

Welcome to the third newsletter from 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.

# Newsletter

September 2013

173 responses to our online survey – thank you!



As our campaign has gained momentum we have been reaching out to you to share your stories and experiences. We have been hearing from people on long-term warfarin who are receiving conflicting, misguided or simply incorrect information or advice about the options for self-monitoring. Over and above this, there appears to be no clear guidance for

medical professionals to follow, leading to variations in the advice and care being given across the UK.

We listened to what you told us and decided to launch a Nationwide online survey for people on long-term warfarin and their carers so we could understand the extent of the issues.

Our aim was to gather accurate information about access to INR self-monitoring across the UK and to highlight the issues that people are facing around self-monitoring. This will give us powerful evidence to use in our campaign activity, in particular enabling us to have meaningful discussions with key national decision makers and stakeholders.

## 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

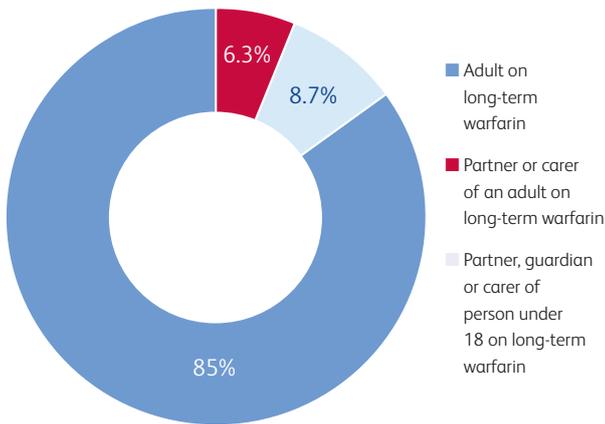
the choice about whether to self-test or self-manage their treatment. We believe that this change would enable improved health outcomes and save time and money for both patients and the NHS.



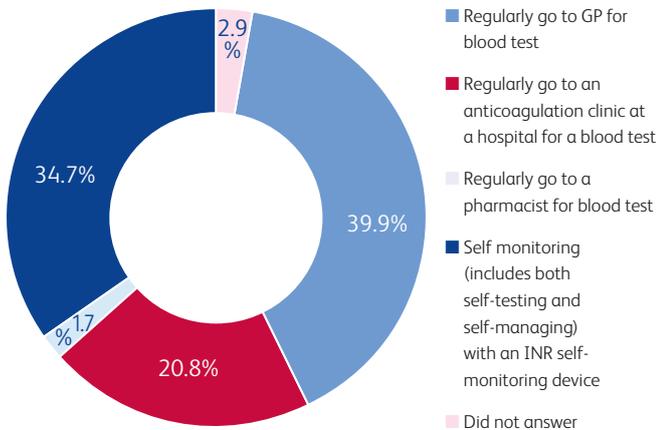
## Results

So far we have received a total of 173 responses from across the country with a 100% completion rate. The results highlight the disparities and variations in practice that are occurring across the country. Some of our key survey findings are given below:

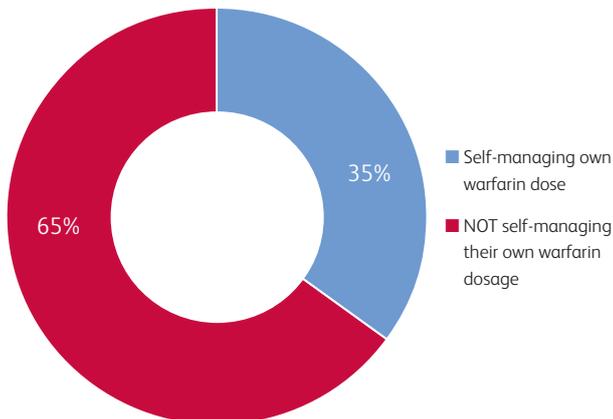
### 1. Who completed our survey:



### 2. How people who completed the survey, or those they are representing, are monitoring their INR



### 3. The number of people who are self-monitoring their INR who are adjusting their own warfarin dose



### 4. For those who are not self-monitoring,

34.7%

have been discouraged by a healthcare professional, who is unaware, unsupportive or cited legal reasons

### 5. Of people have been told that they cannot self-monitor

16%

refer to a healthcare professional, clinic or pharmacist. Of that

40.7%

highlight the GP as the main barrier

### 6. Of those who are self-monitoring but not adjusting their own warfarin

38.5%

are unaware this may be an option or they have been told it is not allowed by a healthcare professional

### 7. Of all those who are regularly self-monitoring

23.3%

say that their GP has said that they are not allowed to prescribe test strips

### 8. The survey allowed people to add in comments about their experiences with self-monitoring. **One person said:**

“ I have been on warfarin for 19 years now and will be for the rest of my life. I would be saving the NHS money by self monitoring by freeing up appointment times, saving on laboratory costs, courier costs etc so for people like me, we should be given them free of charge ”

**Another said:**

“ I feel that this should be provided by the NHS, we already have to pay for warfarin even when the need for this is for life, it does not seem fair how if I were diabetic all the necessary equipment to manage it is free. ”



## Next Steps – we need you!!

The next stage for ACSMA is to take this preliminary evidence to meetings with key stakeholders, this includes a meeting with NHS England.

Whilst the findings are compelling we want to build on this initial survey. Our plan is to re-launch the survey, we are aiming for 500 respondents. We want to be able to identify the regions where patients are unable to have the opportunity to self-monitor more closely and to address this with relevant local MPs, clinicians and Clinical Commissioning Groups.

We will put the link to the survey on our website [www.acsma.org.uk](http://www.acsma.org.uk) and on twitter® as well as signposts on the websites of our alliance members. We really value your support and input to take this campaign to the next level.

## Health Select Committee Inquiry into the Management of long-term conditions

ACSMA has submitted written evidence to the House of Commons Health Committee's inquiry into the management of long-term conditions. The Health Select Committee decided it wanted to examine the way in which the NHS and social care system in England supports people with long-term conditions and we submitted a paper on needs of people on long-term anticoagulation treatment and the challenges they face. You can read our submission on our website <http://www.acsma.org.uk/news/news-articles/>

The first oral evidence session took place on the 18th of June 2013, and heard from four witnesses who were clinicians, representing the NHS Year of Care Partnerships, the Nuffield Trust, and the Department of Health Sciences at the University of York and finally the Institute of Gerontology at Kings College London.

The session focused on the desire for care to be moved into a more integrated and community based setting, which would in turn allow patients to be in control of their long-term condition. It was made clear by the clinicians that primary care should be the default setting for long-term conditions and this in its self would advocate better services for patients. Witnesses noted that at the moment 60% of GPs do not endorse people to be independent decision makers. This is an issue that ACSMA is currently extremely concerned about. The Health Select Committee will continue taking evidence when the House returns in the autumn.

## How can you get involved?

ACSMA now has 637 supporters. If you want to pledge your support for our campaign, would like to tell us your story about living on long-term 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](http://www.acsma.org.uk) or follow on Twitter: [@ACSMA\\_UK](https://twitter.com/ACSMA_UK)