

et al. Health

Big Ideas 2016 - Full Proposal

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et al. Health

For most people, a trip to the doctor is just a part of their routine - and even when it's an emergency, they can feel confident that their doctor will have some way to treat whatever is ailing them. However, things become all but routine when a patient is diagnosed with a rare condition. In many cases, the diagnosing physician is not capable of providing treatment, and patients have to start a difficult journey to find a specialist that understands the nuance of the condition and state of the art in treating it effectively.

Our team learned about this problem when we read a comment posted online by a distressed parent. After exhausting his personal network for leads to specialists, the parent visited an online forum to ask strangers for guidance in searching for a qualified physician. Some responses urged the parent to parse through publically available medical journal metadata from PubMed, a database of 25 million biomedical journal articles and abstracts. After identifying articles relevant to his son's condition, and assessing their validity, the parent was supposed to cross-reference the article's authors with a national physician database to determine whether the author was a licensed clinical professional.



our stories

We listened to segments on NPR where people talked about their feelings of anxiety and isolation after receiving a one-in-million diagnosis. We heard stories during interviews about patients being misdiagnosed with a condition for over a decade, only to find out the truth about their illness after relentlessly researching their symptoms and identifying the a clinical expert. In a few instances, patients noted that they knew more about their rare condition than their initial physician, a feat they only achieved after extensive research and independent study. For many others, they relied on the efforts of family and friends with connections to a specialist.

We were appalled by this absurd requirement to find treatment. Although the recommendations aligned with the National Institutes of Health's (NIH) suggestions for patients diagnosed with a rare condition, the task is extremely labor intensive and requires highly specialized knowledge. As a team of graduate students at the UC Berkeley School of Information, we knew this was an information access problem that could have a big impact on patient health outcomes, and we knew that we were the team to help solve it.

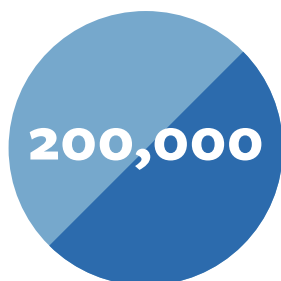
We began speaking to patients to learn more about their experiences finding treatment for their rare disease. In the process, we learned that they scour the web for medical literature, but are confronted with serious challenges throughout the process. We've observed several recurring themes:

- The physician who makes a rare disease diagnosis may not necessarily be qualified to provide treatment or know a specialist to refer them
- The fragmented US healthcare system often forces patients to perform the search for rare disease clinical experts on their own
- Metadata for healthcare providers and research (e.g. journal reputation, clinical affiliation, date published, etc.) are freely available, but difficult to find
- Once patients have found the information, it's dense and requires healthcare domain expertise to parse
- No single source of information measures the clinical research experience of health care providers



