

IDSA Survey: Outcomes Important to Lyme Patients Chartbook

Conducted March 26-April 25, 2015



A **lymedisease.org** Survey

6136

Total Responses

Date Created: Saturday, March 21, 2015

In 2015, the Infectious Diseases Society of America opened comments for its proposed Lyme disease guideline revision process. Although the Institute of Medicine standards on creating trustworthy guidelines, requires that those affected by guidelines be included in the process, the IDSA proposed panel did not include a Lyme disease patient.

On March 24, 2015 LymeDisease.org launched a survey focusing on outcomes Lyme disease patients value. Over 6,000 people responded. This survey was the first to report not only quantitative responses, such as the percentage of patients initially misdiagnosed, but also individual open response comments by patients.

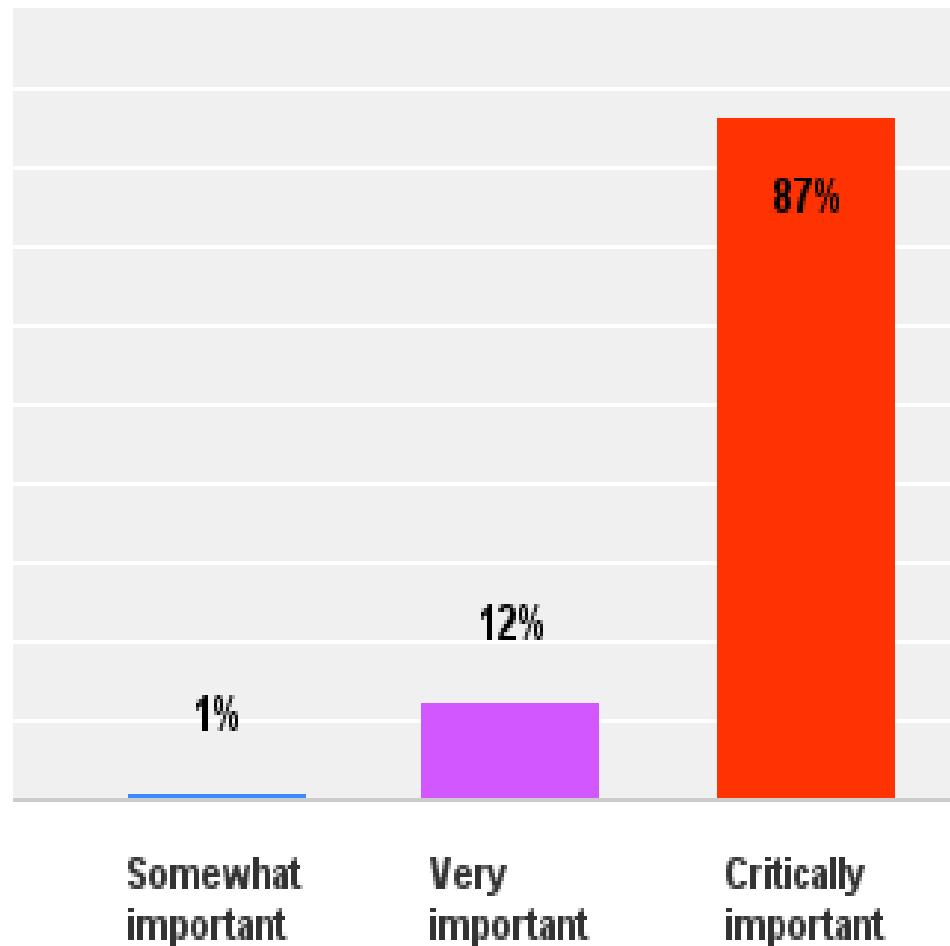
This chart book is the second of a two part report on the results of the survey. The first part of the report is called Real Lives/Real Stories and can be downloaded or read here: <https://www.lymedisease.org/wp-content/uploads/2015/04/lymedisease.org-patient-survey-20151.pdf>

LDo presented the results of the survey, which drew over 6,000 responses in one month, to the IDSA as part of the comments that it filed together with the national Lyme Disease Association on behalf of over 63 Lyme disease patient advocacy groups in the United States.

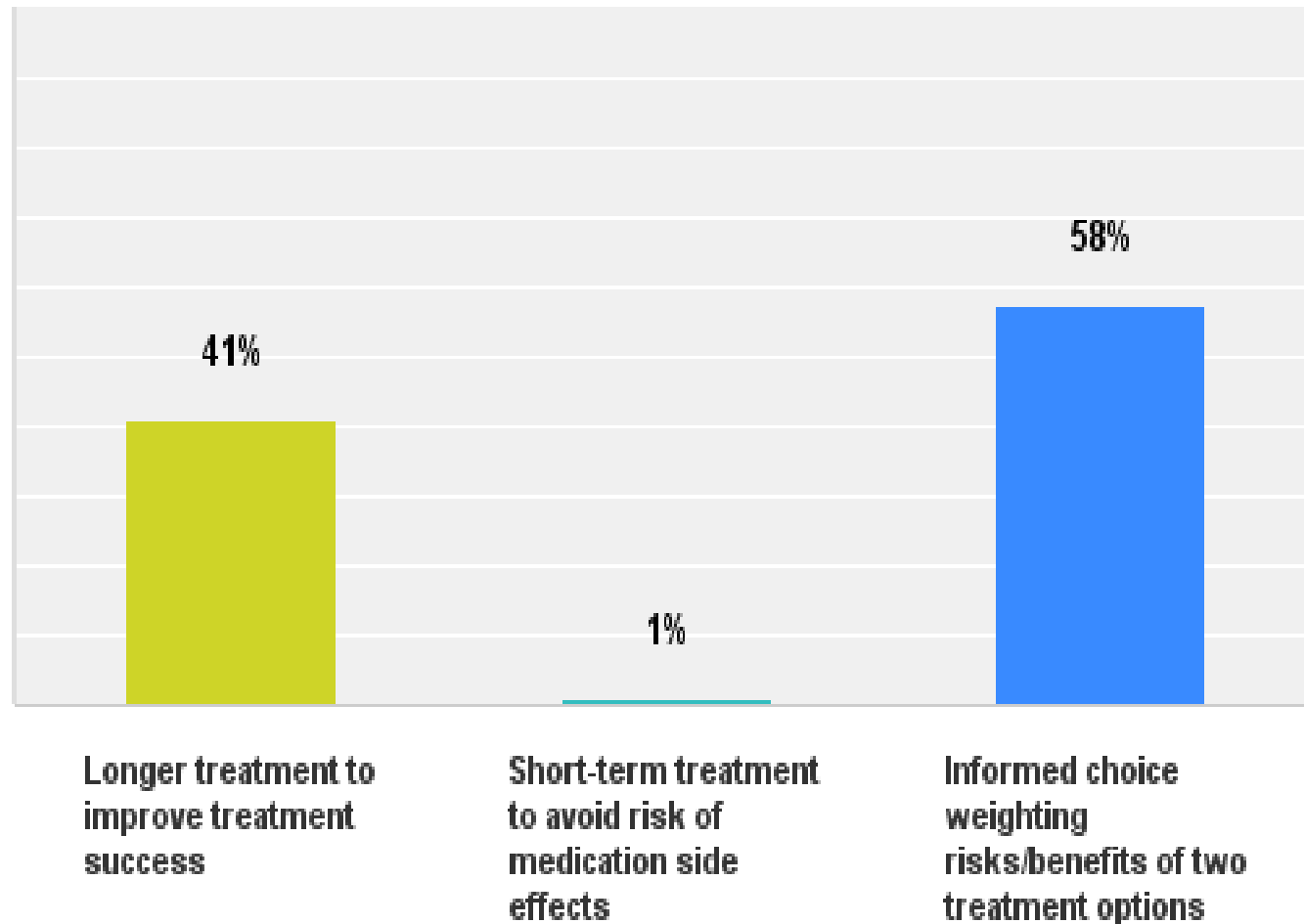
How important do you think it is to obtain higher rates of treatment success in early Lyme?

