Introducing ACE

- Founded in 2000, AntiCoagulation Europe (ACE) is a charity dedicated to supporting patients who take anticoagulant and antiplatelet therapy.

- ACE provides information, education and support via a dedicated helpline, contact network and has a membership base.

- The primary aim of the Charity is to heighten awareness of prevention of VTE and for those already on medication, to help access a first class anticoagulation service which supports patient needs whilst encouraging people to take an active role in their own healthcare.

- Collaborates with medical professionals, other charities, government and industry for continuous improvements in anticoagulation services across UK.

- Provides patient expert for NICE for AF & VTE guidelines and technology appraisals for NOACS.

- Member of ACSMA (Anticoagulation Self-Monitoring Alliance) campaigning for warfarin users to have choice and access to coagulometers on the NHS to help manage their INR (International Normalised Ratio) blood levels effectively and safely.

- Provided Patient Experts to NICE Diagnostic Assessment of Coagulometers with Guidance being issued in Sept 2014 for use in Atrial Fibrillation or heart disease (NICE DG14).

- Successfully campaigned to have the test strips made available on prescription.
The patient story – where it began
Consequences

- Classified as having a long term chronic condition/disease
- Only one treatment available – warfarin requiring regular blood testing
- At risk of having future VTE events
- Discovering genetic disorder – 1:2 risk of passing onto child. Impact on all family members
- Being advised by consultant not to have children
- Potential of developing Post thrombotic syndrome and future circulatory impairment
- Anxiety around every aspect of my life – career prospects, health and wellbeing, relationships
- Being seen or perceived as an ‘ill person’
Warfarin management

• 25 years plus spent in anticoagulation clinics for INR monitoring and dosing

• Calculated approx 6 months of time spent attending hospital for tests

• Impact in work setting – understanding managers and empathetic colleagues (I looked healthy enough?)

• ‘Yellow book syndrome’

• ‘White Coat syndrome’ – clinic visits constant reminder of having a chronic condition

• Evolving list of dietary and lifestyle restrictions – also known as the ‘don’t’ list
1998 - changing direction
A new pathway

- Specialist A/C nurse advised of self testing technology
- Purchased monitor direct from manufacturer
- Brought my own strips – not on NHS tariff then
- Liaised with healthcare professionals - this was the way forward for me
- With consent and support, started self – testing and then moved into self - management.
My current management and compliance regime

- Attend local Anticoagulation clinic at GP practice bi-annually to check my device and INR results against practice device for Quality Assurance purposes

- Repeat prescriptions – put latest INR reading on prescription request and update doctor at any appointment

- Update my yellow book and record on my smartphone using a dedicated app.

- Advise dentist, chiropodist, optician and physiotherapist of current INR result when attending for treatment

- ‘Remind’ locum doctors warfarin user and self-tester to prompt them to check medicines being prescribed for potential interactions with warfarin - taking a pro-active approach
The value added...

- Self –monitoring – personal control
- Gain more comprehensive knowledge and understanding of what can affect INR
- TTR average 70 +
- Peace of mind for patient and family
- Flexibility of when and where to test
- No restrictions on travel for work or pleasure
- Not having to factor in time for blood tests and being reminded that you have a health problem every time you visit a clinic setting.
- Well being – physical and mental. Just get on with life…
- Son and two other affected relatives now self – monitoring
Progressing anticoagulation self–monitoring in the NHS

In 2012, ACE along with other charities formed the AntiCoagulation Self- monitoring Alliance (ACSMA) with the aims of:

• Achieving greater access to self – monitoring technology for people on long term warfarin

• The devices to be made available on prescription for those who to self monitor and are eligible

The campaign continues and to date, ACSMA has more that 1200 individual patient and carer supporters
Campaign milestones

- More than 1200 individual patient and carer supporters
- More than 200 Westminster MPs elect to receive ACSMA updates
- Participation in Medical Technology Week, an opportunity to discuss how technology can improve patient outcomes and be cost saving to NHS
- 1.1 Meetings with MPs and policy makers, NHS England, NHS Wales and most recently, National Clinical Director for Stroke
- Support patient petition in the Scottish Parliament
- 2014 – Freedom of Information request to CCGS to establish position with regard to protocols around self monitoring within their anticoagulation service provision
FOI outcomes – ACSMA Report

211 requests sent – 178 responses

- Only 34% of CCGs allow self testing their INR level with the same % of GPs being able to prescribe device strips on NHS
- Only 28% of all CCGs allow self management (patient dosing)
- Only 7% have any formal or local published guidelines in place
- 75% of CCGs do not offer information on self – monitoring or have any information available.
- This highlights the problems that people are experiencing, people are finding out about self – monitoring by accident, through word of mouth, via a patient organisation or healthcare professional or by trawling through the internet
Challenges...

