Science and Justice Working Group End of the Year Report 2009-2010
And Proposal for 2010-11

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This document describes the activities of the Science and Justice Working Group (SJWG) in the academic year 2009-2010 and presents a proposal for the 2010-2011 academic year.

Contents

I. Introduction

The 2009-2010 academic year was an important year for the Science & Justice Working Group. In particular, this year marked the beginning of the Science & Justice Training Program (SJTP), a graduate student training program inspired by the successes of SWJG. In the summer of 2009, UCSC was awarded a grant from the National Science Foundation to develop a formal training program for graduate students in topics and methods in science and justice. The NSF recognized SJWG's success in building a community dedicated to interdisciplinary inquiry, and it represented a substantial vote of confidence in the future of the program. Although SJWG and SJTP are separate entities, their efforts are mutually reinforcing. Already in the first few months of SJTP's existence, synergy between the two programs increased attendance at SJWG events, created new faculty partnerships, produced numerous proposals for events next year, and generated promising new opportunities for making UCSC a home for interdisciplinary research. Additionally, SJWG hosted nearly twenty colloquia, seminars, and symposia this year which included international scholars, researchers from private industry, faculty from other UC campuses, and USCS faculty from every division. We also developed a new website infrastructure, to be launched Fall 2010, that will increase visibility and 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.

Below we describe SJWG's history, themes, events from the 2009-2010 academic year, the SJTP and it's relationship with the Working Group, our plans for next year, and a proposed budget. Appended are selected documents from this year's events.

History of the Science & Justice Working Group

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. Although SJWG will continue as a distinct organization, the training program formalized the methods of interdisciplinary inquiry developed by SJWG members, shares programming funding, and provides new participants within SJWG.

In the 2009-2010 academic year, SJWG began to implement the NSF grant, continuing our efforts to formalize our successes and create closer relationships across the Divisions at UCSC. Although SJWG and SJTP remain separate organizations, the

synergistic relationship between the two has enabled us to build on the community by producing research and programming, attracting new regular members, and encouraging new collaborations between faculty and graduate students between different divisions. Most importantly, the NSF grant funds the training of and research done by graduate students using the methods developed within the Working Group. The inaugural cohort of Science & Justice Fellows proposed new research clusters and events, much of which will be sponsored by SJWG in the future. 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 geoengineering, both of which grew organically from the interests of SJWG members and drew new members from the sciences and engineerings.

Working Group Themes

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

Curiosity as a Virtue

Doing "science and justice" work means creating an environment that supports efforts to engage with one another across differences. In the context of S&J research seminars, this meant creating an environment in which participants were willing to make mistakes and to revise their own positions, views, and practices. Central to this was the effort to cultivate curiosity as a virtue of the seminar space. "Being curious" implies stepping beyond habitual modes of engagement in order to explore other possible ways of looking, questioning, and intra-acting [this term is too technical to be included in an end-of-year report without a footnote explaining what it means—perhaps replace with a different term, or explain what it means]. Many of our Science and Justice events have been oriented toward cultivating curiosity as a virtue, including our ongoing "critical friends" series.

Scientific Literacy

In recent decades, on both sides of the political spectrum, we have seen an increasing tendency for people to react against new developments in science and technology. Debates about stem cell research and genetically engineered foods are cases in point. We agree that it is absolutely necessary to recognize and address the potentially negative consequences of scientific innovations, but, as SJWG member Donna Haraway suggests, we need to learn to respond to these developments instead of reacting. Whereas "reaction" has the connotation of an unconscious reflex or a conditioned behavior, "response" suggests taking a step back to understand the situation so that one can intervene effectively. In the Working Group, we sought to develop to our ability to respond to both developments in biotechnology and each other's different perspectives on the position of science in society. This was achieved

by incorporating some reflexive discussion in about the Group itself within most events.

These efforts were bolstered by also incorporating Working Group member Karen Barad's emphasis the importance of "scientific literacy". Scientific literacy is not simply a matter of educating non-scientists about how science works. For Barad, the important question is: What does it mean to do science responsibly, and what kind of literacy is required for that? There is no formula for "how to do science responsibly", and therefore what "scientific literacy" means, and whose literacy we are concerned with, depends on the context. The Working Group's problem–based approach proved to be fruitful for developing a broad notion of scientific literacy. The Working Group was able to successfully incorporate ethical, historical, social, and technological contexts and implications of the topics under discussion.

Partnerships in Science and Justice

The demands of thinking critically about science and social justice require that we challenge current notions of "expertise." The idea that we can turn to scientific "experts" to interpret recent scientific findings, or "ethical experts" to explain the ethical implications of emerging technologies has become deeply problematic because fields of expertise can't be separated out so neatly. The really important questions often arise at the limits, boundaries, and intersections of expert domains.

In order to confront the moral and political complexities of our times we need new forms of dialogue, new hybrid languages, and new kinds of research collaborations. This is the idea behind "partnerships in science and justice". Under this heading we explored what kind of partnerships are coming into being that can adequately respond to specific situated concerns at the intersection of scientific practice and social justice activism. Partnerships such as these necessarily transform the meaning of "expertise" because they require a greater degree of communicative competence across fields of knowledge.

