



Hyoumanity™

Social Search and Incentive Alignment in Health Care

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Abstract

We present the design of a web-based platform that facilitates diagnosis via the aggregation and augmentation of extant personal health records. Our platform intends to align the incentives of the diagnostic process with the stakeholders most invested in each stage of healthcare – the clinician is rewarded for finding patients they can help, while the patient is rewarded for good stewardship of their medical information. We describe a data model that leverages existing standards for communication, indexing, and storage of health-related data in a sustainable manner and an interface that conforms to user-centered design principles and best practices in accessibility, information retrieval, and usability.

The Problem

The US National Institutes of Health (NIH) estimate that 7,000 rare diseases cumulatively affect as many as 30 million Americans.¹ A study by the National Organization for Rare Diseases (NORD) found that of these patients, 36% took more than one year following their first doctor visit to receive a diagnosis, while 17% took more than six years to get diagnosed.² At the same time, it is not only individuals with rare diseases who face complex and prolonged diagnostic challenges. A number of more common conditions, such as cancer, type 2 diabetes, multiple sclerosis, hepatitis, lupus, polycystic ovary syndrome, and many other conditions frequently go undiagnosed or misdiagnosed for a prolonged period of time. Because diagnosis is the basis for all subsequent healthcare decisions, the absence of a timely and accurate diagnosis is the limiting factor that prevents patients from pursuing effective treatment.

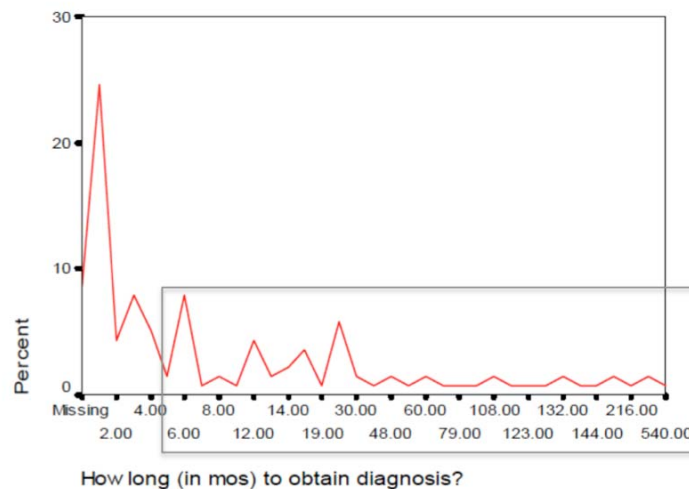


Figure 1: The Long Tail of Diagnosis.³

Several factors contribute to this pervasive problem. A significant factor is complexity – there are over one million permutations of diseases, syndromes, and disorders that afflict humans,⁴ each containing a distinct symptom profile. To further complicate matters, many of these conditions frequently present in a misleading and ambiguous manner, requiring significant specialization and experience to effectively diagnose.

Another is structural. Physicians average twelve minutes per consultation⁵ and are not compensated for additional research time. There are financial disincentives to taking on difficult cases and to spending time to help a patient find a solution. Doctors instead refer these patients to other specialists. However, these referrals are often determined by professional or personal relationships and are limited to a local network rather than careful consideration of matching a patient with the best possible provider. The direct result of these challenges is that a large number of patients remain undiagnosed for an extended period of time.

¹ <http://rarediseases.info.nih.gov/Resources.aspx?PageID=1>

² http://www.rarediseases.org/pdf/Eval_Final_Paper.pdf

³ Marlene G. Krammer, *The National Organization of Rare Disorders and the Experiences of the Rare Disorder Community*, 2003 (available at www.rarediseases.org)

⁴ ICD-10 (These are known conditions. Hypotheses suggest the true number may be in the hundreds of millions.)

⁵ Hutzschenreuter, Anke. *Waiting Patiently: An analysis of the performance aspects of outpatient scheduling in health care institutes.* <http://www.vumc.nl/afdelingen-themas/239911/27797/379816/Hutzschenreuter.pdf>

The implications of this are substantial in both economic and human terms. Unable to find answers, patients continue to see doctor after doctor in hopes that one of them will have a breakthrough insight into their case. For some patients, this can lead to significant out-of-pocket expense for the patient as well as substantial costs to the patient's health insurer. Delayed diagnosis also results in delayed treatment and more advanced disease, leading to worse health outcomes and higher long-term costs. Additional costs include lost productivity for the patient and their family caregivers and draws on public programs such as Social Security disability benefits. Less quantifiable but no less important, patients facing a prolonged period of nondiagnosis or misdiagnosis may experience severe physical, psychological, and emotional pain and suffering.

Our Solution

Given the highly fragmented nature of medical knowledge, resolving many of these cases of difficult diagnosis essentially becomes a matching problem in which a patient with a specific condition must find a clinician with the right expertise to recognize and diagnose it. Under the current structure of the healthcare delivery system, patients lack the required information and resources to complete this search efficiently and effectively, while physicians lack the tools and incentives to independently locate patients to whom their expertise might be most valuable.

We posit that using technology to facilitate the appropriate patient-to-provider match holds the potential to solve many of these difficult cases. Our model is as follows:



1. Patients post a structured case profile on the Hyoumanity online marketplace, including their medical records and a narrative qualifying their illness.
2. Patients offer a cash award for information leading to a correct diagnosis
3. Clinicians register, verifying their licensure, then search and review targeted cases pertinent to their expertise.
4. Clinicians offer suggested diagnoses that may not have been considered or adequately explored, including rationale and guidance for confirming diagnosis.
5. Suggested diagnoses are reviewed for quality control and then released to patients.
6. Patients will explore suggested diagnoses face-to-face with their local doctor, maintaining the traditional doctor-patient relationship.
7. When a correct diagnosis is secured, the promised payment will be released to the doctor who suggested the diagnosis via Hyoumanity, with Hyoumanity retaining a commission.

Despite doctors having all of the relevant information, patients are the ones who are normally forced to undertake the search for the correct provider and a diagnosis. Hyoumanity intends to this search around, providing doctors both the mechanism and incentive to find the patients who they can help.

User Experience

The potential patient audience for Hyoumanity is substantial. In our survey of patients, nearly every

respondent said they would participate, and 30% indicated that they would offer an award in excess of \$100,000 for a diagnosis and an additional 20% said they would offer at least \$10,000.

Attracting a physician audience is more challenging. There are over 900,000 physicians in the U.S., with over 60% focused on a specialty or subspecialty.⁶ Sermo and Medscape Physician Connect, the leading physician social networks, each have approximately 100,000 registered physicians⁷, indicating a high level of active Internet use among physicians. 33% of physicians surveyed by Hyoumanity (n=15) responded that they would be “Somewhat likely” or “Extremely likely” to use the service. Additionally, 58% of physicians surveyed feel that diagnosis can be assisted remotely either “In some cases” or “In many cases”. 80% of these physicians also indicated that a reward of \$5,000 or less for a successful diagnosis would be sufficient for them to spend 30-60 minutes evaluating a case targeted to their specialty.⁸

Dr. Elise Singer commented, “More and more doctors are using web-based tools. If designed well, I think the chance to publicly solve real-time medical mysteries, while simultaneously helping people, could attract many physicians.” Our user experience evolved from these first physician meetings – our belief is that with an appropriately constructed environment, a significant number of clinicians will participate in Hyoumanity, creating a vibrant diagnostic marketplace.

