other patient advocacy organisations, government and even commercial organisations, all of which will give added credibility to your activities and programmes.

How do we identify and approach the right partners to work with?

Goal: Established partnerships between patient advocacy groups and other stakeholder/s, that will add further credibility to your advocacy programmes and campaigns.

	Recommended actions	Useful tips / resources	Action Plan links
1	Conduct a stakeholder mapping audit of potential stakeholder partners in your country / region to identify the most appropriate partners for your planned activity / group's objectives	<p>In addition to web-based research, it is useful to conduct telephone interviews with potential partners, to gain further insights into their background and objectives</p> <p>It is important that you identify partners with mutual objectives to get the most out of your partnerships and avoid any conflicts of interest</p>	
2	Initiate contact with potential partners via an email or letter, introducing yourself and your organisation, its background and objectives and your interest in partnering together	<p>Before starting any partnership activities, you should ensure you have a written agreement in place, outlining the scope and terms of the partnership that both parties have approved and signed</p> <p>A new toolkit is due to be launched by SAFE and the World Stroke Organisation later this year, that will include guidance on patient / professional organisation partnership activities</p>	

How can we work effectively together with different stakeholders?

	Recommended actions	Useful tips / resources	Action Plan links
1	Consider working with family doctor associations to facilitate and add patient perspective to their existing educational programmes		Refer to section 1 for recommendations on coordinating healthcare professional educational workshops
2	Partner with individual professionals / professional organisations to produce educational materials / consensus statements / reports highlighting the current unmet needs in the management of AF-related stroke prevention	<p>The Take Action Now Project Manager can help facilitate introductions between your group and appropriate expert professionals in your country</p> <p>Consider using these type of partnerships to drive awareness raising activities and further communicate with policy makers and payers, to highlight the significant need in prioritising AF and AF-related stroke prevention on the health policy agenda</p>	Refer to sections 1 and 2 for further guidance on impacting HTA decisions and policy maker outreach; Refer to section 4 for simple methods of awareness raising
3	Secure your group's participation at medical congresses / events, to ensure the patient perspective is included on the agenda	Professional partner representatives can participate as guest speakers, providing a clinical overview that will bring added credibility to your presentation / event	Refer to section 4 for further guidance on using these events as a forum for sharing patient experiences
4	Partner with medical societies to engage with the development of national clinical guidelines	Research / establish when reviews of national clinical guidelines are due to take place and plan your activities / partnerships accordingly	Refer to section 1 for further guidance on improving adherence to clinical guidelines
5	Collaborate with professional organisations / individual professionals to conduct policy maker / payer outreach and communicate the cost of AF and AF-related stroke	Professional organisations can often provide useful access to the most current research data and statistics that will help substantiate your communications to policy makers and payers	Refer to sections 1 and 2 for further guidance on impacting HTA decisions and policy maker outreach
6	Partner with other patient organisations to drive larger-scale awareness and educational campaigns around AF and AF-related stroke prevention	Ensure you research potential patient group partners to ensure you have mutual objectives, before entering into a partnership agreement	Refer to section 4 for simple methods of awareness raising
7	Partner with commercial organisations such as pharmacy chains, care homes and pharmaceutical organisations to help drive awareness raising activities and support distribution of educational information		Refer to sections 2, 4 and 5 for further guidance on partnership activities with commercial organisations

4



How can we conduct simple, cost effective awareness-raising activities?

There is a significant lack of awareness amongst AF patients and their communities around AF and stroke prevention, highlighting a need for more effective communication and distribution of information, that will help educate the public, patients and carers about the risk of AF-related stroke.²

Although a plethora of educational information exists, it is not effectively reaching patients and their communities, or enabling them to actively engage with healthcare systems to ensure they receive the best possible care.

In addition, lack of funding and resources have been identified amongst patient advocacy groups as key barriers to driving effective awareness campaigns.

How can we identify and disseminate the most appropriate information on AF and its consequences and AF-related stroke?

Goal: Ensure the most relevant, up-to-date information is easily accessible for AF patients and their carers and that they know how to find it.