30 million, or 1 in 10 Americans have a rare disease

Diseases with less than



total cases in the US qualify as rare

The NIH has identified over



rare diseases

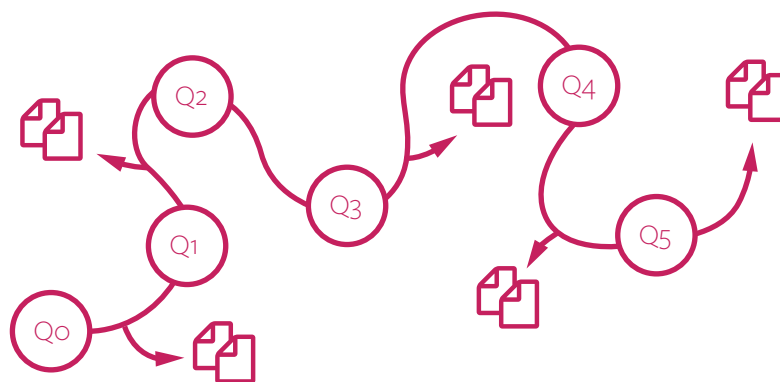


Fig 1: the berry picking model of search, where each circle is a new query

Our conversations with rare disease experts and researchers also confirmed many of the statements made by patients. We also independently conducted research on the problem of searching for rare disease specialists, which suggested an underlying and recurring problem. Currently, people engage in what is known as a dynamic, or ‘berry-picking’, model of search (Bates 1992, Hearst 2002). In the berry-picking model, people go from one source to another, refining their query as they acquire more information and a better understanding of the problem they are trying to solve. According to our interviewees, this often meant learning complicated medical terminology related to their rare condition. Often this would take significant amounts of time, and while this method of searching can be valuable for somebody trying to gain domain knowledge, patients are most often seeking treatment. Our interviews also suggests that rare diseases are physically, mentally, and emotionally taxing. Many of these patients, or parents/ family members of patients, were coming home after long days at work or the hospital and devoting hours upon hours to researching the condition.

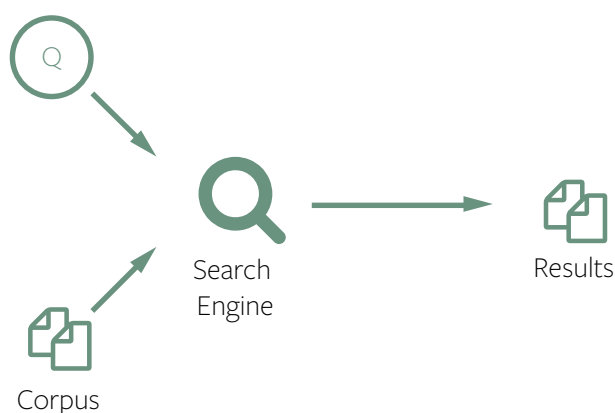


Fig 2. the standard model of search; one query, with one high-quality result

While the berry-picking model for search is effective, it’s intensive. For people that are seeking treatment for themselves or a loved one, it should be reduced to what is known as a standard search model (Hearst 2009). In the standard search model an individual makes a query and gets a result that’s meaningful to them. Patients and their families need a simpler, more focused solution that shows them specialists who can treat their rare disease.

Our Big Idea is to build that solution.

existing solutions

During our research we discovered a variety of solutions but none of them focused on solving the fundamental problem that we have identified: a simple and supportive system to help a patient or their family find the best treatment they can for their rare disease.

	Rare disease patient centered design	Comprehensive, longitudinal care	Transparent Recommendations	ResearchDriven Data
ZocDoc etc	✗	✗	✗	✗
Patient Groups	✓	✗	?	✗
Pubmed	✗	✗	✗	✓
Other Doctors	?	✗	?	?
NIH Call Center	✓	✗	?	?
Patient Navigators	✓	?	?	?
et al Health	✓	✓	✓	✓
	✓ Guaranteed	✗ Not guaranteed	?	No data available

Yelp for Doctors



One of the most commonly used services is Yelp, which allows users to rate their experience with a provider and other businesses. Yelp only allows comparison across doctors based on user submitted reviews, which reflect the patient's subjective experience and not the doctor's expertise. While valuable to some, these reviews typically assess items that aren't relevant to clinical care, such as the temperature in the waiting room or details relating to scheduling an appointment. Furthermore, none of these reviews offer the level of specificity that rare disease patients need. By virtue of treating patients with rare diseases and patients' concerns about releasing personal health information online, doctors that treat patients with rare diseases may not have many user reviews in the first place. Patients may also not feel qualified to grade their doctor's clinical understanding. A number of doctor-specific platforms offer alternatives to Yelp, but these still rely heavily on user submitted reviews and are not designed for the needs of patients with rare diseases.



Zocdoc.com is one of the many online search tools patients can use to find a local doctor and book an appointment. Doctors' profiles on the site include background information, doctor location, and user submitted reviews. Users can select from over 50 specialties, including neurology and gastroenterology, but the list doesn't include any rare diseases. HealthGrades.com is a similar service, which also features the quality of a doctor's affiliated institution. However, users still cannot search for rare diseases, and the heavy use of ads and promoted rankings of certain providers erodes the trust and efficiency of the search results.