Design Objectives

Based on the findings from the initial user survey and our user needs assessment, we identified the following user objectives for our two primary user groups (patients and clinicians) to guide us in designing the site.

Patients:

- Be able to input and update medical information easily
- Be able to present the complete case with all relevant information
- Be able to find a clinician with the right expertise
- Be able to communicate directly with clinicians
- Be able to receive diagnosis in a timely fashion

Doctors:

- Be able to find cases that are relevant
- Be able to interpret the case easily
- Be able to communicate directly to patients for additional information
- Be able to exchange opinions and gain prestige within the clinician user community
- Be able to collect payment

⁶ American Medical Association, Physician Characteristics and Distribution in the US, 2007

⁷ Manhattan Research, Taking the Pulse v8.0

⁸ See Appendices.

Interaction Design

Since the objectives of our patient and clinician users are quite different, we designed the site with two separate sets of functionality to better meet their needs. We believe our users will come to Hyoumanity with one of two primary reasons in mind: either they are looking for a diagnosis (patient) or they are looking for cases to which they might apply their medical expertise (clinician). As these two purposes will lead to completely different courses of action, we direct the first-time users to self-identify their roles right at the home page and send them down two different workflows. Upon logging in, returning users will be taken to the appropriate version of My Hyoumanity; in doing so, we enable them to access relevant information tailored to their role with a minimum of extraneous information or wasted clicks.

The following figures demonstrate the structure and typical flow between facets of the site. Each object represents a page or a function. Beige shapes represent pages with static content that might also serve as gateways to other functions. Gray shapes represent pages that require user input. Red shapes represent pages that not only require user input but also include triggers to some manner of user off-site notification, such as an email sent to a patient alerting him or her of a possible diagnosis.

