IBConnect

Placing patient data at the heart of online communities

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Abstract

Personal Health Records (PHRs), electronic records of health-related information of an individual created and managed by the individual, represent an exciting opportunity for designers and the patients they serve. Tools that collect, analyze, and share personal health data may prove vital to the chronically ill, a population whose health is not managed by doctors but by patients themselves. However, existing PHRs mainly serve as repositories of static information. Less explored is the idea of a data-driven PHR, centered within an online patient community, enabling chronically ill patients to connect and share relevant knowledge.

This thesis project explores design opportunities for next-generation personal health records. The result is IBConnect, a digital personal health record platform for patients with Inflammatory Bowel Disease. By navigating data within a personal health record as a means to explore online community knowledge, patients using IBConnect can manage their individualized illness experience by discovering actionable, relevant and contextualized knowledge. In turn, patients are encouraged to track and contribute more to the IBConnect community enabling access to new knowledge, a resource highly valued by patients.

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Introduction

Early in the morning of January 2nd, 2012, my parents rushed me to the hospital, where I lay for four days, inexplicably unable to walk or use my arms. Blood was taken, painkillers and steroids were given, often without explanation. I saw a physician for a total of ten minutes the entire time I was admitted.

On the third day, having regained the use of my hands, I grabbed my smartphone and logged onto an online community where I slowly and painstakingly described the past few days ordeal. Within hours, I received replies from other people who had experienced something similar, shedding light on a situation that none of the seasoned professionals around me could.

An Exciting Opportunity

While one of the largest and most important challenges for our health care system today is lowering the incidence of preventable chronic diseases, such as cardiovascular disease and diabetes, there exist other types of chronic diseases that are impacting the lives of millions of Americans. These diseases are collectively known as Invisible Chronic Illnesses or ICIs (Donoghue & Siegel, 2000).

While often incredibly painful and debilitating, many patients with ICIs display no physical manifestations of their illness, hence the term "invisible." ICIs have no known causes and are therefore unpreventable. In fact, so little is known about some of these illnesses that there is not a clear course of treatment. Instead, patients face a lifelong path of trial and error, attempting to mitigate their condition through various interventions, including medication, diet, and alternative supplements.

For patients with Inflammatory Bowel Disease (IBD), a category of ICI which includes Crohn's disease and ulcerative colitis (UC), and which I've been suffering from since 2007, navigating the existing healthcare infrastructure is an arduous task. IBD can be difficult to diagnose, and more difficult to manage. Neither Crohn's or UC have a known cause, nor any definitive cure. Instead, most patients experience periods of active disease or flares, and inactive disease, remission.

ABOUT IBD

Inflammatory bowel disease (IBD) involves chronic inflammation of all or part of the digestive tract. Symptoms range from mild and manageable to severe and debilitating, and can include:

Abdominal cramps and pain
Bloody diarrhea
Severe urgency to use restroom
Loss of appetite
Weight loss

While a wide range of treatments exist for IBD, there is no definitive course of action for doctors and patients to follow. Patients respond differently to different medications, necessitating a trial-and-error approach. For many patients, fifteen minutes every few months with their gastroenterologist constitutes all the professional care they receive. Consequently, these patients must manage their own condition (Clark, 2001).

Because many IBD patients are essentially "testing" a variety of treatments at any given time, including medication and diet management, access to transparent, accurate data regarding their condition may prove invaluable for these patients. And armed with little knowledge from diagnosis on, IBD patients often turn to the internet for knowledge and support.

Fortunately for patients with conditions like IBD, recent advances in consumer technology have propelled a new generation of products for the management of health and wellness to market. These products enable patients to "formulate important and possibly novel areas of inquiry, collect data about their experiences and find others with similar interests and conditions with whom to collaborate and mobilize resources" (Swan, 2009).

For example, the association of diet and IBD remains largely tenuous. Despite a general belief in connections between diet and symptoms,

these beliefs are difficult to prove empirically (Rajendran, 2010). But given the explosion of self-tracking tools available, a patient may begin a new diet, for example one free of dairy products, and then use a mobile application to monitor symptoms over time to see if the change in diet has any effect on their symptoms or overall well-being.

We're also beginning to see changes in the structure of our healthcare system's economic incentives. With doctors and hospitals now economically incentivized to keep patients well (Kocher, et al., 2010), more attention and resources will be given to consumer-side health management tools that will keep patients well and out of the hospital.

The Role of Design

My past four years of experience with IBD, including that unexplainable hospital stay, have led me to believe that the current design of the healthcare system, and the tools that support the system are flawed in one important way: more often than not, these tools do not place the patient at the heart of the experience. Research on tools such as the personal health record have focused on their potential to reduce healthcare costs and support patient-provider relationships. Simultaneously, researchers have examined the medical and social benefits of participation in online patient communities, but little has been written on how to improve such services.

Designers have much to contribute to the field of chronic illness management. As a discipline which places the user at the heart of the process, design has not yet fully explored how to leverage technology to support, connect, and empower patients by placing them at the center of their own healthcare experience.

Over the course of nine months, I explored opportunities to support the management strategies of patients with IBD by researching personal health records, an entity often conceptualized from the perspective of the healthcare system, and online patient communities, where little innovation has occurred over the past two decades. My goal was to create a solution to support, empower, and inform patients.

Personal Health Records

A Brief History

Individuals have been keeping track of their personal health information for years. This information, including lab reports and immunization records, is commonly organized in systems of envelopes, binders, and shoeboxes (Detmer, et al., 2008). Over the past decade this information, called personal health records (PHRs), has increasingly become digital and with this change has come a new design opportunity: electronic PHR systems that "capture health data entered by individuals and provide information related to the care of those individuals" (Tang, et al., 2006). Now, patients can manage not only clinical notes and discharge sheets, but also more complex data like blood pressure readings and glucose levels.

In 2005, a symposium on personal health records hosted by the American Medical Informatics Association's College of Medical Informatics to address the issues surrounding electronic personal health records. In 2006, Paul Tang, et al., published a paper summarizing the activities of the symposium, proposing a formalized definition of PHRs and outlining an agenda to push the development of these tools forward.

Tang and his colleagues noted that electronic PHR systems "capture health data entered by individuals and provide information related to the care of those individuals," encouraging "individuals to take a

Currently, there are three models of PHRs, varying in levels of complexity and integration.

Tethered

This type of PHR only provides minimal access to a patient's EHR, a record maintained by their doctor.

Integrated

This type of PHR is an extension of an individual's EHR, providing an expanded view of their care.

Stand-alone

This type of PHR is a stand-alone product, where patients must input and maintain their own health data.

more active role in their health." These patient-centered tools stand in contrast to Electronic Health Records (EHRs), repositories of patient-related data managed by the health care provider. EHRs, while an essential part of managing a patient's care, are developed with only the provider's needs in mind. Thus, Tang, et al., argued that patient-centered tools would improve care by encouraging collaborative disease tracking, lowering communication barriers between patients and their doctors and caretakers.

The symposium also advocated for the design a specific type of record: an integrated personal health record, which would pull in information from the patient's EHR, providing more relevant data to the patient. The other two models, stand-alone and tethered, do not provide a full picture of an individual's health. In 2007, Detmer further advocated for integrated PHRs, arguing that the widespread adoption of integrated PHRs would enable a number of advances in healthcare, including a shift to a "shared control" model of healthcare.

By bringing transparency to the health data of patients, integrated PHRs can promote the emerging notion of "partnership" between patients and providers which entails a collaborative decision care component, where patients and providers make decisions together (Bodenheimer, 2002). In 2008, David Klaeber, lamenting the lack of research compared with the large amount of money invested in PHRs, proposed an agenda that advocated more robust investigation

of the four crucial areas of PHRs: information collecting, sharing, exchange, and self-management.

Current State

Despite growing interest for PHRs within the medical community, a recent survey by the California HealthCare Foundation found that only 7% of individuals reported using a PHR. However, over 50% of respondents reported they were interested in tools and devices to collect and manage their personal health information (Undem, 2010). While the barriers to widespread adoption of PHRs are complex and necessitate the involvement of stakeholders across the medical, public policy, and technology communities, designers are well poised to contribute great innovations to the field of personal health management. However, little literature from a design perspective exists to drive the development of such tools forward.

One study of note was published in 2005 by researchers at the University of Toronto led by Warren Winkelman. Their work outlined a patient-centered framework for the development of Electronic Health Records (EHRs) following an investigation of EHR use by patients with IBD.

While the work addressed EHRs specifically, the principles outlined can apply to PHRs as well, providing a starting point for designers of PHR systems. Winkelman, et al., argued that simply providing access to health information is not useful enough on its own. Instead, technology should be "multifaceted, self-care promoting, and integrated into the patient's existing health...infrastructure."

The work also outlines a method for interviewing patients, then synthesizing those interviews with grounded theory to extrapolate patient values. This makes the study particularly interesting because it probed for patient values and then discussed how such values can be translated to the design of health information systems. This stands in contrast to most literature on health information systems which seek to support existing healthcare systems and stakeholders.

Four themes for a theoretical framework of patient-perceived information and communication technology usefulness

Warren Winkelman, Kevin Leonard & Peter Rossos, 2005

Illness Ownership

If patients perceive ownership of their illness, they are more likely to use tools that facilitate the management and solving of their problems.

Patient-Driven Communication

Such communication offers opportunities for meaningful patient participation in illness management, decision making, and knowledge creation.

Personalized Support

A patient's adjustment to chronic illness is made positive by the perception of support. Support includes nurturing (such as emotional, self-esteem, and network forms of support) and action facilitating (such as informational and tangible forms of support).

