



## **Lyme Disease Priority Setting Partnership**

### **Survey Report**

Prepared by Katherine Cowan

#### **Introduction**

This report presents a final analysis of the James Lind Alliance (JLA) Lyme Disease Priority Setting Partnership (PSP) survey findings. It describes the background to the survey, the methodology and the profile of the respondents. While it presents an overview of the number of raw treatment uncertainties submitted to the survey, it does not attempt to analyse the uncertainties themselves. This work is being carried out by an independent Information Specialist.

#### **About the survey**

The Lyme Disease PSP was established to identify what patients, carers and clinicians believe are the most important research questions for the diagnosis and treatment of Lyme disease. In order to do this, a survey was designed to gather their uncertainties about the diagnosis and treatment of Lyme disease. The method was based on a surveying approach used previously by the JLA, and the questions tailored by the Lyme Disease PSP Steering Group with input from Katherine Cowan, an independent consultant with experience of developing surveys for the JLA. The survey was designed to be carried out online, using the Survey Monkey tool, with email and paper versions made accessible too.

#### **Dissemination**

The survey was launched on 12 August 2011 and remained online until 3 November 2011. It was linked via a dedicated page on the Lyme Disease Action (LDA) website ([www.lymediseaseaction.org.uk/JLA](http://www.lymediseaseaction.org.uk/JLA)), which provided further information on the PSP and the survey. A snowballing technique was used to promote the survey. Primary dissemination methods included: announcements to the LDA mailing list, messages in the JLA newsletter and on the JLA Twitter feed, publicity via Local Medical Committees and targeted emails from Steering Group members to their colleagues and professional networks. The survey was managed by Katherine Cowan, who provided weekly updates on the profile of respondents to the Steering Group. This enabled further targeted dissemination where particular groups appeared to be under-represented.

## SURVEY FINDINGS

A total of 253 respondents completed the survey. Between them, they submitted 810 raw uncertainties. These will subsequently be checked to identify which are genuine uncertainties, and which have already been answered by research.

The largest single category of respondents (57.9 per cent) was adults aged over 18 who have or have had Lyme disease. Over a fifth (20.7 per cent) were clinicians working in primary care, while one in ten (10 per cent) were the carer or relative of an adult who has or has had Lyme disease.

Figure 1 sets out the full scope of respondents – more than one box could be ticked, so totals do not add up to 100 per cent.

