



health+ Lyme Disease

Human-Centered Design Report

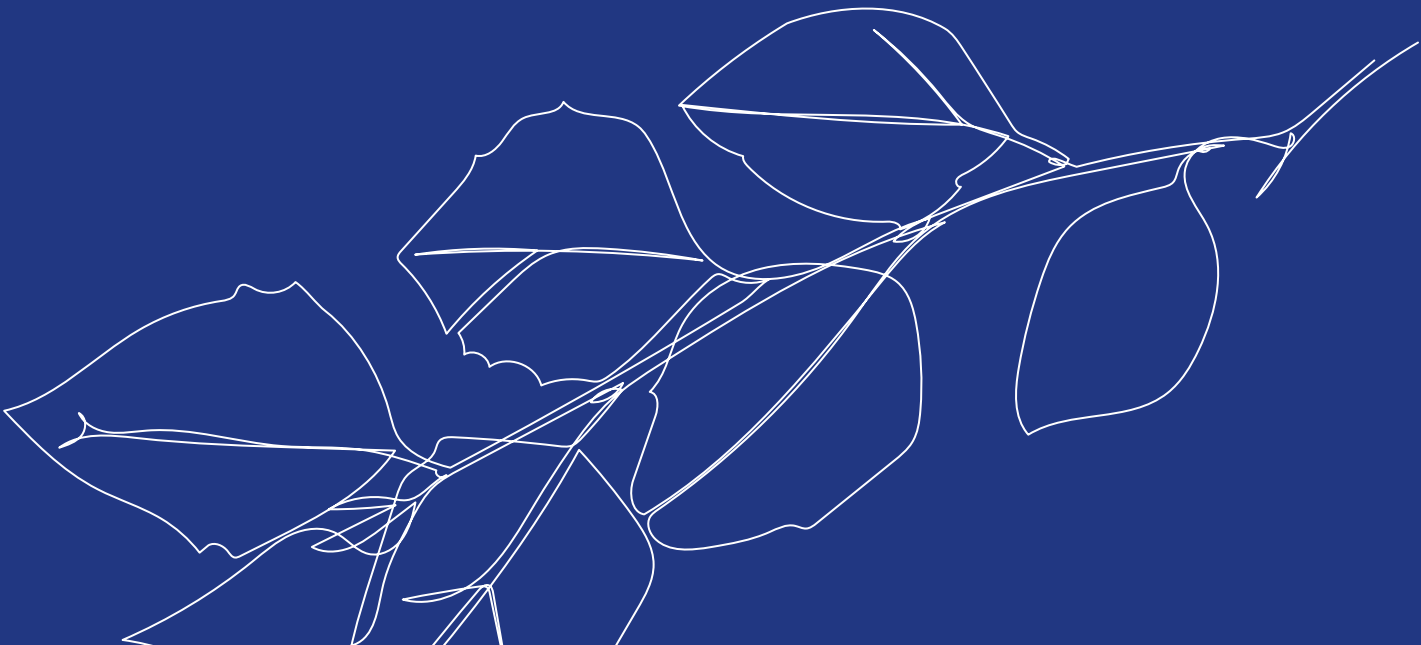


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"The consequences can't be overestimated, now that Lyme disease has become an almost unparalleled threat to regular American life Really anyone—regardless of age, gender, political interest, affluence—can touch a piece of grass and get a tick on them."

—Bennett Nemser, Epidemiologist and Senior Program Officer of the Cohen Lyme and Tickborne Disease Initiative at the Steven & Alexandra Cohen Foundation

"Lyme Disease is Baffling, Even to Experts," *The Atlantic*



About Health+ Lyme Disease

Health+ Lyme Disease leverages the Health+ model to harness the power of human-centered design (HCD) and research methods, drives innovation informed by data, and utilizes technology to build a stronger health safety net for people affected by Lyme.

Through research with Lyme patients, caregivers, leaders, and medical professionals, ongoing cross-collaboration between subject-matter experts (SMEs), and an innovation challenge, Health+ Lyme Disease identifies pressing health challenges that patients face throughout their journey with Lyme disease and responds to those insights by accelerating the implementation of innovative solutions to increase the quality of life for individuals with Lyme disease.

A LymeX Innovation Accelerator Collaboration

The Health+ Lyme Disease program cycle is supporting the LymeX Innovation Accelerator (LymeX), a \$25 million public-private partnership between the Department of Health and Human Services (HHS) and the Steven & Alexandra Cohen Foundation. Coforma facilitates the Health+ Lyme Disease program, collaborating with HHS, PISTIS, CODE, and Ensemble to engage stakeholders, end users, and cross-discipline SMEs to execute the program's component areas.



Our Approach

After onboarding with HHS and other collaborators, our team began its work with desk research, consuming critical papers, studies, and other key publications to develop a comprehensive understanding of the Lyme landscape.

Next, we utilized human-centered design research methodologies to uncover diverse patient stories and experiences. Our research methods included one-on-one interviews, workshops, and diary studies conducted with patients, caregivers, leaders, and medical professionals. We conducted comprehensive recruitment for research participation across a range of demographics, such as age and gender. We also recruited across a variety of geographic locations, including the New England, Great Lakes, and Northern California regions.

The research team synthesized over 50 interviews and workshops with the target groups. Their data-driven findings were compiled as patient archetypes, journey maps, opportunity areas, and recommendations. These findings were reviewed by validation roundtables with key stakeholder groups to confirm their accuracy. The HCD report Coforma generated communicates the validated findings and has been prepared for a diverse set of audiences.

A Comprehensive Approach to Research

We reviewed multiple perspectives on Lyme disease for a comprehensive understanding of today's Lyme landscape.

This report is made possible by the thorough discovery process that preceded it. Discovery involves getting to know stakeholders, consuming existing research, conducting workshops, interviewing and engaging affected audiences, and thoughtfully synthesizing findings.

27
Articles Read

6
Podcasts Series Listened To

53
Hours of Interviews

7.5
Hours of Workshops





OPPORTUNITY AREAS // JOURNEY MAPS // ARCHETYPES

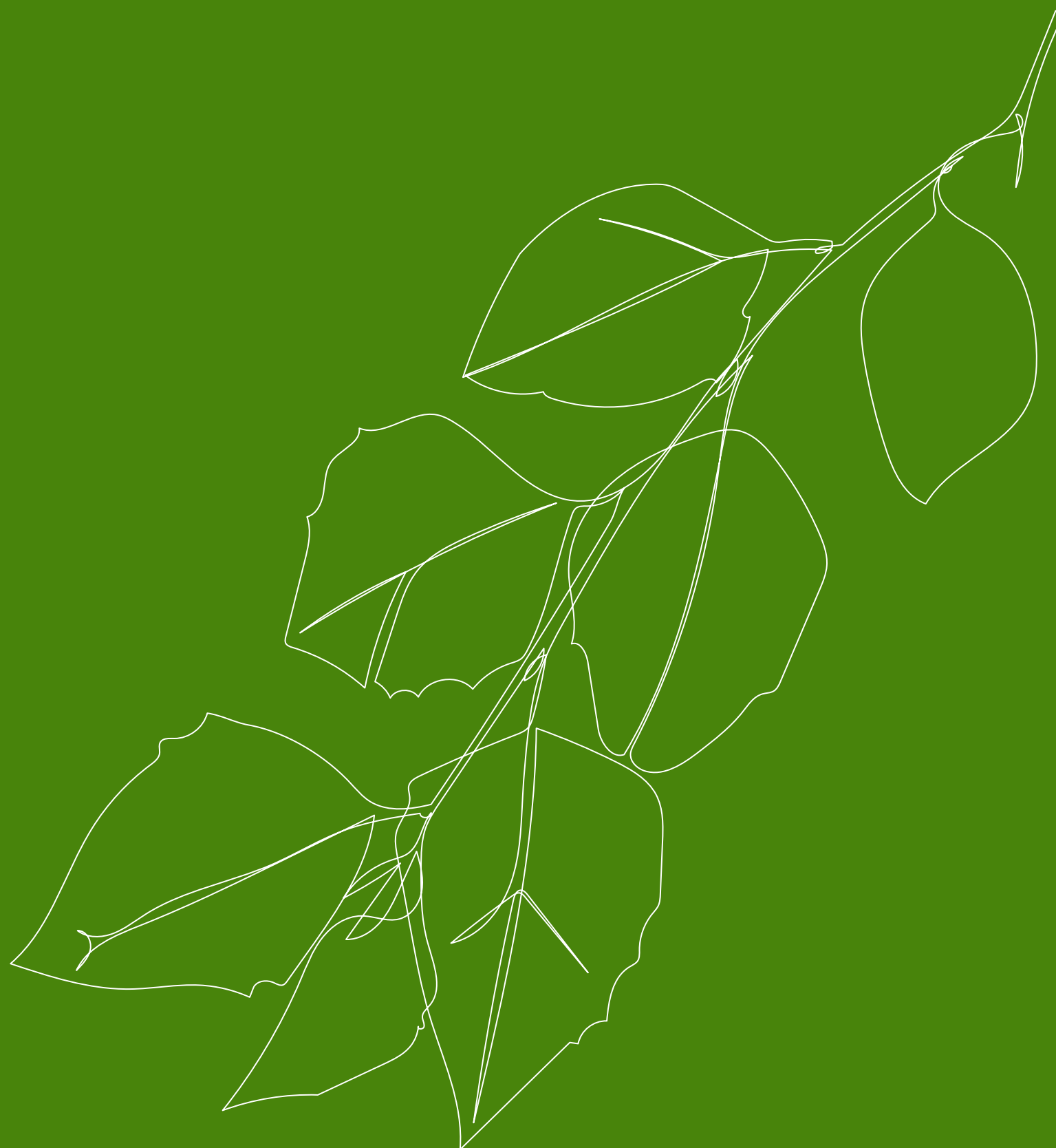
Executive Summary

Before creating innovative solutions around Lyme disease, it's crucial to have a solid understanding of the key opportunities for change within the patient experience, the trends in the needs and perspectives of Lyme patients and caregivers, and the paths—including hurdles and key decision points—

that patients undergo in finding a diagnosis and navigating their care coordination and treatment.

This report details each of these areas in depth. The key, synthesized points that drive the following chapters are contained in the executive summary.





Journey Maps

Speaking directly with patients, caregivers, clinicians, and leaders in the Lyme disease space illuminated two significant journeys for a patient: the diagnostic and the treatment journey for persistent symptoms. These journeys illustrate potential patient experiences they may encounter and paths they travel in their pursuit of diagnosis and treatment. Later in the HCD Report, these journey maps guide and contextualize in-depth stories from patients that help identify clinician touch points, barriers, and the overall patient experience to unlock powerful opportunities for each journey.

Diagnostic Journey

The Lyme disease diagnostic journey can be a crucial and influential phase in the patient's overall journey with Lyme disease.

The length of the journey can vary from one day to potentially decades, with the prospect of emotionally, financially, and physically devastating a patient and caregiver. Through this period of trying to find diagnoses, a patient and caregiver could experience discrimination, misdiagnoses, and mistreatment, forcing them to become their own advocate and find the answers to Lyme's symptoms. The stress and potential trauma from the journey can be so impactful to the patient that it can leave them more vulnerable to Lyme's symptoms.



"So seven-and-a-half years to get to diagnosis. And I'm at about seven-and-a-half years of treatment. I went from literally incapacitated, bed bound, housebound, completely dysfunctional... while trying to raise two children."

—Patient

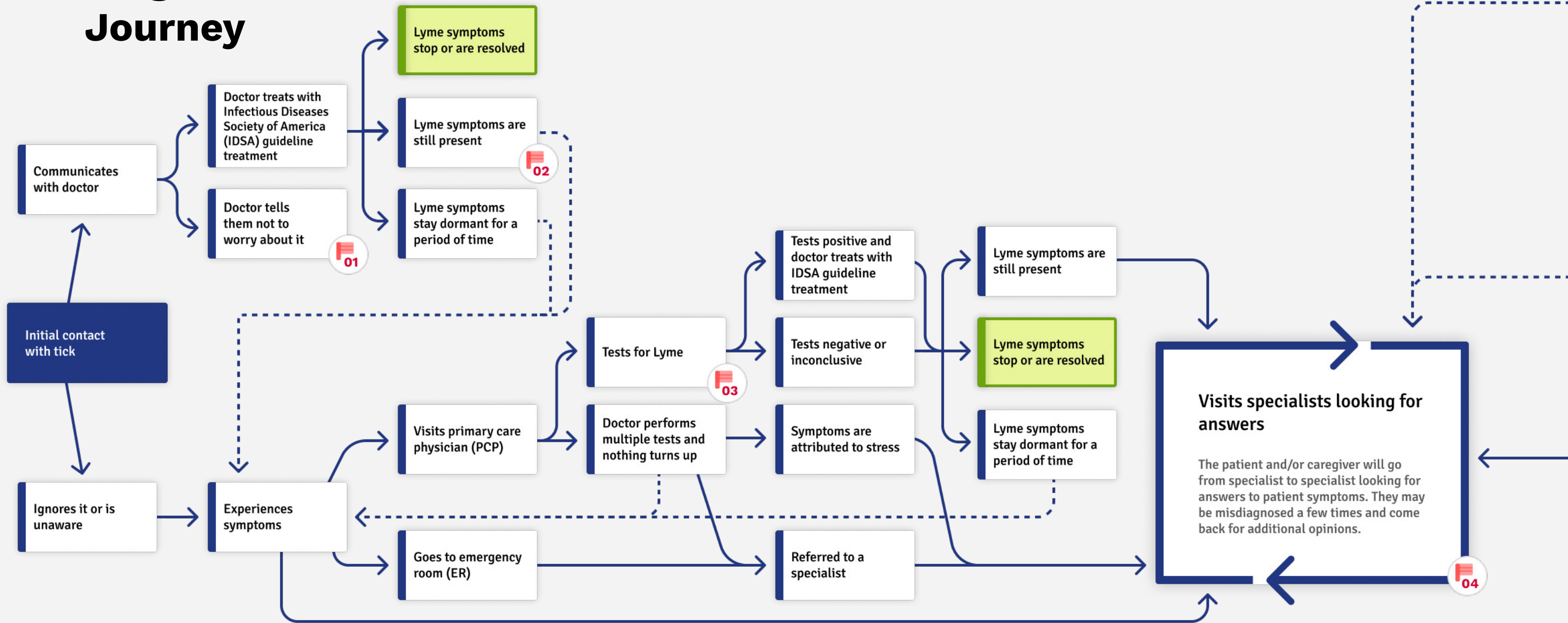
"I was just in and out of doctors for years and all my tests always came back negative and they said, 'Oh, you're a busy student.'"

—Patient

"I spent the next couple of years trying to figure that out. I was under a lot of stress at work. And so a lot of my symptoms were pawned off to depression or anxiety or stress."

—Patient

Diagnostic Journey

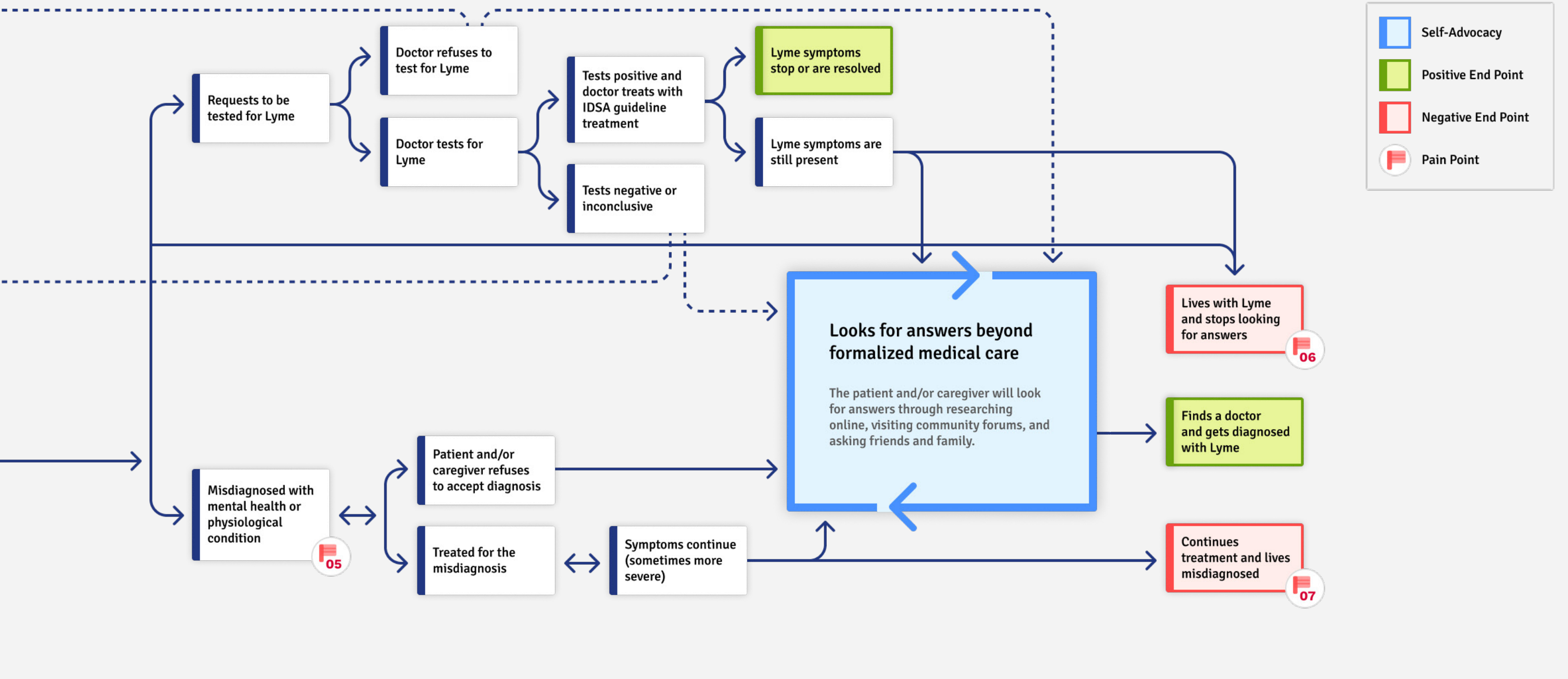


Pain Points

01 Allows the infection to have more time in the body, leading to more severe symptoms

02 Usually no follow up after treatment, leaving the patient without guidance or further medical help

03 Usually doctor will know to test if the patient remembers contact with tick, has a “bull’s-eye” rash, or lives in an endemic area



04
This moment can be overwhelming and financially devastating, sometimes lasting for years without answers

05
This could lead to the patient being given unnecessary medications and surgeries that could cause financial and physical consequences

06 & 07
Symptoms may become more severe and lead to other health complications



Treatment Journey for Persistent Symptoms

The Lyme disease treatment journey for persistent symptoms maps out the potential ways a patient may receive treatment and manage their persistent symptoms.

This journey, for some, is still active, with patients and caregivers still searching for guidance today. Coordinating care for persistent Lyme symptoms forces patients to endure cycles of searching for answers and testing out new and sometimes harsh treatments, while managing their symptoms and life responsibilities.



"We don't really know to keep going or stop. So that was like an impossible decision as a patient, because you could be having some horrible symptoms and say, okay, I'm going to keep going because on the other side of this horrible reaction, I could start to get better. But you don't know if it is actually doing more damage."

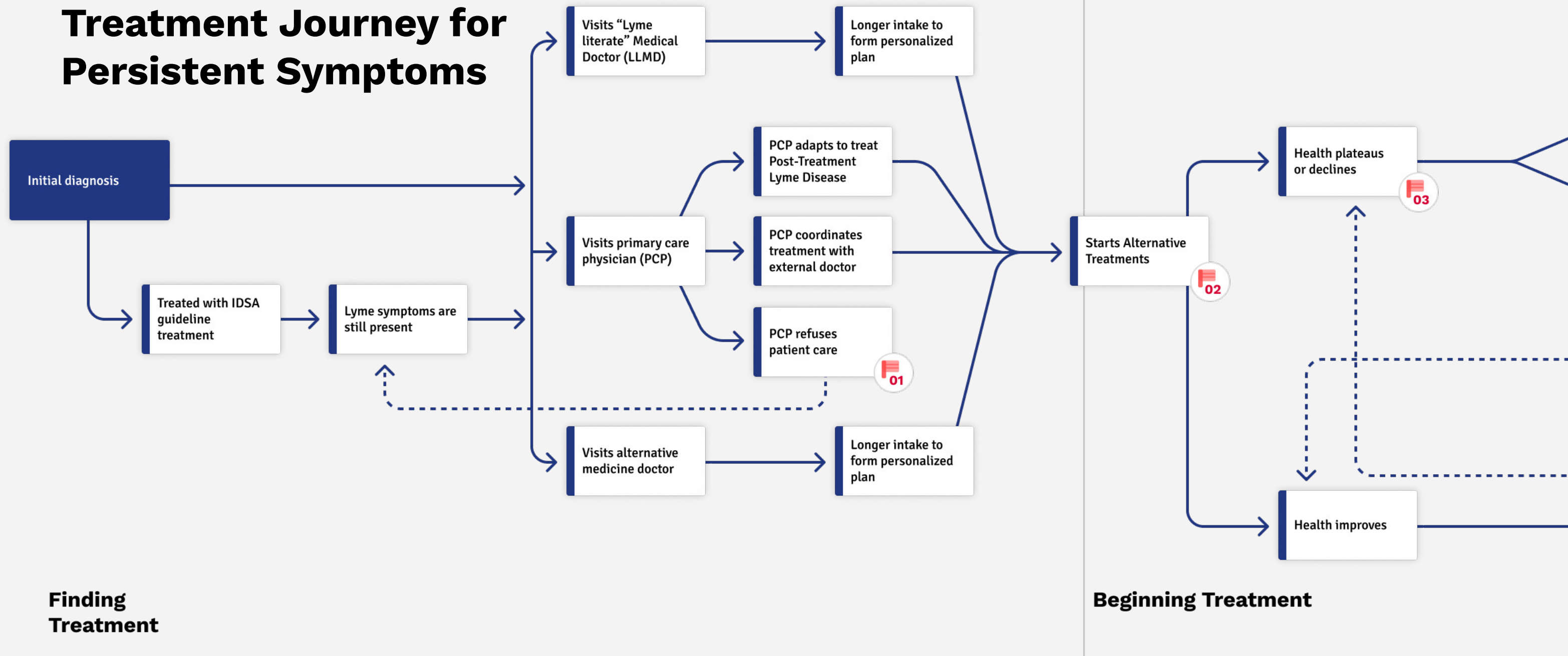
—Patient

"My doctor said for that treatment that some people get better right away while others get better and then plateau. It's impossible to know until you try. I was on treatment for 26 weeks and nothing was happening for me. I finally said, you know what? It's just not happening and we're so deep in debt that I don't want to keep going."

—Patient



Treatment Journey for Persistent Symptoms



Finding Treatment

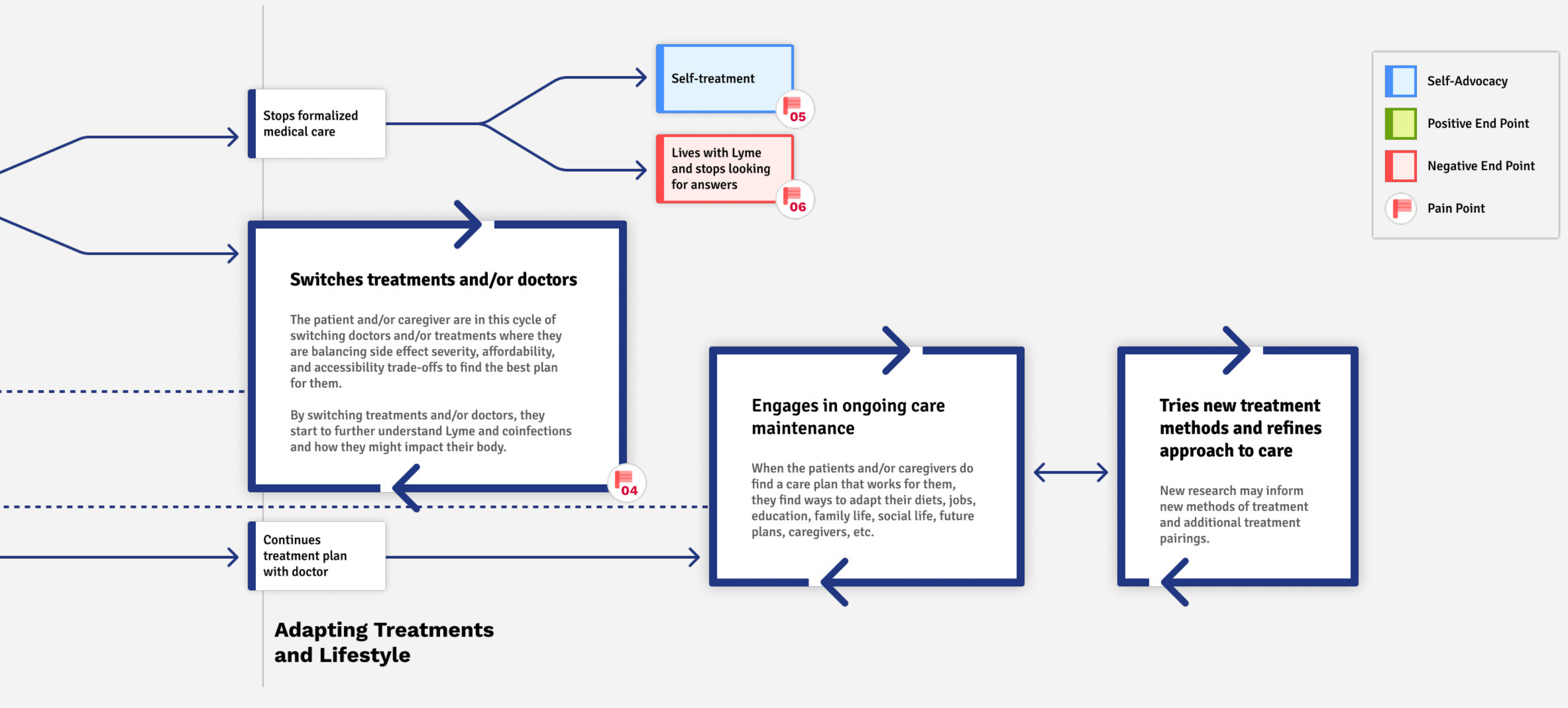
Beginning Treatment

Pain Points

01 Leaves the patient without proper care and still experiencing symptoms

02 Insurance usually drops off at this point, and medical costs start to build up

03 Work and/or employment can be severely impacted at this point



04
Can be financially devastating and have lasting, damaging impact on health

05
Without medical guidance, this could lead to damaging and costly consequences

06
This infection could further harm the body, leading to worse symptoms



The Archetypes of Lyme

Archetypes are a distillation of design discovery insights meant to describe patient needs, goals, barriers, and habits.

They serve as a communication tool that helps teams build empathy towards patients and address their needs. They are developed through analyzing qualitative data and are useful when patients behave differently and their various needs have to be addressed. Four archetypes were developed by combining two distinct variables that help measure each group's barriers, needs, and actions.

Lyme's wide range of symptoms, unpredictable flare-ups, and overall symptom severity considerably disrupt the patients' lives in various ways, including caregiving responsibilities. Because Lyme derails their lives so profoundly, Lyme's level of disruption became the first variable to help group the patients into archetypes. The factors of disruption include but are not limited to symptom unpredictability, enrollment in school, provisions to take leave from their work, and engagement in future family and financial planning.