Mutual Trust

Trusted relationships, with doctors and technology, affirm patients' aptitude to exercise self-care intentions.

The Power of Data

Personal health records, until this point, have been conceptualized as static repositories of information. This notion has ignored a very powerful and important trend as of late: As our computing abilities simultaneously increase in power while decreasing in size and price, we've seen an explosion of consumer products that can sense, monitor, and communicate personal data.

Supporting this movement is a strong base of early adopters, collectively called the Quantified Self (QS) Movement. The QS movement is a collective of tech savvy individuals, passionate about monitoring, collecting, and analyzing the minutiae of their daily life to draw insights and improve themselves.

The movement is a natural fit for the chronically ill. Bringing accurate, quantifiable personal health data to the doctor's office may provide a number of benefits for patient, provider, and the relationship between the two. The first, and most obvious benefit is access to such data can provide doctors with comprehensive information that may help them make more accurate treatment decisions. Patient recall is only so

accurate, and in fact, weighing the two information sources together (the patient's account and the account of the data) may provide an even richer picture for doctors to address.

Access to such data may cultivate a better relationship between patient and provider, enhancing the partnership notion discussed earlier. Specifically, Melanie Swan notes that partnership can transform patients from "minimally-informed advice recipient to an active participant, instigating collaborator, information sharer, peer leader and self-tracker." For many patients, the office visit is a passive experience, one where doctors probe the patients with direct questions, then delve out a prescription. Transforming that experience by bringing in data may alter the way patients approach the management of their disease.

Tools to Engage

However, little work has been done to understand how chronically ill patients are using technology to manage their illness. To better understand if, how, and why patients are tracking data related to their IBD, I deployed a survey through various channels, including online patient communities, Facebook, and Twitter, targeting adult IBD patients.

Survey Results

Of the 166 patients surveyed, 80% reported that they have tracked or are currently tracking data related to their condition and 96% found such tracking to be somewhat to very helpful. A majority of patients use paper to track medications, doctor's visits, symptoms, and diet. However, 45% of patients are using digital tools, including mobile and web applications. When tracking, patients most often value the ability to track easily and quickly and discover interesting trends, patterns, and correlations among their data.

Patients who don't track cite the time required or lack of right tools as reasons they do not or have stopped tracking. Those who stopped tracking most often did so when they went into remission, or if they found tracking wasn't useful for them. For patients who never tracked, access to easy tools is the biggest factor that could encourage them to start tracking.

Once I discovered the functions of tracking tools patients value the most, I explored the current market to examine whether these tools were currently serving patient needs, supporting ease of use, and facilitating trend discovery and sharing.

As of September 2011, eleven tools designed specifically for IBD patients were on the market or being developed. These tools were

Competitive Analysis

| Product	Platform	Description	Focus
Crohnology	Web	Shares the silos of information bottled in each person with IBD.	IBD
Crohnology.MD	Mobile	Helps young adults who suffer from Crohn's disease create visual narratives of their condition to provide feedback to providers about how they feel from day to day.	Crohn's
myiBD	Mobile	Developed by doctors and patients for people living with diseases like Crohn's and Colitis, it has features that will help patients and doctors better understand their condition.	IBD
GI Monitor	Web & Mobile	A disease management application for patients with IBD where the data collected is compiled into easy-to-read reports for physicians, resulting in optimal patient treatment and reduced periods of active disease.	IBD
UC Tracker	Paper	Patients can record today's symptoms as well as factors that might affect their condition, such as medications and diet.	UC
Apriso Tracker	Paper	Through weekly tracking logs, this paper tracker helps patients better understand their condition.	UC
IBS Symptom Tracker	Mobile	This application is a symptom tracker for people with Irritable Bowel Syndrome (IBS) or anybody interested in tracking gut functioning, including IBD patients.	IBS
My GITrack	Mobile	Tracks daily events related to IBD and then shares this information with doctors so he or she evaluate the efficacy of a patient's prescribed medication or specialized diet.	IBD
Crohn's Diary	Mobile	By tracking stress and diet, this product can help patients identify which factors aggravate their IBD.	Crohn's
MedHelp Tracker	Web	Tracks symptoms and treatments relating to Crohn's Disease and Ulcerative Colitis.	IBD
CCFA Medication Log	Paper	Keeps track of medication regimens on a daily basis.	IBD

predominantly mobile (application or paper-based) and all supported self-tracking of various IBD-specific symptoms and measures. Some tools supported diet tracking better, while others had a social component. The tools varied in terms of usability and design and all required a fairly substantial time commitment from its users. Below are three of the most notable tools:

GI Monitor

GI Monitor is a mobile and web application that enables patients to track their IBD related symptoms. The primary interaction is with the mobile platform, where patients track bowel movements, pain, fatigue, stress, and other symptoms. GI Monitor has gained traction, having been one of the first mobile app tools on the market for IBD patients.

While easy to learn, GI Monitor has many usability issues. When a patient has not logged into the application for a couple days, the app forces the user to fill out a long survey to update their missed symptoms. The graph functionality is bulky and difficult to explore, particularly on a mobile device.

GI Monitor recently launched a social feature called "Socialize," where patients can post messages or status updates and other patients can reply with their input and advice. While a great start, this feature is still in its early stages.
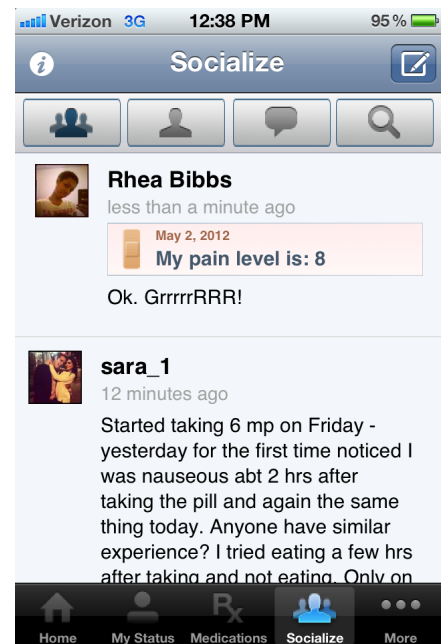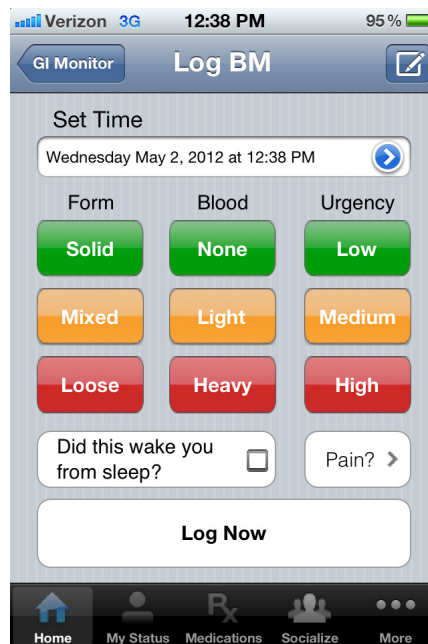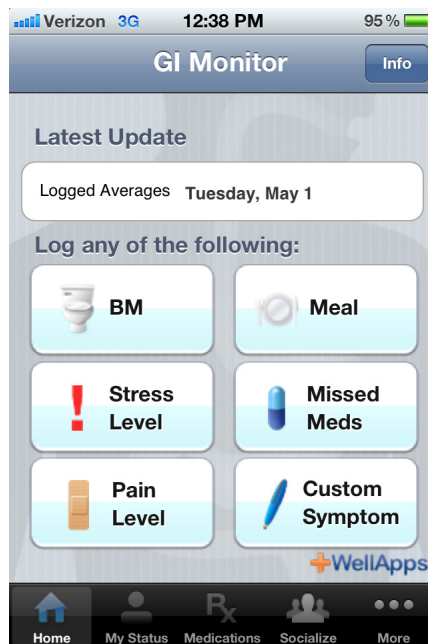
GI Monitor

myIBD

myIBD is an app developed by the C3N project, "an innovation lab, where patients, clinicians and researchers work together as co-designers...to transform the system of chronic illness care." myIBD has many of the same features as GIMonitor, though with a stronger visual aesthetic and some novel features.