In some of our recent events, the Science and Justice working group has considered the promises and challenges of partnerships in environmental justice (popular epidemiology, toxicology and toxicogenomics) and alternative energy and transportation systems (biofuels, personal rapid transit).

Reframing Bioethics

Given the interdisciplinary character of SJWG, there are many opinions of what bioethics as a discipline can and ought to do with regard to biotechnological problems. One of the virtues of the SJWG is the ability to illuminate the many points at which ethical decisions get made, and sometimes the places that they fail to get made. Thus, a common theme in our discussions was opening up the methods available to ethical inquiries. We found that bioethics as a discipline and institution often "arrives too late" at the table to make important interventions. A general consensus in the group is that traditional applied ethics methodologies that understand ethics as abstract value

mediations are partly to blame for this problem. Because biotechnology often involves practices that remakes boundaries that often taken for granted, such as between species or individual human subjects, ethical theories that rely on those boundaries being stable and determinate fit poorly within the challenges that biotechnology presents. Our discussions often sought to reframe ethical inquiries around a broader conception of flourishing for the human and non–human actors under consideration. Such an approach understands that an important aspect of ethical inquiry is accounting for the ways that our knowledge producing practices, our ethical concepts, and the materiality of our scientific endeavors are all entangled together. Thus, our conversations often contained critical engagements with ethical theory and methodology, allowing interdisciplinary reflections of the stakes in biotechnology.

II. Summary of Activities

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

SJWG Steering Committee

In the previous years, a group of regular participants formed Steering Committee in order to shape the agenda of SJWG. The Steering Committee meets three to five times per year, including a year-end meeting to discuss what was accomplished in the past year and discuss goals for the upcoming year. Members of the Steering Committee regularly contribute to the functions of SJWG by planning events, writing reports of events, designing flyers, and reflecting on the methods and culture of SJWG.

The following people served on the Steering Committee in 2009-2010:

- Mark Diekhans, UCSC Genome Browser Team
- Martha Kenney, History of Consciousness
- Jacob Metcalf, Postdoctoral Fellow, Science and Justice Training Program
- Natalie Purcell, Sociology
- Jenny Reardon, Sociology
- Rebecca Roha, Molecular Cellular & Development Biology
- Travis Williams, Sociology

Visiting Scholars

This year the SJWG had two visiting scholars and a postdoctoral fellow. Ruth Müller (University of Vienna), a Ph.D. student, studies the co-constitution of the life sciences and society through the prism of junior researchers' biographies. While at UCSC for four months she worked closely with Reardon, presented her research to SJWG, and helped organize the Engaging Science and Gender colloquium. Joanna Latimer (Cardiff University), a professor of Sociology also visiting UCSF, also came down to Santa Cruz to present her work on the ethical conditions of anti-aging research. Jacob Metcalf was

the Science & Justice Training Program Postdoctoral Fellow and worked closely with both the Training Program and Working Group.

Bi-Weekly Research Seminar, Guest Lectures and Colloquia

The Group's bi–weekly meetings focused on themes that were of common interest to members across the disciplines. Some of these themes were central topics open for discussion in a given week, but they were often points of discussion following presentations or colloquia around a specific problem–based topic. In the 2009-10 academic year, SJWG hosted and co–sponsored a number of guest lectures and colloquia. These events often had sponsors in multiple university divisions.

Visions of Justice, Visions of Science
October 7, 2009

After the steering group met the previous week, we decided it would be good to begin the year by talking about how we might each be envisioning justice and science, and the relations between the two. To give us a common point of reference for the conversation, we read Nancy Fraser's essay "Abnormal Justice," found here). Also, for a particularly striking and increasingly common vision of science and justice, we read the recent article in The Scientist about the genetically modified cassava and hunger, found here. We also discussed plans for the year.

After the meeting, we attended the reception for the new art and science exhibit, Full Disclosure, which is opened at the Sesnon Gallery at Porter College.

Collaborating Across the Arts and Sciences: A Discussion of "Full Disclosure"
A Conversation with Scott Lokey (Chemistry) and E.G. Chrichton (Art)
October 21, 2009

Scott Lokey E.G. Chricton joined us to discuss their collaboration "What is Left Behind," an exhibit which appears in the new Sesnon Gallery show Full Disclosure. The issue of what gets left behind--what we don't make public, what we throw out, or do not discuss--shapes both what we know and don't know, as well as which issues gain our attention and fall from our view. Thus, it is an issue clearly at the intersection of questions of knowledge and questions of justice. Professors Lokey and Chricton described their collaboration, and explored with us this crucial, often over-looked issue.

Language, Models, Mediation: 'The Two Cultures' Revisited
Vicky Kirby (School of Social Sciences and International Studies at The University of New South Wales, Sydney)
November 10, 2009

Presented in collaboration with the Feminist Studies Department

Vicki Kirby joined us to discuss "the two cultures" problem, and experiments she has been engaged in to address it (see details below). Experimenting with collaborations across the sciences and engineering and social sciences, humanities and the arts is a central focus of the SJWG, and Kirby's visit gave us a chance to reflect on our own collaborations.