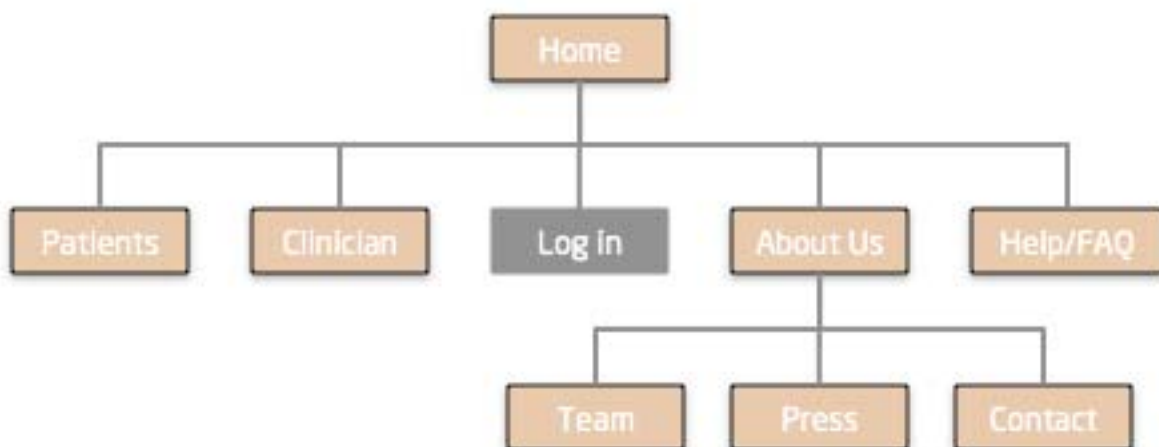


Figure 2: Static Content Navigation

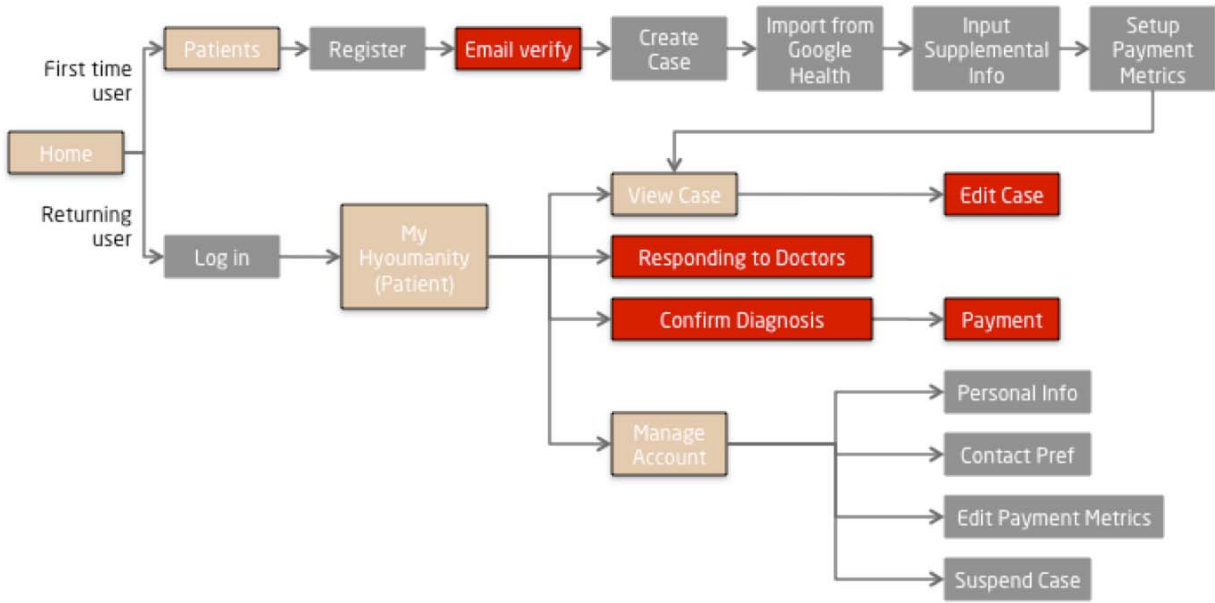


Figure 3: Patient Navigation

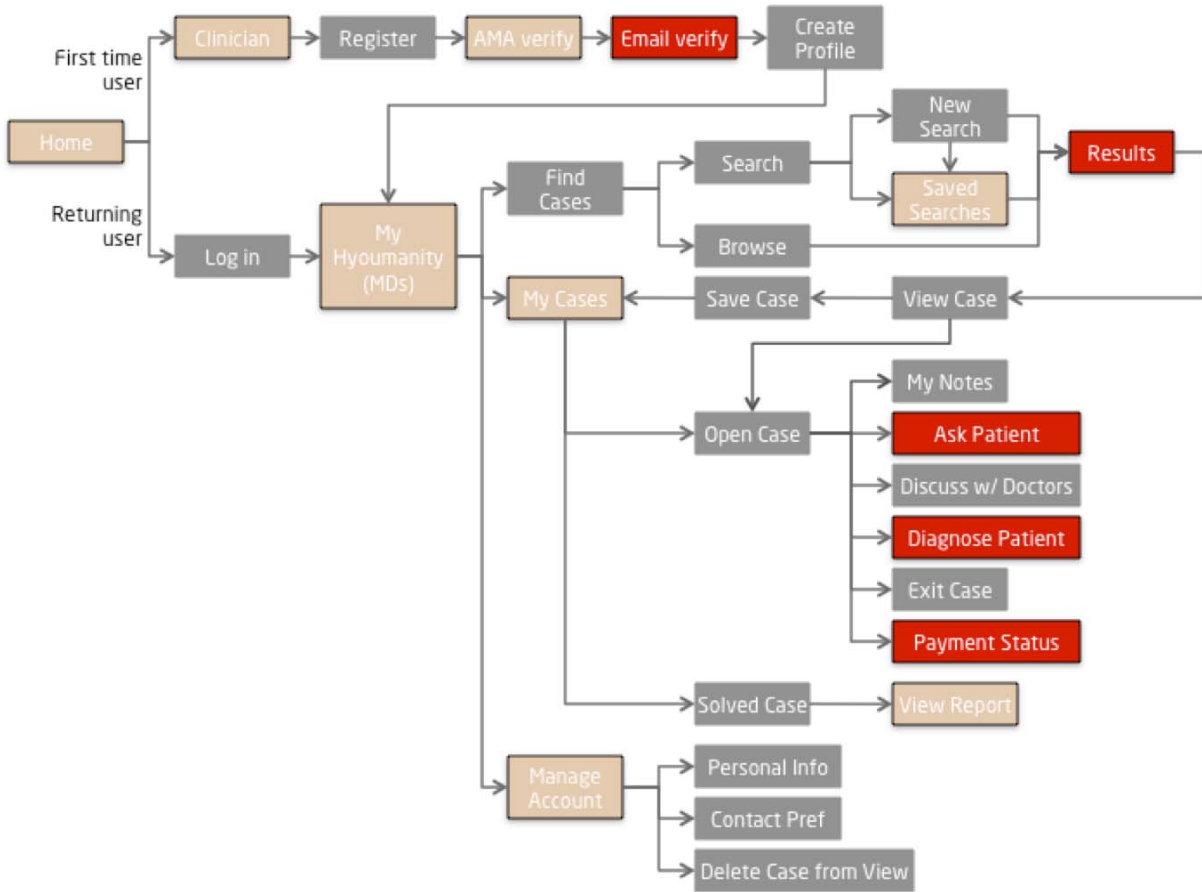


Figure 4: Clinician Navigation

Patients

Hyoumanity allows each patient to create a case. During our initial exploration of the domain, we recognized the work that had been done with existing technology towards developing personal health record systems. Among the services we considered, we found Google Health met our expectations in both depth and breadth of information and ease-of-development. Google Health acts as the interface and platform in which all our patients store their basic medical records. As a team, we determined data crucial to diagnosis that was missing from the Google Health data model, and created a supplementary layer to flesh out patient medical histories.⁹

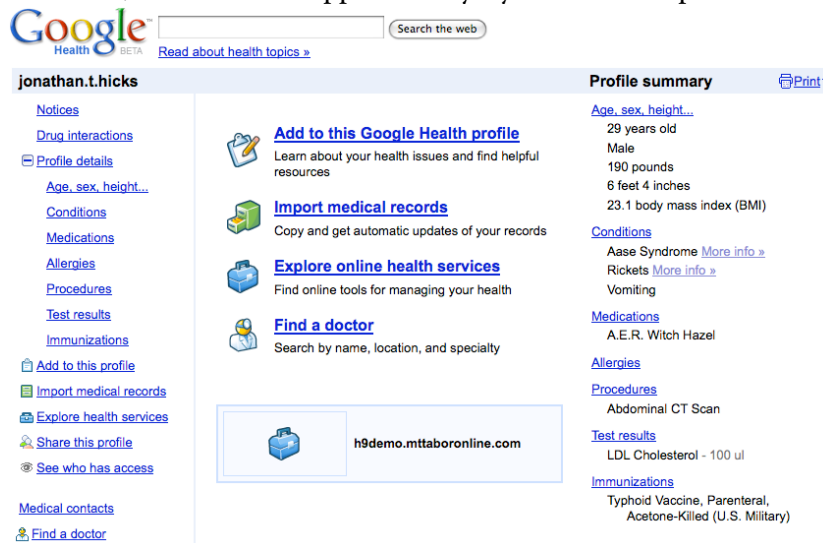


Figure 5: Google Health UI.

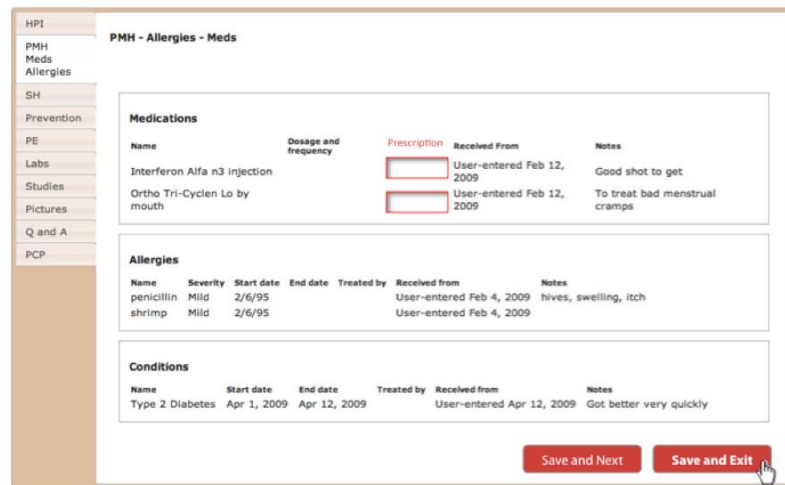


Figure 6: Our Supplementary Data UI. Note fields that are absent in Google Health are displayed in a red border.

As most of the patient interface still resides in Google Health, our focus has been on how to present that now-aggregated information to the clinician.

⁹ See Data Model and Appendices.

Clinicians

Before a clinician can contribute on Hyoumanity, we need to first verify that they are real medical professionals. We check the clinician’s profile and credential information against the American Medical Association (AMA)’s Physician Masterfile¹⁰ and grant access to the site as soon as the confirmation comes back positive.

In order to engage clinicians in our system, we interviewed doctors to explore the most common methods they use to find patients in databases – for example, finding patients to enroll in a clinical trial. From that exploration, we settled on three strategies for information retrieval:

- The clinicians that are in highly specialized fields may only care about certain values in a few tests. To meet their needs, we intend to provide a powerful advanced search to allow clinicians to set values on any pieces of information we capture, and combine those different criteria to customize a search query that works for them. These queries can also be saved, so the system can automatically find matching cases for the users.
- For clinicians in less specialized fields, a simple search against the most frequent complaints or highest awards would permit filtering of cases without eliminating opportunities.
- For clinicians who don’t have particular criteria in mind, we intend to provide a browse function, which allows the clinicians to skim through different cases along a variety of filters to find challenges.

All search results and cases for browsing can be displayed in different sort orders, as one might expect for a database-driven application.