Included is a visual way to rate and track abdominal pain. Users select where on an image of a stomach they are experiencing pain. This data can then be visualized over time so both patients and doctors have a record of how pain intensity and location has changed over time.
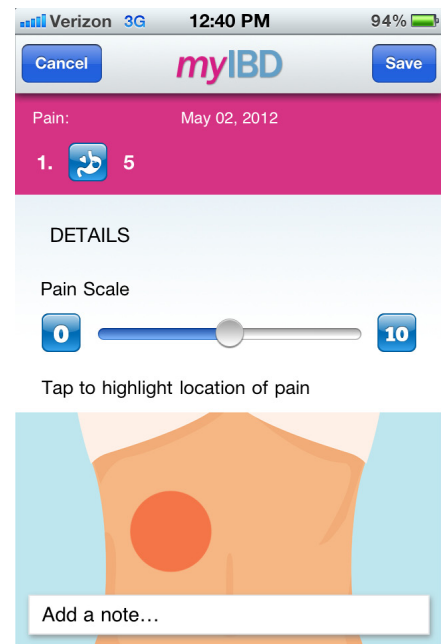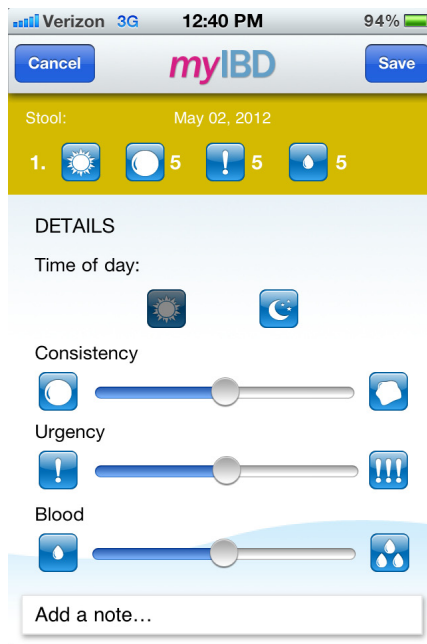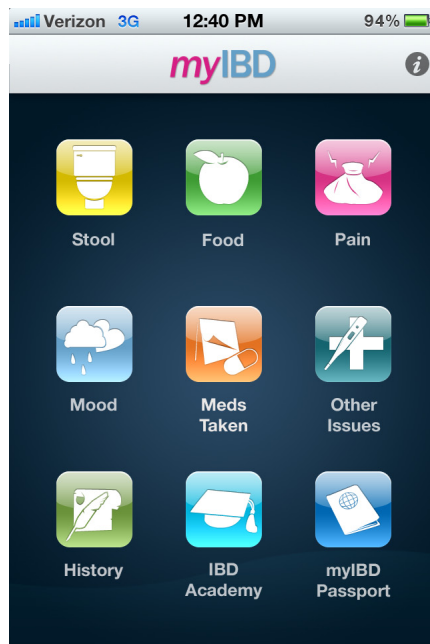
myiBD

Crohnology

Crohnology

Crohnology is a social network for patients with Crohn's and ulcerative colitis developed by a young Crohn's patient, Sean Ahrens. After a stint in the healthcare startup incubator Rock Health, Crohnology has launched in private beta.

After discovering the power of in-person support groups, Ahrens wanted to translate that experience online. The main focus of the site is social, featuring a Facebook-like layout. Users follow each other to keep tabs on their health and course of treatment. The tracking features of the site are rudimentary, including general status. Patients can also rate treatments regarding effectiveness and then explore the ratings of other patients.

Online Patient Communities

Considering the vast amount of data being tracked by patients, how is such information being used to manage their condition? While the majority of patients surveyed claimed they were sharing data with their healthcare provider, and even family or friends, participants in my hour-long in-depth interviews suggested otherwise. These participants used their data to find patterns and discovered correlations, and then shared the *knowledge based on their data* with their healthcare providers, an important distinction from sharing raw data.

I also discovered that patients shared that knowledge with online patient communities, social websites devoted to their specific condition. In these communities, patients are sharing knowledge based on their own experiences, and sometimes their own data, to help solve problems, discover treatments, and share support. In fact, engagement with communities often began with a search for knowledge. Because IBD creates a wide range of individualized problems with little to no direct course of action, patients turn to the internet, and consequently, to other patients on the internet for information. Then, this interaction may or may not turn to support, depending on the level of support patients experience in real life.

As Jen Mankoff, et al. notes in their 2011 paper, "Competing Online Viewpoints and Models of Chronic Illness," health social networks can serve multiple functions, including as "a support network, a source of information, a place to compare treatment options, and

a mechanism for sharing information with caregivers, family, and friends." Participation in these online communities heightens levels of emotional well-being, perceived control over disease, overall personal empowerment, and level of medical knowledge (Wicks, et al., 2010). These communities also have the potential to cultivate the sense of partnership between patients and providers discussed earlier, through increased medical literacy and a sense of empowerment and control.

These online communities are predominantly focused on knowledge, that is information acquired from experience, and not data. The idea of a data-centric online community, where patients freely share their own health data and knowledge, is still a new concept. However, given the recent explosion of tools to collect personal data, now is the ideal time to start exploring this new model.

PatientsLikeMe; A Case Study

One website which has attempted this novel model of sharing data among patients is PatientsLikeMe (PLM). Founded in 2006, PLM began with a community for patients with Lou Gehrig's, or ALS, a terminal disease which causes progressive degeneration of the motor neurons, leading to paralysis. Through extensive tracking of symptoms and quality of life measures, patients using PLM found the site "had helped them understand the side effects of their treatments...[and learn] about a symptom they had experienced." A number of patients

reported being either "moderately" or "a lot more" involved in treatment decisions because of what they learned on PatientsLikeMe (Wicks, et al., 2010).

However, PLM was initially designed to support the activities of a particular kind of patient--one that is terminally, not chronically, ill and has an extremely high level of motivation to track data related to their condition, particularly as a means to discover and extend all possible treatment options. PLM's Director of Research and Development, Paul Wicks, stated in a 2011 talk given at a QS meetup that PLM seeks to serve only those with greatly life-changing illness, such as cancer, leukemia, and HIV. He also noted that the site is not tailored to those less technologically literate. Indeed, the interface is fairly bulky, with a high learning curve. The more data a patient gathers, the more difficult it becomes to discover trends and patterns within the data. Scales are also limited, and may not best describe certain symptoms.

PatientsLikeMe now serves a number of patient communities, across a range of conditions including MS, Parkinson's, and diabetes. PLM also supports IBD patients. But given the design issues discussed above, PLM does not serve patients with chronically illness as well as it could. Because many chronic illnesses, and IBD in particular, are characterized by extreme ups (flares) and downs (remission), the design of patient communities should support these two different states.

PatientsLikeMe
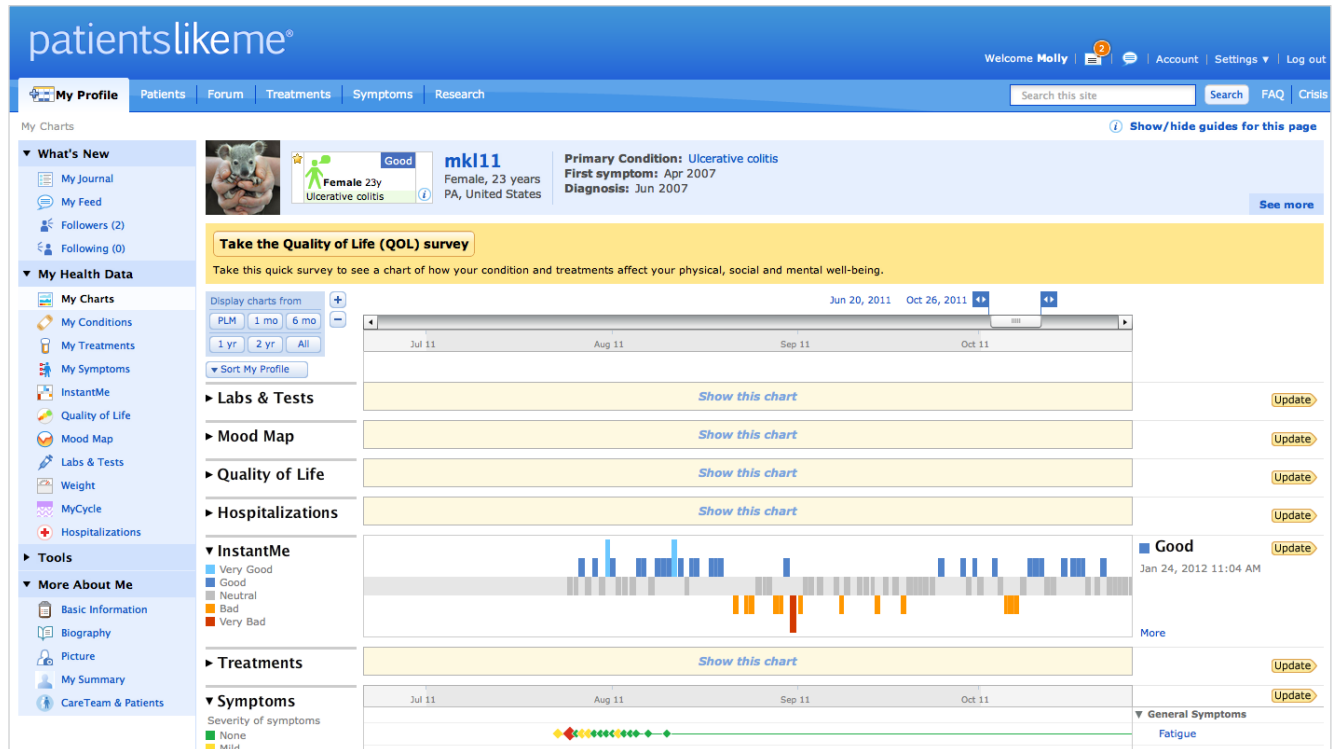
Also, despite the mission that PLM integrates data into patient conversations, the two activities remain very separate. Exploring data within a users' profile reveals a community report--an aggregation of the data-based experiences of other patients. However, I found through my interviews that patients value the one-to-one comparison with other patients that the traditional online community supports.

Indeed "integrating health data with conversations, clarifying presentation of health information, and matching of people in similar situations still remain as critical challenges in the field," according to a 2008 paper by Jeana Frost and Michael Massagli of PLM. A 2012 paper by Jina Huh & Mark Ackerman, echoing Frost and Massagli, acknowledged that finding help to uncommon and individualized problems experienced by chronically ill patients presents a great design challenge. Through extensive research with diabetes patients, the researchers summarized a number of strategies patients use, both online and in support groups, to operationalize shared knowledge and imagine future states of illness. Through the contextualization of shared information, patients are able to generate better individualized strategies.