	Recommended actions	Useful tips / resources	Action Plan links
1	Audit and review central information hosted online via A-A / AFA / ACE and SAFE and identify key materials for local adaptation and translation. Collate all updated information on your website, ensuring it is easily accessible to download	A large selection of patient educational resources are available for your use via the A-A / AFA / ACE and SAFE websites. The following links direct you to centralised information pages and online resources http://www.atrialfibrillation.org.uk/publications/booklets.html http://www.stroke.org.uk/information/resource-library http://www.preventaf-strokecrisis.org/ http://www.anticoagulationeurope.org/publications/	Refer to sections 1, 2 and 3 for example resources you may wish to include / link to on your website
2	Send regular e-communications to all of your existing members, updating them on new resources, activities and events, to ensure regular contact and sustained activation	Consider setting up a regular series of newsletters / updates for your members to sign-up to	Refer to sections 1 and 2 for examples of activities to raise awareness of clinical guidelines and help drive policy activity via e-communications to members
3	Identify a wider distribution area for patient information, for example places that patients are likely to visit, such as libraries, pharmacies, doctors' waiting rooms, care homes, garden centres, supermarkets and workplaces	National databases are an effective way of gaining access to additional contacts outside of your own group membership A-A / AFA / ACE and SAFE also provide additional links to affiliated groups and organisations on their websites	Consider these additional distribution areas for promoting other activities, such as 'Know Your Pulse' campaigns or pulse check initiatives (refer to section 2)
4	Mobilise patient group volunteers to supply key distribution points at regular periods	The Take Action Now Project Manager can assist you in identifying and establishing a volunteer network if you do not have an existing group of volunteers	Use your network of volunteers for promoting your group's activities (refer to sections 1, 2 and 3)
5	Engage in partnerships with commercial / industry organisations, such as pharmacy chains, care homes and pharmaceutical companies to support distribution	Commercial partnerships can provide access to additional resource and funding, helping to drive awareness campaigns on a larger scale	Refer to sections 3 and 5 for guidance on identifying and establishing suitable partnerships

How can patient-to-patient communication and education help mobilise empowered patients?

Goal: Local networks of empowered patients are established who can effectively advocate for change and action in under-treatment of AF-related stroke prevention.

	Recommended actions	Useful tips / resources	Action Plan links
1	Coordinate an 'expert patient' training programme whereby 'motivated patients' are trained to become experts in the management of their condition and actively engage with other AF patients to advocate for change	Please refer to Case Study 6 for details of an Expert Patient Programme currently being rolled-out in Spain	
2	Coordinate national / regional 'patient days' or meetings as a forum to collate and share patient experiences around AF and AF-related stroke	Consider partnering with professional organisations / societies to host patient meetings at existing national / regional events, such as the annual Heart Rhythm Congress	Refer to section 3 for further guidance on establishing partnerships

How can I develop and expand my group's membership?

Goal: Patient advocacy groups have access to appropriate resources to effectively build and maximise their membership.

	Recommended actions	Useful tips / resources	Action Plan links
1	Review and follow the A-A Model to establishing and building a group	<p>The A-A has developed an international toolkit as a practical guide to aid you through the process of establishing an A-A national model. Further details can be found on the Arrhythmia Alliance International website</p> <p>The Take Action Now Project Manager can discuss this Model in greater detail with you and provide further guidance on how you can implement it in your country</p>	

5



How can we raise money to sustain and grow our organisation?

Having clear goals, campaigns and plans for your organisation will help you to achieve real change for patients affected by AF and AF-related stroke. However, without the funding in place, you won't be able to do any of this. Funding for work and securing an organisation's future is one of the biggest challenges that many groups face. Yet, by working to establish a network of supports who share the same goals, this can help you receive funding for the work you want to do and protect your organisation.

There are many sources of funding you can consider. Commercial and pharmaceutical companies are a good way to attract income, as well as charitable trusts and foundations. In addition, many individuals will choose to support a charity that is close to their heart either by giving regularly or taking part in events to raise sponsorship. In many countries the government will also fund charities to undertake work.

