

Case Study: The Story of E-patient Dave

In January 2007, Dave deBronkart was diagnosed with a kidney cancer that had spread to both lungs, bone and muscles. His prognosis was grim. He was treated at Beth Israel Deaconess Medical Center in Boston with a combination of surgery and enrolled in a clinical trial of High Dosage Interleukin-2 (HDIL-2) therapy. That combination did the trick and by July 2007, it was clear that Dave had beaten the cancer. He is now a blogger and an advocate and activist for patient empowerment.

In March 2009, Dave decided to copy his medical record from the Beth Israel Deaconess EHR to Google Health, a personally-controlled health record or PHR. He was motivated by a desire to contribute to a collection of clinical data that could be used for research. Beth Israel Deaconess had worked with Google to create an interface (or conduit) between their medical record and Google Health. Thus, copying the data was automated. Dave clicked all of the options to copy his complete record and pushed the big red button. The data flowed smoothly between computers and the copy process completed in only few moments.

What happened next vividly illustrated the difference between data and information. Multiple urgent warnings immediately appeared (Figure 2.1). Dave was taking hydrochlorothiazide, a common blood pressure medication, but had not had a low potassium level since he had been hospitalized nearly two years earlier.

Worse, the new record contained a long list of deadly diseases (Figure 2.2). Everything that Dave had ever had was transmitted, but with no dates attached. When the dates were attached, they were wrong. Worse, Dave had never had some of the conditions listed in the new record. He was understandably distressed to learn that he had an aortic aneurysm, a potentially deadly expansion of the aorta, the largest artery in the human body.

Why did this happen? In part, it was because the system transmitted billing codes, rather than doctors' diagnoses. Thus, if a doctor ordered a computed tomography (CT) scan, perhaps to track the size of a tumor, but did not put a reason for the test, a clerk may have added a billing code to ensure proper billing (e.g., rule out aortic aneurysm). This billing code became permanently associated with the record.

After Dave described what happened in his online blog² (<http://epatientdave.com/>), the story was picked up by a number of newspapers including the front page of the Boston Globe.³ It also brought international attention to the problem of meaning. It became very clear that transmitting data from system to system is not enough to ensure a usable result. To be useful, systems must not mangle the meaning as they input, store, manipulate and transmit information. Unfortunately, as this story illustrates, even when standard codes are stored electronically, their meaning may not be clear.

Figure 2.1: Urgent warning in e-patient Dave's record



Requires immediate attention



Discuss with your doctor soon

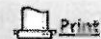
Hydrochlorothiazide and Low Amount of Potassium in the Blood

Medications given to people who have certain conditions can lead to an increase in side effects and/or worsening of the condition.

Hydrochlorothiazide Oral generally should not be given to people with Hypokalemia. This health profile includes this condition.

Figure 2.2: e-patient Dave's conditions as reflected in the newly-created personal health record (PHR)

Profile summary

Conditions

Acidosis [More info >](#)
 Anxiety Disorder [More info >](#)
 Aortic Aneurysm
 Arthroplasty – Hip, Total Replacement
 Bone Disease
 CANCER
 Cancer Metastasis to Bone
 CHEST MASS
 Chronic Lung Disease
 Depressed Mood [More info >](#)
 DEPRESSION [More info >](#)
 Diarrhea
 Elevated Blood Pressure [More info >](#)
 Hair Follicle Inflammation with
 Abscess in Sweat Gland Areas
 HEALTH MAINTENANCE
 HYDRADENITIS
 HYPERTENSION [More info >](#)
 Inflammation of the Large Intestine
 [More info >](#)
 Intestinal Parasitic Infection