Prompt and adequate treatment of early Lyme disease can restore health and prevent long-term complications.

The short-term treatment courses commonly used can result in treatment failures. The National Institute of Health estimates the failure rate could be as high as 20%. Some studies suggest higher treatment failure rates.



If you were considering treatment options after diagnosis of early Lyme disease, which would you prefer?



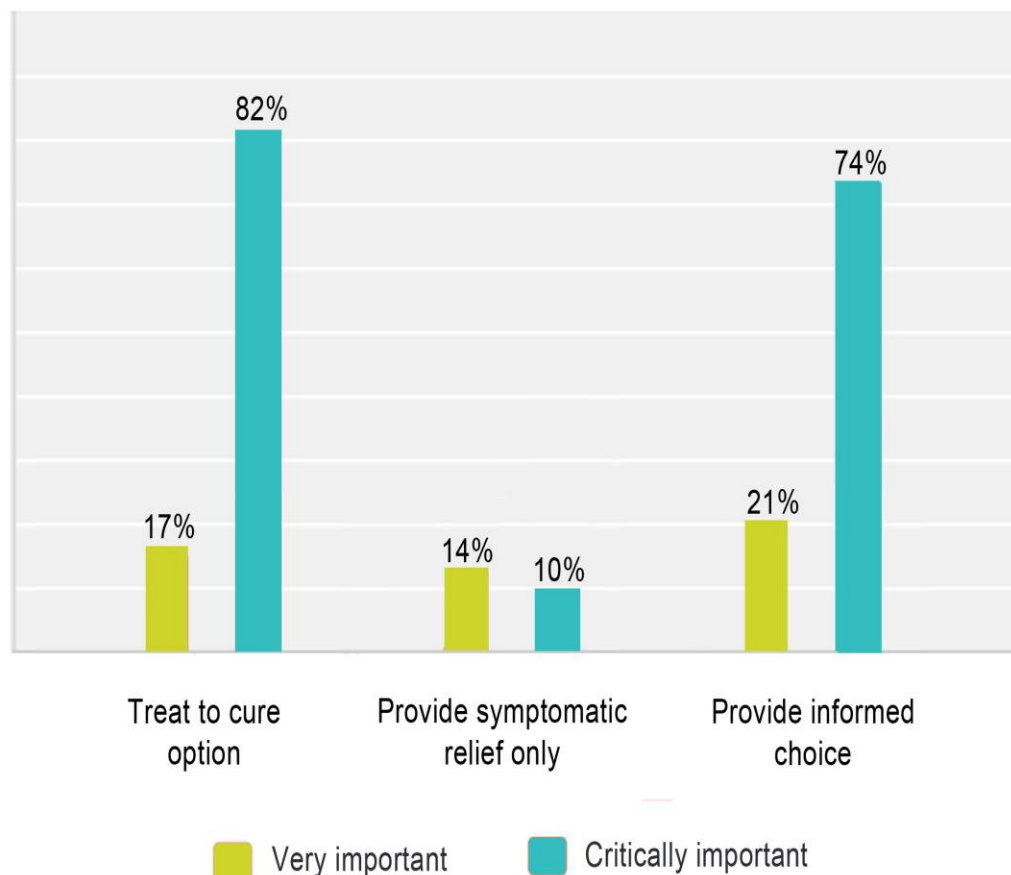
Given the uncertainty regarding the cause of persisting symptoms, rate the importance of the following options to you.

Some forms of treatment are only intended to make patients more comfortable. They do not address the cause of the problem.

In Lyme disease, antibiotics are the only form of treatment shown to be effective to treat the bacterial infection, but not all patients respond to antibiotic therapy.

When symptoms of Lyme disease persist, they may either be caused by a persisting infection, damage to the system, an immune response, or some other cause. There is no currently available test that can demonstrate whether treatment has cured Lyme disease or whether the bacteria persist.

There are risks associated with continuing treatment when infection is not present and there are risks associated with allowing a potential infection to progress without treatment.



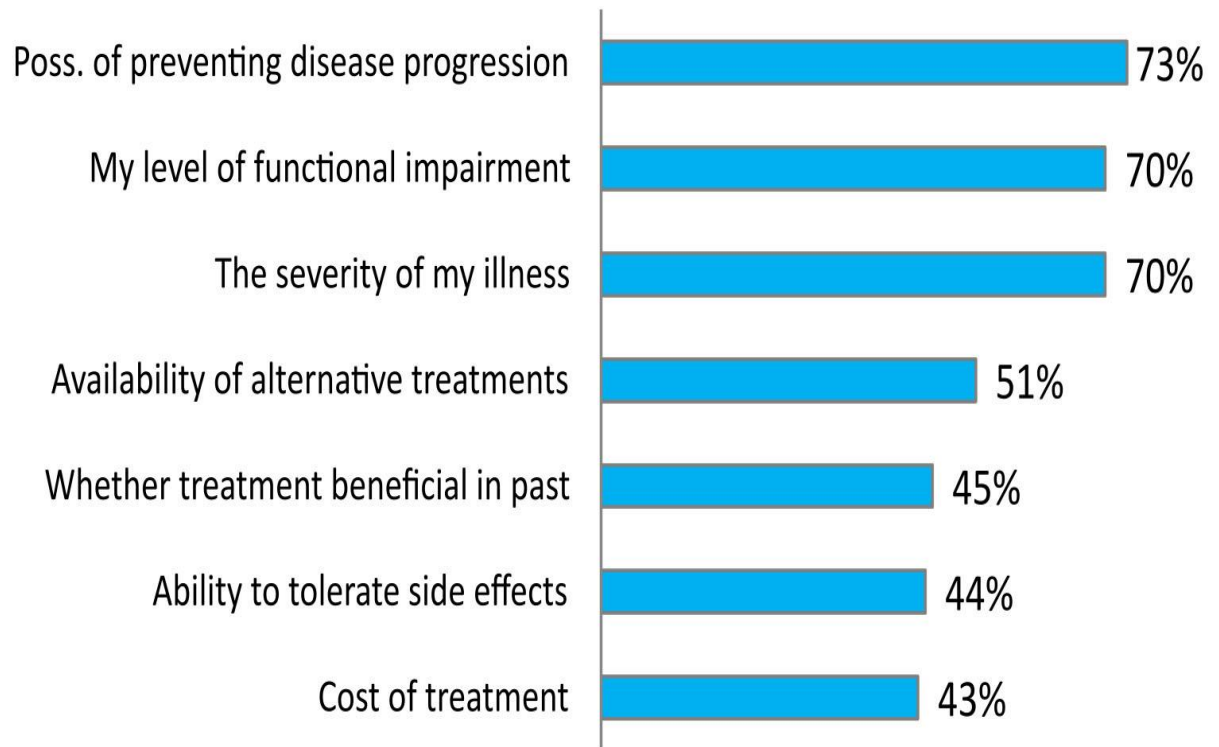
Rate the importance of factors that you consider when deciding to proceed with additional or more risky treatments.

Some treatments are riskier than others.

For example, intravenous antibiotics are more risky than oral antibiotics.

In addition, there is less certainty regarding the benefit from additional treatment when short-term treatment for Lyme disease fails.

