ANTICOAGULATION
UK CHAMPION
SUPPORT PACK

Prioritising clot prevention in your local area
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INTRODUCTION

Welcome to our Anticoagulation UK Champion programme, we hope you are going to enjoy the experience.

In 2000, after two years of market research and identifying the lack of information around anticoagulation therapy, Anticoagulation UK was launched as a charitable organisation to provide information, education and support to individuals who required anticoagulation therapy in the short term or as a life-long treatment for their specific condition.

17 years of proactivity has produced some significant achievements in terms of patient outcomes and these include access to NHS prescriptions for self-monitoring strips for warfarin patients, VTE risk assessment protocols for hospital inpatients to minimise risk of hospital acquired thrombosis, campaigning for anticoagulants to be given to patients diagnosed with atrial fibrillation to reduce stroke risk and most recently, raising awareness of cancer associated thrombosis (CAT) for patients undertaking chemotherapy.

Through our work and reputation as one of the leading patient organisations in the field of anticoagulation, we engage at government level providing the Secretariat for the All Party Parliamentary Thrombosis Group, working with the NHS at strategic level within the Academic Health Science Networks and Clinical Commissioning Groups. We participate in research studies across the UK, providing patient perspective and are instrumental in providing Patient Experts to represent Anticoagulation UK and anticoagulation patients at Technology Appraisals for new treatments and diagnostic technologies.

Our objectives remain consistent today as when the charity started – we are committed to the prevention of thrombosis, and for those already on treatment, to help achieve the best anticoagulation service provision within the NHS.

If you have any questions about the content of this support pack or would like further information about campaigning in your local area please email anticoagulationuk@gmail.com or telephone 020 8289 6875.
WHY DO WE NEED YOUR HELP?

As someone on anticoagulation therapy, or as a family member of someone on anticoagulation therapy, you can help ensure everyone has access to high quality care.

By talking about your experiences, you can help improve services by ensuring that anticoagulation remains a focus for your local councillors, politicians and other stakeholders. This increased scrutiny and support will encourage your local health services to ensure that the best possible anticoagulant care is available to all patients.

What does campaigning mean?
Campaigning involves taking a series of coordinated actions designed to achieve a social or political goal. Campaigning can achieve a number of different things, including:

- Raising awareness
- Tackling misunderstanding
- Winning support from those who can help to make change happen
- Sharing good practice
- Improving the experiences and outcomes of others

Our work tells us that people with, or at risk of, blood clots have reported:

- Feeling that their initial concerns are not being taken seriously and subsequently experiencing delays in securing a diagnosis
- Challenges in accessing the treatment most suitable to their individual needs and lifestyles
- Difficulty accessing information about local services and support
- Difficulty in the ongoing management of their condition

Your voice can make a real difference by:

- Conveying the impact of blood clots in a way that others can relate to
- Sharing real-life experiences
- Demonstrating the weight of a problem and the level of support for an issue
- Compelling local representatives to act in your interest

Being an anticoagulation champion means:

- Being willing to use your voice and your experiences to help others in your local area
- You decide when you want to get involved and how much you want to do
- Volunteering some of your time to contact local services and representatives to talk about your experiences
- Keeping in touch with Anticoagulation UK about any responses you have

It does not mean:

- Having to give up lots of time to support the campaign
There are approximately 152,000 strokes in the UK a year; stroke is the fourth single largest cause of death in the UK and second in the world.

However, there are 1.2 MILLION stroke survivors in the UK. Between April 2015 and March 2016 78.6% of patients admitted with a stroke were seen by a specialist stroke consultant within 24 hours.

FIVE YEARS after a stroke the accumulated costs for the NHS and social care are, on average, £45,233.

It is estimated that 1.36 MILLION people in England have atrial fibrillation. This is equal to 2.4 per cent of the population.

Six months after a stroke, 9 OUT OF 10 stroke survivors in England, Wales and Northern Ireland have returned to live at home.
There are approximately 152,000 strokes in the UK a year; stroke is the fourth single largest cause of death in the UK and second in the world.

However, there are 1.2 million stroke survivors in the UK. Between April 2015 and March 2016, 78.6% of patients admitted with a stroke were seen by a specialist stroke consultant within 24 hours.

Five years after a stroke, the accumulated costs for the NHS and social care are, on average, £45,233.

It is estimated that 1.36 million people in England have atrial fibrillation. This is equal to 2.4 per cent of the population.

Atrial fibrillation related stroke is avoidable. The NHS could avoid an additional 11,600 strokes and save £124M a year through better prescribing of anticoagulants for patients with atrial fibrillation.

The risk of atrial fibrillation increases with age. Approximately 18% of the population over the age of 85 have atrial fibrillation.

Approximately 25 to 30% of patients who have in the past suffered from deep vein thrombosis, go on to suffer severe post thrombotic syndrome, a medical condition where the veins cannot pump enough oxygen-depleted blood back to the heart.

Between April and June 2016, out of 3.7 million patients admitted to NHS acute care in England, 96% were assessed for venous thromboembolism.

**WHAT IS DEEP VEIN THROMBOSIS?**

Deep vein thrombosis (DVT) is a condition where a blood clot forms in one of your deep veins, usually in your leg. It affects about one in 1,000 people every year in the UK.

80 per cent of people living with DVT do not have any symptoms.

**WHAT IS ATRIAL FIBRILLATION?**

It is a heart condition that causes an irregular and often abnormally fast heartbeat.

It can cause problems including dizziness, shortness of breath and tiredness. However, in some people, atrial fibrillation doesn’t cause any symptoms.

People with atrial fibrillation are five times more likely to have a stroke if the condition is not effectively managed.

**WHAT IS A PULMONARY EMBOLISM?**

It is a blockage in the pulmonary artery, the vessel that carries blood from the heart to the lungs.

A pulmonary embolism is often the result of a blood clot, travelling from the deep veins in the legs to the heart and lungs.

The blockage can be life-threatening if it prevents blood reaching the lungs from the heart.
OUR WORK TO IMPROVE ANTICOAGULATION SERVICES

ADVOCATING FOR PATIENTS

Much of our work focuses on the challenges faced by people with anticoagulation needs, by highlighting them in Parliament and encouraging the Government to take action.

