

Assignment 6

Genomics Case

Is the new genomics reconfiguring race and science?

There is a great deal in contemporary science journals and in the popular press about gene, the genome, genomics, race and gender. You may want to work in groups to develop this case.

Read the whole case, but focus on step 1 in preparation for Week 7 of class.

From the 3/12 class: ([audio of work-in-progress](#))

Week 8 of class will be three weeks later and it is then that you will make your presentations on this case. The assumption for this case is that you have tools and experience now for opening up lines of inquiry, focusing in after initial explorations, and formulating a product and presentation that match your interests and intended audience.

1. To untangle what is out there start by studying the following websites:

<http://www.personalgenomes.org/>

<http://www.decode.com/>

<http://www.africandna.com/About.aspx>

- What kinds of knowledge claims are made on these websites?
- What kinds of events and institutions are linked on these websites?
- Who and what are the actors that emerge from these pages and what kinds of actions do they take
- Use Clarke, Chapter 3 as a guide and construct a situational map of the human genome territory opened up by these websites. Be prepared to present and explain the map or maps in class.

2. What do people out in the world—academics, medical scientists and consumers say and think about these websites and the maps that they invite?

Below is a starting bibliography. Choose some portion of it to study and understand.

- What knowledge claims are made in the literature you have chosen?
- What actions are suggested?
- How do these reflect back on the claims and actions made on the original websites from part 1?
- Do these articles introduce new actors including people, things, institutions and technologies?
- Use Clarke, Chapter 5 to map the narrative discourses encountered in your chosen readings

3. What conclusions can you come to about the push to make personal genomes accessible? If they are inevitable, then what actions would you deem necessary to make their acquisition and use scientifically and socially acceptable?

a. Devise a guide that would help an individual decide whether or not to have their own or a

loved one's genome mapped; should they agree to make it public or should it be only for private use? OR

b. Devise a guide for scholars and ethicists that explains the strengths and dangers of developing a mass market for individual genome mapping.

Your starting bibliography:

Gender-based medicine, what causes apparent difference?

Arbuckle, Tye E. "Are there Sex and Gender Differences in Acute Exposure to Chemicals in the Same Setting?" *Environmental Research* 101, no. 2 (June 2006): 195-204.

Commercialization compromising science – e.g., genetic ancestry testing, questionable tests for disease – threatens to erode traditional science approaches.

Hans-Jürgen, Bandelt. Yong-Gang Yao, Martin B. Richards, and Antonio Salas. "[The Brave New Era of Human Genetic Testing.](#)" *BioEssays* 30, no. 11-12 (2008):1246-1251.

Position paper from social scientists, anthropologists, etc. of color v. ancestry testing – responses follow.

Bolnick, Deborah, et al. "[The Science and Business of Genetic Ancestry Testing.](#)" *Science* 318, no. 5849 (2007): 399-400.

Frudakis, Tony. "[Letters: The Legitimacy of Genetic Ancestry Tests.](#)" *Science* 319, no. 5866 (2008): 1039-1040.

Historical overview

Braun, Lundy and Evelynn Hammonds. "[Race, Populations and Genomics: Africa as Laboratory.](#)" *Social Science and Medicine* 67, no. 10. (2008): 1580-1588.

Social studies in labs where the racial/ancestry analysis is taking place – coding and categories.

Fullwiley, Duana. "[The Biological Construction of Race: 'Admixture' Technology and the New Genetic Medicine.](#)" *Social Studies of Science* 38, no.5. (2008): 695-735.

Fullwiley, Duana. "[Race and Genetics: Attempts to Define the Relationship.](#)" *BioSocieties* 2, no. 2 (2007):221-237.

Fullwiley, Duana. "[The Molecularization of Race: Institutionalizing Racial Difference in Pharmacogenetics Practice.](#)" *Science as Culture* 16, no.1. (2007):1-30.

Gender differences in medicine

Gochfeld, Michael. "Framework for Gender Differences in Human and Animal Toxicology." *Environmental Research* 104, no. 1. (2007): 4-21.

Editorial re: bringing social aspects back into the study of biology and disease.

Gross Liza. "Poverty, Human Development, and Basic Biology." *PLoS Biology* 5, no.11. (2007): e295-296.

News report re: 10-minute genomes, efforts on multiple fronts

Hayen, Erika Check. "[Accessible Genomes Move Closer.](#)" *Nature* 455 (2008):1014

Overview of this issue from STS

Hedgecoe, Adam and Paul A. Martin. "Genomics, STS and the Making of Sociotechnical Futures." In [The Handbook of Science and Technology Studies](#). Edited by Edward J. Hackett, Olga Amsterdamska, Michael Lynch, and Judy Wajcman. Cambridge, MA: MIT Press, 2007. ISBN-10: 0262083647 ISBN 13: 9780262083645.

Ethical considerations

Lee, Sandra Soo-Jin, et al. "[The Ethics of Characterizing Difference: Guiding Principles on Using Racial Categories in Human Genetics](#)." *Genome Biology* 9. (2008): 404.

Lee, Sandra Soo-Jin and Ashwin Mudaliar. "[Racing Forward: The Genomics and Personalized Medicine Act](#)." *Science* 323, no. 5912: (2009) p.342.