Vicki Kirby teaches in the School of Social Sciences and International Studies at The University of New South Wales, Sydney. She has published widely in the areas of post-structural and feminist theory, posthumanism and science studies. She was Guest Editor of a special issue of Australian Feminist Studies on "the two cultures" problem in 2008. The motivating question behind her research concerns the nature/culture, body/mind, matter/form divisions. Books include *Telling Flesh: The Substance of the Corporeal* (Routledge 1997); *Judith Butler: Live Theory* (Continuum 2006); and *Quantum Anthropologies: Life at Large* (Duke forthcoming).

Indigenous Peoples and Genomic Research: Building Responsive Science
Kimberly Tallbear (UC Berkeley, Environmental Sciences, Policy and Management)
November 16, 2009

Kimberly Tallbear and Jenny Reardon presented work from collaborative research project with Rebecca Tsosie (ASU Sandra Day O'Connor College of Law) that seeks to understand how genomic research done on, by and for indigenous peoples might better respond to the concerns of indigenous peoples. Reardon and Tallbear suggested that following problems with the Human Genome Diversity Project, many researchers and bioethcists set off some serious ethical issues off to the side as 'indigenous problems.' However, these problems could not be contained as they raise questions of governance that are widely applicable to non-indigenous groups and concerns. For instance, open access regimes favored by some genomics researchers make it challenging to tailor privacy policies to a group's specific concerns. While this problem is particularly acute for indigenous groups, it consequences are not limited to them. Among the topics Reardon and Tallbear sought SJGW feedback on included different approaches to anonymity, open access and property, and what these ethical and legal constructs mean in the contexts of bioinformatic databases and genomic research. For a description of the work see here.

Living Changes in the Life Sciences
Ruth Mueller (University of Vienna)
January 27, 2010

Ruth Mueller, who visited us from the University of Vienna in the Winter and Spring, presented on a research initiative she is part of entitled "Living Changes in the Life

Sciences." The scientific community is increasingly aware of the co-evolution of science and society, altering not only the ways in which knowledge is produced and disseminated, but also potentially affecting the knowledge itself. The central aim of this project is to identify and better understand the process of co-production between society and the life sciences (see here for a fuller description of the project). This project is highly relevant to SJWG's efforts to forge collaborative work here at Santa Cruz aimed at better understanding this mutual constitution of the way we live and the way we know.

Informatics and Social Justice
Elijah Saxon (Sociology, UCSC)
February 10, 2010

Elijah Saxon (Sociology) discussed novel ethical and justice issues raised by the increased importance of surveillances technologies in knowledge production processes, both inside and outside the academy. He also sought input from SJWG regarding a possible research project that both examines and evokes these very issues. Saxon framed his research project with this preface:

"Despite ongoing contestation over the term "information society", there is one observation everyone can agree on: the volume of information in the world is expanding rapidly. This expansion has altered how many fields make knowledge claims. The ability to apply computational analysis to massive datasets is already a requirement for contributing to the most active questions in climate change, epidemiology, global finance, advertising, and state security, to name a few.

In a social justice context, this continued rationalization of information offers many problems and perhaps a few opportunities. For example, in the area communication, both capital and state approaches to information analysis and gathering have troublesome implications for social justice. Internet companies have turned to surveillance as a primary source of revenue, and the US government has turned to blanket surveillance of everyone's social network in order to identify potential terrorists.

For the Science and Justice Working Group, this new way of making sense of the world raises many possible questions. How has the explosion of information affected your field? Can we afford to ignore the great power that computational analytics holds? Is it possible to re-purpose surveillance tools used for control for social justice ends ? What questions are made possible by data mining, and what questions are occluded from view?"

Human Genome Research and Bio-Identity in Colombia
Carlos Andres Barragan (UC Davis)
February 17, 2010

Carlos Andres Barragan joined us to discuss his research on “Iniciativa genómica colombiana” (Colombian Genomic Initiative), a national effort to map the genomes of indigenous, Afro-descendants, and mestizo populations. Barragan’s research follows how the Colombian government’s turn toward multicultural commitments shapes the negotiation between scientists and indigenous organizations on how to gain access to human tissues in indigenous communities. Colombia’s unique racial and socio-economic histories get folded into these debates in a manner that can be highly local. There are also many instances in which scientists and indigenous activists have substantial misconceptions of each other that are produced through these histories. Although scientists recognize ‘they’ crossed a line in the past in dealing with indigenous communities, they believe that ‘we’ are not the ‘them’ who committed misdeeds in the past and therefore should be able to follow modern bioethics protocols unproblematically. In a similar manner, activists believe that every genetics/genomics project creates a lot of capital, and in the light of bioethical discourses of sharing resources the indigenous activists expect pay up front for access to tissues. Barragan proposed the need for a new framework for the trade and negotiation of biomedical material that can at least articulate better politics of identity and understandings of how people allow science into their lives or identities.

Following the meeting, there was a film related to our discussion presented by Juan Mejia & Francia Marquez Mina, entitled “Uprooted: Land Displacement and Resistance in Black Communities in Colombia.”

