



**End of Year Report for 2011-2012
And Proposal for 2012-2013**

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SJRC Year End Report 2011-2012

This document describes the activities of the Science and Justice Working Group (SJWG) in the academic year 2010-2011 and presents a proposal for the 2011-2012 academic year.

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I. Executive Summary

Science & Justice brings together scientists, engineers, humanists, social scientists, and artists to re-imagine what robust, curious and responsible forms of scientific and engineering knowledge could look like. As contemporary lives are increasingly experienced via scientific and technological practices and idioms, it is increasingly important to develop collaborative models for building a diversity of livable worlds. With the assistance of the U.S. National Science Foundation, the University of California, and other funding agencies, we offer a variety of internationally-recognized training programs, research projects, and academic events. In pursuing these ends, Science & Justice builds on the University of California, Santa Cruz's historic commitments to social justice and interdisciplinary research.

In the 2011-2012 academic year Science & Justice saw significant growth, gained substantial national and international attention for our pedagogy and research projects, and made strides toward becoming a core component of UCSC's graduate education and research communities. Most notable was the opening of the Science & Justice Research Center (SJRC), made possible by the success of the Science & Justice Working Group and Training Program. The SJRC is the new hub for all Science & Justice projects and programming, including new collaborative research initiatives and grant writing. Faculty and graduate students from across the university participate in research projects hosted by the SJRC that build empirically robust and ethically responsible knowledge-making practices. Our new facilities located in Oakes College provide a common space for graduate students, visiting scholars, and faculty to collaborate and interact.

In the past year, the Working Group hosted a dozen of our regular colloquia in addition to the SJRC grand opening event and playful poster session at the end of the year. The first cohort of Training Program Fellows concluded their training and the second cohort of Fellows finished their coursework and began their research projects. The instructors of the Training Program courses were able to substantially improve the courses by orienting the reading, discussions, and assignments more toward developing student projects. We also launched a number of initiatives aimed at collaborating with science and engineering departments on campus on programming and pedagogy issues.

Launching the Research Center also provided impetus to rationalize and increase transparency of procedures and develop more formal routes for receiving guidance. We re-constituted a Steering Committee of graduate students for reviewing event proposals and made it easier for a broader audience to propose events. We also established internal and external advisory boards to help direct the priorities of the Research Center. In the next year we will be expanding the advisory board membership beyond academics and inviting foundations, community groups, and industry members to participate. Finally, we appointed two co-Directors, an Assistant Director, and hired an administrative assistant.

II. Funders & Co-Sponsors

Major sponsors

The National Science Foundation
The Division of Social Sciences
The Division of Graduate Studies
The UCSC Office of Research
The Jack Baskin School of Engineering
The Division of Physical and Biological Sciences
Molecular, Cellular and Developmental Biology Department

Co-sponsors of the Science & Justice Training Program Fellows

Anthropology Department
Earth and Planetary Sciences Department
Ecology and Evolutionary Biology Department
Environmental Studies Department
History of Consciousness Department
Philosophy Department
Physics Department
Politics Department
Sociology Department
Division of Graduate Studies

Co-sponsors of Science & Justice Working Group Programming

Anthropology Department
Film & Digital Media
Center for Agroecology and Sustainable Food Systems
Center for Biomolecular Sciences and Engineering—Research Mentoring Institute
Center for Cultural Studies
Critical Race and Ethnic Studies
Molecular, Cellular and Developmental Biology Department
National Science Foundation
Sociology Department
UCSC Cancer Genomic Hub
UCSC Office of Research

III. Introduction

Below we describe SJWG's recent accomplishments, history, themes, events from the 2010-2011 academic year, the Science & Justice Training Program and its relationship with the Working Group, our plans for next year, and a proposed budget. Appended are selected documents describing this year's events.

Summary of 2011-2012 Accomplishments

In the 2011-2012 academic year the Science & Justice community had a number of important accomplishments, and was especially marked by efforts to establish a more visible, integrated and permanent institutional position within the university. We consolidated our programming and pedagogy efforts within the newly opened Science & Justice Research Center, which will provide a hub for our existing projects and a number of new efforts.

The Research Center grew out of the success of the NSF-sponsored graduate Training Program and our Working Group. The SJRC is hosted by the Division of Social Sciences and supported by a number of science and engineering Divisions and Departments¹. For the first time, Science & Justice was able to establish a central physical space on campus, including several offices and a common room in Oakes College. The Research Center will provide a long-term hub for science and society research, with a number of opportunities for UCSC faculty and students and visitors to pursue research projects that may not be possible elsewhere. It has also enabled us to engage in more formal collaborations with regional institutions with science and technology studies programs, including a research initiative focussed on Silicon Valley and opportunities for student exchange. Importantly, the physical space provided by the Research Center has given Science & Justice a place on campus that is easily accessible to our graduate students Fellows to host meetings, colloquia, and discussion groups.

Much of our work in the past year has been directed at establishing the internal structures and procedures necessary for running the Center. For the first time, we were able to hire an administrative assistant, support a Graduate Student Researcher position, and appoint an Assistant Director. We also created a more formal leadership structure, appointing Jenny Reardon and Andrew Mathews as co-Directors who will alternate directorships on a semi-annual basis. Reardon has informally lead the Science & Justice initiatives since the founding of the Working Group, and will hand over direct leadership to Mathews in Fall 2012. Additionally, we focussed on creating and sharing documents that make our procedures more formal and transparent, such as how to

¹ The SJRC is hosted by the UCSC Division of Social Sciences, and supported by the Office of Research, Baskin School of Engineering, the Center for Biomolecular Sciences and Engineering, and Division of Physical and Biological Sciences. We have ongoing collaborations with a number of departments focussed on graduate education, including the Department of Molecular, Cellular, and Developmental Biology.

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propose Working Group Events and how to include Science & Justice in grant applications. This will ultimately broaden participation and make collaboration with other campus groups easier.

Recognizing the need for more diverse input on the directions and goals of the Research Center, we also endeavored to create internal and external advisory boards. The internal advisory board consists of UCSC faculty that meets two or three times annually to identify and facilitate local opportunities for Science & Justice. The external advisory board currently has distinguished representatives from each regional university that hosts science and technology studies research. The external board will meet once per year, and in the future will include members from foundations, advocacy groups, and industry. Together, the advisory boards will help identify possibilities for further research, establish regional collaborations, and opportunities for funding SJRC projects. Advisory board membership and reports from meetings are available in the appendix. Among the proposals arising from the external advisory board meeting were regional email lists, cost-sharing for visitors and conferences, a research group dedicated to Silicon Valley issues, and graduate student exchange programs.

Much of the discussion within the internal advisory board has focussed on the near-term future of the Science and Justice Training Program (SJTP). The SJTP is a unique research and education program that trains science and engineering graduate students alongside social science and humanities graduate students to identify and respond to moments where good scientific and engineering practices require attentiveness to questions of ethics and justice. It was initially funded by the US National Science Foundation with a pilot grant that expires in 2013 and cannot be renewed. Conjointly, it trains humanities, social science, and art scholars to work collaboratively with natural scientists and engineers, a skill set required by anyone who seeks to interpret social and cultural life in an age increasingly mediated by technoscience. It has created one of the only interdisciplinary spaces in which graduate students from the social sciences, engineering, natural sciences, humanities and the arts can collaborate on issues of common concern.

Logistically, the current iteration of the Training Program includes a topical seminar, a methods seminar, intensive mentoring, regular participation in the Science & Justice Working Group's programming, presentation of research in public and academic venues, and fellowship funding for up to two terms for graduate students accepted as Fellows. Additionally, the project funds a Postdoctoral Fellow, supports regular programming of the Working Group, and funds workshops related to the PI's and Postdoctoral Fellow's research. Future iterations of the program will likely have a different structure, and we are currently pursuing several options for reformulating the program around our current resources and possible future funding sources. Proposals include

In the Fall 2011 term, Reardon taught the second iteration of the Methods course, which was designed to assist the second cohort of Fellows develop their research projects and find new opportunities for cross-disciplinary collaboration around common problems.

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Based on feedback from the previous cohort, Reardon and Metcalf significantly redesigned the course. Readings were scaled back, which allowed more time to focus on the Fellow's projects rather than on demonstrating mastery of the methods presented. Although all Fellows learned a wide variety of methods from the humanities, social sciences, and science and engineering, the major assessment of their work was a portfolio of their efforts to use a preferred subset of methods in developing their own projects. The redesigned course also allowed for more extensive group discussion of the Fellows' projects, with an hour of every weekly seminar set aside for informal presentations and discussions. All told, this redesign allowed for Fellows to build more familiarity with each others' projects and establish more relevant and innovative collaborations.

As planned, we continued to develop a more synergistic relationship between the Working Group and Training Program. Because of the larger cohorts, and greater numbers of science and engineering students, we had higher attendance and more disciplinarily diverse graduate students at Working Group meetings. Members of both cohorts presented their SJTP-supported research in a variety of Science & Justice events, including a discussion of Transition Towns (attempts to reorganize villages, towns, and cities in response to climate change) and the international efforts to gain regulatory and scientific recognition of ingestion of the Amazonian drug ayahuasca as a medical and religious practice. Additionally, with the opening of the Center we were able to schedule bi-weekly informal meetings in our common room for Fellows to socialize and present their research for feedback. These meetings contribute to the conviviality that has been a significant component of our community.

The most significant showcase of Fellows' research was our year-end event, at which they presented a playful and provocative 'poster session.' Students organized presentations in a number of formats, including posters, participatory games, and artworks, and held conversations with guests as they circulated. Many Fellows used the event to collect data or input on their projects. Altogether, this demonstrated the success of our model of providing intellectual space, funding, and infrastructure for developing interdisciplinary research and allowing the students to build it out in unexpected and innovative ways. Members of our external advisory board and campus leaders were present for this celebration.

We also initiated an effort to make designing, proposing, and hosting Working Group meetings more accessible and transparent. Faced with too many events that were mostly driven by the interests of the program directors, we developed a protocol for any member of the community to propose an event that emphasizes cross-disciplinary conversations. A Steering Committee composed mostly of our Fellows reviews these proposals and approves events that best meet the criteria of fostering dialogue around common problems. The schedule for next year already features several meetings showcasing Fellows' research.

Based on the success of the Training Program, faculty from the Molecular, Cellular, and Developmental Biology (MCDB) asked Science & Justice for assistance in developing

an ethics curriculum. The MCDB department has a grant from the NIH to provide their students with extended Responsible Conduct of Research training. The faculty member, Susan Strome, felt that the standard programming was not adequately engaging or interdisciplinary. To assist them, we modeled Science & Justice methods and conversations with several visits to their seminar to discuss ethical and social components of research practices. After soliciting the students' interests, we have also scheduled three events to be co-hosted by the Working Group that examine ethical, social, and political aspects of biomedical research, including what researchers owe to donors of personal biological material, ethical issues specific to developmental biology, and how the future of biomedical research will be funded. This collaboration has generated interest from other departments and will provide a pilot example for structuring future iterations of the Training Program.

We have also begun an overhaul of our website, with an emphasis on showcasing the Fellows' research and providing a forum for sharing the many research projects initiated by Science & Justice members.

