

Welcome to the fifth newsletter of the AntiCoagulation Self-Monitoring Alliance (ACSMA). We formed in September 2012 and comprise of four of the UK's leading charities and patient groups – AntiCoagulation Europe; the Children's Heart Federation; the Atrial Fibrillation Association; the Mechanical Heart Valve Support Group. The healthcare company Roche is also part of the alliance.

ACSMA's achievements since November...

Since November last year, we have made Freedom of Information (FOI) requests to all 211 Clinical Commissioning Groups (CCGs) in England, held our first regional meeting and launched our patient choice awards.

Freedom of Information requests to Clinical Commissioning Groups (CCGs)

In the new NHS, CCGs are the key decision-makers when it comes to issues like patient choice, access to self-monitoring and anticoagulation service redesign. The feedback we've had from NHS England and responses to our questions in Parliament has confirmed this. But there is a real need to understand local CCG policies and practices better. We decided to send an FOI request to each of the 211 CCGs in England to find out more.

We have received a fantastic 178 responses. This has given us the data they are currently missing about local

policies and implementation. The main findings are:

- Less than 30% of CCGs allow people to self-manage their own internationalised normal ratio (INR), how long the blood takes to clot
- A third of CCGs allow people to self-test their INR
- Only 7% of CCGs publish guidance/guidelines around self-monitoring
- A third of CCGs provide testing strips on prescription

We aren't surprised by these findings, based upon anecdotal evidence of the

experiences of people on long-term warfarin. However, the CCG's responses were still disappointing as there is a lot of goodwill and support for self-monitoring at a national level. Our campaign has received support from Senior Government Ministers, including Jeremy Hunt, Secretary of State for Health and senior representatives at NHS England. Once we have had a chance to properly analyse all the findings, we will report back in the next newsletter. We plan to use the data to provide strong supporting evidence for ACSMA's campaign locally.

Our Objective

We are campaigning for greater choice for patients on warfarin about how their condition should be managed. Our goal is to empower patients and we believe where possible they should have

the choice about whether to self-test or self-manage their treatment. We believe that this change would enable improved health outcomes and save time and money for both patients and the NHS.



Regional Meeting



We hosted our first regional meeting in Manchester on 24th March 2014.

The aim of the meeting was to provide a forum for healthcare professionals, those working in the NHS and local government, patients and decision-makers in Greater Manchester, Lancashire and the north-west to discuss and debate anticoagulation service provision and practice. The meeting explored

how anticoagulation services can be developed as a model for self-care: improving health outcomes, saving the NHS money, and enhancing patient choice and experience. Some 35 guests participated in the event.

Dr Matt Fay, a GP at Westcliffe Medical Practice in Shipley who chaired the meeting, said: "The event was an excellent opportunity for patients, clinicians and carers to meet, discuss

and share examples of best practice of self-monitoring across the north-west.

Many interesting topics were discussed including patient choice, innovation, technology and person centred care. All of these align with the NHS's agenda. However, people on long-term warfarin need to have greater access to self-monitoring technology on prescription in order to make self-monitoring more widely available."

Following the discussion, a number of recommendations were made by the attendees:

- There needs to be greater publicity around self-monitoring and the benefits, making better use of the substantial evidence base pointing to a better patient experience, prevention of cardiovascular events and improved health outcomes.
- The NHS needs to consider how it can collect and utilise primary care data, particularly on outcomes. This will show how good different localities are at providing opportunities for a patient to self-monitor and will help address the gap in service provision.
- Within local commissioning agreements and protocols, all providers and GP practices should allow long-term warfarin patients the opportunity to self-monitor.
- As healthcare in the UK is changing rapidly, clinicians need to work closely with patients so that they can make informed and joint decisions about a patient's care.
- A standard, unified contract should be developed between GPs and patients. This will outline the individual responsibilities of each party regarding warfarin prescribing and self-monitoring, as well as clarify the governance arrangements.



Would you like to become an ACSMA Ambassador?

We are looking for enthusiastic, passionate and confident individuals who are willing and able to champion our cause to become ACSMA Ambassadors. We are very keen to encourage supporters who want to become involved in campaigning at a local level.

The role of the Ambassadors will be to support and promote our work by local influencing and awareness-raising, for example by meeting with local MPs or CCGs, talking to the local communities or media, or meeting people.

The Ambassadors will help further our aims and objectives at a local level and to be an advocate for us and

the campaign. Our primary objective is to make INR monitoring devices available on NHS prescription to eligible warfarin patients.

The role is voluntary and there will be no set hours; a small time commitment is required on an ad hoc basis although there is scope to develop the role to suit the enthusiasm and preferences of the individual. If Ambassadors want to devote more time to the campaign that would be most welcome.

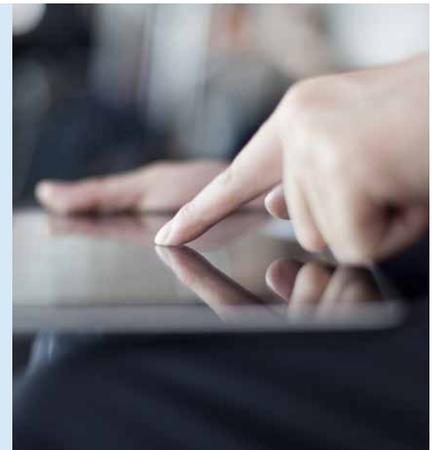
If you would like further information about being an ACSMA Ambassador, please email info@acsma.org.uk or telephone Mark Hill on **01707 330033**.

Are you willing to share your story about self-monitoring?

We would love to hear about your experiences of being on long-term warfarin and the opportunity you have had to self-monitor. By sharing your story, you can help raise awareness of these issues among the general public, with decision-makers and the wider health community.

We want to use your story – and those of other patients – as case studies which we can use in our campaigning. We hope to place case studies on our website, refer to them on social media (e.g. Twitter) and use them in the media.

If you would like to tell your story or find out further information please contact Mark Hill on Tel: **01707 330033** or email info@acsma.org.uk



How can you get involved?

ACSMA now has 820 supporters. If you would like to pledge your support for our campaign, tell us how you would like to self-monitor but have been refused, tell us about living on

warfarin and the benefits of self-monitoring, or would just like to keep up to date with what we are doing please visit www.acsma.org.uk or follow on Twitter: **@ACSMA_UK**