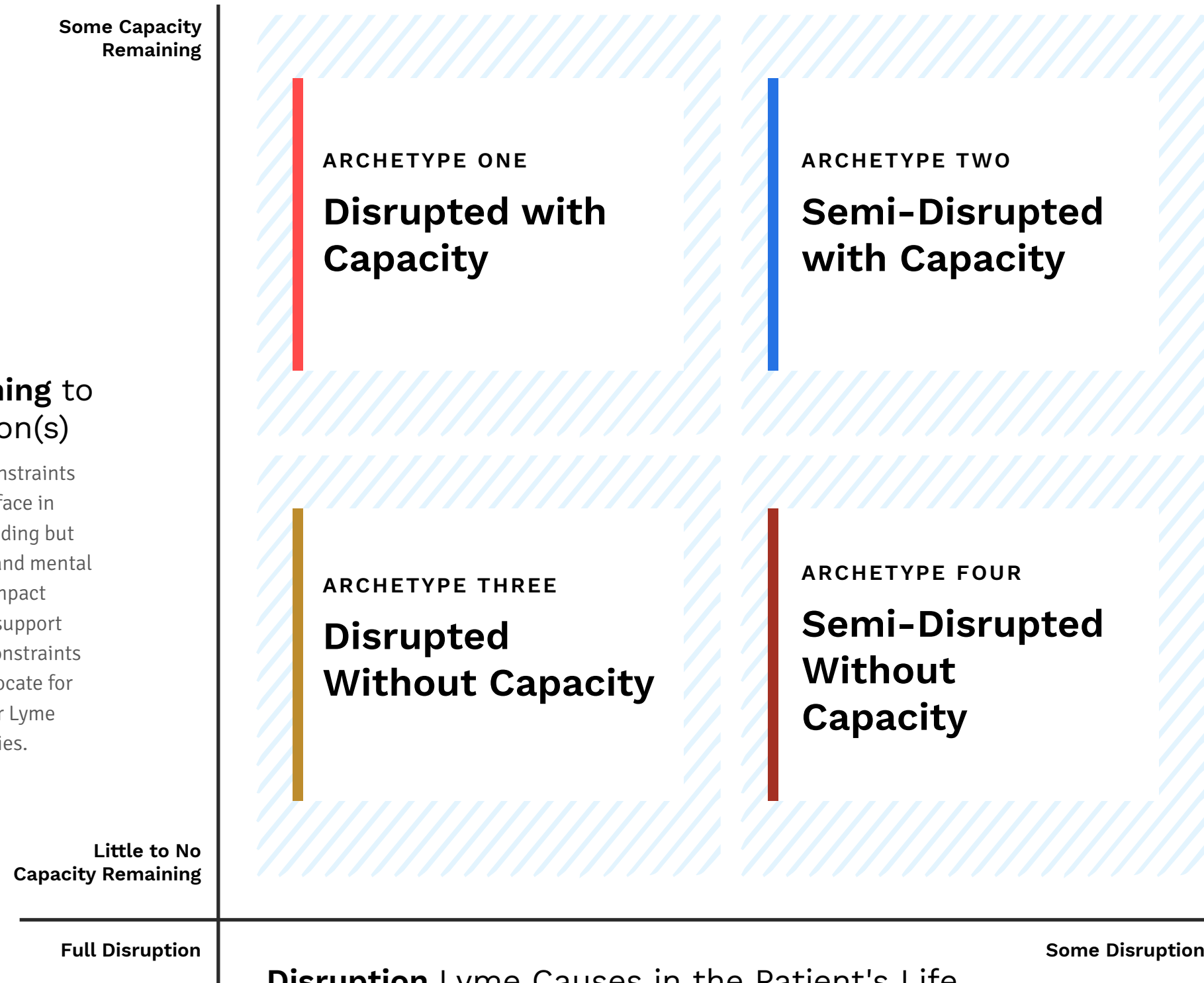
The second variable used to form the archetype groups was the patients' capacity to manage Lyme's disruptions in their lives. Capacity deals with the constraints they face in coordinating their care, including but not limited to their physical and mental state from their symptoms' impact and financial and social support they have access to. These constraints affect patients' ability to advocate for themselves and to balance their Lyme with competing responsibilities.

While capacity and disruption are interrelated, capacity refers to people's empowerment to manage their condition, and disruption deals with the extent to which Lyme interrupts their daily life and responsibilities.



Capacity Remaining to Manage Disruption(s)

Capacity is defined by the constraints that patients and caregivers face in coordinating their care, including but not limited to their physical and mental state from their symptoms' impact and the financial and social support they have access to. These constraints affect patients' ability to advocate for themselves and balance their Lyme with competing responsibilities.



Disruption Lyme Causes in the Patient's Life

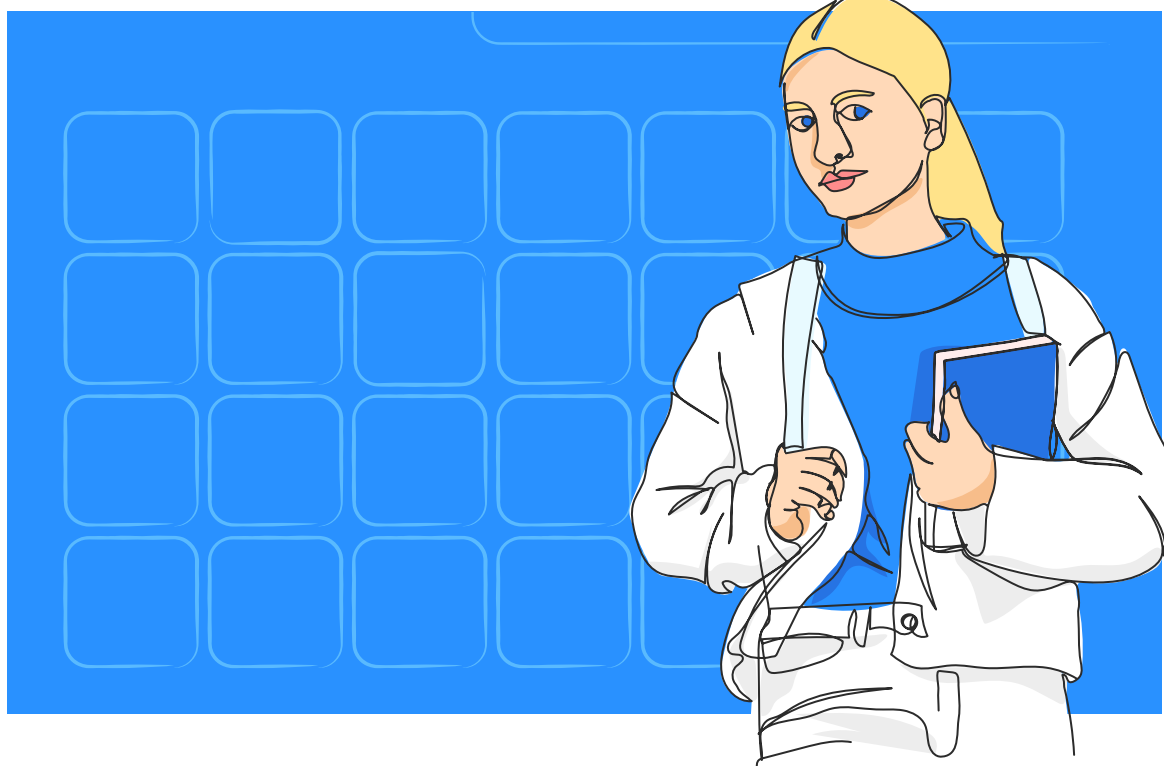
Defined by factors involved in derailing patients' prior responsibilities and social roles. These factors include but are not limited to symptom unpredictability, enrollment in school, provisions to take leave from their work, and engagement in family and financial planning.



ARCHETYPE ONE

Disrupted with Capacity

Lyme has forced this group to forego future planning to deal with urgent needs. They have access to financial and social support that empowers them to take charge of their treatment plan. This helps them navigate tough treatment decisions independently, but it also makes them more prone to exposure to irrelevant or unsafe information without proper guidance.



ARCHETYPE TWO

Semi-Disrupted with Capacity

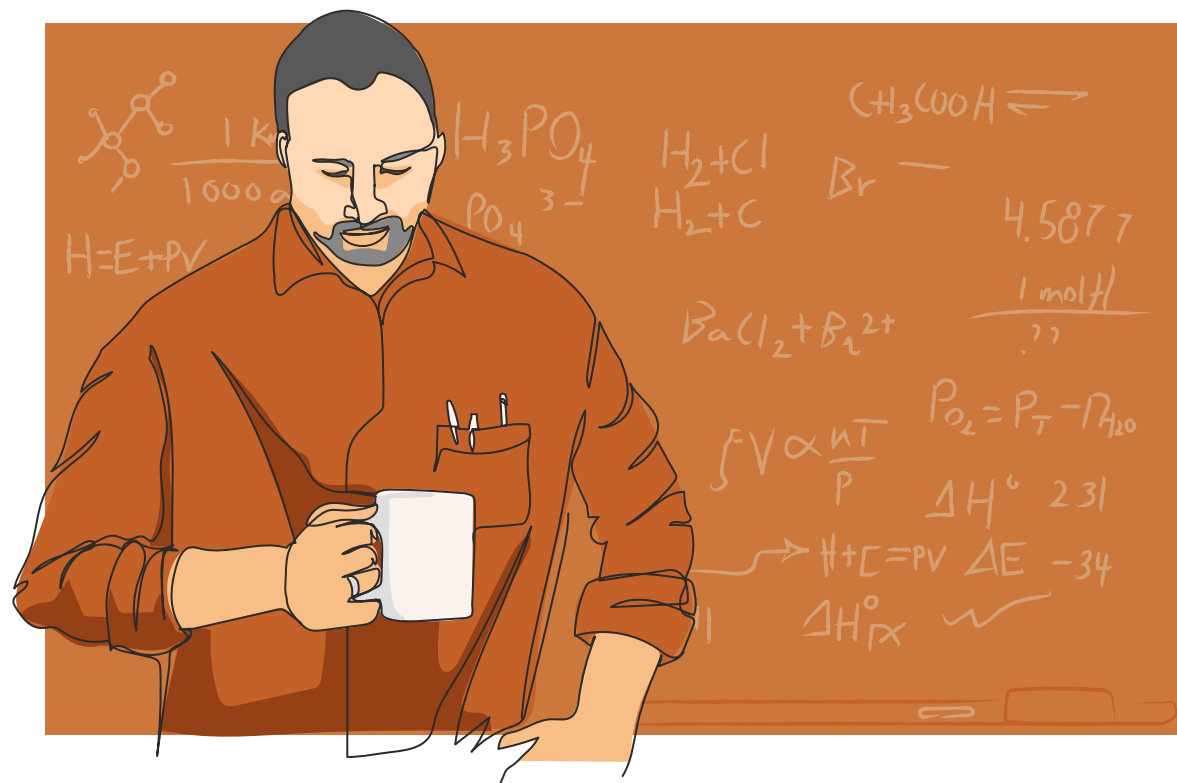
Lyme has put a dent in this group's lives but does not completely throw them off track. They feel empowered to make their treatment plan decisions and are likely to have the financial and social support necessary to carry those decisions through. They orient their treatment around their lives as much as possible.



ARCHETYPE THREE

Disrupted Without Capacity

Lyme has forced this group to forego their current career and future planning to take care of immediate needs. Lyme's severe impact on their condition constrains their ability to make independent decisions surrounding their treatment. They heavily rely on their caregiver for support and work closely with them to navigate treatment decisions.



ARCHETYPE FOUR

Semi-Disrupted Without Capacity

Lyme has forced this group to balance their inconsistent disruptions and the demands to provide for themselves and their loved ones. They are typically restricted financially and lack the caregiver support sometimes needed, which aligns their treatment plans with tried-and-true, low-risk methods to adapt to their work or education.



Opportunity Areas

Research across impacted groups revealed a number of opportunities for improving the lived experience of people who are impacted by Lyme disease. These opportunities for improvement across the patient experience are grouped into four main focus areas. Specific opportunities are articulated in greater detail later in the HCD Report.

01

Broader Awareness of Lyme Disease

- Generate greater public awareness and bolster prevention
- Improve medical awareness of and fluency in Lyme approaches across specializations

03

Cohesive and Comprehensive Care Coordination

- Create seamless coordination between healthcare providers and patients/caregivers
- Provide adequate support and resources to healthcare providers treating Lyme
- Break down medical silos that cause financial burden for patients and caregivers
- Protect patients from abuse and discrimination

02

An Accelerated Diagnostic Process

- Build awareness around symptoms outside of the "bull's-eye" rash to motivate Lyme testing and diagnosis
- Resolve conflicting medical advice around diagnosis and streamline information across provider network
- Empower patients and caregivers to better navigate the process with knowledge and tools

04

Holistic Life and Care Management

- Help patients plan for their future
- Support patients navigating bureaucratic challenges
- Create a long-term support system for patients and caregivers managing persistent Lyme

DIAGNOSTIC JOURNEY // TREATMENT JOURNEY
FOR PERSISTENT SYMPTOMS

Journey Maps

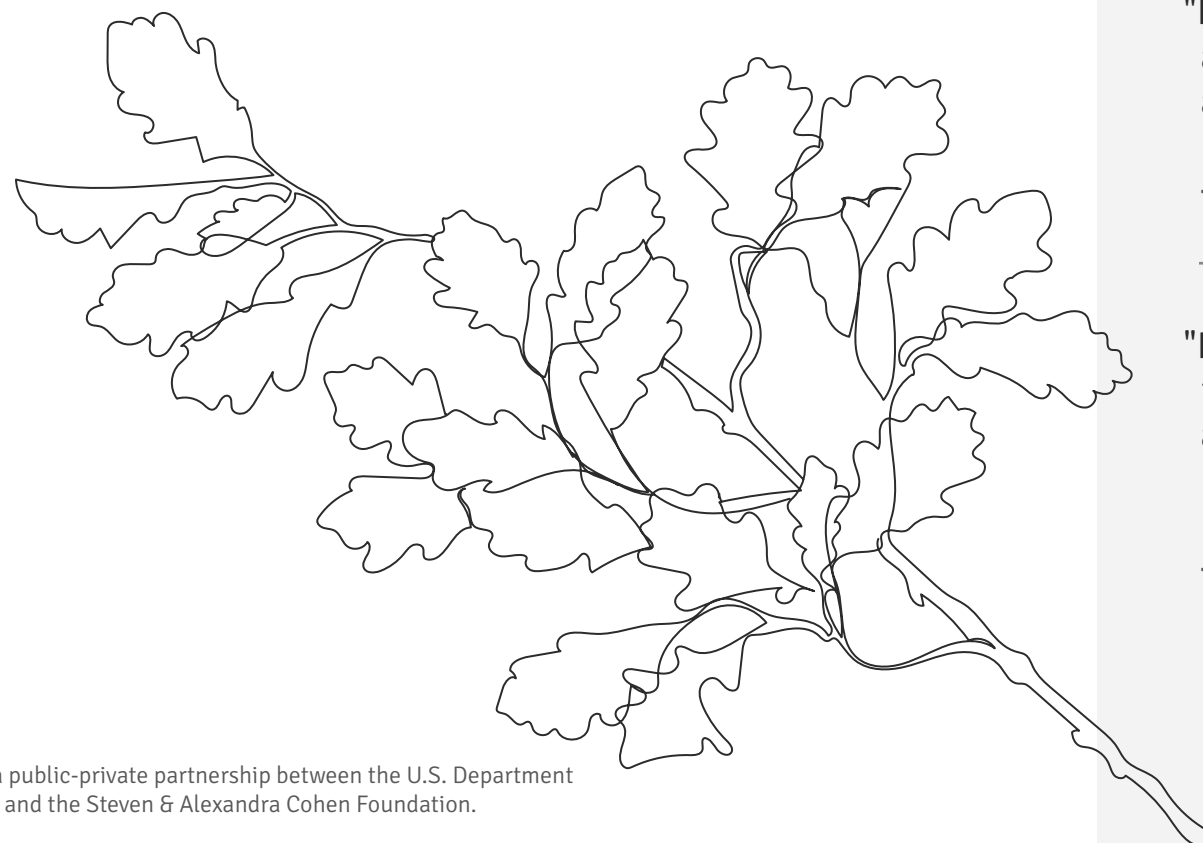




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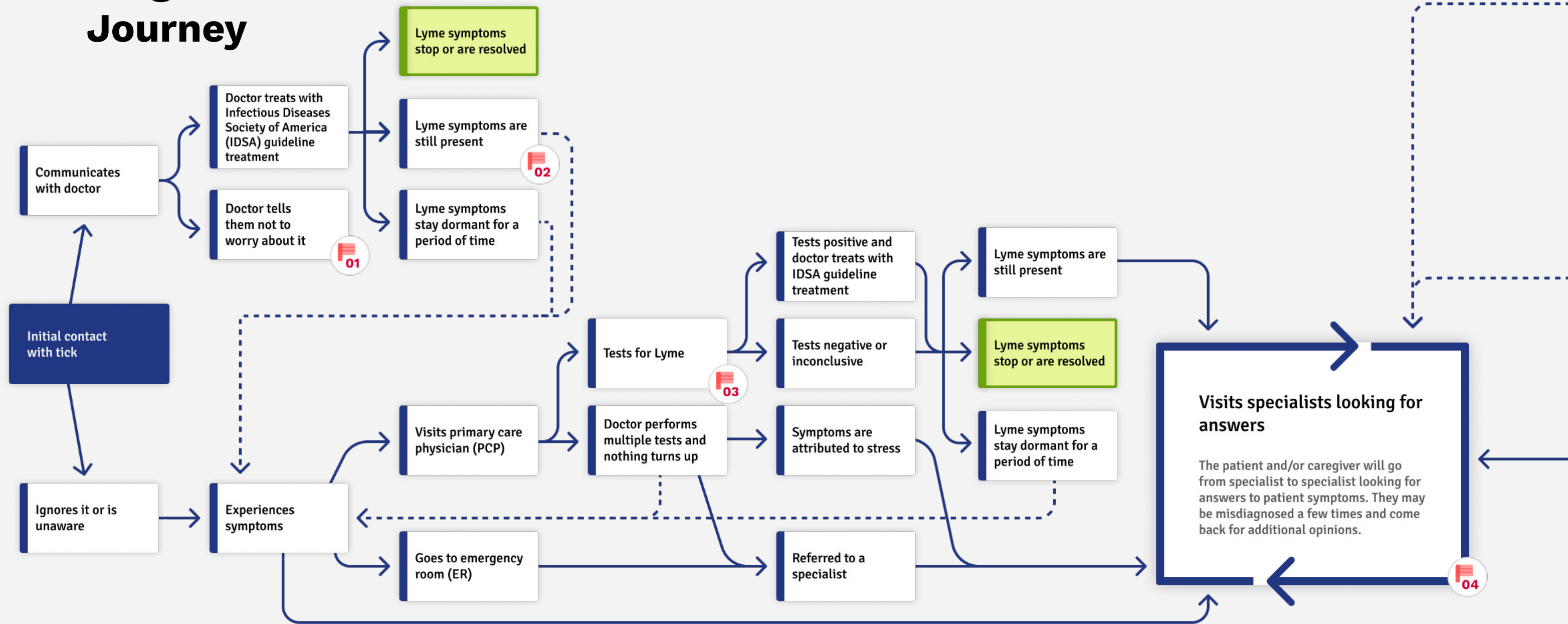
"I was just in and out of doctors for years and all my tests always came back negative and they said, 'Oh, you're a busy student.'"

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Diagnostic Journey

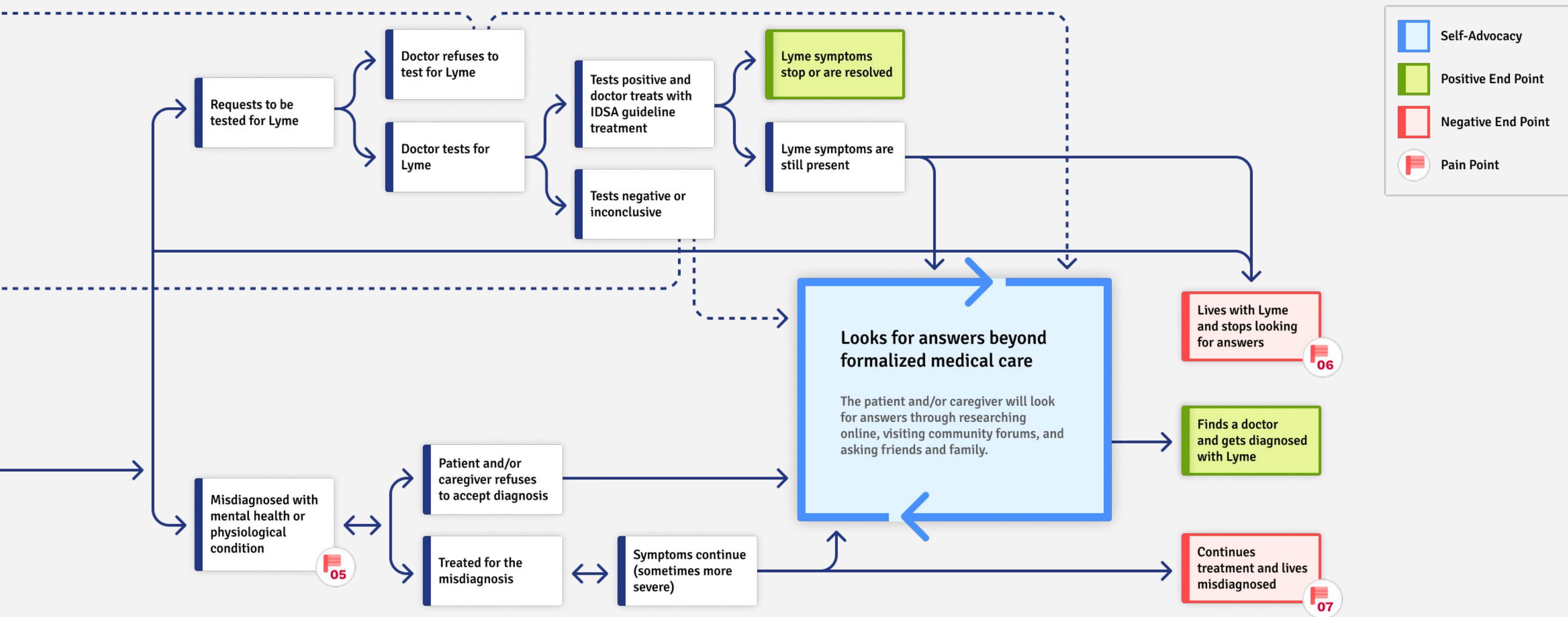


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A Closer Look into the Lyme Diagnostic Journey

The in-depth diagnostic journeys are a composite of multiple, real patient experiences—including real quotes—as shared over the course of the Health+ Lyme Disease discovery phase through multiple patients.

When reading the journey maps, the actions show the high-level steps along the journey, while the other elements reveal research insights that can inform opportunities for improvement. These two in-depth journey maps were created to help visualize the diverse and sometimes harsh experiences that Lyme patients undergo while searching for their Lyme diagnosis.

The two journeys are told through the fictional characters, Mia and Sam. Mia is a young teen who navigates through her diagnosis with the help of her parents. In contrast, Sam is an adult forced to forego his career and plans to find the proper diagnoses. While they both sometimes share similar pain points, their stage of life and the diagnostic path differs significantly, uncovering opportunity areas in their journey.

Journey Map Key



PATIENT QUOTE

These quotes come directly from patients we interviewed.



CLINICIAN TOUCH POINT

Clinician touch points refer to contact between the patient or caregiver and the patient's healthcare provider (HCP).



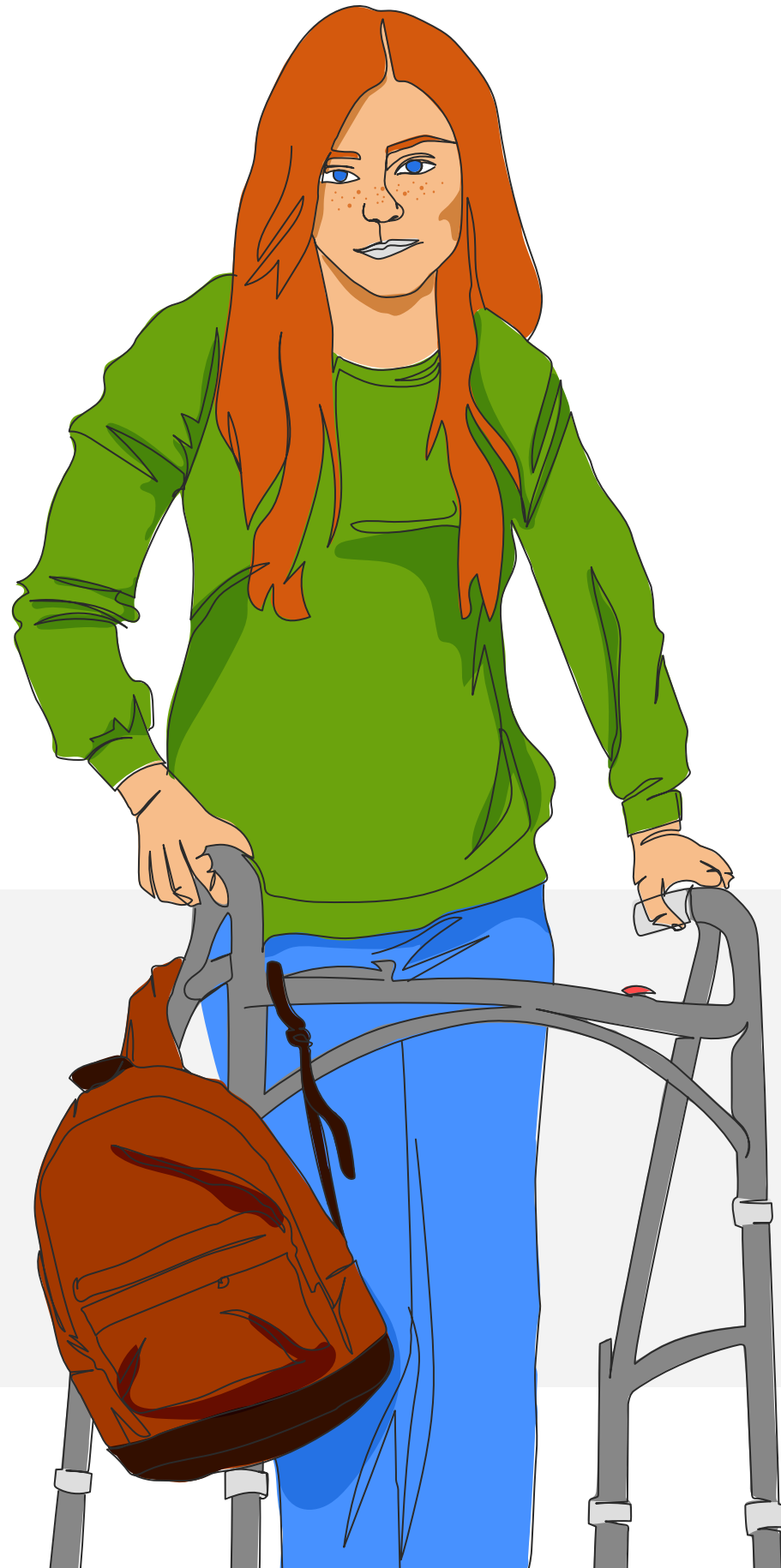
PAIN POINT

Pain points indicate challenges and difficulties that arise along the journey.



RECOMMENDATION

A recommendation is an explicit opportunity to improve a pain point along the patient's journey.



Mia's Diagnostic Journey

Mia was a healthy, 16-year-old girl who played on a varsity sports team and participated fully in her school life.

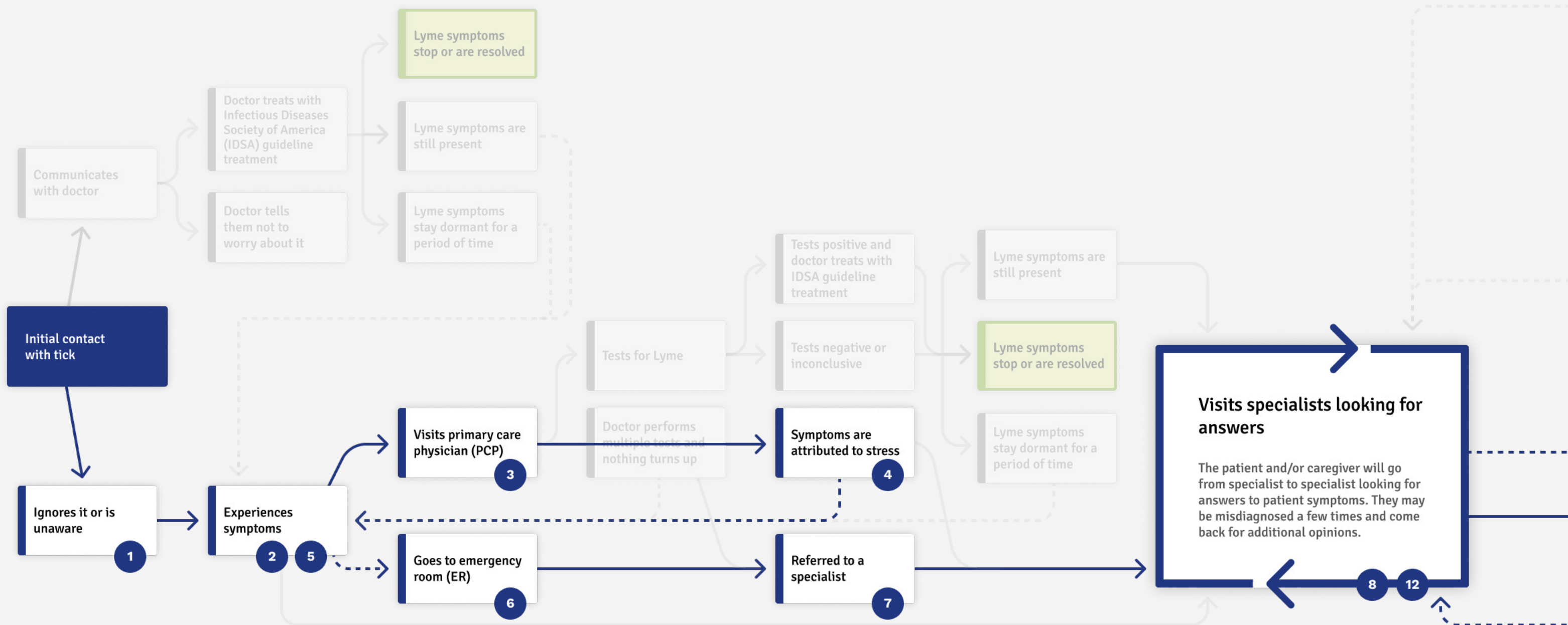
When she started experiencing symptoms, Mia was forced to forego her life as she knew it. Mia faced discrimination and abuse from her doctors, causing trauma along her road to diagnosis. With the help of her parents, Mia was able to get correctly diagnosed after four years of mistreatment and distrust from her doctors.