Public health in the Gaza Strip: When Human Rights Rhetoric Confronts International Politics
Nancy Stoller (Community Studies)
February 24, 2010

This talk by Nancy Stoller began with an overview of the current health situation in the Gaza Strip. First, Stoller highlighted the work of several non-governmental health organizations that use a health justice model to inform their work and advocacy in order to show how the human rights health model can be powerful in local clinical applications, even when there are important structural inadequacies (e.g., poor sanitation, inadequate specialty care). Then she addressed the difficulties of applying the model when there are significant political obstacles to the implementation of the human right to health. This part of the talk explored two human rights challenges to the Gaza border closure and military strikes on the grounds of their health impacts on the population: one challenge by the UN in the form of the Goldstone Report and the other an unsuccessful attempt by some of its members to get the American Public Health Association to publicly support opening Gaza’s closed borders to improve medical and public health services.

Stoller provided some suggested reading prior to the talk:

1. The UN Goldstone report and the UN’s press release announcing the report.

2. Two resolutions submitted to the American Public Health Association during 2008 and 2009.
3. Three short pieces concern conflict between the UN and Israel over responsibility for conditions in Gaza since “Operation Cast Lead.”
4. AIDA one year follow-up report after Gaza attack
5. “Israel: UN is paid for damage in Gaza,” NY Times, Jan. 23, 2010
6. “Israel poised to challenge a UN report on Gaza,” NY Times, Jan. 24, 2010

Gay Genes and the Address of Scientific Stories
Kate O'Riordan (University of Sussex) in conversation with **Herman Gray** (Sociology)
April 7, 2010

The gay gene emerged in the 1990s to both skeptical and appreciative audiences in lesbian, gay, bisexual and trans communities. Since this emergence, science writing on sexuality and the genome [in the UK] has positioned "the discovery" of " the gay gene" attributed to Dean Hamer in 1993 as the origin of genomic sexuality research. As the political culture of the 1990s becomes more distant for both media production and for audiences, the criticality of news reporting in this area has subsided and an acceptance of "the gay gene" as a scientific point of reference has emerged. It resides in scientific databases [OMIM], research discussions and science writing.

Today "the gay gene" is a perilous object somewhere between scientific reality and urban myth. However, rather than seeing this object as the result of media hype, or uncritical audiences, it is important to register that the gay gene is also generated through a particular kind of scientific address. Take up of this address—being spoken to by stories of "gay genes"—generates emotional attachments that can play an important part in everyday life experience and identity.

Drawing on some recent accounts of responses by audiences in the UK, O’Riordan offer some details of these attachments to "the gay gene." She suggested that the ability of scientific institutions to address audiences should not be underestimated, and that looking at the contemporary life of this case study might help to open up questions about what responsibilities arise in these relationships between scientific institutions, media forms and audiences.

Kate O'Riordan from the Media, Film and Music department of the University of Sussex (Brighton, UK) who will join us to discuss a case from her soon to be published book, *The Genome Incorporated: Constructing Biodigital Identity* (Ashgate, 2010). Herman Gray (Sociology, UCSC) will provide a brief commentary.

Engaging with Science and Gender
April 21, 2010

Presented in conjunction with UCSC’s Women in Science and Engineering (WISE)

In this meeting, SJWG and WISE explored the ways in which gender matters in the ideas, practices and lives of working scientists. It brought together approaches from feminist science studies that show how gender matters in scientific knowledge production with initiatives that focus on women advancing in scientific careers. While these two issues are often discussed separately, this meeting will try to make visible how they are connected. By bringing together perspectives from different fields, this event traced how scientific practices are also practices of producing gendered realities.

Speakers:

* Karen Barad (Feminist Studies, UCSC)
* Genevieve Halpenny (President of Women in Science and Engineering, UCSC)
* Zia Isola (Center for Biomelocular Science and Engineering Diversity Programs UCSC)
* Heather Morrison (Astronomy, CASE)

See attached Rapporteur Report for more details.

Exploring the Social, Ethical and Cultural Apsects of Anti-aging Science and Medicine
Joanna Latimer (Cardiff University)
May 12, 2010

Latimer presented her research on how the relations between disease, persons, and molecular biology are fabricated in anti-aging research. In particular, she focused on how anti-aging science and medicine constructs and makes use of notions of frailty and resilience of aging persons and bodies. By understanding medicine as a social institution and knowledge practice, and by recognizing how cultural pre-occupations make being/getting old problematic for many people, Latimer proposed that the rise of anti-aging medicine can be framed in terms of a negotiation between pessimism about aging as inevitable and an intractable hopefulness about biomedical research curing many of the diseases associated with aging. That is, anti-aging medicine and science must create a space in which it can evoke the inevitability of aging and make promises about how biomedical interventions may forestall, ameliorate, or eliminate that process. In part, this occurs by framing aging itself as a preventable or reversible disease process, rather than focusing on aging as a risk factor for other diseases (such as strokes, heart attacks, cancer, etc.).