Huh & Ackerman also suggest a number of possible design implications. By facilitating the sharing of experiences by surfacing other patients similar to themselves, patients can more easily compare strategies, potentially reducing the uncertainty associated with chronic

illness. Possible design features suggested by Huh & Ackerman include:

- Viewing of past history and future treatment plans
- Aligning patient's possible future with those who have gone through same thing
- Suggesting content relevant to one's own post
- Learning about a problem within greater context of problem solving

Through hour-long interviews with 10 IBD patients, I discovered that they, like the diabetes patients of Huh & Ackerman's study, engaged in many of the same behaviors within their online communities. Patients used the experiences of other patients to discover new treatment options and determine if they may or may not be a good fit for them.

For example, they supported their decisions by examining the data contained in other users' signatures to identify other patient likes them. However, these behaviors are not supported by the design of the current online patient communities. In fact, the threaded discussion nature of these communities has not changed much in the past decade.

Heather I give suggestions, do with them what you will.
Status: ...Asacol 3 @ 2x daily; Salofalk enema @ 3rd night (nightly/ flares, tapered/maintenance)
~diagnosed January 1989 UC (proctosigmoiditis)
~Bentylol 20mg as needed; Zantac 150mg; Pulmicort/Airomir (asthma);Effexor XR 37.5 (depression)
~vitamins/minerals/supplements; Probiotics....(RenewLife Ultimate Flora Critical Care+Primadophilus Reuteri capsules @ bedtime)
~Metamucil capsules 6 twice daily with meals; Vitamin D 4500 IU
~URSO for PBC(or PSC?) 500mg X 2 daily (LFTs back to NORMAL!!)
My doc's logic.. "TREAT (FROM)BOTH ENDS" worth it !!!

DX Pancolitis 2003. Subsequent flares limited to left side
Flare every 2-3 years.
Salofalk 12 tabs daily,
Probiotics: VSL#3DS. Fiber: Psyllium.
Allergic to Imuran

Combo antibiotic therapy got me out of a year+ long flare and into full remission! I am now completely off all steroids after being dependent for over a year.

Symptomatic remission as of May 2009
Colonoscopy in Oct. 2011 showed no inflammation
Symptoms began in Nov. 2008, about 4 weeks after birth of first child
Diagnosed with pancolitis in Jan. 2009
Apriso (Four 0.375 g pills once daily), Mesalamine enema twice weekly, multivitamin, vitamin D, probiotic
Used prednisone (starting dose 40 mg) to gain remission, tapered off easily

Patient Signatures

Design Process

How can patient-generated data and online forum behaviors merge to facilitate knowledge sharing?

An Opportunity

Through my exploratory research, I discovered that many patients with Inflammatory Bowel Disease are engaging in tracking behaviors. However these behaviors are isolated from the interactions patients have with their doctors, families, and other patients. While products like PatientsLikeMe attempt to integrate patient data into a community setting, its design does not support or encourage meaningful interaction with data to support these community behaviors.

Current State

Patient
Community

Online
Forum

Design
Opporunity

KNOWLEDGE

Doctor

◄ KNOWLEDGE ►

Patient

◄ HEALTH DATA ►

PHR

40
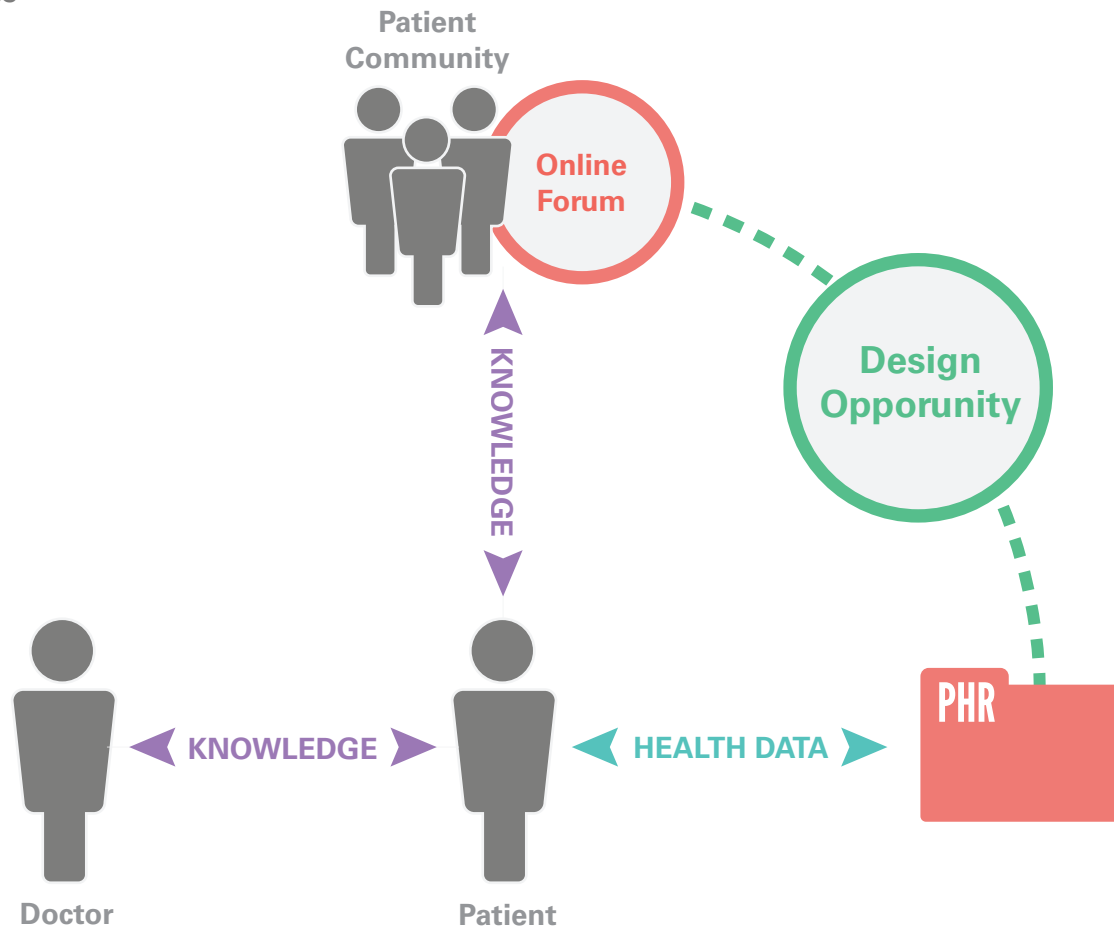
In the current state, knowledge is shared among patients and doctors, and patients and online communities, but data remains isolated within the tools and records patients are using to track. An informal sharing of data is happening among members of online communities, for example through the use of forum signatures. However, this process could be better streamlined by integrating the personal health record and online community forum.

Future State
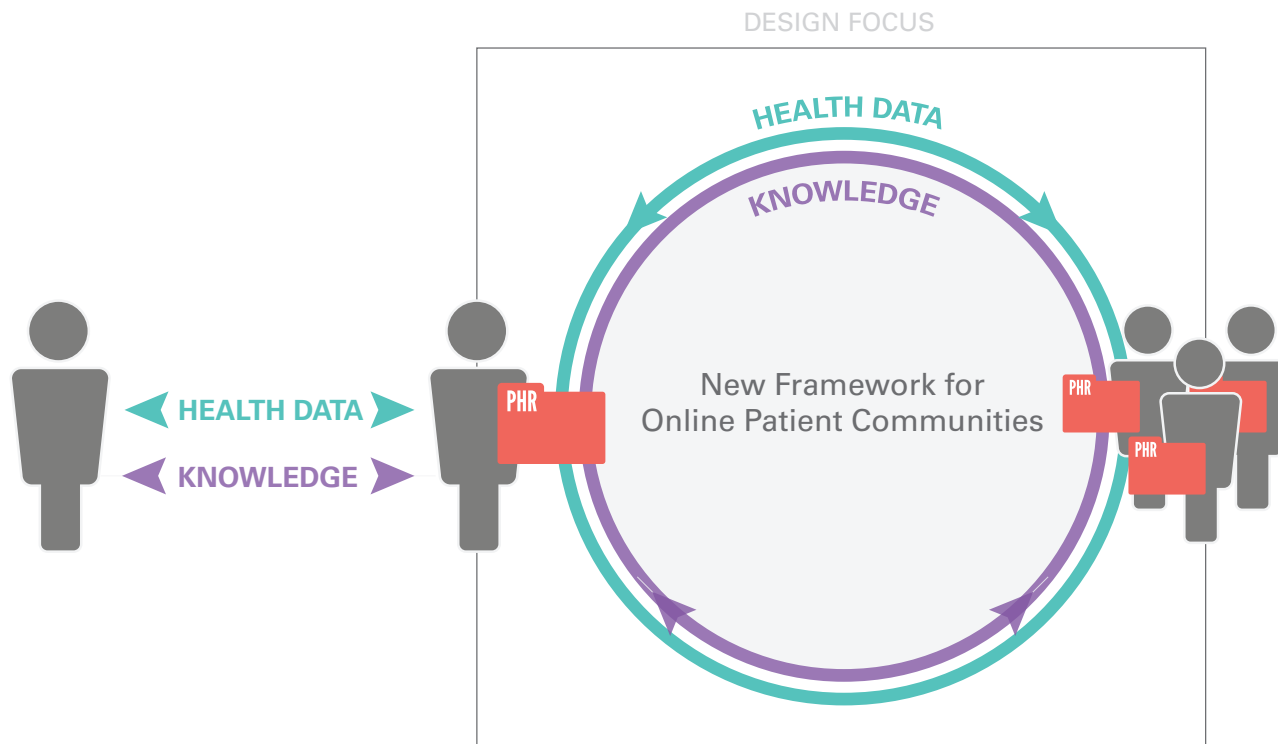
In the future state, knowledge and data sharing among patients of an online community becomes a streamlined experience. Patients continue to engage in the same behaviors, such as examining others' past illness experience, but do so in a more coherent, data-centric manner. This interaction is supported by a new model of motivation.