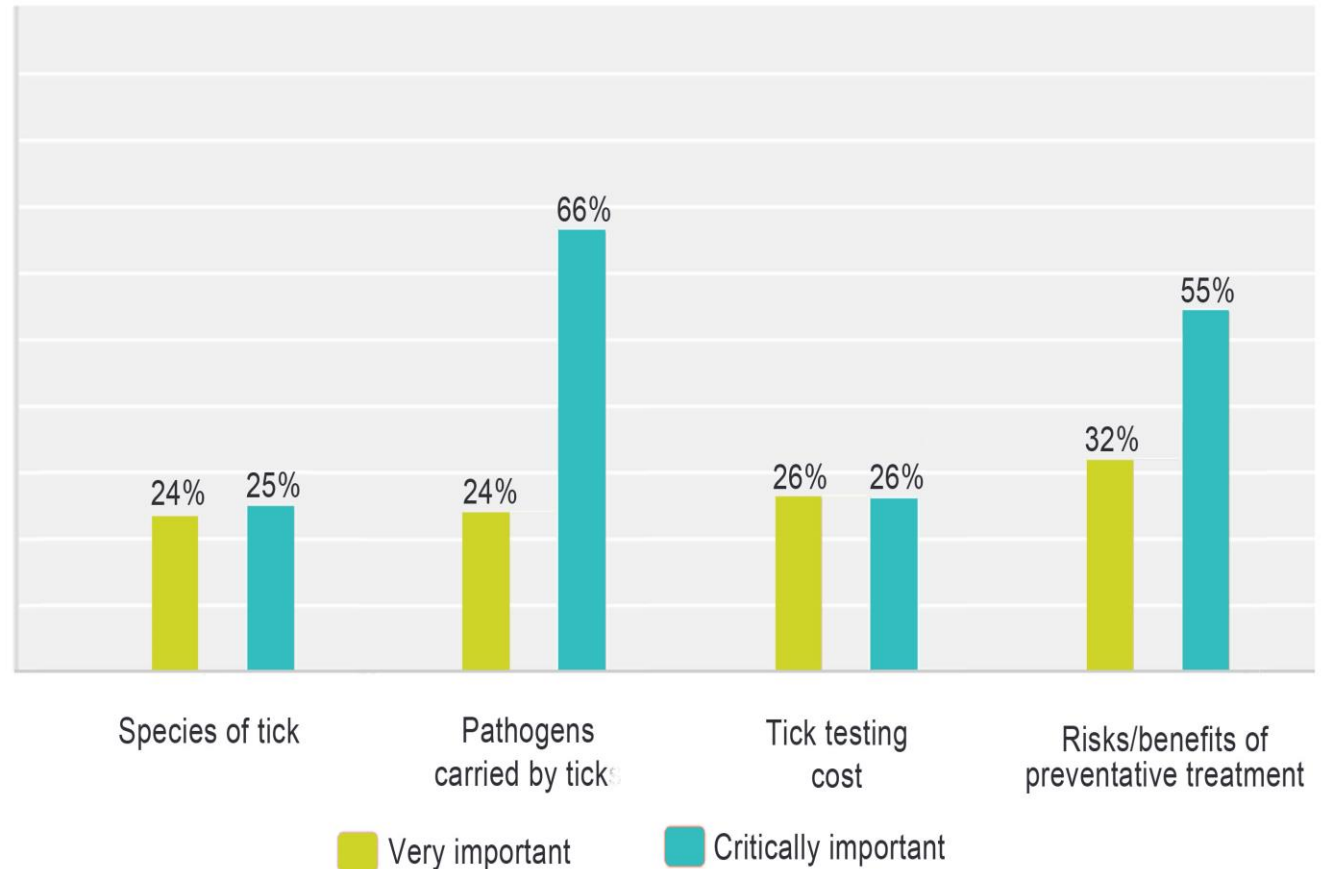
Important factors in treatment decisions



Rate the importance to you of the following if you were bitten by a tick.

Ticks transmit a variety of pathogens (disease agents). Individual ticks can be tested to see which diseases they could potentially transmit but the cost of testing may not be covered by insurance.

Beginning antibiotics within 48 hours of removing an attached tick may prevent disease but the optimal regimen has not been established.

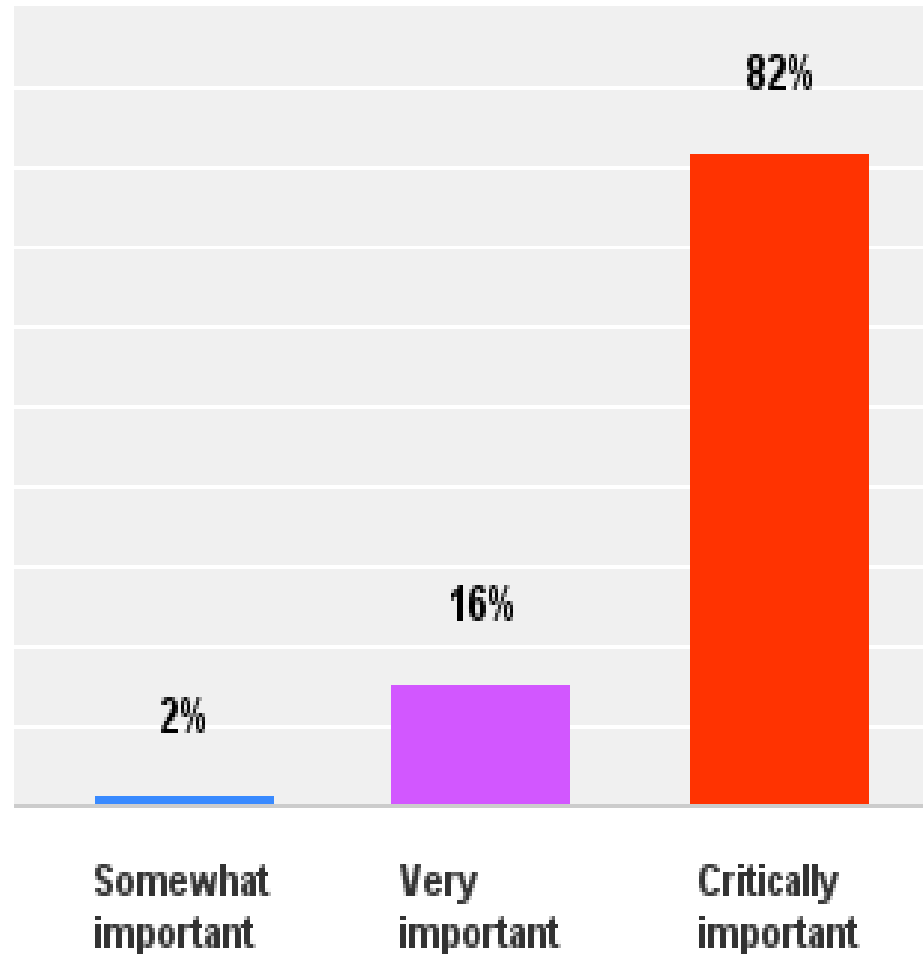


Rate the importance of being given the option to be tested for Lyme disease even if you live in an area where it is not common.