Latimer discussed how anti-aging efforts negotiate these discourses, examining the internal division of anti-aging research between the ‘nutters’ and the ‘legitimate’ researchers. Legitimate researchers emphasize the promotion of healthy aging and wellbeing through limiting the diseases associated with old age, whereas the ‘nutters’ promote longevity and rejuvenatory technologies aimed at increasing and enhancing life. The ‘legitimate’ scientists typically frame this in terms of ‘compressed morbidity,’ in

which medicine will be able to push the worst consequences of aging into a very narrow timeframe at the end of life, rather than having a sometimes decades-long, drawn out process of dying. According to Latimer, the nutters suggest that there is no necessary reason why we cannot live for a much longer time and argue that biomedical research is best directed toward achieving biological immortality. The division between nutters and legitimate research is not as clear the legitimate researchers may hope for by employing the pejorative term to draw that boundary.

Stem Cells and Social Justice: A Conversation with Charis Thompson (UC Berkeley)
May 13, 2010

This was a special lunchtime session with Charis Thompson, Director of the Stem Cell and Society Project and Associate Professor of Gender & Women's Studies at UC Berkeley. Professor Thompson joined with the working group to discuss the following two questions: What, if any, are the connections between stem cell research and questions of social justice? Why should a group interested in science and social justice be interested in stem cell research, and what kind of a research agenda can be developed in this area? In this session, we will be addressing these questions specifically in relation to the local context of California and the UCs.
This event is co-sponsored with the Center for Cultural Studies and the Center for Biomolecular Sciences and Engineering.

See attached Rapporteur Report for more details.

Geoengineering and Glaciers: Risk and Research Guidelines
A conversation between **Slawek Tulaczyk** (Earth and Planetary Sciences) and **Andrew Mathews** (Anthropology).
May 26, 2010

Recent events have demonstrated that reducing carbon emissions is going to be difficult: the Copenhagen climate conference failed to produce concrete results and climate legislation is currently moving slowly through congress. It is in this context that efforts to prevent climate change by other means than reducing carbon emissions have emerged: these include solar radiation management, ocean fertilization, carbon burial and carbon storage, geochemical carbon capture and cloud whitening. Geoengineering approaches have been the topic of increasing discussion among climate scientists, with a recent major report and policy initiatives by Royal Society of Great Britain, hearings in the US Congress and the British House of Commons, and efforts to generate guidelines for research approaches (Oxford principles) and at a conference at (Asilomar, California). Although these discussions have attracted some media notice, they have yet to gain the attention of mainstream policy makers and scientists, nor have they yet captured the imagination of broader publics.

Slawek Tulaczyk described how engineering interventions might be carried out upon glaciers in order to slow down their advance or their rate of melting. Andrew Mathews described his recent research at the Asilomar International Climate Intervention Conference, where scientists tried to generate a set of guidelines for geoengineering research, including possible methods for deciding their riskiness and appropriate public consultation. We then discussed how efforts to define and control the risk of possible research approaches might be applied to interventions on glaciers. This event will kick off a discussion of geoengineering at UCSC, in preparation for the conference, *Emerging Terraformations: Climate Change, Geoengineering and Science Fiction*, which will be held at UCSC on October 22-23, 2010.

See attached Rapporteur Report for more details.

Here is A Human Being: At the Dawn of Personal Genomics
Misha Angrist (Duke University Institute of Genome Sciences and Policy)
May 27, 2010

Misha Angrist presented perspectives from his forthcoming book Here is a Human Being: At the Dawn of Human Genomics. As one of the first ten people whose entire genome has been sequenced and made public in genomic databases through the Personal Genome Project, Angrist has been personally involved in much of the politics and science of personal genomics. He traced a history of personal genomics, starting with the celebration of the Human Genome Project, and discussed what it means and does not mean to have one's genome sequences at this point in time.

Symposia and Conferences

Biocuration Workshop
May 27, 2010

This workshop represented a new format for SJWG events. Funded by the SJTP and Center for Biomolecular Science and Engineering, the Biocuration Workshop was organized by Reardon and Metcalf to develop a conversation not only between researchers from UCSC's Genome Browser, but also included scientists from private industry. The entire event was not open to the public or all SJWG members. In order to provide a space for open and focused discussion, most of the workshop was by invitation only. The final session of the day, a lecture by Misha Angrist on the experience of having his genome sequenced (detailed above), was open to the community. This event demonstrated an important model of inquiry going forward. SJWG's and SJTP's unique position within the university, and UCSC's position within the broader community, make our group an ideal place for carrying out timely research and collaboration on locally important and nationally relevant issues.

As genomic science accumulates greater and greater quantities of raw data, curation and interpretation have become key issues in the production of medical and evolutionary biology. This meeting brought the UC Genome Browser staff together with other key actors working on curating genomes to discuss common issues and problems. The meeting addressed two central questions: Who Can We Trust to Biocurate? Will there be Public Whole Genomes?

