

Intelligent Symptom Tracking for Lyme Disease

MIMS Final Project Report

Usman Raza, Sandeep Pal, Arnav Goyal, Abhishek Sinha

Faculty Advisor: Prof. John Chuang

Date: May 4, 2018

Table of Contents

Abstract.....	4
Background.....	4
Objectives.....	5
Intended Users.....	5
Review of Existing Solutions.....	5
Methods.....	6
System Architecture.....	6
App Design Research and Process.....	6
Semi Structured Interviews.....	7
Surveys.....	7
Affinity Mapping and Personas.....	7
Journey Mapping and User Story Mapping.....	9
Wireframing.....	10
High Fidelity Prototyping.....	11
Cognitive Walkthroughs.....	12
Design Iteration.....	12
Usability Tests.....	12
Data Collection and Storage.....	13
Creation of Dummy Data.....	13
Ethical Approval.....	13
Development.....	14
Technology Decisions.....	14
Front-End Development.....	14
Server-Side Development.....	14
Database Development.....	14
Process.....	14
Data Modeling.....	15
Solution and Results.....	16
Final Product.....	16
Data Analysis and Visualizations.....	20
Frequency of Visits, Symptoms and Medications.....	21
Symptom Progression Over Time.....	23

Summary Dashboard for Doctors	25
Identifying Patient Subpopulations Through Unsupervised Learning	25
Lessons Learned	26
Data Sparsity	26
Incorporating Multiple Perspectives in Design	27
Next Steps	27
References	28
Appendices.....	29
Appendix A - Analysis of Existing Solutions for Symptom Tracking	29
Appendix B - Project Team.....	31
Appendix C - Project Risks and Mitigation	32
Appendix D - Integrative Experience	32
Appendix E - Query Design.....	32
Use Cases	33
Appendix F - Testing the Data Model	33
Patient description of symptoms (anonymized) with important elements identified	33
Symptom Descriptions Using Our Model.....	33

Abstract

This project involved a mobile web app to help Lyme Disease patients keep track of their symptoms and activities and use analytics to identify trends and suggest which factors might improve or worsen their symptoms. Following a design thinking approach, we interviewed 16 Lyme patients and doctors, and surveyed many more, in order to deeply understand the patients' health needs and challenges, their behaviors and motivations, and their relationship with healthcare providers. This was followed by an iterative design process that moved from paper mockups of UI design to low-fidelity and then high-fidelity designs. At each stage, user testing and feedback was utilized to refine the interface and interaction design. The design was translated into a mobile ready web app using AngularJS and Ionic framework. For data storage and reporting functionality, we designed and developed a PostgreSQL database for capturing symptom data along with other patient details. The database model can handle the variety of symptoms faced by Lyme Disease patients. We set up a middle layer web-server using python-Flask framework and implemented secure user authentication and session management. To guide the development of analytics for generating insights from data, we used anonymized and de-identified Lyme patient data, and created visualizations of symptom progression. Unsupervised learning was also used to cluster patients into subpopulations which yielded groups with mild, moderate and severe symptoms. Our final product is a functioning web app with basic features including account creation, symptom selection and tracking, which is ready for alpha release.

Background

Lyme disease is a tick-borne illness affecting mostly people who engage in outdoor activities. It manifests initially as skin rash and flu-like illness but can spread to bones, joints, heart and nervous system. The incidence in US is estimated by CDC to be 300,000 new cases per year [1] and increasing. Diagnosis is history based (only half the people get the typical skin rash). The CDC standard two-tiered testing has poor sensitivity ranging between 27% and 57% for early stage of Lyme Disease [2]. Treatment is disputed with various healthcare provider associations coming up with differing guidelines [3-4]. A sizable proportion of these patients (10-20%) do not respond to treatment or are untreated [5] and continue into a chronic phase of the debilitating symptoms ranging from fatigue and joint pain to cardiac problems and depression. Overall, chronic Lyme Disease is estimated to cost up to US\$ 1.3 billion in return visits and testing alone, with an average US\$3,000 additional cost per year per patient and 87% more outpatient visits than controls [6].

A study conducted by MyLymeData found that over 47% of patients live with Lyme disease for ten or more years; 21% for more than six years; and 27% for more than two years [7]. These patients sometimes track their symptoms in journals or Excel sheets (if they are tech savvy) and keep visiting their physician to try different treatments and lifestyle changes. Physicians treat based on self-reported symptoms from patients but are handicapped in quality and quantity of data they have to work with. Patients report symptoms only during appointments, typically every 3-6 months, usually recalling from memory or cumbersome tracking methods if they do so. Interpreting this data is cumbersome and error prone leading doctors to take a trial-and-error approach to treatment.

We therefore believe that an easy to use, digital and portable symptom tracking tool is critical to capturing symptom data for these patients, and ultimately to be utilized by physicians in making more informed decisions for better treatment of such patients.

Objectives

For the purpose of MIMS Project, we defined our deliverable as a functional prototype that is able to collect data, produce the intended visualizations, and demonstrate the UI concept according to user needs validated through user testing.

Intended Users

We recognize from a systems perspective, that there are multiple stakeholders involved in managing a chronic illness. Our project's primary focus was the patient, but we explored the following three types of users at the beginning of our project:

1. **Lyme disease patients** – We believe that our app will be valuable for such patients, who do not currently have an efficient way of keeping track of their symptoms. The app would enable patients to send data and automated reports to physicians for review and interventions.
2. **Family members of Lyme disease patients** –Family members of patients suffering from Lyme disease would like to keep a track of their family member's progress and potentially also record information if the patients forget to do so.
3. **Healthcare providers treating Lyme disease** – Physicians, who use a dashboard that summarizes data being collected by the app will get better quality data from patients, remotely, while avoiding recall bias. The reports may help physicians prescribe personalized treatment regimens for these patients, and lead to better outcome.

Review of Existing Solutions

Currently there are a few apps on iOS and Android platforms for Lyme's disease which only allow symptom tracking. These apps are meant for patients only and require patient to identify triggers on their own and do not address the link between patients and physicians. The information visualization on some of these apps is good looking but may not be actually useful in decision making.

Lyme disease (and associated Tick-Borne Infections) impact every system of your body and therefore require a large array of tracking capabilities. There are several apps for tracking symptoms for specific disease like migraine, which may not match well with Lyme's disease. The other extreme is generalized symptom trackers that shift the burden of creating symptom lists and entering data too much towards the patient. For example, an app called Flaredown has collected a lot of data on hundreds of conditions and symptoms people are tracking. But their dataset (available on Kaggle) is full of non-standard terms (e.g. > 100 variants of migraine).

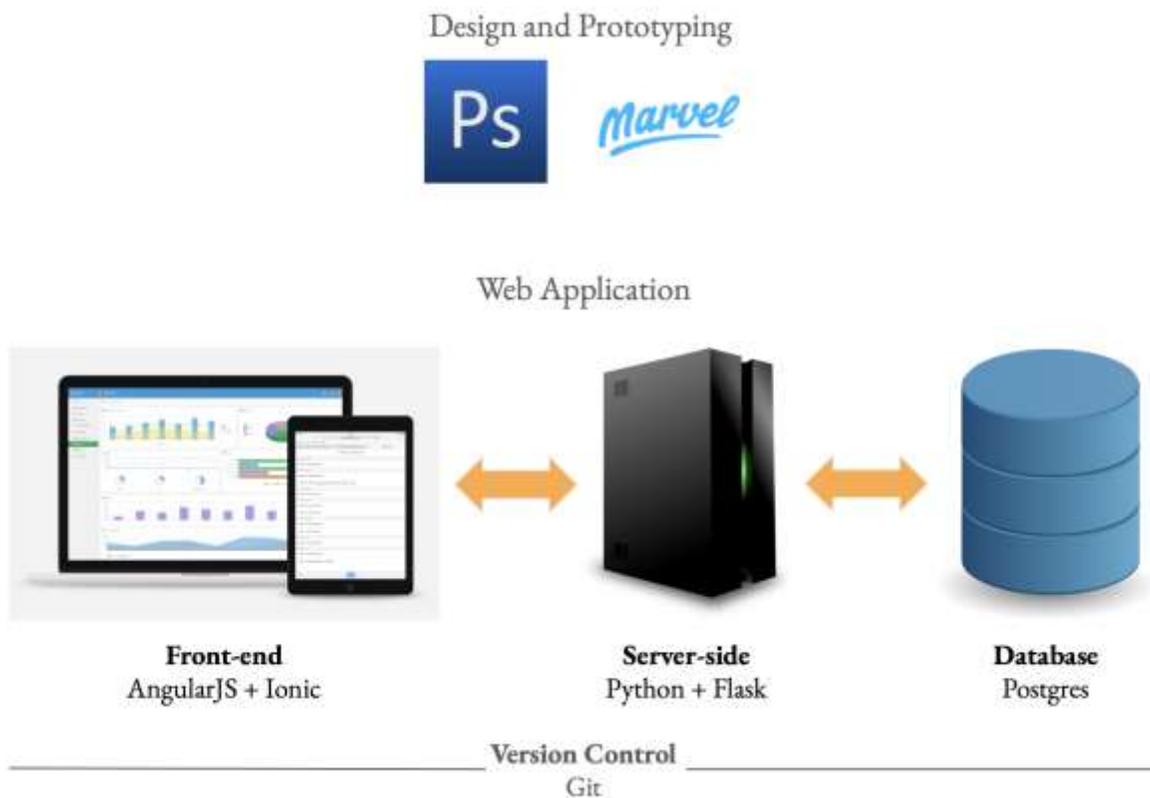
A more detailed analysis of the existing solutions is attached at the end of this document.

