LymeX Health+ Human-Centered Design Report Response

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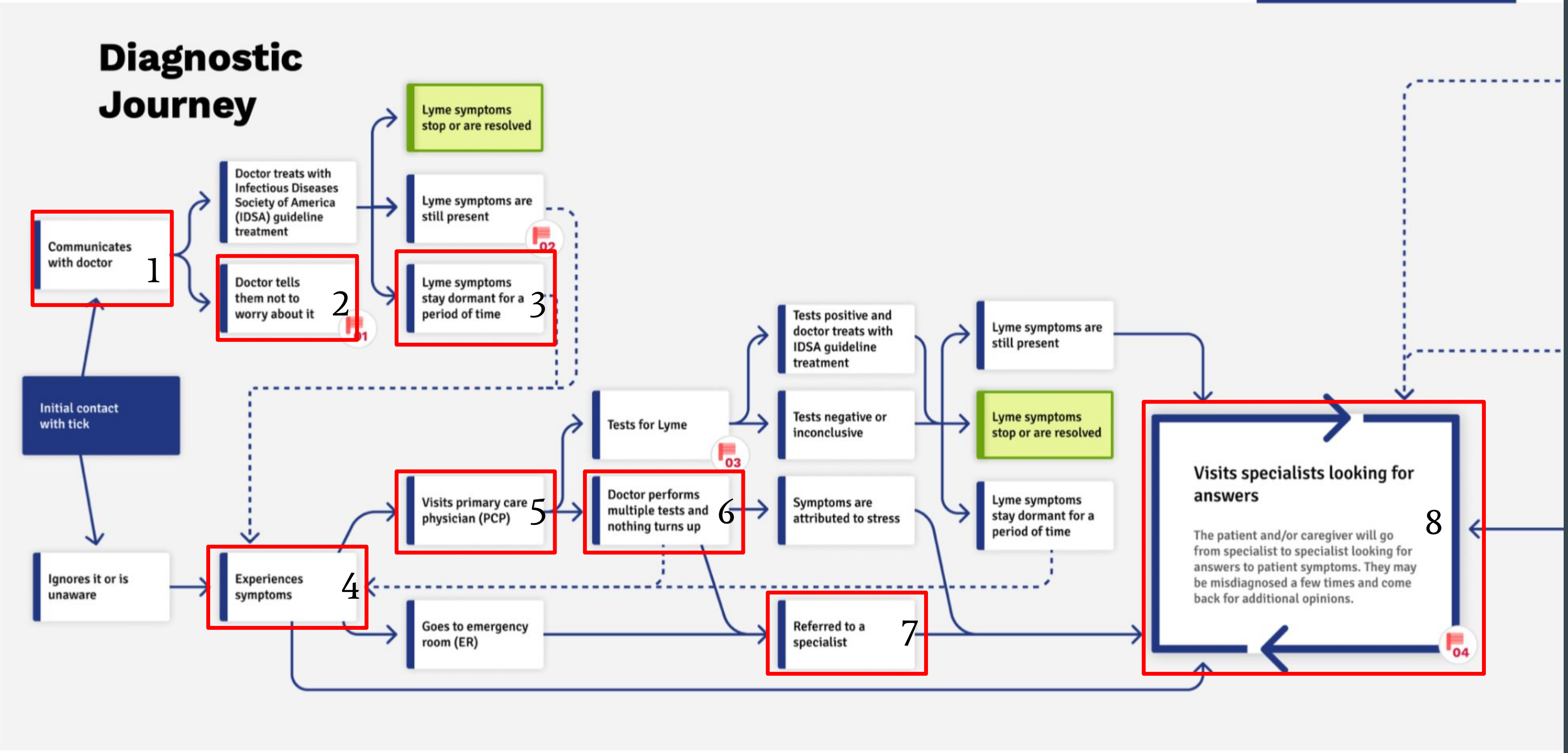
Lyme Disease Patient

> "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

Lyme Patient Journey Maps

Diagnostic Journey



Initial contact with tick

Communicates with doctor 1

Doctor treats with Infectious Diseases Society of America (IDSA) guideline treatment

Doctor tells them not to worry about it 2

Lyme symptoms stop or are resolved

Lyme symptoms are still present

Lyme symptoms stay dormant for a period of time 3

Ignores it or is unaware

Experiences symptoms 4

Visits primary care physician (PCP) 5

Goes to emergency room (ER)