Finally, the opening of the Research Center has provided a number of opportunities for exploring, expanding, and assessing the methods and philosophies at the core of Science & Justice. Pursuing new grants and writing reports and academic papers that summarize our efforts has prompted us to more clearly articulate the commitments that animate Science & Justice. While 'science and ethics' and 'science and society' have become routine topics for many universities, 'science and justice' has been a more fruitful and provocative conjunction here.

History of Science & Justice

The Science and Justice Working Group formed in September of 2006 with the goal of expanding UCSC's historical focus on social justice to include questions about the formation of science and technology, and related public-policy debates. Since its inaugural year, the group has added many members from all University divisions, continued to build cross-divisional intellectual and institutional relationships, and developed new strategies for interdisciplinary collaborations, all while hosting well attended events discussing topics of local importance and national and international relevance.

The initiative grew out of conversations between faculty in the Division of Social Sciences (Jenny Reardon, Sociology; Michael Hutchison, then Dean of the Division of Social Sciences), the School of Engineering (David Haussler, Biomolecular Sciences and Engineering (BMSE); David Deamer, BMSE; Steve Kang, then Dean of the School of Engineering), and the Humanities Division (Donna Haraway, History of Consciousness; Karen Barad, Feminist Studies). The Group recognized early on that to be successful, it would have to emerge from meaningful interdivisional dialogue, involving all five divisions of the University. In the academic year 2006-07, the group focused on building this dialogue. Although at the beginning of the year, the group

consisted mostly of Social Science and Humanities faculty and graduate students, by the year's end, the thirty or so active members of the group (faculty, staff, and graduate students) were almost evenly split between the Social Science, Engineering, Arts, Physical and Biological Sciences and Humanities divisions. The activities the Group pursued to build this interdivisional conversation consisted of a research seminar, a Critical Friends Series, a movie screening series, and end-of-year meeting.

In the 2007–2008 academic year, SJWG built on its success in interdisciplinary events and dialogues, increasing our regular attendance rate and hosting multiple well-attended public events. Our ability to encourage dialogue among people with varying intellectual background was facilitated by two decisions. First, we moved toward a problem driven model of inquiry. Rather than focusing on large, theoretical questions, we used specific problems as a concrete object around which we could discuss the major themes of our group. This model gave all members—social science, humanities, engineering, and natural sciences—entree into the discussions. Second, as the Group developed more familiarity between core members, we found that a habit of “red-flagging” jargon or assumptions that members found disconcerting improved our dialogues.

In the 2008-2009 academic year, SJWG continued to sponsor interdisciplinary programming, hosted several well-attended symposia, and wrote a successful grant to the Ethics Education in Science and Engineering division of the National Science Foundation (NSF). We continued to build on the problem-based model of inquiry adopted in the previous year and emphasized the small symposium format that worked well in the previous year's Race Work event. These events drew in larger than usual audiences, including from science and engineering departments that have not been substantial participants in SJWG's programming previously. The NSF grant (NSF#[0933027](#), “Ethics and Justice in Science and Engineering Training Grant”), written by Jenny Reardon with substantial help from Jake Metcalf (then graduate student in Philosophy and hired as a GSR to assist the development of the working group) and feedback from Zia Isola (CBSE) and Karen Barad (Feminist Studies) was awarded funding to develop a training program for graduate students that will sponsor research on ethics and justice in scientific practice.

The intellectual foundation of the training program—that ethics and justice are inextricable components of scientific practice and cannot be analyzed separately—are the same as those of SJWG. Furthermore, the process of developing the program cemented relationships between SJWG, academic departments in the natural sciences, engineering, humanities, and social sciences. The pedagogical core of the Training Program emphasizes that issues of justice and ethics are integral to the doings of scientific and engineering practices and not simply implications of those practices. This position, informed by Science and Technology Studies scholarship from the last decade, allows us reframe ethics education as a matter of analyzing scientific and engineering practices in situ in terms of their historical, social, and political contexts. This differentiates the Training Program from the most common modes of ethics education in science and engineering that emphasize applying pre-determined ethical tools to

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strictly-bounded problems. By shifting the locus of moral action from the individual scientist to a broader community of practice we encourage collaboration on shared problems and across disciplinary boundaries.

In the 2009-2010 academic year, Science & Justice began to implement the NSF grant, and continued its efforts to formalize our successes and create closer relationships across the Divisions at UCSC. Although SJWG and SJTP remained separate organizations, the synergistic relationship between them facilitated new research and programming, attracted new regular members, and encouraged new collaborations between faculty and graduate students between different divisions. The inaugural cohort of Science & Justice Fellows proposed new research clusters and events. Within the regular research seminar SJWG continued to build on research and collaboration methods, emphasizing problem-driven inquiry. Among our best-attended events was a collaboration with UCSC's branch of Women In Science and Engineering and a conversation about geoen지니어ing, both of which grew organically from the interests of SJWG members and drew new members from the sciences and engineering. Additionally, SJWG hosted nearly twenty colloquia, seminars, and symposia which included international scholars, researchers from private industry, faculty from other UC campuses, and UCSC faculty from every division. We also developed a new website infrastructure that was launched in Fall 2010 designed to increase the visibility of Science and Justice and to host collaborative blogs. SJWG and SJTP also hosted a visiting scholar and postdoctoral fellow for the first time this year, marking UCSC and the Science & Justice networks as a location for producing innovative research.

In the 2010-2011 academic year, SJWG saw a substantial increase in attendance at regular SJWG events, in part assisted by the cohorts of SJTP Fellows who invited colleagues and professors from their departments and hosted events with wide appeal across the university. With the addition of the second cohort which began with SJTP in Spring term, the SJTP saw the fulfillment of several key goals of the grant: to broaden the constituencies of Science & Justice, financial and intellectual support for original research, and the creation of new opportunities for interdisciplinary collaborations. The second cohort of the Training Program began their coursework in Spring 2011.

In the 2011-2012 academic year, the Science & Justice Research Center was launched to consolidate the growing number of initiatives hosted by the Science & Justice community. The SJRC provides a hub for Working Group programming, the Training Program, visiting faculty and graduate students, research projects, grant writing support, and collaborations with science and engineering departments. The Research Center also appointed co-Directors and hired paid staff for the first time, an Assistant Director and an administrative assistant. It also provides a permanent physical space to Science & Justice, with a common room, an administrative office, and a visitors' office. The common room was made available to all Fellows for impromptu meetings and colloquia, in addition to providing a space for hosting informal bi-weekly meeting focussed on Fellows' research. The Research Center also initiated several efforts aimed at receiving more robust guidance from members and external advisors, and focussed on making programming decisions more democratic and transparent.

Working Group Themes

The Working Group has developed a series of themes that guide our research and programming.

1) Public Knowledge/Science

Over the last ten years, a number of major technoscientific endeavors have run into grave political problems, often related to lack of public trust in scientific institutions or criticism of how scientists handle data. Examples include the Climategate scandal, where the detailed practices of climate scientists processing and cleaning data were called into question, and the Human Genome Diversity Project, where common practices in population genetics became the object of international outrage.

What this teaches us is that some of the most important questions facing governments and universities require that the meaning and contours of public science/knowledge be re-forged to respond to the new modes of democratization (such as those enabled by new digital media), privatization (such as the commercialization of genetic information), and globalization (such as the creation of transnational scientific resources and international science communication and policy advocacy). What 'private', 'public' and indeed 'knowledge' mean in these new contexts is a concern of many Science and Justice members, and has emerged as a theme of the working group. Many felt this would be a good theme for the Center as it is of interest to faculty from all five divisions of the University and is critically important to the successful research of all of us.

2) Sustainable Lives in Uncertain/Indeterminate Times

Many contemporary societal problems require making decisions in conditions that are uncertain/indeterminate, and where more precise information may only make the problem worse. The working group has developed particular intra-divisional capacities for addressing uncertain/indeterminate problems in a wide variety of fields, such as climate change models, fisheries management models, water policy, and gene mapping technologies. It has developed particular skills in elucidating different cultures of uncertainty, and how different understandings and approaches to uncertainty affect the ability of scientists, policy makers, activists, NGOs and other key actors to work together to address these problems. Members of the group, led in particular by Karen Barad, have also helped to forge the analytics needed to distinguish between problems of uncertainty and those of indeterminacy.

3) Response-able Science and Engineering

The lessons learned and institutional infrastructures built by the Science & Justice Training Program are a tremendous asset for the University. The question now is how to translate these strengths into novel approaches to credible and sustainable Responsible

Conduct of Research (RCR) programming. In particular, we hope to generate RCR policies that, rather than being bureaucratic hoops, are meaningful practices that build the capacity of UCSC researchers to respond to moments in which doing good science requires addressing questions of ethics and justice. We want to train people in demonstrating substantive ethical practices through their research and communication practices, rather than in formally ticking off boxes while failing to engage with the substance because they are too busy.

4) The meaning of justice in a technoscientific, post-human age

What does it mean to think about justice and democracy in an age where agency can no longer be conceived as human-centric activity? When technoscience mediates and indeed activates so much of social life, how should we parse out responsibility and accountability? Who is the “we” who decides? These questions might be at the heart of a theme on post-human justice, or could just cut across all the Center’s themes.

5) Emergent Themes

We expect that through continued collaborations of SJ faculty and grads, new areas of research will emerge. One possibility in particular is the anthropocene, the geological era which marks the impact of human action on biogeochemical processes at a global level. A number of us are interested in thinking through what it means to do research act politically in the anthropocene, including by asking what kinds of research questions get ignored when environmental crises make previous research seem irrelevant. A second emerging area of interest is around scale: for example, small objects become of large significance at moments of scandal or technological failure. A number of us are concerned with thinking about scale in our research projects and this could be a theme to explore over the next year.

IV. Summary of Activities

Below is a summary of SJWG hosted and sponsored events in the academic year 2009-2010.

SJWG Steering Committee

The Steering Committee reviews and selects proposals for SJWG programming. It consists of SJRC leadership and staff and SJTP graduate student Fellows.

The following people served on the Steering Committee in 2010-2011:

Elaine Gan, Digital Arts and New Media
Colin Hoag, Anthropology
Martha Kenney, History of Consciousness
Andrew Mathews, Anthropology
Jacob Metcalf, SJRC
Jenny Reardon, Sociology
Kathleen Uzilov, Earth and Planetary Sciences
Tiffany Wise-West, Environmental Studies

Advisory Boards

Our advisory boards provide input of the long-term goals of the Science & Justice community and help identify opportunities for funding and new collaborations. The Internal Advisory Board consists of UCSC faculty and meets several times per year, in addition to helping review applications and funding requests from Fellows and potential visitors. The External Advisory Board currently consists of distinguished scholars in science and technology studies with expertise in institution building and familiarity with our program. A goal for the next year is recruiting new board members from industry, foundations, and community groups.

Reports from this year's advisory boards meetings are available in the Appendix below.

Internal Advisory Board Members

Nancy Chen (Anthropology)
Ben Crow (Sociology)
Ed Green (Center for Biomolecular Sciences and Engineering)
Herman Grey (Sociology)
Warren Sack (Digital Arts and New Media)
Susan Strome (Molecular, Cellular, and Developmental Biology)
Anna Tsing (Anthropology)

External Advisory Board Members

Geof Bowker (UC Irvine)
Joe Dumit (UC Davis)
Cori Hayden (UC Berkeley)
Sally Lehrman (Santa Clara)
Laura Mamo (San Francisco State)
Janet Shim (UC San Francisco)
Kim Tallbear (UC Berkeley)
Fred Turner (Stanford)

Visiting Scholars & Postdoctoral Fellows

Postdoctoral Fellow

Jacob Metcalf

Visiting Scholars

Vibeke Pihl, Medical Centre for Science and Technology Studies, Department of Public Health, University of Copenhagen

Science and Justice Colloquia

Below are descriptions of the Science and Justice colloquia for 2010-2011.

