

Vector-Borne Infection Research-Analysis-Strategy



Report of VIRAS Survey on Lyme Disease Testing Delay

January 2018

In January 2018, VIRAS conducted an online survey to investigate the reasons and extent of delays before people are tested for Lyme disease. The survey was publicised in Facebook support and campaign groups for Lyme patients and collected 330 responses.

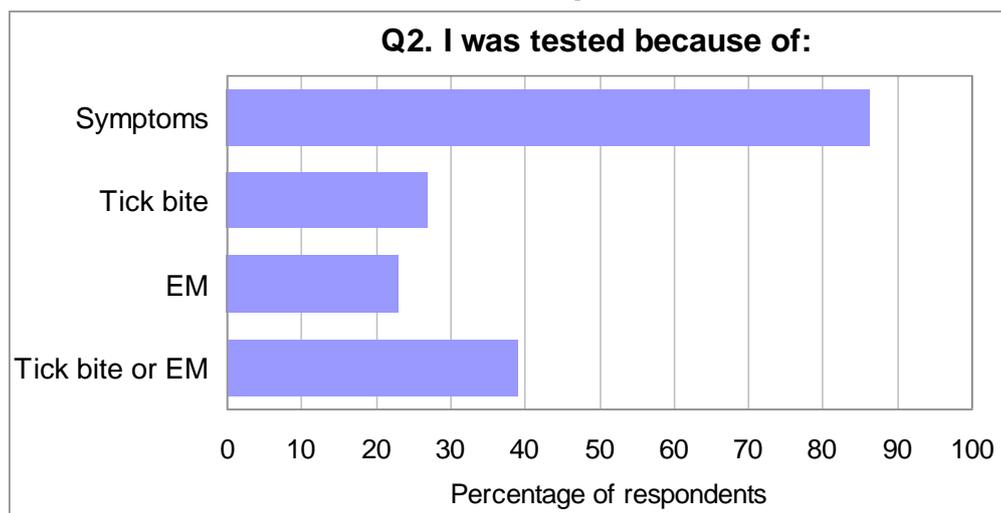
Key points from the survey

- 78% of respondents indicated that their test for Lyme disease was delayed because their doctor 'thought the symptoms were something else'
- 72% of respondents were not tested for Lyme disease within 6 months from the time of a 'bite', EM rash or symptoms. 63% waited more than one year.
- 39% of respondents had taken antibiotics before they were tested. This can invalidate negative test results as false-negative.
- There is a disturbing lack of knowledge amongst doctors which caused delays in 53% of respondents getting tested for Lyme disease. This even occurred when respondents had a tick bite and/or an EM rash.
- There is a lack of knowledge amongst the public about Lyme disease. This factor contributed to delayed testing for 44% of respondents.
- 35% of respondents indicated that their test was delayed because Lyme was thought to be rare or absent where they live. This misconception about the distribution of Lyme disease, will predictably leave patients either undiagnosed or misdiagnosed.

Q1. 88% of respondents are from Ireland, the USA or the UK.

| Q1. In what country do you live? | | | |
|----------------------------------|---|-------------|-----|
| Belgium | 1 | France | 2 |
| Czech Republic | 1 | Singapore | 2 |
| Egypt | 1 | Netherlands | 3 |
| Gabon | 1 | Australia | 5 |
| Germany | 1 | Finland | 6 |
| Italy | 1 | Canada | 11 |
| Spain | 1 | Ireland | 58 |
| Sweden | 1 | USA | 116 |
| United Arab Emirates | 1 | UK | 117 |

Q2. Reasons for getting tested for Lyme disease. Symptoms, known or suspected tick bite, EM rash or other suspicious 'insect' bite reaction.