Tests for Lyme

Doctor performs multiple tests and nothing turns up 6

Tests positive and doctor treats with IDSA guideline treatment

Tests negative or inconclusive

Symptoms are attributed to stress

Referred to a specialist 7

Lyme symptoms are still present

Lyme symptoms stop or are resolved

Lyme symptoms stay dormant for a period of time

Visits specialists looking for answers 8

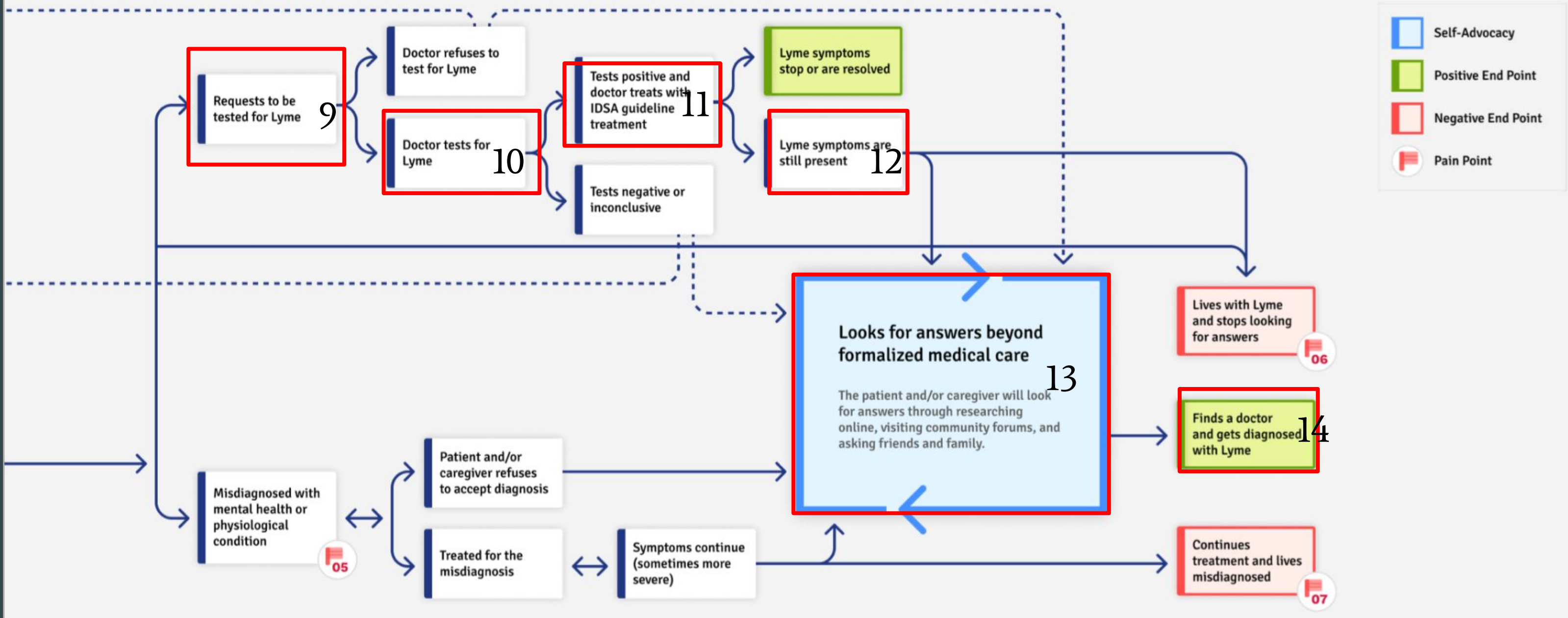
The patient and/or caregiver will go from specialist to specialist looking for answers to patient symptoms. They may be misdiagnosed a few times and come back for additional opinions.

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



Requests to be tested for Lyme 9

Doctor refuses to test for Lyme

Doctor tests for Lyme 10

Tests positive and doctor treats with IDSA guideline treatment 11

Tests negative or inconclusive

Lyme symptoms stop or are resolved

Lyme symptoms are still present 12

Looks for answers beyond formalized medical care

13

The patient and/or caregiver will look for answers through researching online, visiting community forums, and asking friends and family.