Speakers:

Elana Silver (Science Manager, Navigenics)
Shirley Wu (Biocurator, 23andMe)
Robert Kuhn (UCSC Genome Browser)
Mark Diekhans (ENCODE Gene Annotation Project, UCSC)
David Haussler (UCSC Genome Browser, HHMI)
Misha Angrist (Personal Genome Project and Duke University)
Michelle Cargill (Locus Development)
Malia Fullerton (University of Washington)

IV. Future Directions and Proposed Activities

The SJWG will continue to host collaborative and interdisciplinary programming, support timely research on locally important and nationally and internationally relevant issues, further integrate with the Training Program, and develop cross-divisional relationships between students and faculty. To these ends, the SJWG Steering Committee and the SJTP Advisory Board have identified the following as priorities in the following year.

- Develop new tools on the SJWG website. In the past year, Reardon and Metcalf have been developing a new website for SJWG, to be rolled out in Fall 2010. Based on the blogging infrastructure WordPress, this website will offer a number of opportunities for promoting the group's activities as well as supporting networking and research. The website will support personal and group blogs, and will be able to publicize research done by SJTP Fellows.
- The first cohort of SJTP Fellows will begin their formal training and research projects in 2010-11. This will intersect with SJWG in the following ways:
  - The project proposals from the first SJTP cohort include a number of students interested in developing research clusters around themes such as climate change and identity formation in psychological research. These clusters will include symposia and other public discussions that encourage collaboration across academic divisions.
  - A condition of the Fellow's funding is presenting works-in-progress to the SJWG during our regular meetings. This forges a more direct relationship between Fellows and the Working Group by offering opportunities for feedback on the Fellow's projects. We anticipate eight presentations in the next year.
- Pursue more permanent sources of funding for SJTP, such as an Institutional Graduate Education and Research Training grant from the NSF. As discovered

during the formulation of the Training Program's grant, proposing such a program fosters unexpected forms of collaboration between faculty that can support the Working Group over time.

- Establish a regular reading group. This would be hosted by the SJTP Postdoctoral Fellow and would be open to both the Working Group and Training Program members.

V. Addendum Rapporteur Reports

Joanna Latimer (Cardiff): Exploring the Social, Cultural, & Ethical Aspects of Anti-Aging Science & Medicine

5/12/10

Prepared by: Jake Metcalf

Latimer presented her research on how the relations between disease, persons, and molecular biology and fabricated in anti-aging research. In particular, she focused on how anti-aging science and medicine constructs and makes use of notions of frailty and resilience of aging persons and bodies.

Historically, medical care for elderly individuals and scientific and medical research about the biology of aging has been devalued. Latimer suggested the devaluation of aging medicine and science has been connected to:

visible signs of aging;
incidence of chronic disease and its effects on participation with 'normal' social life;
the social, economic, and structural location of older people;
widespread negative cultural representations of aging;
and social and health inequalities that are exacerbated by aging.

The devaluation of older persons results in older persons performing (and struggling to perform) a subjectivity and embodiment that attempts to remain within cultural norms and outside of cultural expectations about the passivity of aging; in other words, elder persons often attempt to maintain a response-ability to cultural expectations of youth. The devaluation of aging medicine and care is made uncanny by the fact that every developed nation spends 60-75% of its health budget on elder care. Yet medical research has so far focused primarily on curing or preventing diseases of younger bodies.

By understanding medicine as a social institution and knowledge practice, and by recognizing cultural pre-occupations that make being/getting old problematic for many people, Latimer proposed that the rise of anti-aging medicine can be framed in terms of a negotiation between pessimism about aging as inevitable and intractable and a hopefulness about biomedical research curing many of the diseases associated with aging. That is, anti-aging medicine and science must create a space in which it can evoke the inevitability of aging and make promises about how biomedical interventions may forestall, ameliorate, or eliminate that process. In part, this occurs by framing aging itself as a preventable or reversible disease process, rather than focusing on aging as a risk factor for other diseases (such as strokes, heart attacks, cancer, etc.).

Latimer also framed her research in terms of her methodological and ethical challenges of participating within anti-aging research without becoming part of the funding network (which includes large amounts of money from cosmetics corporations). Because the stigma of aging is often linked to how we look, and cosmetic companies market themselves in terms of staving off the effects of aging, there is a large pool of funding from cosmetics industry that is driving the biomedical research. Latimer expressed concern about how to maintain her appreciation of the vitality of the aged and her desire to improve upon that vitality, without being co-opted into dominant negative discourses that devalue the elderly. She argued that despite the overarching and problematic social structures of anti-aging research, there are on the ground complexities that must be acknowledged. While aging science is addressing important questions about how to improve elder care, Latimer wants us to focus on *how* they do it. For instance, do they engage in stereotyping to in order to legitimate their work? Do they engage in undesirable forms of biomedicalziation in order to mark their work as legitimate?

Latimer discussed how anti-aging efforts negotiate these discourses, examining the internal division of anti-aging research between the 'nutters' and the 'legitimate' researchers. Legitimate researchers emphasize the promotion of healthy aging and wellbeing through limiting the diseases associated with old age, whereas the nutters promote longevity and rejuvenatory technologies aimed at increasing and enhancing life. The 'legitimate' scientists typically frame this in terms of 'compressed morbidity,' in which medicine will be able to push the worst consequences of aging into a very narrow timeframe at the end of life, rather than having a sometimes decades-long, drawn out process of dying. The nutters suggest that there is no necessary reason why we cannot live for a much longer time and argue that biomedical research is best directed toward achieving biological immortality. The division between nutters and legitimate research is not as clear the legitimate researchers may hope for by employing the pejorative term to draw that boundary.

