




1. I have read the information provided about the survey and give consent for my answers to be used for the stated purposes

		Response Percent	Response Count
Yes		100.0%	152
No		0.0%	0
answered question			152
skipped question			0



2. Eligibility to complete survey. I am:

		Response Percent	Response Count
A person diagnosed with a tick-borne infection/Lyme disease living in the UK or Ireland		96.1%	146
A person diagnosed with a tick-borne infection/Lyme disease (TBI) living abroad but who was in the UK/Ireland during infection and diagnosis or treatment for a TBI		3.9%	6
I have not been infected and diagnosed with a TBI in the UK/Ireland		0.0%	0
answered question			152
skipped question			0











3. Your age in years

	<5 years	5-15	16-25	26-35	36-45	46-55	56-65	65+	Response Count
Age at onset of illness	1.3% (2)	4.6% (7)	12.5% (19)	21.7% (33)	25.0% (38)	21.7% (33)	11.2% (17)	2.0% (3)	152
Age now	0.0% (0)	0.7% (1)	3.9% (6)	11.2% (17)	27.0% (41)	23.7% (36)	26.3% (40)	7.2% (11)	152
answered question									152
skipped question									0










4. Your gender

		Response Percent	Response Count
Male		32.9%	48
Female		67.1%	98
answered question			146
skipped question			6

5. Where have you been bitten?

		Response Percent	Response Count
England		44.7%	68
Scotland		25.0%	38
Wales		3.3%	5
Northern Ireland		1.3%	2
Republic of Ireland		5.9%	9
Channel Islands		0.7%	1
Other European country		9.9%	15
Outside Europe (NOT North America)		3.3%	5
North America		5.9%	9
Don't know		13.2%	20
answered question			152
skipped question			0





6. Where do you live now?

		Response Percent	Response Count
England		69.1%	105
Scotland		14.5%	22
Wales		2.6%	4
Northern Ireland		2.0%	3
Republic of Ireland		6.6%	10
Channel Islands		1.3%	2
Other European country		1.3%	2
Outside Europe (NOT North America)		2.0%	3
North America		0.7%	1
answered question			152
skipped question			0

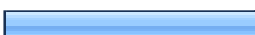
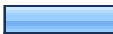


7. In what year did you first become ill with a tick-borne infection related illness?

	Response Count
	128
answered question	128
skipped question	24




8. Do you remember the tick bite which caused your illness?

		Response Percent	Response Count
Yes		48.0%	73
No		38.8%	59
Not sure		9.2%	14
Other (eg. other mode of transmission)		3.9%	6
answered question			152
skipped question			0





9. Did you have a 'bull's eye' or other rash near the time of being bitten?

		Response Percent	Response Count
Yes, distinctly circular rash		40.1%	61
Yes, not circular		17.1%	26
No		29.6%	45
Not sure		13.2%	20
answered question			152
skipped question			0

10. If 'yes', did you show or mention this to your GP or doctor?

		Response Percent	Response Count
Yes		67.3%	72
No		24.3%	26
Not sure/ Can't remember		8.4%	9
answered question			107
skipped question			45

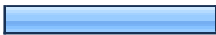



11. From whom did you get your *initial* diagnosis of Lyme/TBI?

		Response Percent	Response Count
GP		30.9%	47
Consultant, NHS (HSE in Eire)-free advice only		19.1%	29
Private doctor/ consultant - include NHS doctors providing private care		48.7%	74
Other healthcare professional (e.g. physiotherapist, psychologist)		1.3%	2
Other (e.g. alternative practitioner)		0.0%	0
Self-diagnosis - no diagnosis by a professional of any kind		0.0%	0
answered question			152
skipped question			0