Lives with Lyme and stops looking for answers 🚩06

Finds a doctor and gets diagnosed with Lyme 14

Misdiagnosed with mental health or physiological condition 🚩05

Patient and/or caregiver refuses to accept diagnosis

Treated for the misdiagnosis

Symptoms continue (sometimes more severe)

Continues treatment and lives misdiagnosed 🚩07

🟦 Self-Advocacy
🟩 Positive End Point
🟥 Negative End Point
🚩 Pain Point

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

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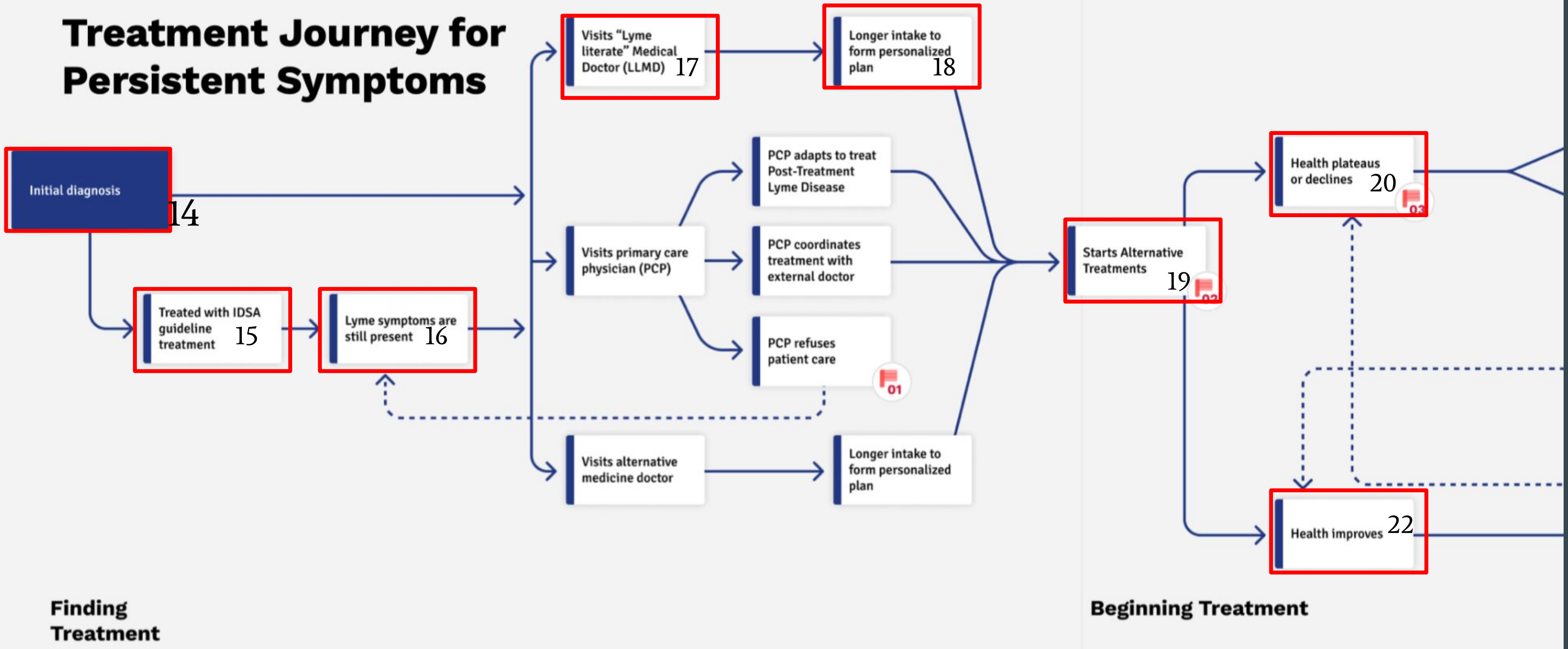
Treatment Journey for Persistent Symptoms



Initial diagnosis 14

Treated with IDSA guideline treatment 15

Lyme symptoms are still present 16

Visits "Lyme literate" Medical Doctor (LLMD) 17

Longer intake to form personalized plan 18

Visits primary care physician (PCP)

