Anticoagulation services and patient access to INR self-monitoring in the NHS in England

A report by the AntiCoagulation Self-Monitoring Alliance (July 2014)

Executive Summary

There are more than 1.2 million people in the UK on warfarin therapy, of whom fewer than two per cent self-monitor their International Normalised Ratio (INR) level, despite evidence that self-monitoring can cut the risk of death by nearly two-fifths and more than halve the risk of strokes[1]. Responses to Freedom of Information (FOI) requests for details on the current anticoagulation services offered by CCGs highlight substantial room for improvement in the role of CCGs, in enabling suitable people on long-term warfarin to have access to self-monitoring opportunities. ACSMA is hopeful that the forthcoming evaluation decision from the National Institute for Health and Care Excellence (NICE) - due in September 2014 – will help convince CCGs of the clinical- and cost-effectiveness of coagulometers such as the CoaguChekXS and INRatio2.

The AntiCoagulation Self-Monitoring Alliance (ACSMA) was set up in October 2012 to raise awareness of the benefits of self-monitoring and to campaign for greater access via NHS prescription to INR self-monitoring technology for patients on long-term warfarin therapy. During the course of the campaign, it became clear that, while Government and Ministers were supportive of self-monitoring and patient self-management of long-term conditions more broadly, this was not necessarily being translated into action by the 211 Clinical Commissioning Groups (CCG) responsible for commissioning and funding anticoagulation services. Anecdotal evidence received from people on warfarin treatment, their carers and healthcare professionals suggested that people were routinely facing a number of obstacles to self-monitoring: some were told that their CCG did not allow self-monitoring on cost grounds or for reasons of safety; alternatively, their GP or anticoagulation nurse had never heard of self-monitoring (despite the technology having been available for twenty years), or was concerned about the medico-legal implications if 'something went wrong'.

As a result, in January 2014 ACSMA undertook an exercise to try and ascertain more clearly what was happening in CCGs across England using FOI requests to elicit information about anticoagulation service provision, current practices and policies directly from the CCGs themselves. The FOI request comprised seven questions regarding the CCG's current anticoagulation service, how it is configured and funded, the CCG's policy towards self-testing and self-monitoring, and the existence of local guidelines and patient information. Completed FOI responses were received from 178 of the 211 CCGs in England (84%).

The FOI responses received supported ACSMA's anecdotal evidence that the vast majority of people on long-term warfarin simply do not have access to self-monitoring opportunities. There is also a huge variation in how and where anticoagulation services are located and paid for, the reasons given why self-monitoring is, or is not, supported, and the criteria applied.

Disappointingly, only one-third (34%) of CCGs allow people to self-test their INR level and 28% of all CCGs allow self-management (which includes self-testing). This means that the vast majority of people on long-term warfarin are being denied the opportunity to self-monitor, despite the benefits to the patient in terms of health outcomes[1], convenience and quality of life, and the long-term cost saving to the

[1] Heneghan C et al. Self-monitoring of oral anticoagulation: a systematic review and meta-analysis. Lancet 2006;367(9508):404-11.

health service. The responses also highlight the reasons why CCGs do not offer self-monitoring, as well as other concerns raised: about the accuracy of the test results, perceived costs, clinical governance, safety and the lack of demand from patients.

Most CCGs (63%) commission their anticoagulation services through a combination of primary care and secondary care, with only 12% of CCGs commissioning via primary care alone. Irrespective of where the service is located, a wide variety of mechanisms are used to commission and fund the service, including block contracts, payment by results (PbR), local enhanced services, local tariffs, on a cost per case, via the 'any qualified provider' route, or a combination of these.

Even though the testing device itself is not available on NHS prescription, it has been possible for people who self-monitor to obtain the test strips on NHS prescription since 2002. ACSMA's information suggested that more and more CCGs were now refusing to allow NHS prescribing of test strips, or were imposing limits on the number of test strips allowed. The FOI responses would seem to confirm that; only one-third (34%) of CCGs currently allow GPs to prescribe test strips on a NHS script.