Different countries have different systems and cultures, so whilst we can only give a guide as to what has worked well, your knowledge of your own country will need to guide you on which of the methods we suggest will in fact work for you. The Institute of Fundraising in your country is often a great place to start, offering training courses and networks which will enable you to learn more about how to raise the money you need.

How can we put together a comprehensive fundraising strategy?

Goal: You have identified the key funding sources in your country and have a plan as to how you will target these and how much income you expect to raise from them.

	Recommended actions	Useful tips / resources	Action Plan links
1	Look at support you currently have and decide whether it can be grown by concentrating more energy on it	Asking for help with an external audit may really help you to appreciate the assets you have. Perhaps a business person may help you with this – offering their time instead of a donation. Consult with your colleagues, trustees and beneficiaries as to their ideas	
2	Look at what other charities in your country are doing, can you learn from their ideas or their success?	Charities' websites usually list the support that they receive from key individuals, companies or foundations. Look at these and build up a list of the funders that exist in your country. Speak to people at other charities, they may be prepared to share their ideas with you	
3	Look at the Institute of Fundraising in your country, not only will they have codes of conduct, and training courses, they will also have networks of fundraising professionals you can join, which will give you great ideas	To find the Institute in your country try one of these links: European Fundraising Association - www.efa-net.eu or The Association of Fundraising Professionals www.afpnet.org	
4	Decide which of the many ways available might work for you and prioritise them	Focusing on activities in sequence can help you to achieve success at one thing before moving onto the next. Don't be tempted to try to do everything at once. Get one or two things right, and then start something else	
5	Define what you are asking for support for. Will it excite and engage people?	People or organisations will want to know what their money will achieve. Be clear on where it will go and how you will communicate this to donors. Ensure you have a range of asks – from large sums to lower amounts to cater for all	
6	Put in place a timed plan to carry them out. Ensure that you have goals against each piece of work, so that you can accurately judge whether it works for you or not	By breaking your plans up into stages, you can monitor your progress and see where you are at regular periods throughout the year to see whether you are on track	

How can we decide which funding method is right for us?

Goal: You have identified the best routes to take, and have then set up a range of income generating partnerships to generate income from these.

	Recommended actions	Useful tips / resources	Action Plan links
1	Raise money from companies so that they can support your work whilst showing their support for the community	<p>Look at companies with similar goals and set up how you can achieve these together</p> <ul style="list-style-type: none">• Pharmaceutical, device and diagnostic companies may wish to raise awareness of AF and AF- related stroke – talk to them about partnership working or them sponsoring your activities. It is in their interests to have strong patient groups• Retail companies may allow you to put information or appeals out through their stores network• Companies may adopt you for a year or two to organise fundraising activities with their employees	Refer to sections 3 and 4 for further information on partnering with third parties to drive awareness raising activities
2	Get individuals to support you	<p>This could be through a variety of ways:</p> <ul style="list-style-type: none">• Many people like to get sponsored to run a marathon or do a parachute jump. You can raise a lot of money this way – have you got any supporters who would like to do this for you?• Perhaps you could encourage people to give regularly – they could set up a direct debit to go out each month or send a regular cheque• Leaving money in your will is a great way to help a charity out, encourage your supporters to do this; whilst you won't get the money for some time, you could stand to receive a generous amount after their death	
3	Organise a fundraising event	<p>This could be any number of things, events are a great way to help people understand more about your charity, and to raise money</p> <ul style="list-style-type: none">• A party with an auction can help you to raise funds – ask companies to donate prizes so that you get all the proceeds• A challenge event, like a bike ride or a walk can really bring people together – encourage them to get sponsorship from friends and family	

	Recommended actions	Useful tips / resources	Action Plan links
4	Seek support from wealthy individuals in your country, many of them are keen to share their good fortune and to help others less fortunate	<p>Try and find out if there are any wealthy people in your country who live with AF or have had an AF related stroke – they will be more likely to want to support your work.</p> <p>Find out if they have supported charities in the past, and when approaching them try and build a relationship with them, helping them to understand more about your organisation before you directly ask them for support</p>	
5	Seek funding from trusts and foundations or the government	<p>In many countries charitable foundations give money to charities to pursue their work. Find out about which ones exist in your country, call them and ask them what kinds of work they support</p> <p>Government, locally or nationally can also sometimes help. Do they give grants for work, or outsource contracts – often for them this is a very cost effective way of getting the work done</p>	