We support the All Party Parliamentary Group on Thrombosis, a cross-party group of MPs and Peers which seeks to raise awareness about the risk and management of venous thromboembolism (VTE). Established in 2006, the Group works to increase knowledge of VTE’s causes, effects, treatments through research and meetings in Parliament; and to monitor the implementation of government initiatives and other research being undertaken. The Group has worked closely with the NHS England National VTE Prevention Programme and Thrombosis UK (Formerly Lifeblood: The Thrombosis Charity) to firmly embed best practice standards in VTE prevention and management into clinical practice. You can find out more about their research here: http://apptg.org.uk/research/

In 2015, we held a ‘Parliamentary Pulse Check’ event in the House of Lords, where we screened 45 MPs and Lords for atrial fibrillation and one new case was diagnosed. After the event, we saw the importance of anticoagulation spoken about in parliamentary debates, as well as by MPs on their websites, in questions to the Government and when they spoke with local media.

Additionally, we are:

— A member of The Anticoagulation in Practice Society (AiP), dedicated to improving the understanding and management of anticoagulation for healthcare professionals and for patients

— A partner in the Anticoagulation Self-monitoring alliance (ACMSA), a collective of charities actively campaigning for access and patient choice to self-monitor warfarin treatment

— A registered stakeholder in the medicines appraisals process for the National Institute for Health and Care Excellence (in England and Wales) and the Scottish Medical Consortium (in Scotland). This means we make sure that patient views are being represented while medicines are being considered for recommendation for NHS use by these groups

— A representative of patients for the National Institute of Health Research, to support research studies across atrial fibrillation, venous thromboembolism and screening for atrial fibrillation

As well as representing patients, we also develop and publish information for patients and their families around all aspects of anticoagulation including risk assessment, clot prevention, different conditions and treatments.

To find out more about our work and research CLICK HERE
ANTICOAGULATION IN A LOCAL SETTING

There are a number of different stakeholders involved in setting up and running anticoagulation services in your local area. Each of these stakeholders will have responsibilities in different areas of anticoagulation, and will be able to influence different aspects of the service provided.

HEALTH AND WELLBEING BOARDS

Health and Wellbeing Boards are run by the local authority and can be found in every upper tier local authority area. They do not have a budget or commission health services but they do oversee the local health and care system.

There is a legal requirement for a health and wellbeing board to include:

- A locally elected representative
- A representative of the local Healthwatch (further details on Healthwatch are available below)
- A representative of each clinical commissioning group in the area (further details on the clinical commissioning group are available below)
- The local authority directors for adult and children’s social services
- The director of public health for the local authority

It is also possible for Health and Wellbeing Boards to expand its membership to include additional members including local voluntary sector organisations and other statutory organisations such as the police.

The responsibility of the Health and Wellbeing Board is to:

- Bring together key decision makers from the NHS and local government
- Encourage integration of services across communities
- Improve democratic accountability
- Tackle inequalities in health
- Set the direction for public health and health and social care commissioning

The local healthcare strategies determined by Health and Wellbeing Boards are detailed in:

- Joint Strategic Needs Assessment– an assessment of the community’s current and future healthcare needs
- Joint Health and Wellbeing Strategy– sets out the commissioning priorities and plans that respond to the needs identified in the joint strategic needs assessment

Health and Wellbeing Boards are important on a local level because they have a legal requirement to involve local people in the preparation of their Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies. This legal requirement to engage local people means the health and well-being board is a good organisation to seek to work with. It is well prepared to listen to your opinions and work to include them in local commissioning priorities.

You might choose to contact your health and well-being board about your local area’s anticoagulation services as they currently are, as well as discussing with them their plans for future services. Before you contact your health and well-being board you might like to speak with your doctor to see if they will support your anticoagulation awareness efforts.

The King’s Fund charity has developed a directory of all Health and Wellbeing Boards which you can use to find out more information CLICK HERE to access

For further information on engaging with your local Health and Wellbeing Board, the charity Compact Voice has developed a guide CLICK HERE to access
Across England there are 209 Clinical Commissioning Groups (CCGs). Clinical Commissioning Groups are provided with an annual budget by NHS England, and are responsible for making decisions about the health services offered to local residents, based both on local needs but also accounting for the cost of providing the service to people who need it. As a result, Clinical Commissioning Groups are responsible for making decisions about the majority of local NHS services, including anticoagulation services and anticoagulation medicines. They have flexibility in how they operate and who they include as members, however, for making key decisions all Clinical Commissioning Groups have a governing body. The governing body is chaired by a General Practitioner (GP) and will also include; other GPs, executive team members, nurses, local partner members and members of the public.

Your local Clinical Commissioning Group is important because it controls 80 per cent of the health budget and it uses information from its local joint strategic needs assessment to identify spending priorities. These priorities might include what type of anticoagulant medications to provide, or whether to fund an atrial fibrillation screening service.

The Clinical Commissioning Group also has a range of further responsibilities:

- To improve the quality of services, such as atrial fibrillation screening
- To reduce health inequalities, such as a high rate of strokes in one area compared to a neighbouring area
- To promote the involvement of each patient in their care by engaging them in treatment decisions such as what appropriate anticoagulant they would like to be prescribed
- To promote public involvement in the activities and decisions of the clinical commissioning group

It is important for you to engage your local Clinical Commissioning Groups (there may be more than one responsible for delivering healthcare in your local area). When engaging with the Clinical Commissioning Groups you might choose to:

- Outline the needs of people on anticoagulation therapies and highlight problems with inequity in care across the country
- Ask the Clinical Commissioning Group to commission services to support the needs of people on anticoagulation therapies
- Share your experiences, both good and bad, of the care you have received from your local health services

Identify your local Clinical Commissioning Groups with this website published by the NHS [CLICK HERE](#).

