NHS COMPUTER SAYS YES... EVENTUALLY... SORT OF!

BY MIKE SILVER

For those of us who need to be anti-coagulated life can sometimes have its challenges. Nonetheless we are more fortunate than those whose medical conditions cannot so easily be controlled with the proviso that we stay within our prescribed therapeutic range for fear of the consequences of doing otherwise. Without doubt Warfarin is a blunt instrument, nevertheless it has been the standard anti-coagulation regime for many decades and thankfully giving evolution to more sophisticated therapies, resulting in an increasingly predictable and consistent action and therefore requiring less-frequent blood testing.

As luck would have it, these new drugs are not suited to everyone nor every condition. We patients with prosthetic heart valves must remain on Warfarin and need to maintain substantial anticoagulation within narrow limits. We are faced with challenges due to intolerance, instability, surgical procedures and dental treatment, holidays, diet, mobility and the like. Even a cut finger can potentially be a mortal risk.

It is good fortune that the NHS provides anti-coagulation services (one would hope throughout the UK) such that patients can attend at directed intervals to have a blood sample taken, their INR assessed and given a revised dosing together with a date to come and repeat the exercise. In my experience it works well although it is labour-intensive for the service and time consuming for the patient.

Introduction of technology such as Roche's CoaguChek brings with it a promise to lighten the burden.

HOW HAS THE NHS EMBRACED THIS TECHNOLOGICAL LEAP?

INR can be checked at will while home or away with instant and dependable results and hopefully peace of mind. The question is – how have the NHS embraced this technological leap? Read on.

In mid-2014 I thought it a good idea to get a CoaguChek. Prior to this I had no problem getting to the local clinic and needing tests on a 1- 2 week basis was tolerable. The main motivation was an impending three week holiday in the US including a cruise without the worry of going off-range that far from home territory. On return I requested from my GP continuing supply of test strips and the practice owner refused, giving no reason but assuring me it was not a matter of cost while evading any alternative.

Whether the strips are patient-funded or prescribed is not simply an issue of who pays. It becomes significant when reporting results to the clinic. If the strips are prescribed the clinic will usually accept the result and dose accordingly. Otherwise they will consider as unofficial action and direct the patient to attend for phlebotomy; rendering the purchase of the £300 machine ineffective and diminishing patients' good intentions to invest and participate in their wellbeing.

Given that I had been with the practice for over 40 years and a chequered medical history of which they were clearly aware, I felt aggrieved. A complaint to the local CCG together with lobbying to its Pharmaceutical Adviser was of scant benefit. The practice owner wrote that he would consider prescribing if I were to be trained by the anticoagulation clinic and were party to a signed agreement that they would take clinical responsibility. Fair enough I thought, but this soon proved to be a curved ball as the clinic stated that they would do no such thing and did not support CoaguChek.

Feeling strongly about my own judgement in this matter, patient choice and an NHS which needed joining-up, I expressed the concern to other bodies over the coming months. ACE of course, were supportive however the likes of the hospital's PALS service, NHS England, the Parliamentary & Health

Service Ombudsman sat firmly on the fence. Given all factors, notably that CoaguChek had established regulatory approval, the strips were on-formulary for prescribing to patients and the frequency in which I need to be tested my intentions made perfect sense and I was dismayed at the surrounding apathy.

THE RECIPIENTS GAVE A MIXTURE OF BLANK STARES

A few words about relative costs. I have tried to find out the cost model that applies between primary and secondary care where the latter carries out patient anti-coagulation testing on behalf of the surgery. Also if the GP agrees to prescribe CoaguChek strips, does this deplete his prescriptions budget and/or the surgery's profitability? Also the costs to the NHS of phlebotomy testing as compared to CoaguChek (machine patient-funded but NHS-supplied strips). All of these enquiries were raised in a courteous manner however the recipients gave a mixture of blank stares and were happy to pass me on to other bodies within the NHS where similar was received.

It is my belief that the annual per-patient cost to the NHS of the two testing methods is closely comparable, given greater frequency of patient testing and management for the former as against much reduced involvement and including periodic (3 months or so) QA visits to establish technique and confirm accuracy together with the cost of strips at contracted pricing to the NHS. Published figures claim the annual per-patient cost to the NHS for self-testing to be around 35% less than for conventional phlebotomy with further savings as result of reduction in 'clinical events'. While impressive, the truth in this context is there is no such thing as a standard patient and even if this were realistic, the cost, convenience and safety considerations to the patient adds weight to the argument.

So how did all this end up? The ongoing stalemate ended when my local hospital were taken over by a Trust in which the dominant hospital had its own anti-coagulation service in which their standard method of care is by CoaguChek. I arranged to be transferred to them (no problem as the previous one were pleased to be rid of me) and they wrote to my GP directing him to add CoaguChek strips to my prescriptions list. He did not need reminding of the consequences to me of refusing and capitulated – it would be a brave doctor who refused to prescribe when directed by secondary care.

The total time between initial approach to my GP and him writing out my first prescription was 15 months. This reflects shamefully on many of those involved and on a regulatory system so lacking in guidance.

The advantages in change of testing method were immediately realised and there was one unexpected bonus. My apparent instability on Warfarin disappeared with the transition and it is now most infrequent that I need to have my dose reassessed. As previously, my blood had been taken at a 'satellite' clinic a few miles from the hospital and its laboratory, my belief is that the integrity of the samples may have been compromised in their storage and transportation. I reported this anomaly in the interest of my former fellow patients but nobody seemed particularly interested.

The account I have given may be extreme in tenacity but not in terms of need. I am active and independent but what of the elderly patient with an arthritic hip and asthma in a rural location who is expected to get on two busses in all weathers at varying regularity to have blood samples taken? If the cognitive skills to use the machine and strips (maybe with a little help from a neighbour) are available, life would be so much easier – and safer.

HINDSIGHT IS A WONDERFUL THING

I hope that my experience is of merit to others who find themselves in a similar situation and they should not be put off by those charged with our care and with a questionable agenda from achieving a sensible objective. Hindsight is a wonderful thing but they would be better off to avoid confrontation and find an anticoagulation clinic who are not self-moitoring adverse and seek registration with them; effectively reverse engineering!

We are fortunate to have a wonderful NHS – but someone needs to sort out the politics, the self- interest, take an encompassing view on costs and have due respect for patient choice for what is after all, lifelong therapy.

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NEW APS TREATMENT FOR SOME

A new study funded by Arthritis Research UK and undertaken at University College London Hospital and St Thomas' Hospital, has shown that rivaroxaban could be a safe and effective treatment for some patients with thrombotic antiphospholipid syndrome.
The results from the Rivaroxaban in APS trial are being published in the Lancet Haematology Journal and Dr Hannah Cohen, Lead researcher, consultant in haematology at UCLH says:

"We have shown in the RAPS trial that rivaroxaban could be an effective, safe and convenient alternative to warfarin in some patients with antiphospholipid syndrome.

We intentionally included in RAPS only antiphospholipid syndrome patients who had venous blood clots requiring standard intensity warfarin, target INR 2.0-3.0. We caution, therefore, that the results do not apply to other groups of patients with antiphospholipid syndrome and venous blood clots who need higher INRs or with blood clots in arteries such as in stroke patients, in whom further studies are required."

To view the full text of the RAPS paper go to: www.thelancet.com/pdfs/journals/lanhae/PIIS2352-3026(16)30079-5.pdf