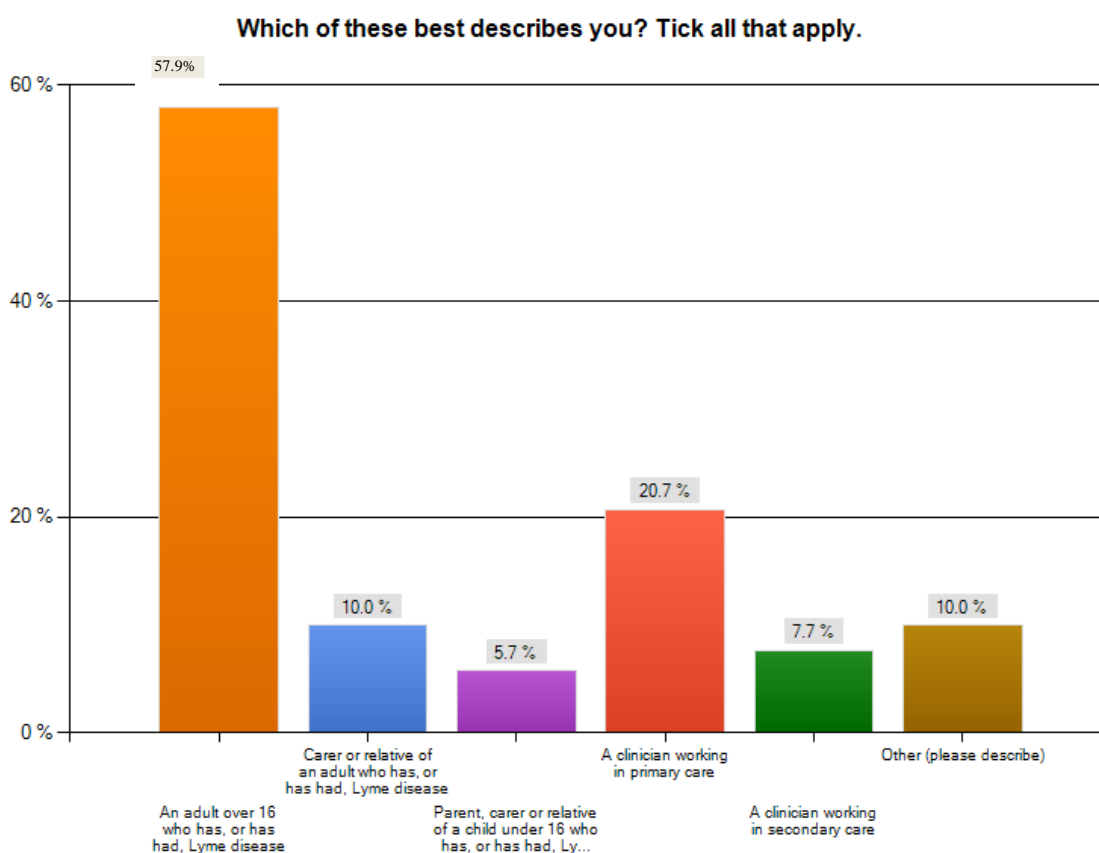


Figure 1: respondent types

Those in the 'Other' category included retired clinicians, medical students, friends of people with ME or Lyme disease, other interested professionals and trainees, and people who suspect they have Lyme disease but have not been officially diagnosed.

## Profile of clinician respondents

The majority of clinician respondents (93.3 per cent) confirmed that they are working in the UK. Almost two thirds (59.8 per cent) identified themselves as GPs, while the next largest category (12.2 per cent) worked in infectious diseases. A small minority (2.4 per cent) worked in neurology and the same proportion worked in mental health. Almost a quarter (23.2 per cent) ticked 'Other', going on to describe themselves variously as nutritionists, A&E practitioners, ecologists, medical students, acute medicine practitioners, environmental medicine experts and members of Chronic Fatigue Syndrome/ME teams. The majority (82.2 per cent) worked in both adult and paediatric settings, while 13.7 per cent worked purely in an adult setting.

Figure 2 describes the number of cases of Lyme disease the clinician respondents reported seeing annually. Over two thirds (67.1 per cent) see fewer than five cases per year. Almost one in 10 (9.8 per cent) were unsure.