My research found that IBD patients value access to knowledge most highly. This need spurs their engagement in online communities. However, designers of self-tracking tools generally focus on behavioral strategies to engage and sustain user tracking behavior. The desire for access to new and actionable knowledge has not yet been leveraged in the design of these tools.

Tracking Model

Surface Knowledge

Motivate Tracking

I hypothesize that by surfacing relevant and new knowledge upon tracking a data point, users will be motivated to track more data, in turn creating more knowledge within the community.

Design Principles

I devised a set of design principles to guide the development of this new type of new tool to facilitate knowledge sharing among patients. Because I was still unsure whether such a tool would require the redesign of the PHR or of the online community, I developed a set principles for both, as guidelines for concept ideation.

Personal Health Record Principles

1 Always present data complemented by knowledge, and knowledge complemented by data.

> Existing tools, like PatientsLikeMe, keep these two things separate. Presenting them together may make information more actionable and relevant to users.

2 Show patients a visualization of their data or surface relevant knowledge when they enter a data point.

> It has been found that when users see immediate feedback when logging a data point, they will be more motivated to track again (Li, 2011).

3   Enable passive tracking for patients with minimal disease activity.

Patients most often stopped tracking when they felt better or went into remission. However, tracking during periods of remission is important for IBD patients so they can identify factors that may be contributing to their flares.

4   Allow data to be imported from a variety of sources, including personal calendars and social networks.

Some participants overlayed their data on their Google Calendar or social network to look for correlations between symptoms and stress or activity levels.

Online Patient Community Principles

1   Always present data complemented by knowledge, and knowledge complemented by data.

Existing tools, like PatientsLikeMe, keep these two things separate. Presenting them together may make information more actionable and relevant to users.

2 Automatically surface knowledge for patients, rather than patients relying on search to discover content.

Patient interviewees complained about the lack of function of their community search tools. It can be time intensive to find information that may be helpful for their situation.

3 Allow patients to isolate parts of their PHR to share with the community when sharing personal experiences.

Sharing data may help patients more effectively and efficiently tell their story and ask for help and support.

4 Provide explicit privacy controls and display clearly whether data is private or public.

While privacy concerns were not a big issue for most patients interviewed, making the controls as explicit and transparent as possible may encourage more tracking, because users are confident in knowing where their data is being shared.

Design Concepts

While I knew I wanted to address the intersection of PHRs and online communities as my design problem, many questions still remained, including:

- *Should I redesign the personal health record? The online patient community? Or create an entirely new model for online patient interaction?*
- *Which of my design principles most support patient values?*
- *What types of interactions with other patients are valued most?*

I began by using a content-centric approach, where I analyzed existing content from an online community to determine how it could be better interacted with, explored, and structured.

- *How could content be better accessed?*
- *Where are the pain points in user interactions?*
- *How can better design ease these interactions?*

Then I sketched out low-fidelity concepts that hit on one or more of my design principles, exploring the opportunities for web- and mobile-based interactions. To give my concepts context, I placed them within two different scenarios. This would help participants imagine how these ideas may support their own experience. By structuring the concepts around these scenarios, I was also able to probe patient values regarding how they manage their own care and how they view their relationship with the GI.

Meet Mary

After recent bloodwork, Mary is told she has a vitamin D deficiency. Over the phone, her GI's nurse gives Mary a prescription for 4000 units of Vitamin D and suggests she start calcium supplement. Over the next week, Mary begins feeling worse. She's irritable and her whole body hurts. What does Mary do next?

Meet Tom

Tom has been feeling really bad lately. He doesn't know what's different, but thinks his mesalamine medication may be causing problems. Tom calls his GI, who instructs him to stay on all his medications, but reduce his Canasa by 1,000mg. Despite his doctor's advice, Tom stops taking his medications. After 48 hours of no medication, he feels okay--not better, but not worse. What does Tom do next?

Scenario Storyboards

Mary shares a data story.

Screen 1:
[Fatigue ▼]
Share Data Story

Screen 2:
Share Data Story
☑ Fatigue
☐ BMs
☐ Blood
☐ Pain
[Add Other Data Type]
Add Your Story
[Share]

Screen 3:
[Medication ▼]

Medication ▲	Dosage
Vitamin D	4000 units
Calcium	60 mg
Asacol	1600mg
Canasa	1000mg

[Add Data Type]

Screen 4:
Share Data Story
☑ Fatigue
☐ BMs
☐ Blood
☐ Pain
☑ Vitamin D

I was diagnosed with a very low deficiency and it wasnt even in the charts, so I started 4000 vitamin d, but its been a week, I
[Share]

Screen 5:
How are you doing?
Let's update your data story!
[No]   [Yes]

Screen 6:
My Data Story
Following my Story
Replies
I've been taking 4000 IU too and don't

Mary shares a story.

Panel 1:
My Profile
About Me / My Data / My Stories / Settings
Mary
32 years old
Ulcerative Colitis

My Data
Timeline / Day View / Month View / Year View
Stories
[Share a Story]
Trying to get off of Pred!
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.
Crohn's and Rheumatoid Arthritis?
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Panel 2:
My Profile
Share Your Story
Timeline / Day View / Month View / Year View
Vitamin D / Fatigue
[Add Data to Story]
Vitamin D & Fatigue
I was diagnosed with a very low deficiency and it wasnt even in the charts, so I started 4000 vitamin d, but its been a week, I feel even worse - i am more irritated and my body hurts. Its frustrating, i dont expect a miracle over night, but to be worse is frustrating...Any advise please.
[Share]

Panel 3:
My Profile
Vitamin D & Fatigue
2/17/2012
Did you have any other tests done, perhaps Vitamin B? Maybe you are low in other things too. Whenever I feel poorly drinking more water perks me up but I also feel bad when constipated. You have to figure out what is making you feel bad by going down the list of possibilities.
24 years old
5 years, UC
Remicade, Folic Acid, B12, Slipper Elm Powder

Mary compares her data with others.

Panel 1:
My Profile
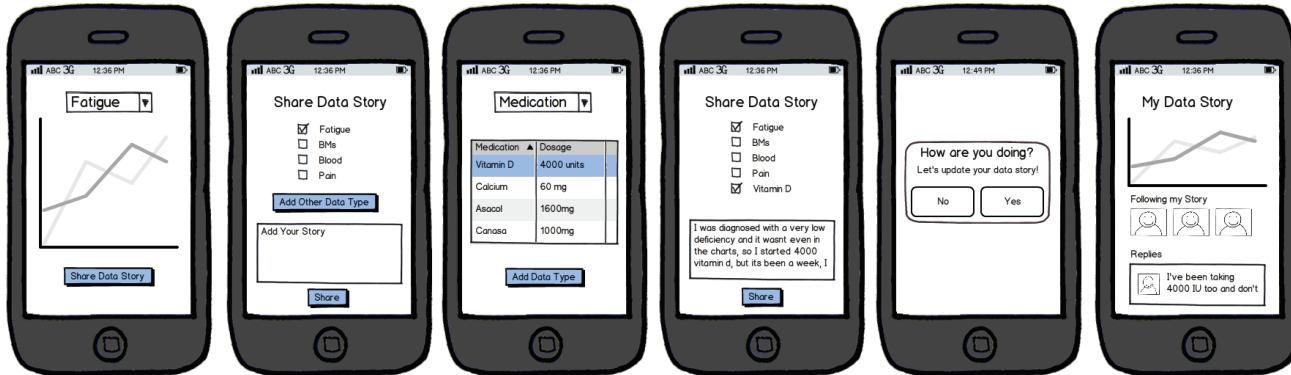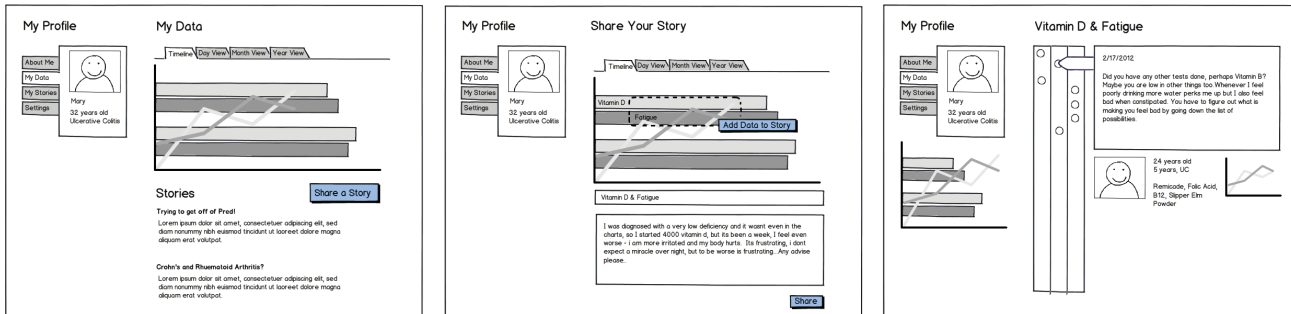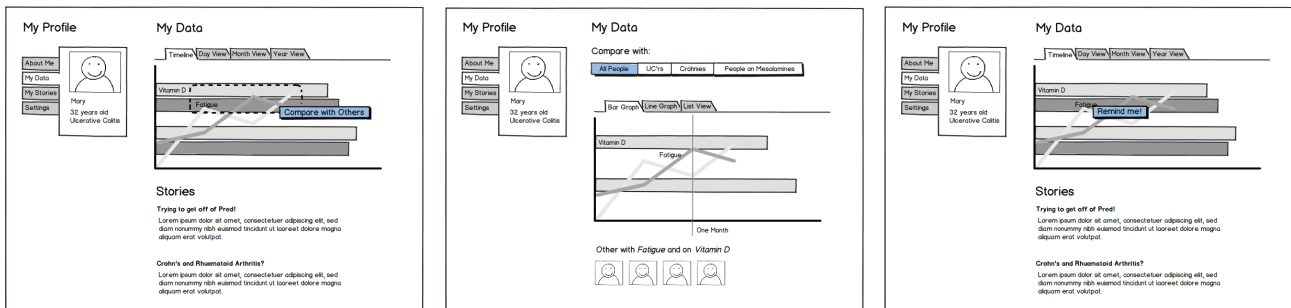About Me / My Data / My Stories / Settings
Mary
32 years old
Ulcerative Colitis
My Data
Timeline / Day View / Month View / Year View
Vitamin D
Fatigue
[Compare with Others]
Stories
Trying to get off of Pred!
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.
Crohn's and Rheumatoid Arthritis?
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Panel 2:
My Profile
About Me / My Data / My Stories / Settings
Mary
32 years old
Ulcerative Colitis
My Data
Compare with:
[All People] UC'rs / Crohnies / People on Mesalamines
Bar Graph / Line Graph / List View
Vitamin D
Fatigue
One Month
Other with *Fatigue* and on *Vitamin D*

