Health Committee Inquiry
Management of Long-Term Conditions

Submission of evidence from the AntiCoagulation Self-Monitoring Alliance (May 2013)

1. About the AntiCoagulation Self-Monitoring Alliance (ACSMA)

1.1 The AntiCoagulation Self-Monitoring Alliance (ACSMA) was established in October 2012 with the objective of achieving greater access to self-monitoring technology for people who are on long-term warfarin and for self-monitoring technologies to be available on NHS prescription.

1.2 ACSMA comprises four of the UK's leading charities and patient groups – AntiCoagulation Europe; the Children's Heart Federation; AF Association; Mechanical Heart Valve Support Group – that exist to provide advice, support and guidance to people on oral anticoagulation therapy, as well as their families and healthcare professionals. Healthcare company Roche is also part of the alliance.

1.3 ACSMA is campaigning for greater choice for people on long-term warfarin about how their condition is managed. Our goal is to enable people - wherever possible, allowing those on long-term warfarin the option to self-monitor their condition. ACSMA is also seeking to raise awareness and to ensure that people are equipped to have informed discussions with their healthcare professionals on this topic.

1.4 We believe that these changes will improve health outcomes, patient choice and convenience, as well save time and money for both individuals and the NHS[1,2]

2. Executive Summary

2.1 We welcome the Health Committee's Inquiry into the Management of Long-Term Conditions, as this topic is one of vital importance for ACSMA and our campaign. Sections 4-8 set out in more detail our thoughts and comments in relation to the specific terms of reference for this Inquiry.

2.2 The key points of our submission can be summarised as follows:

2.2.1 **People with long-term conditions should have the choice to self-monitor their condition. For people on long-term warfarin, this must include having access on NHS prescription to the technologies that can help them achieve that, as well as appropriate support and guidance from their healthcare professional.** NHS service commissioners and providers need to look to how anticoagulation services can be redesigned; liberated from the hospital and primary care clinics to enable those who wish to take control of their treatment to do so, and to

[1] Connock M, Stevens C, Fry-Smith A, Jowett S, Fitzmaurice D, Moore D, et al. Clinical effectiveness and cost-effectiveness of different models of managing long-term oral anticoagulation therapy: a systematic review and economic modelling [online]. Health Technol.Assess. 2007 ix-66; Oct;11(38):iii-iv, ix-66.

[2] Gardiner *et.al*. Patient self-testing is a reliable and acceptable alternative to laboratory monitoring. Br J Haem 2004;128:242-47.

manage their treatment in a way that suits them, their families and their lifestyles.

2.2.2 People with long-term conditions should be managed holistically, as a whole person, rather than treated exclusively for their condition. Although it has been said many times before, a more patient-centric approach really is needed. More clinical services and experts sharing community clinics and managing patients holistically would encourage the sharing of knowledge.

2.2.3 The current assessment of ongoing care needs should be revised. Anticoagulation is a vital part of the ongoing health of our society, whether that is by preventing ill health (by preventing a stroke or thrombosis, for example) or by maintaining the benefits of intervention already undertaken. The importance of effective anticoagulation in terms of disease prevention becomes even more important in the context of an ageing society. Recent NICE guidance has shown that current care is sub-optimal and that the assessment of ongoing care needs should be revised. ACSMA supports this, not only because it will lead to better long-term care, but also because of the opportunities for life-long intervention for those most at risk of a thrombotic event.

2.2.4 There is a lack of knowledge on the part of both patients and healthcare professionals about the self-management of long-term conditions. Addressing this education gap is vitally important and a real priority. Patient education needs to be improved so people can, if they choose, take control of their condition. Clinicians should be educated so they can have informed discussions with their patients about the opportunities that exist and the suitability of one regime over another, and to understand how they can best support patients who choose to self-monitor.

2.2.5 There is an urgent need to address the disconnect between national Government policy - which is supportive of greater self-management and choice for people with long-term conditions - and poor implementation of those policies at local NHS level. Patient choice has been the holy grail for many years now and yet our members and supporters tell us numerous stories of healthcare professionals who refuse to discuss self-monitoring with them, claiming that it is illegal, "not allowed here" or would render the healthcare professional liable to litigation were something to go wrong. We are aware of some localities where clinics refuse to prescribe the strips for the INR monitors, or threaten to refuse to prescribe the warfarin itself, to those patients keen to try self-monitoring. In the meantime, the Government continues to support the principle and practice of self-management through its '3million lives' initiative, the Mandate to NHS England and other policies such as 'Innovation, Health and Wealth'.

2.2.6 **At present, an estimated 2% of the 1.2 million on long-term warfarin are self-monitoring their blood clotting levels[3]. If more people were able to do so, the savings to the NHS would be substantial.**
Current estimates show that the management of oral anticoagulation therapy for patients with stable conditions costs the NHS approximately £409 million[4]. Studies show that if the estimated 1 in 4 self-monitored, the NHS could save up to £62 million a year[5].

