

Genomics and justice: promises and perils in the pursuit of responsible science

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Abstract

This article presents a series of issues and questions relevant to genome scientists and administrators of genomic research who are interested in contributing to the goals of social justice. These issues and questions arose at a meeting entitled, “Genomics and Justice: Promises, Perils, and Paradoxes,” held at the University of California Santa Cruz on May 17-18, 2007.

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With the completion of the Human Genome Project and the start of efforts to translate genomic information into everyday life, it has become clear that genomics neither promises a future of human liberation or oppression. Instead, this young and lively new domain of the life sciences challenges us to re-think our understandings of nature, bodies, and identities; as such, it prompts us to re-examine what concepts like “justice,” the “public good,” and “societal benefit” may mean in the context of biomedical research. What does justice entail in this genomic age, and how might genomic sciences contribute to more just social orders? These and related concerns formed the basis of “Genomics and Justice: Promises, Perils, and Paradoxes,” a meeting held at the University of California Santa Cruz, May 17-18, 2007.

The Genomics and Justice Meeting was part of an ongoing experiment in critical cross-disciplinary engagement linked to the Science and Justice Working Group at UCSC. Genome scientists, sociologists, bioethicists, historians, anthropologists, philosophers, lawyers, community health researchers, and community activists came together to explore the relationship of current genomic practices to the pursuit of social justice. The wide-ranging discussion identified a set of emerging ethical and policy considerations:

- How can researchers and research participants challenge common approaches to property and privacy so as to both foster research and better respect the values and needs of diverse beings?
- In what ways do existing laws and regulations both promote and interfere with responsible research, and how can regulatory frameworks be modified to enhance accountability?
- How do genomic ideas and practices disrupt Western notions of individuality and personhood, and how can researchers and bioethicists respond to these challenges?
- Can genomics remain responsive to histories of injustice and exclusion even as it strives to be responsive to current needs?

These linked themes challenge us to critically examine our understandings of justice and responsibility in the context of genomic research. As speaker Joon-Ho Yu (University of Washington) noted, our understanding of what counts as an ethical issue or a justice issue in the genome sciences can easily become routine, making it important to create spaces in which these understandings can be periodically examined and renegotiated. The purpose of this brief report is to begin this critical re-examination and to invite your participation in further discussion at a UCSC-hosted wiki (linked to the UCSC Science and Justice website at www2.ucsc.edu/scienceandjustice). This online space was developed as part of the UCSC Genome Browser Wiki in order to broaden participation, extend deliberation beyond the meeting’s conclusion, and continue our experiment in cross-disciplinary discussion of genomics and justice.

Private property, public goods, and possibilities for ethical enclosure

A common concern among those exploring the ethical and political dimensions of contemporary genomics centers on potential adverse consequences that could flow from

the privatization of genomic information. At the Genomics and Justice Meeting, genome scientist David Haussler (UC Santa Cruz) spoke critically of “fiefdoms” composed of prominent researchers, universities, and companies who own and control data, and thus retain disproportionate power to set research agendas. He suggested that restricting access to genomic knowledge will result in stymied science, reduced innovation, and the prevention of potentially life-saving (or life-improving) genomic discoveries. However, science policy expert Robert Cook-Deegan (Duke) noted that it is no longer reasonable to treat the public domain as the sole antidote to the ills of privatization. Rather, he suggested, tools of privatization, such as patenting and licensing, can be strategically employed to promote the goals of equity and the just distribution of goods. Cook-Deegan pointed to a Stanford University policy statement, “Nine Points to Consider in Licensing University Technology”⁵ as an example of how universities and researchers might incorporate social justice concerns into their licensing agreements.

While Cook-Deegan cautioned against demonizing intellectual property, ethnographer of science Cori Hayden (UC Berkeley) warned against uncritical celebration of the public domain. Drawing parallels between the genome sciences and pharmaceutical drug production, Hayden suggested that use of the category “public domain,” like the notion of the “generic drug,” could discourage other creative attempts to address problems of access and equitable distribution. To take Hayden’s challenge seriously means questioning received understandings of the “public good” and exploring options for ethical enclosure that transcend the public/private binary. Some conference participants are already innovating such creative ethical enclosures. For instance, medical geneticist Laura Arbour (University of British Columbia) presented the principle of “DNA on Loan.” Through DNA-on-Loan, researchers collect genetic materials from participants (in Arbour’s case, Canadian Aboriginal communities) with the understanding that they are holding such materials in trust, and thus are fully accountable to, and will share benefits equally with, their research subjects. Through this model, Arbour marshals Western notions of property rights to extend protections and control to a public that might otherwise be excluded from such rights.

Arbour and others are enacting creative approaches to property and privacy rights, disrupting scientific practices that might otherwise exclude, harm, and marginalize those they wish to sample and study. If such alternatives are to be effective, the time to consider and debate them is now—as the governments and organizations that manage resource platforms in genomic research make policy decisions about the release and use of genomic samples and information. What other promising “ethical enclosures” are possible within and beyond existing notions of the public and the private?

Law and regulation: operationalizing ethical research

The latter half of the twentieth century has witnessed a proliferation of federal, state, and institutional regulations designed to protect vulnerable research subjects, define ethical protocols, and proscribe certain unethical practices. Yet many within and beyond the

⁵ This document can be accessed at:
http://www.autm.net/aboutTT/Points_to_Consider.pdf.

genomics community see such regulations as impediments to scientific advancement and barriers to a more responsive, justice-oriented, and community-centered science. The uncertain role of legal and regulatory protections in crafting just scientific practice emerged as another central theme at the Genomics and Justice Meeting.

