



Stigma and Privacy in Lyme disease

MyLymeData Privacy Survey 2019

According to the Centers for Disease Control, over 300,000 patients annually contract Lyme disease, which is transmitted primarily through the bite of a tick. (CDC 2015) Patients report significant barriers to accessing care and substantial impairment to their quality of life. (Johnson 2011, Johnson 2014) Privacy, stigma, and discrimination are major concerns for the Lyme disease community, particularly for those with chronic Lyme disease.

Between November 5, 2018 and February 2, 2019, we conducted a survey of over 1,900 patients enrolled in the MyLymeData registry on the topic of privacy, data use, trust, discrimination and stigma (Privacy Survey). The results of that survey are presented here. The data underlying this fact sheet are publicly available on Figshare. (Johnson 2019)

Most patients (78%) are concerned about privacy in Lyme disease. Survey participants say they face disrespect and discrimination both within and outside the healthcare system and worry that healthcare data might be used to discriminate against them by employers and insurers. While the majority of patients tell their family (57%) or close friends (59%) about their illness, it is far less common to tell co-workers (26%) or casual friends (28%).

STIGMA

Lyme disease patients face challenges obtaining care:

- » **74%** treated disrespectfully by clinician
- » **67%** postponed care due to stigma or barriers to care
- » **86%** have difficulty obtaining treatment

Patient worry that their data may be misused by:

- » Insurers to deny coverage as pre-existing condition (**83%**)
- » Employers to limit career opportunities (**48%**)

TRUST

Patients worry about data use by:

- » Government (**56%**)
- » Pharmacies (**49%**)
- » Drug companies (**60%**)

Clinician trust depends on role:

- » **75%** trust clinician treating their Lyme disease
- » **41%** trust other clinicians providing care
- » **18%** trust clinicians not involved with care

DATA USE

» **78%** are concerned about healthcare data privacy generally

Patients care about who is using their data and for what purpose.

» **84%** believe it is important to vet researchers and data use

Patients want data use to be:

- » Solely for the benefit of patients (**82%**)
- » Protected against researcher bias (**66%**)

MyLymeData: My Data, My Trust

Unfortunately, like HIV/AIDs, mental health, and hepatitis C, patients with Lyme disease have been medically stigmatized and marginalized. Because of

this, many share legitimate concerns about patient data being used to further stigmatize, diminish, and dismiss their concerns. Some big data projects sell

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data to pharma or insurers or otherwise allow data to be used for purposes that don't benefit patients. We do not do this.

“ I think people are leery to share personal information because of how it is used by their job, insurance or government, which can all be untrustworthy. Sadly, people in our position have been discriminated against in one way or another.”

— Survey Respondent

MyLymeData requires that patient data be used only for interests that align with the patient community. We call this “patient-centered” open data. Accordingly, we vet researchers and restrict data use and re-use so that it is for the benefit of Lyme disease patients. We also protect patients by providing researchers with access to de-identified data only, by prohibiting re-identification, and by requiring that, like us, researchers limit access to the data, encrypt the data and maintain it securely.

We believe that patients need to be partners in research to ensure that research addresses their interests. Our commitment is to make sure that patient data is used for the benefit of patients—period.

References

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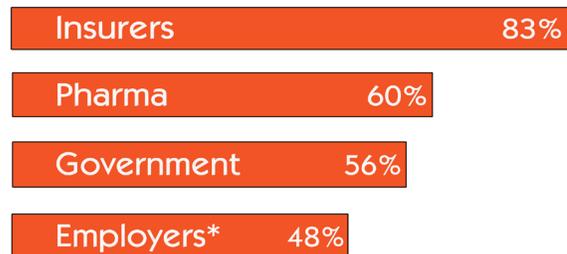


74% have been treated disrespectfully by a clinician



78% worry about healthcare data privacy

Lyme Patients Worry About Use Of Their Data By:



*Includes only those employed or looking for work.



MyLymeData Patient Registry

MyLymeData is a patient-powered Lyme disease research project developed by LymeDisease.org. It was conceived by patients, is run by patients, and addresses the issues that patients care about. It is the largest research project of Lyme disease conducted and has enrolled over 12,000 patients. To join MyLymeData visit MyLymeData.org.