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# Collaborative uses of personal health information: a study of PatientsLikeMe

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**Abstract**

This work explores the collaborative use of what is generally considered private information: personal health data. PatientsLikeMe is an online community where patients with life-altering diseases share and discuss personal health experiences. Users enter their structured data on symptoms, treatments, and health outcomes. This information is rendered as data visualizations on both an individual and an aggregate level. Users discuss this content and general health in forums, private messages, and comments posted to users' profiles. We performed a qualitative analysis of patients' comments, which revealed that patients are appropriately using health information to target treatment questions to others, share personal experience with those to whom it is relevant, and offer personalized support and encouragement. Results point to the benefits of sharing data in patient-to-patient health conversations.

**Keywords**

Data visualization, health, personal health records

**ACM Classification Keywords**

H.4.3 Communications Applications, H.5 Information systems and presentation

## Introduction

This project explored social uses of what is often considered private data: personal health information. There is growing demand for flexible access to personal health information [2]. Generally, the goal is to create a privately held record to help the patient manage interactions with the formal healthcare system [1]. The present work examines an alternate model—a system of a shared personal health information. Specifically, we explore what can happen when patients and caregivers contribute personal health information to a central repository and begin to share and discuss these data with one another.

Employing the tools of the “social web,” PatientsLikeMe was built as a platform for patients and researchers to analyze and conduct research on their own and other members’ experience. The site was first developed for a single condition—Amyotrophic Lateral Sclerosis (ALS) also known as Lou Gehrig’s disease, a neurodegenerative disease that begins with loss of voluntary motor function and progresses to the inability to breath or swallow unaided. There is no cure for ALS, but there are assistive technologies and one treatment that may lengthen life. The ALS model has subsequently been replicated by PatientsLikeMe and tailored to other conditions (Multiple Sclerosis, Parkinson’s disease, HIV/AIDS, and Integrated mood disorders).

This project is a preliminary qualitative analysis of one use of a single type of data within the ALS community: user comments that refer to data posted on other users’ profiles.

## Methods

### *The platform*

The PatientsLikeMe ALS community was launched as a beta site in December 2005, and opened to the public in March 2006. A year and a half after launch, the community contained 1,570 verified patients, about 10% of recently diagnosed ALS patients in the US.

On PatientsLikeMe, patients and caregivers answer questions about their diagnosis history and current treatments, symptoms, and functional level. Each individual’s data are organized and charted within a personal “profile” for their personal use. However, the profile is also available to be browsed and critiqued by other users of the site. Profiles contain a picture, an autobiographical statement, diagnosis history, and a set of charts. The top chart is a line graph of functional level over time, with a backdrop of population level data. Below are color-coded Gantt charts depicting treatments used and symptoms experienced. Charts can be rearranged to explore relationships between data types. See figure 1.

Data are also aggregated across individuals to create community resources, including a report on prevalence of each treatment and every symptom experienced within the group.

Members discuss these data as well as general health concerns through the forum, private messages, and comments they post on one another’s profiles. Each forum post and comment is labeled with an iconic representation that gives a summary view of the health status of the contributor. See figure 2.



Figure 1. An example of charts on a PatientsLikeMe ALS profile. A timeline of function runs across the top. Gantt charts of treatments and symptoms are below.



Figure 2. The ALS status summary. This icon accompanies each post and comment a user enters on the site. Colors on the stick figure indicate location and severity of symptoms; stars indicate frequency of data updates; other symbols indicate use of certain treatments and equipment.

### Sampling and analysis

To identify comments that explicitly reference profile data, we used a strategic sampling procedure. In a preliminary analysis, we identified phrases that

commonly co-occurred with references to profile data. These were: “I see you,” “I can see you,” and “notice you.” The 124 postings containing any of these phrases and the relevant demographic data were pulled from a database table then coded and analyzed using general qualitative methods.

## Results

### Targeted treatment questions

One of the most common types of data-driven comment was requests for advice. In these, users identify someone using a treatment or piece of equipment and request further information. This is epitomized by one woman’s comment: “I notice you are using ginger root and you believe it is slowing your progression. I’m very interested in this. Can you tell me more about how it’s working for you?” Other users made more sophisticated observations, with the author not only noting the presence of a treatment but also the relationship between a treatment and health status. For example, Adam an ALS patient considering the use of a breathing assistance device—a BIPAP—asked:

Hi [D]I am [Adam] in the PLM web site. My als was like yours breathing onset. I see your FRS improved a bit after you went onto BIPAP in april 06. Did it in fact make that much difference.??

Adam interpreted “D’s” profile and asked for confirmation, wanting to know whether to proceed himself. See “D’s” profile in figure 3.

### Unsolicited recommendations

In addition to requests for information, users also examine one another’s profile and offer unsolicited

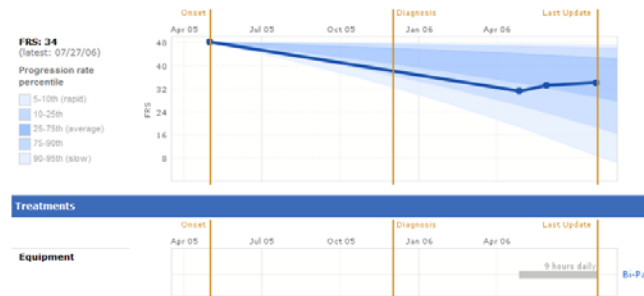


Figure 3. Charts from profile of user "D" showing changes in function and when the user began using a device to assist breathing (a BiPAP).

advice. Many individuals suggested a treatment they had tried to combat a symptom listed by another. For example, one man observed about another: "I see you note emotional lability. I had that very bad, but now I take a compound of dextromethorphan and quinidine that controls it beautifully."

Other users recommend third-party resources. Noticing where the described person lives, many readers suggested local physicians and support groups. In one instance, the reader, noting both an individual's location and type of onset, suggested a local research study on a new technology designed to address her specific situation. Users, in these cases, were able to share experiences and knowledge with the specific individuals who may most benefit from it.

#### *Social support and similarity*

Often times, comments are personal and supportive. Many comments reviewed in this analysis expressed concern or offered to communicate more. They noted similarity of an attribute—diagnosis history, location, or

current symptom—and simply offered to talk. The data visualizations (along with search and other features of the site) supplement other elements of the site to help users connect around a common experience. Users also express concern based on what they see in the profile. For example, several members observed a change in someone's profile, such as an abrupt weight loss, and sent personalized notes of encouragement.

#### **Discussion and conclusion**

PatientsLikeMe encourages a novel use of personal health information by patients. The results of this preliminary analysis suggest that members use data visualizations to broaden their interactions. In comments on the site, members note profile features and in some cases describe relationships between data types, such as treatment and disease progression. They use their observations to compose relevant questions, suggestions, and notes of encouragement—providing community responses to supplement the individual's personal experience. These behaviors suggest the benefits of improving patients' access to data and creating appropriate tools to review data. This work informs the next generation of shared data visualizations as well as supports the model of personal health records as shared resources.

#### **References**

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