A Very Brief Introduction to Risk

John Kadvany (Applied Decision Analysis, Inc.)

October 5, 2011

John Kadvany joined us to discuss the concept of risk. Oxford University Press recently published John's co-authored book on risk, entitled *Risk: A Very Short Introduction*. Given that so many of us in the group are interested in thinking well about risk—whether in the context of genomics or the climate or engineering design—we were particularly pleased to have John kick the year off.

Kadvany often works on project teams organized by an engineering company in charge of a large public works project. His role is to design and help implement a [decision process](#) in which engineers, external stakeholders, lawyers and regulators work their collective way through multiple competing options in an efficient, democratic and cooperative manner. He will design an [analytical framework](#) that's useful all around including the measurement techniques which can be used to accommodate relevant models, data, and professional or lay judgment of various qualities. Often these processes lead to a group "opinion survey", a combined technical-policy document which summarizes stakeholder perspectives. His methods combine the analytical techniques of multiple values decision analysis with the approaches developed in the last two decades through the [public participation](#) movement.

Comparative Tinkering: A Roundtable

October 25th, 2011

Speakers: Karen Barad (UCSC, Feminist Studies), Alan Christy (UCSC, History), Lawrence Cohen (UC-Berkeley, Anthropology), Andrew Matthews (UCSC, Anthropology), Danilyn Rutherford (UCSC, Anthropology), Warren Sack (UCSC, Film & Digital Media), Anna Tsing (UCSC, Anthropology)
Facilitators: Peter Lutz (IT University of Copenhagen, Technologies in Practice) and Heather Swanson (UCSC, Anthropology)

Comparisons are utterly pervasive in anthropology and its neighboring disciplines, including science studies and the sciences more broadly. We compare incessantly, yet we rarely theorize explicitly about our comparative practices. For instance, how do we determine the whats and the whos of our comparisons? At this roundtable we aimed to unfold these practices by exploring the risks and virtues of comparison, especially those emerging in empirical travels like ethnographic fieldwork. What are the analytical detours of our comparative ventures? What work is required to render objects stable and comparable? What are the natures of the comparable beings we evoke and harness? Stability is arguably one of the most once deeply problematic yet virtually inescapable aspects of scientific comparison. Yet how might we make do with comparisons – themselves knots of relations – to reveal their underlying messy travel from desk to field and back again? We explored the possibilities of tinkering with comparisons so that they might destabilize and move.

Sponsored by: SJWG and the Anthropology Department

Modelling pigs and humans: Exploring the practices of models across sciences

Vibeke Pihl (Medical Centre for Science and Technology Studies, Department of Public Health, University of Copenhagen)

October 19, 2011

Vibeke Pihl's research addresses how connections between humans and animals are shaped in contemporary biomedical research on human health. During an ethnographic multi-sited fieldwork, Vibeke has followed a group of Danish biomedical researchers working to establish a pig model for human obesity surgery. In biomedicine, the pig is increasingly established as a preferred model organism in biomedical research on human obesity due to an argued biological resemblance between pigs and human anatomy and physiology. The topic of the SJWG event concerned an analysis of how the use of pigs as models for humans does not rest solely on biological connections, but requires social, moral, economical and cultural connections to support the choice of the pig as the appropriate model for obese human bodies. In addition, the presentation addressed how models are practiced in biomedical science and social science. Drawing upon fieldwork, the presentation focussed on how the analysis of the biomedical

researchers' establishment of a pig model prompt a simultaneous crafting of a social scientific model of human-animal relations. Vibeke asked which connections between humans and pigs are included and excluded in the research practices of biomedical scientists' and the practices of social scientists like her own. With this presentation, Vibeke provided an opening for a stronger mutual engagement between researchers across sciences working with animals as models of humans.

Information, but Meaning? The Value of Genomics

Andro Hsu (GigaGen Inc.) with discussion by **Ted Goldstein** (UCSC, CBSE) and **Whitney Boesel** (UCSC, Sociology)

November 9, 2011

Andro Hsu (VP of Products at GigaGen and former science writer and policy advisor at 23andMe) joined us for a discussion of what we are learning—both about policy/society and biology—as increasing resources are put into turning the ever growing amounts of genomic information into something of value. Ted Goldstein, PhD candidate at the UCSC Center for Biomolecular Sciences and Engineering, and Whitney Boesel, PhD candidate at UCSC in Sociology) provided a response to Hsu's presentation.

Another World is Plantable! Part 4: Documentary on Community Gardening and Food Justice

Ella von der Haide (Director)

October 28, 2011

Director of the the film series *Another World is Plantable!* Ella von der Haide joined us to screen the fourth installment of the series and participate in a Q&A session. In a series of four documentaries, Ella von der Haide features urban community gardens and their connections to emancipatory social movements in South Africa, Argentina, Germany and North America. Urban community gardening is a phenomenon that is spreading throughout the world. At the core of the films are gardening activists who explain how and why their gardens are a "green oasis" within the city, as well as projects of resistance that bring "another world" into being. The films also show the critical and ambivalent ways in which the gardening movements can be instrumented by neoliberal regimes.

North America has a vibrant community garden scene that is currently developing into a broad social movement for food justice. Through the local production of ecological food for subsistence and for sale at farmers' markets, community gardeners not only construct an alternative to the agro-industrial business and "food deserts", they simultaneously create a new local self-reliance and new discourses on justice. The community gardens portrayed in this film, in New York, Detroit, San Francisco and Vancouver, are all engaged in different social change processes, from anti-racist resistance and post-colonial healing to indigenous self-determination and queer-feminist environmental politics.

More information on the film and research is available at: www.communitygarden.de

Sponsored by: SJWG, Film & Digital Media, and Center for Agroecology and Sustainable Food Systems

Eating Information? Food and Metabolism in Epigenetic Perspective

Hannah Landecker (UCLA Center for Genetics and Society)

January 26, 2012

Epigenetics has turned food and its metabolism into a problem that is not just about how the body turns food its basic components—carbohydrates, fat, and protein—but how food acts as a signal of the biological and political environment. Hannah Landecker will explore what this transformation of metabolism and epigenetics reveals about food, environmental politics, and the increased salience of metabolism as a sight for biological understanding and political and moral contestation.

Scientific Research on Ayahuasca and Health

Bia Labate (State University of Campinas)

January 31, 2012

[Beatriz Labate](#) has studied the scientific and social features of psychoactive substances for over 15 years. In this meeting we discussed the situation surrounding the compound ayahuasca, a psychedelic used in both medical and spiritual contexts throughout the Americas. By exploring the frontiers and limits between "therapeutic" and "religious" uses of ayahuasca (and their complicated legal implications) we will better understand the relationship between diverse forms of knowledge production associated with what have been called "sacred technologies."

Cells, Race and Stories: A Discussion with Priscilla Wald about Henrietta Lacks and the HeLa Cell Line

Priscilla Wald (Duke, English and the Center for Genome Ethics, Law and Policy)

February 6, 2012

Priscilla Wald joined us to discuss the narratives that have arisen around Henrietta Lacks and the HeLa cell line. Wald, a literature scholar, drew our attention to the particular contours of how race, medical research, and social justice have come under discussion by the public and academia alike. For example, Wald questioned why Lacks' ultimately random medical condition has been held up as evidence that her family deserves medical care, as opposed as evidence that all persons are both potential sources of medical knowledge and subject to illness and therefore deserve equitable access to medical care. By focussing on the way that Henrietta Lacks' story has been told, Wald was able to highlight overlooked complexities in the social conditions of

Lacks' life and the ethical problems resulting from the research conducted on her cancer cell line.

This event was co-sponsored by Cultural Studies, Center for Biomolecular Sciences and Engineering—Research Mentoring Institute, and the Molecular, Cellular and Developmental Biology Department.

The Black Panther Party and The Fight Against Medical Discrimination

Alondra Nelson (Columbia, Sociology)

March 12, 2012

Between its founding in 1966 and its formal end in 1980, the Black Panther Party blazed a distinctive trail in American political culture. The Black Panthers are most often remembered for their revolutionary rhetoric and militant action. Here Alondra Nelson deftly recovered an indispensable but lesser-known aspect of the organization's broader struggle for social justice: health care.

The Black Panther Party's health activism—its network of free health clinics, its campaign to raise awareness about genetic disease, and its challenges to medical discrimination—was an expression of its founding political philosophy and also a recognition that poor blacks were both underserved by mainstream medicine and overexposed to its harms.

Nelson argued that the Party's focus on health care was practical and ideological and that their understanding of health as a basic human right anticipated current debates about the politics of health and race.

This event was co-sponsored with Sociology and Critical Race and Ethnic Studies.

Can Science Have Progressive Goals?

Alondra Nelson (Columbia University, Sociology)

March 13, 2012

Narratives of scientific progress are often paired with narratives about political progress, suggesting that the expansion of scientific knowledge always—or at least generally—leads to the betterment of humankind as a whole. But many socially disadvantaged and oppressed peoples contend that such "progress" is distributed unevenly and often comes at some cost to them. Alondra Nelson shared some of her research on Black politics and genetic genealogy to open a discussion on whether science can have progressive ends, if there can truly be a "science for the people," and how science and justice can have paired or oppositional goals.

Herman Gray (Sociology) was a respondent.

Too Many P's? Personal, Political, Publics, and Potatoes

5 April 2012

This roundtable was a spirited conversation about the politics of food and kinship—amongst other world-changing matters. At this Science & Justice Working Group event, [Ruth Ozeki](#) read from her novel, *All Over Creation*, joined at the table by [Nancy Chen](#) (Anthropology), [Julie Guthman](#) (Community Studies) and [Steve](#) Gliessman (Environmental Studies). [Joan Haran](#) (Cesagen at Cardiff University) hosted this feast of ideas.

We discussed public engagement with agricultural technology, genetic modification of crops, non-violent direct action and the creative use of generative metaphors. We teased out some relationships between genes, gender and genre along the way, and consider how fiction can help us reimagine and reconfigure food systems.

Ruth Ozeki is a filmmaker, novelist, and novice Zen Buddhist priest. Her award-winning novels, *My Year of Meats* and *All Over Creation*, both New York Times Notable Books, have garnered international critical acclaim for their ability to integrate issues of science, technology, environmental politics and global popular culture into unique hybrid narrative forms. Ruth worked in commercial television and media production, including low budget horror, for over a decade, and her independent films have shown at Sundance and on PBS. Her short fiction and essays have appeared in a number of anthologies, magazines and newspapers, and she has taught and lectured at universities and colleges around the world. A long-time meditator, Ruth was ordained as a Soto Zen Buddhist priest in 2010. She and her husband, environmental artist Oliver Kellhammer, divide their time between New York and Cortes Island, B.C.. Her new novel, *A Tale for the Time Being*, will be published by Viking Penguin in 2013. Her website is www.ruthozeki.com.