For further details on engaging with your local CCG the charity Compact Voice has developed a guide. [CLICK HERE](#) to access.
DIRECTORS OF PUBLIC HEALTH

Directors of Public Health (DPH) are employed by local authorities and are in charge of public health teams. They lead local authority plans to reduce the impact of health inequalities and they are required to guide Clinical Commissioning Groups on how to do this. The law requires every health and well-being board to have a Director of Public Health on it. Directors of Public Health are in charge of commissioning a range of services including drug and alcohol services, mental health, sexual health and smoking cessation services.

When engaging your local Director of Public Health, you might wish to raise with them your thoughts on local anticoagulation services, ask how your area’s services compare to neighbouring areas and seek their thoughts on improving your local services.

SUSTAINABILITY AND TRANSFORMATION PLANS

The NHS and local councils have come together in 44 areas covering all of England to develop proposals and make improvements to health and care. These proposals, called Sustainability and Transformation Plans (STPs), are place-based and built around the needs of the local population. Every proposal is different, and aims to improve patients’ lives in areas ranging from making it easier to see a GP, speeding up cancer diagnosis and offering help faster to people with mental ill-health.

All 44 Sustainability and Transformation Plans are now in the process of being turned into delivery partnerships which will work to implement the proposals. Most of these delivery partnerships will be forums for shared decision-making and will include representatives from across your local health services.

Not all delivery partnerships will focus on anticoagulation services, but some sustainability and transformation plans have included health areas such as the prevention of stroke in their priorities, so their work may look to improve local services.

The plan will let you know the priorities identified in your area, and how you can feed into the work of the local delivery partnership. Even if you cannot see anticoagulation mentioned explicitly within the plan, your local partnership may still be doing some ‘behind-the-scenes’ work in this area, so you may want to contact them to highlight your thoughts.
LOCAL HEALTHWATCH

Each local authority in England has a Local Healthwatch. They bring together individuals and organisations such as those in the voluntary sector. Along with Healthwatch England, they form the Healthwatch network which gives people in the community a say in the commissioning of local health services.

Each health and well-being board is legally required to have the local Healthwatch as a member. Local Healthwatch’s services include:

— Giving advice and information to the public on using local health and social care services
— Gathering the experiences of local people, to influence the commissioning, availability and accountability of local services
— Increasing health service awareness of the importance of engaging with local communities

Local Healthwatch is an important forum to influence because it exists to ensure that the local anticoagulation needs of local people are considered by CCGs, when they are commissioning services.

For further information on your nearest local Healthwatch CLICK HERE
There are four key groups that you can contact to support the improvement of anticoagulation services in your local area:

1. Local MPs and councillors
2. Local commissioners
3. Local healthwatch
4. Media

The following section sets out how you can contact each of these groups and what you can ask them to do to support the campaign.

CONTACTING YOUR LOCAL MP

Members of Parliament (MPs) and councillors are elected to represent the interests and concerns of their constituents as part of the democratic process. Your MP or councillor(s) can assist you in a variety of ways, from making private enquiries on your behalf, to raising matters publicly in the House of Commons or at council meetings. You can also ask your MP or councillor(s) to speak at a local event, pledge their support to a campaign or write to the local media on your behalf.

Not many people contact their MP, so those that do make an impact.

There are two ways to contact your MP:

1. **Write to them to arrange a meeting:** You can write to your MP (post or email), requesting a meeting to talk to them about your experiences of local anticoagulation services, and how they can be improved.

   While meeting your MP in person will have the most impact, if you’re worried about the time commitment, you can always address the issues you are concerned about in your letter. Structure your letter into three sections – information about clot prevention and the local situation, why this issue is important to you, and finally what you would like your MP to do to respond to this situation. Your MP doesn’t have to respond to your letter, but the majority of them do, particularly if you’ve taken the time to share your personal situation. If they don’t reply to you, write to them again to express your disappointment and ask for a response.

2. **Attend a drop-in surgery:** You can meet your MP by arranging to go along to one of their constituency ‘surgeries’. Most MPs hold surgeries – many hold them every week, some hold them once a month. The surgeries are an opportunity for MPs’ constituents to raise personal concerns and seek their MP’s help with their problems. MPs often use local party offices, church halls or rooms in pubs or community centres as the venues, with a number of surgeries possibly being held at different venues around a constituency. They are traditionally held on a Friday afternoon when MPs have returned from sittings of parliament in London. Some MP surgeries are drop-in sessions operating on a first come, first served basis, whilst others require a prearranged appointment. It is therefore best to give your MP’s office a call beforehand to check whether you need to make an appointment. Call them as far in advance as possible because if an appointment is required, they tend to get booked up weeks ahead of a surgery. If it is a drop-in session, turn up early to ensure you have the opportunity to see your MP and enough time to raise your concerns.
Meeting your MP
Some MPs may already have a good understanding about the importance of clot prevention, but others may not. It is best to assume that they know less rather than more. It is important for you to share your own personal story, highlighting why this issue is important to you, as well as providing them with the facts and figures about these issues.

During the meeting you should:
— Thank them for seeing you and establish how much time you have to talk to them
— Outline the background to the issue
— Tell them how and why it impacts on you – use examples if you can
— Tell them how it affects your area – use examples if you can
— Be specific about what your MP can do to help and what exactly you are asking them to do
— Ask them to keep in touch and update you on what they do following your meeting. Make sure you give your full name and address

Top tips for meeting your MP
Plan your message in advance:
— Provide some facts about clot prevention and anticoagulation – use some of the statistics in this pack
— Be ready to talk about your experience – what this issue means to you and what you would like to see changed

Plan your asks:
— What would you like them to do about this issue after the meeting? We’ve suggested some actions they could take below
— Send a follow-up email or call after the meeting to confirm agreed actions

Get your MP to take action!
— They could write to their local Clinical Commissioning Group to find out how they are working to improve anticoagulation services
— They could place a focus on the importance of anticoagulation services in Parliament - they could write to the Secretary of State for Health, or table a parliamentary question
— They could send a supportive press release to local media - a suggested template can be found in the resources section of this pack
— They could support the work of Anticoagulation UK to support people to take an active part in their own healthcare
CONTACTING YOUR LOCAL COUNCILLOR

You can write to your local councillor to request a meeting to talk to them about your experiences of local anticoagulation services, and how they can be improved.

