

Welcome to the sixth 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 May...



NICE's appraisal of self-monitoring technology

The National Institute for Health and Care Excellence (NICE) is currently carrying out a technology assessment of the CoaguChek XS system (manufactured by Roche Diagnostics) and the INRatio2 PT/INR (manufactured by Alere), both coagulometers are for people on long-term vitamin K antagonist therapy (warfarin) who have atrial fibrillation or heart valve disease. NICE has made a provisional recommendation to approve the coagulometers and is expected to make a final recommendation in September.

NICE's appraisal has raised a number of questions about the availability of coagulometers and disposable test strips

on prescription. NICE's appraisal of the coagulometers will determine whether they are clinically-effective and cost-effective for the NHS to use; NICE will not make a recommendation as to whether or not coagulometers should be available on NHS prescription, as that is a decision for the Department of Health and NHS England. Also, the NICE recommendation will not affect the status of the test strips. These are already available on prescription at the discretion of your local GP.

ACSMA has produced a fact sheet for patients to help answer questions and dispel some of the common myths, which can be found on ACSMA's website under the tabs News/News Articles.

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.



Honours given at Patient Choice Awards



On Wednesday 25th June, we held our first Patient Choice Awards in the Westminster Parliament. The awards event celebrated the work of dedicated health professionals in the NHS and campaigners who have helped people on long-term warfarin treatment to monitor their own blood clotting level.

After much deliberation, our selection committee decided upon a short-list, with the following winners announced on the night:

- Individual health professional of the year was Dr Rhona Maclean, consultant haematologist from Royal Hallamshire Hospital
- Health professional team of the year was the cardiac nurse practitioner team from Great Ormond Street Hospital
- The winners of an outstanding achievement award were Peter Birtles, campaigner for people on long-term warfarin, and Eve Knight, founder and Chief Executive of AntiCoagulation Europe



Virendra Sharma, Labour MP for Ealing Southall, who hosted the event, said: "I am delighted to have hosted the Patient Choice Awards for all the hard work people have done for patients to promote and support self-monitoring. Self-monitoring devices are a win-win situation; a win for the NHS as it will help them to reduce potentially life threatening numbers of stroke and save money, and a win for the patient as it increases their independence and encourages empowerment to control their long-term health condition."

Approximately 60 people attended, including MPs, health professionals and patients. MPs who attended included Andrew George (Liberal Democrat MP for St Ives), Kelvin Hopkins (Labour MP for Luton North) and Baroness Gardner of Parkes. The guests heard from two excellent speakers Andrew Gwynne, Shadow Health Minister and Labour MP for Denton and Reddish and Glyn Davies, Conservative MP for Montgomeryshire who spoke about their experiences and views about self-monitoring.

Following the awards event we had some great promotion. A number of MPs wrote about the event on their website including Andrew Gwynne, Virendra Sharma, Nick Hurd (Conservative MP for Ruislip, Northwood and Pinner) and Dame Joan Ruddock (Labour MP for Lewisham Deptford). Additionally there was some press coverage in the local papers in Sheffield.



Select Committee report published on long-term conditions

On 3rd July, the Health Select Committee published its report into the management of long-term conditions.

The most important parts of the report are the conclusions and recommendations because they will be used to monitor the implementation of the report's findings. However, the government might reject some, or all of these recommendations.

The conclusion and recommendations focused on three specific areas:

- Clinical care for people with long-term conditions
- Strategic direction of services for long-term conditions
- Managing the system to deliver better care for long-term conditions



House of Commons Health Committee

The most relevant part for ACSMA is 'clinical care for people with long-term conditions' as nearly all conclusions/recommendations will help people on long-term warfarin gain access to self-monitoring technology.

ACSMA is mentioned within the report regarding commissioning of services. The report quoted directly from the evidence we submitted about how commissioners can be supported in providing an anticoagulation service.

If you would like further information about the Health Select Committee report, please email info@acsma.org.uk or telephone Mark Hill on **01707 330033**.

Would you like to become an ACSMA Ambassador?

In our last newsletter, we advertised for people to become ACSMA Ambassadors - thank you to everyone who has responded. In summary, the role of the Ambassadors will be to support and promote our work by local influencing and awareness-raising. For example, meeting with the local MPs or CCGs, talking to local communities or the media, or

meeting patients. Are you confident, enthusiastic and passionate about self-monitoring? If so, this could be the role for you!

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 have had a great response to our request asking to hear about your experiences of being on long-term warfarin. We want to use your story – and those of other patients – as case studies, which we can use in our campaigning.

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 890 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**