12. Which of the following tick-borne infections have you been diagnosed with (by any doctor) and on what basis?

	Clinical symptoms/ medical history	Test results (NHS)	Private tests for infection	Exposure to ticks	Not known/ not sure	Response Count
Lyme Borreliosis	75.0% (111)	33.8% (50)	46.6% (69)	38.5% (57)	3.4% (5)	148
Bartonella Henselae	22.0% (9)	9.8% (4)	36.6% (15)	12.2% (5)	43.9% (18)	41
Bartonella Quintana	25.8% (8)	0.0% (0)	22.6% (7)	6.5% (2)	64.5% (20)	31
Erlichia	19.4% (6)	3.2% (1)	35.5% (11)	9.7% (3)	58.1% (18)	31
Mycoplasma	12.0% (3)	0.0% (0)	16.0% (4)	0.0% (0)	80.0% (20)	25
Babesia	38.5% (15)	5.1% (2)	33.3% (13)	17.9% (7)	41.0% (16)	39
Other	30.3% (10)	9.1% (3)	21.2% (7)	9.1% (3)	51.5% (17)	33
answered question						152
skipped question						0



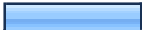



13. Were you positive for Lyme disease on any type of NHS (HSE in Eire) test at any point during your illness?

		Response Percent	Response Count
Yes, positive result		33.6%	51
No, negative result		43.4%	66
Not tested on NHS/HSE		17.8%	27
Don't know		5.3%	8
answered question			152
skipped question			0




14. Which other infections were you tested for by the NHS (or HSE)

	Tested	Not tested	Don't know	Response Count
Bartonella Henselae	5.9% (9)	56.6% (86)	37.5% (57)	152
Bartonella Quintana	3.3% (5)	56.6% (86)	40.1% (61)	152
Ehrlichia	5.3% (8)	56.6% (86)	38.2% (58)	152
Mycoplasma	1.3% (2)	59.9% (91)	38.8% (59)	152
Babesia	6.0% (9)	55.6% (84)	38.4% (58)	151
Q-fever	5.3% (8)	57.2% (87)	37.5% (57)	152
Other	11.4% (16)	46.4% (65)	42.1% (59)	140
answered question				152
skipped question				0

15. Were you given the 'standard' treatment of one month's antibiotics for Lyme disease when initially diagnosed (for ALL patients, however diagnosed)?

		Response Percent	Response Count
Yes		26.8%	40
No, less than one month initially		31.5%	47
No, more than one month initially		21.5%	32
No, not offered treatment with antibiotics		14.8%	22
No, refused treatment with antibiotics		4.7%	7
Don't know		0.7%	1
answered question			149
skipped question			3

16. If you were given more than 1 month of antibiotics for an initial treatment course, how long was this for?

		Response Average	Response Total	Response Count
Weeks		4.33	65	15
Months		6.15	166	27
Years		2.33	28	12
			answered question	52
			skipped question	100

17. Did you experience a relapse of your Lyme symptoms after your initial antibiotic treatment came to an end (regardless of duration of initial treatment)?

		Response Percent	Response Count	
No, condition totally resolved (cured)		17.8%	27	
No, condition stabilised (ongoing symptoms remained the same)		17.1%	26	
Yes, symptoms got worse a few weeks or months after finishing treatment		40.1%	61	
Don't know		9.2%	14	
Wasn't treated		15.8%	24	
			answered question	152
			skipped question	0


















18. For how long - in total - have you had an illness caused by a tick-borne infection?

	Response Average	Response Total	Response Count
Years	10.88	1,305	120
Months	4.43	381	86
answered question			145
skipped question			7





19. How long ago were you first diagnosed with a tick-borne infection related illness?

	Response Average	Response Total	Response Count
Years	70.23	8,568	122
Months	4.67	378	81
answered question			145
skipped question			7