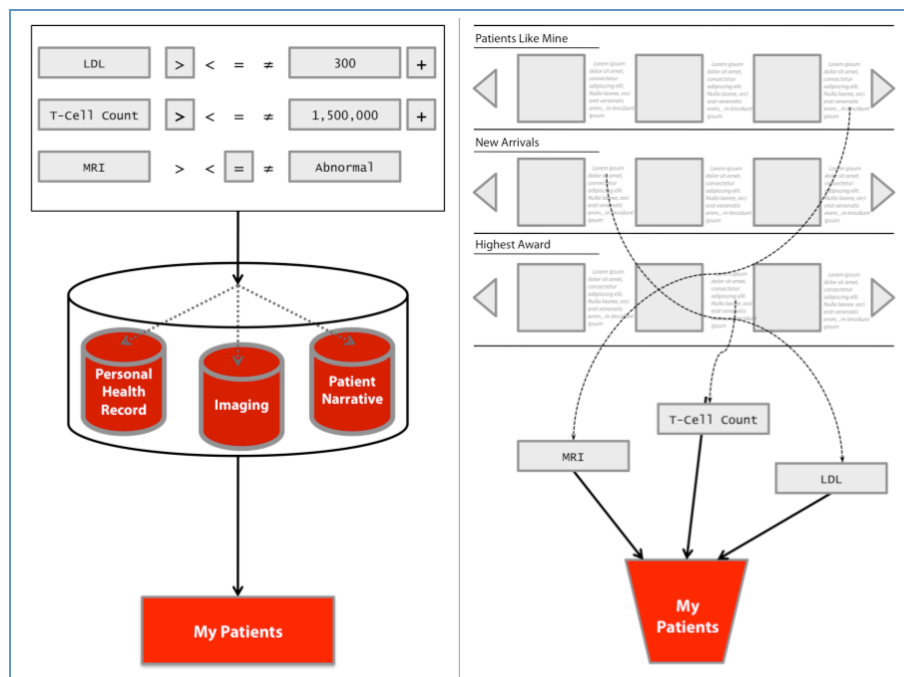


Figure 7: Information Retrieval Methods. A clinician can drag-and-drop attributes of interest, or patients of note, into his or her collection.

¹⁰ See ER Diagram.

After locating and saving a case to diagnose, clinicians can then communicate with the patient, keep notes on a case and eventually issue a diagnosis.

Notifications

Hyoumanity intends to support both on- and off-site notification. On-site notification will be displayed on a user's My Hyoumanity page. Users can also choose to receive off-site notification on their choice of media (email, SMS, etc.). Notifications will be sent to a patient when a clinician saves the case, asks a question, or sends a diagnosis. Similarly, all clinicians who saved a case will receive notifications when the patient updates the case, responds to a question or diagnosis, or issues a payment. In addition, based on the clinician's saved search criteria, the system will periodically check automatically for new cases that match the given clinicians' interests.

User Interface

Hyoumanity aims to have a clean and professional, yet pleasing and friendly, user interface. After studying the interfaces of potential competitors like Sermo, MedHelp, and webMD, we found there is not yet a great interface for clinicians to diagnose patients online. Below is a screen shot of a post on the Rare Diseases forum on MedHelp.org.

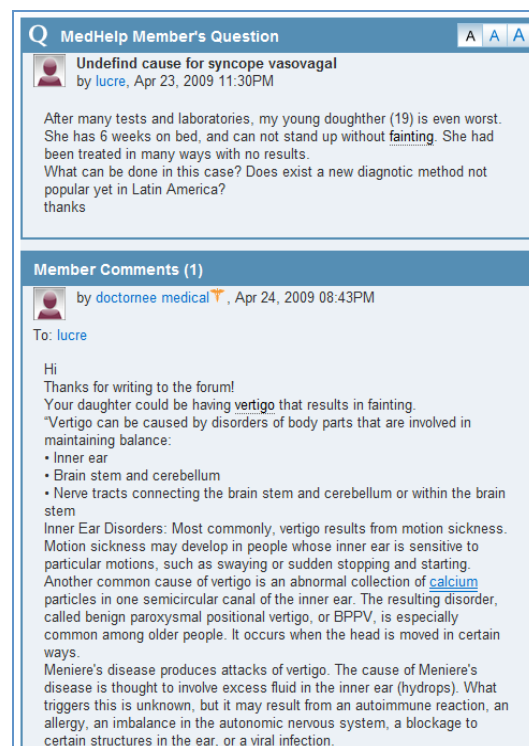


Figure 8: Medhelp Member Commentary.¹¹

Medhelp is an excellent example of the current state of the art. Most of the sites that attempt to provide some manner of diagnostic assistance only provide clinicians with one or two paragraphs of text submitted by the patient about his or her case. These narratives are frequently in ambiguous layperson language and without any formal structure. Postings like these rarely provide enough data to diagnose complex conditions.

¹¹<http://www.medhelp.org/posts/Rare-Diseases/Undefind-cause-for-syncope-vasovagal/show/932926>

In contrast to these postings, conventional medical records are complex structured documents that can easily be hundreds of pages of notes, charts, images and test results. In order to succeed, our interface has to present the information found in a conventional medical record in a way that makes sense to clinicians and allows them to process information quickly. We took inspiration from the traditional paper medical records, which are normally organized in tabbed-folders.



Figure 9: Paper medical records in tabbed folders.¹²

Our physician user research confirmed medical professionals are very comfortable with the tabbed folder metaphor. Inherited from the real world, many popular medical software systems currently used in major hospitals also utilize a tabbed folder interface.

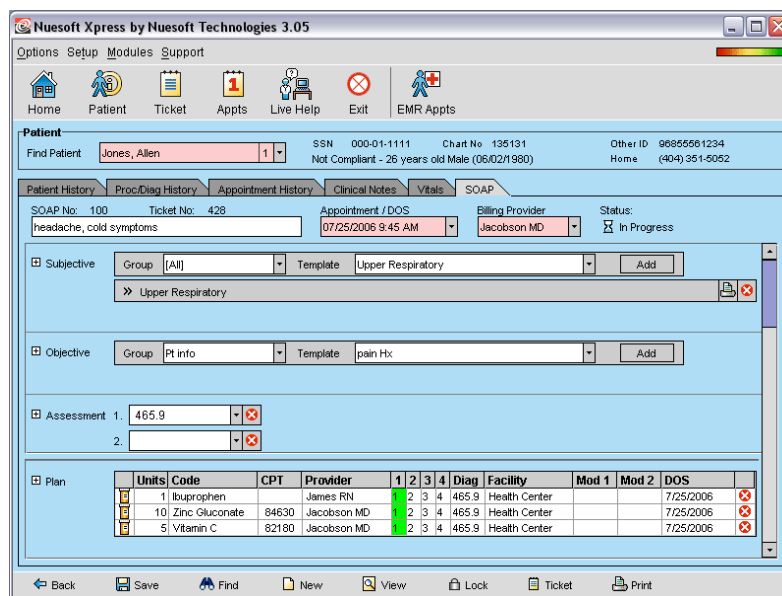


Figure 10: A screen shot of Nuesoft Xpress™, tab oriented UI.¹³

¹² <http://gotocasnet.com/wp-content/uploads/2009/03/medical20records.jpg>

¹³ http://www.nuesoftxpress.com/products/images/full_emr.gif

We attempted to capture the essence of those navigation schemes while still cleanly and accessibly displaying information in a conventional web browser.