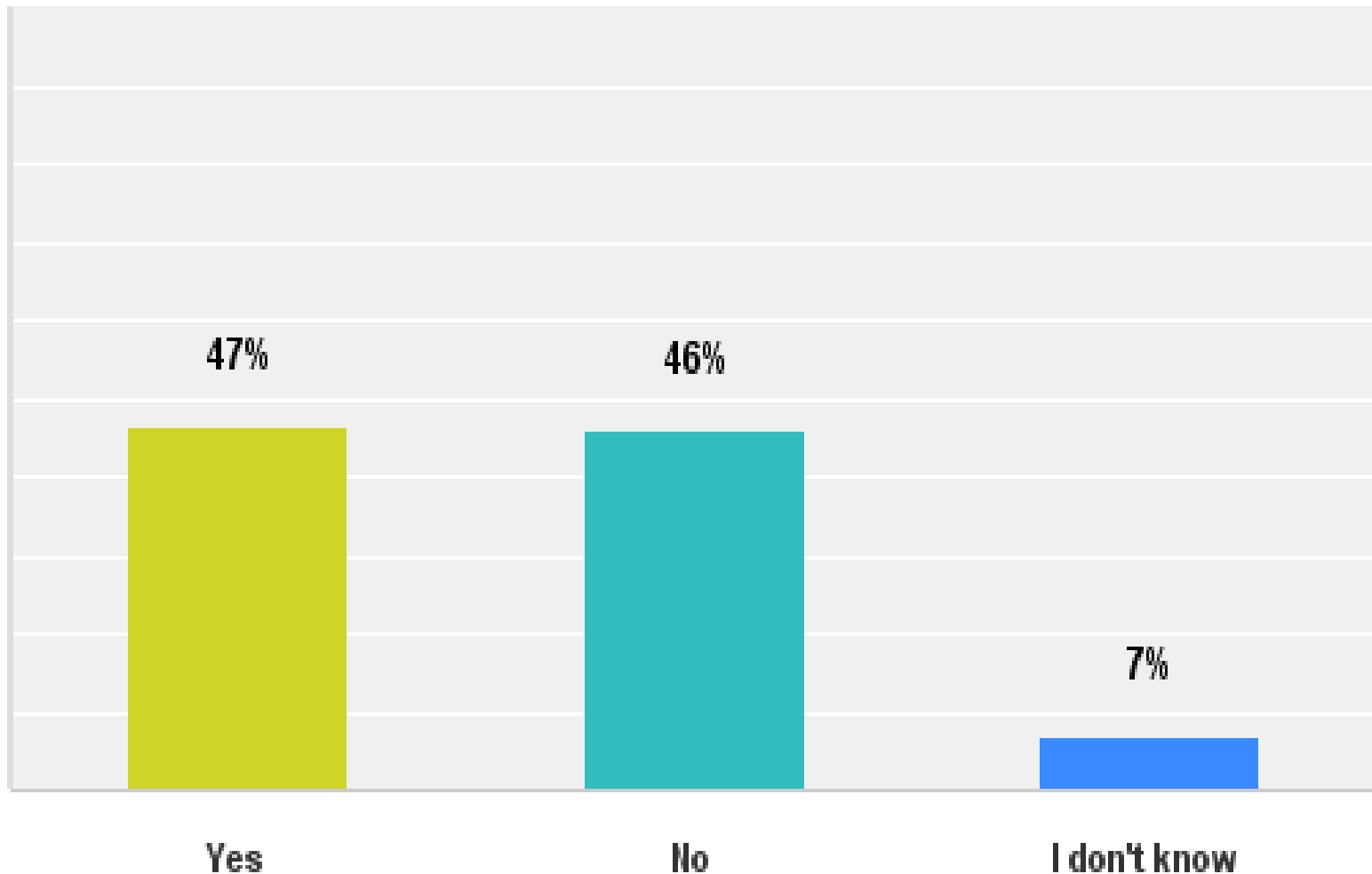
Some people live in areas where Lyme disease is not common.

Others live in areas where there is a lot of Lyme disease.

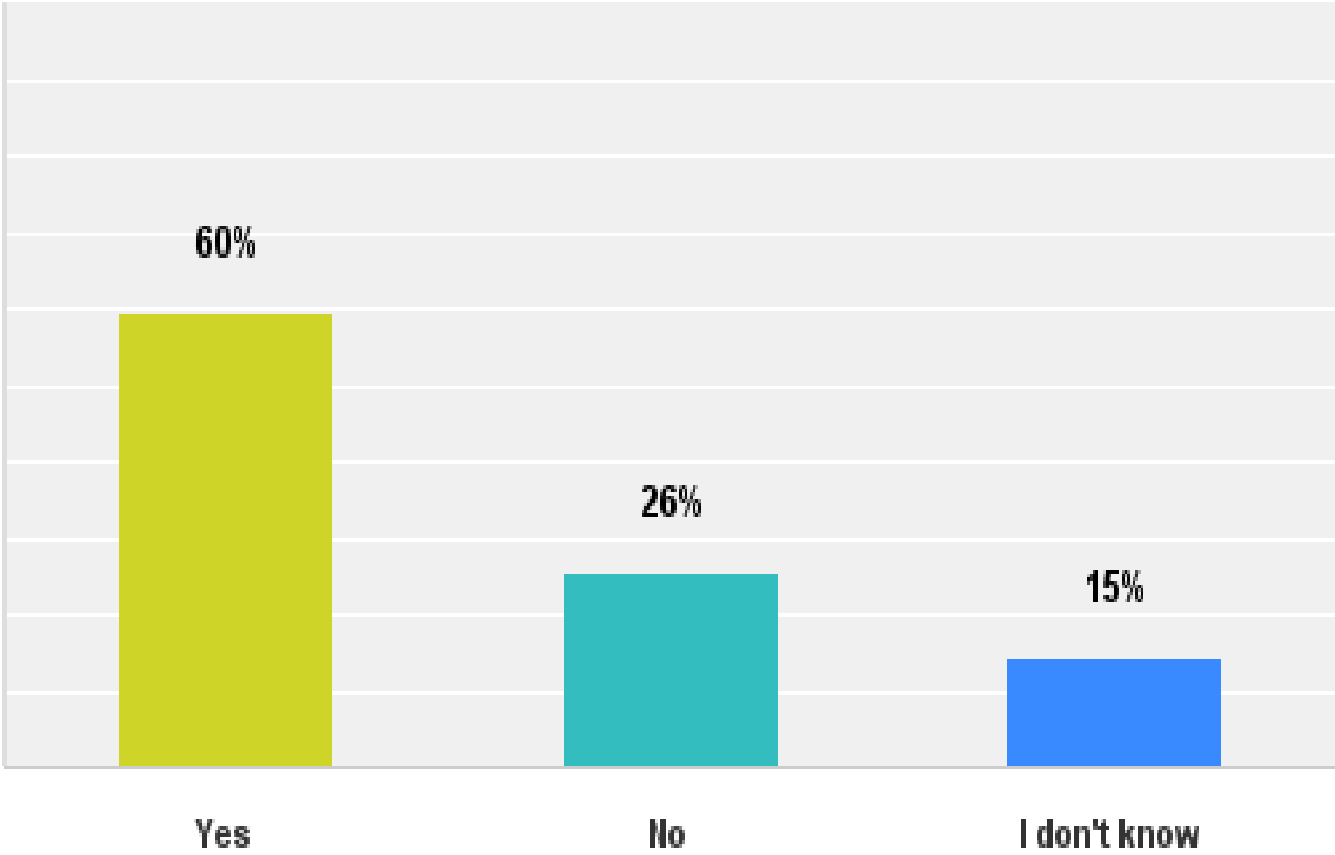
Assume that you are ill with symptoms consistent with Lyme disease, but live in an area where Lyme disease is not common.



