

### Covid-19

We are thinking of you all, particularly those of you we know personally from our conferences and other meetings, and those we have corresponded with by email. We hope that your families, jobs and personal circumstances are not under too much strain.

This pandemic is going to continue having an impact for some considerable time: on everyone's personal lives, and also the work that LDA is engaged with.

### What have we been doing?

#### Sending out tick removers!

Some things haven't been changed by Covid-19 and May has brought its expected surge in tick activity and people needing tick removers.

Many people may have been confined to their gardens, but ticks neither discriminate nor self-isolate and where there is wildlife to feed on there will be ticks.



#### Not attending conferences!

Medical conferences, and associated exhibitions, have been cancelled, so this side of our work in raising awareness amongst health professionals has, for the moment, ground to a halt. Exhibitions are a lot of work and expensive, so in a way this is welcome. Conferences, however, are a forum for exchanging news and ideas, as well as learning, so this is less welcome.

We had been invited to give a talk to the **Society of Microbiologists** in early April but that was cancelled and is being re-scheduled for next year. Although they will then be including talks on Covid-19, there is still a request for a Lyme disease talk. So Lyme disease has not been completely displaced from everyone's agenda.

We had been planning **the next LDA Conference** for November 2020, but that will not be taking place. November may still not be a safe time for large scale meetings and potential speakers may well still be deeply involved in work on Covid-19. We shall see what the autumn and winter brings before planning further.

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## Specialist Clinic - development delayed

We were at the point of putting in a grant application for this, but we needed our NHS partners to sign up with us. As the deadline for the application was drawing near in March, we had to be realistic and understand that nobody had time to read emails from us, let alone to arrange meetings to discuss adding to their workload.

We shall pick this up when the health professionals have time to engage with us.

## What has happened in the UK recently?

### Covid-19 impact

Many UK organisations working in the health arena are re-organising their work to take account of COVID-19. UK Lyme disease research is carrying on to a certain extent, but many individual researchers are drawn into the more important work of supporting the NHS and the pandemic response. One researcher has told us:

*“University researchers are currently being encouraged to volunteer and utilise their appropriate skills in helping to understand and combat COVID-19. This includes:*

- clinical researchers going back to work in the NHS;*
- epidemiologists helping in PHE;*
- diagnostic researchers helping develop new tests and prognostic indicators;*
- social scientists understanding how the disease and its management will impact the whole of UK society.*

*Their regular research projects have not stopped, and they are working on them as and when time, lockdown and research facilities permit.”*

In due course some useful things for Lyme disease will come out of this. There may for example be new insights into patient engagement and virtual health consultations. Maybe even a better all-round understanding of the complexity of disease response.

There is already more public awareness of the uncertainties and difficulties surrounding testing for disease - current disease and past exposure. Politicians, Public Health England, scientists and doctors have all had their reactions to Covid-19 scrutinised and questioned widely.

On the public side, those on the fringes who have in the past claimed that Lyme disease is an epidemic, sometimes even “pandemic”, now have an appreciation of what an epidemic is really like.

Lyme disease is a very minor problem in the current context, but we may be able in the future to tackle its issues with a better balance all round.

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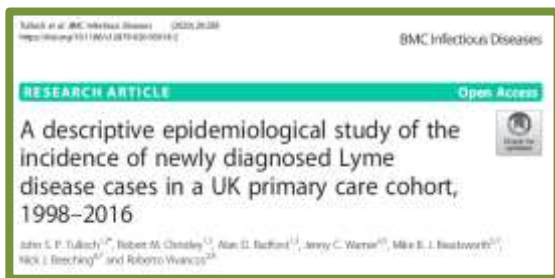
## Published UK Papers

There have been several papers recently reporting on studies trying to get a better handle on the number of people diagnosed with Lyme disease in the UK. We highlighted 3 of them in the last newsletter.

Accurate epidemiology is not as easy as it may first seem. GP Practices use a variety of computer systems, though the number of these has decreased over the last decades and there are now three main ones in use - EMIS, SystmOne and Vision. Each computer system records data in a different way which is what makes interrogating the data very difficult.

CPRD (Clinical Practice Research Datalink) and THIN (The Health Improvement Network) are two databases used by researchers which take anonymised data from VISION systems - this makes it possible to merge data because it is recorded in a consistent way. Researchers can use these databases to interrogate large amounts of Primary Care data. There is one drawback in that VISION is only used by about 9% of GP Practices more in London, the South of England, Greater Manchester and Birmingham rather than randomly spread across the country.

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Open access paper; just click on the image.

Over the years studied, figures from these 700 GP Practices show, on average, just over twice the number of positive test results with a primary care diagnosis logged on the computer system.

This paper reports on data from one of the merged databases - the THIN database covering over 700 GP Practices.

The research difficulties are described well - how do you know Lyme disease has been diagnosed? Codes are used by GPs, but you have to search for the right codes. And what if the GP has recorded an EM code, and a Lyme Arthritis code - is that one disease, a relapse or a second infection?

As we were finalising this newsletter, Caudwell LymeCo published on YouTube a [very good Q&A session](#) with Dr John Tulloch on this and other epidemiology papers.

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This one is about a really interesting Salford University study. The researchers wanted to investigate tick bite consultations. There is no unique code for “tick bite” on GP computer systems, so a questionnaire was used.

These were sent to GP Practices in high (Wiltshire), medium (Cumbria) and low (Wales) areas of Lyme borreliosis incidence to investigate tick bite consultations.

