The Tree of Life

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(Data driven life)^10 featuring Larry Smarr @lsmarr

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Caution: Brain Dump ahead.

I saw (briefly) Larry Smarr today at a TTI Vanguard Conference on Hacking Life. I missed his talk yesterday unfortunately but after my talk today on microbes he sent me this article: The Patient of the Future - Technology Review.

For those of you who do not know Larry, well, you should get to know him as he is a pioneer in getting to know himself. As background - I have known Smarr for about 7 years now as I have interacted with him over metagenomic analysis.

If you want to know more about Smarr's background, well, it is

amazingly impressive as all heck (see his Wikipedia entry for example). He has been a pioneer in computing, supercomputing, and engineering - and is a member of the National Academy of Engineering as well as the head of CaLIT2.

Anywho, a few years ago Smarr had an epiphany of sorts - he became - well - a bit obsessed with his own personal phenotype. This came in part from medical issues that cropped up in his life but I am sure it also came in part from his nature. So rather than sit back and let the winds of general indifference from MDs knock him around, he decided to take control. And now he has gather more information about himself than virtually anyone on the planet.

Over the years Larry has told me about some of his explorations of his own personal information. But I confess I was not really getting the point. But slowly I have come around to the notion. One thing that helped move me in this direction was when I went to a party for the release of Thomas Goetz's book "The Decision Tree." (I note - I also ended up losing a dollar bill to Jason Bobe - but that is another story). I got a copy of the book and read it - and this made me realize that technological advances - which are a big part of my work on microbes - are also making it easier for people to gather data about themselves. Goetz in the book discusses in part how technology can help enable people to engage more in decisions about their health by providing them with more information.

And though I read Goetz's book it all still seemed a bit abstract to me. Certainly - more and more people were engaging in what has been called "The Data Driven Life" or the Quantified Self or the Measured Life. And on some topics I know people were recording information quite obsessively (e.g., about sleep wake cycles, or food consumed, or whatever). But what really opened my eyes to the whole notion was a meeting I had with Smarr about a year ago.

I was in San Diego to give a few talks and participate in some meetings about "Beyond the PDF." And for my talk at UCSD I told my host(s) that I really did not want too many meetings - I just wanted to meet with a couple of people. And Larry Smarr was one of them. I had lunch with Larry and then went to his office where he showed me his data about himself. Holy crap. It was completely mind blowing. In a fascinating way. And a strange way. But more fascinating than strange. He had been ordering blood tests, and microbe tests and genetic tests and reading all the literature and then ordering more tests and recording his health status regarding all sorts of things.

And this is when I think it hit me - this is real - this is about specific individual

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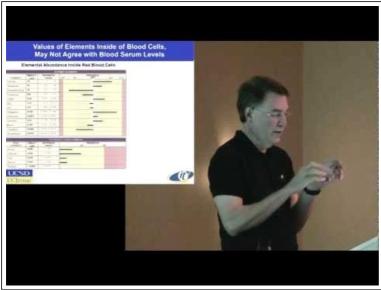
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people. The data is not just a bunch of numbers that a scientist will use to do an in depth study of a person. This is a person doing an in depth study of themselves.

Going back to the new article about Smarr - it discusses his continuing efforts to learn about his own medical ailments as well as predict and monitor his health condition. He will dig and dig and dig as much as he can - even more so than the last time I saw him. For more about Smarr and his self-data question see for example: How one quantified-self patient is working to transform health care and his website which has links to talks, videos, papers, etc.

Here is a recent video of a talk of his:



It is clear in this that Smarr is a pioneer. But he is not alone. Much more is coming. With electronic medical records, with cheaper and cheaper sensors, with better data storage and processing tools - many more people will do this.

Of course, data is not knowledge. I see this issue every day in "metagenomic" studies and in the general and continued overhyping of genomics. But massive amounts of data gathered smartly and used smartly could really revolutionize medicine. Imagine if we all did this. Even better - imagine if we all did this AND shared the data. This notion is in part what the "personal genome" project from George Church is about. In that project people are releasing their genome data as well as personal medical data openly. But as far as I know the Personal Genome Project (PGP) is not driving the massive continuous collection of information about the participants in the way of Smarr. I note - after I saw Smarr in San Diego I began to move more towards sharing my own personal data and now, for example, have posted data to the PGP.

Certainly there are challenges ahead. Privacy for example is a big issue. Target may be able to infer a lot about ones medical conditions from their shopping patterns, but using that information has risks. And of course, even if one is not worried about one's own privacy there are risks. Information about you can reveal information about others. This is obvious in terms of genetics - releasing information about yourself does reveal at least probabilities for your relatives. But it also is true for all sorts of other data. Your microbes for example, could say a lot about other people you interact with (consider the extreme - finding gonorrhea on ones skin ...).

Anyway - just thought it would be good to post about this issue. Sorry if it rambled a bit - been a bit of a long day. Now if only I had been recording all my personal health stats all day I could now if, while I was writing this, I was all here or not ...

Labels: Larry Smarr, the Data Driven Life

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- 1. I am involved with the Public Library of Science in multiple ways, and my brother was a co-founder. I receive no money from them (although in theory I can get compensated for expenses).
- 2. My wife worked for Mendel Biotechnology many years ago and we still own a small amount of their stock.
- 3. I make some money from sales of my Evolution textbook.

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