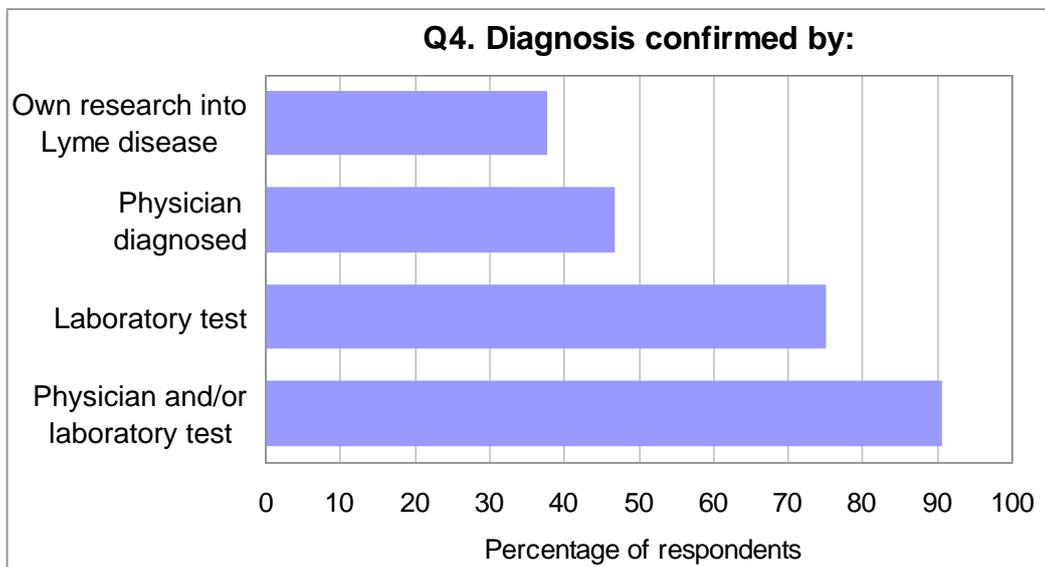


Q3. Antibiotics taken before testing.

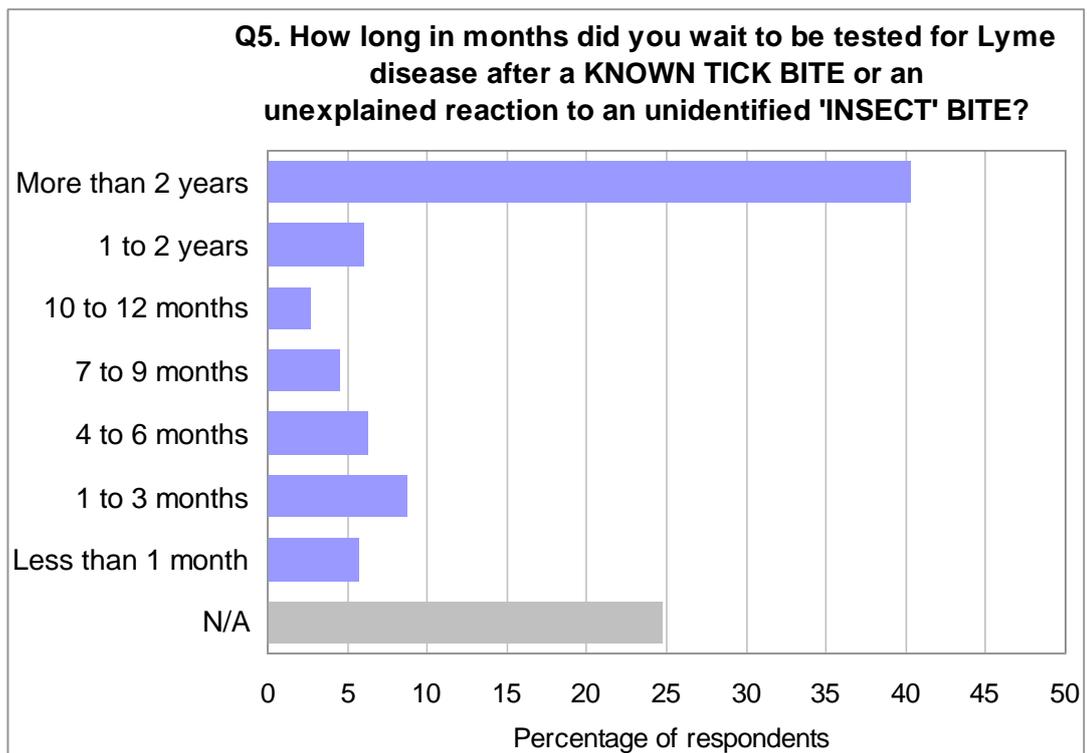
It is known that Lyme disease antibodies can be reduced by antibiotics resulting in false-negative test results. MAOI antidepressants have an [antibiotic effect](#). Fluconazole has action [against borrelia](#) and is an over-the-counter treatment for the common fungal infection, 'thrush'. Other non-antimicrobial medications have also shown [activity against borrelia](#).

| Q3. Did you take any antibiotics in the period between getting bitten or developing symptoms, and getting tested or retested? | |
|---|------------------|
| YES | NO |
| 127 (39%) | 201 (61%) |

Q4. The diagnosis was confirmed by a physician and/or laboratory tests for 91% of respondents.