Methods

Our general approach to the project was based on first developing a deeper understanding of the user needs, and then embarking upon design and development using an iterative approach. The key components of our methodology are described here, while the actual development is explained in the following section.

System Architecture

The following diagram depicts our overall system architecture, which is explained in greater detail below.

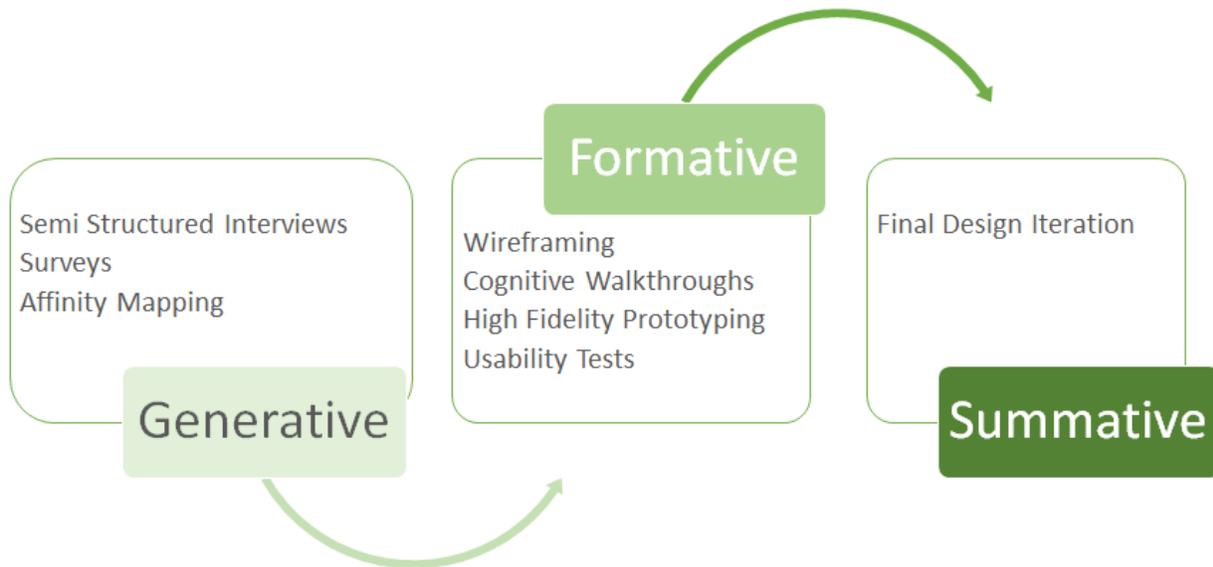


App Design Research and Process

Our design strategy applies the core principles of design thinking, user experience research and agile development processes.

The design process was a standard double diamond design process of diverging then converging to the final designs of the app.

The design process consisted of the following steps:



Semi Structured Interviews

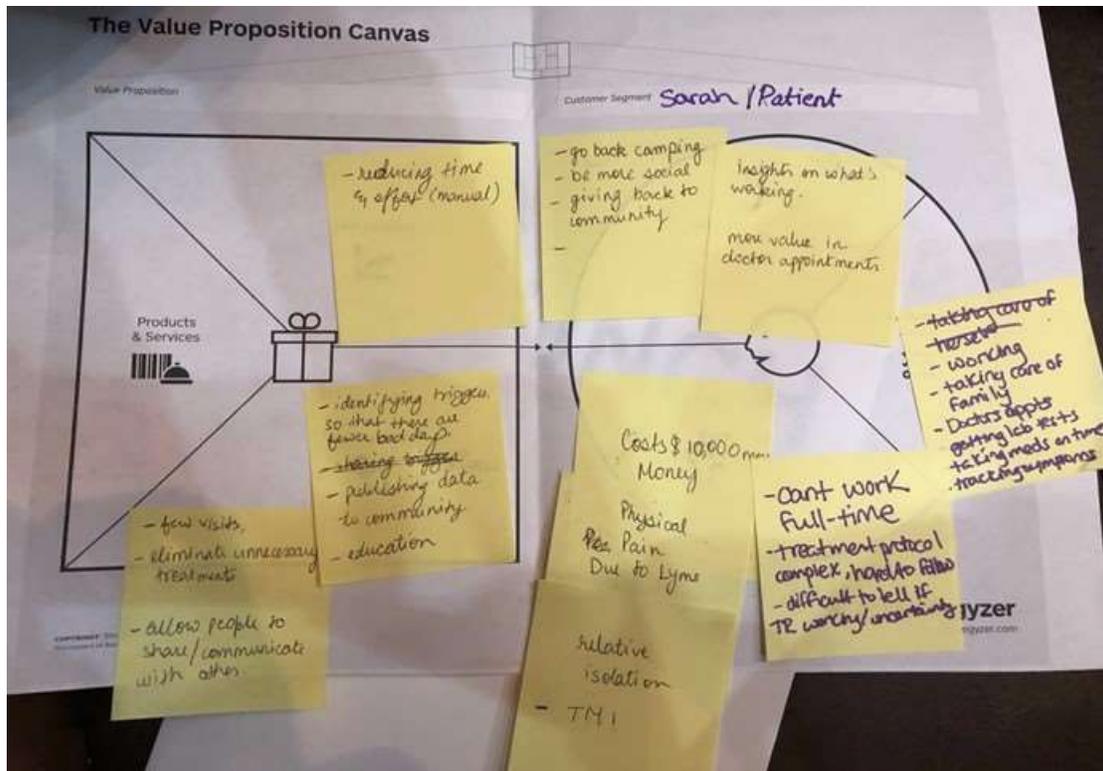
We conducted interviews to find out about the journey of a typical Lyme patient, the symptoms they go through, the treatments they take, the doctors they visit, the cost involved etc. This helped us in understanding the mental model of a Lyme patient. We understood the various emotions they go through due to the lack of clarity about their health condition and this helped us come up with initial features that our app might have.

Surveys

We conducted surveys to find out about the way people think about symptoms and when do they take their symptoms seriously enough to visit doctors. We also asked about the kind of conversations people have with their doctors and how long do they last.

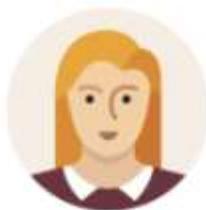
Affinity Mapping and Personas

Once we understood the entire life journey of Lyme patients, we were able to prioritize the features that were necessary for patients to get the most value out of the application. We understood that people need to be notified and they want to see their own recorded data in interesting ways in order to have meaningful conversations with their doctors and keep coming back to the app to record their data.



We used the value proposition canvas to do our affinity mapping. We were able to identify what patient's needs, gains and jobs are and also what features of our app would be useful for those needs, gains and jobs. We also worked on a similar canvas for doctors after interviewing them and finding out their pains, gains and jobs.

We came up with the persona of Sarah and Dr Joe based on this.