Meeting with your local councillor
Some councillors may already have a good understanding about the importance of clot prevention, but others may not. It is best to assume that they know less rather than more. It is important for you share your own personal story, highlighting why this issue is important to you, as well as providing them with the facts and figures about these issues.

During the meeting you should:
— Thank them for seeing you and establish how much time you have to talk to them
— Outline the background to the issue
— Tell them how and why it impacts on you – use examples if you can
— Tell them how it affects your area – use examples if you can
— Be specific about what your councillor can do to help and what exactly you are asking them to do
— Ask them to keep in touch and update you on what they do following your meeting. Make sure you give your full name and address

Top tips for meeting your councillor
Plan your message in advance:
— Provide some facts about clot prevention and anticoagulation – use some of the statistics in this pack
— Be ready to talk about your experience – what this issue means to you and what you would like to see changed

Plan your asks:
— What would you like them to do about this issue after the meeting? We’ve suggested some actions they could take below
— Send a follow-up email or call after the meeting to confirm agreed actions

Get your councillor to take action!
— They could write to the local Clinical Commissioning Group (CCG) to find out how they are working to improve anticoagulation services
— They could send a supportive press release to local media - a suggested template can be found in the resources section of this pack
— They could support the work of Anticoagulation UK to support people to take an active part in their own healthcare

Find your local councillor
You can find out who your local councillors are by typing in your postcode at on this website CLICK HERE. This allows you to contact your councillor directly through the website, but will also provide alternative contact details should you wish to phone or write to them.
Across England, 209 Clinical Commissioning Groups (CCGs) are responsible for planning and purchasing (‘commissioning’) the majority of local NHS services, including anticoagulation services and medicines.

Clinical Commissioning Groups have a statutory duty to design services which meet the needs of their local population, so you can take steps to ensure that the needs of people at risk of blood clots are on their agenda when they plan services.

Your Clinical Commissioning Group’s website will have a ‘get involved section’ – this will set out ways in which you can share your views and experiences. This might include:

— **Going along to public events**: Ask to join your Clinical Commissioning Group’s mailing list for updates on events they are organising, which could include consultations and presentations. You should also be able to find a calendar for public events on the Group’s website.

— **Joining the Clinical Commissioning Group’s patient involvement group**: Clinical Commissioning Groups have a duty to invite patients and carers to participate in local decision-making, placing patients at the heart of decisions about local care. You may be able to join a patient involvement group, but you will be expected to comment on care and services that go beyond anticoagulation.

— **Attending meetings**: Clinical Commissioning Groups want you to know about what they are doing so they hold meetings which members of the public can attend. Agendas for the meetings are made available and you will hear about items such as the Group’s finances, treatment targets and management updates. You will be able to listen but not ask questions, so you might choose to write a letter to your Clinical Commissioning Group after you have attended a meeting.

— **Writing to the Clinical Commissioning Group**: You could write a letter or email to your Clinical Commissioning Group asking them to set out how they are meeting the needs of people at risk of blood clots in the area.

While these types of commitments may seem more daunting, Anticoagulation UK is able to support you every step of the way in your role as an anticoagulation champion. If you would like to discuss your plans or guidance on more information about campaigning in your local area please email anticoagulationuk@gmail.com or telephone 020 8289 6875.
Healthwatch England is the national consumer champion in health and care. The organisation represents the views of patients and ensures that their voice is strengthened and heard by those who plan, deliver and regulate health and care services.

There are 152 local Healthwatch organisations, which review local services and feed into Healthwatch England. The Healthwatch network has a common purpose – to ensure the voices of people who use services are listened to and responded to. Its strategic priorities are:

- To provide leadership, support and advice to local Healthwatch to enable them to deliver their statutory activities and be a powerful advocate for services that work for people
- To bring the public’s view to the heart of national decisions about the NHS and social care
- To build and develop an effective learning and values-based Healthwatch England

How to approach your local Healthwatch

**Write to them:** You can contact your local Healthwatch about any concerns you may have regarding local clot prevention services. They will advise you on how to take forward any specific problems or issues you may have encountered.

**Attend an open meeting:** The local organisation will also organise regular meetings that members of the public are free to attend. You can use this opportunity to share your experiences.

**What could you say?**
Depending on your experience with local anticoagulation services there may be good or bad points that you wish to raise with the local Healthwatch. You might like to provide suggestions on how you think your local service can improve for the future, to benefit the experience of others. If you know other people who use your local anticoagulation service, you could ask them to come with you or ask them what they might like you to say on their behalf.

Find your local Healthwatch

CLICK HERE to can identify your local Healthwatch and its contact details
CONTACT YOUR LOCAL MEDIA

The media can be an incredibly useful tool, to raise awareness of clot prevention and efforts to improve the quality of services. It is also a great way to encourage local representatives (such as MPs and councillors) to get involved in campaigning for better services; and highlight that local action needs to be taken to improve care.

Your local media will include print, online and broadcast media. Before you approach them, think about how your issue can best be portrayed as ‘newsworthy’. The following tips will help you create media interest in a story:

— **Local stories about local people** – something which is relevant to the local population which ideally has a human interest angle

— **A wider national hook** – publication of national guidance or a national awareness day

— **Specific events or actions** – such as Stroke Awareness Month, which takes place annually in May

Three key questions to consider when drafting a press release are:

— Does the story involve local people and have a human interest angle? Something as simple as including a name in your story, or having a photo to accompany it can make all the difference

— Is there a wider topical hook? This could be a national awareness day or event. This can add weight to a story and make a national story relevant to the local area

— What makes it newsworthy? Is the story linked to a recent or forthcoming event either locally or nationally?

In terms of getting a story covered, it is good to make life as easy as possible for journalists, by giving them as much detail as you can and some good ‘sound bites’. We’ve included steps for you to consider on the next page:
1. **Think about WHAT YOUR STORY IS**
   What do you want to highlight in the local media? Consider the key facts in this guide and what makes the story newsworthy. Summarise this information in a simple press release which includes your contact information so a journalist can follow up with you if needed.