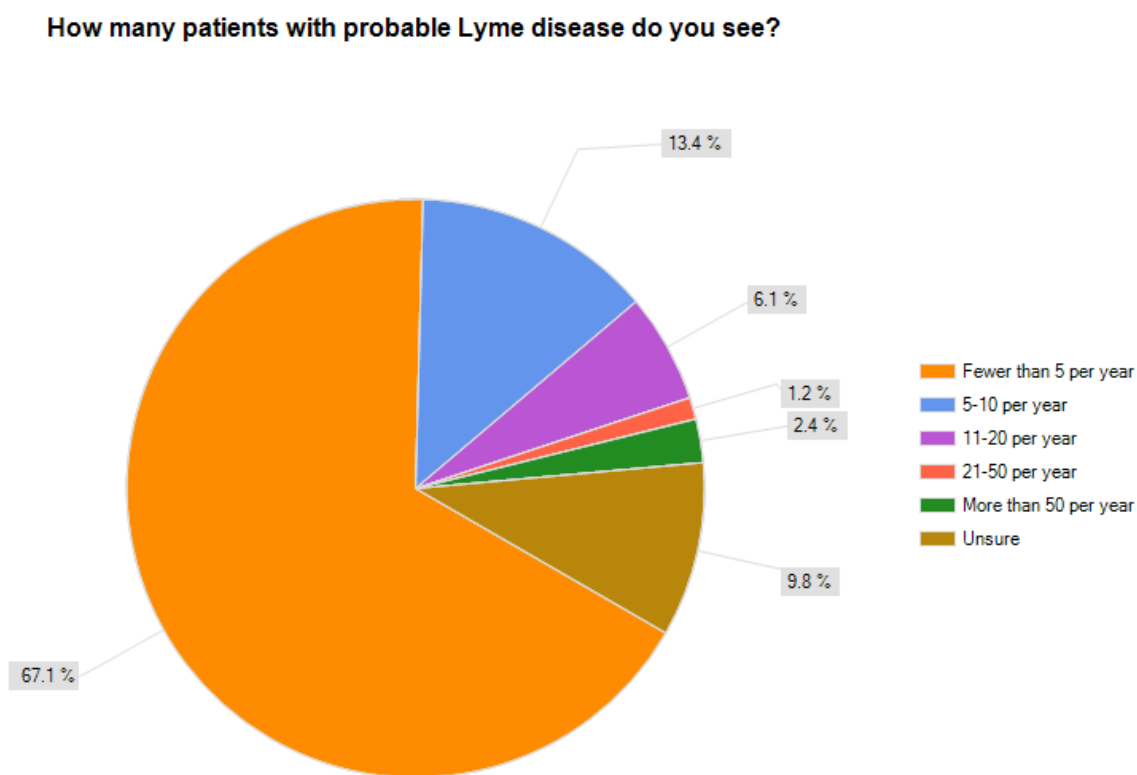


Figure 2: number of cases of Lyme disease seen annually

## Profile of patient and carer respondents

People with Lyme disease were asked to provide basic demographic information and details on their condition – this was optional. Carers were asked to provide that information on behalf of the person with Lyme disease whom they looked after.

The majority of patients (76.5 per cent) were female, with just under a quarter (23.5 per cent) being male. Almost all (93.8 per cent) confirmed that they were UK residents or had been treated in the UK. As shown in Figure 3, people were far more likely to have been diagnosed as adults than as children. Most were aged over 30, with almost a quarter (24 per cent) being aged 30-39 and a similar proportion (23.5 per cent) aged 50-59. No one was aged 80 or over at the time of their diagnosis.

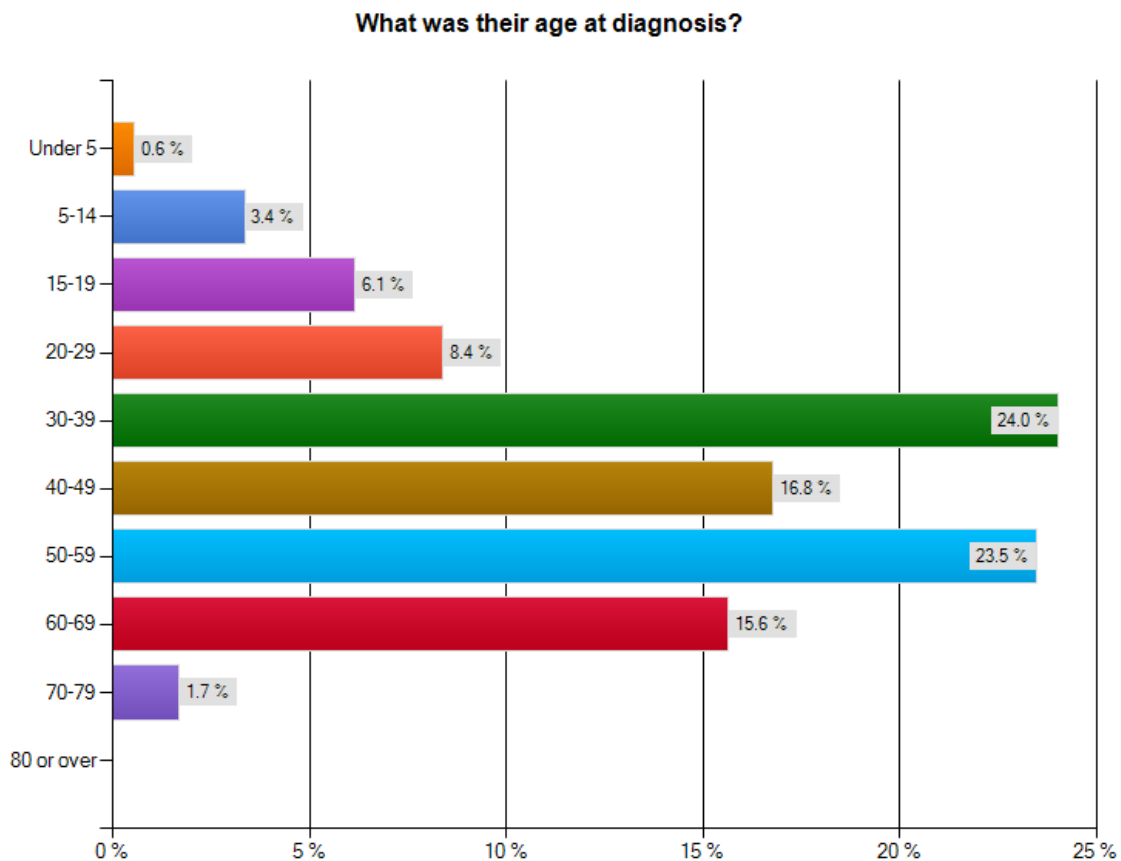


Figure 3: age of patients when diagnosed with Lyme disease

The survey asked about the time between tick bite and the start of treatment. Answers ranged from less than six weeks (15.1 per cent) to over five years (31.8 per cent). More detail is given in Figure 4.