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[3] Data on file. Atrial Fibrillation Association. Anticoagulation Europe 2011.
[4] National Institute for Health and Clinical Excellence. Atrial Fibrillation. Clinical Guideline no. 36. Costing Report. NICE. 2006.
[5] Connock *et al*. Op. cit.

3. **Anticoagulation therapy management**

3.1 People on long-term warfarin need to have regular blood tests to check their internationalised normal ratio (INR), or level of clotting tendency. These blood tests are usually conducted in a hospital outpatient clinic or GP surgery, where the warfarin dose can be adjusted, if required. The time needed to attend regular clinic appointments can quickly begin to affect a person's personal and professional lives; whether they are in full time work, education or are parents of a child on long-term warfarin.

3.2 Evidence shows that there are currently more than 1.2 million people in the UK on warfarin[6,7]. This might be due to a previous stroke, a venous or pulmonary thromboembolism, a deep vein thrombosis – or to prevent a recurrence thereof - or because of atrial fibrillation or the fitting of a mechanical heart valve. Of these, less than two per cent current benefit from self-monitoring[8] despite evidence that it can cut the risk of death by nearly two-fifths[9] and more than halve the risk of strokes[10].

3.3 In all areas where anticoagulation therapy is recommended by guideline and good clinical practice, the benefits to patients in terms of the reduction of clinical risk are substantial. These benefits are without consequence; anticoagulant therapies are not without risk if not monitored appropriately or poorly controlled. For that reason, the solution for anticoagulation provision to date has largely been hospital and clinic-based. Our evidence is that anticoagulation clinics in NHS hospitals are struggling to cope with the volume of people that attend and, although many of these services are of a high quality, both patients and clinicians have been known to make decisions regarding the choice of intervention based what is convenient for the clinic, rather than what is best for the patient.

Turning now to the Inquiry's terms of reference:

4. **The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness.**

4.1 Currently, the provision of anticoagulation monitoring is largely restricted to clinics and hospitals with, as noted above, only a very small percentage of people on long-term warfarin being given the opportunity to self monitor their INR levels at a convenient time to them. As a result, many people who have been returned to good health by some form of clinical intervention (for example, following a stroke) or who have received an intervention to prevent them from further poor health find their lives governed by clinics. This is inconvenient for people on warfarin and their families, as well as costly for the NHS.

4.2 ACSMA supports moves that would allow people on long-term warfarin to self-monitor their INR levels outside a hospital setting using portable INR testing devices. NHS service commissioners and providers need to look to how anticoagulation services can be liberated from the hospital and primary care clinics to enable those who wish to take control of their treatment to do so, and to manage their treatment in a way – and at a time and place - that suits them, their families and their lifestyles.

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[6] Gardiner *et al*. Op. cit.
[7] Office for National Statistics 2008. Accessed 16 June 2011.
[8] Data on file. Op. cit.
[9] Heneghan C et al. Self-monitoring of oral anticoagulation: a systematic review and meta-analysis. Lancet 2006;367(9508):404-11.
[10] Ibid.

4.3 A change to service responsibilities must ensure that people have better access to the technologies that will help them self-monitor their condition and this should include flexibility in how and where they are managed and by whom. The technologies to do so have been available (albeit at the patient's cost) for many years and the diagnostic strips are currently available on NHS prescription. Ensuring better access must include making the self-monitoring devices available on NHS prescription to those who are willing and able to use them, as well as preventing healthcare professionals and clinics from refusing to prescribe either the device or the testing strips on anything other than clinical grounds.

4.4 Any redesign of services for a non-clinical (community or home) setting should also take account of the following factors:

- Management of conditions in the community needs to be consistent – with standards of care being monitored and measured in every setting according to key performance metrics
- All personnel involved will need to be adequately trained in working across the range of anticoagulation services, including self-monitoring, as anticoagulant therapies are not without risk if not monitored appropriately or poorly controlled
- Therapy needs to be suitable for the patient and an agreed management plan put in place

4.5 There are cost implications of redesigning services to empower patients in this way. However, the potential for redesigning anticoagulation services to achieve cost offsets and savings is considerable. Current estimates show that the management of oral anticoagulation therapy for patients with stable conditions costs the NHS approximately £409 million[11]. As noted above, if just one in four self-monitored, the estimated savings to the NHS would be substantial, even taking into account the cost of funding both the INR monitoring device and the test strips on NHS prescription. ACSMA is aware that there is ongoing work to model the likely cost savings to the NHS, based on the latest trial data. We would be happy to share further details of this work if that would be helpful to the Committee.

4.6 As noted below (paragraph 6), this issue will become even more critical with an increasing ageing population that will stretch existing anticoagulant services even further.

5. The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community; and the ability of providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions.

5.1 In our opinion, these two points go hand-in-hand. A readiness to treat people with long-term conditions in the community will be determined by having the right policies, processes and resourcing in place. This can be facilitated by NHS and social care services adopting a patient-centric approach, where the individual is treated as a whole person, rather than as a 'patient' with a particular condition.