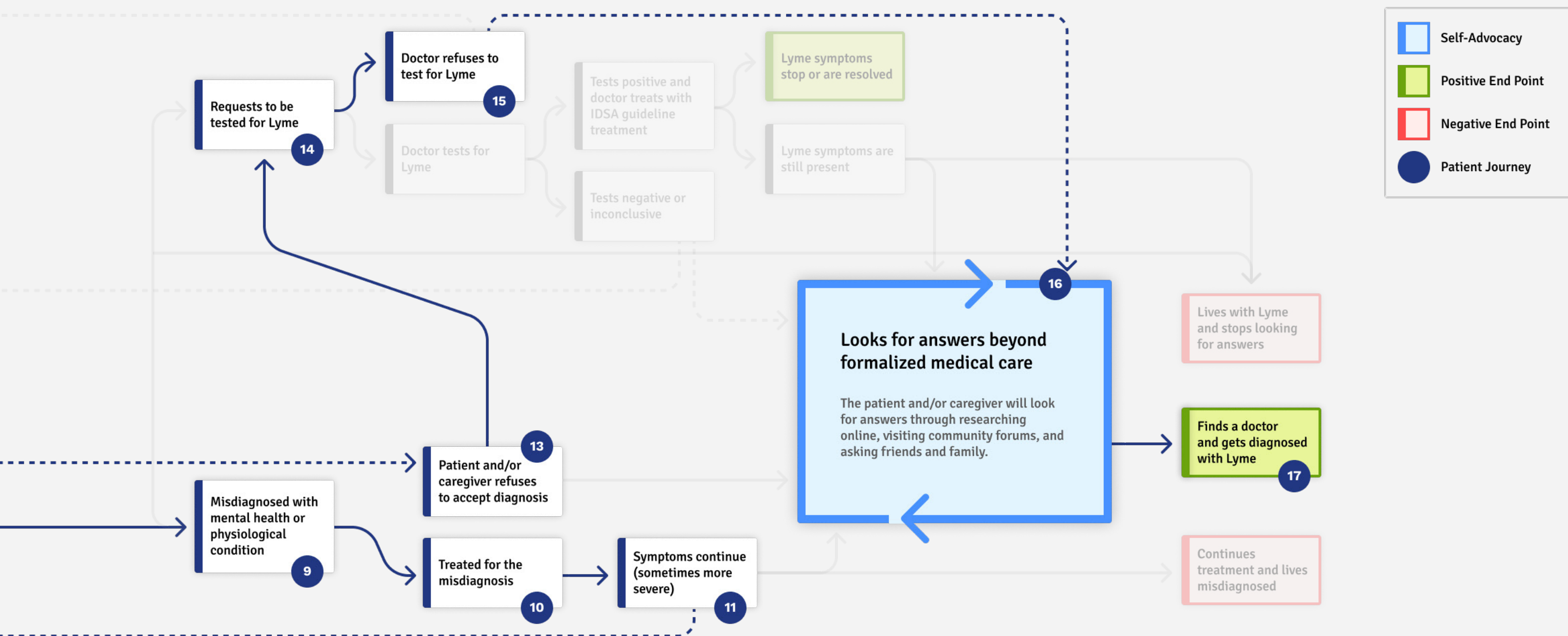


"This was another year lost. And you can't ever go back in time. These are years of lost time with my grandparents. These are years lost with friends. These are years lost. I lost so many years, and I will never get them back. And you know people always say to me, 'You're young. You have so much time to make up for it.'"

—Patient

Mia's Diagnostic Journey





Mia's Diagnostic Journey

Experiences mild symptoms

While in school, Mia began to experience mild symptoms that her parents initially wrote off as growing pains. Once the symptoms started to affect her school participation, they became slightly more concerned.



Visits PCP

While a high achiever, Mia constantly struggled with her symptoms, which impacted her school work and sports team. When her primary care physician saw her, he told her that her symptoms were nothing to be concerned about and gave her advice to help manage them. She and her parents listened to the doctor and continued to push through.



Experiences severe symptoms

Mia's symptoms became much more severe, preventing her from regularly attending school.



Goes to ER and is referred to a specialist

Mia's parents pulled her out of school and took her to the ER, where they gave her quick medical relief and referred her to a specialist to further examine her.



PATIENT QUOTE

"So it wasn't until I was about 12 or 13 that I started developing much more noticeable symptoms. I had terrible knee pain, but I'm also six feet. So the doctors thought, you know, they're growing pains. I grew very quickly, but they didn't go away. You know, I had terrible knee pain for a very long time. I started having back pain and I was really in a fog. Like I just, I never really knew what was going on."



PAIN POINT

Mia and her parents were unaware of her contact with a tick, which made it hard for them to know that Lyme disease was even a possibility. Also, Lyme symptoms in a child are often overlooked as growing pains.



RECOMMENDATION

Create early childhood education modules around Lyme, focused on developing safe outdoor habits with the aim of prevention in early life.



PATIENT QUOTE

"I was very active in school, and I was just pushing because, you know, I wanted to get into a good college. Like I was very motivated and very focused. So I just kept going into the doctor and the pediatrician; you know, you listen to your doctor. It was just what I thought you would do. That doctor says you're fine. I thought I was fine. I just thought, oh man, you know, I'm working really hard."



PAIN POINT

Adolescents like Mia experience difficulty and lack of trust when conveying their symptoms to their doctors and parents. Between those difficulties and the ambiguousness of symptoms, their Lyme symptoms are often overlooked. Since the symptoms go ignored, the infection continues to grow more severe.



CLINICIAN TOUCH POINT

Mia's primary care physician did not take her symptoms seriously, writing them off as another teenager experiencing stress for the first time.



RECOMMENDATION

Develop a way for adolescents to be able to better express their symptoms so their parents and doctors can better understand what they are experiencing.



PATIENT QUOTE

"Essentially I'd be in bed, and I could move, but the pain was so bad. I might as well have just been paralyzed or locked up because I wasn't moving because of the pain. And then sometimes my hands would get stuck and locked in this position and unable to move for days."



PAIN POINT

Once the symptoms became too severe, Mia was forced to withdraw from school. This withdrawal can be isolating and emotionally straining on a patient. Mia's body was also experiencing severe stress and impact. Her condition could have caused other conditions to arise.



RECOMMENDATION

Develop diagnostic programs that help patients with unknown symptoms connect to peers and adapt their lives to their ongoing search for answers to their symptoms.



PATIENT QUOTE

"We tried again for high school, but she wasn't able to last; you know, she would go into seizure activity, and more likely than not, I'd drive her to an ER rather than home."



PAIN POINT

The ER did not have the awareness established to understand Mia's severe Lyme disease symptoms; because of this, the doctors treated Mia with something that caused her symptoms to worsen.



CLINICIAN TOUCH POINT

The ER didn't know the precise cause of the symptoms and referred her to the specialist most closely aligned to her primary symptoms, which was a neurologist.



RECOMMENDATION

Develop educational resources to increase awareness across a diverse range of HCPs (e.g., therapists, ER doctors, insurance advocates, etc.).

Mia's Diagnostic Journey (Continued)

Receives a mental health condition diagnosis from a specialist

While in the hospital, Mia and her parents were taken to a specialist for a diagnosis. The doctor ran a multitude of tests that all came back negative. The doctor then ordered a psychiatric evaluation on Mia that resulted in no answers. Eventually, Mia was diagnosed with a mental condition to which her symptoms were attributed. She received treatment for this condition.



Undergoes treatment for misdiagnosis

Mia and her parents returned home worried and with no answers about her symptoms. Mia started taking newly-prescribed medications and tried to regain a sense of normalcy.



Continues to live with severe symptoms

Mia remained unable to go to school and relied heavily on her parents and in-home tutoring to receive an education without much help from her prior school. Isolation from her friends and school, which was all she had ever known, led Mia to feel a loss of identity.



Visits more specialists

After Mia's health didn't improve, her parents took her to another hospital in search of new answers that could help Mia. They experienced the same mistreatment as the last hospital, which frustrated her parents even further. They refused to believe the new diagnosis they were given.



PATIENT QUOTE

"They said, 'Let's have her evaluated.' And the first psychiatrist team that came ruled her out for everything. They said, 'This is not psychological.' The attending physician was [so] upset with this report that she ordered a second psychological evaluation. You know, she didn't want to take no for an answer. The second one said the same thing, and she decided to order a third After she tested negative for everything, they told us that she was faking it."



PAIN POINT

At this point, Mia was so severely affected by her condition that she could not advocate for herself and was forced to rely on her parents to pursue a diagnosis for her. She also experienced age-related discrimination and was not taken completely seriously by her doctor. Young patients are especially vulnerable to discrimination and medical abuse when they experience symptoms that have no answers.



CLINICIAN TOUCH POINT

Mia's doctor didn't take her condition seriously. Instead, they deemed it either psychological or invented, because there were no clear medical answers for her symptoms.



RECOMMENDATION

Provide a Lyme code of rights that outlines patients' rights to freedom from discrimination, coercion, harassment, and exploitation.



PATIENT QUOTE

"They put me on Zofran and Trazodone, which is for insomnia. You know, they were medicating me left and right."



PAIN POINT

Without any further answers, Mia was treated for a mental condition she didn't have. This treatment caused her symptoms to worsen and the situation left her feeling invalidated and alone.



RECOMMENDATION

Provide neutral, mental healthcare access and advocacy for patients still searching for a diagnosis that doesn't influence their diagnosis, and helps coach them through the process.



PATIENT QUOTE

"We applied for home instruction, believe it or not, and they took until January to approve. It was one of the things my daughter was so adamant about, it was the only thing normal left in her life, her academia. You know, that's been my biggest challenge because I deal with tremendous amounts of indifference from the department of education. They don't care. They keep saying to me, 'She has till she's 21 to finish school. What are you worried about?'"



PAIN POINT

Mia experienced severe isolation and depression from not being believed by her doctors and from having to withdraw from her school and community. Her caregivers became burdened with providing full-time support.



RECOMMENDATION

Create education programs that adapt to the patient's condition while still managing to give them the level of education that peers their age receive, with the potential to also further connect them to peers their age with mentoring help and social time.



PATIENT QUOTE

"And they would read the note like I wasn't there, whispering to each other, reaching for psychological disorder. I'd be like, 'Guys, I know what the health records say I brought them to you. Obviously, I disagree. Look at her, she's running a fever. She's blue. Can we investigate?'"



PAIN POINT

Mia and her parents were openly not trusted or validated by their doctors, causing them to pull away from their doctors even further.



CLINICIAN TOUCH POINT

The new doctors Mia saw didn't take her condition seriously. Again, they deemed it either psychological or invented, because there were no clear medical answers for her symptoms.



RECOMMENDATION

Develop educational resources for HCPs that focus specifically on how the neurological symptoms of Lyme may present themselves.

Mia's Diagnostic Journey (Continued)

Caregiver refuses to accept diagnoses

Mia's parents left the hospital feeling frustrated and confused. They decided it was time to take matters into their own hands since Mia wasn't able to advocate for herself because of her age and the severity of her condition. Mia's parents decided to conduct their own research into her symptoms to find answers, looking at all of the possibilities and potential causes of her symptoms.



Requests to be tested for Lyme, and the doctor refuses

Mia's parents' research led them to believe that Mia's symptoms were caused by Lyme. They brought the information to the doctor, and he refused to test her for Lyme. They left the doctor's office frustrated yet confident that Mia had Lyme.



Looks for answers beyond formalized medical care

Mia's parents looked to Lyme communities and Lyme research to find answers that would help get her care and a diagnosis for Lyme. They quickly became aware of the reasons they were not getting proper treatment from healthcare providers. They found a "Lyme literate" Medical Doctor (LLMD) and made an appointment.



Finds a doctor and gets diagnosed with Lyme

Mia and her parents were immediately received and trusted by their new LLMD. He listened to their prior research and Mia's symptom journey, taking into full account the severity of her situation. For the first time on their journey, the whole family felt validated.



PATIENT QUOTE

"There were lots of little things here and there that made me raise my eyebrows about what was going on. I know that coming from a dad, it sounds ridiculous. But nobody knows my daughter as well as I do. And I'd be the first one to call out anything negative as well as anything positive. I'm very realistic. And all my children will agree. They were calling her crazy. And that's one thing I knew that my daughter was not."



PAIN POINT

Mia's parents were burdened with not only full-time caregiver responsibilities, but also the role of finding the answer to Mia's symptoms. They were forced to put their jobs aside to research what could be causing her issue.



RECOMMENDATION

Provide caregiving platforms that can help monitor and track the patient while the caregiver may be away.



PATIENT QUOTE

"I kept saying, 'We own a home in an endemic area for Lyme. And I remember a bull's-eye rash on my daughter.' And they said, 'No, it can't be Lyme because it's May and it was a hard winter. So it was still cold out. There's no way this could be Lyme.'"



PAIN POINT

Mia's parents left once again frustrated and without answers or help. Doctors without proper Lyme awareness can make bold decisions with devastating consequences to the patient.



CLINICIAN TOUCH POINT

The doctor's narrow education and awareness of Lyme caused him to not consider the Lyme test at all.



RECOMMENDATION

Create a Lyme and coinfection symptom database that can be used to help doctors discern whether a set of symptoms may be Lyme-related, in order to increase Lyme testing.



PATIENT QUOTE

"I was lucky to stumble on that research because there's a lot of misinformation out there as well. And depending on what you're reading, you're either going to believe or not. So I was familiarizing myself really quick with the unreliable testing with, you know, with the dispute between these two medical societies. And I realized right away that the IDSA doctor was not the right doctor for us. You know, it was steering clear of any infectious disease doctor."



PAIN POINT

The parents' hunch that Mia had Lyme disease drove their research. It made them vulnerable to the misleading guidance that exists online. Once they learned that Mia might have Lyme, they were overwhelmed with the controversy surrounding contrary beliefs about Lyme disease.



RECOMMENDATION

Create a platform for patients and caregivers who are struggling with Lyme diagnoses to provide them with Lyme specialists in their area, help guide their research, and help connect them to advocates in their area.



PATIENT QUOTE

"And it was the first time where we're like, 'Oh my gosh, oh my gosh, your doctor's listening to me, a doctor's note, just looking at this one piece to manage that symptom, but they're putting it all together so they can actually help me heal.'"



PAIN POINT

The LLMD listened to Mia and her parents, never shrugging off symptoms or situations that may lead to Lyme. Mia's LLMD sent her blood work off to the lab for a Lyme test and it came back positive.



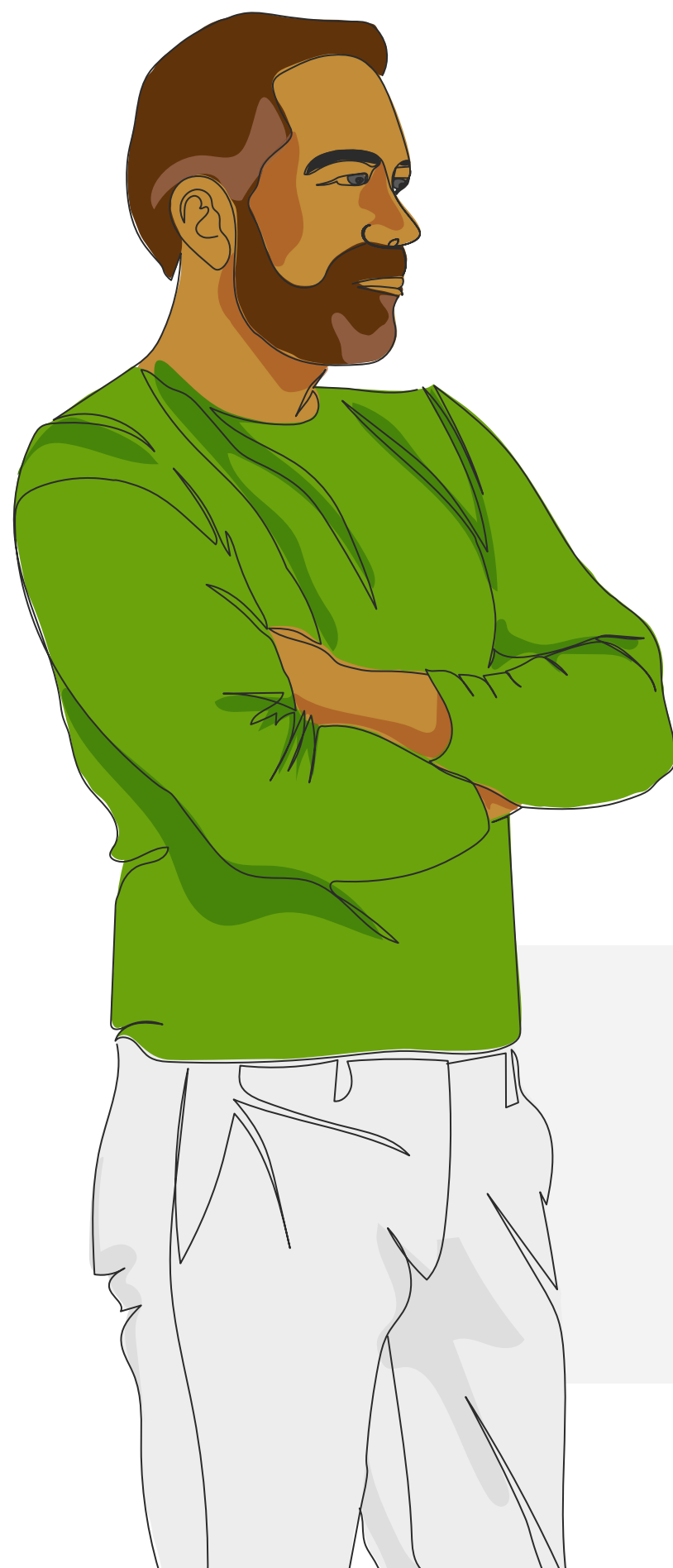
CLINICIAN TOUCH POINT

Mia's LLMD was not covered by her insurance, adding to the medical bills that had already accumulated.



RECOMMENDATION

Provide a healthcare path forward for patients when diagnosed with Lyme to equip them to manage information overload and next steps that need to be taken.



Sam's Diagnostic Journey

Sam is an adult who has struggled with Lyme disease since he was young.

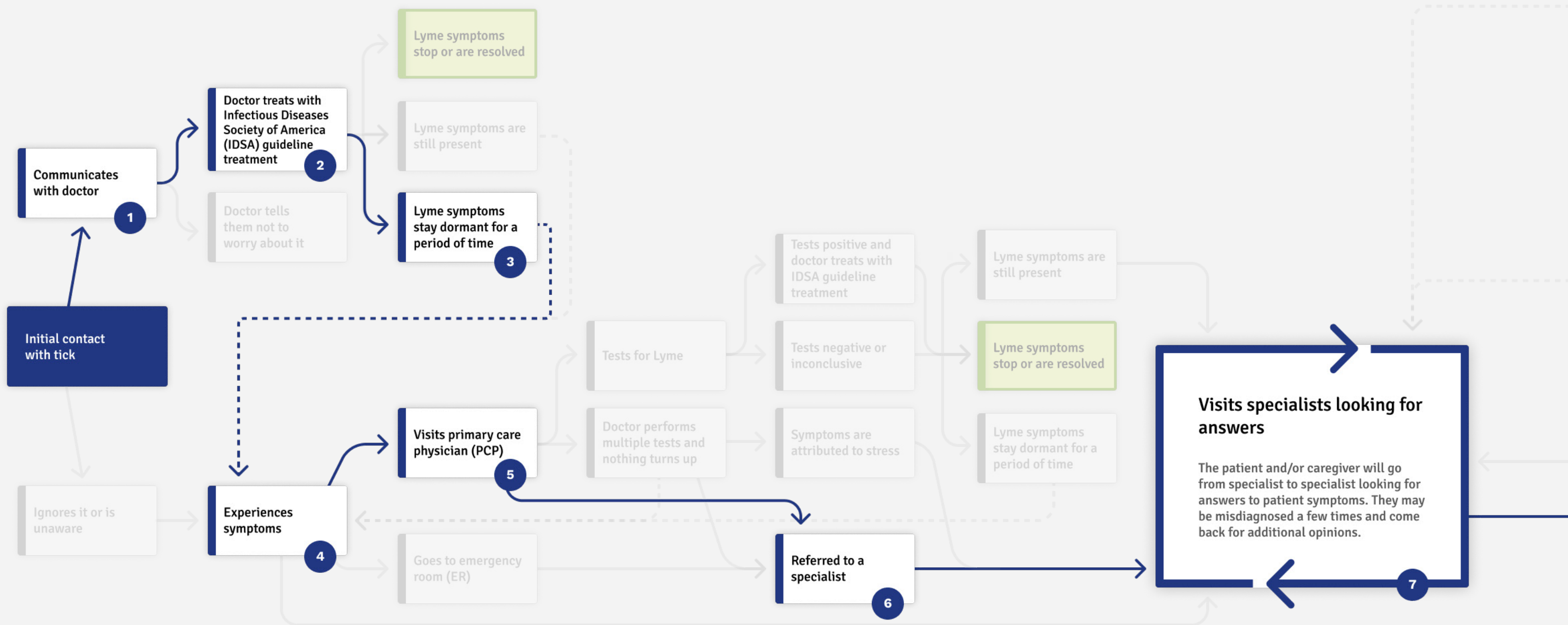
Even though he was accurately diagnosed and treated for Lyme as a kid, it took almost 20 years for Sam to find out the symptoms he experienced were caused by Lyme. Throughout his diagnostic journey, Sam experienced loss of employment, severe financial debt, and ongoing stress that triggered more symptoms. Sam finally found answers through the Lyme community's guidance and received a proper diagnosis.

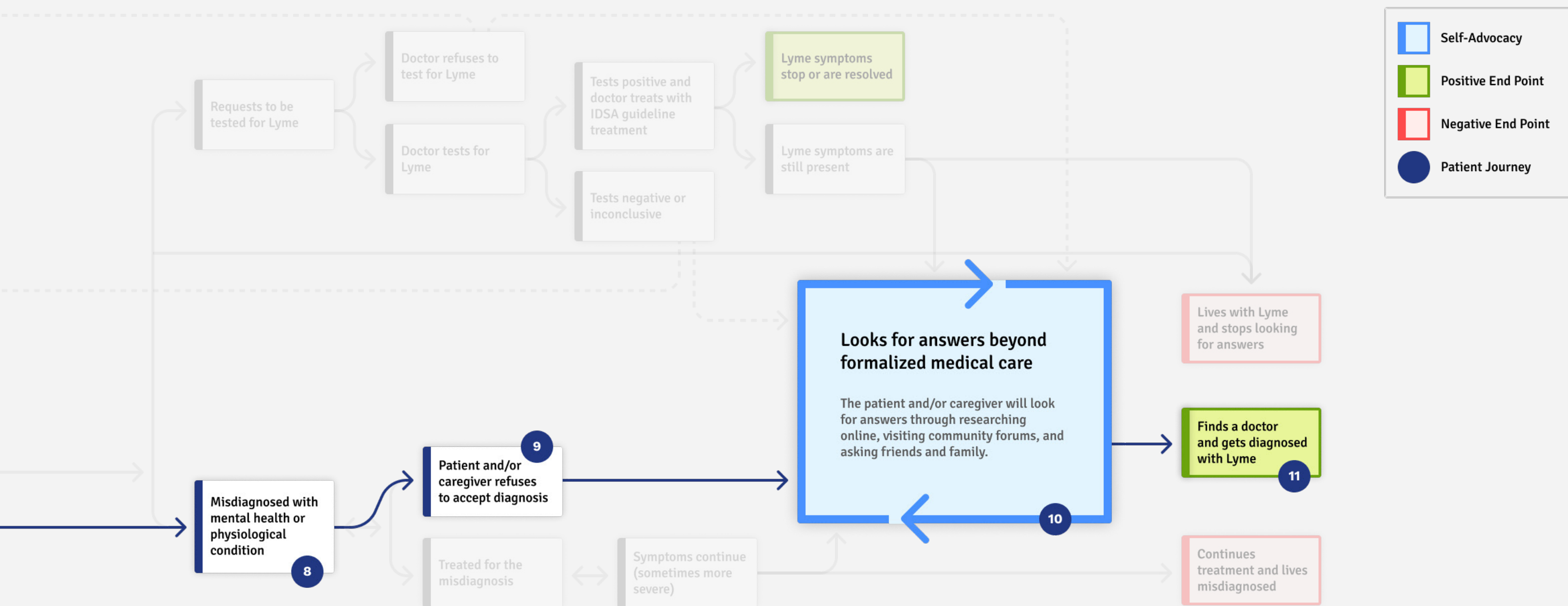


"You know, treatments and procedures and tests and everything, except no one tested me for Lyme, not a single doctor even brought it up, even though I'm from Pennsylvania, which is the number one state currently for Lyme disease."

—Patient

Sam's Diagnostic Journey





Sam's Diagnostic Journey

Comes into contact with a tick and experiences early Lyme symptoms

At the age of 17, Sam spotted a "bull's-eye" rash. Knowledgeable about Lyme, his mother immediately called their Primary Care Physician (PCP).

Communicates with doctor, and doctor immediately treats with IDSA guideline treatment

Sam's physician treated him immediately with the IDSA guideline treatment, and his rash went away. He and his mom felt assured that Lyme was gone and moved on with their lives.

Lyme symptoms stay dormant for a period of time

Years passed by while Sam went to college, eventually got a job, and settled down with a partner. During that time, Sam would get minor headaches or stomach bugs that he contributed to normal human illnesses.

Experiences mild symptoms

Sam's stomach bugs and headaches grew more frequent, and other symptoms started presenting themselves as well. He knew he was starting to take on a lot at work and attributed those symptoms to his workload.



PATIENT QUOTE

"I woke up one day and I had a rash on my chest, "bull's-eye" rash. I didn't know what it was at the time. My mother said, 'I think it's Lyme disease.'"



PAIN POINT

Even though Sam's mom had a general awareness of what a "bull's-eye" rash could signify, she wasn't aware of the potential consequences of Lyme.



RECOMMENDATION

Create early childhood education modules around Lyme, focused on developing safe outdoor habits with the aim of prevention in early life.



PATIENT QUOTE

"So we went to the doctor, got some tetracycline for about two weeks that made it go away. I was fine. Never thought about it again."



PAIN POINT

Sam and his mother felt confident that Lyme was no longer an issue. They never received follow-up tests or appointments to confirm that Sam no longer had Lyme.



CLINICIAN TOUCH POINT

Their PCP knew to immediately treat Sam with the IDSA guideline treatment. Sam took the antibiotics for two weeks and didn't hear from the doctor again.



RECOMMENDATION

Develop a medical protocol following an initial Lyme exposure, including monitoring and recommendations on follow-up appointments.



PATIENT QUOTE

"However, it was about four years later when I woke up one day with a stomach ache and thought it was something I had eaten. So didn't think much about it."



PAIN POINT

Sam's symptoms were never taken into consideration as being caused by Lyme. The infection worsened, and they never knew to look for further help.



RECOMMENDATION

Develop an ongoing Lyme medical check-in and tracker for patients after receiving treatment that allows their HCP to monitor their condition, while also allowing Lyme to be apparent in their future medical records, helping identify dormant symptoms that might reappear.



PATIENT QUOTE

"I was getting like dizzy and my eyes felt blurry and I remember I said, 'I think I might need, you know, to get my eyes checked out. I think my vision is not as good as it used to be.' And so I thought I was having vision issues because it was just kind of blurry. But then the headache and then I started not sleeping. I was just like, not sleeping at night, even though I was tired. So I think, I must be really stressed out. Another week goes by like this and now the headaches are getting pretty bad and they're going down to my neck."



PAIN POINT

As Sam's symptoms worsened, he started experiencing stress from their impact, which caused his symptoms to grow even more severe. Sam had no awareness of the potential severity of his situation and continued pushing past the symptoms, thereby worsening them.



RECOMMENDATION

Develop a medical protocol following an initial Lyme exposure, including monitoring and recommendations on follow-up appointments.

Sam's Diagnostic Journey (Continued)

Experiences severe symptoms

Sam started to experience severe muscle aches and his brain became very foggy. He found it so hard to perform at work that he eventually ended up quitting, realizing it was time to see a doctor.



Visits PCP and gets referral to specialists

His PCP looked through his medical records, performed a range of tests, and couldn't understand what was wrong with him. The doctor then decided to refer him to a neurologist, thinking the brain fog was the clear identifying symptom of whatever he had.



Continues to visit specialists looking for answers

Sam saw the neurologist who passed his condition off as stress, but told him to go get a second opinion. Sam saw around seven specialists for about a year, while his partner supported both of them since Sam was out of work. As medical bills piled up even higher, Sam realized he was going to have to find someone who could give him answers.



Visits the Mayo Clinic

Sam's neighbor had mentioned the Mayo Clinic, describing it as the top-notch diagnostic clinic, so Sam decided to use the last of his borrowed money from his family to purchase a flight and two weeks at a hotel while he underwent testing at the Mayo Clinic. Once Sam arrived, he was tested and examined by a few doctors. He mentioned that he once had Lyme, but they shrugged it off and said that he wouldn't have Lyme now.



PATIENT QUOTE

"So I ended up quitting my job cause I couldn't work full-time anymore. You know, I was going into the office and sometimes I'd fall asleep at my desk and fall asleep for a couple hours and we still didn't know what was wrong with me at the time."