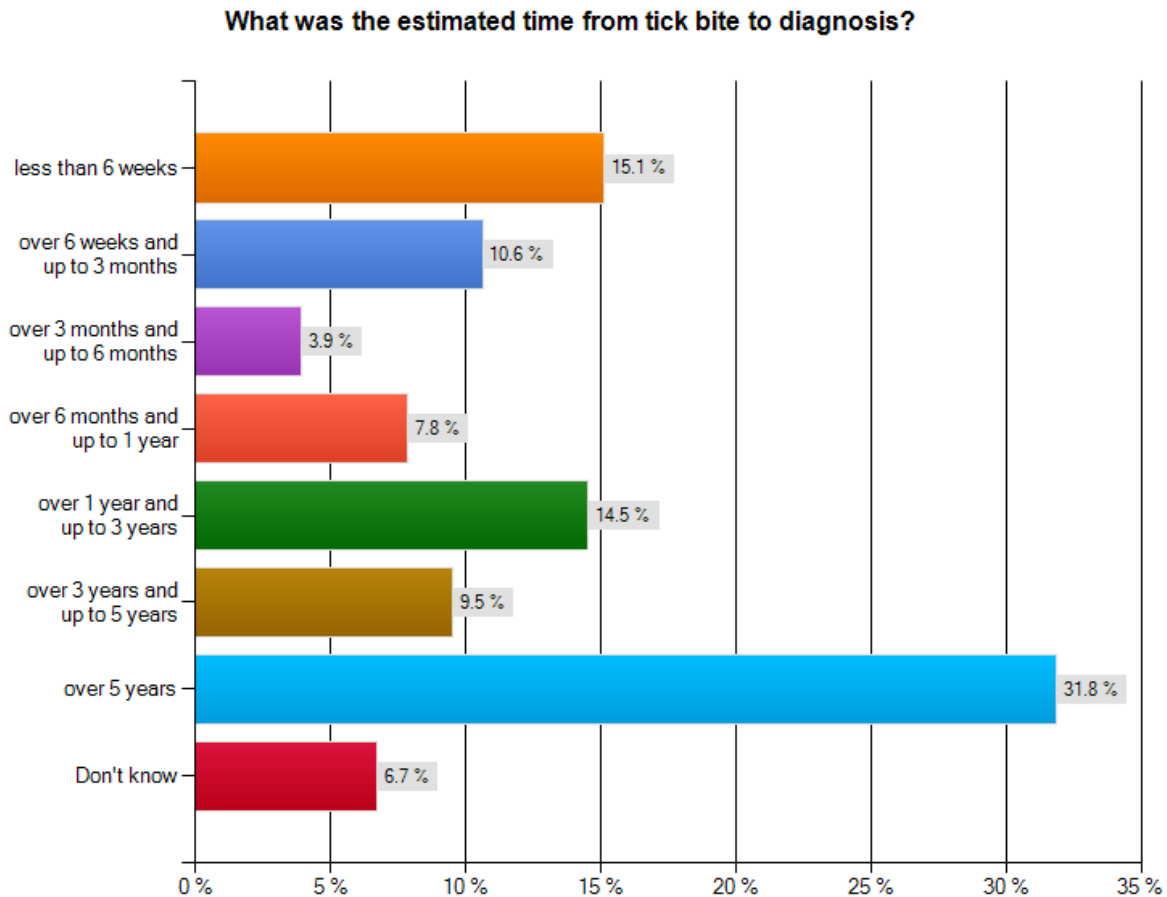


Figure 4: estimated time between tick bite and diagnosis of Lyme disease

Time between tick bite and start of treatment also varied, from less than six weeks (14.3 per cent) to over five years (34.3 per cent), as set out in Figure 5. Just over one in 20 patients (6.7 per cent) did not know the time between the tick bite and their diagnosis, and 2.9 per cent of patients said they had received no treatment.

