Open Cure NOW, Open Data is The Future of Medicine

Take Charge of Your Own Healthcare
Be Informed, Embrace Open Data.

Open Data can increase survival and the quality of life.

In every country people die and suffer for lack of medical knowledge. Much of the medical information that could change our worlds is locked behind paywalls that only those in institutions can access. Imagine with open access and open data all the information that exists could be put into a big data initiatives and ordered and made available for the age of the cure.

Patient rights and empowerment movements have multiplied exponentially over the last decade. Shared data movements and clinical decision-making may contain slogans like ‘having a voice; nothing about me, without me’ and ‘give me my damn data’, all these expressions share the language of loss and blame. Vision and partnership are not built by crying for what we do not have but instead by realistically assessing the situation as it is and working to build collectively with what we have.

Open Data Could Change Science and Medicine
One theme that repeats itself is the concept that open data can add to quality of life and even accelerate the finding of cures. Loved ones share that if only they had known of an intervention or a strategy it would have made a difference. ThinkWell is about helping people find information and do their own trials. The video below is from Salvatore Iaconesi, an Italian tactical media artist diagnosed with brain cancer in September, 2012).

The Open Cure by Salvatore Iaconesi

Salvatore committed himself to finding an Open Cure. After retrieving his digital records he found they were in a proprietary format that further isolated him from the potential to share his vision for an open cure. He hacked his digital imaging records and posted them with the reports online). The following direct quote is from an interview by Patrick Lichty on Furtherfield.org [1]

Salvatore Iaconesi shares, “The first thing you notice at the hospital is that they are not really talking to you. Medical language is difficult and complex, and they rarely take action to make things more understandable to you. This is really not “open”, in any sense. And, in more than one-way, it is an explicit evidence of the approach which medicine has towards patients: they cease to be “humans” and become sets of parameters on a medical record subject to certain protocols and standards. When you are in the hospital, it’s often as if you’re not there. The only thing that matters is your data: blood pressure, heartbeat, magnetic resonance etc.

Data formats may be, technically “open”, meaning that they are described somewhere but they’re really an explicit reflection that when you’re sick you “step out of society”. That data is
usable and accessible only to “professionals” and to those people who have tools and skills to handle them” [2].

Alessandro Liberati was a respected researcher, Cochrane reviewer lead, a patient activist and someone who was given a melanoma cancer diagnosis. He states, “I was no longer a subjectively healthy man but a potentially ill person, with considerable anxiety”. Alessandro lived almost 20 years in this state of unrest and limbo. He explains that even as a research professional he could not get full access to his own medical data and he only later found existing research that may have altered his quality of life.

Patient data is often withheld.

The public has restricted access to peer reviewed journals, evidence based medicine and they lack medical training beyond exposure to illness or trauma to themselves or a family member. Ads for quack treatments, live organ donors, direct to consumer pharmaceutical marketing and genomics appear even on family friendly social networks. The new trend is to expect the public to be informed decision makers. How can they make decisions without knowledge about their own condition and access to their own data? Decisions without information are about as valuable as counting a hello from a parrot as a conversation. It is like asking the blind to read without braille and without auditory prompts. If the doctor and regulators have information and the patient has only what information they have been given by the doctor how can we call any decision they make shared?

The public can’t access their own data and they have signed off on
rights to direct how it is used.

Is this progress? Let us empower the public to collaborate with shared data and research questions. They are untrained but they are still authorities on their own lives. ThinkWell suggests a working partnership where we provide an infrastructure to support the public as they choose to research solutions to conditions that concern them. Want to be a part of patient led trials let us know, We welcome your comments

References