Only 7% of CCGs have any formal local or published guidelines or guidance in place about self-monitoring, which means that even a significant proportion of CCGs which claim to offer self-monitoring do not have any published policy in place. Similarly, 75% of CCGs do not offer information on self-monitoring to patients, or have any information available. This is perhaps not so surprising, given the large proportion of CCGs which do not currently support either self-testing or self-management, but it does highlight a key problem which many people have been writing to ACSMA about: without formal channels of information or support, people are finding out about self-monitoring by accident, through word of mouth or via a supportive patient organisation or health professional.

In conclusion, many patients on long-term warfarin are being denied the opportunity to see if they would be suitable for self-monitoring. Even in those places where people are allowed to self-monitor, the CCG often raises other concerns or adopts other criteria, which precludes self-testing or management from being made routinely available to all: these include cost, clinical safety, the accuracy of testing and medico-legal concerns.

The FOI responses highlight a real lack of interest in wanting to innovate or redesign anticoagulation services around the needs and preferences of the patient. Several CCGs do not believe there is a convincing business case for supporting self-monitoring or that the opportunity costs for developing an anticoagulation service based around self-monitoring for suitable patients would be disproportionate. Other CCGs do not allow people to self-monitor as they believe their current system of anticoagulation provision is safe and effective – in other words, there is no reason to change**.** These responses are disappointing because there is already strong supporting evidence that self-monitoring can improve health outcomes, offer patient choice and convenience, and save time and money for both individuals and the NHS. Hopefully, the forthcoming evaluation decision from the National Institute for Health and Care Excellence (NICE) - due in September 2014 - will help convince CCGs of the clinical- and cost-effectiveness of coagulometers such as the CoaguChekXS and INRatio2.

Although the majority of CCGs do not have a formal CCG-wide policy in place supporting self-monitoring on a routine basis, it does not always means that people on long-term warfarin are denied the opportunity to self-monitor as examples of good local practices exist. A number of CCGs take into account a person's social circumstance, home environment and whether the use of self-monitoring technology could be considered as a safe choice for them. Others have delegated the decision to the GP, for him or her to make in conjunction with the patient and, where appropriate, consultant haematologist. These encouraging examples need to be shared more widely across the country to allow other people the opportunity to self-monitor.

Above all, the FOI responses highlight how little is known by CCGs and, one assumes, healthcare professionals, about the reality of self-monitoring, and the available evidence supporting its clinical and cost-effectiveness, and the benefits to patients in terms of greater control over their own lives, convenience and reassurance.

To help improve access to self-monitoring for people on long-term warfarin, the report makes the following recommendations:

- NHS service commissioners and providers need to look to how anticoagulation services can be redesigned and liberated[2] from the hospital and primary care clinics so as to ensure that, wherever possible, all suitable patients are given the choice to self-monitor their INR levels, should they wish to and are competent to do so.

- There is a lack of knowledge on the part of both patients and healthcare professionals about self-monitoring. CCGs must provide information they can offer to both groups.

- There is an urgent need to address the disconnect between national Government policies - which are supportive of greater self-management and choice for people - and poor implementation of those policies at local NHS level.

- Those who are successfully self-monitoring should be given appropriate support and encouragement to do so; including being allowed to receive test strips on NHS prescription and in terms of information. All too often, ACSMA hears of people having to do battle with their healthcare professional or CCG in order to be allowed to continue to self-monitor.

- Examples of local best practice by CCGs and GPs that allow people to self-monitor need to be promoted and shared widely.

- Whilst ACSMA welcomes NICE's provisional recommendation for the CoaguChek XS and INRatio2 self-monitoring devices, we need to have choice for all people on warfarin and we will work to ensure that self-monitoring becomes available on NHS prescription to all eligible warfarin patients.

[2] Anticoagulation Europe (UK) 'Commissioning effective anticoagulation services for the future' November 2012