### What was the estimated time from tick bite to start of treatment?

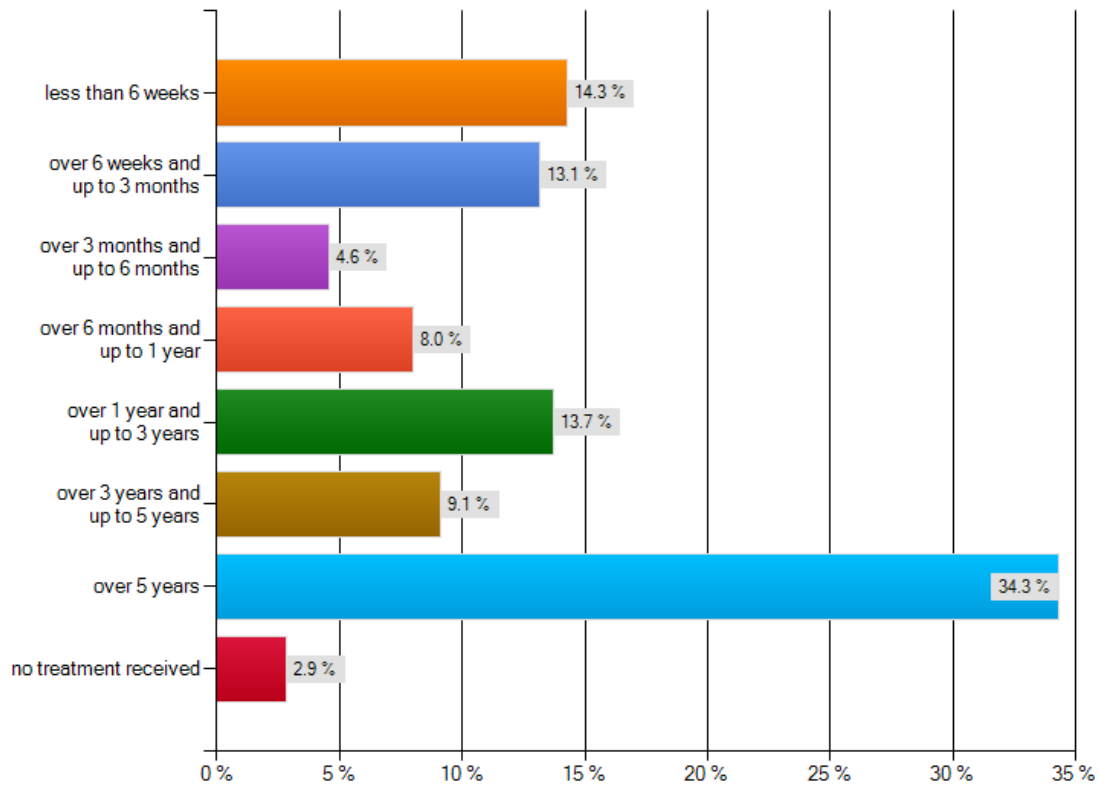


Figure 5: estimated time between tick bite and start of treatment for Lyme disease

The way in which the person with Lyme disease was diagnosed was examined in terms of:

- method
  - Positive blood/spinal fluid test
  - Positive PCR
  - Clinical diagnosis of erythema migrans rash
  - Clinical diagnosis without rash
  - Don't know the basis of diagnosis
- and setting
  - NHS
  - Private
  - Self-diagnosis

The most common method of diagnosis was positive blood/spinal fluid test, predominantly in a private setting.

As Figure 6 demonstrates, showing actual numbers and not percentages, the survey respondents were more likely to gain their diagnosis in a private setting than the NHS, with the exception of clinical diagnosis of erythema migrans rash, where slightly more people were diagnosed by the NHS than privately (although self-diagnosis was more common than either of these).

