



Front Line in Stroke Prevention

A National Picture of
Anticoagulation Services in the UK



This research was carried out by AntiCoagulation Europe, with advice and assistance from Help the Aged.



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Foreword



Eve Knight

The Front Line Report was commissioned to look at the current status of anticoagulation treatment in the UK and to identify key issues that anticoagulation clinics and the patients who attend these clinics face. The clinics provide a valuable service monitoring patients who are often at high risk of stroke. However, over recent years an increasingly ageing population and new NHS guidelines to improve management of older patients, including those at risk of stroke, have led to increased pressure on anticoagulation monitoring facilities. There are concerns over the ability of the clinics to cope with the increasing demand and the impact that this may have on the patients that they monitor.

Stroke is the single biggest cause of severe disability and the third most common cause of death in the UK. Each year 110,000 people in England and Wales have their first stroke, and 30,000 have a further stroke.¹ Every five minutes, somebody in the UK has a stroke.²

Two surveys were carried out to establish how the increasing pressure on already stretched services is impacting on the ability of clinics to provide an effective service and patient experience. The results set out in this report suggest a system that is now stretched to breaking point and indicate that there is an urgent need for improved services and treatment for patients requiring anticoagulation. As highlighted in the document 'Creating a Patient Led NHS' there is a need to provide fast, convenient services, provided more locally and shaped around people's needs and preferences.

The results outlined in this report have helped us to identify key steps which we believe need to be taken now to protect this group of patients who are at high risk of death or disablement from stroke.

We hope that this report will be the first step to highlight this growing issue and drive change in the management of atrial fibrillation and stroke, to ensure improved care and resources for this high-risk group in order to avoid a potential crisis.



Eve Knight, Director,
AntiCoagulation Europe

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Atrial Fibrillation – The Facts



How common is atrial fibrillation and stroke

Approximately 100,000 people in the UK are diagnosed every year with a condition known as atrial fibrillation (or AF).³ Atrial fibrillation is an irregular heart rhythm. Sufferers are at greater risk of a stroke and need anticoagulation treatment to help them to reduce that risk. Atrial fibrillation increases the risk of blood pooling, and blood clots may then form. These can then break away and cause a blockage in an artery to the brain, resulting in a stroke.

More than half a million people in the UK are estimated to have atrial fibrillation which puts them at a five times greater risk of stroke than the general population.^{3, 4, 5, 6, 7}

Atrial fibrillation is primarily a problem for older people affecting 5% of the UK population over the age of 65 years and 10% of those over the age of 75 years.⁸ The number of people suffering from the condition is projected to increase by up to three-fold over the next 50 years.⁸ Additionally, atrial fibrillation and stroke do not only affect the older population, each year, 10,000 people under 55 years and 1,000 people under 30 years old have a stroke.¹

Anticoagulation treatment

Guidelines* recommend that most people with atrial fibrillation over the age of 65 years should be considered for anticoagulation treatment, which prevents the clots from forming, and reduces risk of a stroke.^{7,8,9} The mainstay of treatment for anticoagulation is the drug warfarin. Since many

common medications, foods, and some illnesses can affect a patient's response to warfarin, patients must be monitored frequently with blood tests to identify whether any adjustments to their dose of warfarin are required. Monitoring is typically carried out at an anticoagulation clinic.

It is not unusual for patients to attend such clinics as frequently as fortnightly. The condition therefore can have a dramatic effect on a person's overall quality of life.

Atrial fibrillation currently costs the NHS £459 million a year, including £69.5 million in drug treatment and monitoring and £271.6 million in hospital admissions.¹⁰

Stroke management guidelines

The National Service Framework (NSF) for Older People in England requires that every general practice is able to identify and treat patients at risk of stroke because of atrial fibrillation, high blood pressure and other risk factors. General practices must also offer regular review of those at risk.¹ The Scottish SIGN Guidelines also recommend that all patients with atrial fibrillation should have their risk factors assessed routinely.⁹ Furthermore, the National Institute for Clinical Excellence is currently developing recommendations for the management of patients with atrial fibrillation in England and Wales (with input from the Welsh Assembly Government).