2. **READ LOCAL PAPERS**
   Online and in print – to identify which outlets and journalists have written about health issues before. You can look at the newsdesk's generic email address to send press releases to.

3. **If you are able to demonstrate that THE LOCAL MP supports your efforts and the campaign, this can often be enough of a hook for a journalist to write a story. Your MP’s office may also have links with local journalists so they may offer to provide advice and contact information.**

4. **If you are planning to CONTACT A JOURNALIST using an event, MP meeting or activity as a hook, be sure to contact the journalist a week in advance to ensure the story is on their radar.**

5. **We are keen to collate coverage secured from anticoagulation advocates to showcase the efforts and impact of all those supporting the campaign, so PLEASE SEND ANY COVERAGE received to anticoagulationuk@gmail.com**

Don’t forget Anticoagulation UK can support you with these activities. If you require guidance please email anticoagulationuk@gmail.com or telephone 020 8289 6875.
HOW MIGHT YOU USE THIS SUPPORT PACK?

You can use this support pack to remove barriers to better anticoagulation care in many ways. Please find below a couple of idealised ways in which you might use the information contained in this pack:

BARRIER 1: BEING REFUSED A REQUEST TO CHANGE ANTICOAGULANT

1. While using the HealthUnlocked online forum you have heard about new anticoagulants and you discuss with your doctor the opportunity to consider changing your medication

2. Your doctor advises that whilst the new treatments are licensed and recommended for your condition, and that you meet eligibility criteria for the medicines, they are reluctant to authorise their use due to funding directives

3. You ask to speak, or write, to the Practice Manager to discuss the decision, ask for advice on how you can access the treatments, and ask for the decision to be put in writing

4. You also ask for information around the NICE guidelines referred to by your GP and where you can find the NHS complaints procedure

5. The Practice Manager responds by advising that you need to contact the Clinical Commissioning Group, to raise the matter with the team responsible for prescribing decisions

6. Following on from the information provided, you look at the Clinical Commissioning Group website and:
   
   See that there is a Patient Participation Group in your area which holds monthly meetings for the public to attend. You attend the next meeting, raising the issue and ask for the Clinical Commissioning Group’s Patient and Public Involvement representative to advise you on how your individual situation can be escalated

7. The actions lead to your GP reviewing your medication and they confirm that they are able to discuss all treatment options going forward

OR

You contact the Clinical Commissioning Group directly and they ask for you to put your concerns in writing. The Clinical Commissioning Group responds to your letter acknowledging that you have concerns that you are being denied access to new treatments and outline their prescribing rationale for the new treatments. It is aware that the new treatments are being considered for newly diagnosed patients in secondary care and therefore it will need to incorporate existing patients’ access for the future. You are asked if you would consider talking or making your representations, at the CCG prescribing committee with support from the Patient and Public Involvement representatives
BARRIER 2: BEING DENIED ACCESS TO AN INR SELF-TESTING SERVICE

1. Your friend is currently prescribed warfarin but they are struggling to attend clinic at least every four weeks for a blood test, due to work and family commitments.

2. You hear about a self-testing service for people on warfarin and suggest that your friend writes to their GP about local availability. However, the GP Practice Manager advises that there is no local funding for a warfarin self-testing service as the CCG has made provision and commissioned for all anticoagulated patients to be managed in dedicated clinic settings.

3. You go online and find the Anticoagulation UK website, call the helpline and are told about the NICE guidelines in place for self-monitoring. The Anticoagulation UK representative suggests that you contact your hospital consultant to gain support, or if you do not have a consultant, to get in touch with the Clinical Commissioning Group’s Patient Involvement Group to raise this issue.

4. Anticoagulation UK has also advised that you contact your local Healthwatch meeting raising the case and with information provided by Anticoagulation UK, demonstrate that a postcode lottery for support for self-monitoring is evident across the UK.

5. At the Healthwatch meeting, you raise your issue and ask for advice. You are made aware of the NHS complaints procedure and are told that your Healthwatch representative will present this at the next Clinical Commissioning Group meeting they attend.

6. Anticoagulation UK is supporting you and suggests that you contact your local MP and provide some template letters to help you. You are also referred to a campaign group – Anticoagulation Self-Monitoring Alliance (ACSMA), of which Anticoagulation UK is a partner.

7. You write to your MP and receive a reply asking for more information around the inequalities for access to self-monitoring and any data or statistics you have.

8. You speak with Anticoagulation UK which provides you with comprehensive details around the benefits of self-monitoring, the NICE guidelines references and related information to support your case.

9. On receipt, the MP writes to the Clinical Commissioning Group which has also been contacted by Healthwatch. The Clinical Commissioning Group advises that it needs to go out to consultation to establish how many people may benefit from a self-monitoring service and how this could be integrated into its existing provision.

10. In the interim, your consultant has written to advise that the benefits of self-testing and enabling you to manage your own INR blood tests are significant for your health and wellbeing and with the necessary arrangements in place is happy to recommend commencement of self-testing, either through a dedicated provider or with support from the existing anticoagulation specialist nurse for dosing and management. They write to your GP to advise of this plan.
MORE INFORMATION ABOUT ANTICOAGULATION

This section contains some headline facts and statistics that demonstrate the importance of improving local clot prevention services – messages you can use to explain why this campaign is so important.

Within this section you will find:

a) Some useful information about the importance of preventing blood clots
b) Key statistics to show the scale of the problem
c) Facts to bring to life the impact of blood clots on people and the health service

THE IMPORTANCE OF PREVENTING BLOOD CLOTS

A blood clot is a thickened mass in the blood formed by tiny substances called platelets. Clots form to stop bleeding, such as at the site of a cut. But clots should not form when blood is moving through the body; when clots form inside blood vessels or when blood has a tendency to clot too much, serious health problems can occur.

A blood clot can travel through the bloodstream and block an artery to the brain, which can cause a stroke. If the clot blocks blood flow to the lungs a pulmonary embolism (PE) can occur, and a blood clot that blocks a coronary artery can cause a heart attack.