In particular, both share a goal of re-defining aging as a disease. Because aging is currently considered a risk factor for other diseases, and not a disease itself, anti-aging research does not fit cleanly within funding contexts dedicated to anti-disease research. Both branches of anti-aging research suggest that the most direct route to addressing anti-disease research in general is to conduct anti-aging research.

Latimer conclude with a series of open questions for discussion:

- How do scientists of aging construct different models of aging?
- How do aging scientists conceptualizing aging itself--what does aging become in the world of aging science?
- How do the ways that aging science represents aging legitimate intervention in the biological processes of aging?
- How do these processes of representation and legitimation interact with the historic, economic, social and cultural conditions underpinning knowledge practice in aging science ?

What kinds of bodies and person do aging scientists construct through their work and practices? To what extent are these transformative of ageist representations of growing older or of being older?

Stem Cells and Social Justice: A Conversation with Charis Thompson (UC Berkeley)

5/13/10

Charis Thompson offered a wide-ranging discussion around the question: how can we respond to social justice questions in stem cell technology and biology? In particular, she focused on the local context of California's 2004 Proposition 71 and it's aftermath. The full title of Prop. 71, California Stem Cell Research and Cures Act, immediately raises a series of questions about science and justice by conjoining the terms 'research' and 'cures.' Thompson suggested that 'cure' is often paired with its antonym 'prevention' and it is necessary to pull these terms apart to ask what it means to spend vast amounts of money on cures and so little on prevention. As health and medicine become ever larger portions of the economy it is increasingly common to biomedicalize everything and grow the bench to bedside pipeline in which publicly funded research and technologies are privatized. Tying research and cure together suggests that everything that is worthy of research is also worthy of a cure, laundering market value into debates about public good. Likewise, the market value of cures create exception cases of orphan diseases and their activist communities, who often come to stand for 'the public.' In other words, market logic creates a type of semi-excluded public whose political role is to argue for making markets broader and more powerful.

In this context, philanthropy becomes a public hero for 'giving back' a small amount of the capital that has been accumulated by the wealthy. This model of philanthropic capital limits thinking about justice and medicine, particularly as it merges with developing states to make medicine nearly free and 'gives back' intellectual capital. Philanthropic capital has pushed out models for medical technology that reject intellectual property altogether—we lack models for cures without the transmission of standard intellectual property regimes or other ways of breaking the link between markets and medicine.

Thompson also argued that Prop. 71 represents a discourse that everything needs to be cured—it's text and it's backers produced a very long list of diseases that could be cured by stem cells. This is problematic because it presumes that we know in advance what is wrong with people and needs to be cured. She suggested that we get to the discourses of curing too cheaply because not everything can or should be cured. In many cases, our built environments are too restrictive for a range of human embodiments and this may be a more fruitful and just target for intervention. Biomedicalizing all non-normal embodiments suggests that what it is to be different is to be waiting to be turned back into normal.

Thompson stated it is also necessary to interrogate standard bioethics discourses for problematic assumptions about social justice. For instance, biobanking for research—essentially saving bits of bodies indexed to their provenance and procurement—is often framed in altruism. Yet the folks that move bits of other people's bodies around make substantial money from it. Likewise the differences between the populations that are present in biobanks and forensic databases are remarkable. What are effects of having one type of population in the research biobanks controlled by corporations and universities and another population present only in forensic biobanks controlled by the state?

Geoengineering and Glaciers: Risk and Research Guidelines
A conversation between Slawek Tulaczyk (Earth and Planetary Sciences) and Andrew Mathews (Anthropology).
5/26/10

This conversation between Slawek Tulaczyk (Earth and Planetary Sciences) and Andrew Mathews (Anthropology) focused on the possibility of geoengineering glaciers to ameliorate some of the effects of global warming. Whereas geoengineering was once associated with Soviet projects and was not openly discussed by respectable scientists, it has now gained enough credibility to be the topic of US National Academy of Science and UK Royal Society reports.

Mathews suggested that the growing acceptance of geoengineering as a justifiable and palatable approach to global warming raises a series of questions about the justice of large scale climate engineering. One question is who can do the modeling and how those models can be trusted? For instance, spraying sulfur particle into the stratosphere to increase global albedo—the most commonly proposed and most technologically feasible form of geoengineering—is thought to reduce rain fall in some regions, especially Africa and Asia. In the first major drought after stratospheric sulfur, there could be no way of determining whether that drought was caused or worsened by the geoengineering, and thus no way of knowing whether the model correctly predicted its effects. Such a situation could create substantial distrust and requires careful thought about the distribution of risks, responsibilities, decision-making powers when it comes to ameliorating global warming. Likewise, as the Royal Society and National Academy call for more research on geoengineering it is necessary to address the question of on what scale such research should happen and how one nation can make technological changes to the atmosphere and climate that may affect other nations. The larger the scale of the research, the more likely the knowledge produced will be useful; but it is also more likely that the experiment will affect others who may have not been represented in the decision-making process. There is also the further question of what role publics have in determining reasonable scales of risk and how those publics can be consulted. Mathews argued that a particularly thorny problem is how to evaluate risk by scientists and engineers when the evaluation and governance mechanisms produce risk itself. In other words, the measurement of risk is done by institutions to justify imposing risk upon populations.