PAIN POINT

Sam was no longer able to fully perform at his job, impacting his ability to provide for himself and/or his dependents. He began to struggle with his sense of identity and the stress of not being able to carry out his responsibilities.



RECOMMENDATION

Provide temporary financial assistance for those in the diagnostic stage that are not able work.



PATIENT QUOTE

"And once at my normal PCP doctor, he ran some tests, like a menu of things that all came back negative. And I, after that, he didn't know what was wrong. So he's like, 'Oh, you need to go see a neurologist.'"



PAIN POINT

Sam's PCP didn't take into consideration that Sam once had Lyme and never had a follow-up appointment where he tested negative for Lyme.



CLINICIAN TOUCH POINT

Sam had a different PCP than the one that treated him for Lyme years ago. This physician looked at his medical history and saw nothing that was concerning, so he decided to give Sam a general range of tests to try to diagnose his ambiguous symptoms. The tests all came back negative, so he referred Sam to a neurologist.



RECOMMENDATION

Develop a medical protocol following an initial Lyme exposure, including monitoring and recommendations on follow-up appointments, while also flagging the patient's medical records for doctors to look at in the future.



PATIENT QUOTE

"I was borrowing money from my parents and my sister. And we were going deep into debt. My wife and I were not married at that time, but we were living together. And so that went on for about seven years and never got a diagnosis from anybody."



PAIN POINT

The stress from the medical bills and the inability to work led to a stress spiral, triggering the symptoms to become much more severe. Not one of the numerous specialists took into consideration Sam's previous Lyme history.



CLINICIAN TOUCH POINT

After looking at Sam's medical history, the neurologist couldn't pinpoint the causes of Sam's symptoms. He did, however, know that Sam was taking on stress at work. The neurologist told him to take it easy, and if he de-stressed, the symptoms should go away. Sam looked for other medical opinions as his condition worsened, but he got the same answers or other misdiagnoses.



RECOMMENDATION

Provide neutral, mental health care access and advocacy for patients still searching for a diagnosis that doesn't influence their diagnosis, and helps coach them through the process.



PATIENT QUOTE

"The Mayo Clinic is the best. So whatever they say, I have, I'm going to believe them, you know, as long as they don't say I have fibromyalgia."



PAIN POINT

The expenses from the Mayo Clinic were financially devastating to Sam, piling on top of his other expenses. The Mayo Clinic did not take his previous Lyme diagnosis into consideration.



CLINICIAN TOUCH POINT

The Mayo Clinic noticed nothing alarming in Sam's medical history and gave him a round of diagnostic tests and specialists. Even though Lyme disease was on Sam's medical records, the Mayo Clinic did not retest him for Lyme since there were no obvious symptoms and Sam had already been treated for it long ago.



RECOMMENDATION

Create a protocol for doctors dealing with patients who once tested positive for Lyme that prompts them to retest the patient when going through a diagnostic workup.

Sam's Diagnostic Journey (Continued)

Misdiagnosed at the Mayo Clinic and refuses to accept diagnoses

After two weeks at the Mayo Clinic, Sam left frustrated with a diagnosis for depression that he refused to accept and a \$7,000 dollar medical bill that added to his already large debt.



Experiences symptoms and abandonment

Sam's symptoms grew increasingly worse and were sometimes debilitating. Sam's partner was burdened by the financial stress and the added responsibility of becoming his full-time caregiver. They both began to lose hope.



Looks for answers beyond formalized medical care

Sam decided that he couldn't give up and started to research his symptoms more heavily. His Lyme diagnosis as a kid was the only health issue that lingered in his mind, so he decided to research Lyme. He discovered a Lyme Facebook group, where he saw dozens of posts with stories just like his. The posts validated his entire experience and gave him advice for his next steps.



Finds a doctor and gets diagnosed with Lyme

Sam found an LLMD in his area through the his social group. The LLMD spent about three hours cataloging his symptoms and reviewing his medical records. It was the first time Sam really felt heard in years. The LLMD performed a Lyme test, and it came back positive. Sam finally got the answer he was looking for and felt hopeful about what was to come.



PATIENT QUOTE

"Spent two weeks at the Mayo clinic prior to my diagnosis of Lyme disease and was sent home with a diagnosis of depression. And I can say I was not depressed before I got to Mayo. I was very hopeful when I got to Mayo. I was incredibly depressed when I got back from Mayo with no diagnosis and no relief from symptoms."



PAIN POINT

Sam experienced brutal disappointment and felt abandoned after he left with no answers. A lot of patients drop off after this point and give up.



CLINICIAN TOUCH POINT

The test results were inconclusive and the Mayo Clinic diagnosed Sam with anxiety and depression. They gave him a large bill and sent him on his way with no follow-up.



RECOMMENDATION

Provide an advocate for patients that protects them from being vulnerable to mistreatments that might financially or physically devastate them.



PATIENT QUOTE

"And at this point, I mean, I was like, I don't know what to do. I'm sick and this doctor's not helping me. So we knew that there was at least something that they told me that I had, that wasn't being taken care of."



PAIN POINT

Sam was now neither capable of making a living nor proving a cause that would allow him to receive disability. Without his partner's support, he would have been forced to find support elsewhere. This is a moment where patients can become homeless and abandoned without people willing to help. The stress of this situation on the caregivers can also cause divorce and family separation.



RECOMMENDATION

Provide mental health counseling for patients and their family who are struggling with finding a diagnosis.



PATIENT QUOTE

"Like, you don't know what an LLMD is when you first go, like, you don't know what these terms mean. I didn't even know it was controversial. Yeah. I had no idea. And then it wasn't until I was sick and now hearing two totally different things from two different doctors, it was like, oh my God, what am I dealing with here?"



PAIN POINT

Sam's previous Lyme diagnosis was the only guidance for his research, making him vulnerable to the misleading guidance that exists online. Once he learned he might have Lyme, he was overwhelmed with the controversy surrounding contrary beliefs about Lyme disease and didn't quite know who to trust for further care.



RECOMMENDATION

Create a platform for patients and caregivers who are struggling with Lyme diagnosis to provide them with Lyme specialists in their area, help guide their research, and help connect them to advocates in their area.



PATIENT QUOTE

"I walked in his door and that was the first time in all these years that somebody was giving me back some information that made me think he had some kind of experience or knowledge about this. I spent like three hours with him. He recorded the whole thing. I had been to dozens of doctors at this point and nobody could ever make any sense of anything that I said."



PAIN POINT

Sam was forced to pay out of pocket with the little money he had left to see an LLMD that might give him answers. Once Sam was diagnosed, he was overwhelmed by the complicated and expensive medical journey that lay ahead.



CLINICIAN TOUCH POINT

The LLMD, without the constriction of time allotted by insurance for medical intakes, listened to Sam explain his symptoms for three hours and undertook a critical review of his previous tests and misdiagnoses. The LLMD sent Sam's blood-work off to the lab for a Lyme test and received positive results back.



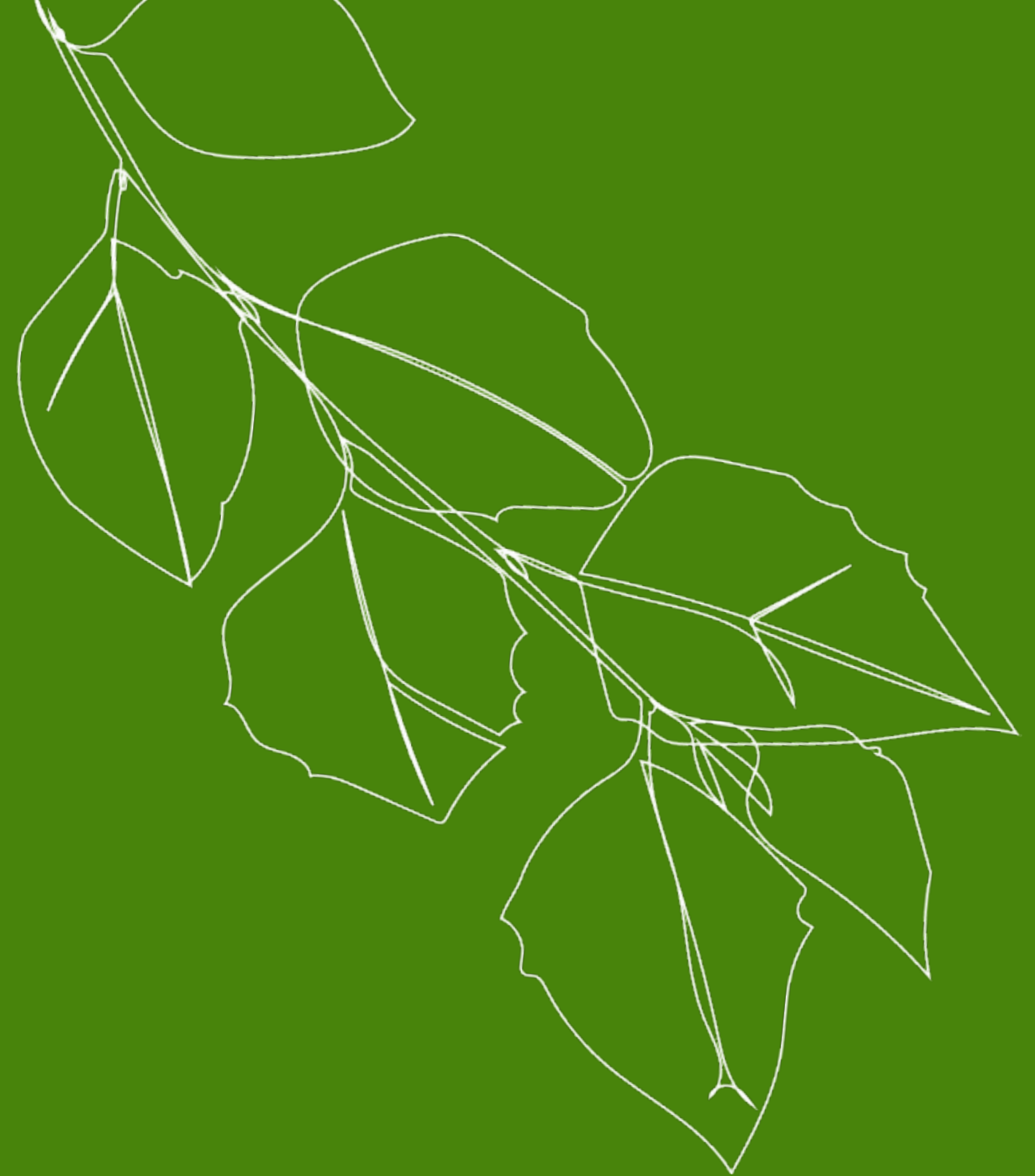
RECOMMENDATION

Develop a Lyme disability qualification cheat sheet, matching frequent Lyme symptoms to accepted conditions and codes to aid in application for financial assistance.



"It took me a long time to come to grips with the fact that it probably wasn't going to change because for the first seven years, I didn't know what it was. And I just thought one of these days, I'll go to the doctor next week and we'll do the test and we'll figure it out and I'll be back to normal again."

—Patient



Treatment Journey for Persistent Symptoms

The Lyme disease treatment journey for persistent symptoms maps out the potential ways a patient may receive treatment and manage their persistent symptoms.

This journey, for some, is still active, with patients and caregivers searching for guidance along this journey today. Getting treatment for persistent Lyme forces patients to endure cycles of searching for answers, testing out new and sometimes harsh treatments, while managing their symptoms and life responsibilities.



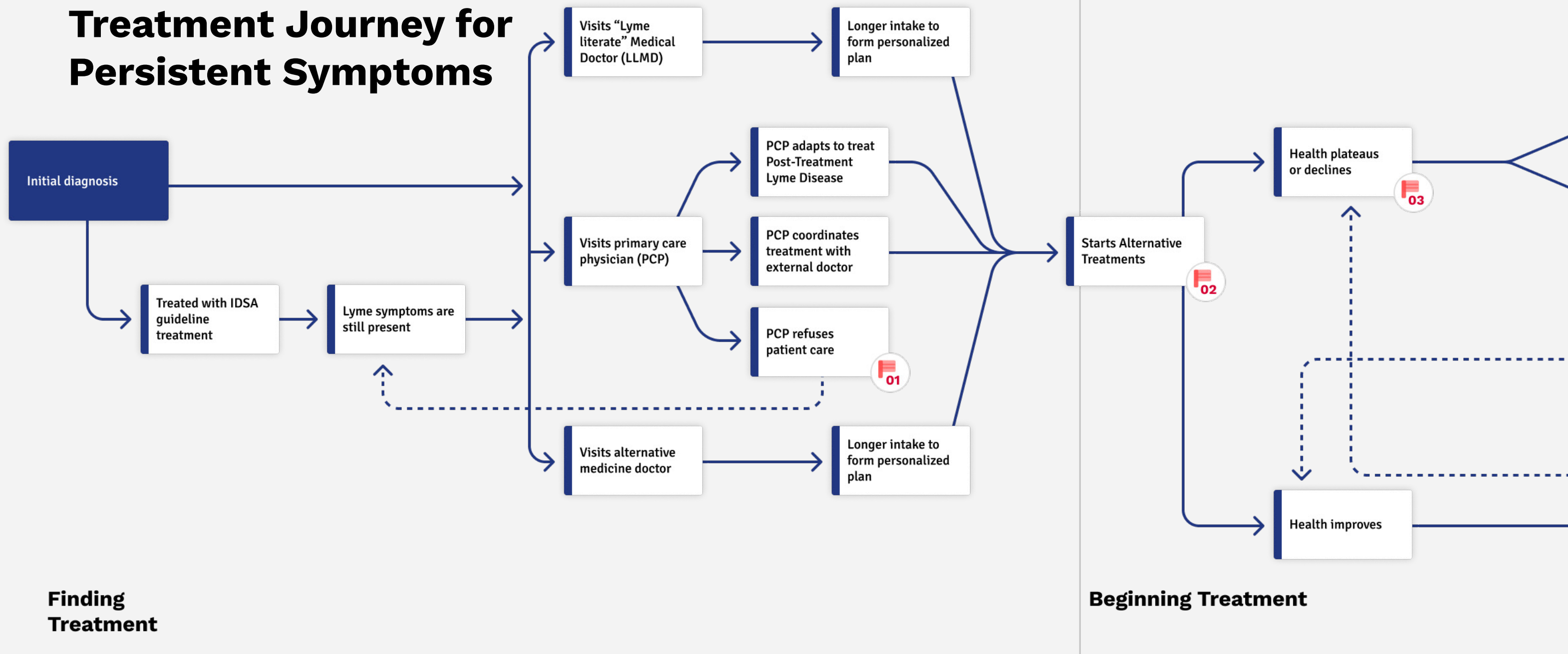
"We don't really know to keep going or stop. So that was like an impossible decision as a patient, because you could be having some horrible symptoms and say, okay, I'm going to keep going because on the other side of this horrible reaction, I could start to get better. But you don't know if it is actually doing more damage."

—Patient

"My doctor said for that treatment that some people get better right away while others get better and then plateau. It's impossible to know until you try. I was on treatment for 26 weeks and nothing was happening for me. I finally said, you know what? It's just not happening and we're so deep in debt that I don't want to keep going."

—Patient

Treatment Journey for Persistent Symptoms

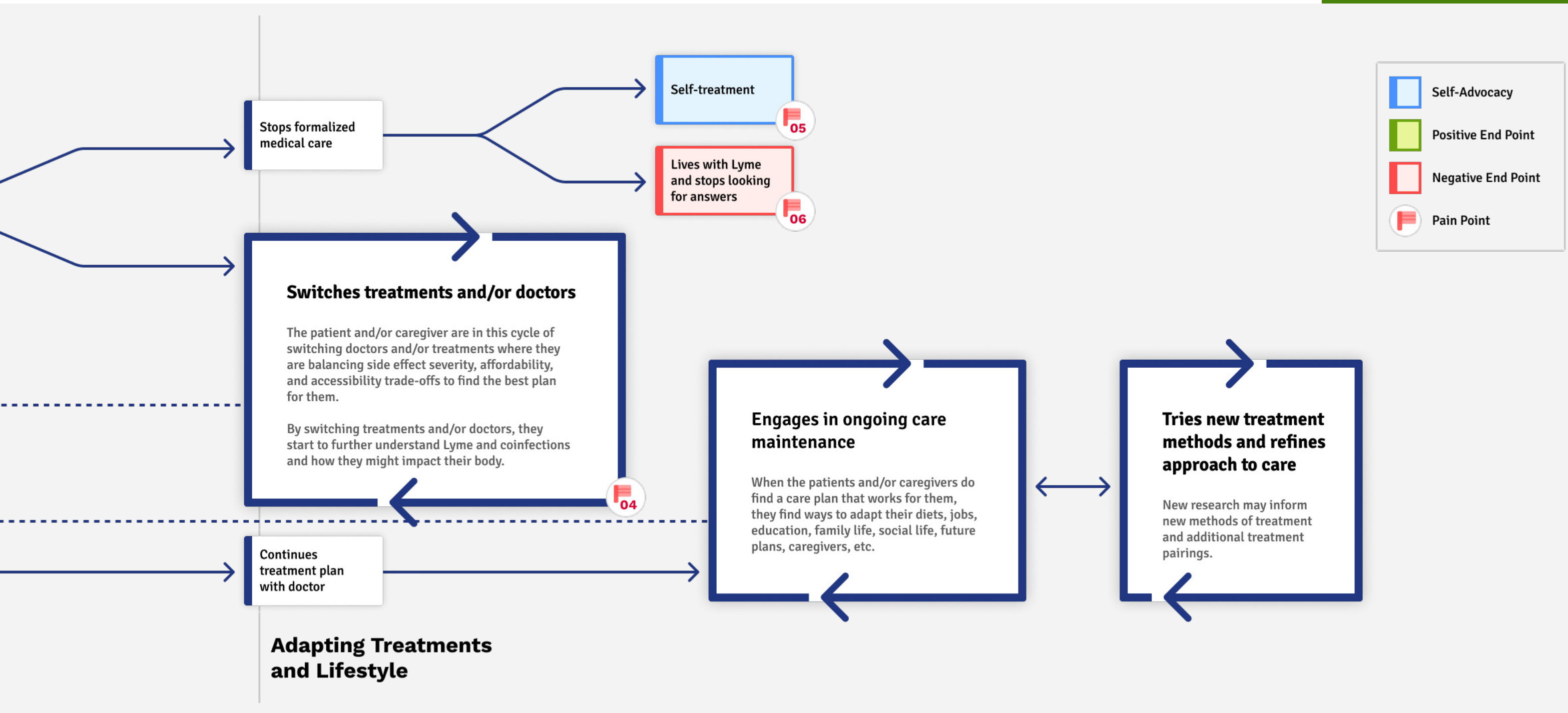


Pain Points

01 Leaves the patient without proper care and still experiencing symptoms

02 Insurance usually drops off at this point, and medical costs start to build up

03 Work and/or employment can be severely impacted at this point



04
Can be financially devastating and have lasting, damaging impact on health

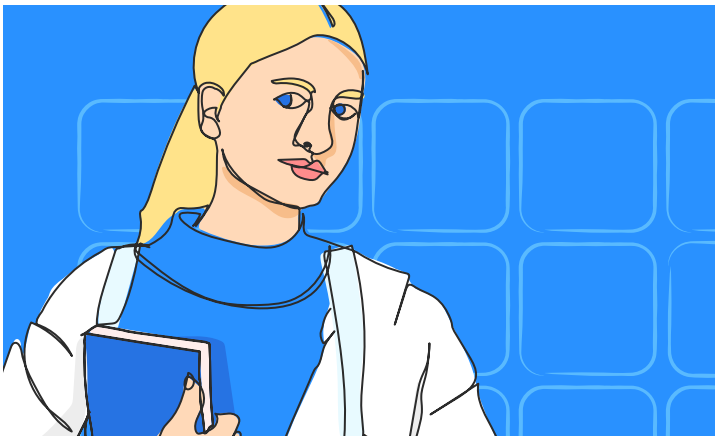
05
Without medical guidance, this could lead to damaging and costly consequences

06
This infection could further harm the body, leading to worse symptoms

PARAMETERS // CARE COORDINATION // LIFE WITH LYME

Archetypes





The Archetypes of Lyme

Archetypes are a distillation of design discovery insights meant to describe patient needs, goals, barriers, and habits.

They serve as a communication tool that helps teams build empathy towards patients and address their needs. They are developed through analyzing qualitative data and are useful when patients behave differently and their various needs have to be addressed. Four archetypes were developed by combining two distinct variables that help measure each group's barriers, needs, and actions.

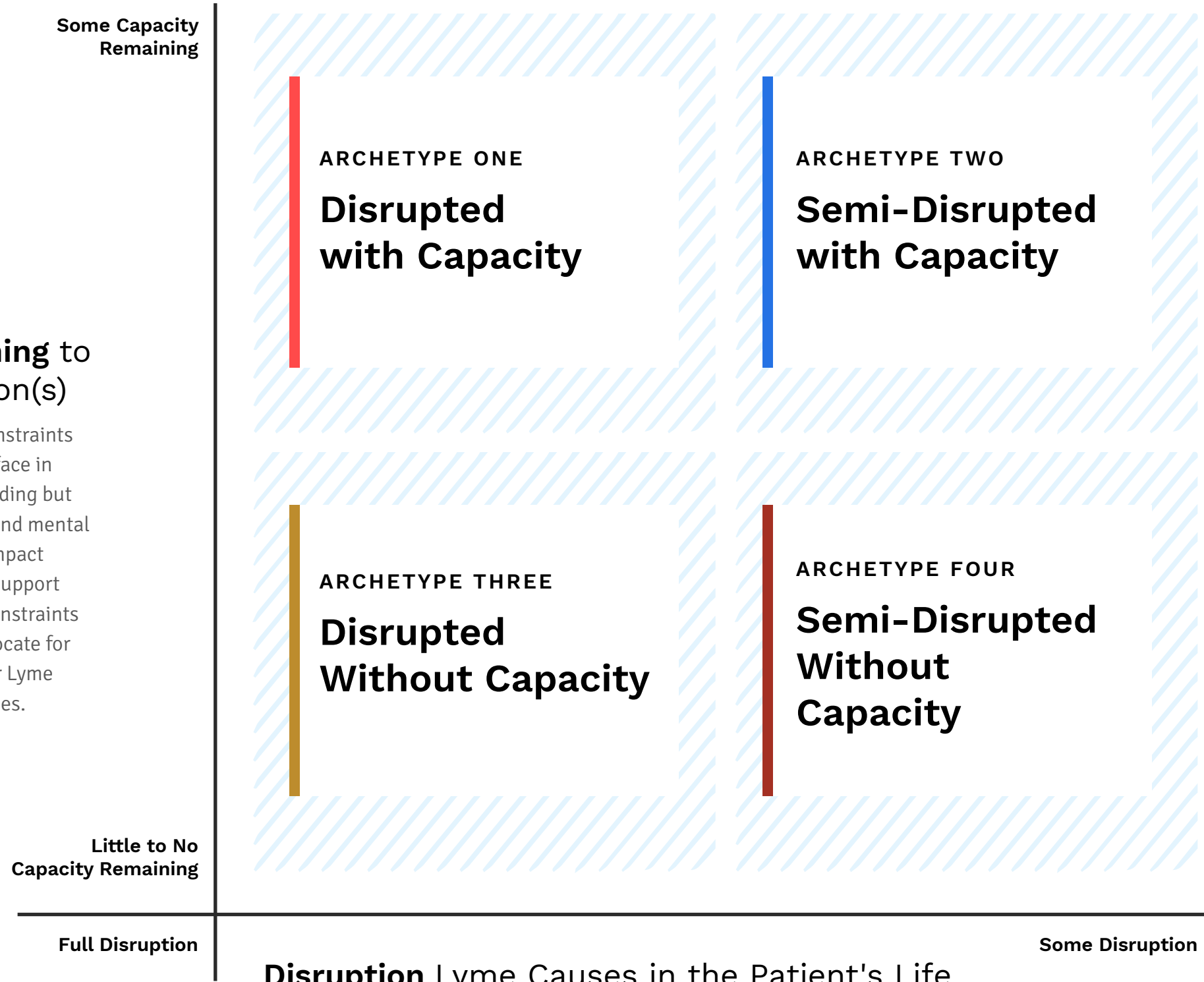
Lyme's wide range of symptoms, unpredictable flare-ups, and overall symptom severity considerably disrupt the patients' lives in various ways, including caregiving responsibilities. A patient explained how the unpredictability impacted their plans. Because Lyme derails their lives so profoundly, Lyme's level of disruption became the first variable to help group the patients into archetypes. The factors of disruption include but are not limited to symptom unpredictability, enrollment in school, provisions to take leave from their work, and engagement in family and financial planning.

The second variable used to form the archetype groups was the patients' capacity to manage Lyme's disruptions in their lives. Capacity deals with the constraints they face in coordinating their care, including but not limited to their physical and mental state from their symptoms' impact and financial and social support they have access to. These constraints affect patients' ability to advocate for themselves and to balance their Lyme with competing responsibilities.

While capacity and disruption are interrelated, capacity refers to people's empowerment to manage their condition, and disruption deals with the extent to which Lyme interrupts their daily life and responsibilities.

Capacity Remaining to Manage Disruption(s)

Capacity is defined by the constraints that patients and caregivers face in coordinating their care, including but not limited to their physical and mental state from their symptoms' impact and the financial and social support they have access to. These constraints affect patients' ability to advocate for themselves and balance their Lyme with competing responsibilities.



Disruption Lyme Causes in the Patient's Life

Defined by factors involved in derailing patients' prior responsibilities and social roles. These factors include but are not limited to symptom unpredictability, enrollment in school, provisions to take leave from their work, and engagement in family and financial planning.



ARCHETYPE ONE

Disrupted with Capacity

They are somewhat equipped to manage Lyme's severe impact on their occupation/education, community, and well-being.

They have the finances, networks, and/or community support necessary to reorient their lives around their Lyme-related disruptions. This allows them to find new resources and information on Lyme, additional social support, take a proactive role in their treatment, and even readjust their source(s) of income.

Due to the capacity they have remaining to manage the disruptions of Lyme and its coinfections, they often take on the role as an informed influencer who speaks to what's happening within their lives in addition to supporting others in navigating their journeys with Lyme. One patient explained taking on a role in their Lyme community, "I said, 'Sure, I'll help. You guys helped me. I mean, I don't, I don't think I would have been validated enough. I had questioned myself for so long. I'm being told I didn't have [Lyme] over and over again.' So, so I started to get more involved."

Because of the range of information regarding Lyme treatment and because their financial and personal support system allows them to explore options, it can sometimes be challenging for this group to filter out what information is directly relevant.

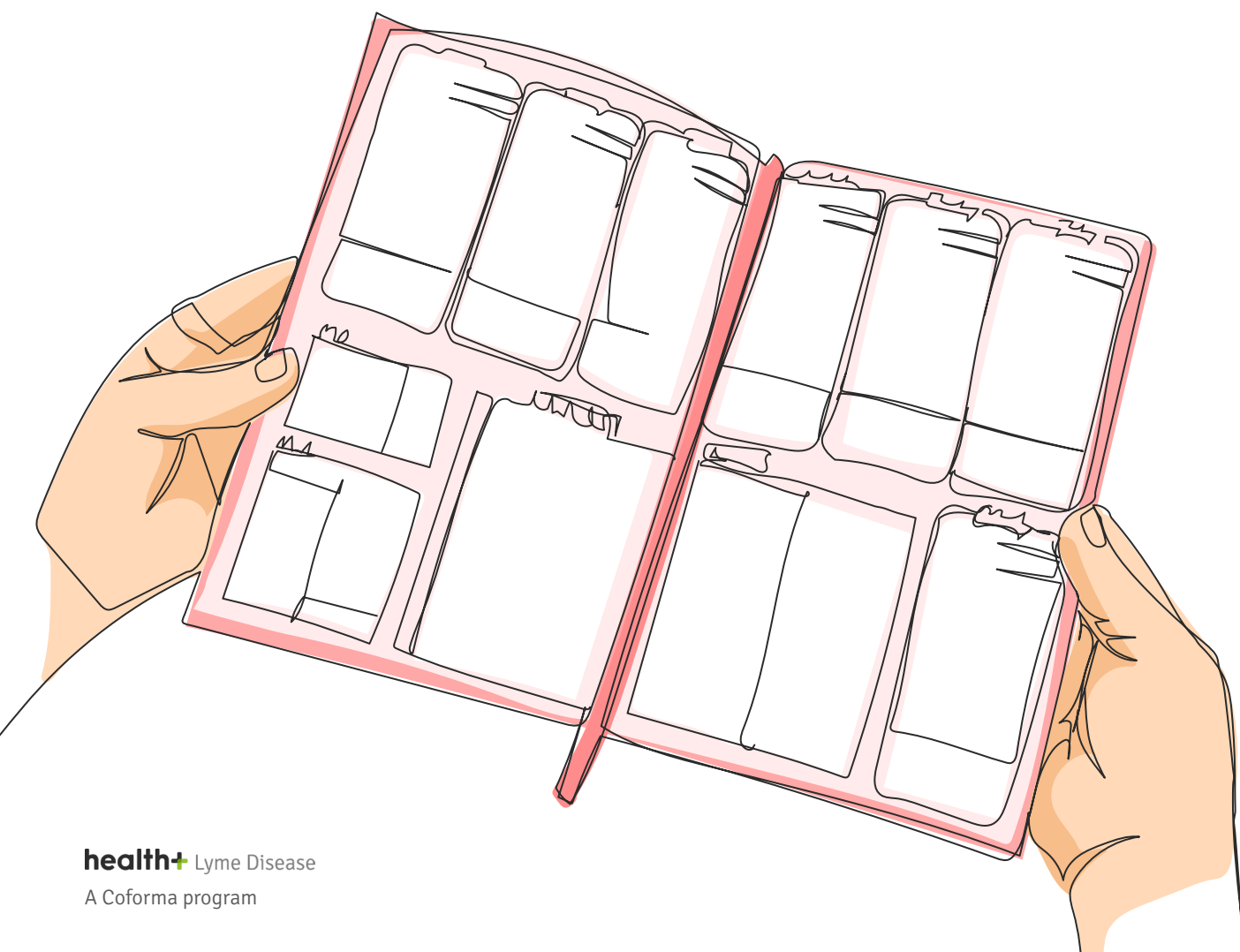
Additionally, even though they are able to afford treatment, it disrupts their future planning for life beyond Lyme—often pouring savings and retirement funds into Lyme treatment. One patient shared, "When you've been sick for so long, you know, basically half my life I've been sick, you are willing to do anything to get better, including spending an insane amount of money."

