BACKGROUND

The United States spent over $2.2 trillion on healthcare in 2007. (Centers for Medicare and Medicaid Services, 2009) Of this sum, chronic illnesses accounted for over 75% of total spending. (Chronic Disease Overview, 2009) Yet, if more hospitals and doctors’ offices adopted Health IT, the potential efficiency savings could average over $77 billion per year. (RAND Health)

As a chronic illness characterized by progressive and destructive inflammation of the digestive system, Inflammatory Bowel Disease (also known as Crohn’s and Ulcerative Colitis) together affect 1.6 million citizens in the US at a cost of $15 billion a year. (Kappleman, 2009) Current treatment strategies are inadequate (Sandborn, 2002), and finding the appropriate therapy for a patient is complicated by a high variance in the nature of the disease across the affected populace.

Thus, central to the dilemma of providing efficient chronic care is the fact that a chronic patient lives with their condition 24 hours a day, through out the year. However this patient will only see their provider for minutes a year, usually on a quarterly basis.

As we approached this problem, we began by conducting both information and experience intensive ethnographies of a typical clinical interaction at the UCSF Mt. Zion Gastroenterology Practice. After formally mapping an existing process, we identified potentially inefficient touch points and produced a “to be” blueprint, informing the design of a prototype personal health application, “Crohnology.MD”

ETHNOGRAPHY

The following sections will provide a detailed perspective of how patients and providers currently collaborate before, during and after clinical appointments as mapped in Figure 1.

![Typical Process Flow Diagram](https://example.com/image.png)

Figure 1. Information process flow of a clinic appointment at UCSF Mt. Zion
I. KEEPING RECORDS

Between clinical appointments, patients experience a variety of symptoms such as abdominal pain and distention, anemia related fatigue, fever, diarrhea, blood loss, low appetite, nausea, vomiting and depression.

Among the 24 Crohn’s patients we surveyed, a majority reported relying on their memory to describe symptoms occurring between appointments. However, a small subset of patients kept ad-hoc journals or spreadsheets in which they recorded their observations. Notably, several younger patients reported posting information about their condition to social networks such as Twitter or Facebook.

II. CONTACTING THE PHYSICIAN BETWEEN VISITS

At UCSF Mt. Zion, IBD patients are in fact able to interact with their physician between scheduled appointments. These patients routinely email their provider when experiencing new symptoms.

In interviews with the Chief of Gastroenterology, the physician reported replying to patients from his mobile phone in between procedures, clinic and rounds. Yet, when responding to patient emails from his mobile phone, our physician does not have easy access to the hospital’s electronic medical records. Thus, these mobile replies are frequently requests back to the patient seeking to quickly clarify relevant information such as their current medications and dosages, so long as this information is well known to the patient.

III. IN-CLINIC INTERACTION

After the patient checks in, their weight is recorded, and noted in a paper chart. Next, a nurse or Intern performs a physical exam, takes vital signs, and interviews the patient for presenting symptoms and recent medical history. Typically, there is a new intern every time. The patient typically presents his or her symptoms verbally to the intern using a mixture of colloquial and loosely defined medical terminology. With the majority of patients in our sample reporting information on an ad-hoc basis or from memory, this touch point presents a challenge to the efficient transfer of accurate clinical data.

After the interview, the intern verbally presents written notes from the initial exam to the doctor. This additional touch point presents another challenge to the efficient and accurate transfer of clinical data.

IV. PRESCRIPTION

After the physician has reviewed the case with the intern, he enters the exam room and consults with the patient for approximately 3-5 minutes. As the physician does not conduct a complete interview, he relies primarily on the information furnished by the intern. During a brief consultation with the patient, the physician suggests adjustments and alternatives to current therapy based on the patient’s subjective description of various unresolved symptoms.

Given a modest amount of objective clinical data in combination with limited resources to obtain more relevant and granular patient reported data, the physician lacks a complete clinical portrait of how the patient has felt since the last visit. Thus, costly decisions must be made quickly with what limited information is available.
We employed a service blueprint to model the existing patient-provider clinical exchange, as we found it to be an effective tool for understanding the consumer (in this case the patient) context.

**THE PROCESS AS-IS**

After directly observing a clinical appointment at the UCSF Mt. Zion Gastroenterology Practice, we were able to study the clinical information flow between an IBD patient and his provider team. We then mapped this interaction using the 5 dimensions in the service-blueprinting model.