5.2 There is a need to have more clinical services and experts sharing community clinics and managing the patient holistically and encouraging sharing of knowledge. For

[11] National Institute for Health and Clinical Excellence. Op. cit.

example, specialist nurses and doctors could be trained to specialise across two or three common disease areas with consultants dealing with more serious cases. As noted below, there is a dearth of specialist clinicians working in communities who are able to offer personalised services. This needs to change.

6. **The implications of an ageing population for the prevalence and type of long-term conditions.**

6.1 As the population ages and acute health services become more adept at allowing people to survive acute cardiac and thrombotic events, the need for effective and adaptable anticoagulation services becomes ever more important – particularly for the prevention of ill-health and to prevent disease recurrence.

6.2 To give one example, the incidence of the heart rhythm disorder atrial fibrillation (AF) is increasing. The current national prevalence of AF is 1.72%, with a massive prevalence of over 10% of the over 65 population[12]. AF carries a five-fold increase in the risk of stroke, with one in three people with AF suffering a stroke within their lifetime[13]. Currently, 15-20% of ischaemic strokes are related to AF[14], and these strokes have been shown to carry a much higher level of an ongoing disability and also mortality.

6.3 Well-managed anticoagulation therapy reduces the risk of stroke by nearly 70%[15]. Several studies[16] have shown that patient self-monitoring can improve the quality of oral anticoagulant therapy, with those who self manage having fewer thromboembolic events and lower mortality rates. Specifically, there is evidence that self-monitoring can cut the risk of death by nearly two-fifths[17] and more than halve the risk of strokes[18].

6.4 National and regional guidelines and the National Quality and Outcomes Framework (QOF) are directing higher levels of anticoagulation in people with AF. For example, QOF indicator AF3 acknowledges that warfarin is under-used in stroke prevention in AF patients and so directs primary care practices to record the percentage of patients with AF who are currently treated with anticoagulation drug therapy[19].

6.5 The incidence of valvular heart disease is also increasing. Many people with this condition require long-term anticoagulation therapy. Although there have been innovations in the range of oral anticoagulants available, these are not suitable for those with valvular disease. Consequently, people remain dependant on warfarin and the need for ongoing INR monitoring. Predicting the needs of an ageing population based on statistical data will confirm key areas of focus.

7. The practical assistance offered to commissioners to support the design of services, which promote community-based care and provide for the integration of health and social care in the management of long-term conditions.

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[12] Bayer Health Care Pharmaceuticals. Taking the pulse of NHS services; stroke prevention and atrial fibrillation. December 2012.
[13] Ibid.
[14] Ibid.
[15] NHS Information Centre. The percentage of patients with atrial fibrillation who are currently treated with anti-coagulation drug therapy or an anti-platelet therapy QOF 3.
[16] The Cochrane Collaboration. Self-monitoring and self-management of oral anticoagulation (Review).
[17] Heneghan *et al.* Op. cit.
[18] Ibid.
[19] NHS Information Centre. Op. cit.

7.1 Despite the obvious benefits, data indicates that many current anticoagulation services are sub-optimal[20]. A NICE 2006 costing report on AF estimated that 46% of patients who should be taking anticoagulation therapy are not currently receiving it, and those who do receive it are not in optimal therapeutic range[21].

7.2 Practical assistance for service commissioners could involve identifying the prevalence and incidence of people requiring anticoagulation services in a local health economy; a national patient experience survey of people using anticoagulation services; incentives and payments directed more towards prevention of ill-health; and engaging with patients and service users in service design.

8. The extent to which patients are being offered personalised services

8.1 ACSMA believes that there is considerable variation and inconsistencies in how care plans are being used for those receiving anticoagulation therapy. There is a lack of specialist clinicians working in communities who are able to offer personalised services. This is due to a variety of reasons, including a limited scope of responsibilities, the costs involved, lack of incentives (payment) and the resourcing required.

8.2 Our experience is that we have a long way to go before patient choice and personalised care become a reality. There is an urgent need to address the disconnect between national Government policy - which is supportive of greater self-management and choice for people with long-term conditions - and poor implementation of those policies at local NHS level.

Conclusions

9. Anti-coagulation is a vital part of the ongoing health of our society, whether that is by preventing ill health, or in maintaining the benefits of intervention already undertaken. However, current service provision is sub-optimal and organised around the needs of the clinic, not the patients. If more people on long-term warfarin were able to self-monitor their INR levels, the benefits in terms of health outcomes, patient choice and the savings to the NHS would be considerable. Raising awareness of self-monitoring and making the devices available on NHS prescription are both key to achieving these benefits.

10. ACSMA would welcome the opportunity to give oral evidence to the Committee's inquiry, if that would be helpful.

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For and on behalf of the AntiCoagulation Self-Monitoring Alliance

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[20] NHS improvement. Atrial Fibrillation in primary care; making an impact on stroke prevention. National priority project final summaries. October 2009.
[21] National Institute for Health and Clinical Excellence. Op. cit.