

Patients changing the world view of Lyme disease

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Introduction and background

Lyme disease is an infectious disease transmitted in nearly all known cases by the bite of an infected tick. Occurring throughout temperate regions it is the most common vector-borne human infection in the UK¹. It has had a difficult recent history with controversy arising between groups in the USA; this now affects every country in Europe².

Recorded incidence in the UK is lower than mainland Europe. Very few doctors have experience of the disease, so there is heavy reliance on serology tests. In the early 2000s NHS expertise became vested in a single reference laboratory of the Health Protection Agency (HPA) which was responsible for confirmatory testing. The HPA maintained that Lyme disease was easy to diagnose and treat; patients however were finding the reality very different.

It became clear to a group of patients that reliable information on the disease was lacking, and a charity, Lyme Disease Action (LDA), was formed in 2003. LDA attempted to engage in dialogue with the Department of Health and the HPA to draw attention to peer reviewed literature which documented uncertainties in diagnosis and treatment.

In 2005 an "Ad Hoc International Lyme Disease Group" formed: its purpose apparently to promote the view that Lyme disease does not survive recommended courses of antibiotics. LDA's arguments were not accepted in the UK, partly because of the "patients are anti-science" portrayal put forward by the ad-hoc group in high impact scientific journals³ inevitably read, and trusted, by UK clinicians.

It was apparent through several years of lobbying that the Department of Health would not change its view despite LDA presenting logical arguments and evidence from peer reviewed literature. LDA decided that a different strategy was required, and a project with the James Lind Alliance (JLA) was initiated.

The JLA was established to provide an infrastructure and process for clinicians and patients to join in prioritising uncertainties for research. In using the JLA, LDA hoped that this rigorous process, carried out by an official organisation, would demonstrate that uncertainties did, in fact, exist, and would counter the confirmation bias which appeared to be widespread amongst health professionals.

Method

A steering group was formed to guide the project. The JLA assumes an equal number of clinicians and patients, so the first challenge was convincing clinicians that this was a worthwhile project. Two GPs expressed interest, one of whom had had Lyme disease, and an infectious diseases consultant was nominated by the British Infection Association (BIA). The HPA decided against participation.

An on-line survey was promoted through patient forums, LMCs, the BIA and the Association of British Neurologists. This survey asked people to contribute questions they would like answered by research.

Questions were sorted and merged, then an information specialist examined systematic reviews to find those questions which were true uncertainties requiring further research. A priority survey was launched to gather views on joint priorities: this generated a shortlist of 26.

The final steering group workshop deciding on the top 10 priorities was witnessed by the Department of Health, HPA, the Netherlands Health Council and a patient support group from the Netherlands.

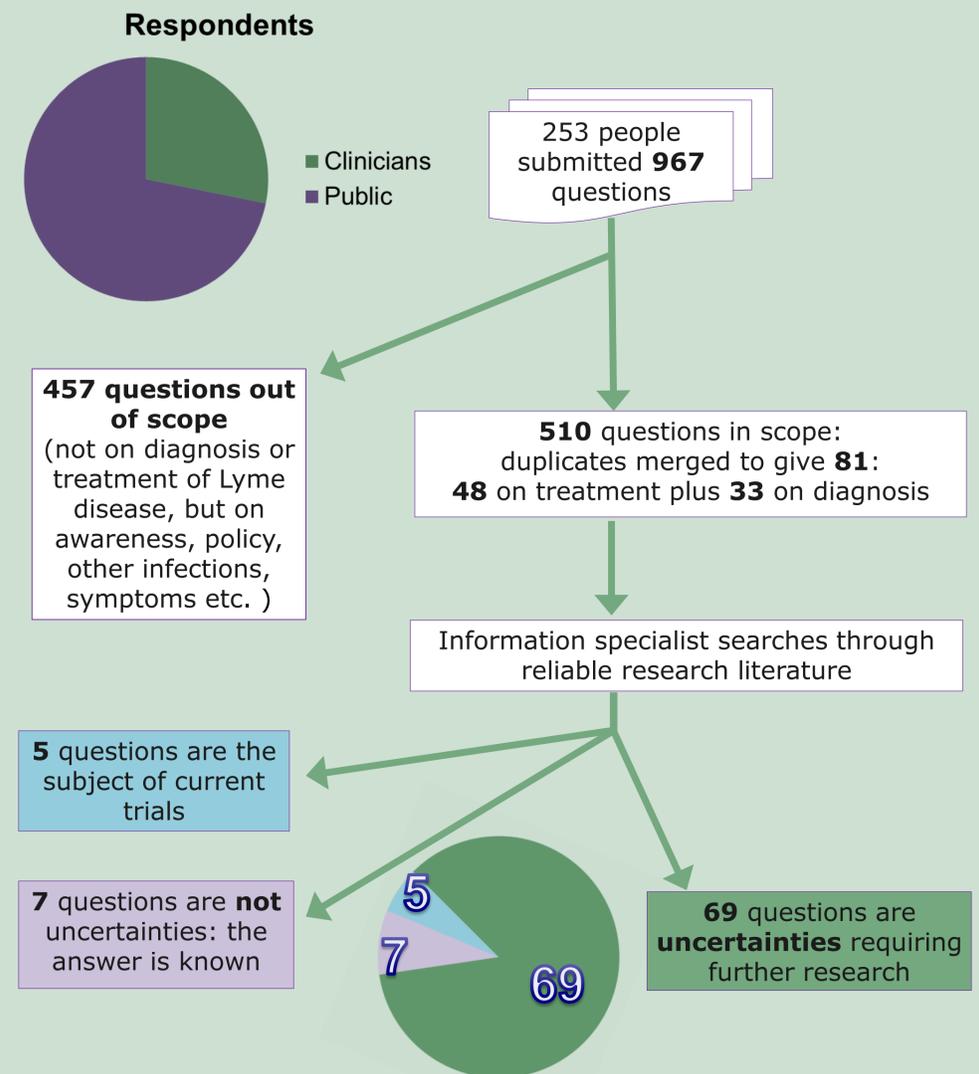
Acknowledgements

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Results



Diagnostic uncertainties include

- The best test for diagnosing or ruling out Lyme disease.
- Whether continuing symptoms following treatment are due to continued infection, or an immune response or other process.
- What key questions (clinical and epidemiological) should be considered to help make a diagnosis of Lyme disease in children and adults in the UK.

Treatment uncertainties include:

- The optimal agent, dose and duration of treatment for early disseminated disease, for late disease and for neuroborreliosis.
- Whether relapse & treatment failure is related to disease stage, gender, co-infections or any other factor.
- Intravenous versus oral antibiotic treatment.
- Effect of time from infection to start of treatment on outcome.

Conclusion

There are very significant uncertainties in the diagnosis and treatment of Lyme disease, and these uncertainties apply across Europe.

At the start of the project it was apparent that the Department, the BIA and other professional associations assumed that the process would educate patients⁴. The Chief Medical Officer had written in the CMO Update of Autumn 2009 "Those claiming to have 'chronic Lyme disease' or who believe it to be the cause of their chronic condition can be diagnosed definitively through using the HPA's tests."

Following completion of the project there is now acknowledgement in some quarters that uncertainties do exist. However, this knowledge has yet to filter down to treating clinicians.

References

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