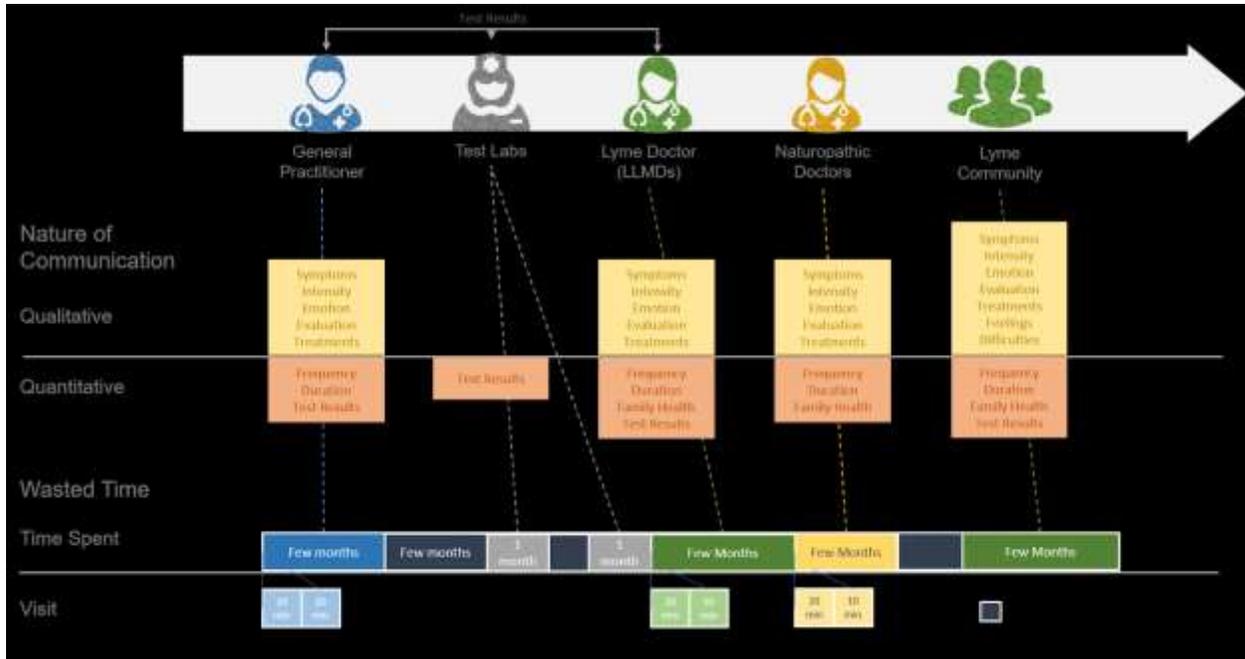
Sarah
35 Years old
Working Mom
Lyme Patient



Dr Joe
50 Years old
Lyme Doctor
50 patients/month

Journey Mapping and User Story Mapping

We created a Journey map based on our interviews and surveys to help us focus on the broader picture and see the minute details of information exchange and time spent with each person in a lyme patient's life during treatment.

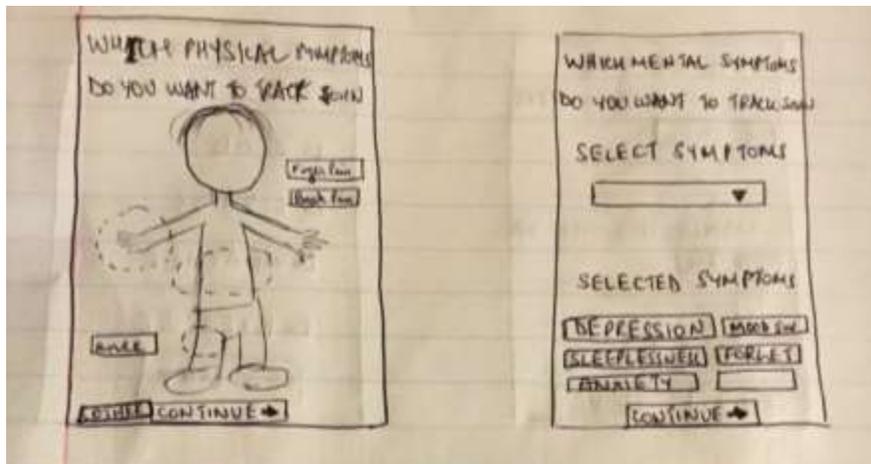
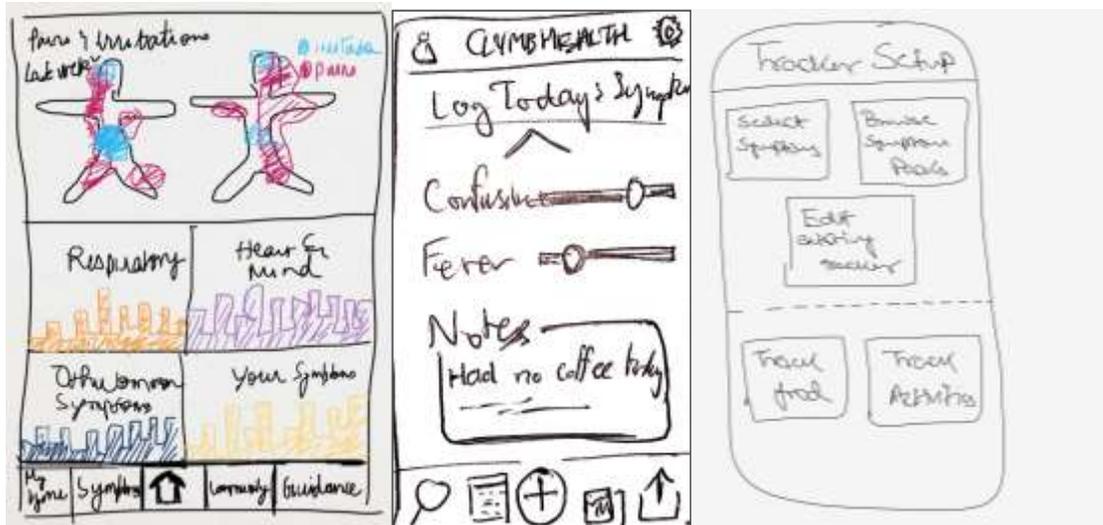


We performed a user story mapping based on the features we felt would target the use cases we were aiming for.



Wireframing

We developed wireframes on paper, validated we had all the tasks in them and quickly created higher fidelity wireframes on PowerPoint to maintain consistency in the designs. We then showed the designs to our stakeholders at Clymb Health to agree on the final features of the app.





High Fidelity Prototyping

After a design review with the business stakeholders, we came to a consensus about the features that needed to be prioritized in order to provide immediate help to patients and also facilitate data collection on a regular basis. We then moved to high fidelity prototypes to be tested with design experts for a cognitive walkthrough.



Cognitive Walkthroughs

We conducted cognitive walkthroughs with three design experts at Berkeley. The key findings were used to modify the designs, making them more usable.

The top recommendations were:

1. Having a consistent and accessible color scale for symptom severity.
2. Making the timeline more intuitive and easy to read.
3. Modifying the information architecture of the progress page.

Design Iteration

We went through a design iteration to reach more consistency and acted upon the recommendations of the cognitive walkthrough activity.



Usability Tests

We created an image linked prototype on Marvel ([link](#)) for our Usability tests. We conducted usability test with three people who either had Lyme disease or have been dealing with a lot of symptoms and taking treatments for them. We asked them to perform tasks of symptom recording, jumping to an earlier date to see data recorded on that date and seeing their progress through visualizations on the app.

There was one primary takeaway from the usability test that the “Save to timeline” button should be always visible to the user in order for them to tap it to save the information.

Data Collection and Storage

For project objectives, we needed a dataset which would at the minimum contain symptom severity of users over a period of time. Initially, a data source with real patient data was not available and the app development was expected to take time. Therefore, we first attempted to use a dataset of symptoms collected by Flaredown App available on Kaggle, which did not prove useful because of the dataset being unstructured and very few users having more than 2 days symptom data. We therefore approached a local Lyme Disease doctor to access anonymized patient data. We used this anonymized and de-identified dataset of 338 Lyme patients for two purposes. First, to conduct exploratory analysis of the symptom data in order to understand its complexity and derive meaningful visualizations. Second, to use this real data to create a dummy dataset that would be used to guide the design and testing of the system (database, query design, front-end UI for patients).

Creation of Dummy Data

The dummy data was based on real patient data extracted from questionnaires answered each time the patient visited her doctor. The data contained symptom severity of patients on a scale of 1 to 4. We extracted the top 5 patients from this list in terms of total visits. Over the 2-year period from 2016 to 2018, the maximum number of doctor visits by a given patient was 7. Dummy data was created by first interpolating symptom severity between each doctor visit. Mathematically, this means that we implemented a line between each pair of consecutive dates. Then for each point along the line, we did a random walk of deviations from this linear trend. The deviations were constrained to a maximum change of +/-2 points. The python code for this is given in Appendix X for reference.

A database was needed to support the backend data storage, analytics and reporting for the smartphone app. For designing the database, we considered the sources of symptom data mentioned above, as well as looked at commonly used symptom surveys for Lyme Disease such as:

1. Lyme disease symptom assessment questionnaire by Richard Horowitz MD ([link](#))
2. Lyme disease symptom checklist by Joseph Burrascano MD ([link](#))

All of these sources were helpful in defining the various types and attributes of symptoms and their measurement scales used by physicians and researchers.

Ethical Approval

The project involved collection of patient symptom data along with personally identifiable information such as name, age, gender, date of diagnosis. Ethical approval was obtained from UC Berkeley Committee for Protection of Human Subjects.