"When you've been sick for so long, you know, basically half my life I've been sick, you are willing to do anything to get better, including spending an insane amount of money."

—Patient

"I created playbooks for my symptoms. Like, here's the challenge and here's the solution. And that's been really helpful for people to understand when I have symptom flare-ups because they'll read stuff on the internet and be like, okay, so for joint pain, you should take this medicine."

—Patient



ARCHETYPE ONE

Disrupted with Capacity

Parameters

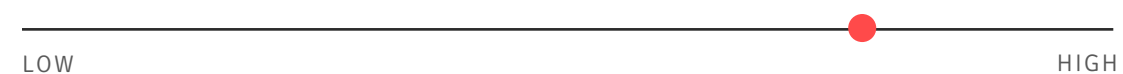
Capacity to be proactive in their care



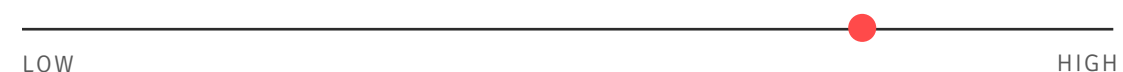
Capacity to independently manage their care



Disruption to their sense of normalcy



Disruption to their health condition



Trust in the community



Care Coordination

When managing their medical care, this archetype has the resources to explore a multitude of treatments.

They have greater flexibility to customize a treatment plan that works for them; however, this is negative in that there are endless possible treatments for Lyme through both conventional and nontraditional

medicine. This speaks to a broader issue with the lack of general guidelines surrounding treatment of Lyme disease with persistent symptoms.

Barriers	Needs	Actions
The overwhelming information surrounding Lyme and the lack of guidance to know which recommendations and treatment plans are safe	Guidance to carve out a treatment plan that will work for them	Seeking out guidance online through community forums and independent research
The disruption caused by the side effects of new and/or unconventional treatments	Support managing side effects and guidance on when to stop a treatment	Working with doctors, or alone, to utilize knowledge gleaned from others' experiences online, in an attempt to lessen side effects
The limitations set by the high costs of Lyme and coinfection treatments	Affordable and vetted treatment options	Seeking financial support from their network and/or going on disability; finding external treatments (mindfulness, yoga) to supplement medical treatments with reduced costs
The lack of updated answers they receive on how to manage their condition and severe disruptions that prevent them from living a "normal" life	Guidance and updated information from trusted resources on research surrounding Lyme that can help give them hope	Seeking answers from online research and using their knowledge to educate their HCPs on new treatments and protocols that they would like to be treated with; and/or independently self-treating



"So I was researching, talking to people. I was really scared at this point because, I mean, a wheelchair? I'd never needed a wheelchair in my life until I started this treatment that just made me so much worse."

—Patient

"I just was being told the same thing over and over, you know. And I started to realize, you know, it's just not true. Like it's up to me, I'm the only one at the end of the day, that's going to get myself, I had to do it on my own because nobody else was doing it."

—Patient

Life with Lyme

In living with Lyme, the Disrupted with Capacity group is completely focused on treating Lyme and thus sidelines other planning for and engagement in other life plans.

Unfortunately, the unpredictability of Lyme forces them to stop working or pursuing education for an unknown period of time. Additionally, it does not let them plan financially, as they devote a significant portion of prior savings towards treating Lyme.

Lastly, the unpredictability of Lyme interferes with their current and future relationships with others, as many have expressed frustrations surrounding dating and family planning with Lyme.

Barriers	Needs	Actions
The impact of Lyme's unpredictable and severe conditions on their future planning	Guidance or assistance in planning for the future they want	Putting off future planning; betting that symptom resolution will bring the opportunity for future planning
The impact of Lyme's unpredictable and severe conditions on their school or employment	School or employment schedule with a flexibility that allows them to adjust their hours to how they feel; an adaptable way to remain productive and/or generate income	Pausing their school or employment or adapting to new careers and flexible ways of working; seeking financial support from their network or relying on disability
The impact of Lyme's unpredictable and severe conditions on their social lives	Community understanding of and flexibility around their condition	Forced to forego plans and engagements with their community, further isolating them
The abandonment they sometimes experience from partners and loved ones that are afraid of the impact that Lyme might bring into their lives	Reassurance and guidance for both them and their partners on Lyme management	Looks for support and connection through Lyme-affiliated communities that already have an understanding of what they are experiencing
Their constrained ability to live a life beyond Lyme's constant disruptions	Ways to find enjoyment and purpose while still experiencing the weight of Lyme's disruptions	Experiences identity loss and depression; may put their energy into advocating for Lyme and/or their communities



"Cause I couldn't do the traveling and the meetings and all that I used to be able to do. Right now doing these podcasts is better for me."

—Patient

"And people message me on Instagram. You know, every day I have multiple new DMs from people that found me. They're like, you're so positive. You inspire me. A lot of people with Lyme end up being very negative."

—Patient



ARCHETYPE ONE

Recommendations

- 01**
Provide an advocate for patients that protect them from being vulnerable to mistreatments that might financially or physically devastate them.
- 02**
Create a platform that personalizes research, community forums, and HCP advice to the patient's symptoms and side effects. Connect this platform to other active communities that are fully established.
- 03**
Create a mentorship program for Lyme navigators, Lyme community leaders and experts who are willing and interested in sharing their experience and research to help individuals navigate the journey.
- 04**
Assist with navigating the bureaucracy of working and getting an education with a persistent illness.
- 05**
Equip patients and caregivers with the resources and tools to help advocate for other Lyme patients and Lyme disease in general.



ARCHETYPE TWO

Semi-Disrupted with Capacity

They are able to manage Lyme's impact while actively pursuing a full occupation and/or education with an optimistic view of their future plans.

Their ability to meet those demands is derived from their access to resources and support that may be provided from family, community, and organizations. They proactively collaborate with their team of doctors and play a significant role in driving their care plan. However, Lyme's unpredictable disruption to their busy schedule may throw them off track and cause them to have the need for adaptable

"Any doctor that saw me always asked me the corny question, 'What is your goal to get out of anything?' and my answer was, 'I need to graduate on time because it was the one thing that kept me going.'"

—Patient

occupational environments from time to time. "Any doctor that saw me always asked me the corny question, 'What is your goal to get out of anything?' And my answer was, 'I need to graduate on time because it was the one thing that kept me going,'" a patient explained.

This archetype demonstrates that even patients with the financial capacity and social support to plan for their futures still face the tremendous task of feeling like they need to appear normal—even occasionally masking significant symptoms and avoiding asking for help whenever possible.



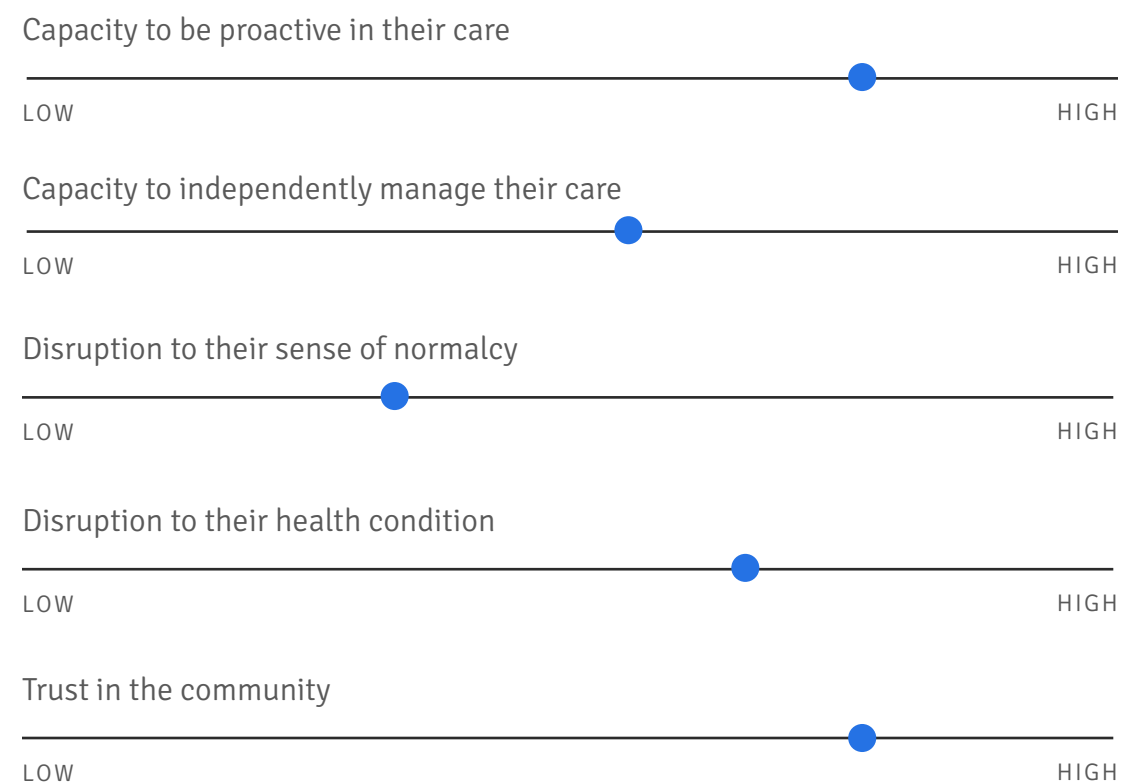
"She's tried real hard to be like a normal teenager and have friends. She's had a job over the summers. We're lucky enough to spend the summers away. So she has had jobs working at the beach over the summers and that has been good. But you know, she gets very, like, not normal fatigue or normal headaches, not normal aches and pains, not normal, like backaches and this and that."

—Caregiver

ARCHETYPE TWO

Semi-Disrupted with Capacity

Parameters



Care Coordination

In managing medical care and treatment, this group aims to integrate their Lyme treatment with other life goals.

Lyme has not completely forced them to move all other arenas of their lives to the back burner. Consequently, they face challenges in fitting their treatment into their daily jobs and/or coursework. For example, they may find ways to shift to remote

work or figure out how to change their work demands to manage their fatigue. They also shoulder the responsibility of providing for and/or shaping their treatment plan, such as caregivers and/or HCPs.

Barriers	Needs	Actions
The unpredictability of their condition causing a disruption in their future planning	To have a solid understanding of what the future of their condition may look like so they can plan around it	Pushing full steam ahead with their future plans and goals for life; reactively adjusting their life to their symptoms
Their experiences aren't always trusted or believed by the medical community because "if they look fine, they should feel fine"	To be listened to and involved in the establishment of their treatment plan	Experiencing discrimination and/or the expectation that they need to feel all right; sometimes receiving less than adequate attention to their condition
The potential severity of their conditions not always being clear to them or their doctors	To have a full understanding of the consequences and unpredictability that Lyme may cause	Potentially being unaware of when symptom flare-ups may happen and not being able to proactively prevent them



"It was like, torture, just like not working, like after being sick, I need to be productive."

—Patient

"If you're diagnosed with Lyme, nobody believes you. They think it's all in your head, you're making up your symptoms. I've had doctors tell me, you know, honey, put some makeup on, get out of bed and go back to school."

—Patient

Life with Lyme

In managing both Lyme and their lives, this group may feel the need to mask their symptoms in the workplace or at school in order to carry out their daily tasks.

In doing so, they may feel pressure to neglect their health and push themselves too far, which in turn can lead to more severe symptoms. When developing

strategies to manage their Lyme, they regularly communicate with those involved in their care to help them meet their long-term life and treatment goals.

Barriers	Needs	Actions
The impact of Lyme’s unpredictable and severe conditions on their school or employment	Flexible school or employment schedule that allows them to adjust their hours to how they feel; an adaptable way to remain productive and/or generate income	Pushing through symptoms where possible; pursuing school or employment rigorously
The abandonment they sometimes experience from partners and loved ones who are afraid of the impact that Lyme might bring into their lives	Reassurance and guidance for both them and their partners on Lyme management	Looks for support and connection through Lyme-affiliated communities that already have an understanding of what they are experiencing
The lack of understanding and empathy they may experience in their communities because their disruptions are not always visible from the outside	Understanding of and support for what they might be going through	Feeling like they need to seem “normal” and masking their symptoms which further isolates them from their community and loved ones

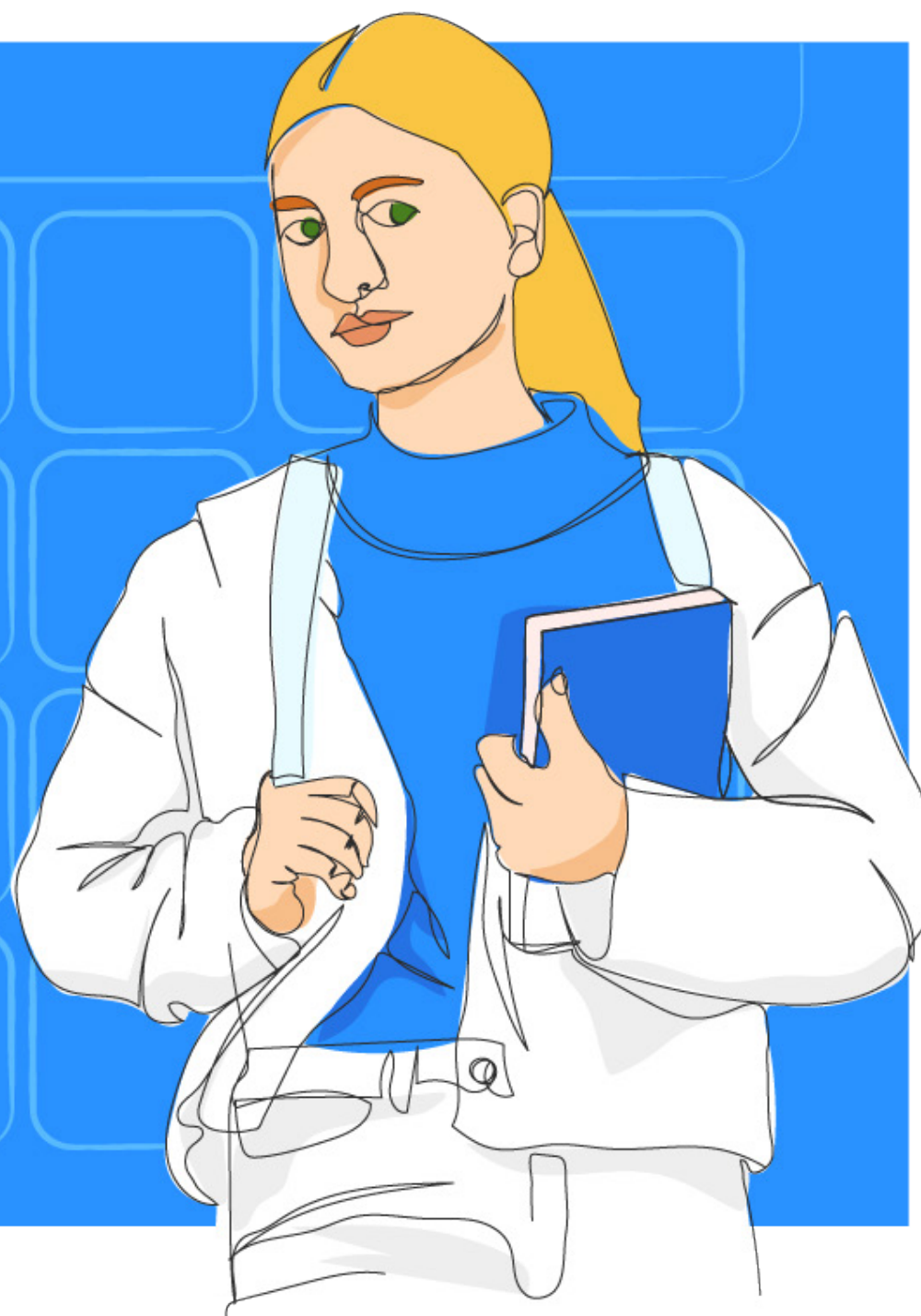


"So I definitely try to mask my symptoms, definitely around my brothers a lot since I don't want, I'm supposed to be like the older sister, I'm supposed to be taking care of them and not the other way around."

—Patient

"I remember being in the second grade and I was in the hospital in and out all the time. The longest time I've ever spent there consecutively was a week. And so that was during school. I felt very isolated."

—Patient



ARCHETYPE TWO

Recommendations

01

Develop a hub for Lyme life planning that points to resources to support with education, employment, and social life management.

02

Create a platform that provides preemptive notifications that gives proactive check-ins or treatment recommendations and care plans. Urgent health signals can trigger nudges to the HCPs (e.g., call patients, auto-save an appointment time to be confirmed via text, etc.).

03

Provide ready-made medical documents excusing patients from school and work.

04

Create education programs that adapt to the patient's condition while still managing to give them the level of education that peers their age receive, with the potential to also further connect them to peers their age with mentoring help and social time.

05

Equip patients and caregivers with the resources and tools to help advocate for other Lyme patients and Lyme disease in general.



ARCHETYPE THREE

Disrupted Without Capacity

They experience a severe Lyme impact in their social lives, health, and school or employment, disrupting their sense of identity.

One patient expressed a loss of identity when sharing, "I was just so pissed off that like my entire life was just done. I went from being successful, the one earning the most money in the house to being depleted physically, financially, emotionally."

This archetype experiences the full gravity of their symptom severity across all facets of life, and they cannot always independently coordinate their

"And they would read the note like I wasn't there, whispering to each other reaching for a psychological disorder."

—Caregiver

care. Therefore, they depend on their caregivers to help them advocate for their diagnostic and care coordination. This disrupted and constrained capacity can leave them vulnerable to medical discrimination and sometimes medical abuse, as they depend heavily on their caregiver to advocate for them.

One caregiver described his experience, "And they would read the note like I wasn't there, whispering to each other reaching for a psychological disorder. I'd be like, 'Guys, I know I know what the health records say; I brought them to you. Obviously, I disagree. Look at her, she's running a fever. She's blue.'" This archetype needs the full support of their caregivers and medical team to help them manage Lyme's severe disruptions in their lives.

"I think I was just so pissed off that my entire life was just done. I went from being successful, the one earning the most money in the house to being depleted physically, financially, emotionally."

—Patient

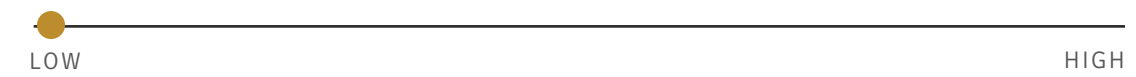


ARCHETYPE THREE

Disrupted Without Capacity

Parameters

Capacity to be proactive in their care



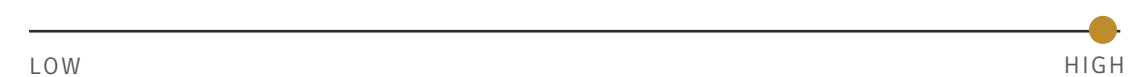
Capacity to independently manage their care



Disruption to their sense of normalcy



Disruption to their health condition



Trust in the community



Care Coordination

This archetype experiences severe to sometimes debilitating symptoms that constrain them from independently coordinating their care.

The onset of their Lyme symptoms can be quite abrupt, leaving them in a critical state with a need for immediate care, without the capacity to advocate

for themselves. This restricted ability to self-advocate can leave them vulnerable to misdiagnoses and discrimination that can worsen their condition.

Barriers	Needs	Actions
The onset of symptoms is usually severe and can instantly put the patient in a critical condition	Urgent, critical care and support that also can help identify the symptoms as a severe case of Lyme	Forced to seek treatment from ER and urgent care facilities that usually misdiagnose and mistreat them, further debilitating their condition
The severe to debilitating disruptions while they search for a diagnosis	Financial, mental health, and caregiving support throughout their diagnostic journey	Depending entirely on their doctors and caregivers to help find the answers to their condition; having no mental health outlet to express themselves without it affecting their diagnosis
Their vulnerability to discrimination around their mental health, leading to their doctors abandoning or misdiagnosing them in a time of need	Advocacy and oversight into the diagnostic and treatment process	Forced to self-advocate or have their caregiver advocate for their well-being and access to care; if they cannot advocate then they may follow their misdiagnosis treatment, which could further worsen their condition
Their capacity constraints that prevent them from independently coordinating their care	Active caregiver and doctors who can advocate for them with their best interests in mind	Depending on their doctors and caregivers to help coordinate their care



"There were times that I needed my family more and times that I was able to do it myself. We shared this burden. I couldn't have done it without them."

—Patient

"So for almost a decade, I had been on any combination of 10 different antidepressants, not at the same time, obviously, sometimes it was two or three at once. The list was exhaustive. It sickens me to know that I was doing all of that for things that didn't need any of it."

—Patient

Life with Lyme

Life for this archetype is severely disrupted, impacting their social lives, work/education, and even sense of identity, further isolating them from the sense of "normalcy" they once enjoyed.

Their isolation escalates with their community's incomprehension of Lyme. One patient revealed, "It was a hard time, you know, I was humiliated and scared. I didn't tell anyone,

and it was like a big secret." As this archetype strives to create a future for themselves while managing Lyme's disruptions, they need their caregivers' and medical team's full support.

Barriers	Needs	Actions
The severity of their condition distances them from a sense of normalcy	Emotional support and guidance for their journey with Lyme	Succumbing to being overwhelmed by their condition and entering a deep state of depression that may trigger worse symptoms; or they can look for support and hope in the Lyme world to find relatable journeys
The lack of understanding and empathy they may experience in their communities	A community that can understand and support what they are experiencing	Ostracizing themselves further from their community and family, feeling like they need to explain themselves to their friends and family; may also experience severe mental health setbacks
Not having the ability to meet the expectations of full-time occupation/education	A level of understanding from their school and/or workplace around their condition	Leaving their education and/or job or heavily adapts their schedule to work with their condition



"I felt like I was dying and there were some days I prayed to the maker to take me because it was terrible. I eventually joined a Lyme group and learned that's how everybody felt at one point in their journey and I thought maybe these are the people I need to talk to."

—Patient

"There were a lot of times when I first left college that were really hard because it was the first time that I had to give in to this disease, and I wasn't in control how I thought I was."

—Patient



ARCHETYPE THREE

Recommendations

01

Create a peer-to-peer mentoring network with patients from their community who have experienced the obstacles of Lyme and can help guide newer, more severe patients.

02

Provide an advocate for patients in severe states that cause them to be vulnerable to abuse and discrimination.

03

Develop a hub for Lyme life planning that points to resources to support with education, employment, and social life management.

04

Assist with navigating the bureaucracy of working and getting an education with a persistent illness.

05

Provide an outlet for full-time caregivers that focuses on their role and stresses that may arise.

06

Provide Lyme education to employers and education programs to help foster an understanding for what the patient and caregiver may be experiencing.



ARCHETYPE FOUR

Semi-Disrupted Without Capacity

They experience Lyme disease's impact while balancing the demands of providing for not only themselves, but also their loved ones.

Their time is an in-demand resource that is continually in low supply. One patient notes his struggle to balance the amount of time he feels well with the demands of life, family, and work: "You know if you have four hours where you feel well enough to be with the world and that's it, how do you portion that? How do you have a job and make a living? How do you have a marriage? How do you be a father? How do you be a son?"

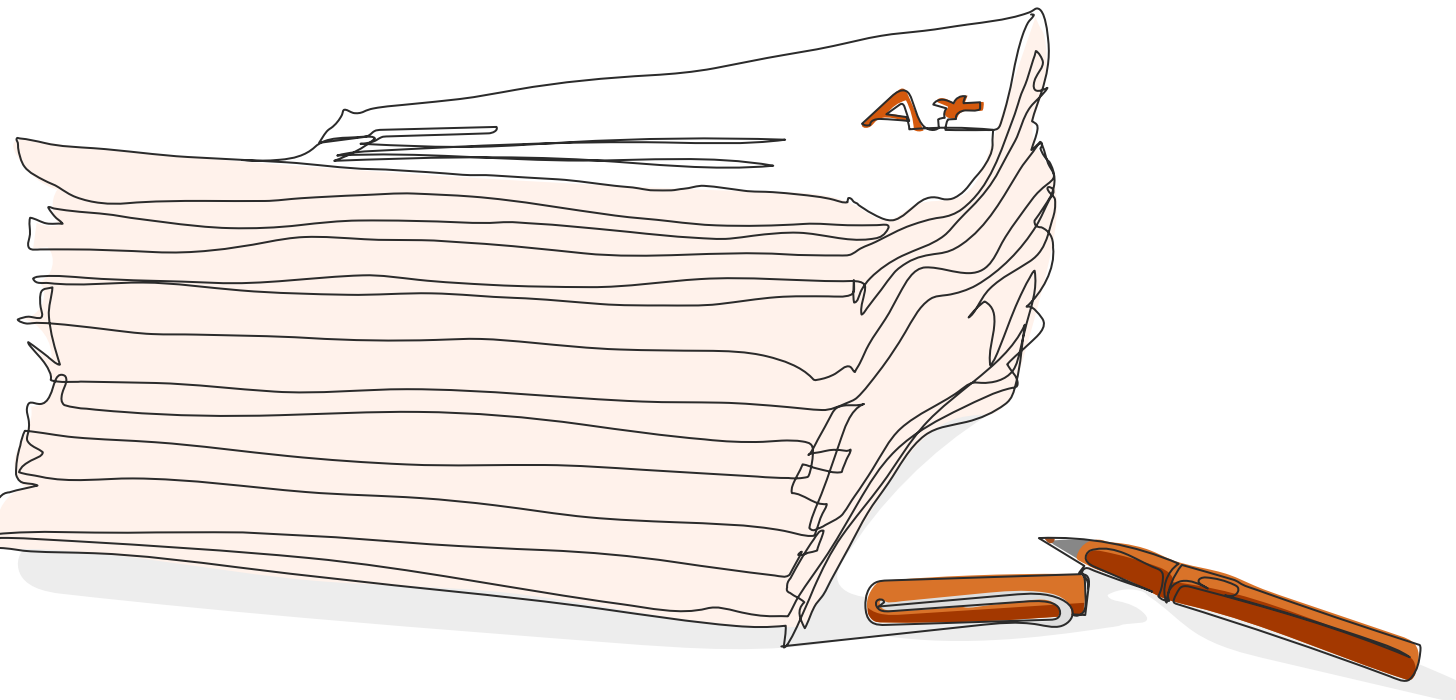
The pressure to perform as a full-time employee and provider emotionally and physically constrains them, preventing them from taking a proactive role in their care. The pressure to perform also forces them to mask their symptoms from their coworkers, community, and family, further isolating them and potentially worsening their symptoms. One patient said of the pressure they feel from the competing needs of work and their family, "I kind of put on a

game face and do what I need to do for the class and the school day. That's always the point of contention with my wife, who is like, you're a completely different person at work. And I'm like, well, yeah, because I'm acting hard, you know, acting a part."

This archetype's demand to balance their responsibilities with their condition risks worsening their condition and makes them vulnerable to more severe disruptions.

"You know if you have four hours where you feel well enough to be with the world and that's it, how do you portion that? How do you have a job and make a living? How do you have a marriage? How do you be a father? How do you be a son?"

—Patient



"I kind of put on a game face and I do what I need to do for the class and for the school day. And so that's, you know, that was always the point of contention with my wife, she's like, you're a completely different person at work. And I'm like, well, yeah, because I'm acting hard, you know, acting a part."