Panel 3:
My Profile
About Me / My Data / My Stories / Settings
Mary
32 years old
Ulcerative Colitis
My Data
Timeline / Day View / Month View / Year View
Vitamin D
Fatigue
[Remind me!]
Stories
Trying to get off of Pred!
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.
Crohn's and Rheumatoid Arthritis?
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Tom shares data with his GI.

Screen 1: [Pain ▼] / [Add Reminder]

Screen 2: Data Reminders
- ☑ Pain
- ☐ BMs
- ☑ Blood
- ☑ Bloating

- ◉ Daily
- ○ Every other day
- ○ Weekly
- ○ Monthy

[Remind Me!]

Screen 3: How are you doing?
Let's update your data story!
[No] [Yes]

Screen 4: My Data
Glad to see you're feeling better!
Relevant Posts
Mesalamines not working?
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed

Screen 5: My Data
[Send Data Report to GI]

Tom discovers existing posts.

My Profile
About Me / My Data / My Stories / Settings
Tom
37 years old
Ulcerative Colitis

Make a New Post
Should I stop ALL Meds?

Earlier this week I felt so awful on 2000 mgs/day of Canasa that I decided to stop all mesalamines including my 4800 mgs/day of Asacol. My doctor, however, thinks I need to stay on everything except taking the Canasa back down...

[Share]

Relevant Posts
Mesalamines Not Working?
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Stopping Canasa
Lorem ipsum dolor sit amet, consectetuer adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Other People on *Mesalamines*

Tom creates a living post.

My Profile
About Me / My Data / My Stories / Settings
Tom
37 years old
Ulcerative Colitis

Share Your Story
Stopping ALL meds?

Earlier this week I felt so awful on 2000 mgs/day of Canasa that I decided to stop all mesalamines including my 4800 mgs/day of Asacol. My doctor, however, thinks I need to stay on everything except taking the Canasa back down...

Add Data

Symptoms	Medications	Remind me to update:
☐ BMs	☑ Asacol	◉ Once a Day
☑ Blood	☑ Canasa	○ Every Other Day
☐ Pain	☐ Vitamin D	○ Once a Week
☑ Bloating	☐ Folic Acid	○ Every Two Weeks
☐ Fatigue	☐ VSL #3	

[Share]

Phone screen 1: How are you doing?
Let's update your symptoms!
[No] [Yes]

Phone screen 2: How are you doing?
Pain
Bloating
[Log Symptoms]

My Profile
About Me / My Data / My Stories / Settings
Tom
37 years old
Ulcerative Colitis

Stopping ALL meds?
Timeline / Day View / Month View / Year View

2/16/2012
I couldn't tolerate any Sasa, besides which they never helped. How about trying:diet, probiotics, slippery elm powder, LDN?

[Slippery Elm Powder Data] [Info about Probiotics]
44 years old
10 years, UC
[People's Experiences with LDN] [Info about Diets]

Feature Speed Dating

Six different concepts were tested with five participants ranging in age and severity of their condition. I began by walking them through the scenarios and asking, "What would *you* do in this situation?" Through this conversation, earlier findings about the differing nature of patients' relationships with their doctor were confirmed. Some patients feel comfortable ignoring their doctor's orders, while others seek their doctor's advice in almost every self-management decisions.

The six concepts included seventeen different feature concepts which I then scored based on the participants response. Below is a list of the most favorably received features:

Comparing my personal data with others

Surfacing posts based on data

Tracking personal data, such as symptoms

Sharing my data with my GI

Sharing a story based on my data

Surfacing other users like me

Updating posts with data over time

Key Findings

The response to the low-fidelity concepts was overwhelmingly positive. After running through the scenarios and concepts, one participant exclaimed, "I'd get a smartphone just to use this!" Many participants acknowledged they were already trying to accomplish many of these tasks, but did not have the adequate tools to do so.

Access to knowledge is a priority for the chronically ill.

With only a few minutes per visit with their doctor the burden of education falls on the patient, so engagement often begins with searches for knowledge.

"I've been looking for something like this. With my current problems, what are my options?" - M 26

Patients learn from other's experiences.

When patients visit their doctor, they may feel like they're getting an aggregated report of what works for everyone else. But chronic illness creates individualized problems, so many patients are interested in one to one comparisons.

"I base what I do off of what they're trying, whether it works or not." - F 24

Communities are a utility to meet patient needs.

While social support remains an important aspect of online communities for many patients, others are primarily interested in discovering actionable information that can be integrated into their own care experience.

"I like the integration of this, it's more interactive than what I'm doing now." -F 20

Design Direction

Perhaps the biggest takeaway from my concept validation sessions was the notion that patients want *their* data at the heart of ***their*** interactions. My participants were less interested in features that allowed them to follow or keep tabs on others, but instead wanted access to social information in the context of their own information. I began to conceptualize a system in which the PHR is at the heart of the user interaction, acting as a dashboard to surface information.

In this model, the PHR is the heart of all user interactions. Users navigate through their own data to discover knowledge relevant to them. They can access the data in other users' PHR to help them discover new treatment strategies and envision their own possible futures. This network of PHRs comprises the patient community.

PHR-centric model

Doctor

HEALTH DATA
KNOWLEDGE

Online Patient Community

PHR

PHR

PHR

PHR
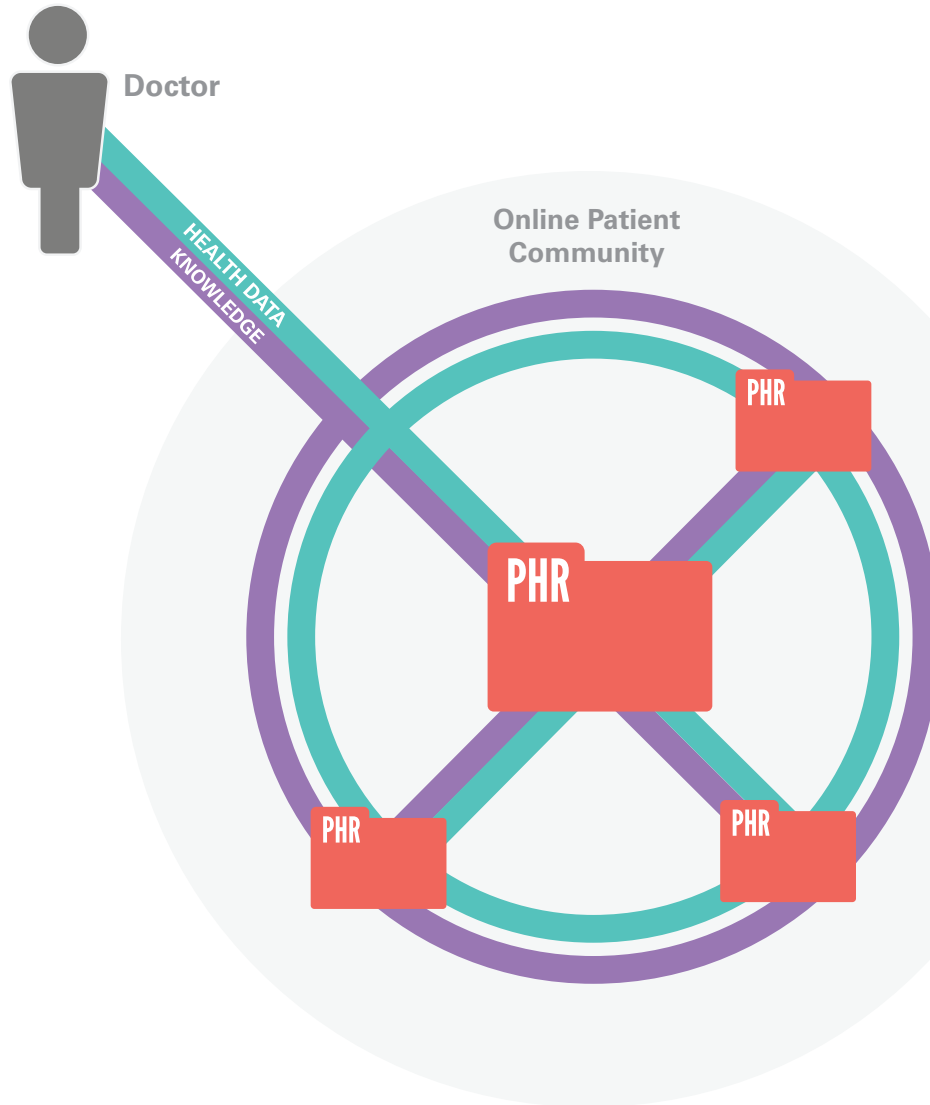
Key Functions

Support discussions with data

Surface relevant posts and people

Discover new strategies

Enable Comparison

Implications of the PHR-centric model

This model has a number of implications for many stakeholders beyond patients, including doctors, researchers, and designers.