Development

Technology Decisions

Front-End Development

We wanted to have a single codebase which could be used to develop apps for multiple platforms. We decided this because of a lack of expertise in platform specific native code development and the rising popularity of multi-platform UI libraries for the web. We chose Ionic as our UI component library because it supports multi-platform UI development through a single codebase and it is compatible with Apache Cordova which provides the necessary APIs that connect with the phone hardware and allow web apps to use full functionality of the phone hardware. The latest version of ionic uses Typescript which compiles to a single JavaScript file when deployed on the web. Typescript along with angular allows one to write UI code in the form of components that can be reused in various ways through custom markups.

Server-Side Development

On the server-side of the application, we have setup a Flask application that provides an API for the WebApp to communicate with the server and handle the different requests generated by the WebApp whenever a user performs an action. Our decision was driven by the different courses that we took at the I School and the different tools and technologies that we were exposed to. Python was the preferred language of choice for majority of course assignments and projects and thus, our choice as the server-side language.

To proceed with the development of our API, we chose the Flask framework. Based on the individual expertise of the project team members, Flask was chosen as first choice ahead of the Django framework.

Database Development

Based on our prior experience in database design and development, we moved ahead with Postgres as our choice for the database solution at the backend. A big advantage of Postgres is the ease with which one can deploy a simple local server at home and begin development without investing huge time in setting up a technical infrastructure.

Process

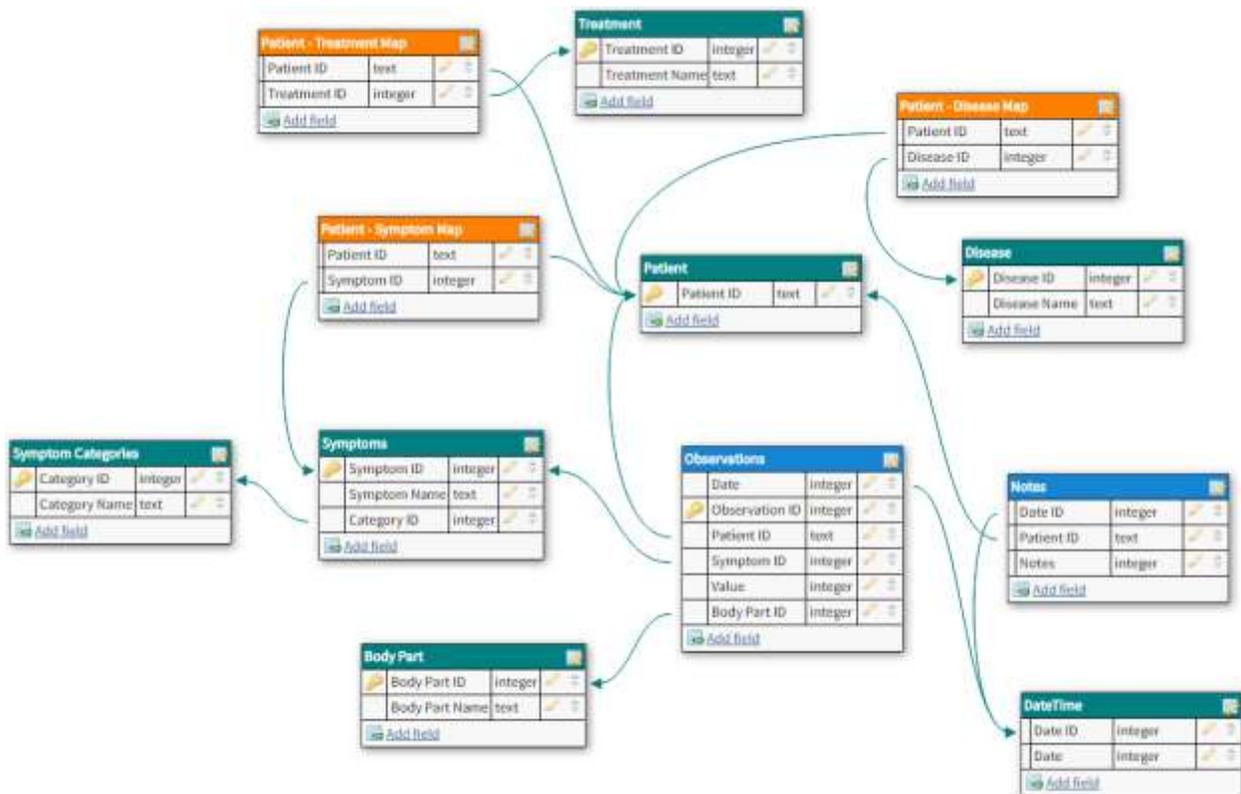
We used a modular approach to both front-end and server-side code development. We created separate components for fetching data, displaying data and saving the information provided by the user. Using a modular approach allowed us to incorporate changes in code much efficiently and made the code easy to understand. Code auditing in the case of bug-fixing and testing was also simplified due to the modular approach.

Furthermore, we tried to make the code for generating the UI as dynamic as possible. We worked together to create different JSON templates for different sets of UI pages. We bound the front-end code to the JSON objects that were dynamically generated by the server based on the different user actions.

On the database front, we wanted to eliminate data redundancy and wanted to design a data warehouse that scales well with changes in the future. We opted for a star-scheme based design which works in perfect harmony with the modular code approach at the server side. A star schema also simplified the process of calculating and retrieving data for complex metrics and other symptom related scores.

Data Modeling

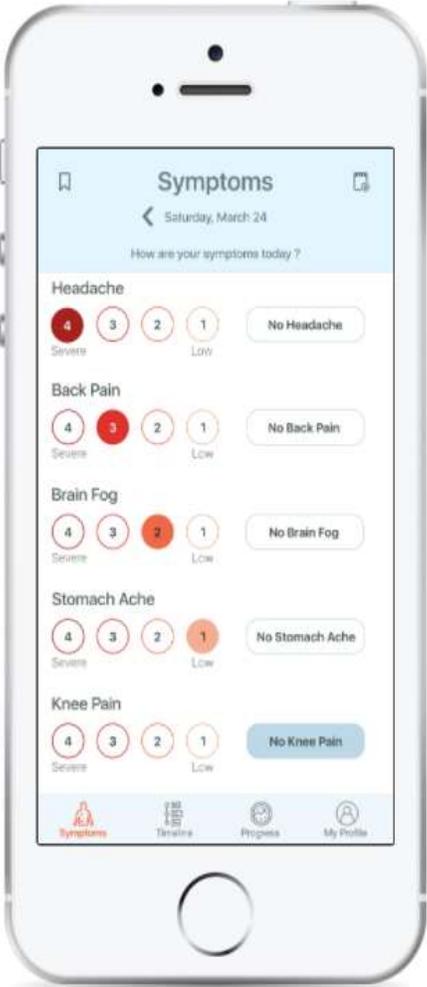
Symptoms can be highly complex and varied in their attributes and how people describe them. Many symptoms cannot be measured using one type of scale. Some are considered binary (e.g. having a nightmare), others are measured using some subjective scale (e.g. severity of pain) and yet others can be measured quantitatively (e.g. fever in Fahrenheit). In addition, some attributes apply to only some symptoms but not others (e.g. pain has a location but fever is systemic in nature). In developing this database, we will have to come up with a design that is flexible enough to handle such variations and still performs well at scale. Below is a snapshot of the star-schema that we designed for the project.



Solution and Results

There are two key outputs of our project. First is the web app we have developed for the purpose of symptom tracking by patients. Second is the set of results we have obtained from data analysis and visualization of actual Lyme Disease patients' data. These are described below.

Final Product



1. A 0-4 severity scale to provide ample flexibility to the user to map severities in the mind to severities as numbers.
2. One tap symptom recording per symptom, drastically reducing the time required to input this on a daily basis.
3. Ability to browse between dates to find pre-recorded information of a day.
4. Ability to mark a day to visually distinguish some days from others.
5. Ability to add notes to enter additional information that users think they might need to refer later on.

1. An Accessible color scale to easily find out which days were bad compared to others and which days a user forgot to record severities.
2. Marked days are distinguished.
3. Users can tap on a date to view the details of that day and can also switch between months.
4. Notes of a month are displayed below the calendar to quickly refer any recorded useful information.
5. Ability to switch to timeline view from the action on the left.
6. Ability to share the recorded data as a chart or csv.