It is estimated that stroke costs the NHS over £2.3 billion every year.¹⁰

* Guidelines for care of people with atrial fibrillation include those produced by SIGN (the Scottish Intercollegiate Guidelines Network) and recommendations published in the British Medical Journal.



SERVICE PROVISION – A Survey of All UK Anticoagulation Clinics¹¹

A questionnaire was sent to all 302 anticoagulation clinics in the UK. Staff from over a quarter of all UK clinics (82 clinics) responded. The survey aimed to review the current status of anticoagulation clinics and the impact on patient experience. The results suggest a system which has been under growing pressure in recent years with demand looking set to increase in the coming years.

Clinic demographics

- The majority of clinics (**70%**) saw 200-500 patients at between 2-5 clinics per week with an average of 14 new patients per week
- Atrial fibrillation was the primary reason for over half of patients to attend **71%** of the clinics

Growth in patient numbers

The survey findings indicated that clinics have experienced a dramatic increase in patient numbers.

- **73%** of clinics surveyed stated that patient numbers had increased by up to **25%** over the past two years
- Most respondents (**86%**) expected demand to increase further in the next 12 months

Impact of increasing patient numbers

Staff at the clinics surveyed anticipated that the growth in patient numbers would have a significant impact on services.

- **90%** of respondents expected that the increase in demand would put more pressure on resources

- Over half of clinics (**56%**) stated that an increase in demand would result in increased waiting times at the clinic with **43%** anticipating an increase in waiting lists
- Over a third (**36%**) of clinics suggested that the quality of anticoagulation service would reduce if demand increases in the next 12 months
- **17%** of clinics surveyed stated that they will have to limit the numbers of new patients accepted in order to cope with the increase in demand

“These results are worrying for patients, particularly as they suggest many clinics will be more overwhelmed in the future leading to even longer waiting lists and increased waiting times. A number of clinics indicate they will be unable to offer a service to some patients possibly forcing them to travel long distances to be monitored or leaving them at increased risk of stroke or other complications.”

*Dr Patrick Kesteven, Consultant Haematologist,
Freeman Hospital, Newcastle*

SERVICE PROVISION – A Survey of All UK Anticoagulation Clinics¹¹ *continued*

Addressing the increasing demand & improving services

Clinics were asked what measures they have in place to manage the expected increase in demand.

- Over a quarter of clinics (**29%**) expected to recruit additional staff to cope with increasing patient numbers
- However, more than a quarter (**28%**) of respondents had no plans to take any additional steps to cope with increasing demand
- Very few clinics said that they were planning to re-allocate patients to existing haematology clinics (**8%**)

Clinics were also asked what single change would help them to deliver a high quality service to their patients in the future.

- Almost half (**49%**) said that increasing staffing levels would help to improve service quality
- **37%** of clinics believed that improving collaboration with primary care healthcare providers e.g. GPs would help them to improve services

- **Over a quarter of respondents stated that there would be no measures taken to cope with the expected increases in demand**
- **Only 4% of clinics stated that they already offered an 'optimal' service**

New patient education

Education for people who are taking anticoagulation is vitally important so that they understand the implications of taking the treatment such as the effect on diet and lifestyle (e.g. some anticoagulants can interact with other medication, certain foods and alcohol, affecting the extent to which they thin the blood). Education and information for new patients was found to be a priority for most clinics.

- Most clinics (**84%**) allocated longer appointments to new patients for educational purposes
- All clinics offered face-to-face information (**100%**) and most provided patients with written information (**86%**)
- A quarter of clinics (**25%**) offered education through video

Stroke management guidelines

Anticoagulation clinics should be aware of the NSF guidelines which specify that every general practice must be able to identify and treat patients at risk of stroke and offer regular review of those at risk. This is likely to increase demand for monitoring services and put additional pressure on clinics.