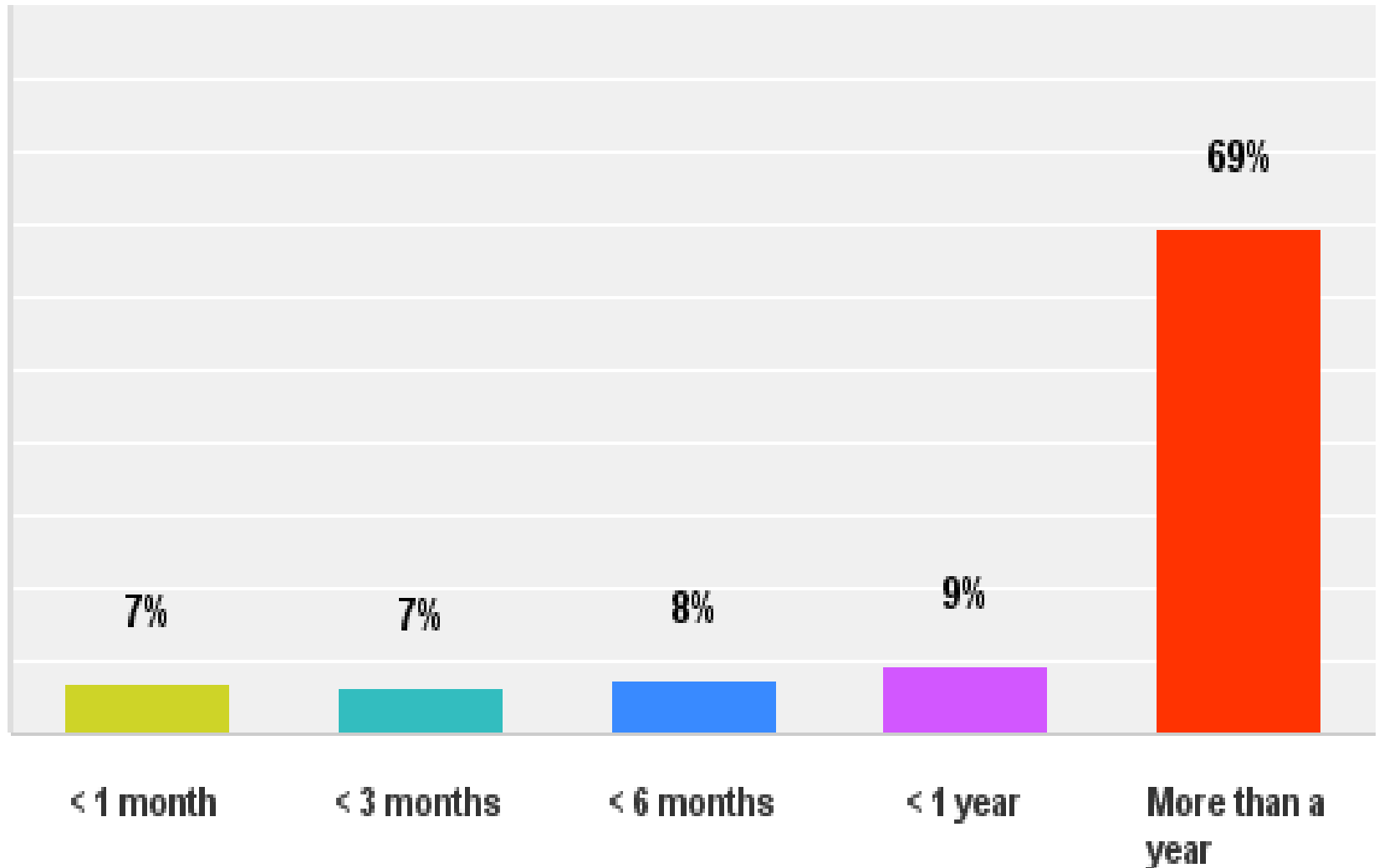
Have you ever had testing for Lyme disease delayed or denied because you lived in an area where Lyme disease was not considered common?



If so, did this delay or refusal to test for Lyme disease delay your diagnosis?



If your diagnosis was delayed, how long did it take for you to become diagnosed after the initial refusal to test for Lyme disease?

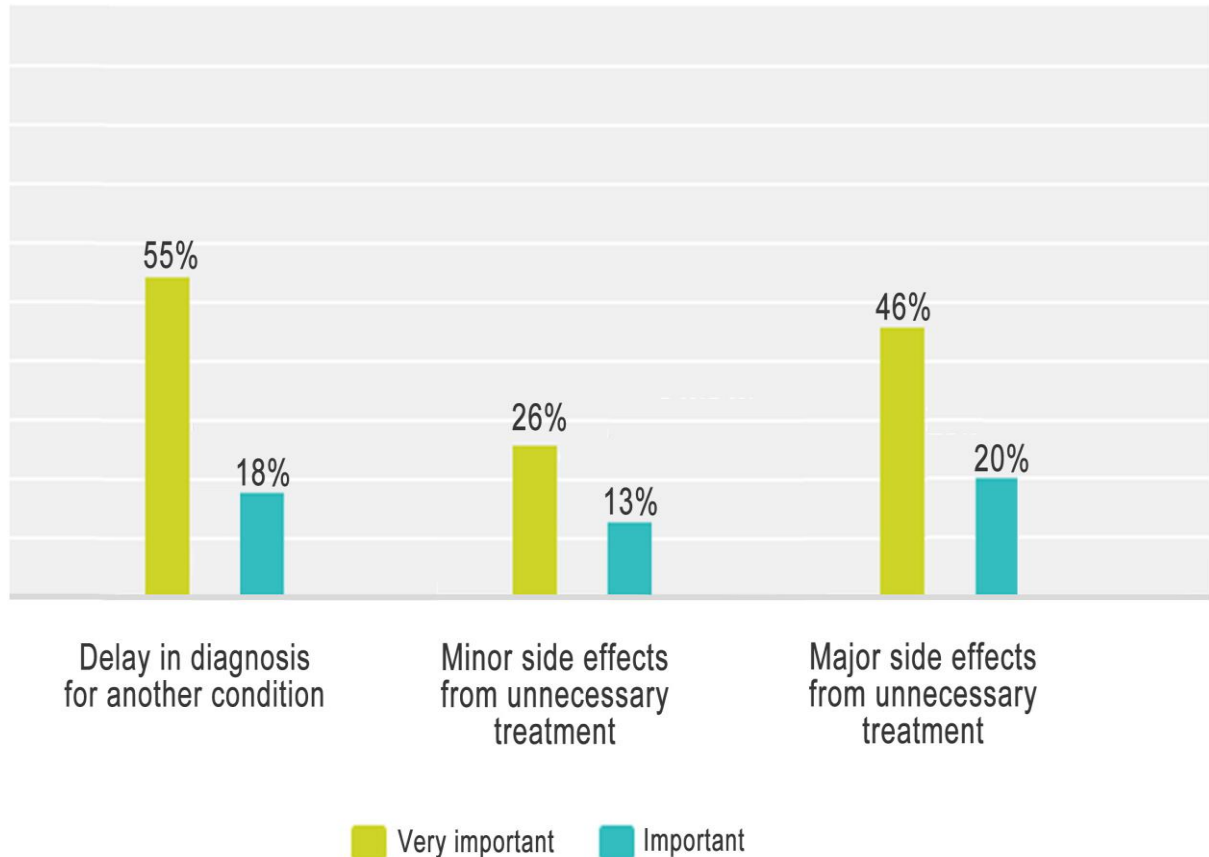


Please rate the importance to you of avoiding the following risks of misdiagnosis.

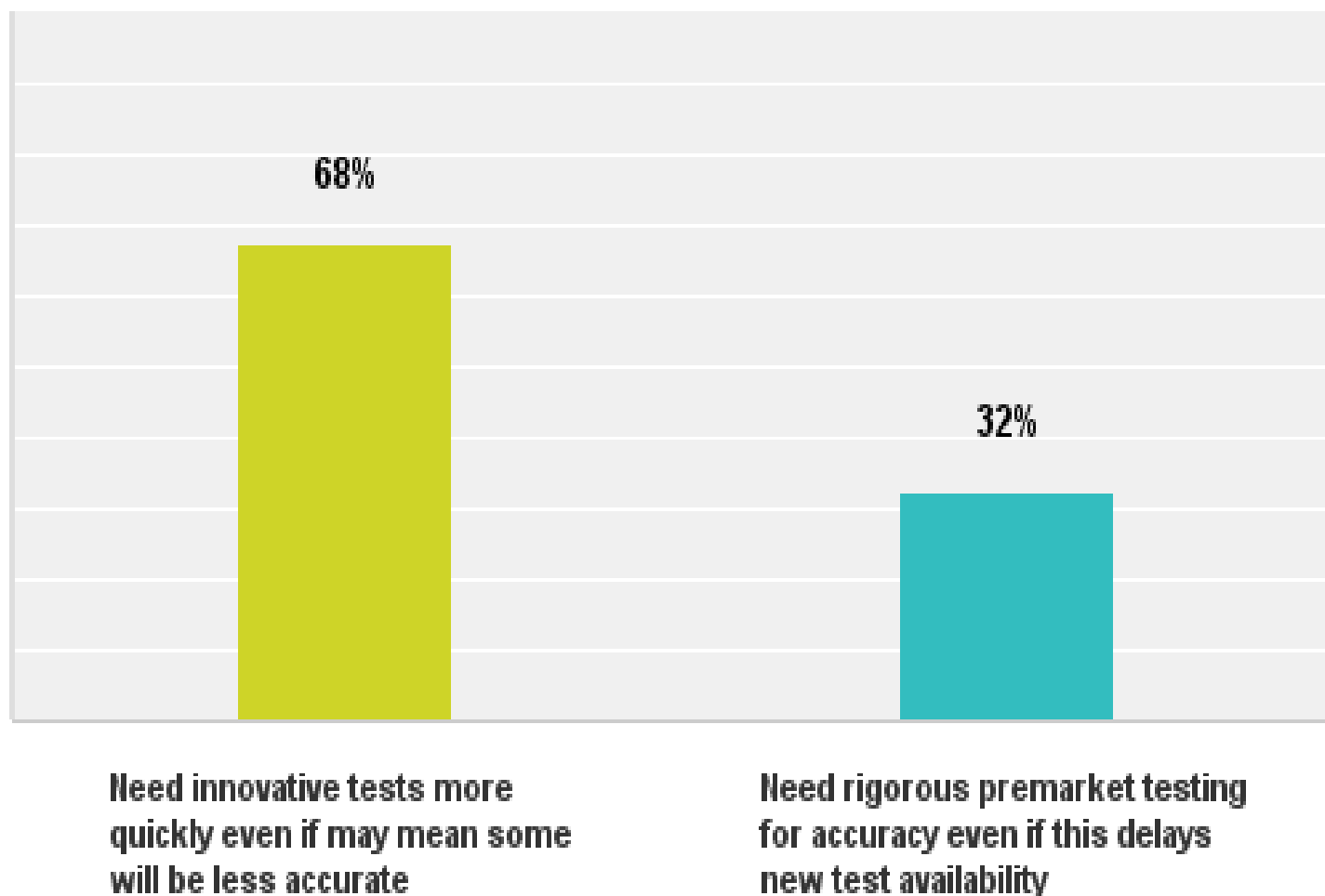
None of the available diagnostic tests for Lyme disease are completely accurate. Some tests are falsely negative in people who have Lyme disease.