Our target populations requires specialists in their particular condition. Across these solutions, the information is too general to be useful to people with rare conditions. Since many rare diseases aren't recognized in the disease classification systems that health care providers use for billing, these solutions can't actually measure how many or how well doctors treat those patients.

patientslikeme®



**Patients
Like Me**

Patient Groups

Patients may also find referrals through online patient groups such as PatientsLikeMe. On these sites, patients are encouraged to talk to each other about their symptoms and treatments. They can also recommend doctors who have treated them. The recommendations from other patients, however, may not be objective or useful for all patients with the same condition. For example, patients tend to concentrate on reviews of a doctor's bedside manner, while ignoring (and lacking qualification) to rate their clinical skill, similar to the problems encountered by Yelp or Zocdoc.com.

Though online communities provide an important source of support and feeling of connectedness, patients' experiences with these sites can vary dramatically depending on their disease. We analyzed the discussion taking place on these sites and found that some diseases had active communities with moderators and patients who would respond to requests for information. For other diseases and disease variants, a users' request for a doctor recommendation might never get an answer. Patients need a resource that will expose all the potential leads for their treatment.

NIH Call Center



NIH

The specialists at the NIH Genetic and Rare Disease call center help patients find contact information for qualified providers by searching a number of the online resources described above. However, this system still burdens the patient, who may be exhausted and feeling isolated, with contacting the physician and ascertaining whether they are taking patients. This presents an opportunity for an all in one service that connects patients to active physicians, and follows the patient longitudinally until the right match is made.

PubMed



PubMed

The NIH recommends a data-driven approach to finding a physician. This process requires that people manually search through author metadata collected from clinical research tools such as PubMed and ClinicalTrials.gov, a database of clinical studies of human participants conducted around the world. For rare conditions, the NIH believes that clinical research activity is a reliable proxy for clinical skill and knowledge. This is an excellent solution, but a challenging one for the average person - PubMed requires domain knowledge and skill to use effectively. Ultimately, people are just trying to find a doctor - they should not need to become an armchair MD and information specialist to do it.

Other Doctors



Other Doctors

For some people, the diagnosing doctor knows a specialist that may be qualified to treat their patient. Many conditions are so rare that the doctor may not know who to contact. Patients may also reach out to their friends and family for help in searching for a doctor - but this process is usually not based on objective data, which makes it challenging to compare doctors with one another. During our research, we spoke to several patients whose primary care physician had no experience with or knowledge of the disease. The doctors either worked above

and beyond their responsibilities to help their patient or gave up, leaving the burden of finding a qualified physician to the patient. Doctors and patients alike could use a tool that simplifies the search process based on research data.



Patient Navigators

Patients can already choose from a number of navigator services, including HealthAdvocate.com and CareCounsel.com. These services match patients with doctors and manage appointment scheduling, insurance, and billing. However, none of these services are designed specifically for rare disease patients and they are not transparent about how they would refer rare disease patients to a specialist.

proposed innovation

The strategic goals of et al. Health are to:

- Create a new signal of doctor quality to help rare disease patients and their loved ones make important decisions about their health care choice.
- Provide a seamless experience when switching between doctors, addressing many of the confusing healthcare decisions throughout this process.
- Empower patients with relevant and actionable information to promote better health outcomes for the rare disease patient community.

Inspired by the NIH's recommendation, we present a two-pronged approach for achieving our goals. The first component is a free online search tool that ranks doctor quality as measured by clinical research experience. The second component is a paid patient navigator service to help patients manage the process of seeking care.



By creating a new signal for assessing a doctor's understanding of a rare condition, patients will now be able to compare physicians based on their research and relevancy to the patient's specific situation. In addition, patients who may be less familiar with navigating the complexity of the United States healthcare system will now have a partner that can help patients manage the information overload and anxiety that often accompanies a rare disease diagnosis. et al. Health aims to put more information in the hands of patients to compare doctors and to bridge the gap between searching for a doctor and managing one's specific health information needs with a simple, mobile-ready web application.