Authority, Expertise and Power in Mexican Forests

Andrew Mathews (UCSC, Anthropology)

May 22, 2012

Greater knowledge and transparency are often promoted as the keys to solving a wide array of governance problems. In *Instituting Nature*, Andrew Mathews describes Mexico's efforts over the past hundred years to manage its forests through forestry science and biodiversity conservation. He shows that transparent knowledge was produced not by official declarations or scientists' expertise but by encounters between the relatively weak forestry bureaucracy and the indigenous people who manage and own the pine forests of Mexico. Mathews charts the performances, collusions, complicities, and evasions that characterize the forestry bureaucracy. He shows that the authority of forestry officials is undermined by the tension between local realities and national policy; officials must juggle sweeping knowledge claims and mundane

concealments, ambitious regulations and routine rule breaking.

Moving from government offices in Mexico City to forests in the state of Oaxaca, Mathews describes how the science of forestry and bureaucratic practices came to Oaxaca in the 1930s and how local environmental and political contexts set the stage for local resistance. He tells how the indigenous Zapotec people learned the theory and practice of industrial forestry as employees and then put these skills to use when they become the owners and managers of the area's pine forests--eventually incorporating forestry into their successful claims for autonomy from the state. Despite the apparently small scale and local contexts of this balancing act between the power of forestry regulations and the resistance of indigenous communities, Mathews shows that it has large implications--for how we understand the modern state, scientific knowledge, and power and for the global carbon markets for which Mexican forests might become valuable.

Conferences and Symposia

Are You My Data?

A Conference hosted by the Science & Justice Working Group, the UCSC Office of Research, and the UCSC Cancer Genomic Hub
May 8, 2012,
UCSC University Center

With a human genome sequenced and a map of variable sites in that genome created, governments and many other public and private actors now seek to make genomic data relevant to health, medicine and the society. However, to do so they must navigate the conjunction of two different approaches to data. Within the biomedical domain there are important, well-articulated infrastructures and commitments arising out of concerns about individual rights, patient privacy and the doctor-patient relationship that limit access to biomedical data. This stands in stark contrast to the culture of open access forged by those who worked on the Human Genome Project, and that has continued to be a central commitment of ongoing Human Genome research. Thus, architects of the genomic revolution face competing, complex technical and ethical challenges that arise from this meeting of these domains with substantially different ethos. Additionally, the rise of social media has led to a broad and contested discussion about the proper relationship between persons and data and who profits through access to it.

The workshop mapped out the challenges of building and controlling genomic data architectures that are responsive to these conditions. Rather than suggesting that either openness or privacy is the answer, the workshop will ask which kinds of openness and privacy might be possible and adequate, and in which contexts? Further, who has the authority to decide? Who can/should authorize the flow of data and what forms of consent are required? What kinds of flow of data should be allowed

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(e.g., ones that lead back to persons, etc.)? Finally, the workshop will consider questions around where and how data should be accessed. Is “the cloud” a viable option? What other options exist to manage deluging data, and what ethical and material challenges do they present?

Speakers

Hosted by **Jenny Reardon**, Associate Professor of Sociology, UCSC

Co-hosted by **Bob Zimmerman**, Program Director, UCSC Cancer Genomics Hub

David Winickoff, Associate Professor of Bioethics and Society, UC Berkeley

Malia Fullerton, Associate Professor in the Department of Bioethics & Humanities at the University of Washington School of Medicine

Mike Keller, Director of Technology and Software Development, Sage Bionetworks

Schedule:

1:00-2:30 Panel 1: The Collision of Privacy and Openness
2:30-2:45 Break
2:45-4:15 Panel 2: Creating and Sustaining Trust
4:15-4:30 Break
4:30-5:00 Agenda Setting for Future Directions

Science & Justice Research Center Grand Opening Event and Poster Session May 31, 2012

To celebrate the opening of the SJRC and the successes of our Training Program Fellows, the SJRC hosted an open house in our new offices. Jenny Reardon provided opening remarks, and noted the breadth of support provided by many members of the Science & Justice community. The Fellows' presented their research in a playful and provocative take on a poster session. Some prepared brief discussions around a question that emerges from their research and include a concrete case from their work. Others conducted interactive games and artistic projects.

IV. Future Directions and Proposed Activities

- Expand pedagogical and programming collaborations with S&E departments
- Recruit external advisory board members
- Establish efforts for funding, especially with foundations
- Develop models for hosting and supporting faculty research projects
- Host visiting scholars

V. Addenda

Selected Rapporteur Reports

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

Ted Goldstein

January 12th, 2012

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.

Rapporteur: Martha Kenney, History of Consciousness

Eating Information? Food and Metabolism in Epigenetic Perspective

Hannah Landecker

January 26th, 2012

Hannah Landecker, Associate Professor at the Society and Genetics Institute at UCLA, spoke to us about her new book project, *American Metabolism*. Although the field that she is interested in is called “nutritional epigenetics,” Landecker has reframed this research as belonging to a longer tradition of studying “metabolism.” For Landecker, metabolism is about trans-substantiation, one substance being changed into another. In recent nutritional epigenetics research, we see new pathways of trans-substantiation. For example, Landecker showed us an article with a mother mouse and her pups captioned: “They are what she ate.”

After giving us an overview of the epigenetics research, Landecker focused on the theory that gene expression is regulated by signals from the environment, creating different phenotypes in the presence of genetic sameness. In research on maternal anxiety behaviors, trans-generational endocrine disruptors, and nutritional effects, we witness how licking, plastic, and food, respectively, are presented as environmental signals. Landecker believes that the category of “signal” is both incredibly productive and not very precise; it is under-theorized by scientists and STS scholars. She wonders if, in the field of nutritional epigenetics, “the social” has become a signal.

In the last part of her talk Landecker compared studies of metabolism in the late 19th century to contemporary research in nutritional epigenetics. Early accounts of metabolism, such as those by Thomas Huxley, figured metabolism as a set of processes the function like a factory or inner laboratory. Landecker argued that this was an industrial paradigm for an industrial era. Key figures and areas of emphasis were: energy, manufacturing, substrate, waste accumulation, labor and fatigue. In the post-industrial era a new set of figures has arisen: Information, regulation, signal (timing), functional asynchrony, sleeping and aging. She strongly believes that changes in the framework for understanding metabolism changes what experiments are conducted and what kind of knowledge is created. She concluded by arguing that it is important to track and understand these changes as they are happening.

During the Q&A key questions revolved around the historical specificity of nutritional epigenetics and issues of social and ethical responsibility arising from this new framework for metabolism. Jake Metcalf compared responsibility in the factory model with the post-industrial model. In the factory model, he argued, one person is responsible for the consumption of food; in the post-industrial regulatory model, many-many humans and non-humans are responsible. How do we delegate responsibility? Playing off of Landecker’s characterization of epigenetics belonging to a biology of the in-between, Jenny Reardon suggests that it is difficult to regulate the in-between.

Metcalf replied that we just don't have the models to make decision-making viable. Landecker characterized this problem as being burdened by complexity. This led to the question of what kind of "actionable knowledge" is created by metabolism research and the figures that underpin it. Responding to a question by Julie Guthman about the DES growth hormone used in cattle farming, Landecker argued that the current DES problem was caused by the industrial model, which tried to produce as much meat possible for as little feed as possible. In other words, the metaphors of a previous generation of science created the material conditions of today's farming. The remaining questions continued to play about this interrelationship between metaphor and materiality. Elaine Gan, for example, suggested that we think about metabolism metaphors in Marx. Landecker explained that these were not only metaphors; Marx was deeply interested in the science of metabolism and believed, for example, that the Irish peasants would not revolt because they lived off of potatoes. This rich discussion foregrounded the importance of tracking the relationship between figures, history, materiality, knowledge, and production when considering questions of science and justice in hot new scientific fields like epigenetics.

Rapporteur: Martha Kenney, History of Consciousness

Scientific Research on Ayahuasca and Health

Bia Labate

January 31st, 2012

Bia Labate, PhD Candidate in Social Anthropology at the University of Campinas, spoke to us about the public debate and competing discourses around Ayahuasca, a psychoactive brew of two plant extracts used around the world in shamanism, healing, sorcery, divination, warfare, and hunting. Because one of the plants, *Psychotria viridis*, contains the Schedule I narcotic DMT, Ayahuasca (the bush, the extract from the bush, and the preparation) has been subjected to a number of diverse regulations worldwide. Labate showed how these regulations are embedded in different local and global discourses, producing new meanings and uses for Ayahuasca. In Brazil it is allowed for ritual and religious use, though not therapeutic use. Whereas in Peru it is considered the "traditional medicine of the indigenous people" and protected as cultural heritage. In the U.S. the regulation of Ayahuasca created tensions between religious freedom and drug laws; for the moment religious freedom has prevailed. While in France Ayahuasca was connected to brainwashing by cults and sects, creating a total ban that includes not just the extract but the bush as well. Through these examples, Labate showed how Ayahuasca became entangled in discourses of religious liberty, traditional medicine, personal use, and religious cults.

In the second half of her talk Labate discussed competing narratives of therapeutic vs. religious use and harm vs. healing. She showed how these categories were difficult to define and took on different contours based on national and cultural specificities. These categories raise important and difficult questions: How do you define a religion? How do you insert traditional medicine into a public health system? Is scientific legitimization

the only route to prove therapeutic properties? How can we define and police cultural authenticity? As different groups try to answer these questions, Labate argues that there is a reciprocal appropriation of legal, anthropological, biomedical discourses. For example, the anthropological category of “ceremony” is taken up by shamans who prepare Ayahuasca. As a sacred ceremony rather than a practice of everyday life, “the Ayahuasca ceremony” is something that can be marketed at pan-indigenous festivals. Labate concluded her talk by arguing for the space of the social sciences in this debate; she believes that if Ayahuasca is studied only in a biomedical framework that we lose important insights into cross-pollination of discourses and identities that happens in this collision of legal, biomedical, and religious categories.

In the Q&A members of the audience were interested in categories that betrayed the simple equation of Ayahuasca with DMT. Andrew Matthews, drawing from his fieldwork on forestry in Mexico, suggested that defining Ayahuasca as more than just the drug could be important for these questions of regulation. Guillermo Delgado suggested that it was necessary to use specific indigenous terms for Ayahuasca use rather than use anthropological or pan-indigenous terms like “shamanism.” Martha Kenney asked if the term “sacred technology” that appeared in the newsletter description of the talk was a useful term in Labate’s work. Craig Reinerman asked about the value of the sociological categories of “set and setting” for understanding how “the same drug” can have different effects in different cultures.

As Labate answered these and other questions, she provided a greater sense of the complexity of Ayahuasca worlds. She explained, for example, how *psychotria viridis* was introduced to Hawaii (and the crisis of regulation that ensued), how she tried to understand Ayahuasca as inducing the experience of “becoming plant,” how “shamanism” is a term that is embraced by many indigenous Ayahuasca preparers, and how environmental regulations were taking the place of drug regulations in some contexts. By illustrating the complexities involved in the global understanding and regulation Ayahuasca, Labate illustrated how the skills of social scientists can contribute to the ongoing dialogue.

