

# Using a New Patient-Powered Research Tool to Answer Critical Questions about Lyme Disease

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## Introduction

MyLymeData is a patient registry developed by LymeDisease.org that enables patients to pool longitudinal healthcare data. Since its launch in November 2015, 5,531 patients have enrolled.

The 4,254 participants in this sample included US residents clinically diagnosed with Lyme disease who completed the survey. A subgroup that characterized themselves as “sick” (86%) or “well” (14%) and identified the stage of their disease at diagnosis (2,387) was analyzed. (See Sample and Exclusions Algorithm on other side.)

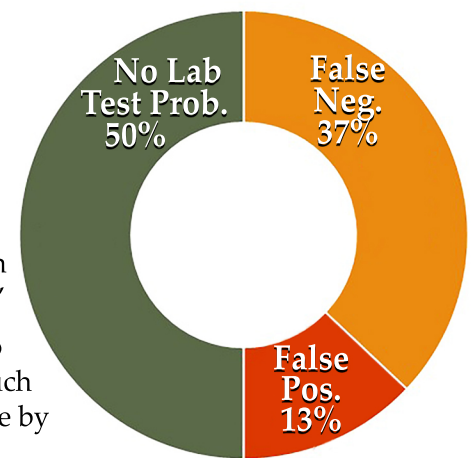
We compare the recovery rate of the 21% diagnosed early with the 79% diagnosed late (untreated for 6 months or more after onset).

## Results

Patients diagnosed early were more likely to be “well” (32%) than patients diagnosed late (9%). Still, a large proportion of patients diagnosed early (68%) and almost all of those diagnosed late (91%) remained ill. These findings suggest the importance of early diagnosis and the need to develop improved treatment regimens for both early and late Lyme disease.

Early or Late Diagnosis and Recovery in Lyme Patients			
	Early	Late	Total
Sick	343 (68%)	1,721 (91%)	2,064 (86%)
Well	159 (32%)	164 (9%)	323 (14%)
Total	502 (100%)	1,885 (100%)	2,387 (100%)

## Causes of diagnostic delays



Diagnostic delays were associated with false negative lab tests (37%), positive lab tests dismissed as “false positives” (13%), and missed diagnostic opportunities when healthcare providers failed to evaluate the patient because “there is no Lyme here.”

Estimates in Colorado suggest the true incidence/prevalence of Lyme disease is too uncertain to prematurely foreclose clinical diagnosis based on predictive models, such as Bayes’ Theorem. CDC acknowledges case reports underestimate actual incidence by a factor of 10 nationwide.

## CBS News: Lyme Disease Diagnoses Difficult In Colorado

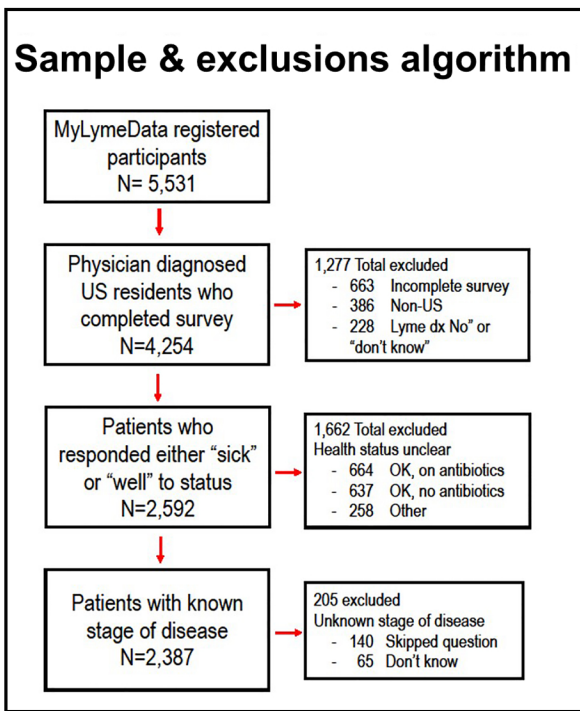
“The common belief is that the disease does not exist here, but patients infected say otherwise.”