The Online Search Tool

In the case of rare disease specialists, a doctor's awareness of recent medical advances, contribution to the medical community, and integration of new knowledge into their clinical practice are critical to the survival and quality of life of patients. Our new signal of doctor quality is the result of aggregating data from PubMed and physician metadata (name, location, specialty, etc.) from the Centers for Medicare and Medicaid Services (CMS). For the first time ever, patients will be able to easily review a verified doctor's research experience for a specific rare disease. Unlike user generated reviews of doctors, our approach leverages the scrutiny and expertise implicit in the journal peer-review process. We also plan to improve our recommendation algorithm by using techniques from the field of bibliometrics, the statistical study of written publications. We will incorporate the impact scores of journals and individual articles, with more prestigious journals and articles with greater citations carrying more weight. We have already retrieved relevant articles for a small subset of rare diseases and

linked authors to the CMS national provider dataset through a machine learning model and natural language processing techniques.

In addition to patients with a rare disease diagnosis, we realize that family members of rare disease patients, doctors looking to make referrals for their patients, and even users not yet diagnosed with a rare condition may also use our service. Though our primary user is the patient, we will consider supporting features and interactions with our services for these secondary populations. Users will be able to filter by geographic region, medical specialty, and other keyphrases that are unique to conditions.

The Patient Navigator

Over the course of user interviews, we discovered that not all patients can navigate the US healthcare system alone, even after they've selected a doctor. Several additional steps may be required after a doctor has agreed to take on a new patient: transfer of medical records from previous doctors, understanding the benefits afforded by one's health insurance plan, knowing which questions to ask when discussing treatment options with the physician, and many more. The entire experience is fraught with anxiety and uncertainty, but could become more bearable with the help of a patient navigator.

Beyond seeking care from a doctor, patients often look for other ways of managing their symptoms. For

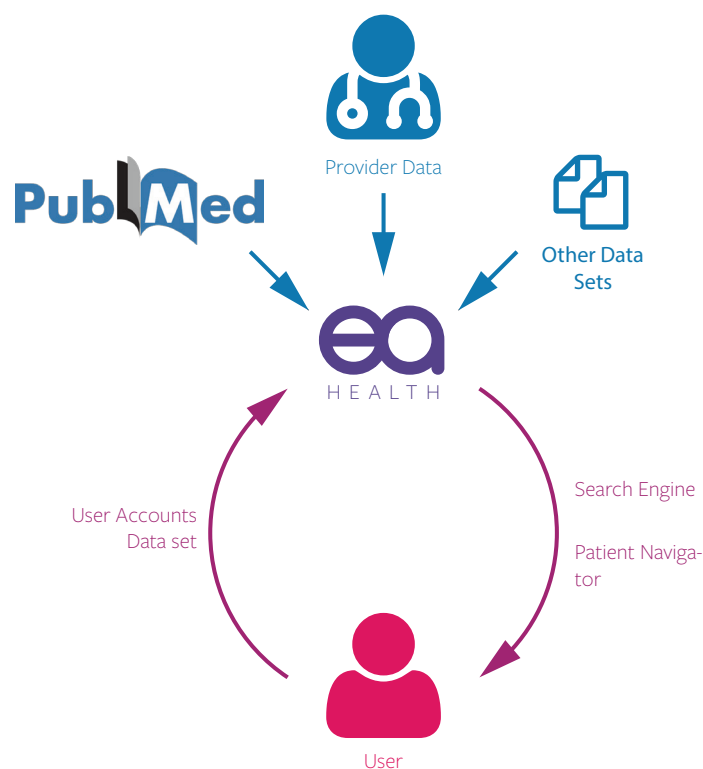


Fig 3. A simplified look at how the et al. Health search tool works

example, some may wish to connect with other patients with the same or similar conditions. Our patient navigator service will guide patients to these resources whether they are online and in person. Additionally, because of our automated system, we'll always be up-to-date on new therapies and research that could potentially save lives. This will provide consistent value to our customers because we can always provide current information about clinical trials, therapies, and even the discounts offered by pharmaceutical companies.

For the initial development of our algorithm and data, we will refine our solutions by focusing on Castleman's disease, a disorder that involves an overgrowth of cells in the lymphatic system, and amyotrophic lateral sclerosis (ALS), a neurological disease that causes nerve cells to gradually break down and die. These diseases represent a relatively common, better-known disease (ALS) and a relatively uncommon (Castleman's) disease, although both are classified as rare. In the future, we intend to scale our system to include all rare diseases discovered and published in the academic literature. We'll also have a domestic focus initially.

the patient

A person directly suffering from a rare disease. May not have a direct support network. Feels alone, because their condition isn't well-documented or supported by the healthcare system.



