

Winchester Lyme disease clinic

Now you see it, now you don't. Or at least, that is the fluctuating view that patients have been given over the last month or so.

This uncertainty is nothing to do with the Department of Health, and in fact when we raised it there, they didn't even know that the clinic might be ceasing. Yes, in its current form, it might be, though agreement has been reached for it to continue to the end of March; after that the future is uncertain. Some people know they have appointments, some people will soon get them, but some people will have to wait for the uncertainty to resolve.

The reality is that the clinic was established on a wing and a prayer before tying all the management knots. Attendance at the clinic should be funded by those Trusts across the country whose patients ask to be referred to the clinic. Any out-of-area-referral like this has to be agreed by the local Clinical Commissioning Group (CCG). The CCGs are new bodies and the administration, decision processes and routes for payments are not all yet in place.

As a result:

- Hampshire Hospitals NHS Foundation Trust (who host the clinic at Winchester) have not seen the money coming in to pay for the administration of bookings, sending of letters and the clinical service.
- Some laboratories have refused to send blood to the Lyme disease reference laboratory for extensive testing, as this has been an unfamiliar route for them.

However, Dr Dryden running the clinic has received immense support from his colleagues and his Trust despite all this and there is a will to find a way forward. Hampshire Hospitals NHS Foundation Trust cannot continue to use their local money to pay for other Trusts' patients, so it is not sustainable in its current form. It hasn't actually broken down; it was never put together firmly in the first place. It was a good idea only held together by good will.

The clinic has not yet closed and discussions are continuing in order to find a solution. Until this is sorted, patients referred to the clinic will have blood tests before an appointment is agreed so priorities can be decided on the basis of test results and the existing questionnaire to patients.

Don't ask LDA whether only those with positive serology will have appointments - we do not have the answer!

Dr Dryden will continue with the work he does at RIPL helping with diagnostics and taking phone calls from GPs who need an explanation of test results, so that support service to Primary Care is being maintained as it was.

On the way forward, LDA is aware that negotiations at the moment include discussing with

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Southampton, where there is an existing academic unit and access to specialists, with a view to hosting the clinic there. As everyone will be aware from the PHE conference, there are [plans for research studies](#), and an academic centre will facilitate this. However, the service for patients with suspected Lyme disease still needs someone with experience of Lyme disease cases to head it.

Will anyone consult with patients about this service? We don't know the answer to that either at the moment, though we would like to remind PHE of NHS England's vision which has been well publicised -

What is our vision of public participation?

'We must put citizen and patient voice absolutely at the heart of every decision we take in purchasing, commissioning and providing services.'

Tim Kelsey
National Director of Patients and Information, NHS England

Every part of our health and care system is shaped and improved by involving those who use and care about our services. Everyone contributes their distinctive perspective, especially those who face the greatest health disadvantage and the poorest health outcomes.

Progressing from listening and understanding to collaboration and responsiveness, we all benefit from a rich understanding of what is needed and how to co-design and deliver services that meet these needs.

While most reported cases of Lyme disease are from the Southern counties of England, there is a crying need for Lyme disease expertise across the whole country. One part-time clinic on the south coast has already been shown to be insufficient to meet the need.

NorTick 2014

In Norway, they are streets ahead. This conference, held in Stavanger in February, saw more than 70 professionals from Norway, with a few from other countries, gathered to discuss what they were doing to advance knowledge in ticks and tick-borne diseases.

From conversations at international conferences we are aware that Norway has similar problems to the UK, including issues with diagnosis and lack of awareness which often drives patients abroad seeking private tests and treatment.

A new Norwegian National Advisory Unit for tick-borne diseases was announced at the conference. With patient and public participation this has been set up specifically to develop, increase and distribute knowledge and competence. The unit will organise courses and symposia for health professionals to cascade knowledge across the country.

[A summary of proceedings](#) is on the LDA website. Could we in the UK learn from this?

What has LDA been up to?

Our highest priority is the **Help desk**. In January we responded to 52 requests for support and information, most involving multiple requests about evolving situations. RIPL are now referring patients to us which has increased our workload considerably. We have had some requests from GPs as well, though most do not yet take us seriously. The [legacy of history](#).

We **presented a poster** at the piExeter conference in November. This described how we had managed to get the uncertainties in Lyme disease diagnosis and treatment documented using the James Lind Alliance priority setting partnership. The poster can be [seen on the LDA website](#). What % of the questions raised by doctors and patients are true uncertainties requiring further research? 85%!

The Norwegians asked us to present the JLA process and the top 10 uncertainties at **NorTick 2014** in February. The Norwegian National Advisory Unit for tick-borne diseases has said that they will use our list of uncertainties, and do not need to repeat the work themselves. So even though this work has been mostly ignored in the UK, someone recognises it as useful!

The Department of Health continues to communicate with us and we keep them abreast of the patient view. The Department, PHE and LDA are all working on awareness notices to tie in with [World Health Day 2014](#), April 7th, which this year is focusing on vector-borne diseases. Other countries may find Malaria or West Nile Virus more important, but in the UK Lyme disease should be on everyone's mind.