20. If you experienced a delay in being diagnosed or treated, what were the reasons for this? (tick all that apply)

		Response Percent	Response Count
No delay/not relevant		9.1%	13
Did not realise I had been bitten		28.0%	40
Did not visit doctor immediately		17.5%	25
Misdiagnosed		63.6%	91
Symptoms not specific to Lyme/TBI		20.3%	29
Symptoms took a long time to develop		22.4%	32
Other tests and investigations took time		20.3%	29
Did not know about Lyme/TBI, did not recognise symptoms		49.0%	70
Exposure to ticks was routine and non-remarkable		9.1%	13
Did not receive timely testing		25.2%	36
Symptoms were ignored		40.6%	58
Referred to wrong specialist		25.9%	37
Slow waiting time for NHS referral		4.2%	6
Negative test results initially		30.8%	44
Complex symptoms not classic for TBI's		9.1%	13
Other		7.7%	11
Don't know/ not sure		2.1%	3
answered question			143
skipped question			9

21. Where were you tested for Lyme infection by the NHS/HSE?

		Response Percent	Response Count
England, Wales, Northern Ireland		63.9%	92
Scotland		12.5%	18
Republic of Ireland		6.3%	9
Not tested on the NHS		17.4%	25
answered question			144
skipped question			8

22. NHS testing in England, Wales and Northern Ireland

	Not tested	Potitive result	Equivocal result	Negative result	Don't know	Response Count
NHS UK ELSIA (Local lab, 1st stage)	1.2% (1)	18.5% (15)	8.6% (7)	49.4% (40)	22.2% (18)	81
NHS UK Western Blot (Southampton, 2nd stage ELISA)	12.5% (9)	27.8% (20)	4.2% (3)	33.3% (24)	22.2% (16)	72
Other test from Southampton lab (please specify)						9
answered question						90
skipped question						62

23. NHS testing in Scotland

	Not tested	Positive result	Equivocal result	Negative result	Don't know	Response Count
Health Protection Scotland ELISA (Inverness lab, 1st stage)	13.3% (2)	33.3% (5)	13.3% (2)	26.7% (4)	13.3% (2)	15
Health Protection Scotland ELISA (other lab, 2nd stage)	38.5% (5)	23.1% (3)	0.0% (0)	0.0% (0)	38.5% (5)	13
Other type of test - Scotland HPS lab	30.8% (4)	15.4% (2)	0.0% (0)	15.4% (2)	38.5% (5)	13
Other test in Scotland (please specify)						3
answered question						17
skipped question						135

24. NHS or HSE testing in Republic of Ireland

	Not tested	Positive result	Equivocal result	Negative result	Don't know	Response Count
HSE Ireland ELISA (1st stage)	0.0% (0)	50.0% (4)	37.5% (3)	12.5% (1)	0.0% (0)	8
NHS UK Western Blot (2nd stage ELISA)	20.0% (1)	0.0% (0)	60.0% (3)	0.0% (0)	20.0% (1)	5
Other lab or test in Ireland (please specify)						1
answered question						8
skipped question						144

25. Have you had Lyme/Borrelia tests done by private labs outside the UK (this includes tests taken in the UK and send to a lab abroad)?

		Response Percent	Response Count
Yes, Igenex lab		33.6%	48
Yes, other lab		18.2%	26
No		48.3%	69
answered question			143
skipped question			9

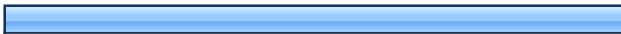
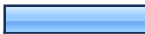

26. Igenex lab

	Result positive CDC	Result positive Igenex	Result Equivocal	Result Negative CDC	Result NEgative Igenex	Response Count
Igenex America	17.6% (6)	41.2% (14)	14.7% (5)	14.7% (5)	11.8% (4)	34
IgM	14.6% (6)	46.3% (19)	12.2% (5)	7.3% (3)	19.5% (8)	41
IgG	2.7% (1)	37.8% (14)	24.3% (9)	10.8% (4)	24.3% (9)	37
answered question						44
skipped question						108