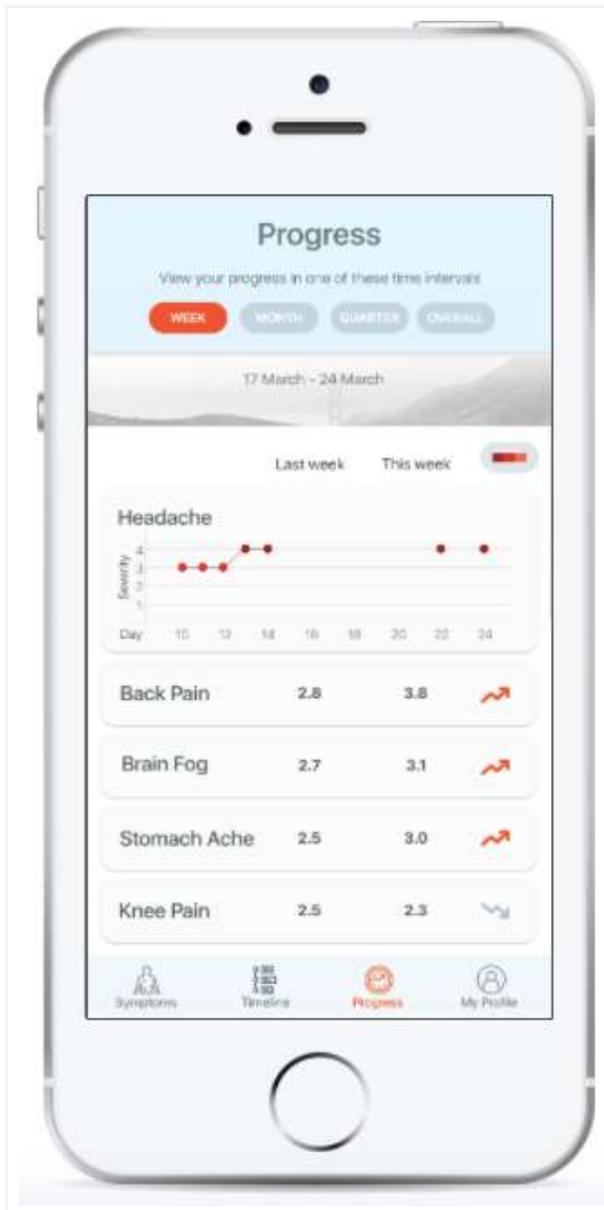




1. Timeline view of symptoms recorded in a month and the ability to switch between months.
2. Each card has symptoms recorded in a day sorted by severity to highlight the symptoms that affected health on a particular day.
3. Large display of score next to the date to easily see how the scores changed over time. Also, an ability to mark days in order to visually distinguish some days from others.

1. Chart showing a total score calculated over the time period selected by the user at the top.
2. Breakup of score calculated by the category of symptoms that the patient is recording daily.
3. Comparison of severities represented in the form of a heatmap to show the change in value of symptoms on a color accessible scale with proper legend to distinguish bothering symptoms from others.





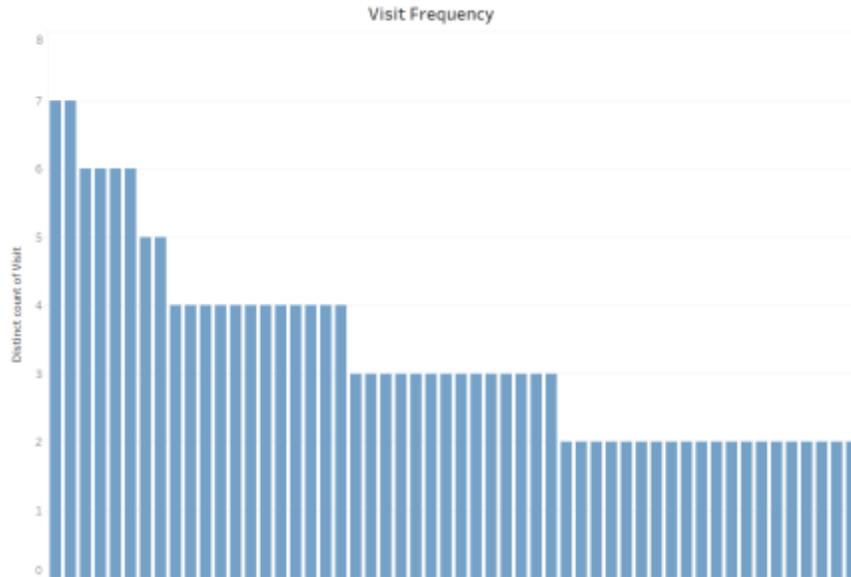
1. Alternate visualization on the progress screen showing change in symptom severity as a line chart for people having difficulty understanding heatmaps.
2. An even easier view showing the average scores of symptoms in the last time period and current time period and a change indicator showing whether the symptom has been improving or worsening over time.

Data Analysis and Visualizations

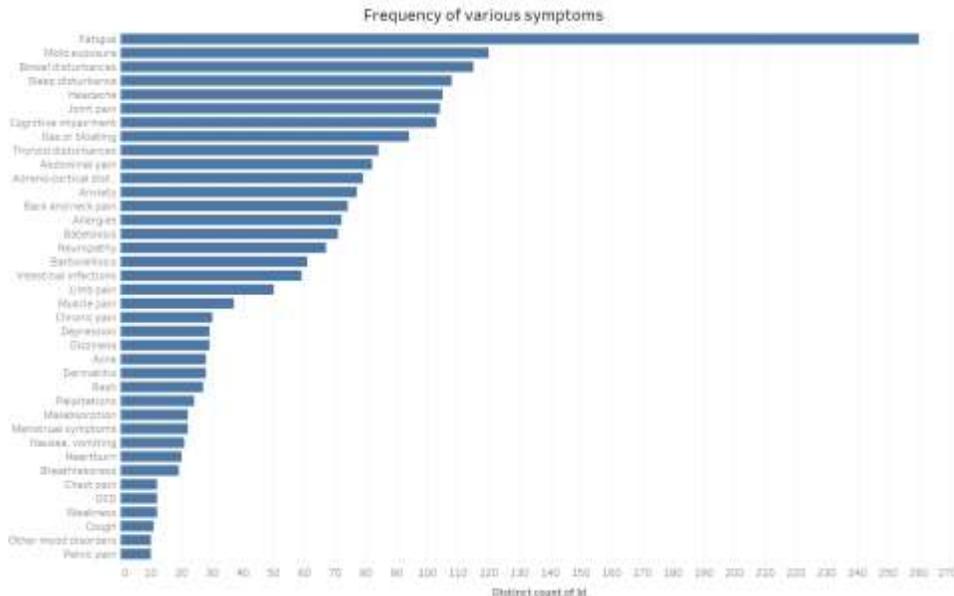
Through this app, we intend to show users how their symptoms have flared up or reduced over time. Since we expect our users to record a plethora of symptoms, it would make sense for them to see meaningful visualizations that convey their symptom progress. At the same time, we wanted to explore potential insights from a healthcare provider perspective as well. For this purpose, we performed exploratory data analysis of anonymized clinic-based Lyme patient data. The data was provided after removal of all personally identifiable information, by a Lyme Specialist doctor who has been working with us on this project. These results are described here.

Frequency of Visits, Symptoms and Medications

The below bar chart shows visit frequency of patients who visited this Lyme doctor's clinic. We observed that there were not many patients who had frequent visits, with only 2 patients who had 7 visits. Most patients had less than 4 visits. From an analytical perspective, this was not a lot of data for each patient to provide actionable insights. This kind of data reinforces the need of an app like ours which provides an easy and effective way to record symptom severity information.



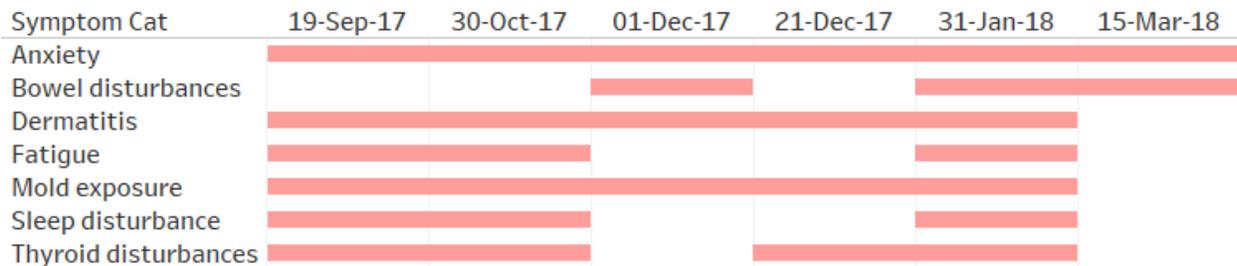
The chart below depicts the frequency of most common symptoms across the sampled patient population. The Lyme doctor who provided the dataset found this visualization useful in understanding what are the most important symptoms across his Lyme patients.