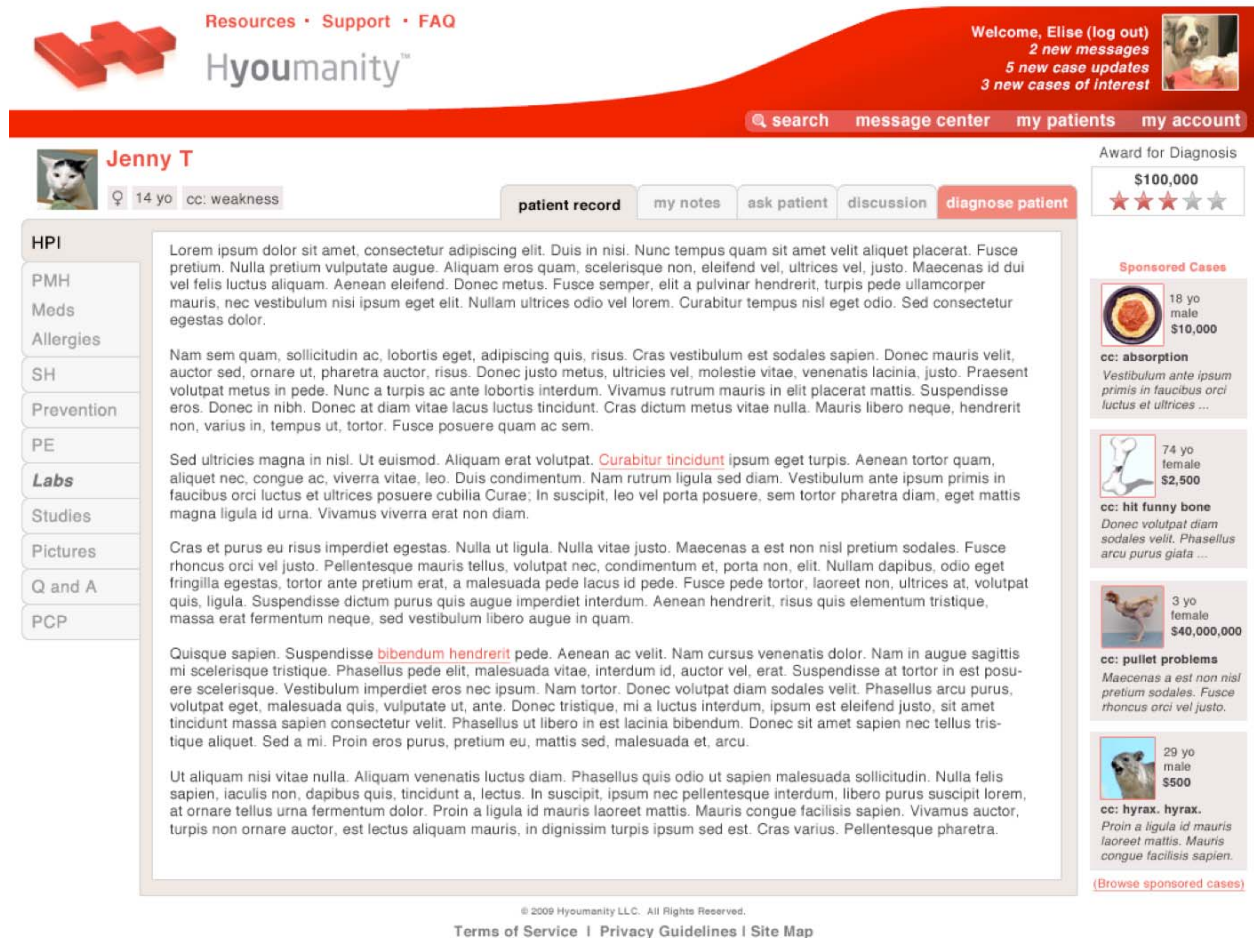


Figure 11: Clinician Interface mockup.

The above mockup represents a physician’s view of a single case. In this case, Jenny is the patient. Below Jenny’s name, there is a list of immediate relevant data points regarding her profile and the chief complaint bringing her to the site. The vertical tabs list all the different sections of her medical record. The labels for those sections are common medical acronyms which are understood by clinicians across the field. The horizontal tabs are different actions a clinician can take with a viewed case. All the information and actions regarding a case are displayed in plain view just one click away, allowing clinicians to sort through information quickly and easily.

The top red banner lists the user’s account information, notifications and higher-level site functions. This will stay with the user from case to case, serving as a context switch to other views.

The following figures showcase some of the tabs which comprise a patient’s case, demonstrating the complexity and variety of the information Hyoumanity presents.

The screenshot shows a web interface with a top navigation bar containing tabs: Patient Record, My Notes, Ask Patient, Discussion, and Diagnose Patient. On the left is a vertical sidebar with menu items: HPI, PMH Meds Allergies, SH, Prevention, PE, Labs, Studies, Pictures, Q and A, and a 'Highlight an item' button. The main content area is divided into three sections:

- PMH (Past Medical History):** A table with columns 'Name', 'Onset', and 'Resolved'.

Name	Onset	Resolved
Femur fracture	1998	
Sinusitis	1996	
Anemia	2000	2002
Hypertension	2008	
Diabetes type II	2008	
- Allergies:** A table with columns 'Name' and 'Reaction'.

Name	Reaction
penicillin	hives, swelling, itch
shrimp	Swollen mouth
aspirin	Can't breathe
wheat	diarrhea, stomach pain
ragweed	runny nose, sneezing
- Medications:** A table with columns 'Name', 'Current', 'Discontinued', 'date', 'Discontinued', 'reason', and 'Reaction'.

Name	Current	Discontinued	date	Discontinued	reason	Reaction
HETZ 25 mg QD 2008	X					
Metformin 500 mg BID 2008	X					weight gain
Vincristine			5/2000	9/2000		
Prednisone			QD 2000	2001		
<i>l</i> -Asparaginase			8 doses 2000	2000		
Doxorubicin			5/2000	9/2000		
Bactam			in K 1996	1996		
Penicillin			2 days 1996	1996	hives	hives

Figure 12: Clinician Interface, Sample view of structured data. We represent the more structural data, such as a past medical history, allergies, and medications data in table view.

The screenshot shows the same web interface as Figure 12, but with a central paper-doll figure. The figure is a simple outline of a human body. Several medical procedures are listed next to the figure, indicating their location on the body:

- MRI Brain 4/8/08 (pointing to the head)
- Mammogram 4/8/08 (pointing to the chest)
- Colonoscopy 1/12/08 (pointing to the lower abdomen)
- Barium Enema 12/23/07 (pointing to the lower abdomen)
- Pap Smear 10/12/08 (pointing to the pelvic area)

Figure 13: Clinician Interface, experimental view of structured data

We experimented with a paper-doll figure interface to map the locations of studies, or procedures, to the patient’s body. Clicking on the text avails the clinicians of more details about that study.

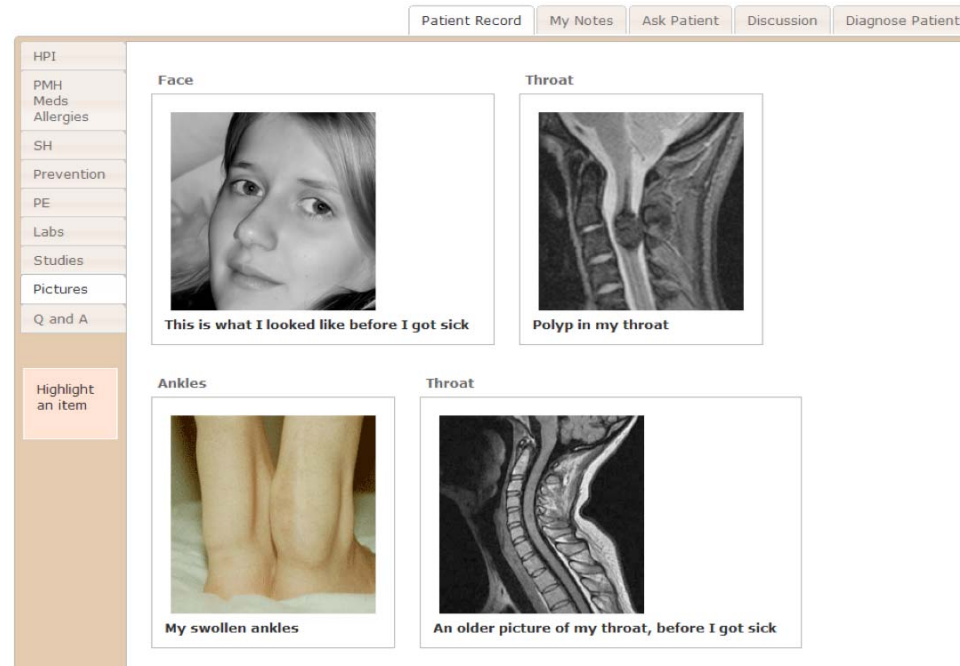


Figure 14: Clinician Interface, Sample view of imaging data

Though originally intended for medical images, user feedback has indicated that an imaging tab could be used to humanize an otherwise depersonalized medical record.