![Figure 2: As-is Service Blueprint](image)

We highlighted the “gaps” in the service experience and identified potential improvements to the process:

![Figure 3: Targeted improvements in the current process.](image)
THE PROCESS TO-BE

The proposed service is blueprinted as follows. Very briefly, the process can be explained thus:

1. The Patient steps on a Bluetooth connected weight scale.
2. A Body Mass Index is displayed and graphed on the mobile phone, as the data is uploaded to the RWJ Common Platform. (an open source personal health application platform)
3. After capturing the BMI, the mobile phone prompts the patient with a standard 5-question survey of their current health status.
4. Upon completion of the survey, the mobile phone presents the patient with a dashboard, displaying information on lab results and medication history combined with a list of recent symptoms.
5. When the patient fills a new prescription at the pharmacy, detailed records are automatically uploaded to Google Health, and forwarded to the Common Platform for visualization in the dashboard.
6. When the patient has new Labs drawn, results are also automatically forwarded from the Lab to Google Health, and into the Common Platform for visualization in the dashboard as well.
7. In addition, if a patient chooses to, they can report symptoms via Twitter. Tweets create a tag cloud of frequently mentioned symptoms, providing a handy list of open issues in the dashboard, for future discussion with the provider.
8. With a complete Crohnology, the patient can now easily communicate accurate information on medication history, lab results and current symptoms. It’s also possible to spot relationships between objective clinical trends and subjective patient experiences, a task made easier by the dashboard’s single touch point display.

Figure 4: Full Service Blueprint
The result is a more accurate and well-rounded portrait of the patient’s current health status, acquired as passively as possible by the patient, and constantly updated for proactive presentation to the provider.

THE BACKSTAGE CONTEXT

An overview of the backstage process is presented more clearly in the Information Architecture diagram. The following artifact represents a high level view of where data is stored along the path from capture to visualization within the multiple contexts of the Crohnology.MD service system.

Information Architecture

![Diagram showing the backstage context of Crohnology.MD](image)

Figure 5: The Backstage Context

PROTOTYPES

Each feature in the Crohnology.MD prototype evolved through a traceable lineage back to the context sensitive needs of users. From our information and experience intensive ethnographies we derived a variety of service blueprints, a set of crucial early artifacts that informed a comprehensive list of functional requirements. Our final prototype reflects this evolutionary arc, from ethnographic observation, to service blueprints, prioritized requirements, and the final set of features depicted below.
In our prototype, we sought to synthesize a solution from previously identified constraints, focusing on what would make the most difference to the outcome of a short clinical encounter. This led to the creation of a single view presenting both objective and subjective clinical data types. In the process as-is, information on patient clinical values such as hemoglobin, weight, current medications, and symptoms were viewed in separate contexts reflecting the siloed nature of their separate storage mediums. In our prototype clinical common frame, information that is most important to patient and physician can be quickly interpreted and actively discussed in the course of a short conversation.

To create a highly consumable presentation of patient data, we merged the patient’s symptoms and clinical data into a single screen, highlighting the interaction of normally separate data relationships on a unified timeline. In this demonstration of real patient data from one of our authors, we can see that the patient displayed is in the process ‘crashing’: a plummeting weight and hemoglobin level persists, despite a potent armada of therapies for Crohn’s and Anemia.

However, we can also tell that when the experimental therapy for Hookworm was terminated, the trend finally leveled out, strongly suggesting the possibility that this clinical action in conjunction with the blood transfusion may have ended the freefall.

This ability to visually enhance the 15 minute clinic visit with a crisp and accurate visualization of this ‘patient narrative’ may increase the efficiency and future outcomes of these short clinical exchanges. Patients can more easily convey their experience with more nuance and detail, while providers can more easily absorb the information to take swift action, leading to better outcomes. Also, with the potential for a provider to be proactively alerted to dramatic drops in patient status, important clinical decisions can be made in advance of a rapid decline leading to a potentially avoidable hospitalization.
In addition, individual Tweets can be aggregated by category in ‘Top Tagged Symptoms’, generating a ready-made list of specific patient concerns to be discussed with a provider. For additional context, the provider can drill down to reveal more about the individual tweets in a given category.

Figure 7: Prototype Interface for Mobile Data Capture

With this prototype data capture interface on a mobile phone, patients can leverage a multi-touch display to reduce the number of movements required for the capture symptom data. In this example, should a Crohn’s patient report high energy, as well as high pain, it’s possible that their disease is in a difficult to diagnose stage. Characterized by little to no inflammation, obstructive symptoms may require surgery. By facilitating this level of granular data capture, patients and providers are afforded new opportunities to escalate therapies more quickly based on information more reliable than just patient recall alone.

CONCLUSION

A significant amount of time had been invested in this project before applying a more methodical approach. Following a systematic, traceable approach to design strengthened some previous findings, but also revealed several surprising facts. The ethnography gave us an insight into the patient psyche – and we realized that having a tool that assists patients in capturing data is not enough. For the tool to be truly successful, it needs to both provide a visual incentive, and reduce the overhead of capturing data. Another key objective of the tool was empowering the patient with his own data. Inflammatory Bowel Disease is very different in how it affects each patient, and hence there is a lack of normative, objective measures. Therefore, utilizing subjective patient data (in the form of twitter updates) and condensing it into topic spaces that effectively describe the patient’s physical state via both objective and subjective measures, we found we could address the pain points of both patients and providers alike.

Future work on this project has been funded by a grant from the Robert Wood Johnson Foundation. In collaboration with the faculty and students of the University of California, Berkeley and the UCSF Mt. Zion
Center for IBD Research, we hope to further refine our design before a final implementation and evaluation within a cohort of 40 Crohn’s patients at UCSF Mt. Zion over the course of the next 24 months.

**WORKS CITED**