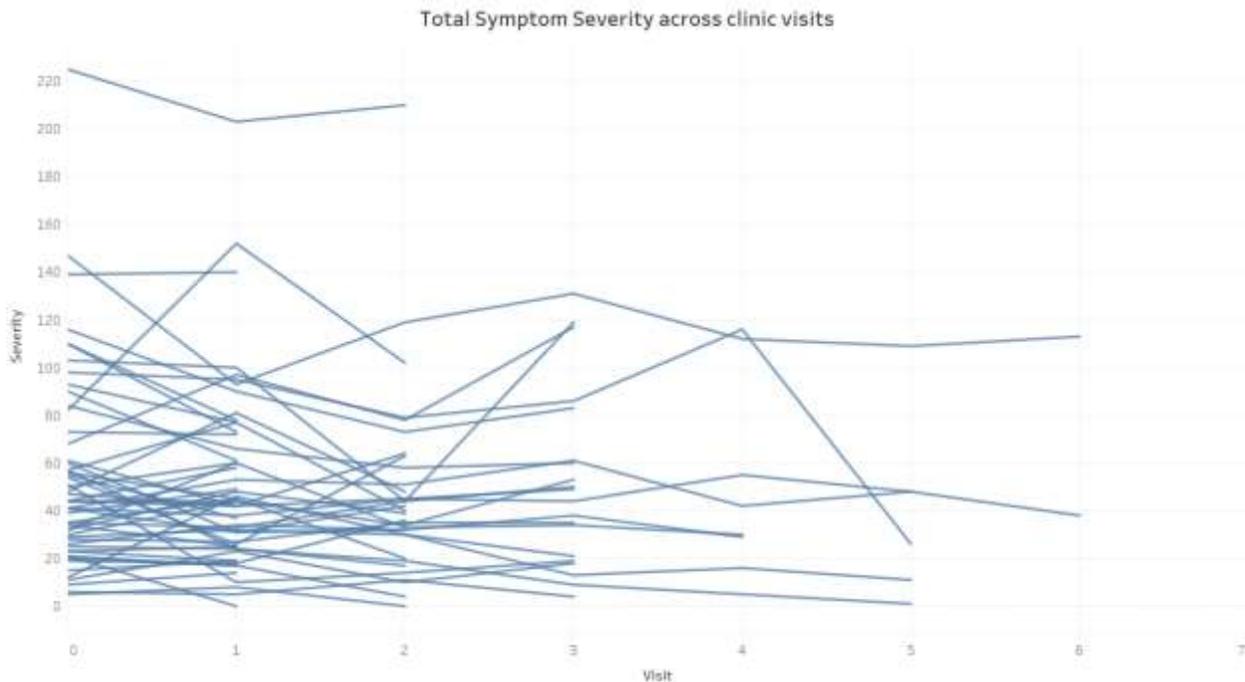
Symptom Progression Over Time

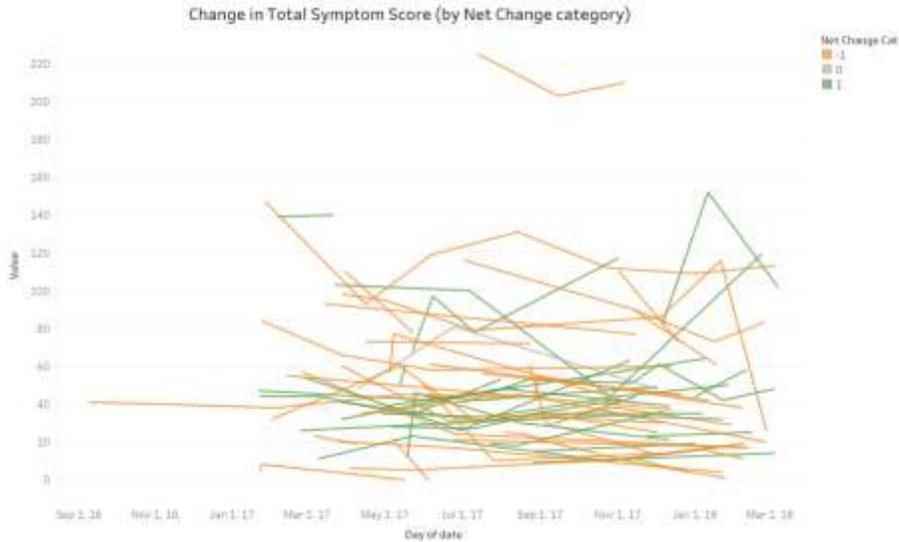
We first tried to analyze symptom progression for an individual. This type of visualization could be useful for users to see if some of their symptoms occur together or not. This could also be useful for medical professionals for analyzing patient history and for planning patient visits.

Individual symptom progression over time

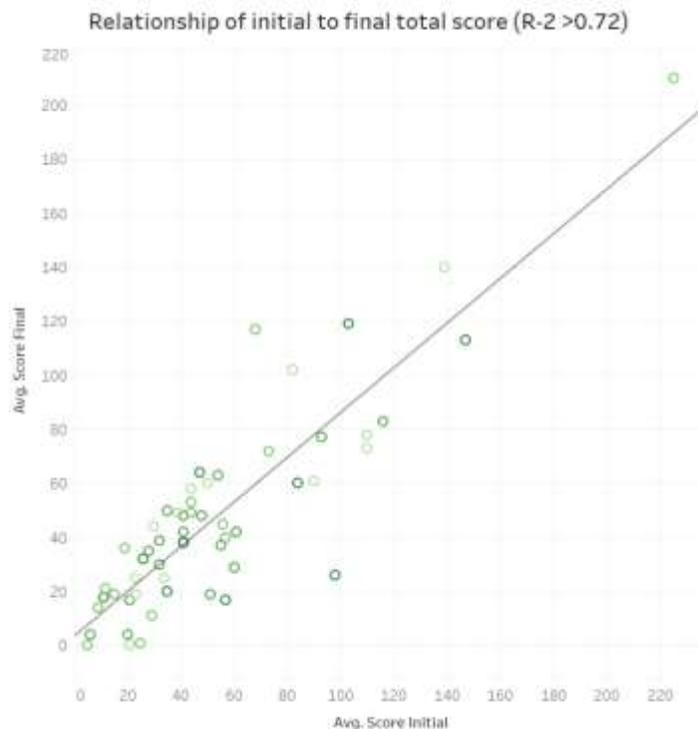


Next, we tried to analyze the symptom severity progress of all patients with multiple patient visits (see figures below). This was done using total symptom scores for a patient over multiple visits. We also tried plotting this information across 3 categories- no change, increase and decrease in symptom scores. We could not discern any patterns or groupings of patients visually from these graphs. However, we recognize the sparsity of data, and implicit assumption that a sum of symptom severities might represent a valid patient outcome.