The patient's interface will be formatted in a similar fashion to the physician UI. However, the label of each medical section will be reworded to be layperson-accessible. Sections and fields that could be hard to understand for patients will also have mouse-over explanations to help patients input and maintain their record.

Incentive Structure

Knowledgeable diagnosis demands effort from both the patients and the clinicians on Hyoumanity. The patients need to update and maintain their case diligently and be responsive to the clinician's inquiries. The clinicians need to work through the cases thoroughly, analyze the information presented and apply their expertise. None of those actions is easy. We now take a closer look at the motivations of our users, and try to understand how Hyoumanity can incentivize them properly to increase the likelihood of correct diagnosis.

Patients

The patients' motivation for using Hyoumanity is readily apparent. Our targeted patient users are suffering from complex conditions and in need of a clear diagnosis to guide treatment. Hyoumanity can provide them with the opportunity to put their cases in front of many more clinicians than they can logistically reach. These patients are likely to have already seen several doctors and done extensive research on their symptoms; they have started to take ownership of their own medical records and are actively seeking new insights on their cases. We anticipate that this population will not have trouble managing their case in this kind of environment. In fact, we posit that Hyoumanity could provide a motivation and a comprehensive structure to organize their health information for future uses. Furthermore, since diagnosis is such a landmark step in disease treatment, we expect that patients who will use our service will already be incentivized to be attentive throughout the process.

Beyond their personal drive to get better, Hyoumanity also motivates the patient users by giving them full control of their cases while providing an easy channel to communicate with interested clinicians. Our philosophy in system design has been to avoid any strict controls on clinician-patient interaction, and to support a more “organic” information flow. Ideally under this system, the more attentive and responsive patients should be rewarded with more information in a more timely fashion with a given case. To foster this effect, our system also provides off-site instant notifications, which will issue notices to a patient’s choice of mediums (email, cell phone, etc.) when there is new activity and inquiry on their cases.

Clinicians

Compared to the patients, the clinicians’ motivations are more diverse. In the initial user survey, we asked the clinicians what their motivation would be for participating in such service. The top three reasons chosen were for “the opportunity to help patients in need” (80%), “financial reward” (73%), and “intellectual challenge” (60%).

Our initial inspiration for the site was also to help people who are in need, which nicely aligns with the clinicians’ motivation. The high participation rate of Sermo’s quiz challenges also demonstrates to us the value of intellectual challenge to clinicians.¹⁴ That feedback gives us some assurance that clinicians will enjoy the Hyoumanity experience. Each case posted to Hyoumanity represents both a difficult challenge to solve and a chance to alleviate a person’s suffering. Beyond altruism, we intentionally allow multiple clinicians to work on the same case simultaneously, hopefully driving clinicians to compete to provide a correct diagnosis quickly.

From the very beginning, we recognized that financial award is one of the primary drives for participation. We list patients’ award and “Payment Assurance” scores in a prominent spot in their cases, and provide the option to sort cases by award amount for those clinicians who are seeking financial award. Finally, a patient will only issue payment to the first clinician who generated a satisfactory diagnosis. We feel this should incentivize the clinicians to review and analyze the cases in a timely fashion.

Other incentive design

Antin and Cheshire in their study on online collective action argued that “social psychological selective incentives are an effective and efficient means to motivate specific types of contributions to online collections of information.”¹⁵ Besides the motivators mentioned above, we also plan to incorporate other features to encourage participation and facilitate case resolution.

Reputation

Researchers have found that reputation can be an effective way to promote valuable online contribution. Donath notes that reputation “amplifies the benefits of behaving well and the costs of misbehavior.”¹⁶

Hyoumanity intends to adopt reputation systems for both the clinician and patient users. For the clinicians, our reputation algorithm will draw from the number of cases they have successfully solved, the number of cases to which they have contributed, and the ratings given by patients. Among these factors, the successfully solved case indicator should be most important determinant, followed by the number of cases to which the clinician has contributed.

The rating from the patient is a more delicate metric. A recent Yahoo! Finance article shows that some

¹⁴ See Appendix.

¹⁵ Antin, Judd and Coye Cheshire. “Designing Social Psychological Incentives for Online Collective Action.” In Proc. General Online Research, Leipzig, Germany, 2007.

¹⁶ Donath, Judith. “Is Reputation Obsolete?” The Publius Project, 2008.

clinicians have strong negative feeling toward online patient rating systems, arguing they do not accurately reflect a clinician's medical skills.¹⁷ While supporting patients' rights to express themselves, we want to carefully balance the weight of this rating to more accurately reflect the clinician's performance as a whole and avoid discouraging skilled clinicians from participating. Similarly, the clinicians can also rate the patients they worked with on their collaboration and responsiveness. The rating on both sides can be issued and changed at any time before the case is closed.

Because of the multi-faceted nature of the clinician users' reputation, we face the decision on whether we should merge the values of each of the three factors into one score for display, or whether we should display them separately. The one-score approach might be more straightforward and intuitive to view. It also allows us to control the calculation of the score by putting different weights to each of the indicators to balance them in an appropriate way. However, after careful consideration, we found the three targeted factors are very different in nature, and might also vary in levels of importance for different users. Therefore, they should be displayed separately to allow users to exercise their own judgment in interpreting this information.

The group is still debating over how to visually represent the reputation information. We find the traditional five-star model can inhibit participation, as it implies only the ones with all five stars are "good" users. This leads us to explore the possibility of a more abstract and categorical representation system, such as thumb ups or eulogistic titles like "expert" or "guru" that award different levels of positive behaviors. We found eBay's Feedback Score system to be a good guide. It displays both a quantitative feedback score (total number of positive feedback – total number of negative feedback) and different kinds of stars based on that score. eBay also recognizes the most successful sellers in the community by awarding them the "power sellers" status. A set of privileges is also granted with this status. eBay's system is both positive and encouraging. It emphasizes only the positive feedback, creates an environment where users are choosing between the "good" and the "better."



Figure 15: A Power Seller on eBay¹⁸

¹⁷ Tanner, Lindsey. "Docs seek gag orders to stop patients' reviews." 4 March 2009. Yahoo! Finance. 7 May 2009 <<http://finance.yahoo.com/news/Docs-seek-gag-orders-to-stop-apf-14538905.html?.v=2>>.

¹⁸ <http://feedback.ebay.com/ws/eBayISAPI.dll?ViewFeedback2&userid=bcbgwearhouse88&ftab=AllFeedback&myworld=true>

In most cases, you'll receive:

- +1 point to your Feedback score for each positive comment and rating left for you.
- No ratings for a neutral comment and rating left for you.
- -1 point to your Feedback score for each negative comment and rating left for you.