- Less than two thirds of respondents from clinics (**63%**) were aware of the NSF targets that every general practice should be able to identify and treat patients identified as being at risk of stroke

A Patient Viewpoint

Marlyn



Marlyn is 64 years old and lives in Warwickshire. She has been taking warfarin for several years following a heart valve replacement. When she first moved to the area she had to travel to hospital to have her blood taken and had to wait for her results before leaving the clinic. Then a small local satellite clinic was set up in a neighbouring village and she went there to get her blood taken and to get her

results from a nurse at the same time. Marlyn found this to be an excellent service and very convenient, but it was closed after a few months. When she wrote to complain she was told that there wasn't enough funding for the clinic.

Marlyn now has to travel to hospital again, and the waiting times have been getting longer and longer. At one appointment she had to wait 2 hours to get her results and when she left the clinic there were still over 20 patients waiting for their results, despite it being the end of the clinic. She is appalled at the service and thinks it has been getting worse and worse. She feels that the clinic just can't cope.

“I understand how important it is to take the medication and get my blood level checked but having to wait for hours to be monitored and get results has made it very difficult. The clinic is clearly overwhelmed and the situation just seems to be getting worse”.

Marlyn

PATIENT EXPERIENCE – A Survey of 1,100 Patients in the UK¹²

A questionnaire was sent to 1,100 patients in the UK who attend anticoagulation clinics, and replies were received from 419 patients. The survey looked at the patients' current experiences and what impact the growing demand on the service has had for them. For many patients, including those with atrial fibrillation, anticoagulation will be a lifelong therapy so ongoing monitoring will become an important part of their lives.

Patient demographics

- The average age of patients responding to the survey was 66 years of age, though ages ranged from under 40 (6%) to over 76 (19%)
- Patients surveyed were either being treated for atrial fibrillation (36%) or venous thrombosis (a blood clot) (26%)
- The majority of patients (60%) were monitored once a month or more
- The majority of patients either go to a clinic at the hospital (51%) or attend a clinic at their GP surgery (32%)

“The survey responses from both the clinics and the patients indicate a service which is struggling to cope with current demand and is ill prepared for the rapidly increasing number of patients requiring the service”.

Dr Gerry Dolan, Consultant Haematologist, Queen's Medical Centre, Nottingham

Patient information

The majority of patients felt they understood the need to take warfarin yet many were not satisfied with the information that had been provided to them.

- 99% of patients surveyed said that they understood what warfarin does
- However, 36% of patients had never been provided with advice on food, drink and other treatments which might interact with their anticoagulation treatment. 41% of patients said that they would like more information on this
- 65% of patients had never received an information leaflet or been shown a video on warfarin treatment

Over 30% of patients surveyed felt they had not received enough information from healthcare professionals on their treatment.

Getting the dose right

Anticoagulation treatment can be complex to manage. A significant proportion of patients found it difficult to remember to take their treatment and/or to get the dose right. Many patients felt that they had not been adequately informed about treatment and didn't receive enough advice when their dose was changed.

- Nearly 1 in 4 people (22%) admitted to occasionally forgetting to take treatment or taking the wrong dose



- **37%** of patients surveyed had had their dose changed 8 or more times in the last year
- **33%** did not receive advice and information on why a change was necessary when their dose was adjusted
- One third of patients (**34%**) have not felt adequately informed about treatment over the time that they have been taking it

Attending a clinic

With regular journeys to an anticoagulation clinic for monitoring a routine part of most patient's lives it is important that these are as convenient as possible. For older patients who may be less independently mobile it is a particularly important issue.

