Ted Goldstein
Genomics Meets the Social Network: On Bioinformatics, Justice and Privacy

Ted Goldstein, a PhD Candidate in Biomolecular Sciences and Engineering and a former VP at Apple, spoke to us about how social technologies can improve cancer treatment and research. Goldstein argued that Health Insurance Portability and Accountability Act (HIPAA) is the number one enemy of cancer science because it creates barriers between patients, physicians and researchers. Given current privacy regulations, he asks: How can we better collaborate to translate genomic and molecular knowledge about cancer into clinical actions that cure patients? Since under HIPAA patients have access to their own data, Goldstein believes that one way to break down barriers is to encourage people to share their data. He envisions a “rapid learning community” centered around patients that will promote personalized medicine for patients, better data for physicians to create treatment plans, and better access to patient data for researchers. Goldstein showed us the “Donate your Data” webpage on standup2cancer.org to illustrate the emergence of this data sharing movement. His current project is to create an application (app) called Medbook where patients can share their data with physicians and researchers. Crowd-sourcing offers the opportunity to sift through large data sets looking for patterns that can improve success of current treatments and lead to new treatments.

During the Q&A participants asked whether peer review acts as an important gatekeeper for reliable information (JR), whether it’s easy for patients to access their data, whether doctors will spend billable hours on Medbook, who will benefit from its use (WB), whether insurance companies will use it to limit patient access to treatment (MK), whether it will be used only by people who tend to be “early adopters” (JM), and whether Medbook would attract venture capital. These questions allowed us to explore some of the technical and practical specificities of Goldstein’s project.

Goldstein was also interested to hear from us whether we thought it was ethical to make money in the medical industry. Audience members engaged with Goldstein’s question less by answering it directly, and more through reframing the terms of the question: Andrew Matthews proposed the question “How can we be attendant to emergent ethics?”; Martha Kenney asked “How could we design Medbook to make it more ethical”? Jenny Reardon suggested that the question of ethics could be approached using language from Hannah Arendt: how can we “communicate that which we do”? Jake Metcalf reframed the question in terms of value: who profits from my tissues. He raised the example of HeLa cells and then questioned how he would feel if Monsanto made a “super pig” from his tissues. By approaching Goldstein’s question from these different angles we were able to articulate different sets of ethical implications arising from the development and use of the Medbook app.