Q5. Delay in testing after a known tick bite or reaction to an 'insect' bite.

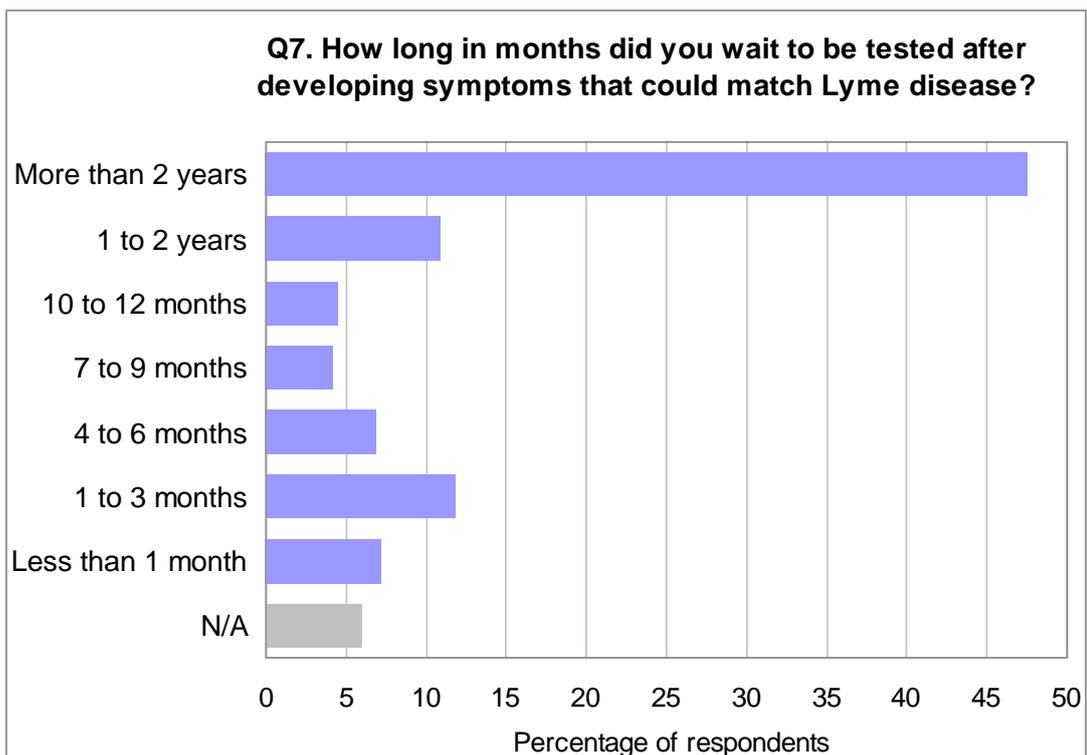


Q6. Delay in testing after an EM rash.