Blood clots may be avoided by lifestyle changes such as not smoking, and by not taking medications that add to the risk. Clotting can also be prevented by following physician recommendations concerning medications. Sometimes, physicians will prescribe an anticoagulant, which discourages the formation of blood clots within a blood vessel.

The NHS could avoid an additional 11,600 strokes and save £124m a year through better prescribing of anticoagulants for patients with atrial fibrillation, a heart rhythm disorder that causes strokes. Deep vein thrombosis (DVT), a condition where a blood clot forms in one of your deep veins, usually in your leg, affects about one in 1,000 people every year in the UK. 80 per cent of DVT are ‘silent’ and do not have any symptoms.

The number of cases of DVT and PE being listed as the primary cause of death reached over 12,200 in 2010.

THE SCALE OF THE PROBLEM

There are approximately 152,000 strokes each year in the UK and stroke is the fourth single largest cause of death in the UK and second in the world. In 2014, 39,284 people died of stroke; 16,224 men and 23,060 women.

Many patients are left permanently disabled following a stroke. Of patients admitted to hospital with a stroke from June 2014 to June 2015, around 40 per cent were discharged needing help with daily activities and 85 per cent of patients required physiotherapy.

Approximately 25 to 30 per cent of patients who have in the past had DVT go on to suffer severe post thrombotic syndrome, a medical condition where the veins cannot pump enough oxygen-depleted blood back to the heart.
Below you can read Valerie’s experience of asking her doctor to change to a different anticoagulant treatment.

I was diagnosed with Atrial Fibrillation with a CHA2DS2-VASc score of 3 in December 2013 making me a high risk for a stroke. The heart consultant at the hospital suggested I go on warfarin and I asked if there was any alternative as I explained that I feel ill and faint every time I have a blood test. He said that there were some new drugs available but there was no antidote for them if I should have a bleed. Whereas there was one for warfarin and it was tried and tested. I said I would like to think about it. The consultant said he could not prescribe any medication and I would have to see a consultant for the blood who could prescribe medication.

An appointment was made and I saw this consultant in March 2014. During the intervening period, I contacted the Heart Foundation specialist nurse who pointed me to Anticoagulation UK and the Atrial Fibrillation Association and both were a great help in giving me guidance and information regarding warfarin and the three new oral anticoagulation drugs. Consequently I had a lot of questions to ask the consultant when I saw him at the appointment. I explained my objection to taking warfarin and it was clear that he would not entertain prescribing me the newer oral anticoagulants as he said “that he would not prescribe them to a dog”. It was obvious to me then that if I carried on under his care it was warfarin or nothing.

I wrote to my GP saying I was not happy with the situation and asking that I have a second opinion with another consultant at a different hospital. The GP was in agreement and wrote a letter so I could see another heart consultant at another hospital. This I did and once again I explained why it would be difficult for me to take warfarin and that I knew there were new anticoagulation drugs available. He said that I seemed a candidate for these and would arrange an appointment with the consultant dealing with this side of treatment. I had this appointment in August last year and the tone of the meeting was completely different. There was much more discussion about treatments and I was very much involved in deciding the best way forward for me. The outcome was that I was put on new anticoagulant and I am still on this medication. So my experience was that I had to fight for the new oral anticoagulation drugs with a lot of time wasted from the diagnosis of Atrial Fibrillation to receiving the new drugs.

This Case Study is also available on the Anticoagulation UK website.
CLICK HERE to visit the site.
Anticoagulant — a medication that reduces the risk of stroke by decreasing the chances of blood clot formation

Anticoagulation — use of an anticoagulant medication, frequently called a blood thinner, to prevent an atrial fibrillation-related stroke

Antiplatelet drugs — is medication used to decrease the risk of heart attacks and certain strokes, and to treat artery blockages in the legs. These drugs work by preventing a part of the blood called platelets from clumping together to form clots and thus help prevent heart attacks and strokes

Atrial Fibrillation — is a quivering or irregular heartbeat that can lead to blood clots, stroke, heart failure and other heart-related complications

Blood clot — a clot that forms inside the body when blood flow is slowed or stopped long enough to allow coagulation, it can travel through the bloodstream to the heart, where it can cause a heart attack, or to the brain, where it can cause a stroke

Clinical Commissioning Groups — are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area

Coagulation — the formation of a blood clot

Deep Vein Thrombosis — a blood clot in a vein. Blood clots in veins most often occur in the legs but can occur elsewhere in the body, including the arms

Health and Wellbeing Board — Health and Wellbeing Boards were established under the Health and Social Care Act 2012 to act as a forum in which key leaders from the local health and care system could work together to improve the health and wellbeing of their local population

Healthwatch — is a statutory watchdog, their role is to ensure that health and social care services, and the Government, put people at the heart of their care

Ischemic stroke — is a stroke that occurs when blood flow to the brain is blocked by a clot or other obstruction. An ischemic stroke typically occurs when a blood clot from elsewhere in the body travels to the brain, blocking the blood flow and oxygen supply to part of the brain and causing brain cells in that region to die

The Kings Fund — The King’s Fund is an English health charity that shapes health and social care policy and practice, provides NHS leadership development, and hosts health care events

Nonvalvular atrial fibrillation — is atrial fibrillation that is not caused by underlying heart valve disease or issues

Post Thrombotic Syndrome — is a medical condition where the veins cannot pump enough oxygen-depleted blood back to the heart

Pulmonary embolism — is a blockage in the pulmonary artery, the blood vessel that carries blood from the heart to the lungs

Stroke — is a disruption of blood flow to the brain that deprives the brain of oxygen. Without oxygen, brain cells can die, causing permanent disability in the affected parts of the brain

Sustainability and Transformation Plans — NHS organisations and local authorities in different parts of England have come together to develop ‘place-based plans’ for the future of health and care services in their area

Thrombus — is a clot that forms inside the body when blood flow is slowed or stopped long enough to allow coagulation
Anticoagulation UK is a UK registered charity founded in the year 2000. It works with patients, healthcare professionals, NHS trusts, Industry, Governments, other charities and patient groups, and a wide range of other organisations.

