

2011 – Internet survey of patients diagnosed with Lyme disease

Survey results

- The results are provided as a PDF, with the results for all patients for each question asked.
- For more details about the *structure of the questionnaire*, the 'reference point' for questions, or the logic of the 'questionnaire flow' - please contact the author.
- Patients that stated they were 'self-diagnosed', rather than being diagnosed by professional were excluded from this particular dataset.
- For more detailed breakdown of the data e.g. answers broken down by test results (such as positive negative), or by 'who initially diagnosed' etc – please request the spreadsheet from the author.
- The author takes no responsibility for any summary or analysis/interpretation of this data, undertaken by any members of the public, or researchers.
- The author requests that the limitations of the survey are taken into account in this regard.
- The survey was designed initially to inform the work of Lyme patients and Lyme groups, to negotiate access to treatment, feed into policy-making, and also to allow others to explore the policy and practice issues related to Lyme patients in the UK.
- Study looking at the experience of patients in order to stimulate debate about that experience.

The limitations of the study are the following;

- The people answering the questionnaire were self-selected, and recruited via an Internet network and forums. They are therefore **not representative** of 'all the patients diagnosed with Lyme disease in the UK', and may be clinically, or socially different from the 'general Lyme patients population'.
- The questions may not have been completed in a wholly consistent manner, so there may be some questions where information is missing – this may affect the 'quality' of the overall information.
- The questions represent patient's experiences of care, health services, of their illness, and this is a 'social experience' rather than biological reality. This is equally valid to a biological reality, since the survey is based on sociological approaches.
- The group of patients answering the survey may be those who are more dissatisfied with care, and/or have poorer treatment outcomes. People who have poorer experience of care more likely to answer questionnaires this kind.
- The survey provides a snapshot view of people with *very different experiences*, as well as *different clinical histories*, responses treatment etc. Some have been somewhere at a very early stage of treatment, others have received ongoing treatment for many years.
- The outcomes data is therefore **not indicative** of the potential outcomes of any one individual diagnosed with Lyme disease and treated in any particular way. The outcomes from treatment data is also not predictive as would be possible from a full-blown clinical trial - based on random selection, and following patients through in a consistent and scientific manner. The treatment outcomes data is therefore not generalizable to another defined patient population.