PCP adapts to treat Post-Treatment Lyme Disease

PCP coordinates treatment with external doctor

PCP refuses patient care 01

Visits alternative medicine doctor

Longer intake to form personalized plan

Starts Alternative Treatments 19 02

Health plateaus or declines 20 03

Health improves 22

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

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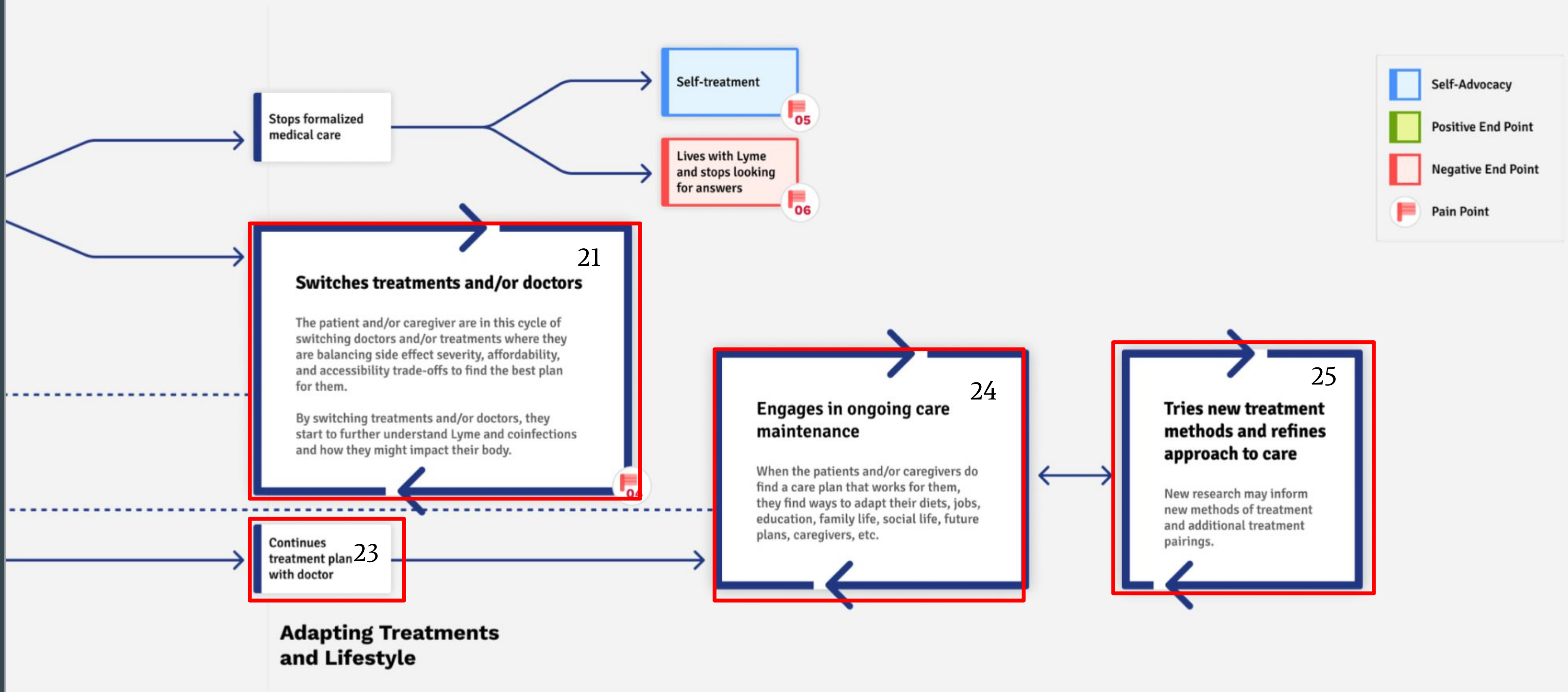

Stops formalized medical care

Self-treatment

Lives with Lyme and stops looking for answers

21

Switches treatments and/or doctors

The patient and/or caregiver are in this cycle of switching doctors and/or treatments where they are balancing side effect severity, affordability, and accessibility trade-offs to find the best plan for them.

By switching treatments and/or doctors, they start to further understand Lyme and coinfections and how they might impact their body.

Continues treatment plan with doctor 23

24

Engages in ongoing care maintenance

When the patients and/or caregivers do find a care plan that works for them, they find ways to adapt their diets, jobs, education, family life, social life, future plans, caregivers, etc.

25

Tries new treatment methods and refines approach to care

New research may inform new methods of treatment and additional treatment pairings.