- Funding
- Governance and safety
- Medico-legal concerns
- Lack of awareness and education on the part of the healthcare professionals
- Lack of patient awareness of technology
Overcoming barriers
Self-monitoring and self-management of oral anticoagulation therapy

Published:
16 May 2012

Authors:

Primary Review Group:
Heart Group

New patient safety and care testing devices have made it possible for people on long-term oral anticoagulation to monitor their blood clotting time measured as the international normalized ratio (INR) in the home setting. Patients who self-test can either adjust their medication dose according to a pre-determined dose-INR schedule (self-management) or they can call a clinic to be told the appropriate dose adjustment (self-monitoring). Several published studies suggest these methods of monitoring anticoagulation therapy may be equal to or better than standard monitoring by a physician.

In total, we found 18 randomized trials that compared self-monitoring and self-management with standard monitoring. The combined results of these trials showed a halving of thromboembolic events and all-cause mortality with self-monitoring and self-management and no reduction in the number of major bleeds. Self-management had similar reductions in thromboembolic events and mortality to the overall benefit, with no effect on major bleeds. Self-monitoring halved the number of major haemorrhages that occurred but did not significantly reduce the rates of thromboembolic events or all-cause mortality.

In conclusion, self-monitoring or self-management can improve the quality of oral anticoagulant therapy, leading to fewer thromboembolic events and lower mortality, without a reduction in the number of major bleeds. Self-monitoring and self-management are not feasible for all patients, which requires the identification and education of suitable patients.
Atrial fibrillation and heart valve disease: self-monitoring coagulation status using point-of-care coagulometers (the CoaguChek XS system and the INRatio2 PT/INR monitor)

NICE diagnostics guidance [DG14]  Published date: September 2014

NICE has assessed 2 point-of-care coagulometers to help the NHS decide whether to use these products. They are called CoaguChek XS and INRatio2 PT/INR.

Coagulometers monitor blood clotting in people taking long-term anticoagulation drugs (such as warfarin) to reduce their risk of blood clots. These tests allow people taking anti-blood clotting drugs to monitor blood clotting themselves. They can then change their dose in agreement with their health professional.

Both coagulometers are recommended for use by people taking long-term anti-blood clotting therapy who have atrial fibrillation or heart valve disease, if they prefer and are able to effectively use this type of monitoring.

People (and their carers) who will be using 1 of these devices should be given training, and their doctor should regularly assess self-monitoring.
Example – Bury CCG
Dosage chart for INR target 2.5

If you are taking **3 mg or less**

<table>
<thead>
<tr>
<th>Blood test result</th>
<th>Action</th>
<th>Next test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over 5</td>
<td>!</td>
<td>as advised</td>
</tr>
<tr>
<td>3.1 – 4.9</td>
<td>Decrease dose by ½ mg</td>
<td>1 week</td>
</tr>
<tr>
<td>2 – 3</td>
<td>Remain on same dose</td>
<td>2 weeks</td>
</tr>
<tr>
<td>1.6 – 1.9</td>
<td>Increase dose by ½ mg</td>
<td>1 week</td>
</tr>
<tr>
<td>Under 1.5</td>
<td>!</td>
<td>as advised</td>
</tr>
</tbody>
</table>

Brown tablet = 1 mg
Blue tablet = 3 mg
Pink tablet = 5 mg

Contact your doctor

Before you make contact:

Think. Have you taken too many or missed any warfarin tablets?

Have you started any new medications recently?

Carry out an internal quality control test (not necessary for the CoaguChek® XS System) and note down your result to tell your doctor
MEDIA INFORMATION
3 February 2015
Basildon Hospital helping patients take control of their care

Patient Roy Johnson (left) with Russell Lee, lead anticoagulation nurse

Nurses at Basildon University Hospital are helping patients at risk of blood clots avoid visits to blood-testing clinics and take more control of their lives.

It is essential for people who take Warfarin, a ‘blood-thinning’ anticoagulant medication to have frequent blood tests, but this can be time-consuming and inconvenient. Now by using a pocket-sized monitor, some patients, depending on their circumstances, can test their blood at home.