Rapporteur: Martha Kenney, History of Consciousness

Cells, Race and Stories: A Discussion about Henrietta Lacks and the HeLa Cell Line

Priscilla Wald

February 6th, 2012

Priscilla Wald, Professor of English at Duke University, spoke to us about the ethical implications of the Henrietta Lacks case, which has recently become widely known due to the popularity of Rebecca Skloot’s book, *The Immortal Life of Henrietta Lacks*. Henrietta Lacks was a black woman born in 1920 in Virginia, whose cancer cells were used to develop an immortal cell line known as HeLa cells. Although these cells became important to biomedical research, Lacks herself died of cancer on a segregated

hospital ward in 1951. Neither Lacks nor her family knew that the cells were taken from here nor did they profit from the HeLa cell line. This case has become a touchstone for many people in thinking about bioethics in the 20th and 21st centuries.

Wald argued that many of the stories about Lacks do not help us address key issues of science and justice. For example, some stories center around medical wrongdoing; however, it is not clear what the specific wrongdoing was or how it could have addressed. When accounts focus on wrongdoing they often imply that Lacks should have been treated better because she had “special cells.” According to Wald, these stories miss the role that institutionalized racial inequality played in the Lacks case along with hundreds of thousands of other, less spectacular cases.

Wald’s own approach to narrating the Henrietta Lacks is located in a tradition that focuses on structural violence. Thinkers in this tradition map the differential effects of the power through stratified populations, analyze the language through which these structures appear to be unchangeable, highlight where we have the responsibility to change it, chart the continuing abuses of structural inequality, and call for reparative measures in the present for violence of the past. Wald wants to use this model of critique as a means to redress (which has flourished in ethnic studies) as a model for understanding scientific change and biopolitics.

Wald believes we need to pay attention to what kinds of stories are being told about Lacks and the HeLa cell line and think about how structural racism figures in these stories. Wald gave examples of how, after the disclosure that the cell line was developed from Lacks’ tissue, that the cells themselves became gendered, racialized and sexed. When it appeared that HeLa cells were making their way into other cell lines and biological specimens in laboratories, negative language was used to describe the situation. It was said that HeLa cells were “virulent” and “ruined” other cell lines. Racial overtones were especially evident in a case where a white baby’s cells were “contaminated” with HeLa cells and appearing biologically “black,” leading to racist humor about sexual promiscuity and uncertain paternity. When HeLa cells showed up in Russian cell lines, they were figured as out of control American agents, cellular Mata Haris.

Wald argued that these racialized stories are taking the focus off of real-world solutions to biomedical disparity. For example, talking about the Lacks case in terms of “bioslavery,” spectacularly summoned the past to conjure a dystopian future where our tissues were no longer our own property. According to Wald these kind of stories deflect attention from how historical racism is still at work in the present. She argued that we should be having a better debate about the healthcare system rather than entertaining anxieties about a sci-fi future. Wald concluded by arguing that we should pay attention to institutional racisms and structural violence and endeavor to turn critique into change. We need better stories that combine this kind of critique with a belief in new possibilities.

During the discussion audience members were interested in what Wald meant by stories and what it means to intervene at the level of the story. Sandra Harvey, who was struck by the pain of Lacks' family in Skloot's book, asked how scientists could understand their pain as a way into the justice questions. Jake Metcalf wondered if scientists have particular justice obligations in biomedical matters. Donna Haraway argued that scientists are more responsible because knowledge carries obligations and stories are important because they evoke the ability to care in thicker ways. One biologist wondered what the "take home message" of the talk was and what he was capable of doing to promote social justice. Martha Kenney affirmed her belief in storytelling, but wondered what other caring practices scientists and others could do alongside telling good stories. The discussion foregrounded the complex relationship between stories, science, and biomedical justice.

Rapporteur: Martha Kenney, History of Consciousness

Can Science Have Progressive Goals?

Alondra Nelson

March 13th, 2012

Alondra Nelson, Associate Professor of Sociology at Columbia, spoke to us about DNA testing in African American communities. She framed her talk with articles from Nicholas Wade and Craig Venter that argued that genomics has not lived up to its original hype. Nelson said that despite these pronouncements there is currently a lot going in genomics outside of medicine. She suggested that the logics of DNA analysis have made their way into our culture as social and political technologies.

Nelson used the popularity of the genetic ancestry testing company "African Ancestry" as her primary example. When she conducted her fieldwork, Nelson was interested in "how and why African Americans would put their DNA in an envelope and send it to a stranger," especially given the vulnerability of African American communities in the history of American biomedical institutions. She found that "African Ancestry" appealed to pre-existing genealogical organizations, whose members were mainly middle class women, ages 50+ engaged in practices of "kin keeping." In this context Nelson became interested in what she calls "the social life of DNA," the way that DNA and genetic technologies takes on meaning in social worlds. "The social life of DNA" serves as a reminder that genetic technologies are not only one thing (e.g. bio-informatic technologies tied to histories of oppression) but take on different political possibilities in different historical and social contexts.

Nelson also found that African American consumers were drawn to "African Ancestry" because of the involvement of a scientist named Rick Kittles. Early in his career Kittles had been instrumental in contesting how the remains in an African American burial ground in Lower Manhattan were classified. Familiar with the racism in the history of physiology, Kittles believed the remains should be analyzed for what he framed as their "ethnic" origins not their race. This earned Kittles the trust of African American

communities; Nelson referred to him an “authentic expert”—someone who is seen as authentically holding African American values and is a scientific expert by way of his training and standing in scientific communities. Her discussion of Kittles foregrounded how authenticity and expertise make ancestry testing a viable option for kin-making in African American communities, and how critiques of scientific racism have shaped biological categories (e.g., the use of ethnicity instead of race) and scientific practices of classification, creating new ways of constructing biological kinship.

In the final part of her talk, Nelson discussed how genetic technologies were being imbricated into issues of racial slavery and cultural memory. In the case *Farmer-Paellmann v. FleetBoston*, which sought reparations for descendants of slaves who were bought and sold by a private corporation, genetic ancestry testing was used to constitute proof of slave ancestry. This evidence did not prove substantive, however, because the court drew a distinction between genetic and genealogical connection, arguing that the plaintiffs needed to prove the latter. The other example raised by Nelson was the Leon H Sullivan Foundation, which has argued that African Americans and Africans share a linked fate. In the context of genetic technologies they have argued that African Americans should target their philanthropy to the groups they are genetically connected to. These two cases offered examples of people enrolling genetic technologies in their political initiatives, claiming kinship (to slaves and African communities) that was otherwise unknown or denied to them with other kinds of evidence. Nelson ended on these examples to bring us to her central question: “can science have progressive goals?” If ancestry tests have been creating new kinds of kinship that can serve as a basis for forming political identities, are there ways to develop these potentialities further and in different directions?

Herman Gray, Professor of Sociology at UC Santa Cruz, acted as a respondent to Nelson’s talk. He was curious about what relationships between individuals and collectives are made in the practice of genetic ancestry tests: What kinds of imagined communities (Benedict Anderson) do they create? How are these communities formed? And how do they foster a sense of belonging? Gray wondered about authority and expertise in the cases laid out by Nelson: What is the relationship between legitimization and expert knowledge? What is the nature of people’s claims on experts? And how do people become implicated in state projects—in particular, neoliberal ones that emphasize individual responsibility—in these configurations of science and expertise? What kind of politics—if any—are possible in these sorts of state projects? Finally, drawing on critical race theorist Sadiya Hartman, Gray asked what kinds of genealogical fantasies are created through the practice of genetic ancestry testing. In Gray’s response, he expressed more trepidation than Nelson about the political potentials of genetic testing. He felt that the desire for ancestry testing in African American communities played into the forms of individualism encouraged in American society and relied on outside expertise to make authoritative knowledge claims. In her response to Gray, Nelson emphasized that genetics is never only about the individual, but is a basis for affiliation. She returned to Rick Kittles, whom she characterized as having a special kind of post-Civil-Rights expertise. Nelson also took the opportunity to flesh out her concept of “the social life of DNA,” which she defined as

an analytic that understands that there are different spheres with different stakes in genetic technologies, but they co-authorize one another. She also emphasized that genetic ancestry testing is a kind of politics, if we are to define politics as people trying to make change. In this way Nelson endeavored to take seriously the political and scientific desires of the people she interviewed rather than explaining them away as motivated by unconscious ideologies.

During the Q&A, Ed Green asked if African American consumers were satisfied with their test results, because he did not feel he got useful ancestry information from his own genetic testing; the time-scale was too large. Whitney Boesel followed up on this question later by asking about the relationship between ancestry information and medical information; did people who wanted ancestry tests also want medical information? Lisa Petrella was curious about what Nelson meant by “progressive”—is it about political or scientific progress? Megan Moodie wondered what the connections and disconnections between African Americans’ interest in ancestry tests and Mormons’. Max Tabatchnik asked how African American communities understand the difference between race and ethnicity in the context of Rick Kittles and the politics of these biological categories in general. Continuing the theme of political possibilities, Jenny Reardon asked what kind of stories produced something as politically “actionable” in this context. Pierre du Plasiss and Herman Gray were curious about the difference between a politics of recognition and a politics of representation. Through the audience questions and Alondra Nelson’s thoughtful responses, questions of political and scientific categories, community and identity, authenticity and expertise, arose in their specific relationships to violent histories (slavery and scientific racism). Without answering the question “can science have progressive goals?” Nelson presented a complex landscape where different communities have incorporated genetic technologies into their practices of making community and telling histories. Staying true to the political yearnings of her interview/ethnographic subject, while asking questions from critical race theory and Science and Technology Studies, Nelson provided compelling ways to approach the complexities of doing politics with and through emerging technologies.

Rapporteur: Martha Kenney, History of Consciousness

Too Many Ps: Personal, Political, Publics and Potatoes

Ruth Ozeki

April 5th, 2012

At this event novelist Ruth Ozeki read from her 2003 book *All Over Creation*, which weaves concerns about potato farming and biotechnology together with themes of family, morality, solidarity, loss, and belonging. After Ozeki’s readings there were responses from Julie Guthman (Community Studies), Steve Gliessman (Agroecology), Nancy Chen (Anthropology), and Joan Haran (Cardiff University). There was also a reception with organic local food, some of which was donated by event participants.

After the Ozeki read from the beginning of her novel, Julie Guthman, Professor in Community Studies at UCSC, gave the first response. Guthman was impressed by how the novel conveyed truths about farming and technology. She argued that *All Over Creation* informs the reader how farmers are prone to boom and bust cycles; contracts and futures can make or break farmers; farmers are compelled by the market to use technological innovations; GMOs are not just about playing god, but about intellectual property rights. Guthman believes that in contemporary food movements people are more focused on building alternatives rather than critiquing the elements of the current system, such as those illuminated by Ozeki. Guthman called for more intellectual work in the food movement and the deployment of science against claims of the biotech industry. She wondered if food movements are currently “too fun” and suggested that more hard work was necessary to mount a serious resistance against big biotech agriculture. Overall, Guthman’s response expressed both curiosity and anxiety about the divisions between fact/fiction in Ozeki’s novel and seriousness/fun in food activism. The second response was given by Steve Gliessman, Professor of Agroecology at UCSC. He began by explaining that the field of agroecology is characterized by a balance of science, agricultural practice, and social change. He gave an example of a recent visit to a Mayan university that was studying traditional Mayan farming systems, where different crops are grown together. He was struck by the way that the kitchen and food preparation were part of the agricultural practices. Gliessman is interested in the cultural side of the relationship between growing and eating food—something he saw in Ozeki’s novel. He believes that our task is to identify pressure points for bringing about change and putting the “culture” back into agriculture.