Here's what the different stars mean:

Yellow star (★) = 10 to 49 ratings

Blue star (★) = 50 to 99 ratings

Turquoise star (★) = 100 to 499 ratings

Purple star (★) = 500 to 999 ratings

Red star (★) = 1,000 to 4,999 ratings

Green star (★) = 5,000 to 9,999 ratings

Yellow shooting star (★) = 10,000 to 24,999 ratings

Turquoise shooting star (★) = 25,000 to 49,999 ratings

Purple shooting star (★) = 50,000 to 99,999 ratings

Red shooting star (★) = 100,000 to 499,999 ratings

Green shooting star (★) = 500,000 to 999,999 ratings

Silver shooting star (★) = 1,000,000 ratings or more

💡 Tip: In most cases, a high Feedback score is a good sign, but you should always check a member's Feedback profile to read comments and look for negative remarks.

Figure 16: eBay's feedback score system¹⁹

Gratitude and Historical Reminder

Besides reputation, researchers also found other feedback mechanisms – namely gratitude and historical reminders – also can have significant impact on repeat contributions online.²⁰ At Hyoumanity, by providing direct messaging channels between patients and clinicians, patients will be able to deliver their gratitude about a clinician's contribution or diagnosis directly. To compound that value, part of the reputation metric is the number of cases to which a clinician has contributed and solved, which serves as a historical reminder of their effort and a marker of progress. On the home page, we will also display the latest number of cases that have been solved on Hyoumanity. This can be a well-deserved recognition to the entire community on the good work they are doing.

The success of Hyoumanity largely depends on motivated users making valuable contributions. We expect to devote a lot of effort to build a strong incentive structure within the site. We hope by implementing the above designs, Hyoumanity will be able to provide continuous incentives to induce high-quality participation at both ends.

¹⁹ <http://pages.ebay.com/help/feedback/questions/star.html>

²⁰ Cheshire, Coye and Judd Antin. "The Social Psychological Effects of Feedback on the Production of Internet Information Pools." *Journal of Computer-Mediated Communication* (2008): 13 (3).

Information Architecture

Data Model

Hyoumanity’s architecture is designed to be a flexible and scalable platform upon which to aggregate data from a variety of sources, some user-determined, others established systems. Currently, much of our patient information data model is derived from the Continuity of Care Record (CCR) format, an XML document specification for storing relevant information about a patient’s health care. That decision was motivated in part by our primary partner, Google Health, and in part by its relative simplicity.

Beyond the sizable cost-savings of avoiding recreating a patient UI from scratch, Hyoumanity will also benefit from ongoing improvements that Google makes to its service. Google’s size and credibility also mean that it will be able to continue signing important partnerships for directly importing patient data, such as those it has already created with CVS, Cleveland Clinic, and Beth Israel Deaconess Medical Center. We have met with the general manager of Google Health and he believes that Hyoumanity would be a perfect complement for their service; our hope is to develop our partnership into a privileged relationship we can use to drive Hyoumanity forward.

In the interim, our reliance on Google Health will give Hyoumanity users access to a fully functional and constantly improving best-of-breed personal health record (PHR). Our partnership enables us to be quick to launch while minimizing up-front development costs, allowing us to focus on adding value to those records.

In the long term, our data model is built to support importing health records not only from Google Health, but from health care providers and Regional Health Information Organizations (RHIOs) using both modern XML and the more common Health Level 7 (HL7) messaging standards.

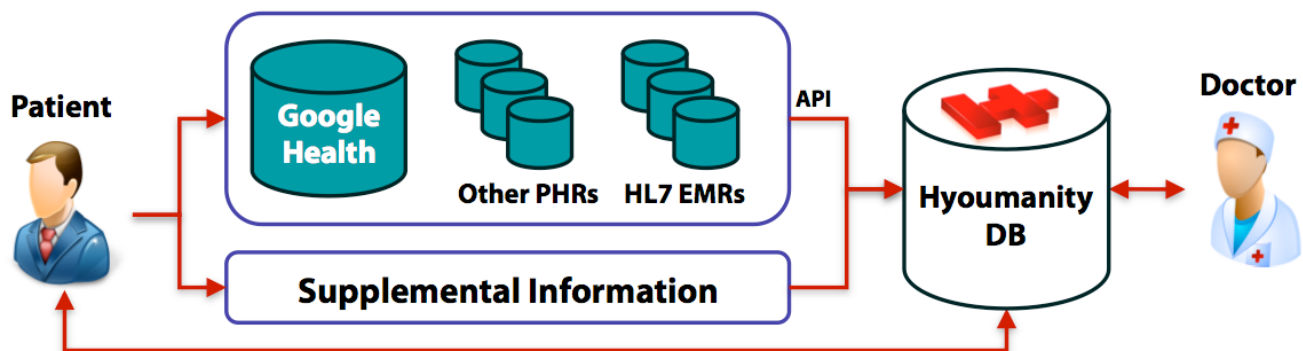


Figure 17: High level view of Hyoumanity's data model.

Figure 17 demonstrates the silos of information Hyoumanity’s data model is designed to navigate. The clinician interacts solely with our database, while the patient aggregates his or her medical record from a smorgasbord of established systems combined with our own supplementary layer, aligning the data management workload with the patient. Figure 18 shows a more nuanced view of the same data model – beige objects represent internal entities while red objects are foreign entities or externally derived data types. Solid lines indicate extant connections while dotted lines indicate future work.