Indicators of true incidence of Lyme disease in Colorado vary widely.	
Source	# of Cases
CDC cases (1994-2014)	12
10X multiplier of CDC cases	120
MLD cases (launch Nov 2016)	85
MLD tick bites	23
ILADS physician referral requests (2014-16)	742
Canine cases (rolling 5 years)	515

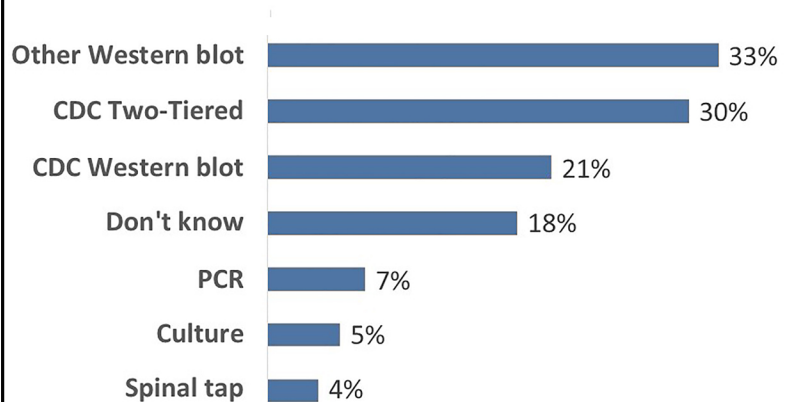
CBS News Denver featured Lyme disease advocate Monica White describing challenges of being diagnosed in Colorado, where people are told “We don’t have Lyme in Colorado, so you don’t need to worry.”

## Sample & exclusions algorithm



## Supporting Diagnostic Tests

Most patients (78%) enrolled in MyLymeData report their diagnosis is supported by positive lab tests. 17% do not have supporting serology and 5% responded, "Don't know."



## Conclusions

Lyme disease patients have significantly better outcomes when they are diagnosed early. Reducing barriers to diagnosis and improving treatments should be a public health priority. Physicians should be advised that lab tests are insensitive and may give false negative results. Patients with an erythema migrans rash should be promptly treated without lab testing as false negative test results at this stage are typical. Positive test results should not be discounted in symptomatic patients. Public health officials should be aware that CDC case numbers may greatly underestimate the true incidence of Lyme disease in an area. Finally, even in areas where Lyme disease is less common, symptomatic patients need to be tested and accurately diagnosed to prevent unnecessary suffering. It is time to focus on prompt diagnosis and early intervention to prevent chronic Lyme disease from developing.

## Limitations and Future Research

This analysis is correlational and cannot determine cause and effect. We do not examine treatment effects. Future studies might explore the association between treatment and restoration of health.

## Further Information

For further information about this poster session or MyLymeData, please contact Lorraine Johnson: [lbjohnson@LymeDisease.org](mailto:lbjohnson@LymeDisease.org). MyLymeData can assist researchers in many ways, for example, by providing patient registry data; collecting new survey data; recruiting patients for studies; and providing long term follow-up for completed trials.

## Literature cited

Canine cases: IDEXX Laboratories. Canine Vector-Borne Disease Prevalence Map (Rolling 5 years). [http://www.dogsandticks.com/diseases\\_in\\_your\\_area.php](http://www.dogsandticks.com/diseases_in_your_area.php)

Centers for Disease Control and Prevention. 2002-2014 (8 cases) <http://www.cdc.gov/lyme/stats/survfq.html>;

1992-2001 (4 Cases) [www.cdc.gov/lyme/resources/LDpublicuse.csv](http://www.cdc.gov/lyme/resources/LDpublicuse.csv)

### Acknowledgments:

The authors would like to acknowledge the patients who participate in MyLymeData. We would also like to acknowledge the International Lyme and Associated Diseases Society for sharing their information on physician referrals for Lyme disease.

CBS News (Denver) Lyme Disease Diagnoses Difficult In Colorado <http://denver.cbslocal.com/video/category/spoken-word-kcnctv/3433398-lyme-disease-diagnoses-difficult-in-colorado/>

MyLymeData Registrants residing in Colorado enrolled since registry launched November 12, 2015.

MyLymeData Registrants enrolled since registry launched November 12, 2015 who recall and identify tick bite location as Colorado.

International Lyme and Associated Diseases Society, Results of Physician Referral Analysis (personal correspondence.)