6



Practical examples and resources

Case Study 1

Anticoagulation Educational Workshops

Country: Belgium



Challenge

There is a significant disconnect between physician and patients in their understanding and approach to the management of AF and AF-related stroke prevention. Belgian patient group Girtac – Vibast, in partnership with national professional organisations, are addressing this by supporting patients in gaining a better understanding of their situation and helping to facilitate more effective communication between patients and their healthcare professionals about the most appropriate treatments for them as individuals.

Overview

A travelling “anticoagulation” school has been created, to provide information sessions for professionals and patients on various topics relating to the management of patients receiving anticoagulation treatment.

The national project was initiated in July 2011 and will run until the end of June 2012. Instructors have been selected from a list of key opinion leaders (including both physicians and paramedical professionals) and the target audience are specialist physicians, family doctors, home care nurses, pharmacists, patients and patients’ families.

The training sessions cover various topics including effective management of AF and AF-related stroke prevention, an overview of newer OAC therapies and the recommendations issued by the French Health Products Safety Agency (AFSSAP).

To ensure a wide audience reach, training sessions have been set up at four French language hospital centres, four Dutch language hospital centres and one hospital centre in Brussels and have been organised with the support of professional associations including The Union of Dutch- and French-speaking General Practitioners and The Belgian Society of Cardiology.

Results

Feedback on held sessions from attending professionals and patients has been highly positive. More sessions are currently being planned for later this year.

Case Study 2

Patient group participation in HTA assessments

Country: UK



Several patient associations were involved in the National Institute for Health and Clinical Excellence (NICE) Health Technology Appraisal for Dabigatran etexilate for the prevention of stroke or systemic embolism in atrial fibrillation. Patient associations that accepted an invitation to participate in the appraisal included the Atrial Fibrillation Association, the Arrhythmia Alliance, AntiCoagulation Europe and the Stroke Association.

As part of their role as “Consultees” for the appraisal process, patient associations could participate in the consultation on the draft scope, the Assessment Report and the Appraisal Consultation Document and they were invited to nominate clinical specialists and patient experts to present their advocacy group’s views to the Appraisal Committee.

It is common for patient advocacy groups to consult with medical experts when developing a response to ensure balance, accuracy and credibility.

Taking an active role in decision-making by engaging with bodies responsible for making recommendations on treatment and access to funding, such as health technology appraisal committees, will ensure your group is supporting AF patients in getting access to the most appropriate treatments that will help manage their condition and prevent AF-related stroke.

Case Study 3

Professional / patient group collaboration to impact health authority decision-making

Country: Spain



Challenge

Local government regulations within some regions of Spain are preventing family doctors from prescribing of anticoagulation treatment, which is limited to secondary care only. Patient advocacy groups and professional organisations are working together to lobby for a change in regulations that will allow family doctor prescribing of newer OACs.

Overview

The Spanish Cardiology Society, SEMFYC and the Spanish Society of Internal Medicine are collaborating with Federación Española de Asociaciones de Anticoagulados (FEASAN) to develop a document for presentation to local health authorities, outlining the case for AF and AF-related stroke prevention to be addressed as a priority, allowing primary care physicians responsibility to prescribe anticoagulation treatment.

The document will present an overview of the context for anti-coagulated patients in Spain, an analysis of the current situation and proposed actions. It puts forward the following key points:

- There is a need to ensure education is provided for patients on anti-coagulation medication
- There is an urgent case for equal, timely access to appropriate anti-coagulants for all appropriate patients
 - The document requests that all health authorities address currently inconsistent patient access to treatment by giving primary care physicians responsibility to prescribe anticoagulation treatment as well as secondary care specialists throughout Spain. Providing family doctors with the authority to prescribe will enable atrial fibrillation patients at risk of stroke greater access to the most appropriate treatments for them as individuals
- There is a need to increase the numbers of patients who are able to self-manage their anti-coagulation medication

Providing family doctors with the authority to prescribe will enable AF patients at risk of stroke greater access to the most appropriate treatments for them as individuals.