We collaborated with the **Map of Medicine** to review and considerably update the content of the [care pathway for Lyme disease](#). Map of Medicine had queries from GPs when they originally decided to drop this so it is now re-instated in updated form. This is also available to patients under NHS Choices.

Then there's planning the **LDA conference** and the **e-learning video for GPs** to come.

Pass this on

Last summer [PHE published a leaflet](#) for GPs, placed it on their website and asked the Royal College of GPs to circulate it to members. It is a good leaflet and has helped patients and GPs. However one patient, on asking her GP to look at it, was told "I don't download information from the Internet"!

If everyone could **print** a copy and take it into their GP Practice during March or April (World Health Day?), it might do a lot of good as it contains some very useful information. We are regularly told that "Lyme disease is not in this country" so this leaflet should dispel some myths in Primary Care.

PHE Leaflet for GPs states

- not everyone recalls a tick
- transmission can be within a day
- LB occurs across the country
- the rash may be absent
- the rash should be treated
- early tests may be negative

LDA is helping to produce an e-learning video for GPs together with the RCGP. This will be available in the summer from the RCGP website; we shall let you know when it goes live.

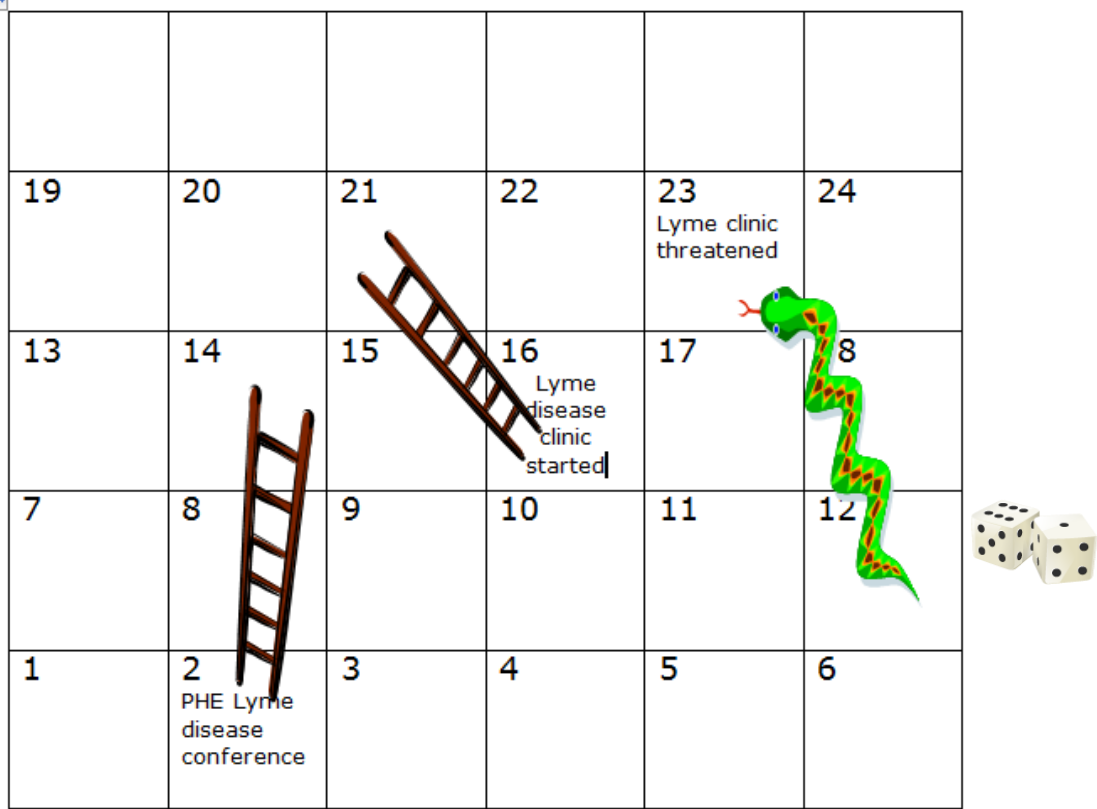
Where are we now?

Slightly further forward than this time last year, though the promise from the October PHE conference has not yet materialised into substantial action.

It is early days yet and we know that plans are shaping up to take forward the following actions agreed with Public Health England:

- Develop patient information for publication & distribution jointly between PHE, NHS Scotland & LDA.
- Review and rewrite PHE website and links in consultation with stakeholders.
- Establish a committee to write UK guidance on Lyme Disease according to NICE principles; produce initial draft of medical information for GPs.
- Work with LDA and others to support patient’s interests and assist with specific patient problems in accordance with evidence-based medical practice.
- RIPL and Raigmore Hospital LD testing service to work together on improving diagnostic tests and share best practice.
- Examine feasibility of enhanced reporting of cases of clinically diagnosed Lyme disease.
- Apply for research funding for clinical studies and laboratory testing in Lyme Disease.

We are still on this game board -



See our summary of the [position at the start of 2014](#) on the LDA website. We hope the next addition will be a ladder, not a snake.