27. Other lab abroad

	Result positive	Result Equivocal	Result Negative	Response Count
Melisa - Bremen, Germany (e.g. LTT test)	52.2% (12)	34.8% (8)	13.0% (3)	23
BCA - Augsburg, Germany (e.g. Elispot test)	100.0% (12)	0.0% (0)	0.0% (0)	12
answered question				28
skipped question				124


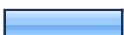





28. If you have had any other types of test done in labs abroad, please specify country, lab and type of test and result (e.g. America, Western Blot, PCR joint fluid, equivocal)

		Response Percent	Response Count
1		100.0%	40
2		22.5%	9
3		15.0%	6
answered question			40
skipped question			112

29. What other diagnoses, were you given over time (other than a tick-borne infection)?

	Tick all that apply	Response Count
None	100.0% (33)	33
M.E.	100.0% (41)	41
Chronic fatigue syndrome	100.0% (59)	59
Fibromyalgia	100.0% (29)	29
Multiple sclerosis	100.0% (6)	6
Depression/psychiatric illness	100.0% (42)	42
Anxiety/stress	100.0% (42)	42
Viral infection/post viral syndrome	100.0% (45)	45
Parkinson's disease	0.0% (0)	0
Functional disorder	100.0% (5)	5
Don't know	100.0% (5)	5
	Other (please specify)	45
answered question		123
skipped question		29


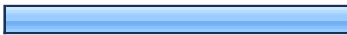

30. What type of places were you in when you were exposed to tick(s) that caused your illness (tick all that apply)?

		Response Percent	Response Count
Don't know/not sure of bite/no knowledge of bite		23.4%	33
Garden		18.4%	26
Allotment		3.5%	5
Park		7.8%	11
Campsite/picnic area/outdoor leisure site		12.8%	18
Wild space e.g forest, national park, moorland		59.6%	84
Farmland		19.9%	28
	Other (please specify)		30




answered question 141

skipped question 11





31. Around the time you first became ill were you being bitten by ticks regularly?

		Response Percent	Response Count
Yes		19.1%	27
No		55.3%	78
Not sure/Don't know		25.5%	36
	answered question		141
	skipped question		11




32. Are you being bitten regularly by ticks nowadays?

		Response Percent	Response Count
Yes		15.6%	22
No		78.0%	110
Not sure/Don't know		6.4%	9
answered question			141
skipped question			11









33. If 'Yes' please indicate why this is (tick all that apply). Because of...

		Response Percent	Response Count
Where you live, e.g. near fields or large garden		36.4%	12
Work, i.e. occupational exposure		36.4%	12
Engaging in leisure or other outdoor pursuits, e.g. hiking, festivals, etc		60.6%	20
Exposure to pets or animals		33.3%	11
Other (please specify)			11
answered question			33
skipped question			119



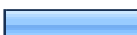

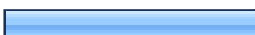





34. Have you ever made a formal complaint of any kind, related to how your health problems have been dealt with by the NHS?

		Response Percent	Response Count
Not relevant, happy with treatment		12.8%	18
Yes, about my own case or NHS policy in general		21.3%	30
No		66.0%	93
answered question			141
skipped question			11





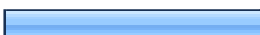


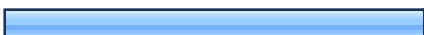
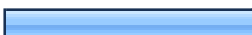
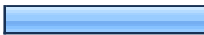
35. If 'Yes' who did you make your complaint to? (tick any that apply)

		Response Percent	Response Count
Didn't make complaint/not relevant		0.0%	0
Local hospital		46.4%	13
PCT (Primary Care Trust)		35.7%	10
Department of Health (DoH)		14.3%	4
Health Protection Agency (HPA) or Irish HPSC		21.4%	6
Southampton (reference) laboratory		10.7%	3
Other reference laboratory		0.0%	0
MP (or Irish TD)		50.0%	14
GP/local health clinic or practice		17.9%	5
UK or Irish Ombudsman		7.1%	2
Other (please specify)			5
answered question			28
skipped question			124