“Nobody knows what it feels like. Nobody really has it. Getting diagnosed is difficult, but getting treated can be just as hard.”

- Tired and/or otherwise incapacitated
- Has geographic concerns - worried about traveling far for treatment
- Knows a little about medicine

- Finding treatment to alleviate symptoms
- Activism around condition
- Hope

the doctor

Diagnosed a patient with a rare disease that they had never heard of. They care about their patient but it's outside of their responsibilities to find them a provider.



“I don't have time to give my patients the care they deserve. If I want to help, it's in my spare time.”

Key Characteristics

- Has too many patients to care for
- Averse to new technology/time wastes
- Medical expert, but not up to date in the latest/obscure fields

Driven By

- Professionalism
- Care for patient
- Saving time

the parent

A family member or close friend has a condition, and they are assisting in finding treatment. They spend significant amounts of their free time doing research on the condition.



“I was driving the questions. I feel like I had to - I owed it to my daughter. I was reading a lot of stuff I didn't understand.”

- No medical background but doing lots of medical research
- Tenacious; not afraid to challenge doctors and make demands
- Bouncing between care providers

- Love/familial tenderness
- Community and connectedness
- Finding optimal treatment for family member

persona illustrations by Ellen Van Wyk

Business Strategy

Our search tool will be offered for free. This will help people get low-friction access to the treatment and information that they need, and also works within the expectation of free access for web applications today (Anderson 2008). This aligns nicely with our goal of connecting people with high-quality health care as well as providing a simple way to introduce people to the et al. Health service.

The search tool serves as an entry point to our core service. As people use the search tool, we'll introduce them to our subscription-based patient navigator. With our paid navigator service, we will use a system of versioning and bundling

that's meaningful to our consumers - for example, we could offer business hour service as a baseline, and 24/7 service for those who are willing to pay a higher subscription price. This will allow for segmentation of our market across meaningful boundaries (Shiller & Waldfogel 2009). We'll identify segments organically during the interviewing process and create associated patient navigator bundles that appeal to each market segment.

Finally, we will offer everything on a monthly subscription basis. We do not want to lock customers into et al. Health, because our product will help them get better. We see the subscription model as a bold assertion that our service can help improve health outcomes. As stated in the budget, we expect our average monthly price to be around \$50. Finalizing the prices of our subscription fee, however, will require further study and consumer surveys to assess one's willingness to pay. This price is justified because Acquisti and Varian (2009) identified that services like ours increase in value over time. As people build relationships with our patient navigators, there's an implicit price conditioning effect; patients pay the same rate over time, but the value of the service increases for them. In order to foster adoption, we'll explore explicit forms of price conditioning. For example, we can offer people the patient navigator service at a free or discounted rate for a trial period, exposing them to the service so they can better understand how it solves their particular needs.

Marketing Strategy

We'll also accompany the launch of our patient navigator service with digital advertising campaigns to drive users to both to our search tool and our paid service. In our budget we have accounted for campaigns on two platforms that rare disease patients commonly use during their online research: Google and Facebook. Since successful campaigns depend on carefully targeted and attractive ads, our team will leverage our digital advertising and graphic design experience in addition to our understanding of behaviors on these platforms. We will optimize our Google campaign by using our knowledge of users' search patterns that we gleaned from patient interviews. On Facebook, we will target rare disease patient groups and organizations, such as the International FOP (Fibrodysplasia Ossificans Progressiva) Association page.

As an additional marketing strategy, we will continue to establish partnerships with rare disease patient networks such as the Castleman Disease Collaborative Network (CDCN). The rare disease community has many disease-specific community groups and patient networks serve as opinion leaders in the rare disease domain. Endorsements from community groups will help diffuse our solution - or at the very least awareness of it - directly to the community that needs it (Katz 1957, Rogers 2003).