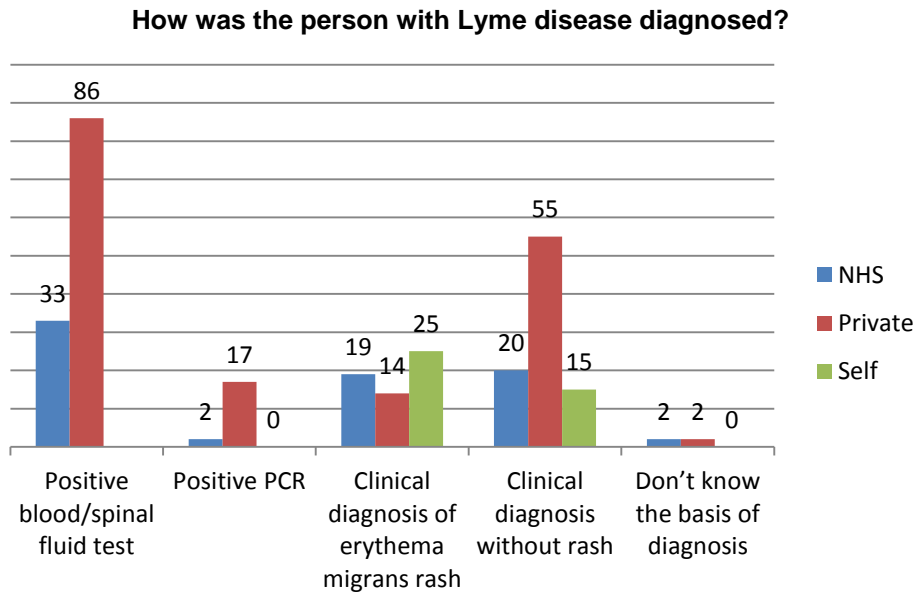


Figure 6: actual number of patients and the methods by which their Lyme disease was diagnosed

Please note that that some respondents reported both an NHS and private diagnosis, and some have included a self-diagnosis which may later have been confirmed by an NHS or private diagnosis.

The number of clinicians, including all health professionals, which patients consulted about their Lyme disease ranged from one to 40. The most frequently-cited number (the mode) was four.

Finally, the survey asked for a reported improvement in symptoms, ranging from negligible to partial to almost complete and complete. Half (50 per cent) reported a partial improvement, while almost a quarter (23 per cent) said the improvement in their symptoms was almost complete. Slightly more respondents reported a negligible improvement (13.8 per cent) than those reporting complete improvement (13.2 per cent). This is set out in Figure 7 below.

### Has the improvement in symptoms to date been

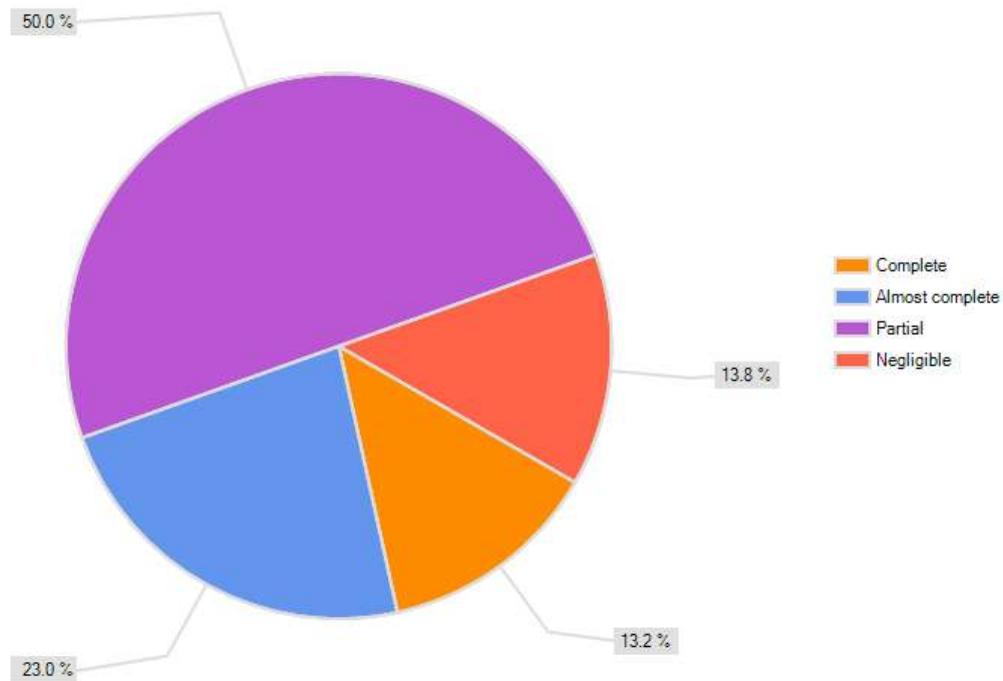


Figure 7: level of improvement in patients' Lyme disease symptoms

### Conclusion

Comparison with other JLA PSP surveys suggests that the Lyme Disease PSP survey response was very high. The significance of this is underlined by the limited understanding about the condition which the Lyme Disease Action reports.

It is not unusual in a JLA PSP to engage more patients than clinicians as survey respondents. Without baseline data on the demographic profile of Lyme disease patients, it is not possible to know whether or not male respondents are under-represented, or if it is predominantly a female condition.

Overall, this survey has provided a strong data set with which to start the JLA process of checking the uncertainties, then working with patients, carers and clinicians to prioritise them for research.

**Prepared by Katherine Cowan, November 2011**