Basildon Hospital runs one the biggest self-testing programmes in the country, with six per cent of 4,500 Warfarin patients taking part. The national average for self-testing is two per cent.

Roy Johnson, 65, a patient at Basildon Hospital, says his life has been improved by self-testing and has appeared in a short YouTube film to explain the benefits of self-testing to other Warfarin patients. He also praises the support he has received from the anticoagulation nurses at Basildon Hospital, and encourages others find out more about self-testing from their health services.

more ...
Satisfied customers

• ‘It’s two minutes once a week, which means I can live my life again’ (Phillipa 34)

• ‘The biggest benefit of self-monitoring is that it has put me in control of my own health (AF) without being so reliant on others’ (Rex 66)

• ‘I strongly believe that my ability to self-manage has had a beneficial and liberating effect on my everyday life’ (Yvonne)

• ‘My daughter has to use an INR machine, we are lucky as we have been provided with one to use at home – everyone should have access to one. It’s hard enough having a child with a heart condition without added stress’ (Emma)
Current landscape 2015

- CCGs redesigned anticoagulation services including appointing AQPs – self monitoring options not being factored into provision or contracts
- NICE Guidance (DG14) not being integrated into national policy and local implementation, discussions continue with NHS England
- Strips scripts being refused, withdrawn or limited by GPs
- Disparity between GP practices in a CCG in being able to access strips
- Issues around patient safety – who’s responsible?
- Patients who have successfully being self monitoring for several years being told they will need to come back to clinic
Engagement tactics

- **Liaise** with recognised patient advocacy groups who are able to provide evidence and information surrounding challenges and issues of current anticoagulation services.

- Surveys can be undertaken via the membership organisation and patient experts can provide constructive observation as to impact and efficacy of the services that they are engaged with.

- **Invite** patients/patient groups to act as ‘lay representatives’ when redesigning anticoagulation services.

- **Encourage** patients to attend GP patient forums to discuss improvements in services.
Examples of ACE involvement the bigger picture

- Ready for Change report for CCGs – published 2013

- Patient experts invited to NICE Appraisal technologies for new anticoagulants, review of VTE and AF guidelines

- ACE member of PIN (Patients involved in NICE) and NIC (NICE Implementation Collaborative) a partnership which involves organisations and individuals from across the healthcare system working to improve patient outcomes for all

- Invitation to participate in studies for self-monitoring, diagnostic DVT devices and software programmes to capture patient INR results

- Support to the All Party Parliamentary Thrombosis Group
Further examples…

- Direct approaches from CCGs requesting input when assessing/re-designing services
- Direct approaches from AQP (any qualified provider) considering the tendering process for future services
- ACE patient representatives participating in a range of medical research/studies relating to NOACS across the country.
- NHS England developing ‘Participation Academy’ and inviting input from patients, service users, public voice representatives and healthcare staff
Public engagement

Posts

**Inr 1.4 below target range of 2.5 - 3.5. Help please**
I've had a bad infection antibiotics finished last Thursday My inr has been down to 1.3, 1.4, and today 1.4. I'm on 7mg daily for another...
By callum19 a month ago 20 Replies

**Inr still low 4 weeks on**
My inr is still low 1.4, 1.5. What could of caused it. Thanks any advice would be appreciated
By callum19 a month ago 18 Replies

**Joints aches and pains**
Hi I have been on Warfarin since 1998 and I have my own home testing machine as well as having it checked from time to time with the Nurse...
By Bizzle a month ago 17 Replies

**Is self monitoring inr a possibility?**
recently been diagnosed with multiple bilateral pe. Now on warfarin but as yet not got a correct dose. Travel quite a lot and am concerned...
By mikel46 a month ago 15 Replies

**INR up**
My INR has stayed within Target 2-3 for about 18 months and my blood tests now every 12 weeks. Recent one has gone up to 3.8 and I have...
By jackdaw50 a month ago 14 Replies
Patient expectations

• Consistency in approach to the management of their therapy
• Accurate and current information relating to new therapies, self-testing options and changes to local anticoagulation services
• Signposting to information sources relating to their conditions and treatment options
• Opportunity to network and engage with other patients to share knowledge and experience
• Access to all treatment options – not restricted by local directives
• Pathway to challenge decisions constructively
Thank you for your interest
Any questions?
Diane Eaton

AntiCoagulation Europe (ACE)

www.anticoagulationeurope.org