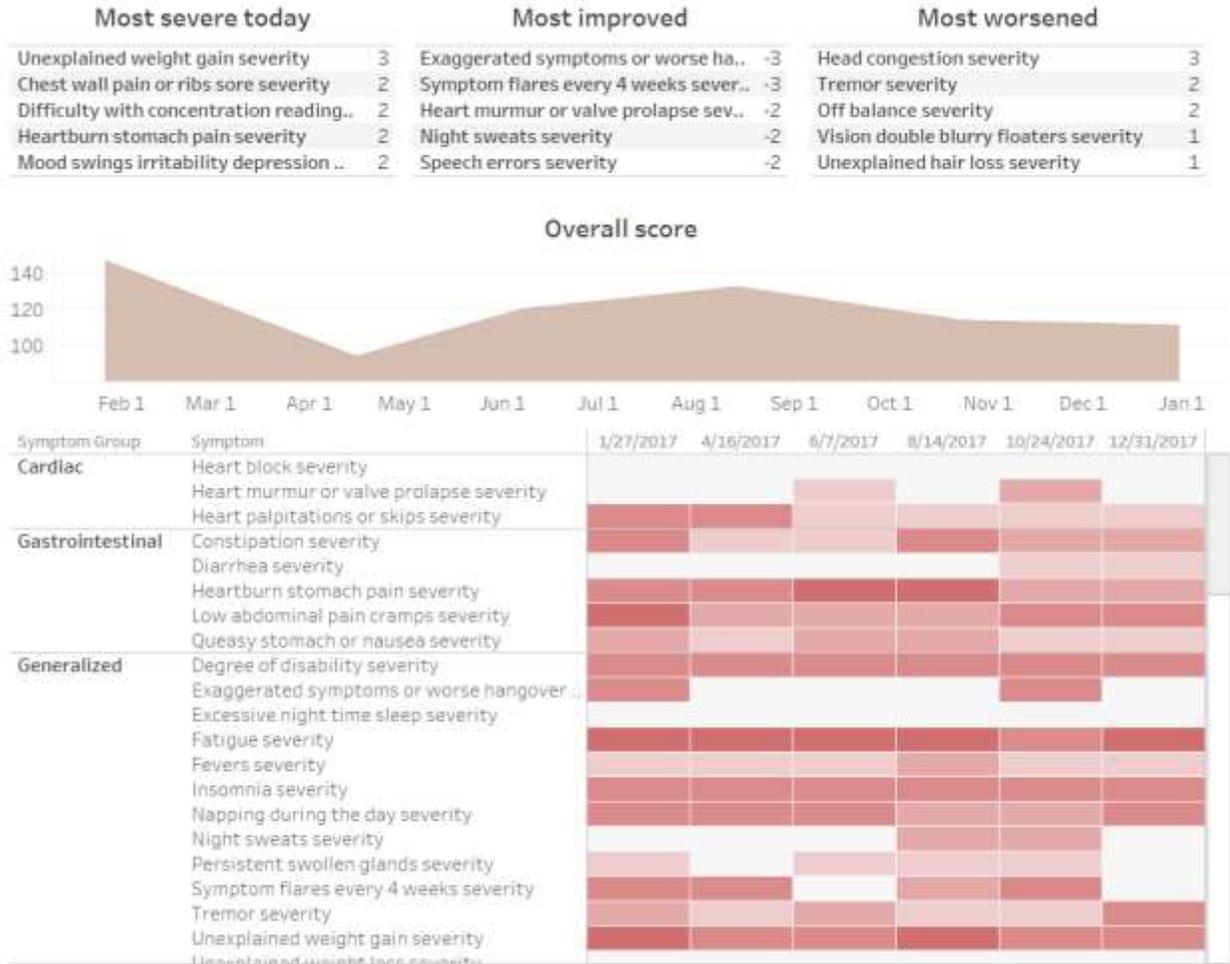


Perhaps the most interesting and unexpected insight to come out of our analysis was the graph shown below. We found that the average final symptom score was positively correlated to the average initial symptom score. This correlation had an R-squared value of 0.72 and this effect was statistically significant. We did not really expect the initial and final symptom scores to be so highly and positively correlated and therefore we also attempted to visualize the duration of patient’s treatment (see legend in figure below). However, duration did not seem to bring out any patterns. The conclusion from this graph is that either symptom score is not a good measure of patient outcome, or there is a real correlation between initial and final symptoms. The former requires validation of symptom scores with another reliable indicator of patient condition. The latter would raise significant questions for treatment strategy and needs further analysis using more variables describing the patient.



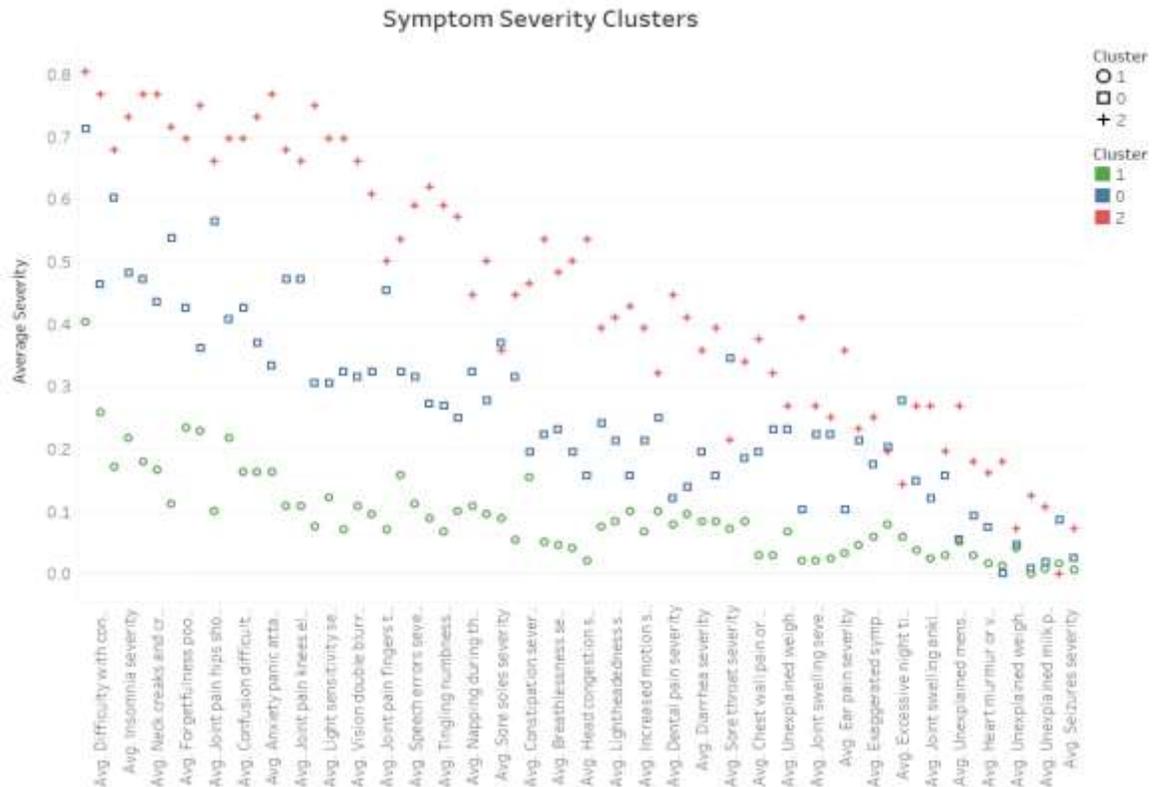
Summary Dashboard for Doctors

While the idea of this application started with sole focus on Lyme patients, we felt doctors could benefit from a dashboard like the one shown above. This dashboard gives an exhaustive summary of a patient's progress. We believe that frequent use of our application can generate enough continuous data for a user which can be converted to a dashboard like this which would be most useful for a doctor to better understand the progress of a patient.



Identifying Patient Subpopulations Through Unsupervised Learning

Lyme disease is not covered by most healthcare providers and we hope this situation changes soon given the fact that a lot people suffer from Lyme. We feel that if somehow healthcare providers can identify risk groups with Lyme patients, they can tailor their products and services for Lyme patients. In accordance with this idea, we decided to create clusters of the symptom data to see if we could find any trends with these clusters. Since the time series data of patients was very sparse, we couldn't really work on a patient-level.



The above visualization shows the clustering of various symptoms based on the average severity as reported by the patients. The idea here was to find if certain symptoms could be grouped together based on any 'similarities' that we could find about them from clustering. Eventually, we would want enough continuous time-series data of symptoms so that we can cluster patients together based on their symptom severity for different symptoms. From these clusters of patients, healthcare providers could find the high and low risk groups and provide them different medical plans and services.

Lessons Learned

Data Sparsity

We learnt that clinic based Electronic Medical Record (EMR) data is very sparse in at least two dimensions. First, the symptom data gets collected only when a patient visits, which can be far and few in between. This the symptom data is sporadic with no visibility between the visits. Second, the medication data from EMR only indicates the date a drug was prescribed and is not indicative of whether and how long a patient used that drug. These lead to a very sparse dataset, as shown for a sample patient in the figure below. Identifying trends and determining associations from such sparse data is difficult and has low certainty. This fact only strengthens the case for our product, which allows for a regular data capture from patients, providing much more visibility into the patient's condition and also enabling advanced analytics.



Incorporating Multiple Perspectives in Design

In tackling a problem like creating an application for Lyme disease patients, we need to ask for and consider multiple perspectives to develop the best possible solution. Though our app is primarily intended for Lyme patients, doctors could benefit from it as well. In such a situation, we needed to make design decisions in a manner that our end-product would benefit all users. This meant balancing the needs of both patients and doctors without removing any functionality that would make the app less useful.

Next Steps

We believe we achieved the core objective of the project by developing a functional web app for symptom tracking. As next step, we intend to take the following steps:

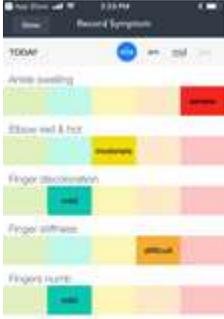
1. Make the app available to real patients as planned, and start collecting symptom tracking data for analysis.
2. Incorporate treatment, exercise and environmental data tracking into the app.
3. Develop a notification feature whereby users would get notified to log their data if they forget to do so.
4. Develop and test a functioning doctor dashboard for exploring their patients' symptom and treatment data for insights.