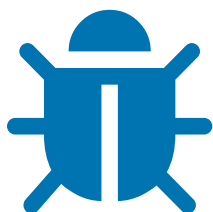


CDCN

The Castleman Disease Collaborative Network is a global initiative dedicated to accelerating research and treatment for Castleman disease (CD) to improve survival for all patients with CD. We've been working with them over the last few months to learn more about people with rare diseases and their journey to find treatment. We're proud to say that they're excited about et al. Health!

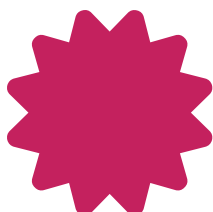
challenges

In addition to the smaller issues that we have identified above, we've identified four fundamental challenges that we will face over the coming year.



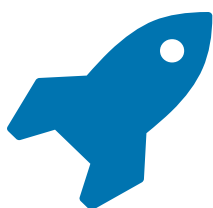
Measuring and Improving Doctor Recommendation Quality

Our doctor recommendation engine powers our business - but our datasets are large, dirty, and heterogenous, which presents challenges when aggregating and merging these sources together to create a meaningful signal of a doctor's research experience. By starting with two diseases with different patient communities, we'll build a general, automated data integration pipeline to ingest and mine fresh, relevant data for our users. We'll validate the performance of our recommendation engine based on the results of an internally curated list of clinical experts from one rare disease patient group.



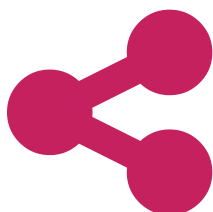
HIPAA Compliance

While we won't provide clinical care or medical advice, HIPAA still applies to et al. Health's patient navigator service. To fulfill the HIPAA requirements for business associates, we'll leverage two services: Accountable (for compliance training) and Aptible (for digital services). These services will help us create, receive, transmit, or maintain protected health information (e.g. patient identifiers and health information) on behalf of "covered entities", which include doctors, hospitals, health insurers, and health insurance claims clearinghouses.



Scaling Patient Navigators

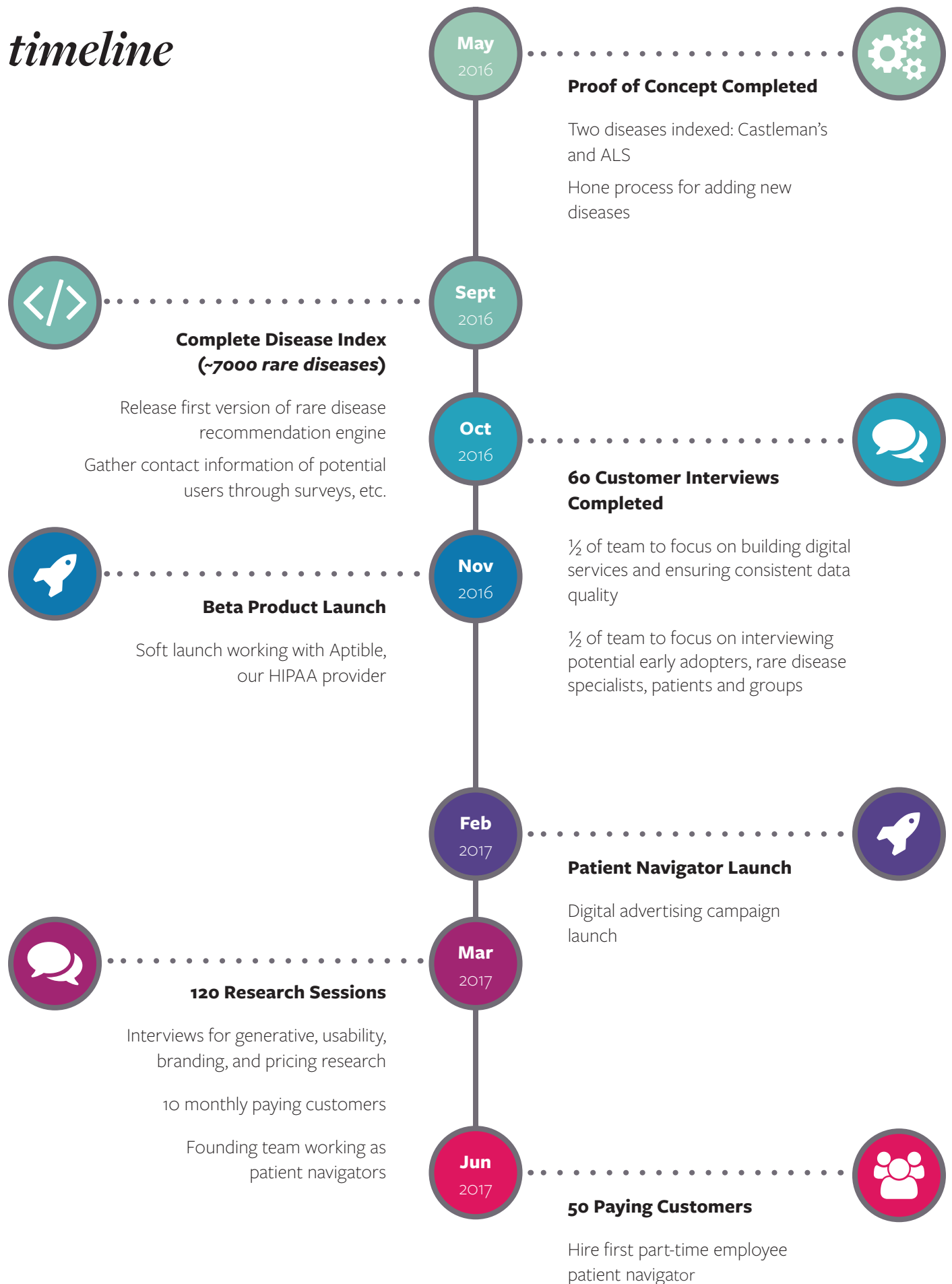
Initially, we plan on working as the patient navigators. We recognize, however, that this is not a sustainable solution. We plan on documenting our process and laying a framework that ensures seamless onboarding once we hire our first employee. By leveraging our data science skill set, we can also create internal tools and resources for our patient navigators to streamline communication with clients and their health care providers.