Visible Data for Doctors
Supplementing patient narratives with patient-generated data during office visits has the potential to inform doctors' decision making and nurture the notion of partnership between patients and providers. Doctors will also experience more engaged, motivated patients.

Valuable Data for Researchers
Existing data-centric communities, such as PatientsLikeMe, anonymize patient data and sell the data to researchers for study. This model would open up a wider base of trackers and more valuable data for researchers.

A Modular Model for Designers
While the work presented here focuses on IBD, this model could extend to a number of different types of conditions. Also, given the PHR-centric nature of the model, online patient communities could be designed in such a way that PHRs could be "plugged" in to various online patient communities, surfacing relevant knowledge across different conditions based on a single PHR.

Final Design

IBConnect is an new type of patient community, placing patient data at the heart of online communities.

By navigating data within a personal health record as a means to explore online community knowledge, patients using IBConnect can manage their individualized illness experience by discovering actionable, relevant and contextualized knowledge. In turn, patients are encouraged to track and contribute more to the IBConnect community because access to new knowledge is highly valued by patients.

Your Dashboard

How are you doing?

Amy
KnitterMom
Flaring
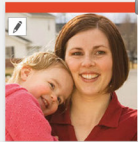
UC since 1/2009

Imuran
100mg
Vitamin D
2000 IU/Daily

Share Story　　View Treatment Plan

SYMPTOMS

3　Overall Status
8　Fatigue
7　Bloating
5　Abdominal Pain
6　Stress Level

BOWEL MOVEMENTS

Average: 3x/day

TREATMENTS

Imuran
SUPPLEMENTS
Vitamin D

Welcome back, Amy!

View: Posts　Filter: Relevant

Bad gas and bloating...cause?

I've recently switched from Salofalk (3000mg-4500mg/per day) to Asacol 2400/mg per day and Salofalk...

Read More

Prednisone tapering...

Today I went to the gym for the first time in 2months and was horrified by how I looked in the mirrors. I know...

Read More

Aloe Verra Juice

I've been doing some research on treatment and found that aloe verra juice is supposed...

Read More

View More

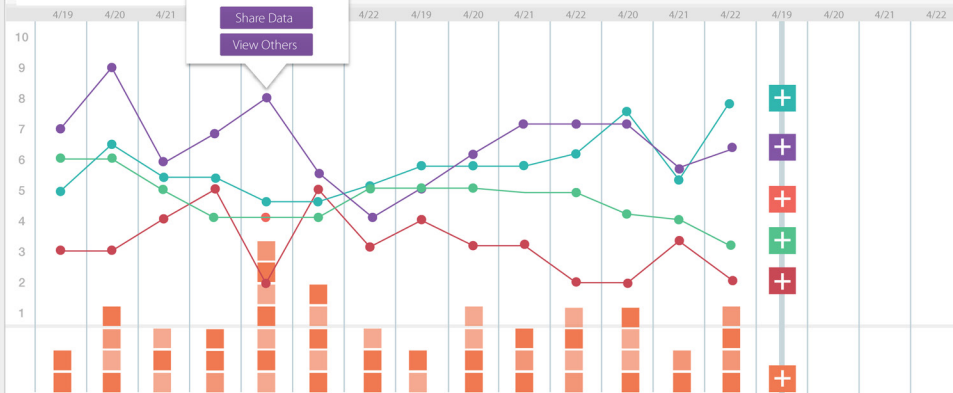View: Two Weeks

April 20
Stress: **7**
Average (since 4/1): 5.4
Share Data
View Others

4/19　4/20　4/21　　　4/19　4/20　4/21　4/22　4/19　4/20　4/21　4/22　4/20　4/21　4/22　4/19　4/20　4/21　4/22

10
9
8
7
6
5
4
3
2
1

VITAMIN D
IMURAN

Dashboard

Communicating Status

Visual badges allow patients to express their current health status, and provide a quick view of relevant data, including current medications and length of disease. These take the place of text-only signatures used in current online communities.

Visualizing Illness Experience

By tracking data about their condition, patients can make their illness experience visible. Through this visualization, patients can discover trends and patterns within their data.

Increasing Control Over Data

By controlling privacy on the dashboard, as opposed to a "Settings" page, patients can more easily and transparently control which data is public and which data is kept private.

Motivating Tracking

Patients are motivated to track because when a new data point is logged, IBConnect surfaces relevant knowledge from their community.

Logging in Context

Many tracking tools have patients log data on a screen separate from the data visualization, isolating data from its context. Here, data points are logged on the graph so patients can log each new point in context of the previous point, encouraging more consistent tracking.

IBCONNECT

MY HEALTH   SUPPORT

Hi, Amy! ▾

Back to Dashboard

Browse People

View: People ▾   Filter ▾   Imuran ●   In Remission ●   Showing **5** of **78 people** ›

Amy [Flaring]
KnitterMom
UC since 1/2009
Imuran   Vitamin D
100mg   2000 IU/day

| Diagnosed | 2010 | 2011 | 2012 | Joined |

VITAMIN D
IMURAN
ASACOL
COZACOL

Joyce [Remission]
Joyce34
UC since 3/2004
Imuran   Gluten-Free
100mg   Since 2009

2004 | First Symptoms | 2007 | 2011 | 2012 | Joined
Diagnosed

IMURAN
COLAZAL
ASACOL   PENTASA

View Profile   Follow Steven

Steven [Remission]
STJ163
UC since 2001

Remicade
Since 2/2001

2001 | First Symptoms | 2008 | 2011 | Joined | 2012
Diagnosed

GLUTEN-FREE
REMICADE
IMURAN
PREDNISONE
ASACOL   LIALDA

Sandra [Remission]
SWalt
UC since 2007
Imuran   Apriso
75mg   3.75mg

2007 | Diagnosed | 2009 | 2011 | Joined | 2012

COLAZAL
LIALDA
APRISO

62

Browsing Other Users

Visualizing Illness Trajectories

> Through the use of "illness timelines" users can quickly compare their illness progression with others and imagine possible futures based on the experiences of others.

Discovering new options

> Within illness timelines and profile, treatment options that a user hasn't tried are highlighting, to facilitate the discovery of alternate options.

MY HEALTH

SUPPORT

Hi, Amy! ⌄

Side Effect Support

April 15th, 2012

Amy `Flaring`
KnitterMom
UC since 1/2009

Imuran   Vitamin D
100mg   2000 UI/daily

Kat `Remission`
PhoenixKL
UC since 2005

Imuran   Asacol
100mg   12 pills/day

[View Profile]   [Send Message]

Jeremy `Flaring`
STJ163
UC since 2/09

Imuran   High Fiber

Imuran and Fatigue?   `Imuran` `side effects` `fatigue`

I started **Imuran** about **8 weeks ago**. I'm still building up my dose but I'm currently at **100 mg** and I'm just feeling yucky.

I'm **not really flaring** (just mucuous and stuff) but I have been feeling so fatigued. Kind of lethargic. I wouldn't even say sleepy because I'm not sleeping all that great but I could just lay around all day.

I hate to want to quit this med because I think it may be helping me but I'm in my last semester of nursing school and can not afford to be sick or tired!

Any advice on how to kick the fatigue or feel better? Thanks for all your help!