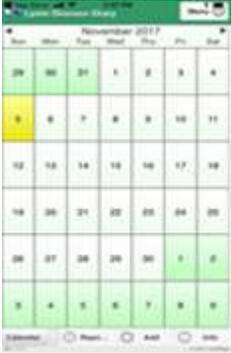
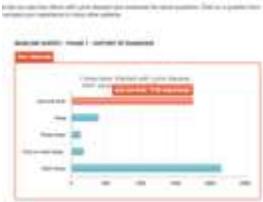
References

1. How many people get Lyme disease? Centers for Disease Control and Prevention. September 30, 2015. Accessed Dec 1, 2017. Available at: <https://www.cdc.gov/lyme/stats/humancases.html>
2. Branda JA, Linskey K, Kim YA, Steere AC, Ferraro MJ. Two-tiered antibody testing for Lyme disease with use of 2 enzyme immunoassays, a whole-cell sonicate enzyme immunoassay followed by a VlsE C6 peptide enzyme immunoassay. *Clinical infectious diseases*. 2011 Sep 15;53(6):541-7.
3. ILADS Working Group. Evidence-based guidelines for the management of Lyme disease. Expert review of anti-infective therapy. 2004 Feb 1;2(sup1):S1-3.
4. Wormser GP, Nadelman RB, Dattwyler RJ, Dennis DT, Shapiro ED, Steere AC, Rush TJ, Rahn DW, Coyle PK, Persing DH, Fish D. Practice guidelines for the treatment of Lyme disease. *Clinical infectious diseases*. 2000 Jul 1;31(Supplement_1):S1-4.
5. Marques A. Chronic Lyme disease: a review. *Infectious Disease Clinics*. 2008 Jun 1;22(2):341-60.
6. Adrion ER, Aucott J, Lemke KW, Weiner JP. Health care costs, utilization and patterns of care following Lyme disease. *PloS one*. 2015 Feb 4;10(2):e0116767.
7. Johnson L, Aylward A, Stricker RB. Healthcare access and burden of care for patients with Lyme disease: a large United States survey. *Health Policy*. 2011 Sep 1;102(1):64-71.

Appendices

Appendix A - Analysis of Existing Solutions for Symptom Tracking

<p>Symple Symptom Tracking</p> 	<p>Free</p> <ul style="list-style-type: none"> Track up to 5 symptoms and factors Attach photos Sync to Apple Health <p>Paid - \$9.99</p> <ul style="list-style-type: none"> Passcode protection Interactive Journal <p><5 symptoms and factor tracking</p>	<p>Strengths</p> <ul style="list-style-type: none"> Easily integrates with other health trackers on your phone UI/UX is clean, colorful and easy to use Factor tracking <p>Weaknesses</p> <ul style="list-style-type: none"> Only allows you functionality to track 5 symptoms on the free version Prompts user to upgrade after almost every screen
<p>FlareDown</p> 	<p>Free Only</p> <ul style="list-style-type: none"> Tracks symptoms, treatments, "factors" and notes View reports <p>Blog feature to post questions and receive answers from other users</p>	<p>Strengths</p> <ul style="list-style-type: none"> Easy workflow to move through recording daily symptoms <p>Weaknesses</p> <ul style="list-style-type: none"> Allows free form entries for symptoms and treatments creating messy data on the backend Lack of specificity - for example, "Lyme Disease" is a symptom Scale asks for how "active" your symptoms are, rather than severity

<p>Lyme Disease Diary</p> 	<p>Paid Only - \$4.99</p> <ul style="list-style-type: none"> • Document and track symptoms • Treatment tracking • Record notes <p>Record appointments, test results, surgeries</p>	<p>Strengths</p> <ul style="list-style-type: none"> - Very detailed, allows you to track a lot of data in one place - Comprehensive reporting options <p>Weaknesses</p> <ul style="list-style-type: none"> - Complicated UI - All symptoms rated the same severity - User must identify their triggers
<p>MyLymeData</p> 	<p>Free</p> <ul style="list-style-type: none"> • Respond to pre-populated surveys • View how your data compares to other users • Store medical files and test results (in pdf form) • Track doctors you have spoken too <p>Manage accounts for dependents and/or give access to family members</p>	<p>Strengths</p> <ul style="list-style-type: none"> - Largest database of Lyme Disease Data - 9,000+ patients enrolled to date <p>Weaknesses</p> <ul style="list-style-type: none"> - Data collected, most frequently, on a quarterly basis - Data entered incorrectly cannot be reconciled - Patients do not have access to their raw data - 9,000 patients may not all be active users or maintaining

Appendix B - Project Team

Faculty Advisor: Prof. John Chuang, School of Information, UC Berkeley

Name, Qualifications and Expertise	Expected role in project
<p>Usman Raza, MBBS, MS, MIMS Candidate</p> <p>Expertise: Public health, product and project management, analytics</p>	<p>Overall project management, coordination with non-I school collaborators, contribution in UX/UI development, medical inputs, designing metrics</p>
<p>Abhishek Sinha, B.E, MIMS Candidate</p> <p>Expertise: Data Analytics, Product Management, Quantitative Research</p>	<p>Healthcare Analytics, Quantitative Research, Wireframing & iterative prototyping, Literature review and synthesis</p>
<p>Arnav Goyal, BTech, MIMS Candidate</p> <p>Expertise: Data Engineering, Product Management, Data Science</p>	<p>Information Architecture and Database Management, Data Engineering and Analytics, Metric Design</p>
<p>Sandeep Pal, BE(Computer Science), MIMS Candidate</p> <p>Expertise: User Experience, Product Management, Data Science</p>	<p>Customer Discovery, Finding Product Market fit, UX Design, Data Analysis, Usability Testing.</p>

Non- I School Contributors

Name	Affiliation	Role
Shannon Herline	MBA student at Haas, UC Berkeley	Providing inputs on business aspects, connecting us with patients and Lyme disease associations
Not mentioned for privacy	Independent Lyme disease patient	Providing inputs on interface design, connecting with other Lyme disease patients for same purpose
Sunjya Schweig, MD	California Center for Functional Medicine	Providing physician perspective on the design and development of app

Appendix C - Project Risks and Mitigation

Risk	Impact	Mitigation strategy
Delay in usability study due to delay in obtaining permissions	Product launch gets delayed.	Apply for approval process early to get permission in time to conduct human subject research (interviews, surveys, user testing for prototypes).
Not accessing enough patients for user testing	The design quality may be affected with limited feedback	We plan to access Lyme disease associations such as the Bay Area Lyme Foundation and Facebook groups for reaching out to enough users.
Not collecting enough data to apply machine learning methods	Can limit the development of advanced features	The initial focus will be on developing visualizations that facilitate decision making; ML based identification will be introduced as a secondary feature i.e. the app's core value will not be dependent on this feature.

Appendix D - Integrative Experience

The proposed project is a great match for a capstone requirement of the MIMS program because it involves combining knowledge and skills from many different areas of information science. Below is a list of coursework that is directly or indirectly relevant to our project components:

- Lean/Agile Product Management: Overall product development
- UID, Needs & Usability, Social Aspects of Information: Developing the app interface that is pleasing and useful
- Information Organization: Designing how disease data is collected and organized
- InfoViz: Developing visualizations of symptom data
- Policy & Law: Targeting users in a manner compatible with privacy laws
- Sensors, Humans, Data, Apps: Sensor integration (if feasible) and other data sources
- Quantitative Research Methods: Survey design, statistical analyses of survey results and developing preliminary data models
- Qualitative Research Methods: To understand qualitative factors about patients' behavior around this disease and also effectively assess impacts of our design
- Database Management: A cloud-based database management solution to capture, transform and use patient, disease and symptom information
- Applied ML and Data Mining & Analytics: Using ML and modeling techniques for trigger identification from patient data.
- Programming Courses: Generally used throughout the project for various components

Appendix E - Query Design

The purpose of the database is not only storage of symptom data, but also allowing analysis and visualizations of symptom data for patients and physicians. Through these analyses and visualizations, the

intent is to answer questions like “Are my symptoms getting better or worse?”, “Has anything improved after I started treatment X?”. Our initial list of use cases and queries was revised based on feedback from users during usability testing. The following is a set of revised use cases and definitions of outputs required for the app:

Use Cases

1. Average Symptom Score (for a selected time period)
Sum of severity score of all symptoms being tracked, averaged for the defined time period
2. Proportion of Symptom Contribution to Average Symptom Score (for a selected time period)
Sum of severity score of all symptoms group by categories, averaged for the defined time period
3. Compare Symptom Severities across Time Periods
Average of symptom severity for each symptom over the two time periods

Appendix F - Testing the Data Model

To test whether the ER model can handle real life data, we anonymized symptom description of a Lyme Disease patient from an online public forum and applied the symptom and observation components of the model to represent the symptoms described by the patient. This test exercise is summarized below.

Patient description of symptoms (anonymized) with important elements identified

“My symptoms are constant debilitating fatigue, tingling all over body, pain all over that is hard to localize and describe. The pain is constant and does not seem to be muscle related nor joint related as moving does not seem to make the pain worse. The pain is just there constantly, the tingling all over my body is constant. I feel flu-like all the time but without a fever. My hands and feet are ice cold and my memory and concentration is not good. Brain fog is there. The only time I feel I can function is when I’m sleep deprived, it’s as it numbs everything.”

Symptom Descriptions Using Our Model

We were able to map the different symptoms reported by the patient to the symptoms stored in our database and insert corresponding records to the patient – symptom mapping. Our Observation and Notes tables allow us to capture the symptom tracking information and important notes about the day from the patient; notes about how their day went and if there was anything specific that they’d want to write down for future reference. Further, the option of specifying a body-part when tracking symptoms allows the patient to report what he/she is experiencing with maximum accuracy.