Trust in Genomics: A challenge for scientists and ethicists alike
Speakers: Wylie Burke and Barbara Koenig with comments by David Haussler
Moderated by Jenny Reardon
Rapporteur Report by Lizzy Hare

This event was the second in a series of discussions that the Science & Justice Research Center is hosting on Data Justice. This working group meeting brought medical geneticist Wylie Burke (University of Washington) and cultural anthropologist and bioethicist Barbara Koenig (University of California San Francisco) into conversation with Science & Justice Center Director Jenny Reardon and David Haussler (Director of the UCSC Center for Biomolecular Science and Engineering). Drs. Burke and Koenig shared their experiences working with biobanks, researchers and patients to build better data sets by attending to matters of trust and respect. Matters of trust were central to the first Working Group meeting on Data Justice that was held in January of 2014. The goal of this meeting was to extend that conversation and explore those issues more fully.

Jenny Reardon’s introduction provided an overview of some of the concerns that the Working Group hoped to pursue with the Data Justice series and this event in particular.

Wylie Burke started the discussion by talking about the University of Washington’s (UW) “biotrust” efforts. They are seeking to collect clinical samples and health information as patients receive care at affiliated institutions. UW consulted with ethicists during the development of this biobank and the result was an opt-in process rather than the opt-out format that most institutions use. In order to explain how UW’s biotrust efforts are distinct from others, she explained the case of a five site research consortia that was seeking to understand to what extent data in electronic records could determine phenotypes for genetic research. Once the research was completed, the funder required that the health and genomic data be sent to a central repository. UW was the only one of the five sites where the Institutional Review Board (IRB) required that they seek additional consent from patients, arguing that sending information to a federal repository was of a different order of magnitude the research that had been specified in the original consent forms. Burke and her colleagues were able to gain extra funds to survey people about how they felt about the reconsent, and overwhelmingly they wanted to be asked and did not see it as a nuisance.

Barbara Koenig wanted to turn the conversation away from trust and towards trustworthiness, which places the onus on the institution to be worthy of the trust of patients and the community. While working at the Mayo clinic, Koenig was a part of the same research consortia as Burke. The Mayo clinic had used a 3-way checkbox consent form that had been considered sufficient by the IRB, but the clinic ultimately decided that the form was insufficient. The clinic took the issue to their community advisory board, and that board decided that it was acceptable notify patients and allow them to opt out rather than go through the process of reconsent. Koenig referred to the act of consulting with a community advisory board as “deliberative community engagement”, and the strategies are based on deliberative democracy. The goal is to bring individuals who represent the community together to discuss data governance. This method will not replace informed consent, but will enrich it, because consent alone might not be sufficient to deal with future obligations and findings.

David Haussler joined the conversation and voiced his concern with establishing trust for large, global alliances through local efforts like those that Koenig and Burke had discussed.
Haussler believes that large data sets collected through international collaborations are necessary for understanding complex problems such as cancer and inherited diseases. He was excited by the conversation at this meeting because he’s been working as a part of the Global Alliance (an international effort to share genomic data) and they have been having a tremendous issue with establishing trustworthiness. Burke and Koenig reiterated that trust needs to start locally, and that local procedures need to cover rules about access to data, even if that information will be used as a part of a global research effort.

The central issue seems to be a lack of agreement on how much data could be shared, and where that information would be stored. Restricting access might make the process and the institutions involved more trustworthy for community members and patients, but restricting access prevents creativity and potentially groundbreaking uses, as well as raising concerns about who is able to determine access to the information. Jenny mentioned the adage “information wants to be free”, but our worlds have borders and those borders allow us to make decisions about which values count in a particular place. Jake Metcalf reminded us that there is a second part to this famous adage, and that is that information wants to be free, but it also wants to be expensive. In our quickness to speak of information as something that has a will and desires to freedom, we tend to ignore the infrastructures that are required to share that information and to allow its use.