Tulaczyk discussed the role of glaciers in global climate cycles and technical challenges involved in engineering glaciers to reduce the impact of global warming. Widely accepted models predict a major rise in sea levels with climate change. As the oceans warm, the water itself becomes less dense, and this will be exacerbated by the melting of major glaciers at the poles. In Tulaczyk's research in Antarctica, most ice reaches the oceans by calving, and not melting. Although Antarctica remains cold enough to not be heavily affected by increased global temperatures, if engineers could prevent the calving of glaciers they could reduce the sea-rise effects of global warming by around half. Because calving is caused by glaciers sliding on water underneath the ice sheets, solutions could include pumping out that water or trying to freeze it. However, such an effort could be so expensive as to raise the question of whether it is more economical to do it, or just cope with sea levels rising.

In conversation Tulacyzk suggested that it is still potential career suicide to study geoengineering—it is a high risk, high reward field. Mathews suggested that one reason for this is a cultural concern about anything that manipulates a system that is perceived as proceeding naturally. The line between natural and unnatural interventions in global climate appears linked to the line between respectable and disreputable science, and this boundary is fought over. Whereas people who use forest conservation as a tool against global warming don't want anything to do with geoengineering, people who work on big climate models want to fold forest conservation into their projects to make use of their respectability.

The discussion also addressed the relationship between geoengineering social/cultural/political alterations to human behavior. Sulfur particles remain in the atmosphere temporarily, thus necessitating constant spraying (as soon as the particles were not sprayed in the atmosphere all the ameliorated temperature increases would quickly spike). Thus geoengineering still requires behavioral and structural changes, but may buy us some time. Mathews argued that many find geoengineering so distasteful that just its suggestion may encourage movement from nations that don't yet have sufficient reason to act.

Misha Angrist: Here is a Human Being: At the Dawn of Human Genomics
5/27/10

Misha Angrist (Duke) presented perspectives from his forthcoming book *Here is a Human Being: At the Dawn of Human Genomics*. As one of the people whose entire genome has been sequenced and made public in genomic databases through the Personal Genome Project, Angrist has been personally involved in much of the politics and science of personal genomics. He traced a history of personal genomics, starting with the celebration of the Human Genome Project. Around 2004, people started to speak out loud about the potential future uses of genomics knowledge. Once there was a consensus haploid genome, it would become possible to start doing many more genomes. George Church (PGP) and Ryan Phelan (DNA Direct) started to frame genetic testing as a form of empowerment over one's body and health. 2005 saw the

Human Genographic Project and ClinENCODE, a clinical genomics project funded by the NHGRI. In 2006, Church argued in *Scientific American* that it was necessary to turn humans into a model organism to follow through on the promises of human genomics, proselytizing 'genomes for all.' Angrist suggested that 2007 and 2008 were the years in which the idea of DIY genomics really took off and the public finally had access to tools for sequencing and interpreting genomes. Part of the effort to get genomics into the hands of civilians was the need to circumvent institutional review boards. One element of the DIY effort was to provide access to knowledge with very little editorializing; for instance, SNPedia is an open source tool for interpreting one's SNP results just links out to the scientific literature. In 2007 the first personal genomics companies appeared on the scene. The year 2007 also saw the public efforts by a clinical geneticist and father of a daughter with Marfan's Syndrome Hugh Reinhoff draw attention to rare genetic diseases—a form of research politics Angrist called 'very personal genomics.' Angrist noted a common origin story for these early advocates of personal genomics in a frustration with NIH funding limitations, the challenges of getting SNPs into molecular diagnostic labs, and the lack of progress in getting genomics data to lay people. Correlated with these efforts was a shift in the mood of administrators about personal genomics, including positive editorials in major scientific journals and Francis Collins touting the potentials of consumer genomics in 2008. In 2009, a series of studies emerged about the early users of personal genomics which allayed some of the fears of its critics. Now, in 2010, the attention paid to personal genomics has exploded, including the plans to sell direct to consumer kits at drug stores, campaigns to end preventable genetic diseases through testing, the ruling against Myriad's BRCA patents, and a paper in the Lancet advocating for incorporating personal genomics into clinical assessment.

In discussion, Angrist was asked why there appears to be only two models of the relationship between genetic data and medical care: doctors are supposed be gatekeepers, but data is also supposed to be public. He responded that PGP aims for full individual control over one's own data, but the funding mechanisms and limited resources have made a sophisticated redaction mechanism out of reach. Furthermore, it is perhaps impossible to scrub data out of one's genome sequence without putting huge scars in the sequence.