Anticoagulation UK’s stated aims include: the prevention of thrombosis; the provision of information, education and support; the promotion of independence - supporting people to take an active part in their own healthcare.

You can learn more about Anticoagulation UK on its website: www.anticoagulationeurope.org/about-us or by calling 020 8289 6875.

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A guide on how to engage your Clinical Commissioning Group: www.compactvoice.org.uk/sites/default/files/engaging_with_clinical_commissioning_groups.pdf


Clinical Commissioning Group directory: www.nhs.uk/ServiceDirectories/Pages/CCGListing.aspx


Find your MP (using your postcode): http://www.parliament.uk/mps-lords-and-offices/mps/

Find your local Councillor(s) (using your postcode): www.writetothem.com

HealthUnlocked online forum: https://healthunlocked.com/

Healthwatch directory: www.healthwatch.co.uk/find-local-healthwatch


Sustainability and Transformation Plan directory: https://www.england.nhs.uk/stps/view-stps/
Dear [insert MP’s name]

I am writing to you, as my local MP in [insert constituency name], to request a meeting to discuss the local anticoagulation service. [I am currently a patient there / I am a carer of a current patient there / A family member is currently a patient there], and I would be grateful for your support in ensuring that everyone using these services has access to the best quality care and treatment.

Atrial fibrillation (AF) increases the risk of stroke by a factor of five and strokes caused by AF are often more severe with higher mortality and greater disability. The condition affects over one million people in the UK. Anticoagulation substantially reduces the risk of stroke in people with AF. Despite this, AF is underdiagnosed and under treated: about one third of people with AF are unaware they have the condition and even when diagnosed, large numbers do not receive anticoagulants or have poor anticoagulant control.

[As a patient / carer of a current patient / family member of a patient] with atrial fibrillation, my experience with anticoagulation is a particularly personal one. [Insert personal experience]

There are a number of challenges that face people affected by atrial fibrillation. More needs to be done to raise awareness and improve diagnosis, particularly given that so many are unaware of their condition. Additionally, anticoagulation services must be more patient-friendly; levels of information and support for patients vary, a lack of access to the full range of NICE recommended treatments can be frustrating and follow up and review can be inconsistent.

As a result of my own experiences, I am now an Anticoagulation Champion for Anticoagulation UK, a charity which supports patients who have anticoagulation needs.

I write to you to ask for your support in ensuring that all people with anticoagulation needs are being diagnosed and receive the most appropriate treatment and personalised care. I would be delighted if you could let me know a suitable date to meet with you, to further discuss what more can be done to deliver patient-centred anticoagulation services.

I look forward to hearing from you.
Yours sincerely
[Your name]

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1 Stroke. Atrial fibrillation as an independent risk factor for stroke: the Framingham Study. 1981. Available online via: http://stroke.ahajournals.org/content/22/8/983.long
Dear [insert MP’s name]

I am writing to you, as my local MP in [insert constituency name], to request a meeting to discuss the local anticoagulation service. [I am currently a patient there / I am a carer of a current patient there / A family member is currently a patient there], and I would be grateful for your support in ensuring that everyone using these services has access to the best quality care and treatment.

A deep vein thrombosis (DVT) is a blood clot in a vein (usually a leg vein). DVT can block the flow of blood partially or completely and this causes the symptoms of DVT. If the clot lodges in the lungs a potentially serious and sometimes fatal condition, pulmonary embolism (PE), occurs. In 2013 estimates showed that more than one in 1,000 adults were potentially affected by DVT in England, with 86 in 100,000 potentially affected by PE.¹

[As a patient / carer of a current patient / family member of a patient] who has had [deep vein thrombosis / a pulmonary embolism], my experience with anticoagulation is a particularly personal one. [Insert personal experience]

There are a number of challenges that face people affected by deep vein thrombosis. More needs to be done to raise awareness, prevent and improve diagnosis of the condition, particularly as 80 per cent of DVT incidents are ‘silent’ and do not show any symptoms.² Additionally, anticoagulation services must be more patient-friendly; levels of information and support for patients vary, a lack of access to the full range of medicines can be frustrating and follow up and review can be inconsistent.

As a result of my own experiences, I am now an Anticoagulation Champion for Anticoagulation UK, a charity which supports patients who have anticoagulation needs.

I write to you to ask for your support in ensuring that all people with anticoagulation needs are being diagnosed and receive the most appropriate treatment and personalised care. I would be delighted if you could let me know a suitable date to meet with you, to further discuss what more can be done to deliver patient-centred anticoagulation services.

I look forward to hearing from you.
Yours sincerely
[Your name]
Dear [insert Councillor’s name]

I am writing to you, as my local councillor in [insert ward or council name], to request a meeting to discuss the local anticoagulation service at [I am currently a patient there / I am a carer of a current patient there / A family member is currently a patient there], and I would be grateful for your support in working towards securing improvements to the service provided.

Atrial fibrillation (AF) increases the risk of stroke by a factor of five and strokes caused by AF are often more severe with higher mortality and greater disability. The condition affects over one million people in the UK. Anticoagulation substantially reduces the risk of stroke in people with AF. Despite this, AF is underdiagnosed and under treated: about one third of people with AF are unaware they have the condition and even when diagnosed, large numbers do not receive anticoagulants or have poor anticoagulant control.

[As a patient / carer of a current patient / family member of a patient] with atrial fibrillation, my experience with anticoagulation is a particularly personal one. [Insert personal experience]

There are a number of challenges that face people affected by atrial fibrillation. More needs to be done to raise awareness and improve diagnosis, particularly given that so many are unaware of their condition. Additionally, anticoagulation services must be more patient-friendly; levels of information and support for patients vary, a lack of access to the full range of medicines can be frustrating and follow up and review can be inconsistent.

As a result of my own experiences, I am now an Anticoagulation Champion for Anticoagulation UK, a charity which supports patients who have anticoagulation needs. I am writing to understand what steps your organisation is taking to ensure that all people with anticoagulation needs are being diagnosed and receive the most appropriate treatment and personalised care.

I would be delighted if you could let me know a suitable date to meet with you, to further discuss what more can be done to deliver patient-centred anticoagulation services.