During the first question and answer period, one central question was what it means to read and write fiction. Donna Haraway was interested in the kinds of “worldings” produced by different genres of writing and how novels create feelings of comfort and discomfort in their readers. Julie Guthman said that she would not teach Ozeki’s novel in her class because her students need to be taught “the facts” in order to be effective activists. Although, she added, it might be good for an introductory class to get them interested in biotech issues. In her response to these questions Ruth Ozeki shifted the terms of the conversation from the reader’s response to her own motivation for writing. She said that she wrote this novel because she was afraid of biotechnology and wanted to learn more: “A book is a reason to learn about something” —a research assignment. She hung out with geneticists and learned about science. She didn’t want her own politics to flood the novel. She also explained that it was a reaction to her father’s death. She was so angry when he was dying, she said, so filled with impotence and regret. Her novel was a way to work with and through her feelings. Authors, she said, have no control over how their novels are read; they write for other reasons. After we returned from the break, Ruth Ozeki read more from *All Over Creation*. Nancy Chen, Professor of Anthropology at UCSC, then gave a response that focused on the promises, pleasures, and perils (3 more Ps) of learning about biotech in Ozeki’s novel. She was drawn in by the pleasures of the connections in the novel to events and movements in the food world. Also the pleasures at learning about plants—for example: finding out about the promiscuity of squashes. She drew our attention to themes of reproduction and fertility that ran through *All Over Creation*: the productivity of farms and

the infertility of the farmers. Chen believes that there is much at stake in the themes and problems explored in the novel. The rise of biotech agriculture means the loss of ways of life. Farmers are transformed into clients and lose the kind of firsthand knowledge that comes from intimate engagement with plants.

Joan Haran, Research Fellow at the Centre for Economic and Social Aspects of Genomics (Cesagen) at Cardiff University, gave the final response. She said that she appreciated All Over Creation because it presented a more creative possibility for presenting science to publics. She is interested in highlighting creative communication strategies and the work that goes into crafting messages and making meaning around biotech. She pointed to the neologism “Frankenfoods” as an example of this kind of meaning making. In the last part of her remarks she read excerpts from reviews of Ozeki’s novel. One of the reviewers commented that the humor of the book undercuts the seriousness of its message. Haran argued that treating humor and seriousness as qualities opposed to one another does a disservice to the texture of the novel. Drawing our attention to how the novel upsets the dichotomy between humor/seriousness, she connected to the dichotomies between truth/fiction and seriousness/fun that Guthman raised in her response. Haran encouraged us to pay attention to the richness of meaning that is made when otherwise separate genres collide. To keep up with this creative polysemy, we must become better readers.

During the final question and answer period, audience members focused on the stakes they felt in Ozeki’s novel. One person asked about hope and despair in All Over Creation. Ozeki said that hope comes from not knowing what is going to happen. Despair comes from thinking we already know. She said that plants are resilient. She spoke of Ailanthus trees exploding through the sidewalk. Jake Metcalf said what struck him about the novel was the Ozeki was neither on the side of biotech or activists, but on the side of the farmers. Ozeki’s answer to Metcalf’s question gave the audience a sense of her process. She said that she felt she didn’t give the farmers enough space in her earlier book My Year of Meats; her focus on farmers in All Over Creation was partially an atonement for her oversight. Donna Haraway was interested in the way our projects come out of remorse. She drew on Kris Weller’s idea that all we can muster is palliative care. Palliation and mediation are all that are possible; not reconciliation or restoration. In this context, she argued that humor is driven by remorse. We are all groping for practices of being responsible in the face of how big the problem is. Despite the melancholy of Haraway’s remarks, they offered a fitting end to an event that grappled with the difficult specificities of contemporary agriculture and explored different modes of writing to struggle to respond to these intricate challenges.

Rapporteur: Martha Kenney, History of Consciousness

Authority, Expertise and Power in Mexican Forests

Andrew Mathews

May 22nd, 2012

Andrew Mathews, Assistant Professor of Anthropology at UCSC, spoke to us about his new book, *Instituting Nature: Authority, Expertise and Power in Mexican Forests*. Drawing on his background in forest ecology, Mathews investigated the uses of and discourses around fire in Mexican forests using historical, ethnographic, and scientific methods. Although pine forests need fire for growth and regeneration, the Mexican state has demonized the use of fire, characterizing it as destructive, catastrophic, and abnormal. For officials, who are tasked with the responsibility of maintaining orderly landscapes, the practice of using fire to maintain the forest seems messy and incomprehensible. Because of the dominance of this official discourse and because of the illegality of burning many of the people Mathews spoke to claimed that fire was not used to maintain the surrounding forests (even though there was evidence of fire histories). Although there is an official form to apply for permission to burn, no one has ever applied. Mathews argued that these “official channels” prevent agricultural practices from becoming official knowledge, silences multiple knowledges, and prevents people from understanding the agricultural uses for fire. His ethnographic work, for example, shows that the younger generation only had negative views of fire as something that needed to be fought and controlled. Older people, on the other hand, tended to see fire as a kind of ally in growing crops, not a dangerous force outside of human sociality. As fire is made illegal, agricultural history is forgotten. The government’s demands for legibility and transparency are producing doubt and confusion. Overall, Mathews showed how looking at fire helps us to think about “The State” in a concrete way and opens up important questions about which forest management practices can survive and in what form.

During the Q&A Jenny Reardon asked about how Mathews’ hybrid methods articulated different forms of evidence. Mathews said that he looked for resistances and uncertainty in his methods. He was interested in surprise and the limits of method. Multiple knowledges destabilize each other in productive ways. Anna Tsing picked up the question of science and justice and wanted to know if there was such a thing as “justice for pines.” Mathews talked about the agencies of pines and how they have memory and imagination build into their structure. Matthias wanted to know what nations have against fire. Mathews said that the distrust of fire stems from imaginaries of rural disorder and power of fire to transform landscapes in unpredictable ways. Transformation is difficult for governments to deal with, since they strive to create order. These and other questions helped to further draw out the stakes of Mathews’ project and connect them to larger S&J questions about interdisciplinary knowledge, more-than-human justice, and the role of discourse and state regulation in shaping technoscientific practices.

Rapporteur: Martha Kenney, *History of Consciousness*

Science and Justice Conferences

Are You My Data?

May 8, 2012

UCSC University Center

Sponsored by: Science & Justice Working Group and UCSC Office of Research

With a human genome sequenced and a map of variable sites in that genome created, governments and many other public and private actors now seek to make genomic data relevant to health, medicine and the society. However, to do so they must navigate the conjunction of two different approaches to data. Within the biomedical domain there are important, well-articulated infrastructures and commitments arising out of concerns about individual rights, patient privacy and the doctor-patient relationship that limit access to biomedical data. This stands in stark contrast to the culture of open access forged by those who worked on the Human Genome Project, and that has continued to be a central commitment of ongoing Human Genome research. Thus, architects of the genomic revolution face competing, complex technical and ethical challenges that arise from this meeting of these domains with substantially different ethos. Additionally, the rise of social media has led to a broad and contested discussion about the proper relationship between persons and data and who profits through access to it.

The workshop will mapped out the challenges of building and controlling genomic data architectures that are responsive to these conditions. Rather than suggesting that either openness or privacy is the answer, the workshop will ask which kinds of openness and privacy might be possible and adequate, and in which contexts? Further, who has the authority to decide? Who can/should authorize the flow of data and what forms of consent are required? What kinds of flow of data should be allowed (e.g., ones that lead back to persons, etc.)? Finally, the workshop will consider questions around where and how data should be accessed. Is “the cloud” a viable option? What other options exist to manage deluging data, and what ethical and material challenges do they present?

Hosts

Hosted by Jenny Reardon, Associate Professor of Sociology, UCSC

Co-hosted by Bob Zimmerman, Program Director, UCSC Cancer Genomics Hub

Speakers

David Winickoff, Associate Professor of Bioethics and Society, UC Berkeley

Malia Fullerton, Associate Professor in the Department of Bioethics & Humanities at the University of Washington School of Medicine

Mike Kellen, Director of Technology and Software Development, Sage Bionetworks

Opening Remarks by Jenny Reardon

After acknowledging supporters of the meeting and thanking the speakers, Reardon opened with a discussion of the new relations between data and bodies. We often

imagine that data makes bodies frictionless and movable, that by transforming tissue or other material into information we can overcome the restraints on the movement of physical material. Reardon suggested that this belief in the frictionless nature of data is misplaced. Rather than resting on the generality of that belief, she pointed to the unasked question of what kind of particularity about bodies do we lose when we turn bodies into data, and what particularities do we want to keep?

We still live in a world where embodiment matters to governance, where bodies are what matters most. The apparatuses built to protect data privacy are ultimately about protecting 'body' privacy—it is the data attached to bodies that is the most sensitive, largely because the histories of bioethics is directed toward protecting bodies. This history hitches governance to place, which causes conflict when data is imagined to be placeless and able to move without friction. Now we find that a lot of effort is put into studying data and not highly-constrained bodies.

Data isn't bounded by obvious physical limits, this ultimately ups the ante for dealing with governance. We have millennia of thinking about ourselves as bodies, and only a few years of thinking about ourselves as collections of data. Once the body is rendered as 0's and 1's, should that data be able to go wherever the Internet goes, or does it need to be made bounded and emplaced like the body is in order to make sense of it under our current modes of governance?

This conflict is especially potent in biomedicine and bioinformatics. Early networkers are much more likely to think of data as something freely moving wherever we wish. Biomecial researchers tend to feel that the data is embodied somehow and expect it to receive the same care granted to the bodies from which it originates. This leaves us with the questions of how are we going to recontextualize data? Who has the power to decide these things? What the spaces for making decisions, who would to turn toward to ask them?

Panel 1: Collision of Privacy and Openness

Panel: David Winickoff (UC Berkeley, Environmental Sciences Policy and Management), Bob Zimmerman (UCSC Cancer Genomics Hub)

Discussant: Greg Biggers (Genomera)

Reardon asked the panel to consider what happens when the culture and infrastructures of medical privacy collide with the practices of openness found in computing worlds.

David Winickoff

Winickoff recalled a conversation he had with Jamie Hayward, founder of Patients like Me, a website that collects and shares patients' experiences and outcomes with drug

regimens in a social networking-like format. Hayward told Winickoff that, "Bioethicists have killed more people in the past year than adverse drug effects" because of the medical privacy policies that slow down research and prevent sharing of information. His brother had ALS, and in order to address the slow pace of ALS research Hayward set out to create online network of ALS sufferers to upload as much personal data as they were comfortable with, and then connect with pharmaceutical companies and other patients. Hayward strongly believes that there is a need to work around the biomedical discovery system that limits connections between patients and researchers every step of the way. Winickoff asked if physicians are important gatekeepers of medical records and was laughed off by Hayward.