Business Viability

Our research, interviews, and competitive analysis point to our patient navigator as a viable and sustainable business. As we learn more about people in the rare disease community, we will continue to develop other business opportunities with patients, providers, and other industry partners. For example, biotechnology and pharmaceutical companies may be interested in identifying clinical experts for assistance in developing new drugs or medical devices that may benefit the rare disease communities.

timeline



technical success



7000 Diseases Indexed

With a little bit of data science magic, users can find high-quality, accurate physician recommendations for 7,000 conditions by early Fall 2016.



95% Accuracy

The information in our system meets strict accuracy requirements; we'll use conditions with better data as an inductive proof of quality



United States Specialists

In the first year, our system will have United States rare disease specialists covered, setting us up for expanded coverage of specialists.

design success



120 Interviews

We're committed to our users; by March 2017, we'll have conducted 120 interviews for development, usability, branding, and pricing.



100% AA Accessibility

Our system will have 100% AA accessibility, and 90% AAA accessibility. This is a World Wide Web Consortium standard - a gold star for accessibility.



95% Task Completion Rate

Our system will be usable - using best practices and a user-centered design approach, we'll make sure that 95% of tasks are completed in tests.

business success



50 Paying Customers

We'll have 50 paying customers by the end of the year, demonstrating a viable business model and a useful solution for people with rare diseases.



Prepped for Growth

By the end of that first year, we hope we're overwhelmed. Once our concept is validated and profitable, we can go forward and start hiring!



Community Recognition

We'll be active community members, with a blog or medium account by the end of the year - and we hope people are listening on social media, etc.

