

Where's The Data? **Making the Case for Establishing a Health Information Tracking Standard**

by
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Introduction

Imagine for a moment that you have a 12-year old daughter, and she has just been diagnosed with a serious brain tumor. Twenty four hours later she has an 8-hour brain surgery to remove the tumor. By the time you leave the hospital five days later, you've met with your oncology team and have been informed that the tumor is in fact malignant and your daughter's cancer is a type that conventional "burning and poisoning" treatments have had little or no success treating. Nevertheless, these are the recommended treatments. So what do you do? Do you give up? Not hardly.

You begin researching on your own. You read. You study. You make phone calls. And very soon you discover a whole new world (that is, new to you) called Alternative Medicine. You immediately begin to realize that your daughter's diet is going to be a huge factor in winning her upcoming battle. But you find many differing opinions on what diet would be best for her. And you also discover dozens of alternative treatments, therapies, and supplements such as laetrile, IP6, shark cartilage, Rife, Noni Juice, Burzynski, Cancell, MGN-3, and on and on. But how do you know what has credibility? There isn't much, if any, real data to back up claims that are made...only anecdotal evidence.

Then you begin researching the alternative clinics in the U.S., Mexico and Canada. You're looking for data that shows you a treatment or therapy protocol that has been successfully used for teenage girls with the same type of cancer. The data must also include each patient's diet, lifestyle, symptoms and their trends over time, and all medications, vitamins, and supplements that were being taken. You wonder why these clinics don't have each patient keep track of everything they do and make that data available as a resource for others.

By now you become overwhelmed with information and the realization that you need to make some decisions, but you don't have the right type of data necessary to make an informed decision. You've received a plethora of opinions from many qualified doctors and practitioners, but even they don't have the data you want and need. You feel like you're going into a battle against an enemy that has armored tanks, and all you have is a squirt gun.

My daughter Brittney died of brain cancer (glioblastoma) in July of 1999. Her battle lasted only 9 months, but in that short period of time I developed an acute awareness of the "information gap" which exists in the health care industry. It has become my life's passion to close that gap in order to give patients a better chance at making informed decisions, and to give practitioners and doctors better "information tools" to help their patients.

¹ Scott Flowers (BS in Electrical Engineering, Purdue University) has been in the computer software field for over 25 years, focusing on multimedia training and information management applications. Scott's world was turned upside down in 1998 when his 12-year old daughter was diagnosed with a brain tumor and died 9 months later. After the loss of his daughter, Scott started The BRIT Team, Inc., a company whose mission is to educate people on the merits and value of many alternative therapies and supplements, and to develop a better system for tracking health information.

The Purpose

The purpose of this White Paper is to make the case for establishing a standard for tracking and reporting health information. Most industries today rely on information as the life blood of their business. For example, a manager at an automotive plant can click a couple of buttons on his computer screen and see up-to-the-minute reports on the number of cars built so far that day, the downtime minutes and the causes for downtime, and much more. (I know this to be true, because I write computer software programs for this purpose.) In stark contrast, the vast majority of doctors and practitioners have little or no up-to-date health information² about each of their patients. So it's accurate to conclude that an automotive executive is better informed to make a decision about building a car than a typical medical professional is about helping someone save their life. If you agree with me that this is a tragedy and is simply not acceptable, then join me in my efforts to change the system.

“We believe our patients are healthier from following our therapeutic and lifestyle recommendations, but where is the data?”

Townsend Notes

The Best, and Worst, of Natural and Alternative Medicine

Joseph E. Pizzorno, Jr., ND
President, Bastyr University

The Target

Allopathic medicine is, for the most part, a system that focuses on treating symptoms. This approach to medicine requires very little information – the symptom or set of symptoms is all that is needed. Find the medication that makes the symptoms disappear, and “case closed” (for now).

I'm targeting those medical professionals that focus on helping their patients find the root cause of poor health and disease. A growing number of these professionals are developing their own method of gathering important health information from their patients. Usually this is a paper-based system of forms that requires a fair amount of effort to “computerize” the data into information that can be used for analysis. And there is certainly no standard that has been established that would give the practitioners and patients the ability to easily share information and learn from each other.

Another very important segment of the medical community that I'm targeting for this health information tracking standard are those companies that manufacture or represent products that claim to provide some kind of health benefit. So where is the data that backs up your claims of “improved health”? While it's understandable that clinical trials are far too costly for most companies to endure (except those pharmaceuticals with deep pockets and connections to the FDA), too many companies rely on anecdotal stories to promote their products. Truth and credibility can only be established with accurate and complete data³.

The Standard...A Starting Point

So what should a “health information tracking system” look like? It makes sense to start with these famous five questions: who?, what?, when?, where?, and how?