Results

This collaboration between key patient and professional organisations is already making an impact, with some Spanish regions already changing their regulations to allow primary care prescribing.

Case Study 4

World Heart Rhythm Week Screening Initiative

Country: Belgium



Challenge

There continues to be a significant unmet need in the effective detection of AF and therefore prevention of AF-related stroke, due to poor understanding and lack of knowledge amongst patients and the general public.

Overview

Girtac – Vibast, in collaboration with the Belgium Heart Rhythm Association, coordinated a successful screening initiative throughout Belgian hospitals during 2011 World Heart Rhythm Week. The initiative was designed to raise awareness of AF and AF-related stroke and educate patients and their carers/families around appropriate management of their condition.

The programme is being repeated again in 2012.

The initiative also provided a great platform for media activity with print publications, radio and television all showing interest in screening events.

Results

Last year, 20,000 patients were screened throughout 80 hospitals. Of those 20,000, 49 patients were referred instantly to a cardiologist to receive further help.

In 2012, the number of hospitals participating in the screening initiative increased to 90 with screenings being oversubscribed in many instances. The campaign's website received 46,000 visits during World Heart Rhythm Week this year with users spending on average, five minutes reading information on AF. In addition, media articles were published in over 90 print publications alone!

Case Study 5

Establishing an Expert Patient Programme

Country: Spain



Challenge

AF patients are not taking control and / or managing their illness effectively as they could. There is a need for improved education to support self-management of AF, thereby helping patients to reduce their risk of AF-related stroke. Patients who are experts in managing their own condition can also effectively educate other patients through the sharing of peer-to-peer information.

Overview

Federación Española de Asociaciones de Anticoagulados (FEASAN), the Spanish patient association, has coordinated a health education programme, which aims to reduce the risk of stroke in AF patients through educational tools for responsible self-management. The programme incorporates several key elements including; a patient education and training website (www.pacientexperto.org) covering areas such as AF aetiology, prevalence, treatment, risks, prevention; development of an AF patient self-management guidance toolkit and 'expert patient' training followed by AF self-management sessions, hosted by expert patients.

- The programme, which launched in March 2012, is currently being rolled out across 10 Spanish communities, in collaboration with smaller regional organisations
- 11 AF candidates are being selected to undertake blended learning on their illness and training skills
- All candidates will have access to educational materials and a tutor who will support them in their learning process and assess the knowledge they have acquired
- Face-to-face sessions will mainly focus on training the patients to train other patients
- A self-management guide for patients with AF will be developed and provided to patients who participate in the health education sessions. It will also be available to download from www.pacientexperto.org
- Once they have completed their training, each expert patient will provide sessions for patients with AF, scheduled through their respective associations. Each session will involve a maximum of 20 patients and they will receive six weekly health training sessions

Evaluation Metrics

- Patients' disease awareness, attitudes and behaviours are evaluated before and after each workshop, to assess the change in knowledge as a result of the training
 - The data obtained will be analysed and a final report of the pilot will be developed
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Case Study 6

AF-related Stroke Prevention Screening with Pharmacies

Country: Italy



Challenge

The risk of AF-related stroke can be managed if AF is detected, diagnosed and treated. The general public has a very limited understanding of AF and AF-related stroke risk. Also of note is that around half of all AF is not accompanied by symptoms, so many people with AF will not know unless they self-check or are subject to screening. Those at potential risk need to be educated on the importance of checking for AF, and how to check for AF either with pulse checks or with monitoring devices. Pharmacists are well placed to help fill this knowledge gap by offering advice and support, including guidance on how people can detect signs of AF with manual pulse checks, or by using in-pharmacy devices that analyse the pulse and measure blood pressure, another powerful risk factor for stroke.