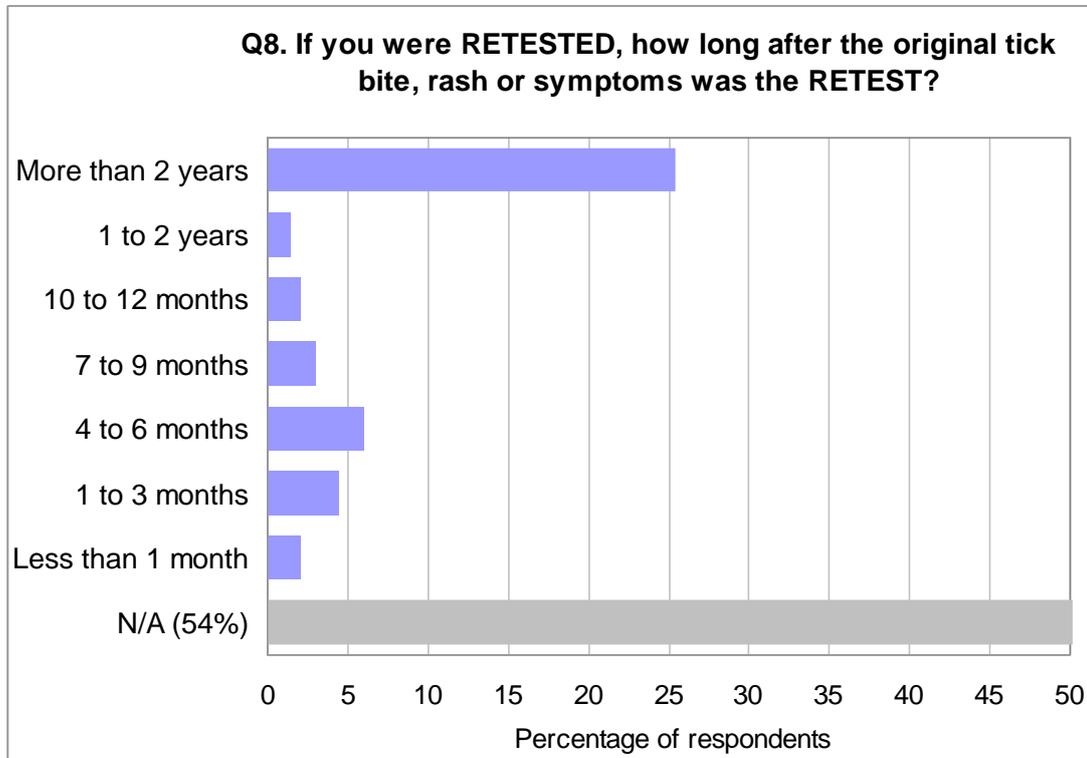
An EM rash occurs in [around 25%](#) of cases of Lyme disease. Exaggeration of the incidence of the rash has skewed awareness and probably contributed to only 52% of respondents replying 'not applicable' to this question, when a higher percentage should be expected.



Q7. The vast majority of respondents tested had symptoms. 59% of respondents were not tested within 1 year of developing symptoms.



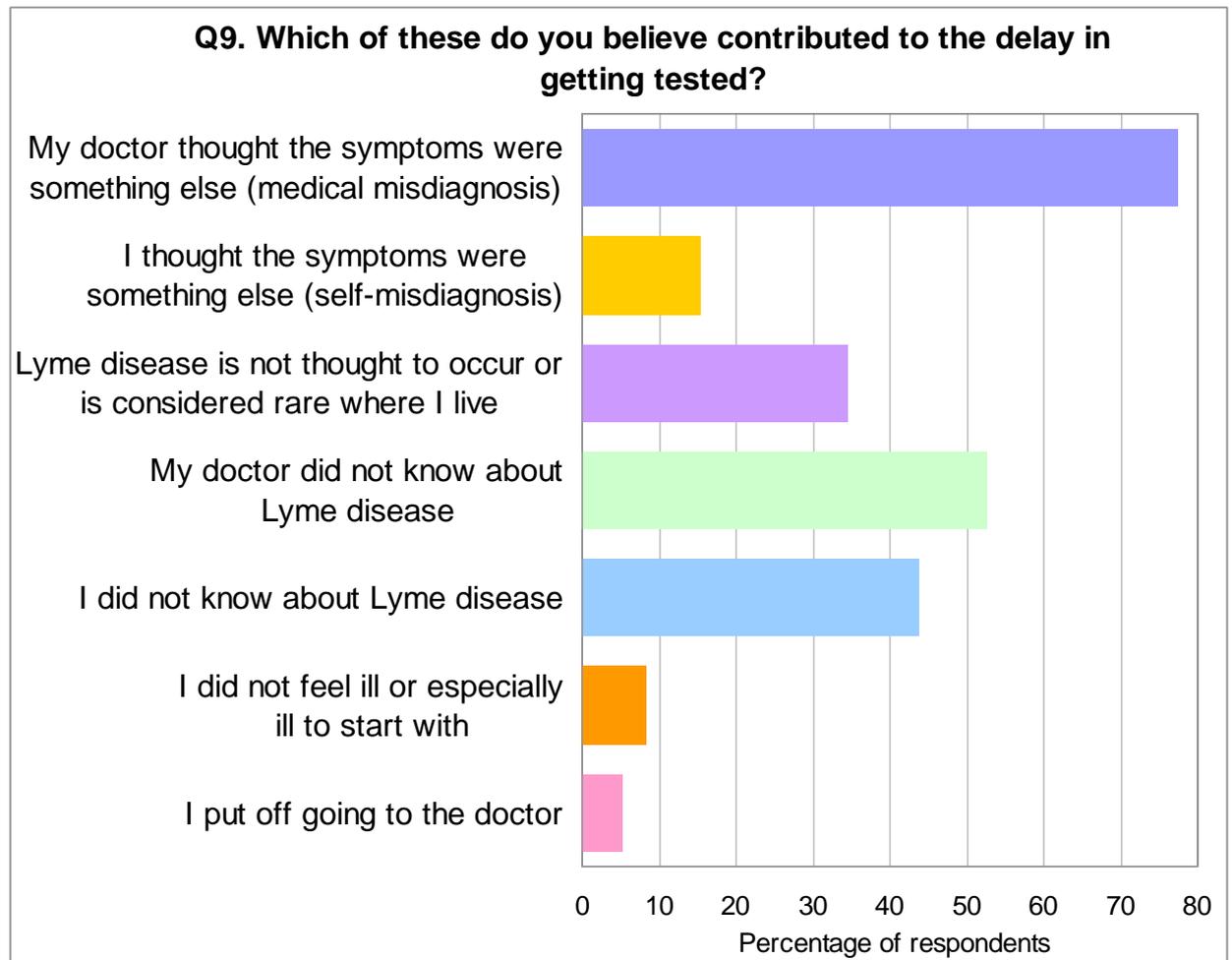
Q8. This was intended to collect retest data after an equivocal, or dubious negative test result. The question failed to make this clear which means that retesting after chronic or progressive symptoms is not differentiated.