Haussler, for example, pointed to the potentially chilling effect of excessive concern with individual privacy, which many fear will preclude certain forms of genomic investigation and wide sharing of data or findings. Research Compliance Officer Caitlin Deck (UC Santa Cruz) worried that, as existing regulatory frameworks have expanded over time to extend formal protections to previously excluded groups, the emphasis on uniform application of rules has promoted a form of inflexibility which may ultimately harm more than it helps. This is because strong legal protections are often inimical to the local negotiation, decentralized decision-making, and culturally-specific value systems that foster greater community control over research. Addressing similar concerns about the expansion of dominant regulatory frameworks, anthropologist Deborah Gordon (UC Berkeley), questioned the prominent role of informed consent in the research exchange. Gordon suggested that by clinging to the illusion that risks to research subjects can be defined, enumerated, and clearly communicated in a consent document, researchers may believe they can absolve themselves of responsibility for the downstream consequences of their research.

In existing regulatory frameworks, preoccupation with individual rights and insufficient attention to public and community goods has also led to a relative neglect of community-level risks and benefits. For example, legal scholar Rebecca Tsosie (Arizona State University) described how tort law (which is often the only recourse for those who feel violated by a researcher or a research institution) requires the demonstration of clear and quantifiable harm to an individual. It does not recognize cultural harms, immaterial injuries to a people, or intangible harms such as violations of deeply held community values. Without the possibility of legal remedy, it is unsurprising that many North American tribes are reluctant to involve themselves in genomic research, notwithstanding recent trends toward greater community engagement.

Although existing legal and ethical frameworks are the only formal mechanisms to ensure responsible research practice, they are clearly limited in important respects. Can legal instruments be reworked to protect individuals and communities without sacrificing flexibility, cultural specificity, and local control?

Beyond the individual: creating an accountable genomics

Many of those assembled at the Genomics and Justice meeting agreed that creating such instruments will require acknowledging the challenges genomics poses to the notion of an autonomous individual. Participants at the Genomics and Justice Meeting grappled with how to create an ethical and accountable genomics in the light of these challenges.

Jenny Reardon (UC Santa Cruz) noted that classic understandings of human personhood are increasingly unsustainable in light of recent developments that allow a diverse array of genomic, proteomic, and epigenetic data to be generated from the same tissue sample, and then stored alongside relevant clinical records and linked information regarding personal health behaviors and environmental exposures. The result is a

complex bioinformatic data set. If a human subject, with rights and responsibilities, is no longer recognizable in this data set, then important questions follow about how this information will be owned, controlled, and regulated.

As genomic research practices challenge conventional understandings of the Western individual, they also renew focus on individual identity (e.g., by promoting genetic ancestry testing). Anthropologist Kaushik Sunder Rajan (UC Irvine) worried that, by bringing attention to definitions of race and ethnicity, the genome sciences may play a role in obscuring the socioeconomic and/or structural conditions that perpetuate injustice. As such, genomics might encourage identity-based politics at a time when many activists and scholars are calling for mobilizations that transcend identity categories.

Given these problems, philosopher/physicist Karen Barad (UC Santa Cruz) urged a shift in focus from a bioethics centered on individuals and identities to one grounded in the *relational* processes of knowledge production. Ethical questions enter into the everyday decisions of scientists as they engage with one another, with research participants, and with the objects (programs, microscopes, datasets, etc.) entailed in doing scientific research. For Barad, a responsible ethics for genomic science would bring into view the multi-faceted “intra-actions” among scientists and their subjects and objects of study, thus encouraging greater accountability within scientific relationships.

Rapid advances in the genome sciences promise to complicate and extend many established social ontologies that inform legal and regulatory bodies. In what other ways does genomics ask us to re-think identity, personhood, and social relationships, and how might these new understandings inform how we conceive and pursue justice today?

Toward a genomics and justice of the present

Finally, significant attention at the Genomics and Justice meeting focused on the often-discussed disconnect between the promise of genomics’ future benefit and the tangible present-day concerns of communities asked to participate in genomic research. Such concerns loom large for Maile Taulii (Urban Indian Health Institute, Seattle Indian Health Board) who reminded conference participants of the histories of exclusion, dispossession, and deprivation common to many marginalized groups—realities that must be substantively addressed *before* such populations are likely to participate in research that speculatively promises better health outcomes in the future. These are, understandably, difficult issues for genome scientists who may feel that they had no role to play in past abuses and have nothing substantive to add (beyond their specific research programs) to concrete solutions. Nevertheless, historian and critical theorist of the life sciences Donna Haraway (UC Santa Cruz) suggested that “there is strong reason to be suspicious of future orientations that ignore histories of injustice and injury,” as they follow many unfulfilled promises to link scientific advancement with a better and more just future for all.

In light of this, speaker Astrid Schrader (UC Santa Cruz) urged us to critique future-focused promises and instead “inquire about possibilities for justice here and now.” The challenge, then, is to conduct genomic research that takes into account current and historical injustices, and that responds to present concerns. Genomic scientists can play an important role in this endeavor. Because a great deal of collaborative conceptual

and empirical work must accompany these efforts, we ask you to think with us about the practical challenges and opportunities involved in building responsible ethics into everyday scientific practice. Please visit our wiki (www2.ucsc.edu/scienceandjustice) and contribute to our collective experiment in conceptualizing and fostering a just genomics.

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