🟦 Self-Advocacy

🟩 Positive End Point

🟥 Negative End Point

⚑ Pain Point

Adapting Treatments and Lifestyle

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

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Recommendations

01

Broader Awareness of Lyme Disease

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

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

03

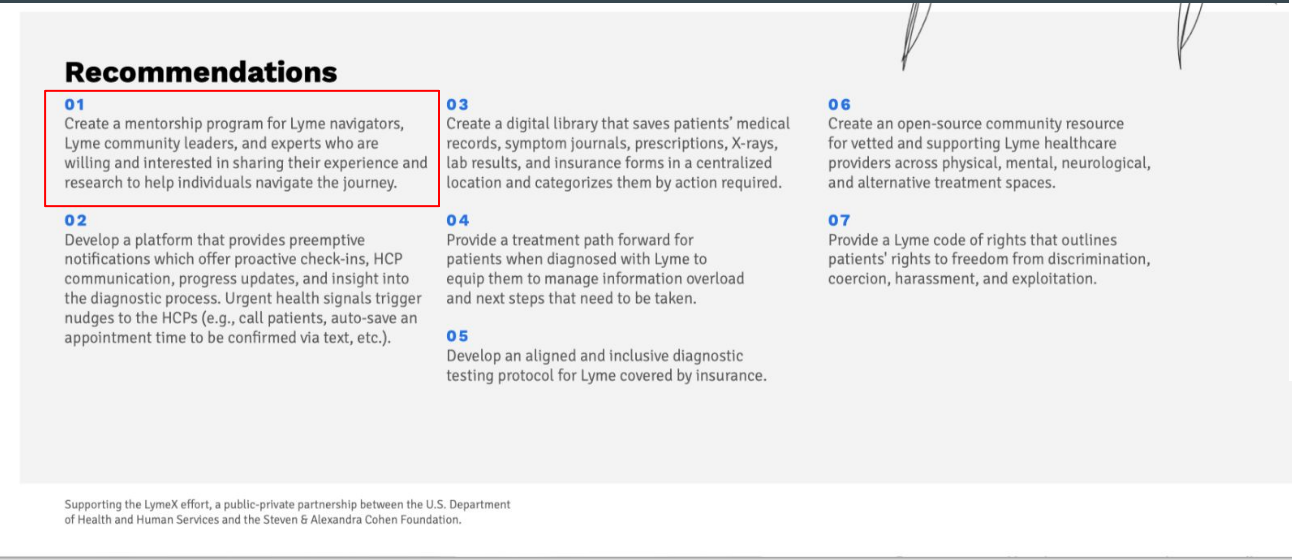
Cohesive and Comprehensive Care Coordination

- 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

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



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.

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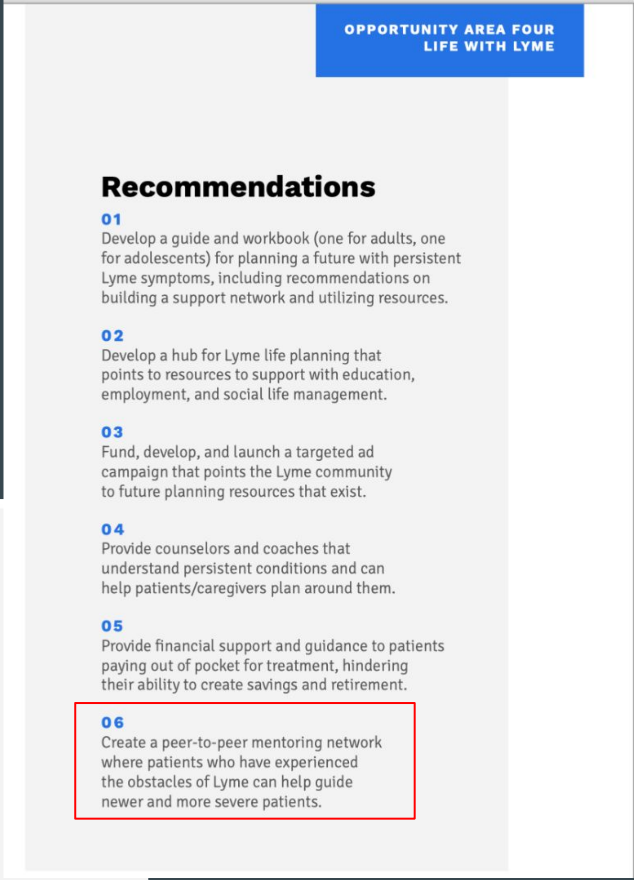

OPPORTUNITY AREA FOUR
LIFE WITH LYME

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.