Q9. 79% of respondents indicate that their doctor thought that their presenting symptoms were 'something else'. 54% say that their doctor did not know about Lyme disease. 28 respondents who had an EM rash and 37 who had a tick or other 'insect' bite, indicated that their GP's lack of knowledge about Lyme contributed to the delay in getting tested. These factors could be sufficient to explain why 38% of respondents chose to confirm their infection by their own research, whether or not they had a physician or laboratory confirmed infection.

45% of respondents did not know about Lyme disease and 35% indicated that Lyme disease is considered rare or absent where they live. Combined with the frequent lack of knowledge amongst doctors, these factors represent a serious risk to public health from delayed testing.

Only 16% of respondents thought that their symptoms were due to 'something else'. This calls into question the correctness of the oft repeated "flu-like symptoms" supposed to occur in some people during early infection. If this were accurate, then it is likely that many more respondents would have thought 'I have a cold or the flu', and this would have contributed to delays in getting tested. As only 9% of respondents indicated that they did not feel 'especially ill to start with', it may be concluded that early symptoms were significant and intrusive and they were not mistakenly considered to be 'flu-like' symptoms. A better and more accurate description of early symptoms is required to avoid misleading patients.



Discussion

The survey provides important information about the frequency and extent of delays in testing for Lyme disease. It shows that delayed testing for respondents was a common occurrence, frequently running into many months or years.

Among respondents comments were indications that some did not have insurance coverage or were refused a test by their GP and could not afford a private test. Cost factors might not only add to delays in getting tested, but could prevent testing altogether. They might also obstruct patients and/or doctors from ordering more sophisticated and expensive tests, which might nevertheless be more suitable tests for a patient's infection.

212 respondents provided informative comments with their survey and analysis and examples of these will be published in a separate document.

If testing is delayed and as a result, diagnosis and treatment are delayed, a Lyme infection can progress and cause serious injury. A delayed diagnosis of Lyme disease can result in the infection becoming more difficult to treat. Due to its

ability to [suppress the immune-system](#), a long-standing Lyme infection can also become impossible to detect with standard antibody tests.

Large numbers of respondent's laboratory tests were delayed by over one year. In their experiment using infected monkeys, [Embers et al](#) showed that by this stage, the antibodies detected by a common screening-test (first-tier of a two-tier test), which relies on the C6 peptide of VISE, could have sensitivity as low as 20%. This could mean 8 out of 10 these delayed tests returning false-negative results, obstructing diagnosis and preventing proper treatment for the infection.

Some of these matters are the responsibility of public health authorities appointed with the task of protecting their nation's health. In view of the excessive delays in testing many respondents, it can be concluded that the lack of knowledge about Lyme disease prevalent amongst doctors, is similarly common within these institutions.

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