Winickoff questioned why people are now talking about privacy and openness of medical records with much more intensity. The dominant way to protect data traditionally has been anonymization and deidentification, which is impossible to promise with any certainty, at least given the current state of informatics. The options appear to be just coping with non-anonymity or harden our systems for privacy. Typically our culture frames science and technology as moving society forward, as if they are separate entities with one acting on the other. But co-production or co-evolution model shows that categories cross between the two, a hybridity of science and society. The very categories of de-identification and anonymization have technical definitions that must be articulated to understanding of what a person's identity and what exactly anonymity protects. Commonly, a human subject is defined as someone identifiable, and once deidentified is no longer a subject and thus is in different legal category. While these categories are socially and legally produced in the first place, technology makes them fuzzier than expected.

New models of identity and privacy have been generated by patient advocacy. GWAS has largely disappointed those who expected quick therapies. Now the idea seems to be make ever larger data sets to make analysis more powerful. There are now many efforts to use crowd sourcing to make databases bigger, but that requires moving more 'private' data across borders between informatic systems. This is co-emerging with patient advocacy that leverages the control patients have over their own data and contributing to discovery of disease. Some efforts have decided to flout privacy explicitly, and reject research subject and protection apparatus in favor of speed, scaling up, and networking. This puts pressure on traditional models of thinking about subjects and privacy, ultimately shifting control over data in new ways. For instance, the Personal Genomes Project, claims that the risks to medical privacy are overblown and has recruited subjects who disclose everything and. This is not just an experiment in new ways of making scientific knowledge, it is also an experiment in making the private public.

Now there is a question about these complex emergences. We care about protecting subjects and privacy on some level, but when there is this complex interpenetration with new tech, how do we hold the line on cherished ideals and maintain flexibility in the face of change? In this new moment of co-evolution, we have choices to make in terms of what we want to hold tight and what we want to let go—we could define things rigidly or

become extremely flexible. However it's hard to be rigid when the basis of cherished ideas is undercut.

A second issue is the political economy of data. We should see data and network architecture as a field of power, where resources are distributed in particular ways. We imagine privacy as shielding, openness as flatland. Openness and privacy allocate power as they are embodied in policies. So it's not a question of 'openness or not'. Things are open in certain ways, closed in others and we need to track continuum of openness.

Furthermore, openness is as much a function of property as it is of privacy. Both privacy and property are about control and access. To what extent do researchers have property in data? Protected under law, and constrained by confidentiality agreements. But property rights are allocated in this stuff. Another form of romanticism around the tainting of the moral economy of sciences. Despite common narratives of science being founded on radical openness and common access to knowledge, there has always been secrecy in science historically and secrecy creates incentives for discovery. It is still going on now, but now we have architectures of sharing that far outstrip our ability or desire to share. Since the mid-90s patient groups have assembled their own data. By restricting access to databases, they create higher value and incentivize research by pharmaceutical companies. This should complicate our moral intuitions about openness because closedness might be a tool that we as individuals can leverage on our behalf.

Although there is a lot of pushback against their regulatory role, we should recognize the importance of mediating institutions. Currently, patients can choose not to participate, or else participate completely on the powerful organizations' terms. So the pressing questions is how to make it possible to do research on patient's terms. When we think consent happens at a single point of time that authorizes all future research, it is necessary to have someone paying attention to what is done with data and be accountable to it.

Bob Zimmerman

Zimmerman started by arguing that sharing is fundamental to evidence-based medicine. Sharing data is essential to create feedback loops to evaluate the long term effectiveness of experimental therapies. To judge the effectiveness and safety of therapies, we need more than a snapshot to understand a disease and it is necessary to look at longer terms processes of disease. For this, research efforts can't just have individual patients and need to see people in clusters by disease or organs.

The recently launched Cancer Genomics Hub is hosting data from three large sources. It then analyzes of how cleanly and clearly tumor types are differentiated on a genetic level. This kind of research produces new ways of differentiating tumor types. Looking at the genomic basis of the disease, you see very clearly delineated types and different

successes with therapies. Among the early discoveries is that there are surprisingly varied forms of breast cancer.

In order to do this kind of comparative work, we need to share data to cobble together large enough data pools. This requires figuring out how to move beyond the culture of shielded privacy that is enshrined in medicine and create a culture of sharing and participation that has openness and trust. It is obvious at this point that legislation alone is not enough. We can legislate protections, but there are much larger problems with cultures and values, which is almost as challenging to understand and intervene in as disease processes themselves. Genomics looks promising for analyses based on facts and statistical analysis. But how do we develop that culture of trust? Data sharing of mutations is necessary for treating disease processes, but to really get robust therapies we will need more than single points of data when the patient comes in for treatment.

If we look at history of science, there has been much secrecy, but there is also deep roots of sharing, such as foundations of journals. The commons cannot protect itself, it must be maintained and cultured and protected from abuse. When we start to think about patients in the future we should be guided by Brian Gibson's insight that, "The future is already here, it is just not evenly distributed." This is evidenced by the fact that we have seen several prominent scientists share publicly their own personal 'omics' profiles, but these intensive efforts are not currently available outside of their well-funded labs (see <http://med.stanford.edu/ism/2012/march/snyder.html> and <http://m.technologyreview.com/biomedicine/39636/>).

One particularly tricky area to navigate is the difference between a donor and a partner. Two places we see this being worked out is Stand Up to Cancer and the US Office of Research Protection's proposed changes to the Common Rule (the standard privacy protection protocol that guides all medical research). Most scientists don't have time and access to legislative analysts, but for however hard they think it is, patients find it harder to deal with.

The overly ambitious goal of public health has been how do we reduce disease, disability, and untimely death. That's what genomics is really about. As we are starting to open the box of medical genomics data, we need to have access to the patient data to fulfill this and really understand how environment influences gene expression. There is an emerging awareness of cancer as not just a genetic disease, but a failure of body's regulatory systems to deal with mutations and their consequences. We need social collaboration networks with raw data collaboration networks and interdisciplinary work.

Zimmerman offered three closing questions:

As we try to aggregate data, how do we try to protect individuals. What fears are real and what fears are bogey men?

How can we acquire and analyze enough data to improve public health and human capital? Researchers want and need open data culture and we are seeing early moments of self-monitoring and sharing in the 'self-quants.'

We need better means for sharing and consent. How do we build these effectively? What are the best ways of building culture of sharing and trust? If we can harness science to build better understanding of disease, we can have much better lives.

Greg Biggers

Biggers spends most of his time as entrepreneur, yet many of these ideas are always on his mind. There is a new tide of health research that is ultimately asking questions about equity as it affects patients, access, public health. At the same time, there is a collision of privacy and openness. When it comes to collisions, there will always be a person investigating has to figure out fault, or who is the collider and who is the colidee? Thus it is important to get into the locus of control of these conflicts. "Complex emergencies" is good phrase for how this tide has medicine going from policy-driven to patient-driven research. The last 15-20 years of health rhetoric have been about protecting privacy, but shouldn't we also be helping people express rights to property? Anxiety over sharing and openness is largely about the arrival of new technologies for sharing. At the core of the problem is the locus of control, whose will is being expressed, setting up a conflict between an act of protection and an act of expression. Trust is a much bigger issue than an action that takes place at time of consent. The Kaiser case study shows trust as operationalization of a concept, not a single event. We should not back into the corner of "how do we talk people out of their data?" Does the power of data make us feel compelled to grab at the new data? Much of the difficulty the world has right now about opacity is about replication, a core value of scientific practices. Openness allows many more people to get into replication of results. Bench to bedside, to bench, to bedside, to bench, to carside, to pharmacy, to bench. etc.

Q&A

Ted Goldstein: Where is the sense of disgust that people are being prevented from developing cures?

BZ: Pace of sharing is very frustrating. The fact that only 20% of reimbursable procedures have gone through double blind study should be scary. Doctors as they are now trained cannot deal with people who want real information. And reimbursement structures cannot support it.

DW: By working in a regime of total exchange, where everything goes in, there are other actors who can take advantage of my data in ways that I never could. The commons doesn't actually benefit people equally, people have differential capabilities to extract value from commons.

GB: This problems is less about control of information than it is about control of value. Commons is based in real estate, so need to be careful. Tissue is corporeal, and the

commons is often extra-corporeal. Have we gone too far toward the individual? Emergence of new kind of engagement and collaboration that dissolves some of the boundaries between researchers, collaborators, subjects, and participants.

Second Panel: Creating and Sustaining Trust

Panel: Malia Fullerton (University of Washington School of Medicine) and Mike Kellen (Sage Bionetworks)

Discussant: Warren Sack (UCSC)

Jacob Metcalf introduced the second panel and asked the panel to consider what practices and infrastructures are necessary to create and sustain trust over time in data-intensive biomedical research.

Malia Fullerton

Fullerton argued that facilitating respectful ongoing engagement in research process will be important moving forward. There is a widespread assumption that to be ethical in science is to share widely and be open. But this must be tempered by the knowledge that we are sharing things that belong to people who are largely absent from daily lab life.

In this regard, bioethics has perhaps overemphasized the concepts of beneficence and non-maleficence, neglecting other aspects of the process of producing medically useful knowledge, such as how we convey courtesy and respect as research moves forward. There have been significant consequences to the preoccupation with de-identification as a proxy for ethical treatment of biomedical research subjects. With contemporary medical research scandals we are seeing a common thread of patients reacting with the feeling of, "I was participating in something and now things have changed and I wasn't aware of the changes." Key examples of this are the Havasupai genetic research case in Arizona, the discussions swirling around the HeLa cell line, and the Texas biobank that misled the parents of infants whose blood samples were banked. Thus we are seeing a pushback against the idea that de-identifiers are a solution to all problems.

Fullerton suggested that rather than simply removing 'identifiers' and moving forward with the research, it is necessary to gather written consent on an on-going basis or that explicitly clears the samples for other kinds of research. She cited a bioethics study she co-authored (Ludman et al., 2010, <http://www.ncbi.nlm.nih.gov/pubmed/20831417>) that demonstrated patients tend to have a strong preference to being re-consented when their de-identified samples might be used for other forms of research. The less onerous alternatives to affirmative re-consent—opting-out and notification-only—were largely considered inadequate. The authors concluded that the best practices for re-consenting

the use of biomedical data treated the participants as stakeholders in the research, including methods to keep the participants informed, ways of providing access to information on how samples were being used on an individual and study-wide basis, create transparent and accountable oversight processes, and provide opportunities to provide input.

Fullerton also cited a study by Kaye et al. (2012, <http://www.ncbi.nlm.nih.gov/pubmed/22473380>) that identified the major challenge of consent in bioinformatics as making 'visible' research participants, whose DNA and health information are essential for meaningful progress. Their research suggests that research participants do care about how their data are used and wish to be kept informed (which is different from control). This will require sustained investment in keeping in touch with patients.

Michael Kellen

Kellen introduced SAGE Bionetworks as a response to the concern that research was being blocked by lack of access. SAGE's founder, Steve Friend, was a researcher at Merck and found that he could not get innovations out fast enough despite all the investments and power of the pharmaceutical industry. Working off the principle that we will all be patients some day, he wanted to accelerate the pace of the medical discovery process and generate more innovations. Thus SAGE has sought to pilot new ways of doing research using the values of openness and transparency.

Kellen asked who is the privacy for? Is privacy for the patients' benefits? When privacy becomes a technical question driven by paperwork, we can lose sight of the fact that privacy is at its root a matter of people being concerned with dignity and respect. Experience indicates respect and dignity matters more than privacy for people with chronic disease. In many cases, privacy and consent procedures are built around the physicians' needs, particularly their desire to keep research proprietary, not the interests of the patients.

