

TRUST BUT VERIFY

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A doctor I see for my thyroid tumor recently made a mistake. While the recommendation of the specialist, an endocrinologist, in this case didn't cause me to lose a limb or seriously jeopardize my health, the experience did give me first-hand insight of how easy medical mistakes happen when doctors don't have access to information when making decisions.

In 2001, I was diagnosed with a thyroid nodule, which, thankfully, turned out to be benign. Recently, since I hadn't seen an endocrinologist for three years, my primary care physician referred me to a leading expert in the field to see if the tumor had grown. The specialist gave me a clinical exam and pronounced the tumor had not grown, perhaps even shrunk. To substantiate that finding, she referred me for an ultrasound. The ultrasound report conflicted with the clinical findings and stated that the tumor had grown.

What happened next eroded my trust in our health care system and convinced me that patients need to play a bigger role in their own health care. Those patients who blindly put full faith in our current health care system, I'm now convinced, are those most likely to incur a medical mistake. If we are involved, it can sometimes mean the difference between getting the right care or getting the wrong care, or perhaps life and death.

Thanks to an effort by Beth Israel Deaconess Medical Center and other Boston-area institutions to allow patients to access their medical information on-line, I am able to electronically track my health care services, maintain my medical records and test results, and e-mail my primary care doctor. The initiative, called PatientSite, is a great resource for patients for many reasons, but I'm most grateful for how it allowed me to avoid a medical error.

Before my specialist called me about my ultrasound results, I was able to check the results myself from home via PatientSite. The first thing I noticed was that the results contradicted what the specialist found from her clinical examination. According to the new report my tumor was bigger. Puzzled and concerned, I pulled up my original 2001 report and compared those results to the new report. Then, I realized the new radiologist report was wrong.

The size of the original tumor they were referencing was wrong. As I could access my 2001 report to verify the size of the original tumor – something the radiologists did not do – I saw that my tumor had not in fact changed in size. Was the radiologists' reference based on someone else's tumor?

When the endocrinologist called me she told me right away my tumor had grown and I needed a biopsy. I knew she too had failed to pull up my original report, even though the new results conflicted with the results of her clinical exam. When I reminded her of that, she seemed more alarmed that I was questioning her and the two radiologists who signed off on the results than the fact that the ultrasound was different from the findings of her own clinical exam. When I told her that I could access my own medical records and discovered the mistake, she seemed surprised. Then she said she had a problem with me viewing my results before she did.

No, that's not a problem, I thought. The problem is that medical mistakes happen too frequently. If we want to be involved in our own medical care, working in partnership with our doctors, we need tools to do that. I've read that nearly 100,000 patients die needlessly each year in hospitals. How many patients die because of medical mistakes outside the hospital? I don't know, but I do know how easily it can happen.

I'm fortunate though. Simply by having access to my medical information and previous test results, I have more control over decisions regarding my treatment.

Most patients don't have the tools they need to become their own health advocates. Thanks to PatientSite, I do. Unfortunately, the days of Marcus Welby, M.D., are long gone. While well intentioned, doctors are now often overworked and overwhelmed. I can trust but also verify the information doctors give me. I now have the ability to reduce the chances of a medical error happening to me.