² At a minimum, health information by this author is defined as symptoms, test results, diet, exercise, treatments and therapies, vitamins and supplements, medications, and lifestyle.

³ Data would include hundreds of users of the product (by age and gender) along with their symptom trends and all other factors that could influence health outcomes, such as diet, medications, supplements, and lifestyle.

Who?

Anyone with a chronic or degenerative disease should most certainly keep track of their own health information. Also, those who want to help validate the benefits of a particular product would also be a participant in the process of tracking their own health.

What?

The information tracking standard should include:

1. *Symptoms*. Symptoms should be graded on a scale of 0 – 9, where 0 means “no symptom” and 9 is the worse that symptom has ever been.
2. *Test results*. This could be blood tests, MRIs and CAT scans, or any other types of diagnosis that results in data that can be compared over a period of time to assess trends.
3. *Treatments and therapies*. This would include any activity that could be considered as having an influence on overall health, such as a chemo treatment, a reiki session, any form of exercise, meditation, prayer, etc.
4. *Vitamins, supplements, and homeopathic remedies*. This would be anything put into the body for purposes of improving health that is not considered a medication.
5. *Medications*. No explanation necessary.
6. *Diet*. It could be an exhaustive process to document every food consumed each day, so a compromise would be to use types of foods or food groups and their portions. For example, 3 meats, 4 vegetables, 3 fruits, 1 ice cream, 2 alcohols, etc.

When?

Documenting personal health information on a daily basis would be the optimum approach. This would result in the most accurate information in the least amount of time. Remembering what one ate three days ago, for example, could actually cause frustration and stress. Not a good idea.

Where?

Convenience is the key. If the information is to be documented on paper, then the forms should be kept where they are “handy at all times.” If a computer is used to enter the information, then it would be a good idea to establish a habit of sitting down in front of the computer at the same time every day, maybe sometime in the evening or first thing in the morning. An option to use a PDA (Personal Digital Assistant, which is a small handheld computer) to enter the information should also be available.

How?

Above all else, the information logging process must be SIMPLE. The patients should be able to complete their daily logs in just a few minutes. If the information is entered on a computer, then the patient should be able to easily print out a report that shows all relevant information, and then that report can be handed to the doctor/practitioner for immediate assessment of trends and progress. It should also be a simple process of sending the information via email for assessment between appointments or for a “virtual consultation”.

If the information is entered using a PDA, then the patient would bring the PDA to the next appointment and the doctor/practitioner would extract the information in one easy step and generate a report.

If the information is documented on paper-based forms, then those forms should be standardized and simple to use. The populated forms would be given to the doctor/practitioner at each appointment (or mailed), and the doctor/practitioner would enter the data into a computer.

The Ramifications

There are many positive ramifications that would result from the widespread use of a health information tracking standard.

1. Doctors and practitioners would be more efficient and far more informed about how to help their patients. Consider these typical questions:

What is the effect of taking a certain supplement along with a medication?...or combining multiple supplements?

What is causing a certain symptom to occur?

How does the body respond to certain foods?

What is the therapeutic effect of certain treatments and therapies?

Does a simple exercise regimen enhance someone's physical and mental health?

Answers to these and many other complex questions would be possible when armed with the right information.

2. Virtual networks could be established. Practitioners could help one another on a complicated case by sharing information, and patients could “compare notes” with hundreds or even thousands of others having similar health problems.
3. Empower people to take control of their own health. It's time that people began to realize that they must be active participants in their battle to defeat disease and regain optimum health. Keeping a daily log of symptoms, therapies, supplements, etc. is an ideal method to engage the patient in the process of becoming more intimate with one's own body and its healing capacities.
4. Manufacturers and vendors. It's time to get beyond anecdotal stories of the wonders of products promising great health benefits, and hold companies accountable for their claims with real data. What if a company could include on its website a list of hundreds of customers that have used their product along with symptom trends and other information discussed here in this paper? This would help companies validate their products, and consumers would be far more informed and prepared to make better decisions. Eventually, all companies would be forced to validate their products' results with real data in order to compete. And what about those products that don't live up to the claims? They would be exposed to the public as what they truly are...ineffective and a waste of time and money.

If there was a computer-based program that made it simple to collect the kinds of information discussed here, then all it would take to derive these benefits is a small investment of time and a little dedication from the patient and doctor/practitioner.

The Health Tracking Assistant

The Health Tracking Assistant is a computer-based program that simplifies the process of capturing and reporting personal health information. This unique program represents a giant leap forward in the quest to establish a health information tracking standard. For more information, go to

www.thebritteam.com/hta.htm.

A Call to Action

If you would like to help close the “information gap” that I've described here, I would love to hear from you. I can be reached at:

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