I look forward to hearing from you. 
Yours sincerely
[Your name]
APPENDIX: TEMPLATE LETTER TO CLINICAL COMMISSIONING GROUP

(atrial fibrillation)

Dear [insert name of cardiovascular lead at CCG]

I am writing to you to request further information on [insert name of CCG] Clinical Commissioning Group’s efforts to improve local anticoagulation services.

Atrial fibrillation (AF) increases the risk of stroke by a factor of five\(^1\) and strokes caused by AF are often more severe with higher mortality and greater disability.\(^2\) The condition affects over one million people in the UK.\(^3\) Anticoagulation substantially reduces the risk of stroke in people with AF. Despite this, AF is underdiagnosed and under treated: about one third of people with AF are unaware they have the condition\(^4\) and even when diagnosed, large numbers do not receive anticoagulants or have poor anticoagulant control.

[As a patient / carer of a current patient / family member of a patient] with atrial fibrillation, my experience with anticoagulation is a particularly personal one. [Insert personal experience]

There are a number of challenges that face people affected by atrial fibrillation. More needs to be done to raise awareness and improve diagnosis, particularly given that so many are unaware of their condition. Additionally, anticoagulation services must be more patient-friendly; levels of available information and support vary, a lack of access to the full range of medicines can be frustrating and follow up and review of treatment is inconsistent.

In November 2016 Public Health England (PHE) published a plan to reduce the incidence of avoidable AF-related strokes by 5,000 nationally over the next five years. The aim is to increase the number of people with AF who are diagnosed and optimally managed, through the use of NHS Health Checks.\(^5\)

As a result of my own experiences, I am now an Anticoagulation Champion for Anticoagulation UK, a charity which supports patients who have anticoagulation needs.

I would be grateful if you could write to me outlining actions the CCG is taking to address the important issues of under-diagnosis and under-treatment and to improve local anticoagulation services.

Yours sincerely
[Your name]

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APPENDIX: TEMPLATE LETTER TO CLINICAL COMMISSIONING GROUP (DEEP VEIN THROMBOSIS AND PULMONARY EMBOLISM)

Dear [insert name of cardiovascular lead at CCG]

I am writing to you to request further information on [insert name of CCG] Clinical Commissioning Group’s efforts to improve local anticoagulation services.

As [patient / carer of a current patient / family member of a patient] who has had [deep vein thrombosis/a pulmonary embolism], my experience with anticoagulation is a particularly personal one. [Insert personal experience]

The NHS has identified improving the prevention and treatment of cardiovascular disease as a major priority.

A deep vein thrombosis (DVT) is a blood clot in a vein (usually a leg vein). DVT can block the flow of blood partially or completely and this causes the symptoms of DVT. If the clot lodges in the lungs a potentially serious and sometimes fatal condition, pulmonary embolism (PE), occurs. In 2013 estimates showed that more than one in 1,000 adults were potentially affected by DVT in England, with 86 in 100,000 potentially affected by PE.¹

Anticoagulation UK, a charity which works to support patients living with DVT, has identified five key areas for improvement to ensure that patients have access to the best possible support for their anticoagulation needs:
— Data collection
— Patient experience
— Ensuring access to all appropriate treatments
— Commissioning effective anticoagulation services
— Managing risk and improving outcomes

As a result of my own experiences, I am now an Anticoagulation Champion for Anticoagulation UK, a charity which supports patients who have anticoagulation needs.

I would be grateful if you could write to me outlining actions the CCG will be taking to tackle DVT and PE, and to promote patient-centred anticoagulation services.

Yours sincerely

[Your name]

Dear Secretary of State

I am writing to you regarding the quality of care being provided through anticoagulation services through the National Health Service.

I recently met with my constituent [insert name] who described their experience with anticoagulation treatments in some detail. Following this meeting I have decided to seek more detail on the Government’s efforts to improve anticoagulation services, both in my [insert constituency] and more broadly across England.

The NHS has identified improving the prevention and treatment of cardiovascular disease as a major priority.

Atrial fibrillation (AF) increases the risk of stroke by a factor of five\(^1\) and strokes caused by AF are often more severe with higher mortality and greater disability.\(^2\) The condition affects over one million people in the UK.\(^3\) Anticoagulation substantially reduces the risk of stroke in people with AF. Despite this, AF is underdiagnosed and under treated: about one third of people with AF are unaware they have the condition\(^4\) and even when diagnosed, large numbers do not receive anticoagulants or have poor anticoagulant control. It is estimated that if AF was adequately treated in England, the NHS could avoid 11,600 strokes and save £124 million.\(^5\)

Anticoagulation UK, a charity which works to support patients living with DVT, has previously stated that to continue to tackle the burden of AF-related stroke on patients, their families and the NHS, more must be done to improve rates of diagnosis and effective treatment of patients with AF.

I would be grateful if you could write to me outlining the actions which the Department of Health and NHS are taking to diagnose AF, prevent AF-related stroke, and to promote patient-centred anticoagulation services, including whether there are any plans to develop a national cardiovascular disease and/or stroke strategy.

I look forward to hearing from you.

Yours sincerely

[Your name]
Dear Secretary of State

I am writing to you regarding the quality of care being provided through anticoagulation services by the National Health Service.

I recently met with my constituent [insert name] who described their experience with anticoagulation treatments in some detail. Following this meeting I have decided to seek more detail on the Government’s efforts to improve anticoagulation services, both in my [insert constituency] and more broadly across England.

The NHS has identified improving the prevention and treatment of cardiovascular disease as a major priority.

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Anticoagulation UK, a charity which works to support patients living with DVT, has identified five key areas for improvement to ensure that patients have access to the best possible support for their anticoagulation needs:
— Data collection
— Patient experience
— Ensuring access to all appropriate treatments
— Commissioning effective anticoagulation services
— Managing risk and improving outcomes

I would be grateful if you could write to me outlining the actions the Department of Health and National Health Service are taking to tackle DVT and PE, and to promote patient-centred anticoagulation services.

I look forward to hearing from you.

Yours sincerely
[Your name]
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