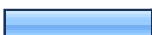
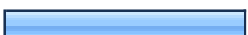


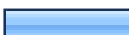
36. If 'No', what was your reason for not making a complaint? (tick all that apply)

		Response Percent	Response Count
Didn't want to complain/not relevant		22.6%	19
Too ill		50.0%	42
Didn't know how to		21.4%	18
Afraid of consequences		33.3%	28
Believe there is no point, system unchangeable		40.5%	34
Told there was no point, e.g. by lawyer or advisor		2.4%	2
Didn't have enough information or evidence		22.6%	19
Would rather just pay for treatment		23.8%	20
Don't understand the policy or system sufficiently		20.2%	17
Complaints system too difficult/complicated		21.4%	18
	Other (please specify)		19
answered question			84
skipped question			68

37. Do you have any ongoing complications caused by your infection(s)? (tick all that apply)

		Response Percent	Response Count
No		11.6%	16
Don't know		11.6%	16
Rheumatological, i.e. joint pain/inflammation		50.0%	69
Neurological (e.g. nerve function, numbness, co-ordination, inflammation, etc)		65.9%	91
Immunological (mal-functioning immune system)		41.3%	57
Psychological/psychiatric (e.g. depression, anxiety, mental distress, etc)		39.9%	55
Dermatological (skin problems e.g. tingling, pain)		38.4%	53
Chronic fatigue (e.g. memory, cognitive function, brain fog, word processing)		67.4%	93
Gastric/bowel/digestion		39.9%	55
Eye or sight problems		31.9%	44
	Other (please specify)		44
answered question			138
skipped question			14

38. Have you had access to any antibiotics as a therapy for a chronic condition (i.e. an illness that lasted more than a year)?

		Response Percent	Response Count
Yes, NHS		23.6%	33
Yes, private healthcare source		38.6%	54
No, don't want antibiotics		3.6%	5
No, not been offered or had access to them		14.3%	20
Not relevant (treatment complete or other treatment required)		20.0%	28
answered question			140
skipped question			12

39. If 'Yes', on relecting back, how much improvement have you had from antibiotics? (Thin impact of the course of treatment within two months of when it finished. This would include and combination therapy. Do not include relapses that occurred more than several months impact of treatment is ongoing, think about how you felt in general 'looking back'.)

	Very much worse	Much Worse	A little worse	No change	A little better	Much Better	Very Much better	N/A /didn't have this treatment	Ra Ave
Short term oral antibiotics (1 week to 1 month)	9.5% (6)	9.5% (6)	9.5% (6)	20.6% (13)	17.5% (11)	6.3% (4)	12.7% (8)	14.3% (9)	
Medium term oral antibiotics (1 month to 6 months)	1.9% (1)	3.7% (2)	5.6% (3)	18.5% (10)	37.0% (20)	16.7% (9)	3.7% (2)	13.0% (7)	
Long term oral antibiotics (6 months or more)	1.4% (1)	0.0% (0)	1.4% (1)	5.5% (4)	24.7% (18)	23.3% (17)	30.1% (22)	13.7% (10)	
Intravenous (IV) antibiotics (any length of time)	0.0% (0)	0.0% (0)	7.7% (4)	7.7% (4)	9.6% (5)	13.5% (7)	11.5% (6)	50.0% (26)	
Any other kind of antibiotic treatment (e'g' penicillin, IM injections)	0.0% (0)	0.0% (0)	2.3% (1)	0.0% (0)	4.5% (2)	18.2% (8)	4.5% (2)	70.5% (31)	