Other tests are falsely positive in people who don't have Lyme disease. Both false positive and false negative results carry risks to patients. False positive results may lead to unnecessary antibiotic treatment and its associated costs and risks. There may also be a delay in establishing the correct diagnosis, which may carry additional risks. False negative results may lead to a delay in being diagnosed with Lyme disease, which is associated with disease progression and poorer outcomes.

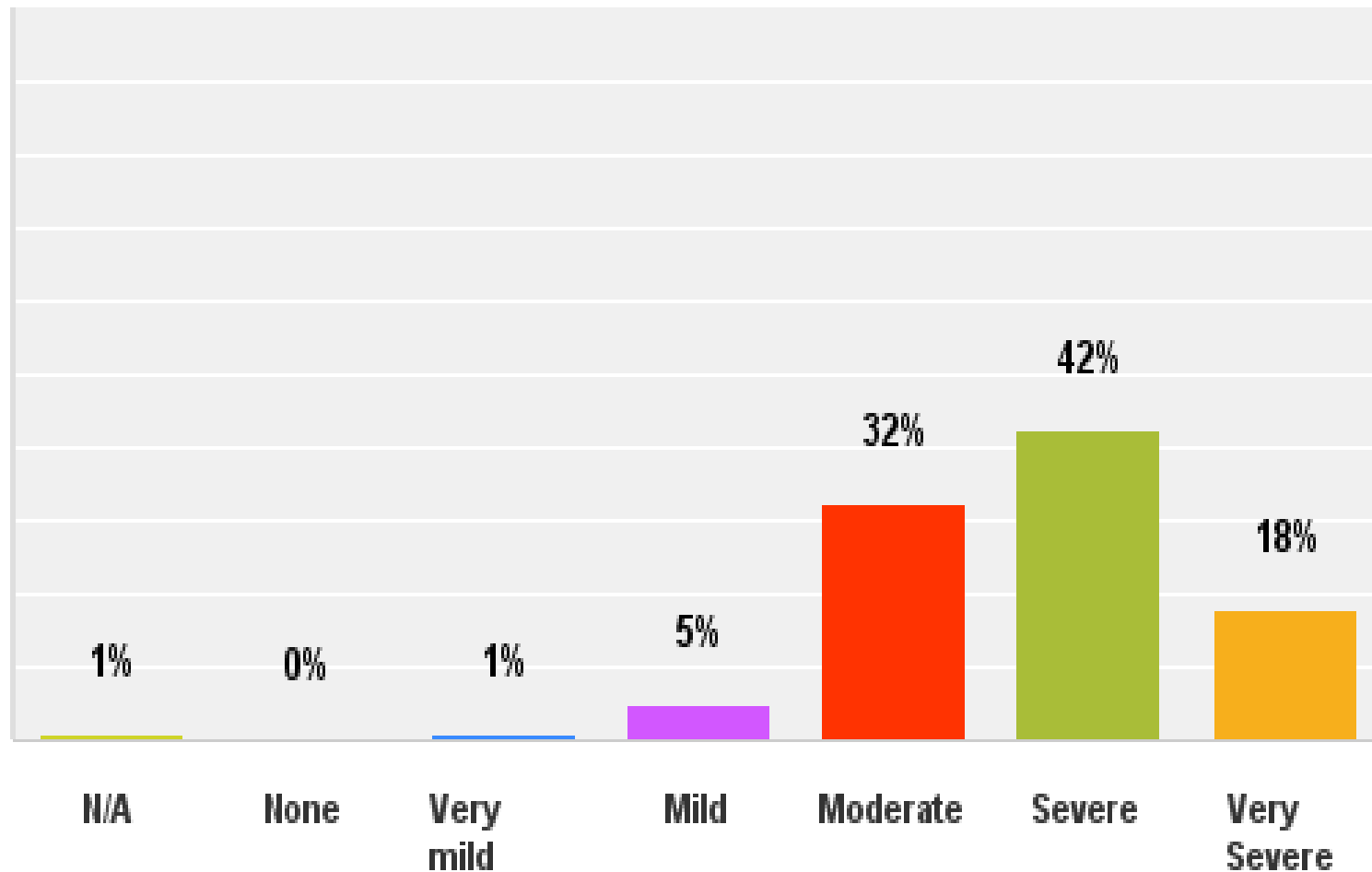
The two-tier testing protocol endorsed by the CDC rarely produces false positives but it often produces false negatives.