77 out of the 211 GP Practices contacted returned the questionnaire, which is quite good going given how busy they generally are. It is always possible that those who saw more tick bites were more inclined to complete a survey, and that again illustrates the difficulty in trying to get accurate data.



Practices surveyed in Cumbria reported more tick bite consultations than those in Wiltshire or Wales, despite Cumbria having fewer reported cases of Lyme disease than Wiltshire.

The study showed that GPs provided advice to patients but also that they wanted it themselves. NICE guideline published after the study was completed, may now have helped in this.

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All in all, recent UK studies - on both Primary Care and Hospital data - have shown that there have been many more diagnosed Lyme disease cases in the country than those officially reported in the laboratory confirmed figures, but we still really don't know how many.

**This does matter.** The National Institute for Health Research which provides funding for studies has told us that the first thing it needs to know is ***"how many people will benefit from proposed research?"***

These studies provide the first backup to the statement “more cases than reported” so may help in accessing whatever future funding is left from Covid-19 research.

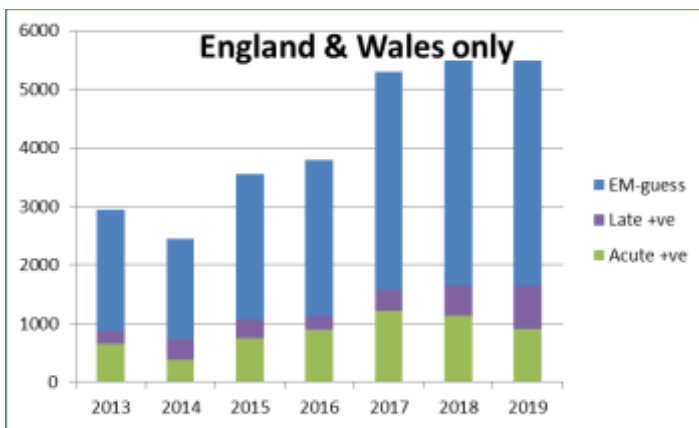
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## Laboratory confirmed cases 2019: late v acute A sideways look at figures

Statistics from England and Wales are more readily available, and more quickly published, than from Scotland and N Ireland. Public Health England have for some years now separated acute from late diagnosed cases. We don't know exactly by what criteria late is distinguished from acute - when we have another meeting with the reference lab at RIPL we shall find out.

Assuming "acute" is with relatively recent onset of symptoms (3-4 months perhaps?) we would be hoping to have a high percentage of people now being diagnosed in the early window when treatment is most effective. If we put a finger in the air and use the above Tulloch paper estimate of 2.35 times as many people diagnosed without a blood test as with, we get the chart below. Bear in mind that this is not *actual* EM - it is still a guess - and will not have been the same 2.35 times in all those years.



**You can see a significant band of people diagnosed late.**

At least they were, finally, diagnosed with Lyme disease and should have received appropriate treatment and a chance of recovery!

Of course, we don't know how many are still waiting for a diagnosis - we shall see some of those come out in the 2020 "late" group.

It is the late diagnosed who are likely to suffer the most and be the greatest call on the NHS. Follow up of these cases is something we intend to explore further:

- How long did it take to get a diagnosis?
  - How many recover completely?
    - What treatment did they have? Any repeats?
      - How long did they take to recover?
        - What proportion still have lingering symptoms?

We will follow up on figures from Scotland and N Ireland, where GP awareness, and therefore the overall picture, may differ.

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A recent editorial in the British Journal of General Practice highlights the difficulties of diagnosis and the possibilities of long-term problems if treatment is delayed.

Further resources to help GPs are listed, so this should help to raise awareness in Primary Care. Fewer cases diagnosed late in the future perhaps?



## What has happened elsewhere?

### Covid-19 impact is universal

**WHO** International Clinical Trials Registry Platform is closed because of heavy traffic generated by the Covid-19 outbreak. So we are not bringing you news of any Lyme disease trials.

We shall have an item on these in our next newsletter.

**International conferences for 2020** have been cancelled for this year.

**The NorthTick project** is probably more or less in limbo as researchers and healthcare professionals are inevitably occupied with the emergency in their countries.

We shall report on European and N American research in the next newsletter.

## What next for LDA?

We are continuing to send out tick removers and we are ready to send out our revised and re-printed leaflets when lockdown eases, as we expect a renewal of requests from parks, gardens and outdoor leisure facilities.

We expect a drop in income this year as large fundraising events, such as the London Marathon and Ride London, have been cancelled and fundraising is inevitably down as many people are rightly concentrating on helping the charities which are directly coping with the outfall from Covid-19.

Our financial reserves are robust and we have no fixed outgoings other than leaflet re-prints and regulatory ones (accounts auditing, insurance, data protection etc.), so we are thankfully able to sit this out, unlike many other charities.

At our last trustee meeting this month, via Cisco Webex, we decided to use what time we have (which for us volunteers is limited!) to re-assess our priorities and how we achieve our aims.

Please feel free to contact us via [other@LymeDiseaseAction.org.uk](mailto:other@LymeDiseaseAction.org.uk) with any thoughts, ideas or offers to participate in any way.

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## Access the past newsletters



You will find them in the ["What we are doing"](#) section, you can see all past newsletters, with an index of what's where.

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## **Lyme Disease Action** **Striving for the prevention and treatment** **of Lyme disease and associated tick-borne diseases**

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