—Patient

ARCHETYPE FOUR

Semi-Disrupted Without Capacity

Parameters

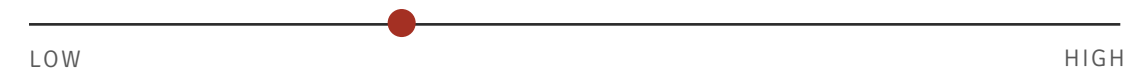
Capacity to be proactive in their care



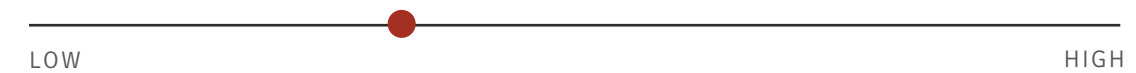
Capacity to independently manage their care



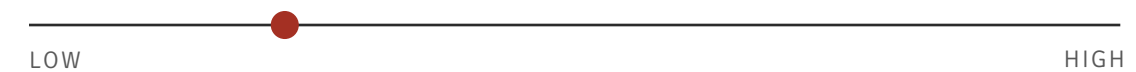
Disruption to their sense of normalcy



Disruption to their health condition



Trust in the community



Care Coordination

The pressure to carry the weight of their responsibilities restricts this archetype's ability to manage their Lyme to the full degree they desire.

Their financial and time constraints cause them to search for in-network answers when looking for diagnoses and treatment, sometimes leading to a costly and frustrating cycle of being misdiagnosed or untreated. Once they

find a proper diagnosis and treatment, they are limited by their diminished capacity to be proactive in their care. These constraints force them to be dependent on their doctors and "less expensive, less invasive" treatment options.

Barriers	Needs	Actions
The lack of support from medical doctors covered by insurance while on the diagnostic journey	Streamlined diagnoses to Lyme that prevents the costly cycle of searching for answers	Searching for answers from specialists to specialists in-network, while taking on the expenses of being misdiagnosed and undiagnosed
The limited out-of-network providers that are willing to care for them	An affordable way to manage their symptoms at a level where they can still provide for themselves and their family	Trying treatments that are low-risk and low-cost while taking on full workloads that sometimes trigger more symptoms
The limited resources and time to be proactive in their care	Active guidance and structure to help them find the best care and management for their condition	Depending entirely on their doctor for their care, sometimes being led down costly and damaging treatment routes



"My idea has been to try things that are less expensive, less invasive, and that I can see some possible reason why it could possibly work."

—Patient

"My mom asked, 'So why don't you go talk to somebody who's specialized in Lyme disease?' And I thought, I've been tested for Lyme disease a couple of times and I've been to all these doctors and have even been to the Mayo Clinic. These are supposed to be the smart people."

—Patient

Life with Lyme

Their circumstances and limited access to resources force them to push through employment or school as if nothing is wrong.

This demand also requires them to mask their symptoms and appear well when they are not well, further isolating them and potentially triggering more symptoms. With this isolation comes guilt and depression from not participating

in their loved ones' lives and missing out on their own lives. With most of their limited resources going to treatment, they are left without a strong safety net if their condition worsens.

Barriers	Needs	Actions
The pressure to perform and seem okay in front of their coworkers, friends, and family	A better understanding from those around them of the severity and impact of Lyme	Masking their symptoms and pushing themselves further than they feel like they can go
The impact of Lyme's unpredictable conditions on their school/employment	Work/school with a flexible schedule that allows them to adjust their hours to how they feel	Changing the course of their career/education to better fit their needs
The lack of safety net and future plans they have been able to plan and maintain	Guidance on the future state of their condition	Living at-risk with the hopes that their condition will not worsen with the stress of this situation causes symptoms to trigger
The isolation and guilt that they experience from the disruption of their condition	Communities and support systems that understand what they might be going through	Transferring their guilt into stress, further triggering their symptoms

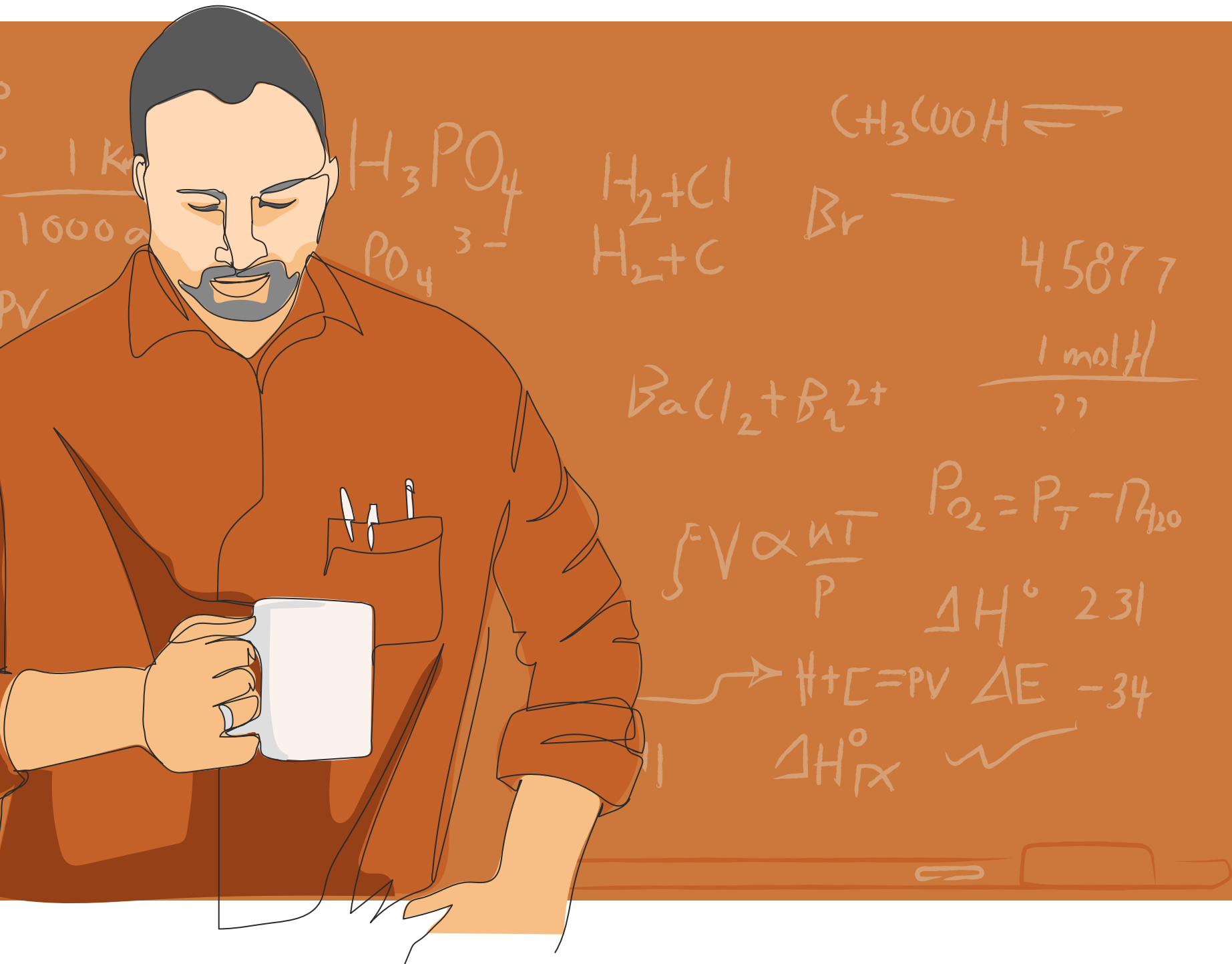


"With work, it's hard not to like to compare your performance with others. Like I can tell I don't perform as well with my work stuff. I don't know. I guess I tend to get critical of myself, and just, I want to get back to where I was before."

—Patient

"I don't think I'm going to feel well when we get to one. And so everybody's excited about going to the movie at one o'clock and I have to cancel. So then they decide, well, should we go alone and leave him home? But that's not fun. We want all to be together. Well, so they're all going to stay home now and just sit around the house for a couple hours while I sleep. So it does affect everybody. And it's really hard."

—Patient



ARCHETYPE FOUR

Recommendations

01

Develop an adult guide and workbook for planning a future with persistent Lyme symptoms, including recommendations on building a support network, adapting their career/education, and utilizing resources.

02

Create a digital library that saves patients' medical records, symptom journals, prescriptions, X-rays, lab results, and insurance forms in a centralized location and categorizes them by action required.

03

Develop and maintain a cost-of-care resource that estimates the total cost of types of Lyme care, to be used in informed discussions on the viability of a treatment option on a patient-by-patient situational basis.

04

Provide Lyme education to employers and educational institutions to help foster an understanding of what the patient and caregiver may be experiencing.

05

Connect patients with career and educational counselors that can help with the adjustments needed for their condition.

06

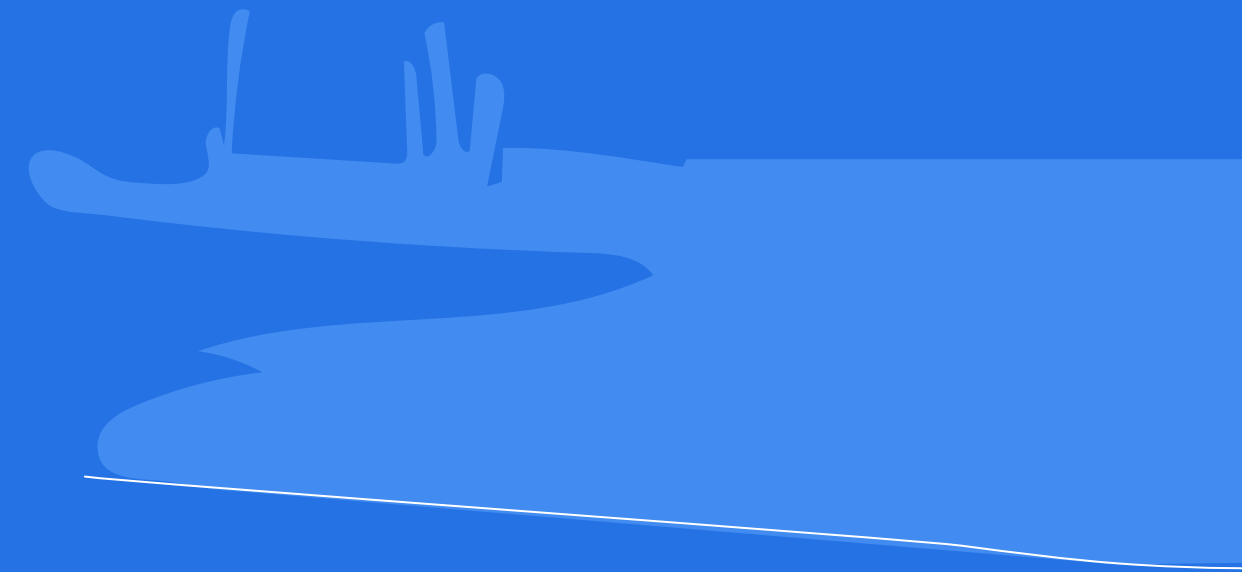
Provide community and childcare support for parents and caregivers dealing with persistent Lyme.

07

Provide financial support for patients and caregivers with dependents who cannot go on disability.

THE PROBLEM // THE OPPORTUNITY // THE RECOMMENDATION

Opportunity Areas







"Lyme disease, the most rapidly spreading vector-borne disease in the country, is the AIDS of our time: Patients with persisting Lyme disease often are dismissed by doctors without help, publicly ridiculed and otherwise diminished in news media, and many develop a mysterious, progressively debilitating illness that federal public health agencies have shown little interest in researching. Many patients go bankrupt trying to piece together help for their conditions before they become disabled, and too many end their own lives in desperation Patients of no other disease since AIDS have suffered publicly sanctioned derision for seeking help for their serious medical conditions."

—David Michael Conner, Journalist and Health Writer

01

Broader Awareness of Lyme Disease

- Generate greater public awareness and bolster prevention
- Improve medical awareness of and fluency in Lyme approaches across specializations

03

Cohesive and Comprehensive Care Coordination

- Create seamless coordination between healthcare providers and patients/caregivers
- Provide adequate support and resources to healthcare providers treating Lyme
- Break down medical silos that cause financial burden for patients and caregivers
- Protect patients from abuse and discrimination

02

An Accelerated Diagnostic Process

- Build awareness around symptoms outside of the "bull's-eye" rash to motivate Lyme testing and diagnosis
- Resolve conflicting medical advice around diagnosis and streamline information across provider network
- Empower patients and caregivers to better navigate the process with knowledge and tools

04

Holistic Life and Care Management

- Help patients plan for their future
- Support patients navigating bureaucratic challenges
- Create a long-term support system for patients and caregivers managing persistent Lyme

OPPORTUNITY AREA ONE

Broader Awareness of Lyme Disease

A deep level of Lyme awareness is lacking from initial prevention, through treatment. As instances of Lyme disease—one of the fastest growing epidemics to date—increase, the risk of exposure becomes more frequent and increased awareness of the vector-borne illness becomes even more essential.

In addition to regions known for ticks, Americans encounter tick exposure in places they don't expect them—on the job, while gardening or playing in the backyard, in urban areas, and even in regions not historically associated with Lyme. "I didn't even know what a tick was," said one patient. "I lived in Southern California by the beach. You know, people never talked about it. I never heard of it." Another reported, "I went through my whole military career, including field exercises, including crawling around in the fields of Eastern North Carolina. It was never taught. We weren't taught what ticks were or what

symptoms to look for." A Lyme leader and caregiver corroborated this lack of awareness: "Especially for the new guys and gals who are going through like general training, they are getting bit constantly, but then over in like Saudi Arabia and over in Japan, all of these military personnel are getting bit by ticks and having different diseases coming back. And they're getting medically discharged."

When patients knowingly encountered a tick, most of them pulled the tick off and moved on. One patient recalled, "And I got bit on my ankle by

what I thought was a mosquito. It was very itchy, but I didn't have, you know, any other symptoms or I didn't have a Lyme rash. You know, the typical 'bull's-eye' rash you might've heard of. I didn't have that. I just thought it was a mosquito bite that sort of stuck around." Because of limited, and in some cases, lack of knowledge of Lyme's complexity, initial contact with a tick can be taken too lightly, leading to individuals not seeking the more effective, timely treatments until they experience symptoms too disruptive to ignore.

"Yeah, I think what's mind-boggling is the fact that not a single doctor even asked about Lyme disease, not one brought it up and I wasn't aware enough to ask them."

—Lyme Leader

Atypical tick encounters, such as those that don't result in a "bull's-eye" rash, can also be downplayed by doctors when they're reported by patients, leading to missed early diagnosis and missed opportunities to treat Lyme before the onset of symptoms. Another patient reported, "My mom found a tick on my right ear. And she immediately called the pediatrician, and the doctor said, 'Don't worry about it. If she has symptoms in a month, bring her in, and we'll deal with it.' Looking back, that was a crucial time and if I had been treated

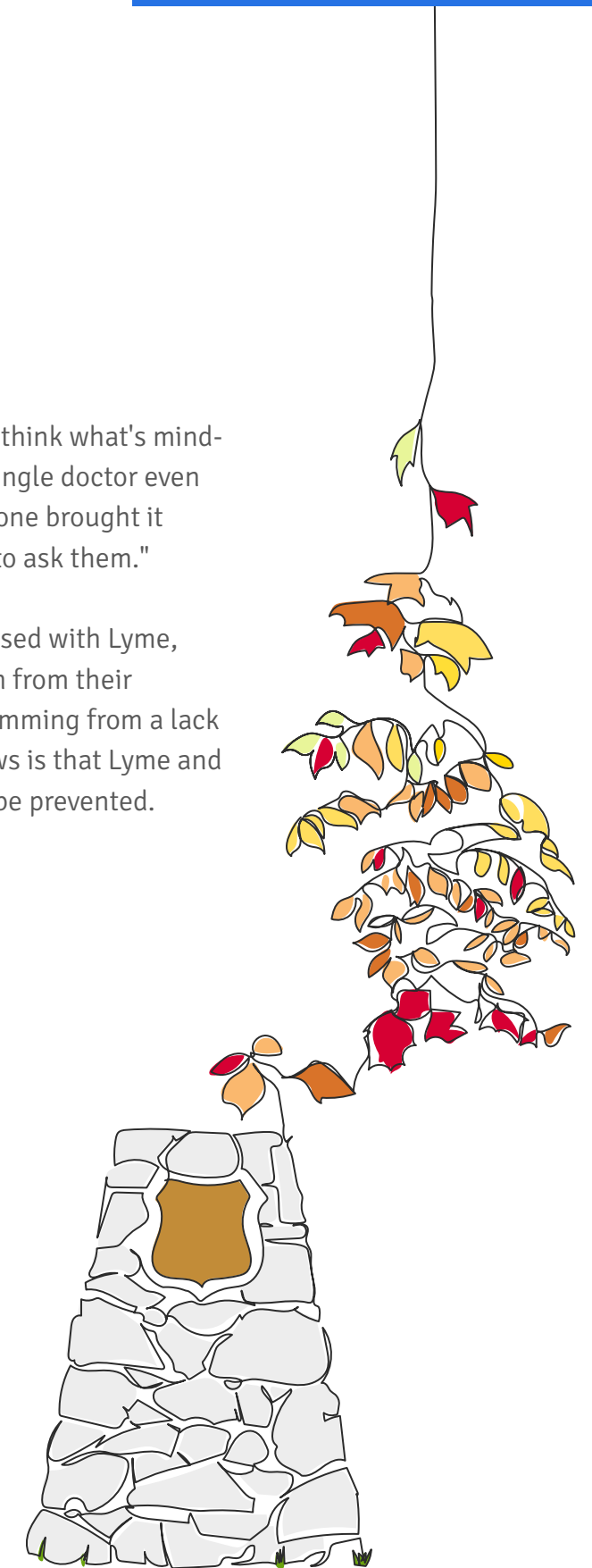
right away. I wouldn't be here." Once the patient does experience recognized Lyme symptoms, the lack of medical awareness they encounter when seeking medical attention can further negatively affect the diagnostic and treatment process, leading to consequential health and financial outcomes.

"My mom found a tick on my right ear. And she immediately called the pediatrician and the doctor said, 'Don't worry about it. If she has symptoms in a month, bring her in and we'll deal with it.' Looking back, that was a crucial time and if I had been treated right away. I wouldn't be here."

—Patient

One patient recounted, "Yeah, I think what's mind-boggling is the fact that not a single doctor even asked about Lyme disease, not one brought it up, and I wasn't aware enough to ask them."

When a patient is finally diagnosed with Lyme, many experience discrimination from their providers and communities, stemming from a lack of understanding. The good news is that Lyme and its complex consequences can be prevented.





BROADER AWARENESS OF LYME DISEASE

Generate Greater Public Awareness and Bolster Prevention

There is an opportunity to push for awareness and education within the public sector by looking at the gaps in the knowledge today and providing the best way for each population to learn about and understand Lyme disease.



"I went through my whole military career, including field exercises, including crawling around in the fields of Eastern North Carolina. It was never taught. We weren't taught what ticks were or what symptoms to look for."

—Lyme Leader

"I was a wildlife biologist working for the federal government and I knew nothing about Lyme disease. I knew nothing about, I didn't know, there was more than one kind of tick. I didn't know that ticks carry, you know, almost 20 different pathogens."

—Lyme Leader

Contributing Factors

01

The shortage of awareness and clarity around the potential transmission of tick-borne infections for prospective parents and romantic partners

02

The shortage of awareness and understanding of Lyme's potential severity and impact on a patient, causing:

- a lack of understanding from a patient's job and/or education, often causing unrealistic expectations on the patient's performance
- a lack of understanding from a patient's community, often causing patients to go without proper community support and care



Interview patient's former outdoor job

03

The lack of environmental awareness of Lyme disease, including:

- limited awareness of Lyme disease's existence and prevalence in non-endemic areas preventing proper prevention education and diagnostic abilities
- limited education and prevention recommendations for employers to share with employees that are frequently exposed to ticks (e.g., military personnel, landscaper, firefighter, etc.)
- limited education for Lyme's reach across urban or non-urban environments



Recommendations

01

Create clinical and public education programs surrounding Lyme and tick-borne diseases to prevent infections by particular ticks.

02

Develop employee education modules surrounding Lyme and other tick-borne infections for professions forced to work in higher-risk tick exposure settings in endemic and non-endemic areas.

03

Create early childhood education modules around Lyme, focused on developing safe outdoor habits with the aim of prevention in early life.

04

Develop and launch an awareness campaign that targets communities within non-endemic and endemic areas, speaking to the risks of Lyme and showing the prevalence of Lyme in that community; awareness materials could be distributed in doctors' offices, parks, urban nature areas, searches for regional parks, and elsewhere.

05

Increase funding towards developing and promoting apps to track ticks, such as TickTracker.

06

Coordinate proactive smart device alerts that appear when entering potential contamination areas.

BROADER AWARENESS OF LYME DISEASE

Improve Medical Awareness and Fluency in Lyme Approaches Across Specializations

There is an opportunity to create clear medical guidance and awareness surrounding Lyme disease, which will help streamline diagnosis and treatment for Lyme patients across the types of providers patients are likely to encounter in seeking treatment.

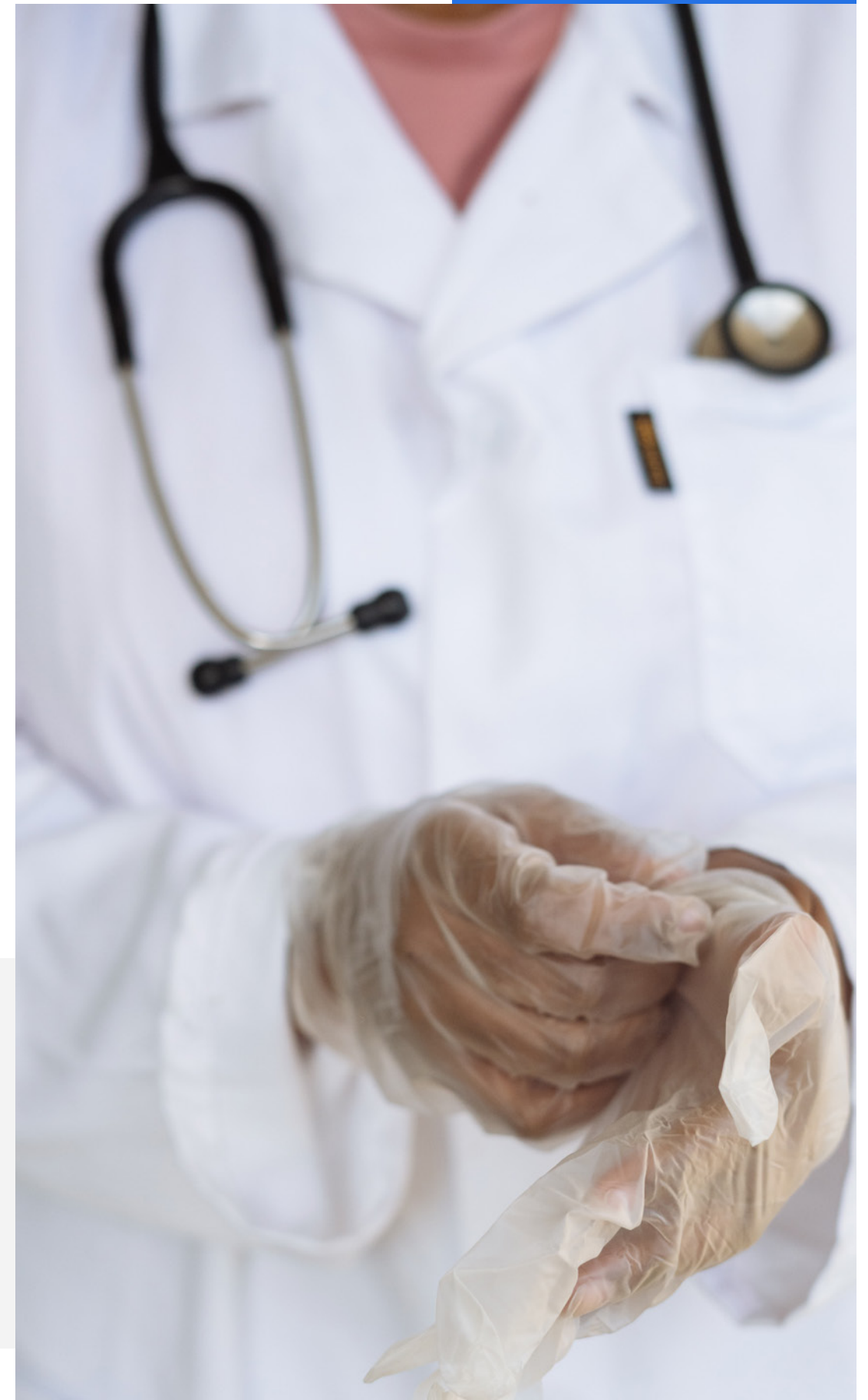


"So it's really easy to get pissed and throw spears at doctors, but we give them four hours in medical school to learn that Lyme disease is easy to treat. I empathize with their lack of knowledge, with the lack of resources, diagnostic tools."

—Lyme Leader

"And I got bit on my ankle, by what I thought was a mosquito. It was very itchy, but I didn't have, you know, any other symptoms or I didn't have a Lyme rash. The typical 'bull's-eye' rash, I didn't have that."

—Patient



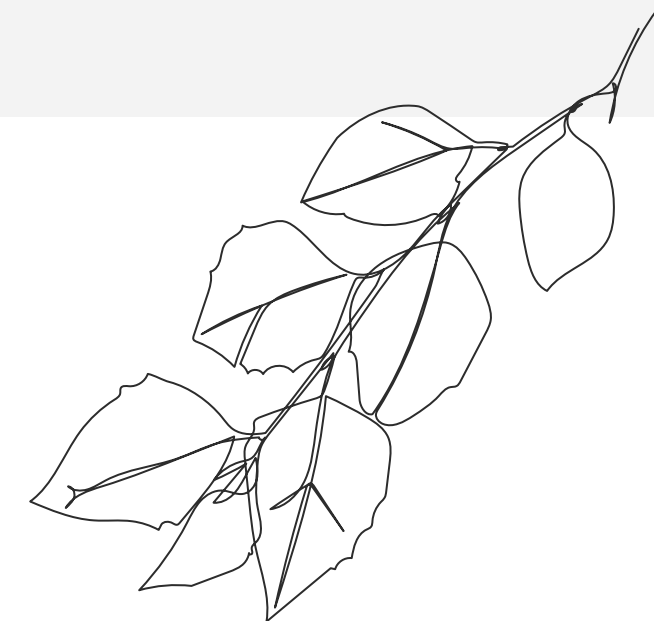


Contributing Factors

- 01** The lack of awareness of the vast array of symptoms presented by Lyme and its coinfections, above and beyond the iconic "bull's-eye" rash
- 02** The unclear follow-up protocol after the implementation of The Infectious Diseases Society of America's (IDSA) recommended guidelines, leading to patient confusion and potential further infection
- 03** The unclear guidance on what to do after exposure to a tick, leading to potential further infection
- 04** The lack of clarity surrounding comorbidity of Lyme and other tick-borne infections
- 05** The lack of unified education surrounding the approach to Lyme diagnosis within the medical community
- 06** The lack of awareness about continued treatment of Lyme and coinfections beyond IDSA-recommended guidelines

Recommendations

- 01** Create a Lyme and coinfection symptom database that can be used to help doctors discern whether a set of symptoms may be Lyme-related, in order to increase Lyme testing.
- 02** Develop a medical protocol following an initial Lyme exposure, including monitoring and recommendations on follow-up appointments.
- 03** Create a simple and clear campaign and slogan (e.g., "Stop, drop, and roll" and "call before you dig") to help with awareness of what to do right after a tick bite.
- 04** Update CDC websites and recommendations as new data becomes available, stating transparently what is known and what is unknown by the agency.



OPPORTUNITY AREA TWO

An Accelerated Diagnostic Process

Because Lyme's symptoms are diverse, misleading, and often incorrectly attributed to other illnesses, patients can face a long diagnostic journey. Just as rapid identification of symptoms and treatment can result in positive outcomes for patients, delayed diagnosis and misdiagnosis may lead to more severe and prolonged symptoms.

One patient reported, "But at the time, I didn't know. And you know, that's what happens with time is you attribute your symptoms to two different things. Oh, it must be this. Or it must be this. So yeah, I had it written down, and I mean, I even had a body map where I had drawn just like a simple stick figure and arrows pointing to different parts of my body with what was going on with me." Another said of their diagnostic journey, "It took seven-and-a-half years to get to a diagnosis. And I'm at about seven-and-a-half years in treatment. During that time, I improved from incapacitated, bed-bound, housebound, completely dysfunctional in just about every system of my body while trying to raise two children."

Patients whose diagnosis is delayed for any reason (e.g., misdiagnosis, their own or their doctor's lack

of knowledge) can experience such severe Lyme-related disturbances in their lives that they can end up financially, emotionally, and physically devastated with little reserves left to manage the disease itself. Additionally, they may experience stigmatization around mental health issues and be ignored by their doctors, leaving them to manage their symptoms alone, feeling isolated and abandoned. One patient reported that they "spent two weeks at the Mayo Clinic prior to my diagnosis of Lyme disease and was sent home with a diagnosis of idiopathic pancreatitis and depression. And I can say I was not depressed before I got to Mayo." They said, "I was very hopeful when I got to Mayo. I was incredibly depressed when I got back from Mayo with no diagnosis and no relief from symptoms."