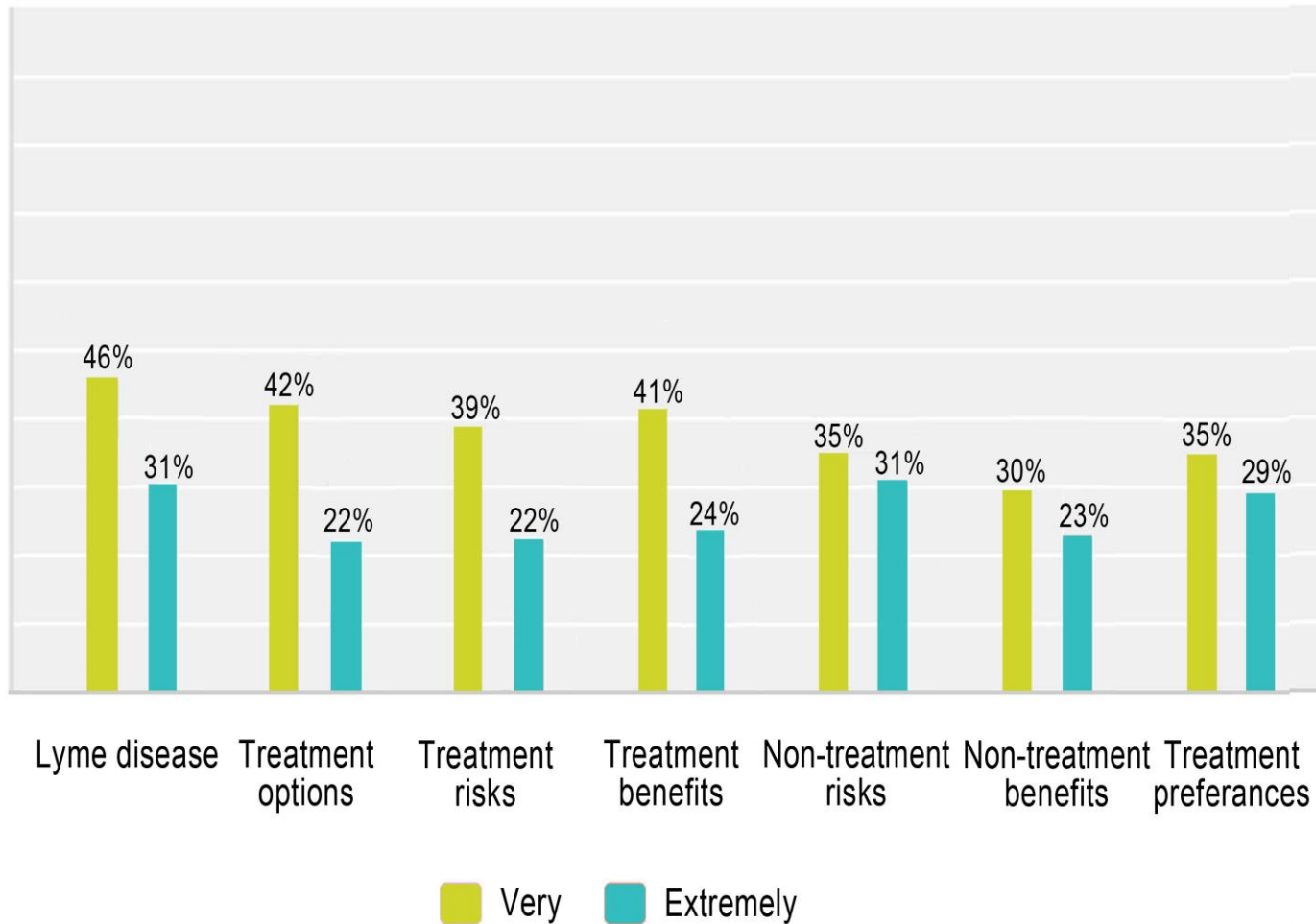
In your view, what is the most important aspect of Lyme disease test development:



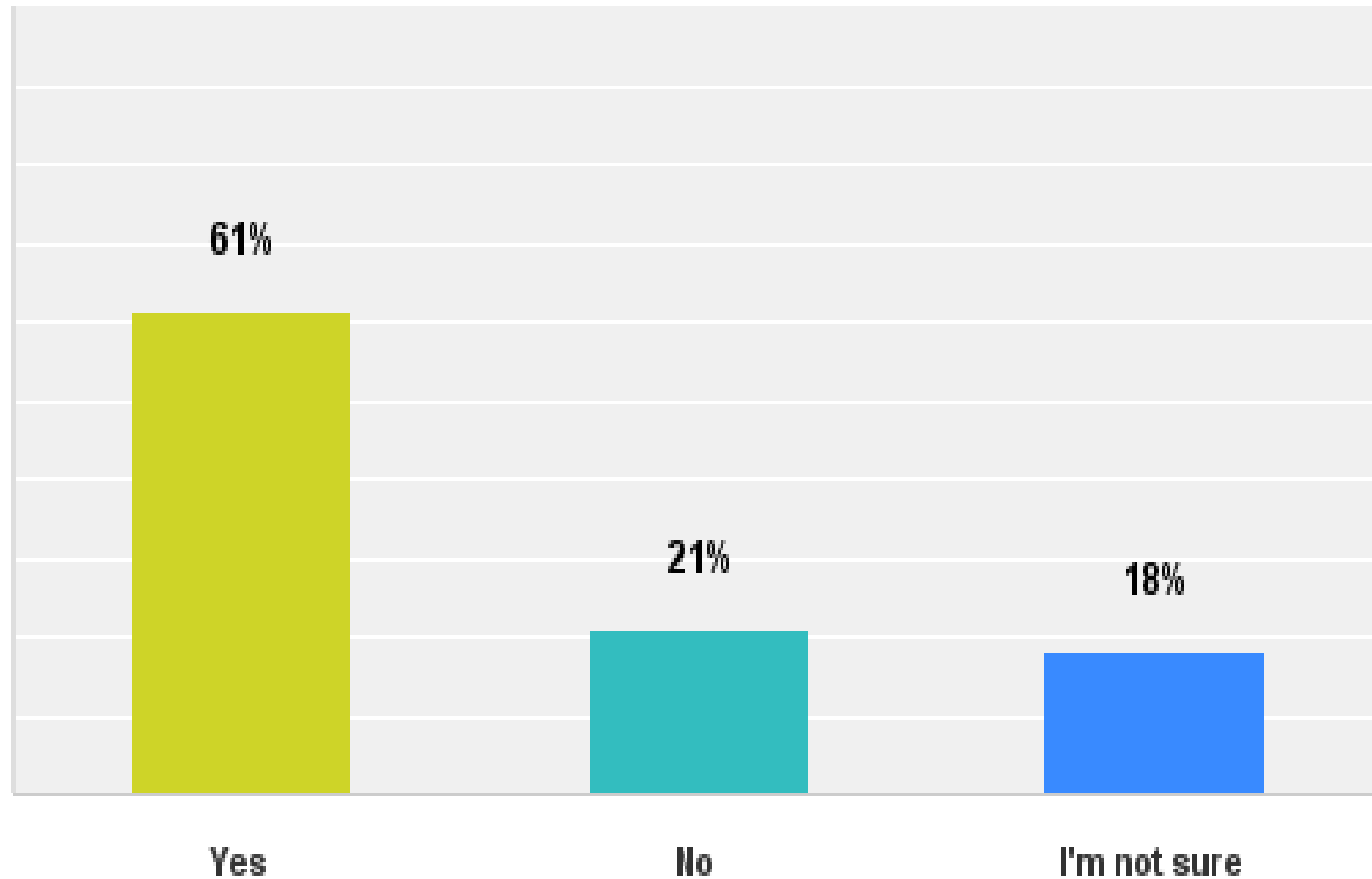
How would you rate the intensity of your Lyme disease symptoms in general?