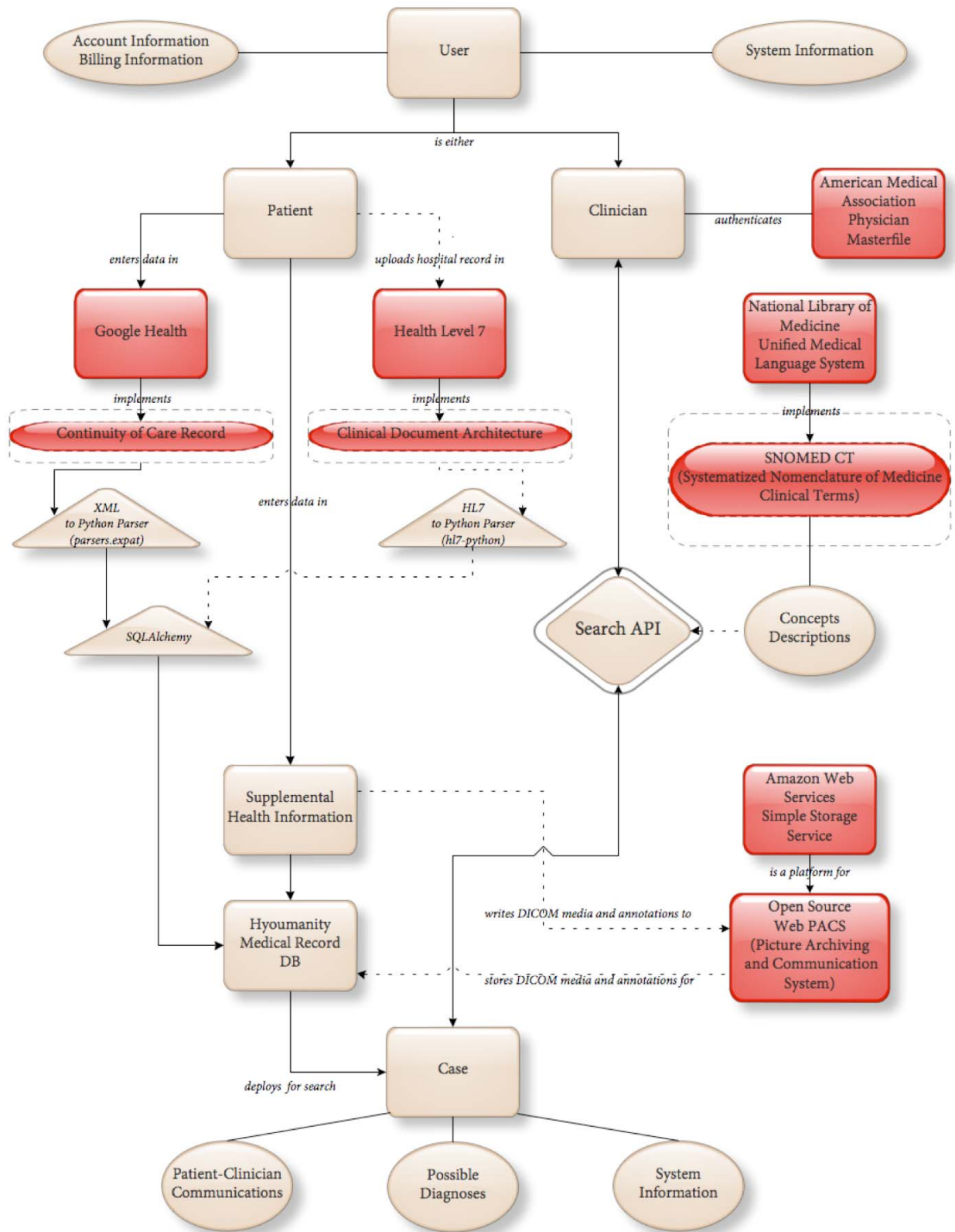


Figure 18: Hyoumanity's Entity-Relationship Diagram.

Development Environment

Frontend

Hyoumanity's interface is being developed in accessible, standards-compliant XHTML and CSS, with DOM and AJAX functionality provided via the jQuery JavaScript library. The design itself is grounded in proven usability heuristics and stakeholder feedback. Each stage of the design has been subject to physician and patient critiques. Larger scale user focus groups are to be convened at UCSF's School of Medicine and Duke University Medical Center's private diagnostic clinics, with additional sites enrolled as partners come on board.

Backend

Hyoumanity's systems are being developed using open source, proven web technologies. The current framework rests upon a Python 2.5/MySQL 5.0 system using a modified version of the Pylons application framework, allowing the Hyoumanity software to take advantage of the portability of the Web Server Gateway Interface standard and the modularity of Genshi's XML-derived design templates. Hosting for Hyoumanity is co-located in a HIPAA-compliant facility and all protected health information will be stored and transmitted in full compliance with technical safeguards outlined in HIPAA § 164.312.²¹

Each foreign component of the data model is its own integration challenge – As an example, one foreign component that has proved deceptively challenging to implement has been imaging. Medical images are typically stored in the Digital Imaging and Communications in Medicine (DICOM) standard, but different software and hardware vendors apply different metadata to those images, and each vendor has its own proprietary viewer. We'd like to provide a web-based viewer for these images in what is called a Picture Archiving and Communication System (PACS), but no standalone open source solution appears to exist in Python. Recently we've been introduced to Jorge Cuadros, a professor in the School of Optometry who is the primary investigator on a grant devoted to developing a PACS system for eye exams. With some luck, we may be able to implement a modified version of his software over the summer.

Google Health

Google Health consists of a data repository and an end-user interface. The repository is comprised of two separate data elements, one that stores the patient's Profile and a second that stores Notices related to the profile. The Profile is the patient's actual health summary, containing the complaints, medications, test results, immunizations, and other clinical data pertaining to the patient. Each patient has a single unique profile, which is represented upon export as an XML document.

Notices are other XML documents that a user or a 3rd-party application like ourselves may upload to Google Health and associate with a patient profile. Notices may contain the initial "seed" data for a new patient profile or various updates to an existing patient profile, such as new lab results, prescriptions, immunization records, hospital discharge summaries, and so forth. Each patient's record may have many Notices and new Notices may be continually added over time. The data within Notices are automatically imported into the patient's Profile and an auto-reconciliation process (flagged from inside a Notice) helps to prevent the addition of duplicate or inconsistent data from Notices. Users may also populate and update a patient Profile directly through Google Health's UI. Hyoumanity's current data model does not incorporate write-access to Profiles, but the potential to update a record (presuming the user is comfortable reconciling notices from Hyoumanity) exists should user demand head in that direction.

²¹ See legal appendix.

The data within both Profiles and Notices are based on the ASTM Continuity of Care Record standard (CCR). Each profile is a single document structured using a structured subset of the CCR, specifically defined by Google for Google Health. Google Health provides external applications read-only access to the patient's Profile via the Google Data API, which is based on the Atom XML-document retrieval interface. The available APIs allow an application to retrieve the entire Profile as a single document or retrieve specific categories of data from the Profile document, with significant control over granularity; as developers could retrieve all medications containing ibuprofen, or all hospitalizations requiring a stay of more than two days, or the like. As of late April 2009, the gdata-python-client library provided by Google permits direct queries in python instead of in raw HTTP and XML.

Dictionaries

In order to most effectively leverage the potential of AJAX in dictionary-driven search, Hyoumanity purports to utilize the National Library of Medicine's Unified Medical Language System (UMLS), specifically the Systematized Nomenclature of Medicine -- Clinical Terms (SNOMED-CT) component of its Metathesaurus.

The purpose of NLM's Unified Medical Language System® (UMLS) is “to facilitate the development of computer systems that behave as if they ‘understand’ the meaning of the language of biomedicine and health.”²²²³ The UMLS is largely a toolkit with which system developers can process, index, and retrieve structured medical information – not just a collection of controlled vocabularies, but a variety of tools to help parse and organize them.

One of those tools, and the most relevant to Hyoumanity, is the Metathesaurus. The Metathesaurus is an extensive vocabulary database derived from a substantial collection of different thesauri, classifications, code sets, and listings of controlled terms used in many different domains inside medicine, among them patient care and clinical services. It contains not only the names and descriptions of those terms but also the relationships between terms. From the Metathesaurus, we extracted SNOMED-CT, which contains a list of clinical terms already mapped to Google Health's Profiles. Using SNOMED-CT, we anticipate encapsulating a majority of clinician searches within the bounds of a controlled vocabulary.

Future Work

In April 2009, Hyoumanity was awarded two grants. One, from the Center for Information Technology Research in the Interest of Society, provides \$8,000 in funding to be used to pay technical costs and further operational and legal research. The second, from Amazon.com, provides an initial grant of \$400 to be used to explore the possible applications of Amazon Web Services in future development.

We hope to begin enrolling patients in our system by the end of May 2009, a milestone pending Google Health's formal acceptance of our software. Our pilot patients will be recruited from the pediatric space in California in the summer and fall of 2009, expanding to other regions and specialties in 2010.

Much work remains to be done on the data model and user experience – we need to finish implementing and connecting both systems to each other, and ensuring that our prototype search engine is capable of scaling up to meet demand.

²²“Unified Medical Language System Factsheet.” <http://www.nlm.nih.gov/pubs/factsheets/umls.html>

²³Unfortunately, despite being a government initiative, some of the components of the Metathesaurus are copyrighted by private companies, and as such access is strictly controlled – despite applying in March, our application was approved in late April.

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