Overview

The Italian patient advocacy group, A.L.I.Ce. Italia, Associazione per la Lotta all'Ictus Cerebrale - Association for the Fight against Stroke, worked in partnership with pharmacies, the device company Microlife and the pharmaceutical company Boehringer Ingelheim to launch a stroke prevention campaign during the week of 22-29 October, which included World Stroke Day (29/10). The aim was to raise awareness of AF-related stroke prevention, screen the general public for AF, identify AF patients at risk of stroke and encourage them to seek advice and information from their pharmacist or doctor.

Together they created campaign materials to communicate to the general public that *'Three out of four AF-related strokes can be prevented – if you are already diagnosed. People who have been diagnosed with AF have already taken the first step to preventing AF-related strokes. Get your blood pressure and atrial fibrillation under control to reduce the risk of stroke'*.

The campaign included 'The Prevention Days', during which a free screening facility was set up in around 3,500 Italian pharmacies. Members of the public were offered atrial fibrillation screening using simple AF screening devices, provided by Microlife, to measure their blood pressure and identify their risk of stroke. During the screening they were also provided with educational materials and advice from pharmacists to consult a doctor or specialist if necessary. A media campaign and the A.L.I.Ce website (<http://www.aliceitalia.org>) supported this initiative.

Results

The campaign story received a lot of media interest and coverage including six national TV news announcements and two in-depth pieces including a patient interview, three radio interviews, 35 print articles including online media as well as seven TV and nine radio station adverts aired up to 50 times a day over several days. TG1, the major Italian TV station, ran a story on the campaign and conducted interviews with pharmacist, Professor Paolo Pagani, and vascular neurologist, Professor Maria Luisa Sacchetti.

The campaign is a good example of idea sharing from one country to another as it was considered so successful that the campaign and partnership was replicated in France by the French association against strokes, France AVC Fédération Nationale.

Example Policy Maker Meeting Agenda

Following is an example of an agenda you may wish to use for a meeting you have set up with a policy-maker or influencer in your country. Please amend titles and topics, and enlist appropriate local expert assistance, to meet your local needs, as every country will have its own specific healthcare access issues. If you involve a patient in your meeting, ensure that their attendance is in line with local industry rules regarding communicating medical information to patients – they may only be able to attend part of the meeting to help illustrate the impact of AF or stroke.

TAKE ACTION NOW – SUPPORTING THE PREVENTION OF AF-RELATED STROKE

AGENDA

CRISIS IN WAITING: ATRIAL FIBRILLATION AND STROKE

[INSERT COUNTRY NAME]

AGENDA

Date:

Time:

Location:

Attendees: [Insert policy maker's name and full official title]
[Insert any additional support attending e.g. medical expert]
[Insert any additional support attending e.g. patient with AF or health service provider]
[Insert your name and title]
[Insert name of any other person attending]

1. Welcome and introductions

2. Meeting objective

3. Atrial Fibrillation and stroke prevention in [insert country]

- AF and its effects
- Scope of the problem in [insert country]
- Available treatment options
- Benefits and risks

NB You may want to invite a local medical expert (haematologist or cardiologist – either third party or affiliated with your organisation as an official advisor) to discuss this part of the agenda

4. Cost implications

- Burden of AF and stroke (outline local figures for the costs of AF and stroke treatment in your country)
- The role of practice guidelines in disease cost management

5. Overview of clinical guidelines

- ESC guidelines 2012 and [insert national guidelines where appropriate]
- Recommendations for change (indications for where you would hope to see changes to national guidance if not in line with current international best practice)
- Results and impact of change

6. Impacting results

- Patient petition [or survey results]
- Best practice examples (share examples of healthcare service provision in your country or elsewhere that demonstrate innovation and consistent quality)

7. Next steps (clearly state what you are asking the policy maker to do – attempt to secure a definite commitment within a certain timeframe)

8. Meeting close

References

- 1 Kirchof P et al. How Can We Avoid a Stroke Crisis? Working Group Report: Stroke Prevention in Patients with Atrial Fibrillation. 2009
 - 2 Atrial Fibrillation Preventing a Stroke Crisis. 2011.
 - 3 ESC Clinical Practice Guidelines: Atrial Fibrillation (Management of) 2010 and Focused Update (2012), <http://www.escardio.org/guidelines-surveys/esc-guidelines/Pages/atrial-fibrillation.aspx>
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