



SELF HELP

INR and self-testing

Most Hughes/antiphospholipid syndrome patients will take life-long anticoagulation and, for those who have had a serious clotting event, the current treatment usually takes the form of warfarin.

Your blood needs to be regularly monitored when you take warfarin because its thickness must match the INR range specified by your doctor; if it is too high, there is a risk of bleeding, but if it is too low there is a danger of clotting.

Many patients who have heart conditions, such as atrial fibrillation, are set an INR of between 2.0-3.0; however, people with Hughes/antiphospholipid syndrome often have to keep a higher INR range, between 3.0-4.5. The aim is to set an INR target as low as possible, but for the patient to be relatively symptom-free. This message is very important as people who keep their INR too low continue to live with severe symptoms and may even have further clotting episodes.

As warfarin is affected by many external factors including diet, alcohol and other medication, it can take several weeks until your target INR is reached and becomes stable. Many Hughes/antiphospholipid syndrome patients will find that their INR fluctuates for reasons still unknown and it rarely stabilises. Consequently, a lot of people have benefitted from self-testing their INR at home as it means they are free from frequent visits to the anticoagulation clinic.

You self-test using a hand-held machine to measure the INR in a drop of blood. In the UK, there are currently two on the market: the CoaguChek XS and INRatio. You give your INR readings to your doctor or nurse and they will then advise you on the dose of warfarin you need to take. Following training and experience, some people feel confident enough to self-manage. This means they take the INR reading and adjust the dosage themselves.

Finger-prick testing is just as accurate as venous tests with many surgeries now opting for finger-prick testing as standard, but be aware that it is common for the INR results between the two to differ slightly – usually between 0.1-0.8. Therefore, it is important to run parallel testing for several weeks in which your own monitor results are compared to those obtained in the anticoagulation clinic venous tests, and that your healthcare team is aware of this difference.

We advise that you recheck this differential each time you use a new batch of testing strips as it can vary slightly. When you open a new batch of testing strips, ensure you get a venous reading from the anticoagulation clinic, compare this with your monitor's results and make a note of the difference.

Once the differential has been identified, self-testing for Hughes/antiphospholipid syndrome patients is considered to be safe but there are special precautions for people who test positive for the lupus anticoagulant (LA). In a very small number of cases the LA has been found to interfere with the reagents used in the self-testing strips and have given false high readings. If you are LA positive, then your anticoagulation clinic needs to be aware of this and should run parallel venous testing alongside your own finger-prick readings for three months.

INR AND SELF TESTING

Points to consider before buying a self-testing machine

Self-monitoring is not for everyone, but it can give you a better quality of life and lets you play an active role in your own health care. However, before you make the decision to buy a monitor, please consider the following points:

- 1 You must be manually dexterous so you can operate the machine. It involves taking a finger-prick test and applying it to a test strip.
- 2 You should have reasonable eyesight so you can take the readings as well as use the monitor.
- 3 Can you get the test strips on prescription? If your GP's surgery is unable to prescribe the strips they cost approximately £65 for a box of 24 (based on 2013 prices) – this is unaffordable for most people.
- 4 Will you have the full support of your GP and/or anticoagulation clinic? This is essential as they will help to train you to use the monitor, be prepared to take your readings and decide what to do with the results. We suggest you make an appointment at your GP surgery/clinic to discuss your options before you consider buying the monitor.
- 5 Does your budget stretch to £300? Both monitors on the UK market currently retail for £299 excluding VAT and they are not available on the NHS. The Coaguchek XS can now be bought on a 24 month payment plan which puts the cost at around £13 a month.
- 6 You should still be prepared to make regular visits to the surgery/clinic initially so that the readings you take from your monitor can be compared to readings obtained at the clinic.
- 7 If you are positive for the lupus anticoagulant, there could be a small chance that the readings are falsely high so you would need to run parallel tests at the anticoagulation clinic for three months.