One patient received a series of misdiagnoses before learning they had Lyme: "But yeah, it was, I know there's other doctors there, you know, it was misdiagnosed with ulcerative colitis. I was misdiagnosed with IBS. I was misdiagnosed with celiac disease. I was misdiagnosed with migraines cause they weren't really migraines." Such misdiagnosis of Lyme is not only common but also can be so severe that patients even undergo surgeries and treatments for illnesses they do not have, further devastating their health condition. Another patient reported, "Instead of recovering after the surgeries, I just got sicker and sicker and sicker. I don't know if sicker is the right word, but it took seven and a half years to get to an accurate diagnosis of Lyme disease and multiple tick-borne infections."

Delayed diagnosis, misdiagnosis, and the persistent inconsistency of Lyme awareness and diagnostics within the medical community forces patients and caregivers to become self-advocates and waste their waning energy on trying to convince their doctors that they have Lyme and it's not all in their head. One caregiver said, "I started Googling her symptoms, and I would get hundreds of different disorders, you know? And one by one, I would ask them, can you test it for this? Can you test it for that? And her tests would come back normal for everything. And then we started bouncing around from hospital to hospital and specialist to specialist."

"I started Googling her symptoms, and I would get hundreds of different disorders, you know? And one by one, I would ask them, can you test it for this? Can you test it for that? And her tests would come back normal for everything. And then we started bouncing around from hospital to hospital and specialist to specialist."

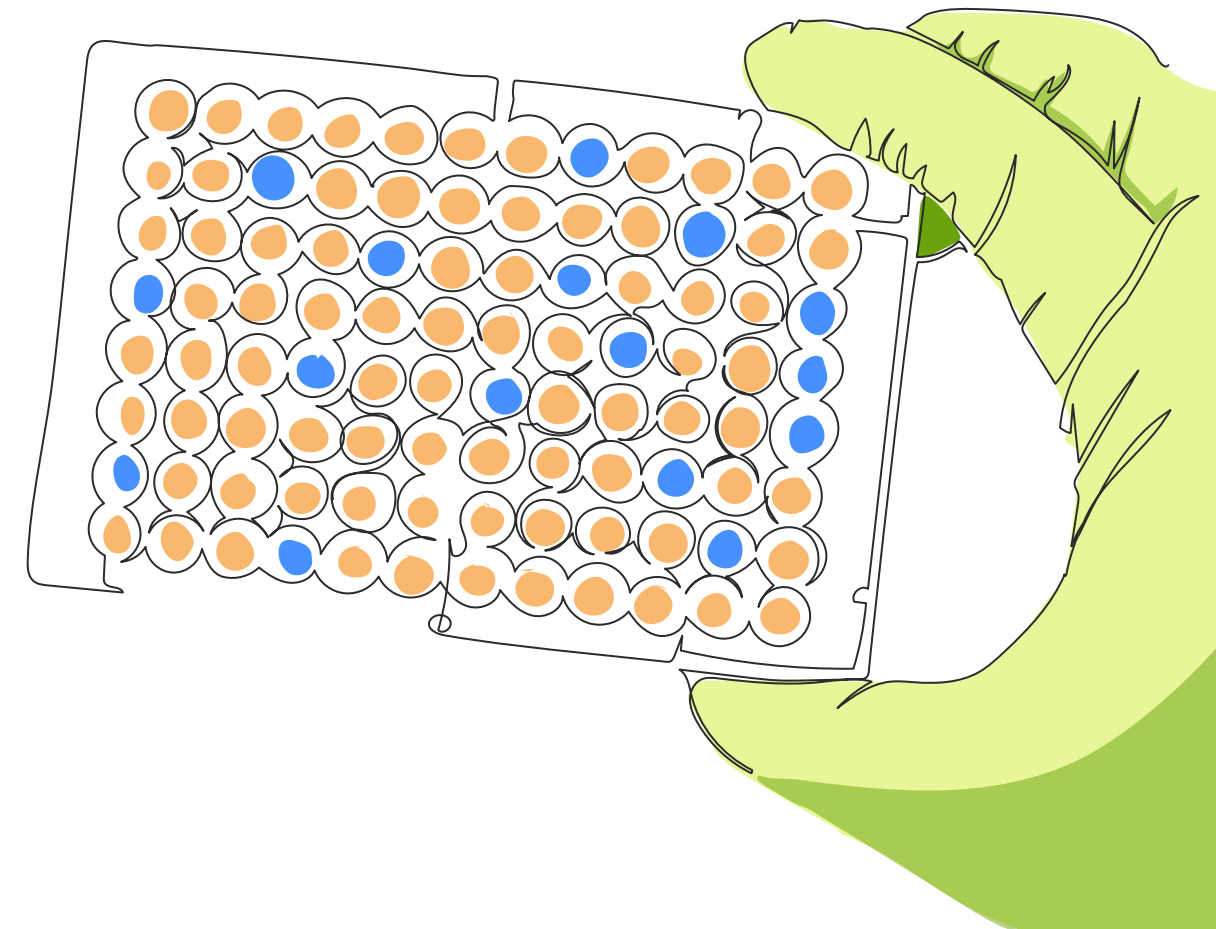
—Lyme Leader

Most out of the sample set of patients interviewed finally learned they had Lyme through their community or hearing a story of similar symptoms after spending thousands of dollars on misdiagnosis and countless hours researching their symptoms. Another patient said, "And then finally, a friend of mine had posted a video about this girl who had Lyme, and I reached out to her being like, I think I might have Lyme. We had coffee, and she told me every single symptom you're mentioning is Lyme disease."

The stigmatization, gaslighting, and lack of understanding patients face in seeking a diagnosis doesn't end upon receiving confirmation. Once they are tested and diagnosed, Lyme patients still may not receive proper guidance or validation for their Lyme status. Another patient reported their "doctor was terrible. She was so dismissive. And she said, so based on the Western blot, you don't have Lyme. You probably have another tick-borne illness, but you know, you're supposed to have five bands test positive, and you only have three, and you know, stay on the Doxycycline." Worse yet, some patients never receive a

diagnosis. They're left without answers and continue to struggle today.

Difficulty with Lyme diagnosis is not limited to the patient experience; doctors also face challenges around diagnosis because there is a shortage of consistent, comprehensive information and procedures within the Lyme diagnostic process. Both Lyme patients and doctors would benefit from improved and standardized diagnostic processes.



AN ACCELERATED DIAGNOSTIC PROCESS

Build Awareness Around Symptoms Outside of the “Bull’s-Eye” Rash to Motivate Lyme Testing and Diagnosis

There is an opportunity to educate the public and healthcare providers about Lyme’s diverse set of symptoms outside of the “bull’s-eye” rash. Including Lyme in a differential diagnosis model for its associated symptoms can shortcut years, even decades, of treatment early on, alleviating the patient’s financial, physical, and emotional burden experienced through the diagnostic journey.



"She diagnosed me with chronic fatigue and sent me to a psychiatrist, which is kind of the go-to. If the doctor doesn't know physically what's going on, they'll send you to a therapist and put you on antidepressants."

—Patient

Contributing Factors

01

The lack of medical and scientific consensus surrounding symptoms that warrant testing for Lyme

02

The lack of updated education surrounding potential diagnoses for Lyme

03

The improper identification of symptoms in children with Lyme

04

The varying and unpredictable patient entry points to Lyme that put any healthcare provider at the front lines of diagnoses

05

The neurological constraints a patient may face when experiencing symptoms while pursuing diagnoses

06

The mental health stigmatization patients often receive from their HCPs after expressing symptoms

Recommendations

01

Create a Lyme and coinfection symptom database that can be used to help doctors discern whether a set of symptoms may be Lyme-related to increase Lyme testing.

02

Develop a protocol following a known tick exposure that doesn't rely on the presence of symptoms that may lay dormant.

03

Develop educational resources to help a diverse range of HCPs (e.g., therapists, ER doctors, insurance advocates, etc.).

04

Develop pediatric Lyme disease and coinfection symptom educational resources for healthcare providers dealing with adolescents.

05

Develop an interactive platform where patients can enter and monitor their symptoms that provides them with diagnostic guidance.



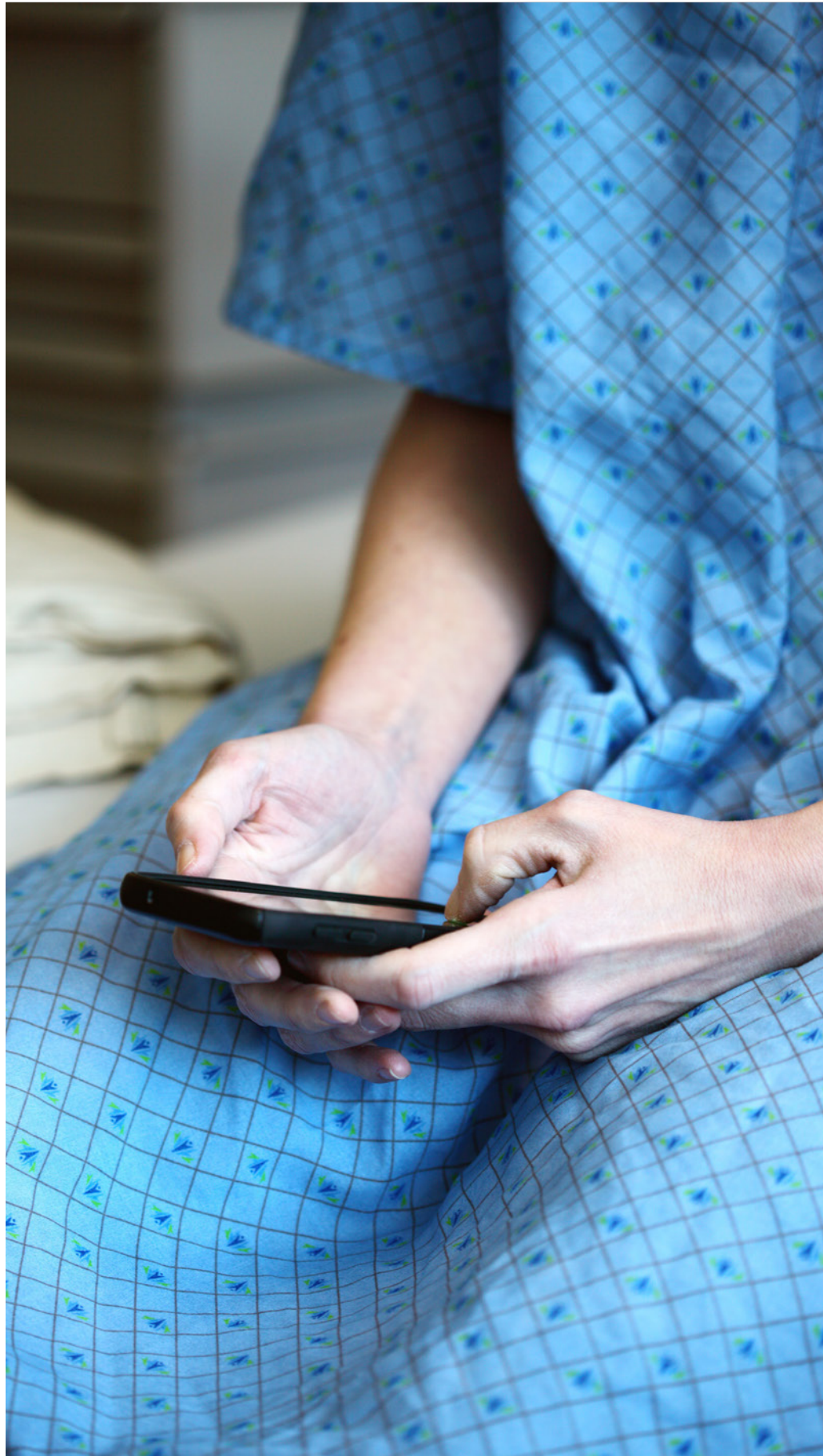
AN ACCELERATED DIAGNOSTIC PROCESS

Resolve Conflicting Medical Advice and Streamline Across Provider Network

There is an opportunity to resolve conflicting medical advice for patients who still experience health complications from Lyme and other tick-borne coinfections after being treated with the 60-day regimen recommended by the IDSA guideline treatment.

Because many patients still face symptoms after being treated with the IDSA guideline treatment, they seek additional information regarding their Lyme diagnosis and treatment, sometimes leading them down a path of overwhelming and conflicting information. Even when patients seek information solely from medical professionals, they often

receive contradictory advice on how to best proceed. By providing aligned guidance on the next steps after the 60-day antibiotic treatment, patients and healthcare practitioners will be equipped with the knowledge and resources to coordinate their care.



Contributing Factors

- 01** IDSA's stronghold over diagnostic guidelines
- 02** The medical silos formed around treatment philosophy and approaches create confusion and distrust for patients and HCPs
- 03** The lack of established differential diagnostic approaches requiring the employee to be in situations that risk their exposure to ticks (e.g., Military personnel, landscaper, firefighter, etc.)
- 04** The lack of guidance and care coordination for patients with persisting symptoms
- 05** The abandonment and confusion a patient may experience if they still are experiencing symptoms after treatment

Recommendations

- 01** Develop a medical protocol following an initial Lyme exposure, including monitoring and recommendations on follow-up appointments.
- 02** Develop a treatment path outline that recommends steps after the IDSA guideline treatment, should symptoms persist.
- 03** Develop an ongoing Lyme medical check-in and tracker for patients after receiving treatment that allows their HCP to monitor their condition, while also allowing Lyme to be apparent in their future medical records, helping identify dormant symptoms that might reappear.



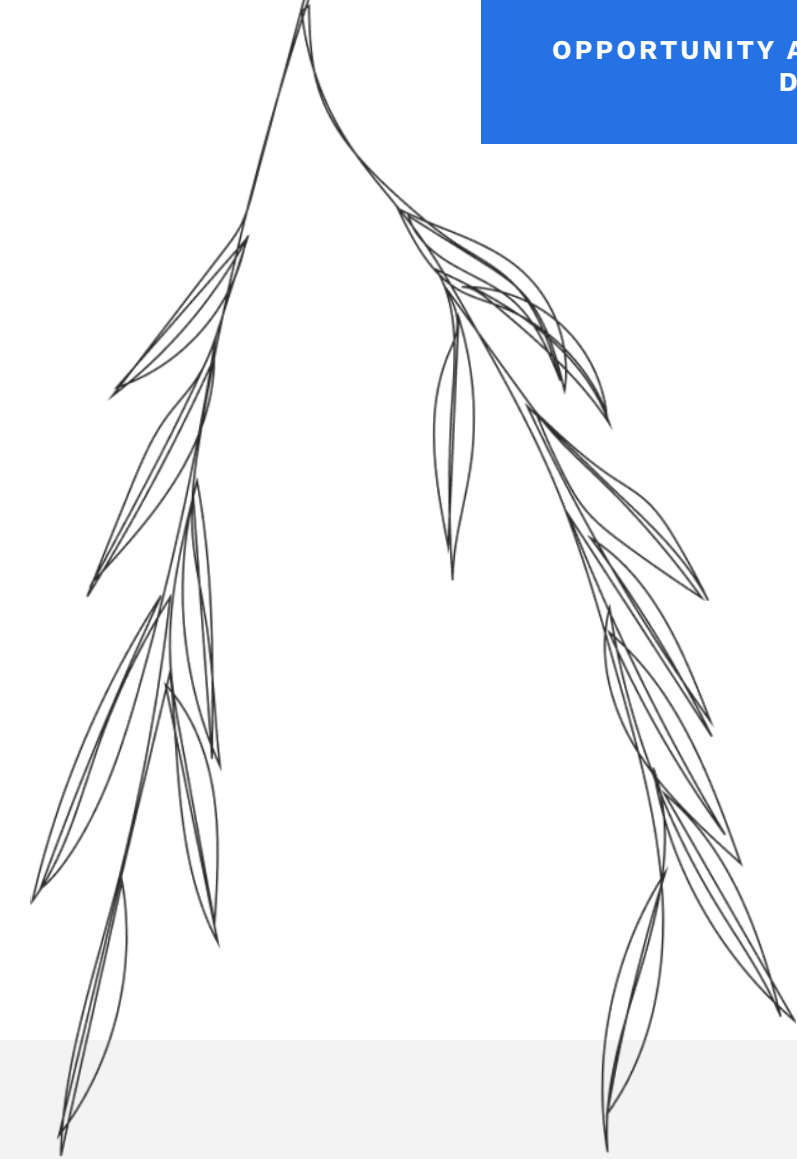
AN ACCELERATED DIAGNOSTIC PROCESS

Empower Patients and Caregivers to Better Navigate the Process with Knowledge and Tools

There is an opportunity to provide patients and caregivers with the guidance and tools necessary to help them self-navigate their diagnostic journey when they are dealing with misdiagnoses, discrimination, and general confusion around Lyme.

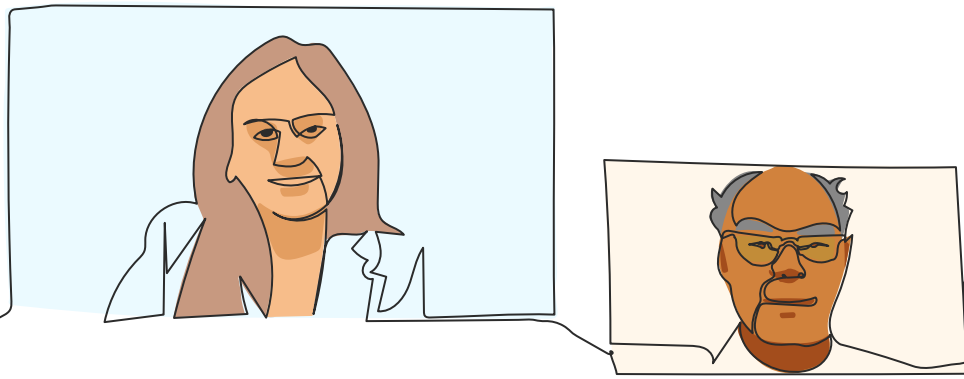
Contributing Factors

- 01**
The mental health stigmatization patients often receive from their HCPs after expressing symptoms
- 02**
The overwhelming amount of conflicting information around Lyme
- 03**
The financial and physical burden of being misdiagnosed and mistreated
- 04**
The lack of guidance and care coordination for patients with persistent symptoms
- 05**
The sometimes inaccessible and unaligned testing for Lyme
- 06**
The Lyme community's assistance with a patient's Lyme diagnosis



Recommendations

- 01**
Create a mentorship program for Lyme navigators, Lyme community leaders, and experts who are willing and interested in sharing their experience and research to help individuals navigate the journey.
- 02**
Develop a platform that provides preemptive notifications which offer proactive check-ins, HCP communication, progress updates, and insight into the diagnostic process. Urgent health signals trigger nudges to the HCPs (e.g., call patients, auto-save an appointment time to be confirmed via text, etc.).
- 03**
Create a digital library that saves patients' medical records, symptom journals, prescriptions, X-rays, lab results, and insurance forms in a centralized location and categorizes them by action required.
- 04**
Provide a treatment path forward for patients when diagnosed with Lyme to equip them to manage information overload and next steps that need to be taken.
- 05**
Develop an aligned and inclusive diagnostic testing protocol for Lyme covered by insurance.
- 06**
Create an open-source community resource for vetted and supporting Lyme healthcare providers across physical, mental, neurological, and alternative treatment spaces.
- 07**
Provide a Lyme code of rights that outlines patients' rights to freedom from discrimination, coercion, harassment, and exploitation.



OPPORTUNITY AREA THREE

Cohesive and Comprehensive Care Coordination

The extraordinary efforts undertaken by patients to secure coordinated, consistent, ongoing, and effective care further impedes their ability to heal from Lyme while draining their resources. Difficulties around care coordination span the entire care journey, from the search for appropriate care to interpersonal and physical treatment of the patient by medical providers once care is engaged.

Difficulty securing care is attributed to doctors' disbelief in patient symptoms and their reluctance to treat them, resulting in patients feeling abandoned by healthcare providers. One patient said, "So that's when my primary care began treatment for me, and I immediately started to respond. But when I hit the three months, he said, no more. I can't do it. And I'm like, what do you mean? I like getting better. You can't take away my medicine. So that's how I got from, you know, seven and a half years of misdiagnosis and becoming completely debilitated to making progress towards wellness."

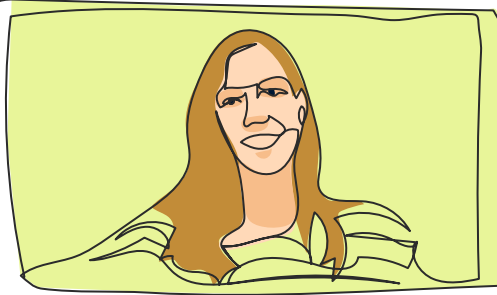
Even after finding a physician that will treat them, patients are expected to guide their own care path without any official guidance from the government, which can lead to financial and health consequences. They are forced to hop from doctor to doctor looking for someone to care for them, a phenomenon another

patient referred to as "common practice": "When you show up with these doctors, they're used to people seeing 20 different doctors before, I think the average is 20 doctors before they get to the right doctor." The doctors that do eventually treat Lyme patients bear the burden of managing their entire health plan since other doctors refuse to coordinate with them.

Patients are burdened with steep costs and additional challenges when they need to travel great distances to find a doctor who will treat them. A patient explained that access to care seems easier for those who are wealthy and have access to long-distance travel: "When the doctor won't work with you [the patients] have to travel to get treated and unfortunately in that sense, it becomes Wealthcare on some level, you know, instead of healthcare, and it can't be that the only people who get better from Lyme are the

wealthy. That's just not reasonable." Another spoke to the geographic scarcity of appropriate care: "We had to travel to New York because after I got my diagnosis; my children and husband got their diagnosis. And because we couldn't find anybody to treat us here in Colorado, we ended up flying to New York every three months for two years, just to see a 'Lyme literate' medical doctor there."

The patient-doctor experience itself is also fraught with concerns. For instance, patients are constantly given differing advice from doctors, not knowing who to believe or what to do because there is no consensus on the treatment provided by the government. One patient stated, "I was being told the same thing over and over, 'I'm the one that can help you. So if you didn't come to me, you're not going to be helped.' And I started to realize, you know, it's just not true. Like it's up to me. I'm the only



"It's kind of like when you go to a hairdresser. They say, 'Oh, my God, you're too blonde. Whoever did your hair before is blind.' And then they fix it, and then it looks great. And then, a month later, it looks as blonde as it was before. But every hairdresser knows better. That's how it feels like when every doctor you go to knows better. They're also all selling different protocols. They're all selling a different way of doing things."

—Patient

one at the end of the day that's going to get myself well, you know? I had to do it on my own because nobody else was doing it." Another said, "How are you supposed to know? You know, I was, you know, 20 years old and doing what I was told." A third patient made an apt comparison: "It's kind of like when you go to a hairdresser. They say, 'Oh, my God, you're too blonde. Whoever did your hair before is blind.' And then they fix it, and then it looks great.

And then, a month later, it looks as blonde as it was before. But every hairdresser knows better. That's how it feels like when every doctor you go to knows better. They're also all selling different protocols. They're all selling a different way of doing things." Lyme patients further cite medical abuse and discrimination by providers who do not trust them. A Lyme caregiver reported, "The doctor brought us outside and said, [the patient] is faking it During the first couple of hospitals she stayed at, the doctors would come in while she was sleeping, take skewers, break them. So they would show up and stab her in the feet to test if she was not faking [her coma induced by Lyme]." Additionally, patients are forced to be the guinea pig for their treatments, sometimes leading to debilitating side effects while also taking on significant financial debt. One patient summarized the experience: "There's no one size fits all answer, so you just have to keep trying different doctors and treatments hoping something will work." As with diagnosis, both patients and doctors are impacted by the lack of coordinated care around Lyme. Doctors looking to help their patients with persistent Lyme bear the burden of searching for treatment guidance. One doctor said, "We try to

be realistic. We're not like, you know, saying you're gonna get better. It's, you know, for a lot of these people, it's a long road. And I think, you know, they appreciate that and try to put a positive spin, like, continuing to support you, but, you know, it might take some time." They're also faced with the difficult task of managing their patients' disappointment when they learn about the complexity of recovering from persistent Lyme. Another doctor said, "There's no clear path, you know, I can never tell anyone, you know, Oh, okay. Go to this doctor. They'll help you. You'll be fine. It just doesn't work like that. You know, it kills me whenever we get one of these calls because I know it's not, it's not going to be quick. It's not going to be easy. It's not going to be cheap. It could be 10 years before they notice anything. And that's very hard to tell someone when they're just finding out that they have Lyme."

Even after finally finding one doctor who tries to help improve a patient's outcome, further communication with other doctors in the patient's network poses new obstacles, as some do not believe persistent Lyme exists.



COHESIVE AND COMPREHENSIVE CARE COORDINATION

Create Seamless Coordination Between Healthcare Providers and Patients/Caregivers

There is an opportunity to improve the coordination between HCPs and patients/caregivers in order to help identify the HCP appropriate for their treatment goals, priorities, and budget. This is particularly the case for those with persistent symptoms who may be experiencing debilitating symptoms for an unknown period of time, and require an HCP to personalize their treatment plan for their health and lifestyle needs.



Contributing Factors

01

The lack of clear guidance on what information to trust when patients are exposed to a variety of treatment options

02

The need for patients and caregivers to carry the burden of actively advocating for themselves to receive proper care coordination

03

The lack of access to doctors willing to treat patients with persistent symptoms

04

The abuse and abandonment a patient may experience when searching for HCPs willing to care for them

05

The overwhelming confusion and fear a patient may experience when first being diagnosed with Lyme without guidance on what to do next



Recommendations

01

Develop and maintain a cost-of-care resource that estimates the total cost of types of Lyme care, to be used in informed discussions on the viability of a treatment option on a patient-by-patient situational basis.

02

Provide a platform where Lyme patients can connect to HCPs willing to treat their condition with the option of telehealth if HCPs are not in their region.

03

Develop a database with trusted resources and guidance for patients to utilize when looking for answers to their persistent symptoms.

04

Create a platform that provides preemptive notifications for proactive check-ins or treatment recommendations and care plans. Urgent health signals trigger nudges to the HCPs (e.g., call patients, auto-save an appointment time to be confirmed via text, etc.).

05

Equip and encourage more HCPs to focus on Lyme and persisting symptoms, especially in areas not historically known for Lyme, such as urban healthcare centers.

COHESIVE AND COMPREHENSIVE CARE COORDINATION

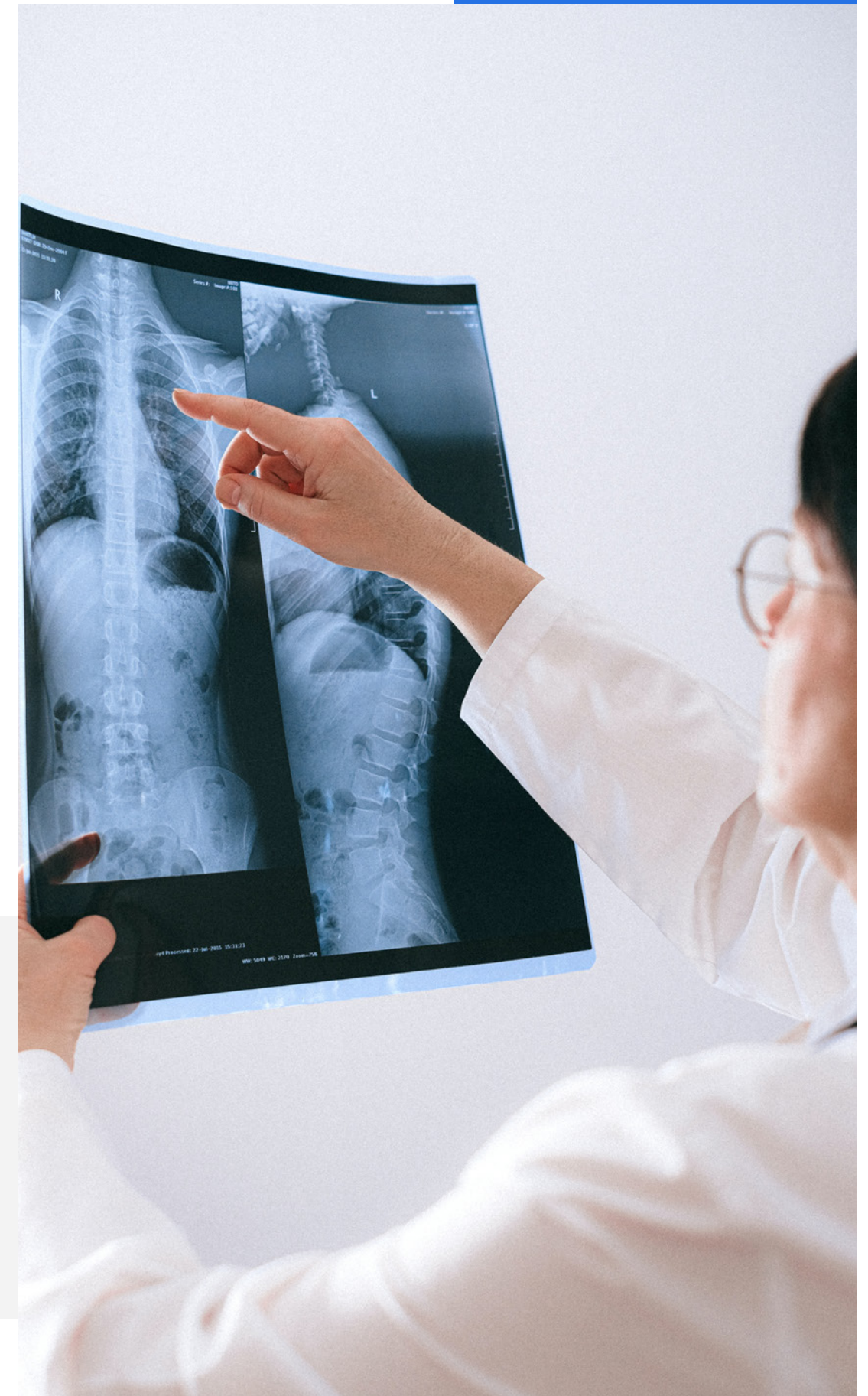
Provide Adequate Support and Resources to Healthcare Providers Treating Lyme

There is an opportunity to improve the conditions for HCPs treating Lyme today. By pursuing collaborative research, HCP communication, and aligned guidance on persistent Lyme, HCPs can be best equipped to treat their patients.