- **35%** of patients felt that anticoagulation monitoring had made a significant impact on their lives
- **37%** felt frequent clinic visits led to disruption as they were unable to plan their lives
- The majority of patients said that they drive, walk or take public transport to the clinic, and 1 in 5 said that the availability of transport/parking affects their ability to get to a clinic

Waiting and appointment times

Many patients appear to experience long waiting times at the clinic, and short periods of time with the healthcare professional.

- **41% of patients have had to wait for an hour or longer to be seen at a clinic (15% have had to wait over 2 hours to be seen)**
- Nearly all patients (**93%**) have less than 10 minutes with a healthcare professional during an appointment and **54%** have less than 5 minutes

15% of patients have had to wait longer than two hours to see a healthcare professional.

Patient hopes for the future

Many patients highlighted that their condition had significantly affected their life (**50%**) with the most frequently stated impact including:

- tiredness/lack of energy (**15%**);
- difficulty travelling/taking holidays (**10%**);
- constant worry (**9%**);
- restricted diet (**9%**);
- the need for constant testing (**7%**) and
- restricted activities (**7%**).

When asked what features of their treatment they would like to change, the top 4 responses were:

- the ability to self-test (**19%**);
- an alternative to warfarin (**16%**);
- to be able to stop taking warfarin (or any medication) (**7%**);
- and less frequent visits for monitoring (**4%**).

When asked what two things would make the biggest difference to their experiences of treatment, or the healthcare system, the top four responses were:

- self-testing/monitoring (**22%**);
- an alternative to warfarin (**14%**);
- more information (**7%**); and
- fewer clinic visits (**4%**).

Summary & Conclusions



Dr Patrick Kesteven



Dr Gerry Dolan

In the past anticoagulation clinics have 'absorbed' increasing numbers of patients. Waiting lists for new patients are now not uncommon in some clinics and waiting times of up to three hours are not unusual. However specialists, such as Dr Kesteven and Dr Dolan, suggest that waiting lists for patients who need regular review cannot be in the best interests of either their staff or the patients. The patient and clinic surveys both show that, whilst clinics are working hard to manage the increased demand, the system is struggling to cope.

Whilst in many cases strategies such as staff recruitment and additional clinics are being implemented to cope with the increase in demand, the results suggest that almost one third of clinics were not intending to take any action and one fifth would limit the number of new patients for treatment in order to deal with increasing demand.

The clinics themselves suggest that a quality service is most likely to be achieved through an increase in staffing levels and an improvement in the collaboration with primary care. On the other hand, patients express a desire for self-testing to enable them to take more control over their condition, and to reduce the need to attend the clinics.

The findings suggest that new patient education is a priority for the clinics. However, many patients still feel that they need more information, including written documents that they can refer back to.

With demand for anticoagulation services widely expected to increase in the next 12 months many believe that this extra demand will have a detrimental effect upon the resources available to clinics and the overall quality of anticoagulation

service provided. To combat this, steps need to be taken to ensure that patients do not find themselves with fewer services, less choice or longer waiting times.

The Need for Change

To manage increasing demand and to continue to deliver a high quality service to patients, it is recommended that

- Patients should receive ongoing education and information about their treatment, including more written information
- Clinics should strengthen multi-disciplinary collaboration between secondary and primary care services to provide additional services
- Additional staff should be recruited and trained where possible – this could include additional training for nurses and pharmacists as managers of anticoagulation services
- Primary Care Organisations should work with hospitals to review current and future demand for anticoagulation monitoring services to help them plan to meet these needs.

Acknowledgements and References

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- AntiCoagulation Europe (ACE) is a charity providing information and advice to people on oral anticoagulation therapy.
- Help the Aged is a charity that works to attack and remove the barriers to active and fulfilled later life, including combating poverty, reducing isolation, defeating ageism and promoting quality in care.
- The research was run by Plus Four Market Research Ltd, and was supported by an unrestricted educational grant from AstraZeneca UK Ltd. Note: patients were not asked for personal details in the patient survey, therefore the exact geographical spread of responses from across the UK is not known.

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