[Reply to Kat]

View: 2/20 - Today ⌄   ● Fatigue   ● Overall Status

March 7th
Started Imuran

IMURAN
ASACOL
VITAMIN D

Sort by: Newest ⌄

April 15th, 2012

I too am retrying imuran. I am so fatigued all the time. It helped a little when i started taking the imuran at night. Before i took it about 11 am and by 2 i could hardly move. Now I am still just unable to do my usual. I have no suggestions, sorry, but am interested if

[Reply to Jeremy]

Browsing Posts

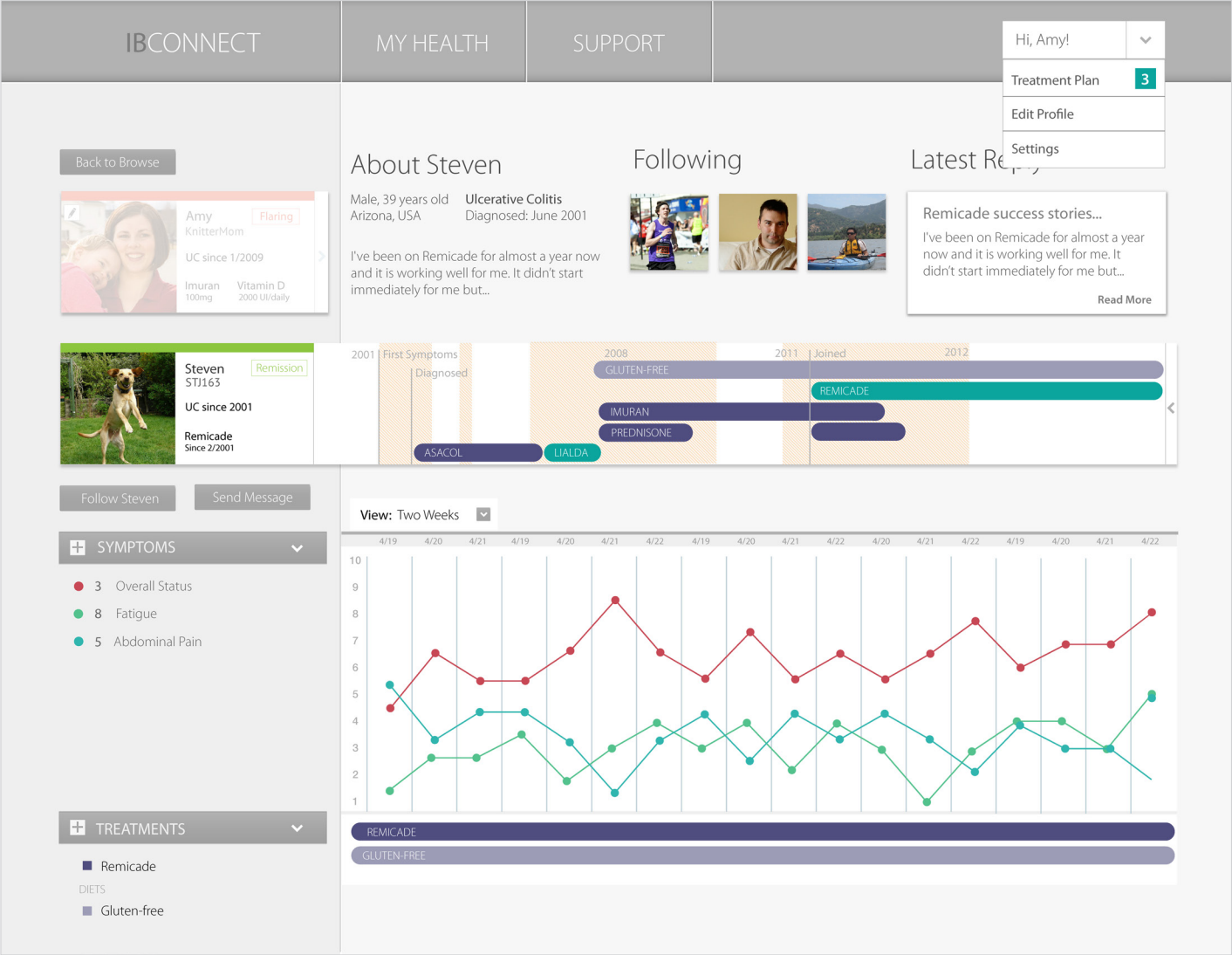*Utilizing Similar Experiences*

By exploring other patient experiences, users can discover new management strategies, learn more about their condition, and learn to cope with illness-related challenges.

Data-centric Discussions

In IBConnect, patient discussions are centered data. When users share data as part of their story, the data continues to be updated over time.

Encouraging Resolution

One challenge within online communities is that once a user finds an adequate answer to their question, they don't often return to report on the effectiveness of that answer. By continuously tracking data, these resolutions can be communicated, even within threads that are no longer active.

MY HEALTH

SUPPORT

Hi, Amy!

Treatment Plan **3**

Edit Profile

Settings

Back to Browse

Amy — Flaring
KnitterMom

UC since 1/2009

Imuran — Vitamin D
100mg — 2000 UI/daily

About Steven

Male, 39 years old — Ulcerative Colitis
Arizona, USA — Diagnosed: June 2001

I've been on Remicade for almost a year now
and it is working well for me. It didn't start
immediately for me but...

Following

Latest Reply

Remicade success stories...

I've been on Remicade for almost a year
now and it is working well for me. It
didn't start immediately for me but...

Read More

Steven — Remission
STJ163

UC since 2001

Remicade
Since 2/2001

2001 | First Symptoms
Diagnosed

2008

GLUTEN-FREE

2011 | Joined

2012

REMICADE

IMURAN

PREDNISONE

ASACOL

LIALDA

Follow Steven — Send Message

View: Two Weeks

SYMPTOMS

- 3 Overall Status
- 8 Fatigue
- 5 Abdominal Pain

10
9
8
7
6
5
4
3
2
1

4/19 4/20 4/21 4/22 4/19 4/20 4/21 4/22 4/19 4/20 4/21 4/22 4/19 4/20 4/21 4/22

REMICADE

GLUTEN-FREE

TREATMENTS

- Remicade

DIETS

- Gluten-free

Comparing Data

Diving into data

Users can closely explore others' data to discover individual experiences with various treatments and approaches. For example, users can see how long it took for a certain medication to take effect.

Discussing with their doctor

As patients discover alternate treatment options, these can be stored in a treatment plan, which allows patients to keep a record of strategies they'd like to discuss at their next visit and perhaps explore further.

Design Implications

The key to improving the illness experience of patients is to encourage them to become informed, active participants in their health. Given the confluence of developing technologies, changing economic incentives, and shifting notions of the role of the patient, designers interested in healthcare should focus their efforts on tools to support patient values, empowering them through access to knowledge and support.

IBConnect, as a model, has the potential to transform the way patients interact online. By conceptualizing the PHR as the center of the patient community experience, IBConnect changes the way people think about both their personal health data collection and their interaction with other patients. It also has the potential to transform the patient-provider relationship.

Impact on Patients

Through my research, I discovered that patients value the knowledge they receive from other patients, particularly if that knowledge is actionable and relevant. iBConnect is a patient-centered tool designed to support patient values, rather than support the values of the healthcare system and its providers. Tools that support values, in turn, empower patients to become more engaged agents in their healthcare experience.

With IBConnect, patients can:

- Track data to understand their own illness experience
- Discover actionable, relevant information to help support their illness experience
- Connect with other patients in a novel, meaningful way that would not be possible without technology

Impact on Healthcare Providers & Organizations

The role of the healthcare provider is evolving rapidly. As we seek to address the grave issues facing our healthcare system, including high costs and the increasing incidences of preventable diseases, doctors are becoming more focused more on prevention. Rather than treating sickness, doctors are focusing on wellness.

While IBConnect specifically targets a non-preventable disease, tools that help patients help themselves will ultimately help doctors as well. Tracking transparent data about their condition with IBConnect will empower IBD patients to identify when their condition is worsening, and seek help before their condition turns serious.

With patients who use IBConnect, doctors can:

- Have more productive and efficient office visits
- Engage with more knowledgeable, motivated patients
- Make more informed treatment decisions based on data

Conclusion

The time to begin engaging patients in the management of the health experience is now. Given the confluence of consumer tracking technologies and online patient engagement, designers are well poised to contribute great innovations to this area. Through my thesis work, I created a model which can serve any number of patient communities and inform the design of future patient-centered management technologies.

However, the work is far from done. Throughout my process, I uncovered a number of issues that I unfortunately did not have the time to address. These include:

The Role of the Doctor

How will patient-generated data transform the relationship between patient and providers?

One of the biggest challenges in designing these types of tools is integrating the healthcare provider in a productive manner. While I chose specifically to focus on patient-to-patient interactions, the patient-provider interaction deserves the focus of another thesis project.

The Role of the Caregiver

Similarly, how can we empower and engage the caregiver through the use of patient-centered tools?

There are opportunities for caregivers to both leverage patient-generated data, as well as create data of their own to help support their role as a caregiver.

Opportunities for Economic Impact

How can patient-centered tools help lower healthcare costs?

Supporting patients in their own self-management reduce the burden of management on healthcare providers and organizations. While our current healthcare system incentivizes doctors and hospitals to treat sick patients, these financial structures are changing, and will soon encourage the healthcare system to keep patients well.

Encouraging content creation

How can we facilitate sharing of stories so content doesn't become stagnant over time?

If patients are only tracking data to surface knowledge, we run the risk of implicitly discouraging users from creating new knowledge and sharing new stories.

The Evolving Role of Mobile

How can patients engage with a community on their mobile devices? What is the role of tablet technologies in the management of chronic illness?

Mobile technologies are the key to encouraging user tracking behavior. However, the role of mobile technologies is continually changing. As mobile devices become the center of people's interactions with technology, more experiences may move away from the desktop.

Developing a Modular Model

How can the PHR-centered model apply to other conditions?

It was important to focus my work on a specific disease so that I could deliver a solution that adequately meets their needs. However, I am hoping that this model could be extended to other ICIs and long-term conditions. This work presents a new model for the design of online patient communities. In this model, the PHR could become a modular piece, plugged into various online communities to surface knowledge, since chronic illnesses come together.

Learnings on Design

While I've learned much about design, healthcare, and the challenges and opportunities presented when tackling both, perhaps the biggest takeaway has been a renewed respect for the power of the human-centered design process. Because I chose to tackle a thesis I am personally passionate about and invested in, and of which I am the ideal user, I at times worried I didn't quite respect the "you are not your user" mantra. However, the project could not have possibly become what it did without the engagement of other patients. While my own struggles with IBD enabled me to relate to and engage my participants on a very intimate level, their experiences and insights, shaped by my designerly intuition, ultimately drove the project forward.

Acknowledgments

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