SAGE operates on the assumption that speed in research systems is improved by openness. John Willbanks, one of their directors, has focussed on the problem of portable consent. Often data can only be used in one study due to the legal status of the consent forms, and thus the full utility of data generated is not met. Researchers are usually only trying to answer one question and do not build future utility of their data into the experimental design and ethics procedures. Portable consent would be a key part of any system in which participating in one trial results in data being shared with other trials and/or be placed in the public domain. Widespread portable consent will require consistent legal language that can be dropped into informed consent forms.

SAGE is aiming at treating portable-consented biomedical data like an open-source software system. With the Synapse project they are attempting to track the history of who has done what with which data. Synapse is modeled on GitHub (<https://github.com/>), a central tool in open source coding that tracks versioning. Fast paced

biomedical research cannot wait for work to be distributed as papers, which are too granular and take too long to write, review, and publish. Instead, Synapse aims to get down to level of individual steps and small analyses. This helps establish trust with patients because they can see that their data is well used and is transparent. It is easy to wonder why patients won't share, yet they have more to lose so scientists need to share more to also be at risk.

Kellen argued that we need a system of reward for researchers that does not encourage keeping data proprietary and secret. The challenge of medical discovery should be like Tour de France, with stage victories and not just a single race. Every step along the way should be designed to build on each success. This is the model of the Breast Cancer Predictive Modeling, which puts all the data in the public domain and asks who can make the best software for predicting disease process. Each attempt is transparently available to other designers.

SAGE's forthcoming Bridge Project (<http://sagebridge.org/about>) is aimed at creating tools to keep patients actively involved by engaging the patient community to provide researchers an agenda. Patients are also participants who self-report data. This changes incentives for people who do the research—this model is not about who 'wins' a research race, but enabling others to see what the techniques are and use them in new contexts.

Warren Sack

Playing off of the pun and logo used for the symposium, Sack claimed that the Personal Genome Project is like the 'Snort' character in the classic children's book *Are You My Mother?* It reunites us with our family. That is one story we could tell about this field, it is a set of tools for personal discovery. Sack suggested that in these discussions, the arts could play the role of identifying the many positions of actors in personal genomics. There is a wider diversity of people involved than we typically discuss: there are funders, regulators, advocates, patients, researchers, families, undertakers, etc. Part of the effort to generate respectful engagement could include the 'game-i-fication' of research—the informatic technologies should be joined with narratives that make the research meaningful to people's lives. There must be engagement with research subjects in a capacity as something more than a source for data. The challenge at hand is how do people find a common cause to become a public? There are always many different publics. Personal genomics stories have been personal stories about celebrity genomes, such as Steven Pinker writing about his participation in the PGP. In the next stage, there needs to be stories about the public good in order to create a public. The arts should have a role in this.

Concluding Discussion: Future Directions

Bob Zimmerman pointed to the multi-dimensionality of all the issues and that tackling these problems will require that we make a habit of locking everyone in a room together for discussion. We will eventually be doing studies that need far better patient data

about a variety of things, like lifestyle, drug compliance, environmental exposures. By the time it gets to us, very downstream of aggressive de-identification. Only looking at 500 tumors in each organ category are they actually able to make progress.

David Winickoff asked if we really need to get rid of privacy. It's used as a placeholder for 'bioethics' but does not capture the rich possibilities for relationships between people, researchers, and data. Can there be a shared kind of control? Privacy remains important because the people who are comfortable with medicine and research want to get rid of privacy protections. People who feel threatened shouldn't be subjected to all this terrible freedom. He pointed to the example of Iceland- people with mental illness objected.

Jenny Reardon asked how do we get past an us vs them framework of ethics? Defining characteristics of these conflicts is mistrust of large institutions. How do we re-narrate the story to create common cause? How are we telling this story getting past big actors and little actors?

Ted Goldstein argued that bioethicists have focussed on certain stories as policy motivators, such as HIV and HIPAA. Bioethicists have reasoned from case studies rather than large scale quantification. But there is little evidence of harm coming from privacy breaches. If we don't actively correct racial bias in our genetic knowledge we will further cement the bias in our medical system. We need to actively engineer the society we want rather than just protect against possible harms. There is a responsibility to share data with people we share genes with, everyone must be willing to give up a little bit of risk in order to help others.

Greg Biggers reminded us that all medicine is experimental. There are fundamental epistemic issues at play within the development of data-intensive biomedicine—how do we know what we think we know? We need to receive feedback from everyone.

Malia Fullerton pointed to widespread public narrative about personal genomics. People have had conversations with their families who didn't want them to participate. Participation is getting negotiated on a family by family basis. Regulatory structures unable to deal these relationships. She also warned against sloppily sliding back and forth between patients and research participants. These categories are experienced differently whether or not the research benefits you, particularly given the difference between medical care and experiment.

Mike Kellen said we need a better sense of what incentives drive researcher behavior. At some point health data will leak and what happens with the inherent power differentials between researchers and subjects? How do you align ethical behavior with incentives?

Warren Sack noted that there is a big PR problem in the sense that it isn't clear how big data mining project leads to helping my Uncle Joe. People trust a group where they

have a particular role to play. What is the public to which one belongs that you have common cause?

Reardon closed by suggesting three primary topical areas for future discussion:

Equitable Participation
Privacy and Property
Experimental Medicine

She suggested that we need to rethink genomics away from cures and re-articulate it to broader meanings. How do we create space for that discussion, about what it means now and not just 30 years from now? Do people feel empowered as citizens in the world that we are creating? We are not going to cure cancer tomorrow, and so need to address how I live my mortal life now with respect. We especially need scientists to take these question as integral to the scientific endeavor, not just side projects that come after their research is done.

Rapporteur: Jacob Metcalf, Science & Justice Research Center

Advisory Board Meeting Summaries

Summary of Advisory Board Meeting
29 May 2012

Present: Jenny Reardon, Jacob Metcalf, Martha Kenney, Susan Strome, Ben Crow, Kim Tallbear, Anna Tsing, Fred Turner, Laura Mamo, Nancy Chen, Joe Dumit, Herman Grey, Sally Lehrman

Introductory Remarks: After thanking everyone for attending, Jenny Reardon started the discussion by asking, “Why justice?,” which has been a running theme in the UCSC Science & Justice community. She suggested that justice opens up a series of questions about what it is we want in the world, and that these questions are often what lead scientists, humanists, artists, and social scientists alike into academia in the first place. Currently, it is a major intellectual and institutional question about how to get back to that question. Ethics has become too wrapped up in bureaucratic issues, and has largely become a series of hoops to jump through. In contrast, justice offers something aspirational. Especially compared to ethics, justice makes it easier to orient around a collective.

Reardon asked next what we need to do in order to engage the challenges and opportunities posed by conjoining justice with knowledge production. Especially here at UCSC, justice has provided a way to reach outside of existing institutions to make an appeal for collaborative and innovative research and pedagogy. In particular, we have

succeeded in creating intellectual and physical spaces where members the university community can approach us with problems that require working outside of typical disciplinary boundaries. We have also recently had significant success in convincing the university to recognize such efforts as important and worthy of support. The last several years we have focussed on our NSF-funded graduate Training Program, which aimed at taking the processes from our Working Group and teaching graduate students methodologies for collaborative and cross disciplinary research practices. We leveraged the success of this program into support for founding the Science & Justice Research Center, which is hosted in the Division of Social Sciences and receives support from a number of science and engineering units.

As the NSF funding is expiring shortly and there are many opportunities are on our short- and long-term horizons, we convened our External Advisory Board for this meeting to discuss where to focus our efforts next and how we might become a greater resource for similar communities at other campuses. Reardon asked Advisory Board members to discuss how their work might benefit from being in such a space and what themes, issues, approaches, might be helpful.

The following is summary of some of the themes and institutional needs and opportunities discussed.

Themes:

- Bringing justice into the conversation on more campuses. Fred Turner noted that justice is not part of the science and technology education and research efforts at Stanford. Although they have groups such as the Liberation Technology Group, the pedagogy and research is oriented around development shop models and are driven by engineering ethics. UCSC may have some unique history and institutional dynamics that make discussing justice easier, but by sharing resources and stretching conversations across campuses we may be able to shape these conversations.
- Funding models. There is a proliferation of funding models, and these new funding models appear to support new modes of knowledge production. Reardon pointed to groups like Kickstarter and Sage Bionetworks as examples of funding efforts that are built around asking individuals “do you want this to happen in the world?” This produces opportunities for anyone to become a patron and participant, which is a significant divergence from the previously dominant model of venture capital and corporate investment. How do different funding models affect what sorts of research questions are possible? How could Science & Justice take advantage of these new models?
- Wider participation. Kim Tallbear noted that despite aspirations to pluralism, Science and Technology Studies (STS) programs and research projects often do not have a wide diversity of perspectives. She suggested that we need to focus on having a wider diversity of people who are approaching our research

questions in radically different ways. For example, she argued that what tribal peoples need and want from universities are not more humanities and social science experts, but technological and engineering expertise. How can the SJRC help facilitate this? Reardon replied that Science & Justice had enabled her to be much more open to non-traditional forms of research. STS scholars should not assume to know much in advance and need to focus on amplifying interesting projects that are already happening.

Institutional Needs and Opportunities:

- Does Science & Justice want to be a regional hub? UCSC, Stanford, and Berkeley all now have departments or research units that are focussed on science and society issues and have some staff that can coordinate on issues such as mailing lists, calendars, and logistics. How might we work together, share resources, and collaborate on building up the community together? UCSC may be willing to take on a good chunk of the responsibilities for maintaining this, but needs to consider priorities and available resources.
- Regional convocation and conference, with rotating campus responsibilities. Reardon proposed an annual conference where we could share costs to bring in a significant figure in STS and host a conference that represents the regional approaches to STS (emphasizing justice and ethics issues in technoscience). There was enthusiasm from most members for this idea.
- Email lists. There appears to be a need for two or three email lists. First, there needs to be a small list that reaches the leadership of regional STS programs. This list could discuss issues like cost sharing, programming, and building collaborations. There is also a need for lists that share upcoming dates and opportunities, possibly including scholarships, student research positions, and jobs. Jake Metcalf (Assistant Director at the SJRC) will collaborate with his compatriots at Stanford and Berkeley to put these lists together.
- Support for graduate training program. The NSF funding for our graduate training program expires later this calendar year. The grant that funded it was a pilot grant only and cannot be renewed. We are testing several models for funding future training and will be pursuing endowments from foundations. One major arm of our funding efforts will be to include graduate training and course components in soft-money grants.
- Sharing graduate students. There is some need for sharing graduate students across campuses. The SJRC has some office space available and can easily provide visitors with non-financial support and an intellectual community.
- Field trips. There was some enthusiasm over organizing one or two field trips per year, especially to sites important to the history of Silicon Valley.

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- Silicon Valley Research Group. There is currently no regional research group dedicated to Silicon Valley. In the past there was a group centered around the UCSC History of Consciousness department, called the Silicon Valley Research Group. The SJRC will look into reviving this idea and pursue opportunities for a regional collaboration.
- Other sites for collaboration:
 - Health Equity Institute at SFSU
 - Annual STS Retreat at Marin Headlands
 - Santa Clara's Center for STS has many industry ties