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Ed Boyden's blog

Ed Boyden is an assistant professor in the MIT Media Lab. His lab broadly invents new tools to engineer brain circuits, in order to treat intractable disorders, augment cognition, and better understand the nature of existence.

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   (March 2007)

Monday, January 19, 2009

Civilization as Experiment

Mining the insights of humanity.

From birth, parents raise us in different ways, teachers teach us in different styles, and doctors treat us with different medicines and give us different advice. These experiences set us upon our paths in life, sculpting how we learn and how we stay healthy. We can think of each interaction between a teacher and a student, or between a doctor and a patient, as a little miniexperiment, with an outcome that can be evaluated: Did the student learn and become able to use the information to do creative and useful things throughout life? Did the patient improve in health and develop proactive health-related behaviors? With almost one million physicians, and about four million educators of children, in the U.S. alone, we are as a society conducting millions of perturbations of behavior every day. However, we do not take advantage of the enormous amount of empirical data that, in principle, could be collected and analyzed in the process. A tool for generating and mining such a data set could not only reveal general empirical facts and principles about how best to teach, or to prevent and treat disease, but also allow individuals to monitor their own personal parameters that govern how they best operate, empowering them to better themselves.

Consider the idea of an ongoing clinical trial. Currently a clinical trial for a drug involves, typically, a blinded test of a treatment versus a control, which lasts a certain amount of time, and progresses in multiple stages, increasing the number of people each time, and looking for certain outcomes. Then, if the trial ends successfully, the drug can be sold. However, it's been observed that a great many drugs likely work for only a fraction of the patients who receive them. Indeed, drugs that may be bad if prescribed indiscriminately are sometimes useful for specific subpopulations (e.g., consider the story of thalidomide). Furthermore, after a drug is out in the world, it can be used off-label by doctors. If side effects appear in a subpopulation of patients, there isn't a forum to interactively analyze the properties of that subpopulation in a rapid way. Clinicians can publish the results of such observations in journals, but such observations often stand alone.

A complementary approach might be to continually accumulate data about a drug as it is used to treat different diseases, in different populations, over time. Each individual patient would be permanently associated with a data point, so that follow-up and further examination would become possible. As genomic information, brain imaging, and other information-dense measures

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become increasingly cheap to acquire, tracking multiple variables within a patient over long periods of time will become more and more valuable, allowing one to find better predictors of future outcomes in response to a specific treatment, and to derive conclusions that would be impossible from a limited snapshot of a person's life. This could speed up the process of testing out technologies, allowing evidence to be accumulated and analyzed in a distributed and open fashion, and enabling cures to be developed and tested faster. It could also simplify prospective studies, in which patients are tracked before and after disease onset, say for conditions such as autism or schizophrenia; right now it is very hard to do this because detailed studies of people before a disease occurs are difficult for all but the most common diseases. With integrated database design and accessibility, it would become possible to perform this analysis. Such a system would also need to have instantaneous peer review that would occur in a rewardable way; the system must track real identities and real reputations of people who comment on or synthesize insights from the database, to synthesize accountability, reputation, and trust, and to separate the experts from the nonexperts. Perhaps free access to the database's wealth of data would motivate people to contribute; people who contribute less, or who contribute lower-quality judgment, might instead pay to access it.

It's possible that this methodology could apply to other domains of life, exploring how to assist people to become better--for example, consider how to evaluate trajectories for the approximately two million inmates in U.S. prisons. Or consider mental health, in which many styles of therapy are continually being explored by a diverse set of psychologists, therapists, and psychiatrists. Or the economy: perhaps a way to help economies self-regulate is to build in self-analysis at every step of the way, continuously generating models and testing theories to catch disasters before they happen.
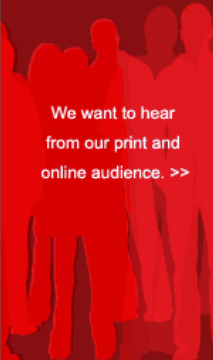
How many approaches to life ever get validated? When does a strategy or method need to be personalized to an individual, and when is an insight a general piece of wisdom? Systems that enable these questions to be answered by providing a continuously updated snapshot of the best practices of the world may change the way we live, and enable a new age of rational decision making. "Those who can't remember the past are doomed to repeat it." Well, currently that's just about all of us.

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Tags: education, health, medicine, prevention, data mining, evaluation, metrics, quality, schools, statistics

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realism

a great idea, but not very realistic
do you think, for example, that the sellers of products like pharma drugs ACTUALLY want it to be revealed that they only work for some people, some of the time?

do you think the goal of producers is to make sure that their products meet real needs?   or do you think that the producers of products, instead spend lots of money creating needs and then more money convincing consumers that their products are the best to meet these "manufactured" needs?

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complexity in health care

I've become increasingly concerned at the irrationality I perceive as hard-wired into health care as it exists today. Here's a comment I made in response to a NYT blog:
--
"Dr. Lisa V. Rubinstein, president of the Society of General Internal Medicine, said that sharing in decision-making "will help raise the quality of care given by any clinician, because it will sharpen the focus on the key decision points and help the clinician put a plan in place that the patient understands and agrees with.""

I couldn't agree more. The issue, as I've said before, is not a doctor's skill in deploying a set of prepackaged protocols to achieve a standardized outcome. It's this exclusive focus on the proximal outcome that's the problem – a problem made worse by evidence-based medicine. As a recent commentary in JAMA argues(1), through an emphasis on evidence-based guidelines, "perverse incentives may be introduced for clinicians to advocate treatments that are counter to what patients want and value."

Patients don't choose between discrete eventual states of a proximal outcome. They choose between different life-configurations. In other words, the goal needs to be to find a good engineering solution to kinks in a dynamic complex system, comprised both of medical and non-medical (life-trajectory, trade-offs) processes. I.e., to either raise the evolved state of that overall system to a higher equilibrium, or to keep it from sinking to a lower one (i.e., doing no harm). No disrespect to the medical profession, but physicians seem to have a "trained blindness" toward the non-medical elements, which by default seem to get conceptualized as subjective preferences, as opposed to objective case-specific facts. The medical focus remains on the proximal outcome, perhaps at the expense of the total system (at which point, harm is done). In contrast, a patient's choices are usually aimed at optimizing that overall configuration - perhaps even if the proximal outcome is negatively affected (a.k.a. non-compliance). The danger there, of course, is incorrect estimation of eventual state due to a lack of

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