"When I have the opportunity to interact with somebody who's actually interested, it's phenomenal. You know, there is like, a lot of them say things like, 'Listen, we've worked this patient up. We don't know what's wrong. They seem to be getting better. So I don't care what it is. I just want this person to be better.' And it's like, yeah, me too."

—Healthcare Provider



Contributing Factors

01

The long-standing differences in treatment philosophies and approaches between medical silos that discourage collaboration between the network of doctors

02

The lack of research and guidance around coinfections

03

The lack of financial and federal support for the International Lyme and Associated Diseases Society (ILADS)

04

The lack of HCP training to identify and treat persistent symptoms of Lyme and tick-borne coinfections, requiring self-education

05

The fear of persecution many doctors face from state medical boards

06

The trial-and-error method HCPs are forced to use when providing care to patients due to the personalized nature of the disease and lack of aligned protocol for persistent symptom treatment

07

The shortage of HCPs that specialize in persistent Lyme, resulting in high demand and creating a harsh reality around accessibility for patients looking for care

08

The insurance restrictions preventing HCPs from thoroughly assessing and providing procedures needed to treat Lyme

Recommendations

01

Develop a Lyme starter toolkit for HCPs looking to specialize in Lyme.

02

Create a tool that has a filterable referral management feature to provide tailored continuity of care through specialist referrals in-network and is specific to personalized patient health data.

03

Further support and collaborate with organizations with a focus on Lyme, such as ILADS.

04

Create a database platform for HCPs treating Lyme containing smart algorithms that highlight relevant research, clinical studies, and data spotlights.

05

Relieve the risk of persecution for HCPs who treat persistent Lyme.

06

Equip and encourage more HCPs to focus on Lyme and persisting symptoms especially in areas not historically known for Lyme, such as urban healthcare centers.

07

Develop a database and platform for collaborative research on Lyme and coinfections.

08

Create a platform for HCPs to be able to communicate and collaborate on their patient's persistent Lyme treatment on their patient's network of HCPs.

09

Create insurance codes that allow HCPs treating persistent Lyme to have the ability to provide the treatment needed.



COHESIVE AND COMPREHENSIVE CARE COORDINATION

Break Down Medical Silos that Cause Financial Burden for Patients and Caregivers

There is an opportunity to alleviate some of the patients' and caregivers' financial strain caused by Lyme treatment by improving care coordination between doctors. Financial considerations for any treatment are often costly for post-treatment Lyme disease syndrome, especially because many treatments are not covered by insurance.



"We obviously have some people who have the means to pay for this, but we have other people that are really struggling, you know, to kind of, and to have to make choices between treatment and testing and things like that."

—Healthcare Provider

"When you've been sick for so long, you know, basically half my life I've been sick, you are willing to do anything to get better, including spending an insane amount of money."

—Patient

Description	Qty	Unit Price	Amount
28 Day Lyme Protocol	1	Package	\$21,000
		Subtotal	\$21,000
		Discount	\$2,400
		Total	\$18,600
		Total Amount	\$18,600

* All prices are in US Dollars

An interview patient's medical bill

Contributing Factors

01

The long-standing differences in treatment philosophies and approaches between medical silos discourage collaboration between the network of doctors

02

The lack of insurance coverage and codes for Lyme disease

03

Lyme not being a qualifier for Social Security disability benefits on its own; patient and caregiver reliance on matching their specific symptoms to those that have coverage in order to qualify

04

The high expenses necessary for patients to undergo well-regarded Lyme treatment, from care costs to travel

05

The costs associated with repeat testing due to lack of trust in findings among HCPs

Recommendations

01

Develop and maintain a cost-of-care resource that estimates the total cost of types of Lyme care, to be used in having informed discussions on the viability of a treatment option on a patient-by-patient situational basis.

02

Provide financial guidance and support for patients taking on large amounts of medical expenses.

03

Create a list of certified tests for Lyme that should be recognized and accepted across provider types.

04

Develop a Lyme disability qualification cheat sheet, matching frequent Lyme symptoms to accepted conditions and codes to aid in application for financial assistance.

05

Provide legal assistance to those looking to receive disability.

06

Assist and assure patients when deciding which medical treatments match their budgets.

COHESIVE AND COMPREHENSIVE CARE COORDINATION

Protect Patients from Abuse and Discrimination

There is an opportunity to provide clarity around Lyme disease in order to prevent abuse and discrimination from HCPs who do not believe patients, as well as prevent significant financial investment in treatments for misdiagnoses and unnecessary side effects from such medication.



"The doctor brought us outside and said, [the patient] is faking it During the first couple of hospitals she stayed at, the doctors would come in while she was sleeping, take skewers, break them. So they would show up and stab her in the feet to test if she was not faking [her coma induced by Lyme]."

—Caregiver

"Patients are disbelieved, especially ones with persistent symptoms, gaslight, and treated rudely. And it's worse than that. Patients are treated with contempt. When did the medical system start treating suffering people with contempt?"

—Lyme Leader





Contributing Factors

01

The lack of unified education surrounding the approach to Lyme diagnosis within the medical community

02

The patient's lack of ability to be able to self-advocate for their care, whether due to age or level of Lyme disruption

03

The lack of education surrounding Lyme, specifically within the mental health field

04

The lack of oversight in regards to in-patient care and HCP communication

05

The discrimination patients experiencing neurological Lyme symptoms face, especially for adolescents

Recommendations

01

Develop educational resources that focus specifically on how the neurological symptoms of Lyme may present themselves.

02

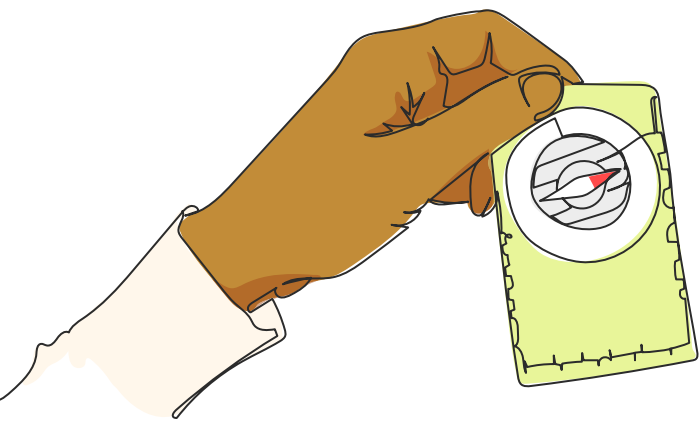
Provide optional, neutral third parties to help advocate for the patient when they are unequipped to direct their care coordination.

03

Provide neutral, mental health care access and advocacy for patients still searching for a diagnosis that doesn't influence their diagnosis, and helps coach them through the process.

04

Provide legal assistance for patients and caregivers who have experienced medical abuse.



OPPORTUNITY AREA FOUR

Holistic Life and Care Management

Patients living with the persistent symptoms of Lyme experience significant emotional and physical changes. The toll Lyme takes on patients requires them to adapt to new ways of existing and to adopt new ways of managing their lives.

As the burden of Lyme is both isolating by nature and patients already feel abandoned by the medical community, they would benefit from an improved safety net of resources that assist with the variety of lifestyle and well-being challenges they face in dealing with persistent Lyme.

Once patients realize their Lyme illness is persistent, they tend to have a hard time coming to terms with losing their sense of normal and their personal identity. One patient shared, "One thing I've forgotten is how far away I am from being normal." Another described it like this: "I can barely put one foot in front of the other. And I'm just thinking of collapsing into that train seat and getting home. And I look at all these other people around, they're chatting happily, they're all out for lunch with their buddies and they're going to have a nice lunch for an hour. And then they're gonna go back to

the office for five more hours or six more hours and then go home. It shocks me how far off I am from normal. And so sometimes I forget that."

The typical social support structures of friends, family, and community that exist when individuals experience other illnesses are not always available to support patients who experience Lyme, due to a lack of understanding from the community. This forces further isolation when symptoms prevent patients from socializing. "It's really sad to say, but I really don't have any friends. I really lost them all being sick. I was so young and they didn't understand it when I said, you know, I'm still sick. I can't do this. I can't do that. I'm still sick. So they went away. There were some that, you know, tried, but they don't understand what this means," one patient revealed. Another faced both isolation and doubt that they even had an illness: "I had very

little support from my family because they didn't understand the disease. They couldn't fathom that I could possibly have a disease that could be that debilitating that doctors didn't recognize. So that was really hard with family. I can't tell you how many times [they said], well, maybe it's just in your head."

As a result of the combination of a lack of understanding within the community and no access to support resources, patients often isolate themselves, feeling like they need to mask their symptoms and appear to "feel fine" in front of their family and friends. One patient said, "I went to bed crying every night, and I never showed that to my family. I never showed it to my parents. I never showed it to my brother or my stepdad, or anybody. I wanted everyone to believe I was okay. I put on such a face for everybody, such a happy face. And they thought I was fine, and finally, I broke." Another



showed strength in the face of persistent struggle: "We always try to make the best of everything. I would try very hard not to cry and break down in front of the kids or if I was having a good day, 'cause that would happen. The symptoms would wax and wane. And if I was having a good day, like we did stuff, like, I did as much as I possibly could."

Patients experience guilt and feel they are missing out on their own life and their family's lives. One patient shared, "There's a lot of events. I was not there for my son, you know, when he was playing soccer, when he could play soccer, he never made it through a whole season. He was never physically capable of making it through a whole season. But you know, my husband would bring a chair to the field and a sleeping bag and three fleece blankets. And I would sit bundled up in a chair and he would carry everything and he would hold my arm getting from the field to the car." Another patient explained how their illness affects the whole family. They said, "I don't think I'm going to feel well when we get to one. And so everybody's excited about going to the movie at one o'clock and I have to cancel. So then they decide, well, should we go alone and leave him home? But that's not fun. We want all to

"And I, if I had known I was going to be this way my whole life, we wouldn't have kids. It would have changed our financial situation, which could have helped a lot."

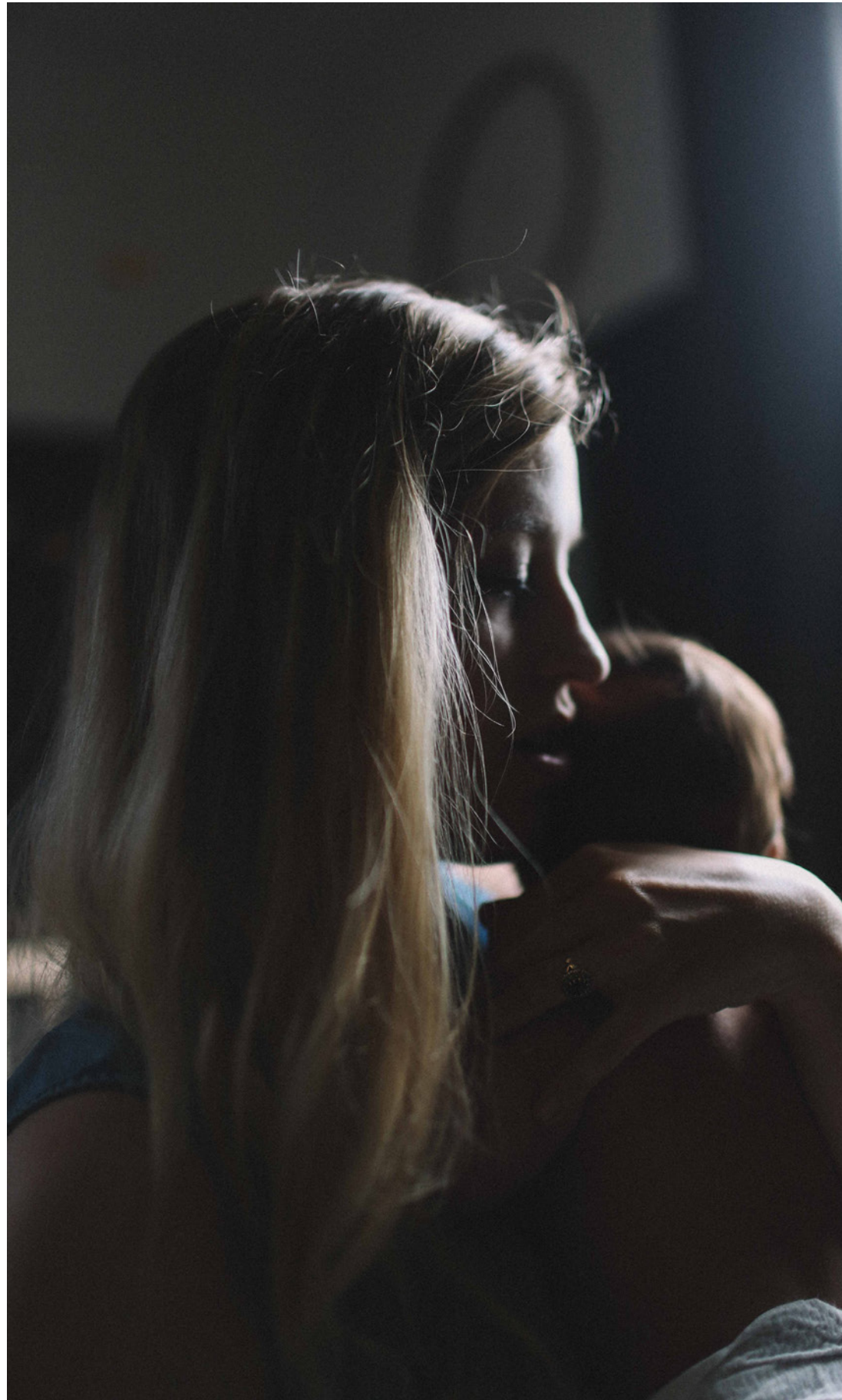
—Patient

be together. Well, so they're all going to stay home now and just sit around the house for a couple of hours while I sleep. So it does affect everybody. And it's really hard, I think for them to continually be patient and continually, you know, put off what they would like to do for something else that they kind of have to do, or have to go with at that moment."

Without the medical recognition of persistent Lyme, patients have a hard time planning for the future, thinking one day their illness might go away. A patient reconsidered their choices, saying, "And I, if I had known I was going to be this way my whole life, we wouldn't have kids. It would have changed our financial situation, which could have helped a lot." And older patients, too, faced challenges in contextualizing their future with their Lyme

condition: "And so here we are, I'm in my fifties, my wife's older. We've got a retirement coming up on the horizon there and we're nowhere near where we'd like to be, or could be, or should be in terms of preparing ourselves. So does that mean I'm going to have to work when I'm 70 or 75, when I find it hard enough to work now? I don't know."

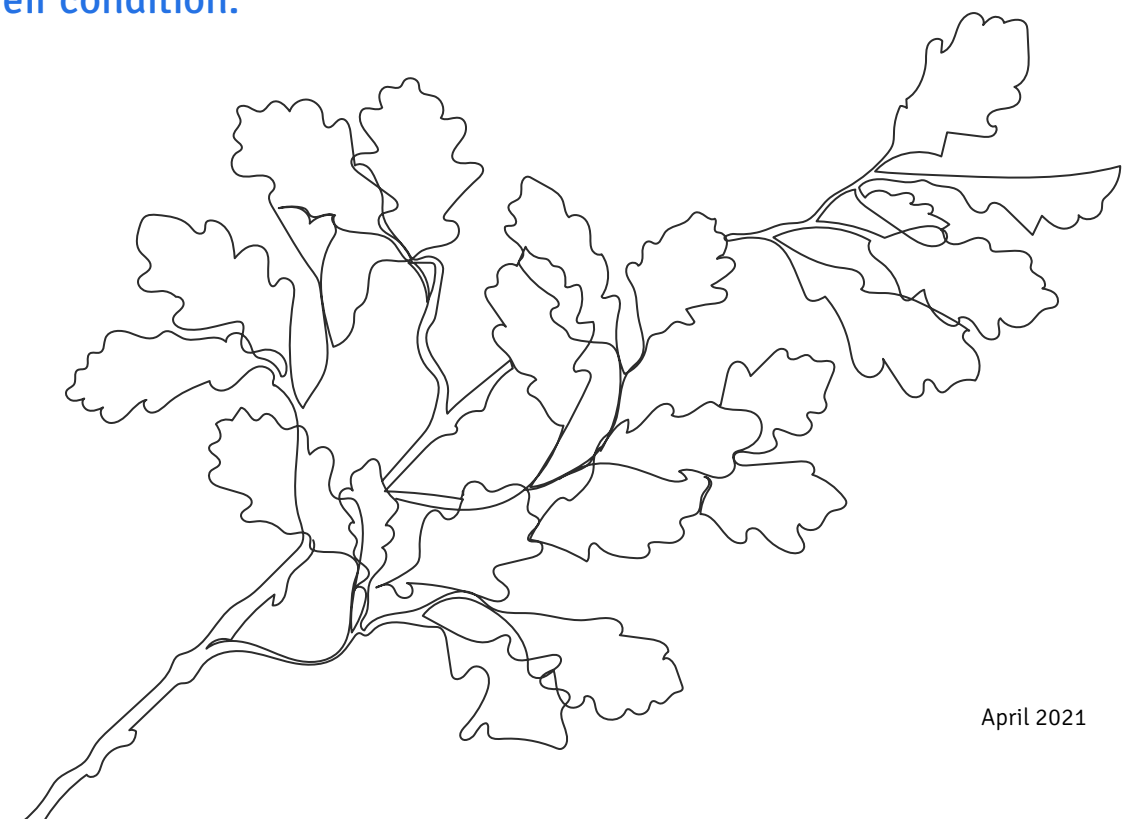
Persistent Lyme symptoms affect not only family life, but work and education plans, too. As with family planning and participation, patients are forced to adapt all aspects of their lives to their symptoms. One patient said, "So I decided I had to do something else to try to make a living because a full-time job just wasn't working. So I decided to try to become a consultant. I thought that I could work from home and if I just don't feel well, I just have my desk right here and my bed right here. And when I need to go to bed, I just go to bed and I could get up later, but I didn't have an interest in being an entrepreneur or a consultant."



HOLISTIC LIFE AND CARE MANAGEMENT

Help Patients Plan for Their Future

There is an opportunity to assist patients facing difficulties in readjusting their expectations when experiencing financial, social, and work/school disruptions as a result of Lyme. Patients may, at first, be overwhelmed with their circumstances and loss of identity and need further guidance on how to adjust to their condition.



"It's very difficult to make any plans ahead of time with anyone or to plan anything because you never know when it's going to hit you. You never know when you're going to be on the floor. You never know when you're going to be having an attack or something."

—Patient

Contributing Factors

01

The inconsistent and unpredictable severity of symptoms changing day to day making it hard for patients to consistently follow a solidified schedule

02

The vague treatment timeline that prevents patients from planning around their care plan

03

The belief that Lyme is resolved outright after the IDSA guideline treatment, preventing patients from managing persistent Lyme symptoms and making future plans around their condition

04

The complexity of factors like neurological issues, mental health challenges, and fears of childbearing—passing on Lyme

05

The complications of disability coverage and the lack of ability patients sometimes have due to their symptoms

Recommendations

01

Develop a guide and workbook (one for adults, one for adolescents) for planning a future with persistent Lyme symptoms, including recommendations on building a support network and utilizing resources.

02

Develop a hub for Lyme life planning that points to resources to support with education, employment, and social life management.

03

Fund, develop, and launch a targeted ad campaign that points the Lyme community to future planning resources that exist.

04

Provide counselors and coaches that understand persistent conditions and can help patients/caregivers plan around them.

05

Provide financial support and guidance to patients paying out of pocket for treatment, hindering their ability to create savings and retirement.

06

Create a peer-to-peer mentoring network where patients who have experienced the obstacles of Lyme can help guide newer and more severe patients.



HOLISTIC LIFE AND CARE MANAGEMENT

Support Patients Navigating Bureaucratic Challenges

There is an opportunity to assist patients and caregivers facing bureaucratic challenges in receiving government assistance, completing school, or navigating workplace demands.

Patients may experience a sudden bout of symptoms that unpredictably take them out of school or work. Government assistance, schools, and workplaces can create inconsistent and challenging loopholes that a patient and caregiver may not have the capacity to

see through. To navigate these bureaucratic challenges, patients and caregivers need both federal assistance and assistance from their direct, meso-level institutions.





Contributing Factors

- 01** Lack of understanding within government agencies and within meso-level institutional settings surrounding potentially debilitating nature of symptoms associated with Lyme
- 02** The debilitating physical and neurological effects of Lyme preventing patients from being able to actively participate in a full schedule
- 03** The patient's capacity being so burdened by Lyme's disruption that they cannot advocate for themselves to complicated bureaucratic organizations

- 04** The varying and unpredictable severity of symptoms changing from day to day, making it hard for patients to consistently follow a solidified schedule
- 05** The lack of assistance available to caregivers trying to balance a full-time job while also providing full-time care

Recommendations

- 01** Develop an introduction to Lyme for institutions that outlines some of the common symptoms, as well as practical accommodations that can be provided to better support Lyme patients.
- 02** Create a platform where patients can find jobs and education programs that are flexible to their needs and availability.
- 03** Connect patients with career and educational counselors that can help with the adjustments needed for their condition.
- 04** Provide legal assistance for patients/caregivers entangled in bureaucratic challenges.
- 05** Create education programs that adapt to the patient's condition while still managing to give them the level of education that peers their age receive, with the potential to also further connect them to peers their age with mentoring help and social time.

HOLISTIC LIFE AND CARE MANAGEMENT

Create a Long-Term Support System for Patients and Caregivers Managing Persistent Lyme

There is an opportunity to help patients and their caregivers find community support in dealing with Lyme by forming groups that can provide information, emotional support, and a social foundation for patients and caregivers to better manage Lyme's long-term impacts.



Contributing Factors

01

The lack of community awareness surrounding what patients are going through

02

The fear of worrying their loved ones or being ostracized from their community, driving patients to mask their symptoms

03

The lack of validation for persistent symptoms of Lyme from the medical community at large

"It was a hard time, you know, I was humiliated and scared. I didn't tell anyone and it was like a big secret. I spent the whole summer hiding this because how do you tell people what's wrong with you? They might think I'm crazy."

—Patient

Recommendations

01

Create an open-source community resource for vetting and supporting Lyme healthcare providers across physical, mental, neurological, and alternative treatment spaces.

02

Create a mentorship program for Lyme navigators, Lyme community leaders and experts who are willing and interested in sharing their experience and research to help individuals navigate the journey.

03

Create a platform to help educate the patient's community and family on what they might be feeling, alleviating some of the burden on the patient who might not be able to communicate the pain they're experiencing.

04

Develop a way to explain persistent Lyme to adolescents so they might be able to better understand what they and/or their parents are experiencing.

05

Create a peer-to-peer mentoring network where patients who have experienced the obstacles of Lyme can help guide newer and more severe patients.

06

Provide caregiving platforms that can help monitor and track the patient while the caregiver may be away.

07

Create a platform that provides preemptive notifications which offer proactive check-ins, HCP communication, progress updates, and insight into the diagnostic process. Urgent health signals trigger nudges to the HCPs (e.g., call patients, auto-save an appointment time to be confirmed via text, etc.).

WHAT'S STEPS // GLOSSARY OF TERMS // HEALTH+ //
HOW IT WORKS // ACKNOWLEDGMENTS

Appendix & Glossary



What's Next?

It is our hope and intention that the HCD Report will be used by HHS, Health+ Lyme's stakeholders' organizations, and healthcare innovators to leverage findings within and across areas of expertise to collaboratively and concretely develop new, improved methods of providing healthcare, a stronger health safety net, and an increased quality of life for individuals living with Lyme disease.

To that end, upon distribution of the HCD Report, an innovation challenge will leverage collaboration, data, and technology to develop new solutions that directly address the challenges and opportunities identified by the HCD Report. Individuals and teams will work to develop creative solutions, ranging from marketing needs, to policy adjustments, to new technology and design prototypes. Solutions will be evaluated by a panel of professionals across fields and expertise,

and, paired with appropriate implementation means, ranging from formal publication to mentorship to design and development. The planned innovation efforts that are underway are not restrictive of efforts conducted independent of Health+ program activities. Individuals and groups who utilize our research findings to develop innovative solutions are invited and encouraged to share their progress and achievements with us by emailing us at HealthPlus@coforma.io.

Glossary of Terms

Archetypes

Archetypes are a distillation of design discovery insights meant to describe user needs, goals, pain points and habits—a communication tool that helps teams build empathy towards end users, and address all use cases. They are developed through analyzing qualitative and quantitative data, and are useful when different types of users behave differently and their various use cases and needs have to be addressed.

Desk Research

Desk research is performed by our team at the start of each engagement. It includes critical papers, studies, and other key publications to develop a comprehensive understanding of the landscape around the health issue placed in focus. Desk research helps our researchers formulate objectives, questions, and goals for their interviews, workshops, and diary studies with patients and other people affected by the disease.

Diary Studies

A diary study follows a research participant for a period of time, providing researchers with the opportunity to observe behaviors over time and capture qualitative insights, without actually being in someone's space, where bias (and COVID germs!) can get in the way.

Health+ Workshop

The workshop portion of the Health+ program provides researchers with a chance to talk through diverse experiences and perspectives, capturing feedback and insights and leveraging research methodologies that allow for deeper understanding, organization, and prioritization of the pain points and opportunities that exist within the diverse set of patient experiences.

Health+ Validation Roundtable

A roundtable refers to the research validation process performed by subject-matter experts and target audiences within the high-impact health issue area. During this phase of the program, discovery findings are validated in collaborative sessions and used to identify, prioritize, and ideate around the direction of possible solutions.

Journey Maps

A journey map is a visual representation of the patient's experience from beginning to end. It documents the steps they take across the course of the experience, the tools and resources they use to complete certain steps, the challenges or pain points that pose obstacles along the way, and the opportunities for enhancing or improving the experience.

Stakeholder Interviews

These interviews are administered by our research team and conducted with identified stakeholders. Stakeholder interviews may include key voices within collaboration teams, cross-discipline subject matter experts, and others whose insights help us develop a full understanding of the health issue being studied.

User Interviews

User interviews are conducted one-on-one and in small groups with each of the target audiences. We develop interview guides that are comprehensive, ethical, and sensitive. Our documentation process ensures interviewees' privacy is protected.

Acronyms

- PCP: Primary Care Provider
- HCP: Healthcare Provider
- IDSA: Infectious Diseases Society of America
- LLMD: "Lyme literate" Medical Doctor
- SME: Subject-Matter Expert
- ILADS: International Lyme and Associated Diseases Society
- HHS: Health and Human Services
- CDC: Centers for Disease Control and Prevention
- HCD: Human-Centered Design

Human-Centered Design (HCD) is a problem-solving approach focused on the needs, contexts, behaviors, and emotions of the people that will be served by a product. It involves incorporating user research in every step of the design process.



The Health+ Program

Health+ ("health plus") is an ongoing series of research and prototyping cycles aimed at providing insights, stories, journeys, and opportunities around the experiences of people living with high-impact health issues.

Each Health+ cycle includes key phases and components that are as essential to the program's success as our close collaboration with cycle partners. One of the most important areas of the program is our HCD research. By hearing directly from people living with the high-impact health issue placed in focus, we ensure that future solutions are crafted to solve the most pressing challenges faced by those individuals.

How It Works

Health+ cycles are successfully delivered through a series of connected phases.



Intake

Working closely with stakeholders to assess candidate health issues for program fit and budget, alignment is established around high-level goals, identification of stakeholders and key audiences, and a high-level project plan.



Ideation and Validation

Working with subject-matter experts and target audiences, discovery findings are validated in collaborative sessions and used to identify, prioritize, and ideate around the direction of possible solutions.



Discovery

Discovery involves getting to know stakeholders, consuming existing research, conducting workshops, interviewing and engaging affected audiences, and synthesizing findings into a highly-functional report.



Implementation

A Healthathon—a play on the typical hack-a-thon that's focused on the creation of solutions in the healthcare space—is conducted with stakeholders, target audiences, and others as collaborators.

The HCD Report is a product of the first three phases of this program and is meant to empower implementation in the next phase and in work created by HHS and other stakeholders above and beyond the scope of this program.



Learn more at Health+ Site:
HealthPlusProgram.io



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Learn more about LymeX
Site: <https://bit.ly/3sX0fhx>



Disclaimer: This report makes no claims at providing medical advice or direction. Readers should not consider the report or any part of it to be guidance or instruction regarding diagnosis, care, or treatment of Lyme disease or other tick-borne diseases or to supersede in any way existing guidance.

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health+ Lyme Disease