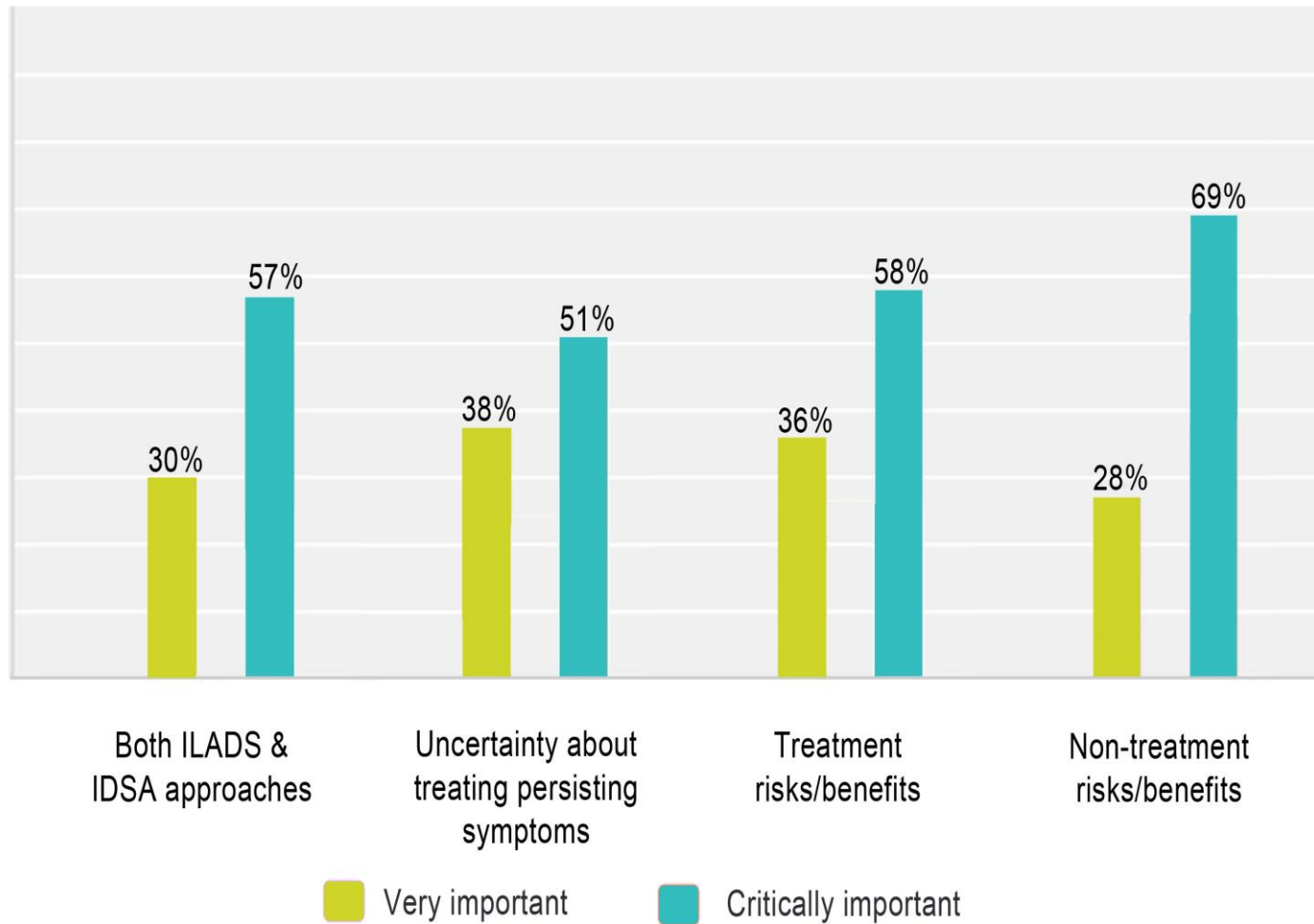
How knowledgeable do you feel about:



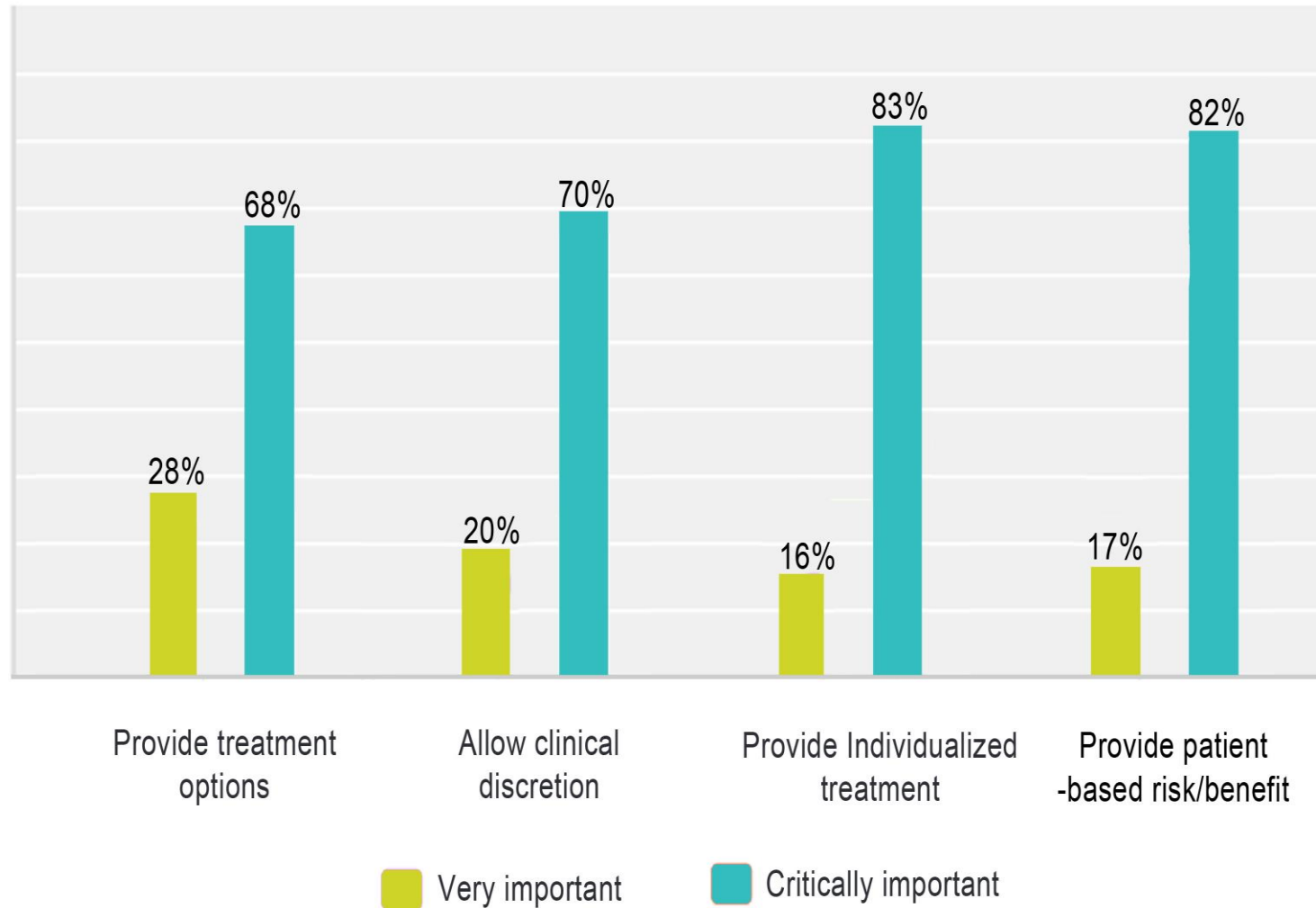
Do you feel you have sufficient information regarding the risks and benefits of treatment options for Lyme disease to make informed choices regarding your own treatment?



In the treatment of Lyme disease, how important do you think it is for treatment guidelines to inform patients about:



How important do you think it is for treatment guidelines to:



Patients believe treatment guidelines should inform and provide treatment options.

Over 85% of patients believed that:

- Both the ILADS and IDSA viewpoints should be reflected in treatment guidelines;
 - Treatment guidelines should inform patients regarding the uncertainty about treating persisting symptoms;
 - Patients should be informed about the risks and benefits of both treating and not treating Lyme disease;
 - Treatment guidelines should provide treatment options, allow the exercise of clinical judgment, provide for individualized treatment, and provide for a “patient-based” risk/benefit assessment; and
 - Treatment guidelines should provide patients with the option to treat a potential infection to cure and provide for informed choice.
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Notes:

This survey was conducted over the internet in the United States during a one month period beginning March 26, 2015. It drew over 6,000 responses in that period.

The survey was answered by patients, parents of children affected by Lyme and spouses of those with Lyme disease. The average age was 48 and 82% of respondents were female.

For more than ten years, LymeDisease.org has been conducting patient surveys to bring the perspective of patients to the forefront. You can read the results of two of our peer reviewed surveys listed below or follow the results of our other surveys at LymeDisease.org. In 2015, LDo launched its big data project, MyLymeData, which is a PCORnet project.

For further information, contact the lead author, Lorraine Johnson, JD, MBA at lbjohnson@lymedisease.org.

Johnson L, Aylward A, Stricker RB. Healthcare access and burden of care for patients with Lyme disease: a large United States survey. Health Policy. 2011 Sep;102(1):64-71. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21676482>.

Johnson L, Wilcox S, Mankoff J, Stricker RB. Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey. PeerJ. 2014; 2. Available from: <http://dx.doi.org/10.7717/peerj.322>.

Visit LymeDisease.org for more information about our patient surveys and our big data project, MyLymeData.



A **lyme**disease.org Survey