projected expenses

Infrastructure	Per Unit Cost	Multiplier	Multiplier Desc.	Total
Database (AWS RDS - db.m4.large)	\$0.18	8760	24hrs * 200days	\$1,594.32
SSD Storage (AWS EBS)	\$0.10	600	50gbs * 12mo	\$60.00
Production Servers (AWS EC2 - t2.medium)	\$0.05	8760	24hrs * 365days	\$455.52
Development Servers (AWS EC2 - m4.large)	\$0.12	480	40hrs/mo * 12mo	\$57.60
General Data Storage (AWS S3)	\$0.03	1200	100gbs * 12mo	\$36.00
SSL Certificate	\$99.95	1	one year	\$99.95
			Subtotal	\$2,303.39
Design & Development	Per Unit Cost	Multiplier	Multiplier Desc.	Total
Design Software (Adobe Creative Cloud)	\$70.00	12	Months	\$840.00
E-mail List Management (Mailchimp)	\$25.00	12	Months	\$300.00
Prototyping Software (Sketch)	\$150.00	1	1 Extended License	\$150.00
			Subtotal	\$1,290.00
Regulatory Compliance	Per Unit Cost	Multiplier	Multiplier Desc.	Total
Accountable for HIPAA Compliance (Training)	\$99.00	6	Months	\$594.00
Aptible for HIPAA Compliance (Development)	\$160.00	3	Months	\$480.00
Aptible for HIPAA Compliance (Production)	\$899.00	4	Months	\$3,596.00
			Subtotal	\$4,670.00
Research & Biz Dev	Per Unit Cost	Multiplier	Multiplier Desc.	Total
Surveys + Analytics (e.g., Google Consumer Surveys)	\$2,500.00	1		\$2,500.00
Comping in-person interview participants	\$20.00	120		\$2,400.00
Advertising (Including Facebook & Google)	\$2,000.00	1		\$2,000.00
			Subtotal	\$6,900.00
			TOTAL EXPENSES	\$15,163.39
Projected Revenue	Revenue	Customers		Total
Customers Month 9	\$50	5		\$250.00
Customers Month 10	\$50	15		\$750.00
Customers Month 11	\$50	30		\$1,500.00
Customer's Month 12	\$50	50		\$2,500.00
			Total Revenue	\$5,000.00
			Funding Gap	-\$10,163.39

the team

with special thanks to maryam ziaei
& marti hearst for their mentorship. ☺



Bill Chambers | *Data Engineering & Business Development*

Bill is a data scientist who's focused on building large scale technical information systems. Prior to Berkeley, he worked in a variety of positions, from tech support, door to door sales, and most recently as a business analyst where he built the internal analytics and reporting systems at a high growth software company. At Berkeley he has focused on machine learning and is currently teaching a class on data analysis for the Master's in Data Science program at Berkeley. Bill is particularly excited about et al. Health because, as the son of two doctors, he is proud to continue the tradition of helping people find treatment for their conditions - but with a data science flair.



Ricky Holtz | *Front-End Dev, Design & Business Development*

Ricky is a designer, a front-end developer, and a firm believer in the Oxford comma. He currently works as a graduate student instructor for Media Studies and the Jacobs Design Institute. His professional experience includes a summer as a product design intern at Salesforce, and a data analyst for Nickelodeon Game & App analytics. He also led a philanthropy event called HuskyTHON, an 18-hour event that raised over \$457,000 for Connecticut Children's Medical Center. He's still an active donor, and so he hopes that et al. Health can help kids across the country find the care they deserve!



John Semerdjian | *Data Science, Domain Expertise & Research*

John is a data scientist interested in the intersection of health technology and machine learning. He is excited to use his background in healthcare to improve information access needs for underserved communities. Prior to graduate school, John was a Senior Data Analyst at the Safety Net Institute, where he lead healthcare quality data analysis for California hospitals. He was also a public health researcher for the California Department of Public Health and Stanford School of Medicine, where he studied pertussis, meningococcal disease, and health IT use across neonatal intensive care units. As a graduate student he was a teaching assistant for Professor Marti Hearst's Applied Natural Language Processing graduate course.



Ellen Van Wyk | *Design, Development, Research & Marketing Strategy*

Ellen Van Wyk is a user experience designer with a background in neurobiology, visual art, and research. Before coming to Berkeley, she helped found an undergraduate neuroscience journal and studied the cognitive neuroscience of language at the University of Washington. At Berkeley, she studies interactive experiences to enable creativity and scientific thinking. Her recent projects include a UX Design internship at Amazon, teaching design at UC Berkeley, and educational game design. She is currently researching learning environments for youth tech and data literacy under advisor Tapan Parikh. She's excited to work on et al. Health because she's always looking for new ways to expose and democratize scientific information.

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