

New Course Probes Precision Medicine and Big Data

What do your doctor's electronically recorded notes about your last visit, your parents' nutritional status, Google maps, your smartphone, and your entire internet browsing history all have in common? Students in "Studies in Contemporary Biosciences" (MHB 734, fall 2013) will explore this question and more in a new course being co-taught by Linda Hogle and Kris Saha. This interdisciplinary Science and Technology Studies course will use perspectives from anthropology, bioethics, history, biomedical engineering and policy studies to probe social and ethical issues related to contemporary topics in biomedicine. The course will focus on three broad areas: the ownership and control over data produced in the course of research, new ways of defining disease through *in vitro* modeling and "Big Data," and the increasingly blurring boundaries between research and clinical practice.

Personalized medicine has been the bellweather of the past decade, but the National Academies of Science and the National Institutes of Health are calling for an even more specific way of identifying and treating disorders, even before they manifest. "Precision medicine," as it is being called, involves cross-referencing individuals' personal medical and behavioral histories (acquired from electronic medical records) with their biological information (acquired from samples, such as routine blood tests or donated tissue specimens) and behavior patterns (found in social media, GPS tracking, purchase & consumer patterns) in order to identify associations that may flag potential ill health. Research on data on individuals produced from these sources will be aggregated across populations, but it requires the widespread collection and analyses of massive amounts of data using Big Data analytics, adopted from consumer and finance industries. At the same time, new capabilities to be able to model diseases in the lab—while utilizing matched data acquired from healthy and ill individuals—opens the possibility for more comprehensive understanding of disease, including, potentially, figuring in environmental influences.

Major shifts will take place as a result. First, boundaries among patients, donors, research participants/subjects, consumers, and citizen will be renegotiated as patients become research subjects in the course of routine care. New players, such as data visualization companies, mobile health device companies, and biorepositories will become the ciphers through which health status is defined and represented and care plans are determined. Finally, entirely new ways of thinking about and classifying disease will be constructed.

Students in the course will excavate the many social, ethical and policy issues that arise as a result of such major changes. Traditional concepts of privacy, autonomy and property are reformulated as human biomaterials and data travel among various research institutions and the even the cloud. The new technoscience can be a raw substrate for claiming new rights – like a right to see my own genome – creating new spaces where biology and the law come together. As healthcare increasingly becomes a focal point for social justice issues, these new techniques of data analysis may be tasked, perhaps unreasonably, to detect or deal with social

vulnerabilities and disparities. What counts as “valid” evidence of disease and under what conditions and to whom are core questions to be studied through STS lenses.

The course will be co-taught by Linda Hogle and Kris Saha. Kris Saha is a biomedical engineer with science & technology studies training. The Saha lab seeks to examine the social and cultural implications of modeling diseases in a dish with patient's biosamples. The group has new capabilities of engineering any blood or skin sample into embryonic-like cells that putatively represent cells residing in the biosample donor's body. They are interested in how donors become patients, citizens, and consumers of this research and its downstream translated products through these postgenomic technologies. Linda Hogle is an anthropologist of science, technology and medicine with experience studying innovations in regenerative medicine and biomedical engineering. Her interests in precision medicine focus on how concepts and classifications of disease and health change under political, social and economic conditions that characterize the twenty-first century, and how such changes in turn affect clinical and research practices. Students interested in taking the course can contact either Kris or Linda for further information about enrolling in the course.