Other type of treatment (please specify treatment and level of improvement)

answered ques

skipped ques

40. How do you feel about the care you received?

	Completely adequate	Mostly adequate	Sometimes adequate	Neutral	Sometimes inadequate	Mostly inadequate	C ir
NHS/free care	14.7% (20)	11.8% (16)	3.7% (5)	1.5% (2)	10.3% (14)	18.4% (25)	3
Private care (including NHS doctors providing private/paid care)	23.4% (25)	30.8% (33)	10.3% (11)	5.6% (6)	6.5% (7)	4.7% (5)	





41. Was your treatment 'appropriate' (for your clinical history or diagnosis)?

	Completely appropriate	Somewhat appropriate	Neutral	Somewhat inappropriate	Completely inappropriate	N/A, could not have treatment or not sure
NHS treatment	16.9% (23)	16.2% (22)	6.6% (9)	12.5% (17)	40.4% (55)	7.4% (10)
Private treatment	53.9% (55)	17.6% (18)	9.8% (10)	3.9% (4)	2.9% (3)	11.8% (12)
						answered question
						skipped question



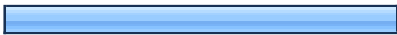

42. Was your treatment 'relevant' (to your symptoms)?

	Completely relevant	Somewhat relevant	Neutral	Somewhat irrelevant	Completely irrelevant	N/A, did not have treatment, not sure
NHS treatment	20.4% (28)	18.2% (25)	5.8% (8)	19.7% (27)	29.2% (40)	6.6% (9)
Private/paid for	61.6% (61)	17.2% (17)	4.0% (4)	5.1% (5)	2.0% (2)	10.1% (10)
						answered question
						skipped question


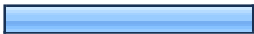
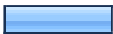

43. Do you feel your GP was informed about infections from ticks when you became ill?

		Response Percent	Response Count
Yes, fully informed		14.2%	20
Yes, partially informed		19.9%	28
No		61.7%	87
Don't know		4.3%	6
		answered question	141
		skipped question	11






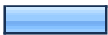

44. Do you or did you feel that the main consultants from the NHS (or Irish HSE) involved in your care were equipped to deal with your health problems?

		Response Percent	Response Count
Yes, fully equipped		8.5%	12
Yes, partially equipped		14.2%	20
No		63.1%	89
Don't know		0.0%	0
Not applicable/didn't see a consultant		14.2%	20
answered question			141
skipped question			11


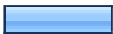


45. Were you able, if you needed it, to access private medical treatment for your condition? (Please do not include herbal or other types of treatment from professionals that are not medical doctors)

		Response Percent	Response Count
Yes, all the treatment I needed		20.6%	29
Yes, some		39.7%	56
No, did not need private treatment		17.0%	24
No, none		22.7%	32
answered question			141
skipped question			11

46. Who else in your community, that you know of, has had a tick-borne infection?

		Response Percent	Response Count
None that I know of		33.1%	45
Family members		15.4%	21
Local friends and neighbours		29.4%	40
People in my activity group (e.g. hill walking)		10.3%	14
People at my workplace		17.6%	24
People at my GP surgery/health clinic		16.2%	22
Other		19.9%	27
answered question			136
skipped question			16

47. Do you feel that you were adequately informed about the risks of infections from ticks around the time that you became ill?

		Response Percent	Response Count
Yes, fully informed		11.0%	15
Partially informed/limited information		16.9%	23
No information at all		70.6%	96
Not sure/don't remember		1.5%	2
answered question			136
skipped question			16

48. If you would like to contribute further by providing more detail about your case for follow-up research, or if you would like a research summary sent to you, please enter your email address into the textbox provided. Full confidentiality and process of informed consent is guaranteed.

**Response
Count**

96

answered question 96

skipped question 56

49. If you wish to, use this textbox to tell us about your experience of the testing process for Lyme. Try to include the overall impact it has had on your experience of care.

**Response
Count**

90

answered question 90

skipped question 62

50. Use this textbox if there any other comments you wish to make about your experience of being diagnosed and treated, both good and bad experiences.

**Response
Count**

96

answered question 96

skipped question 56