What are the implications of the personalized genome?

McBride, Colleen et al. "[Putting Science of Supposition in the Arena of Personalized Genomics](#)." *Nature Genetics* 40, no. 8. (2008): 939-942.

Muers, Mary. "[Human Genomics: Which Differences Make Us Different?](#)" *Nature Reviews Genetics* 9. (October 2008): 729.

"Official" science response

Anonymous. "Getting Personal." *Nature* 455, no. 7216. (2008): 1007.

Neame, Elizabeth. "[Born to Run? A DNA Test to Identify Future Sports Stars](#)." *Nature Reviews Genetics* 10 (February 2009):74.

Sociology studies of people who have taken part in ancestry studies

Nelson, Alondra. "[Bio Science: Genetic Ancestry Testing and the Pursuit of African Ancestry](#)." *Social Studies of Science* 39, no. 5 (2008): 759-783.

Stance: ignore racial issues, pursue personal genomics instead

Ng, PC, Q Zhao, S. Levy, RL Strausberg and JC Ventner. "[Individualized Genomes Instead of Race for Personalized Medicine](#)." *Clinical Pharmacology and Therapeutics* 84, no. 3. (2008): 306-309.

Gender and disease

Ober, Carole, Dagan A. Loisel and Yoav Gilad. "[Sex-Specific Genetic Architecture of Human Disease](#)." *Nature Reviews Genetics* 9 (December 2008): 911-922.

Pinker, Steven. "[My Genome. My Self](#)." *The New York Times Magazine*. January 11, 2009. pp 24-32.

Sequence analysis of adaptive systems

Rea, Thomas J., Christine M. Brown, and Charles F. Sing. "[Complex Adaptive System Models and the Genetic Analysis of Plasma HDL-Cholesterol Concentration](#)." *Perspectives in Biology*

and Medicine 49, no. 4. (2006):490-503.

Reports on mechanics, background behind genetic survey efforts

Reardon, Jennifer. "[Creating Participatory Subjects: Science, Race and Democracy in a Genomic Age.](#)" In *The New Political Sociology of Science: Institutions, Networks and Power*. Edited by Scott Fricke and Kelly Moore. Madison, WI: University of Wisconsin Press, 2006. ISBN: 9780299213305.

Reardon, Jennifer. "Decoding Race and Human Difference in a Genomic Age." *Differences* 15, no. 3 (2004):38-65.

Reardon, Jennifer. "[Democratic Mis-haps: The Problem of Democratization in a Time of Biopolitics.](#)" *Biosocieties* 2 (2007): 239-256.

Social Studies of Science "Special issue on Race" (details in the syllabus); select relevant articles, follow their reference trails

Geneticists bringing environment back into the mix

Varki, Ajit, Daniel Geschwind, and Evan Eichler. Explaining Human Uniqueness: Genome Interactions with Environment, Behavior and Culture." *Nature Reviews Genetics* 9 (October 2008): 749-763.

Single-topic issue debating the question of where to put the first efforts & dollars.

Yamey, Gavin. "[Which Single Intervention Would Do the Most to Improve the Health of Those Living on Less than \\$1 per Day?](#)" *PLoS Medicine* 4, no 10. (2007): e303.

Bibliographic Supplements from Peter Taylor

On giving meaning to accessible genomes, see
Khoury, M. J., Little, J., Gwinn, M., & Ioannidis, J. P. "[On the Synthesis and Interpretation of Consistent but Weak Gene-Disease Associations in the era of Genome-Wide Association Studies.](#)" *International Journal of Epidemiology*, 36 (2007): 439-445.

On STS analysis of this issue, see
Taylor, P. J. "Infrastructure and Scaffolding: Interpretation and Change of Research Involving Human Genetic Information," *Science as Culture*, 2009.

On imbalance between collection of genetic and environmental information, see
Frank, J. "A Tale of (More Than ?) Two Cohorts." 3rd International Conference on Developmental Origins of Health and Disease, Canada, 2005. (discussed in "Infrastructure and scaffolding.")

On the challenges of using genetic information in the best and probably simplest case of diagnosable genetic disease, namely, PKU, see
Paul, D. *The History of Newborn Phenylketonuria Screening in the U.S. Final Report of the Task on Genetic Testing*. Baltimore, MD: Johns Hopkins University Press, 1998. (discussed in "Infrastructure and scaffolding")

On the whole topic:

Shields, Alexandra, et. al. "[The Use of Race Variables in Genetic Studies of Complex Traits and the Goal of Reducing Health Disparities: A Transdisciplinary Perspective.](#)" *American Psychologist* 60, no. 1. (2005): 77-103

On disease and patient groups, see

Epstein in the STS Handbook and Rayna Rapp's work with Faye Ginsburg on parent advocacy groups for children with rare genetic conditions. (I heard her talk about it in a session that AFS also spoke in. Not sure what she has published on this.)

<http://as.nyu.edu/object/raynarapp.html>

On activist groups, see

[GeneWatch](#)

On bioethics, see

commentaries on ELSI, including one done by Jan Coe

On bringing the environment in see

Frank above (<http://www.cihr-irsc.gc.ca/e/13967.html>)

On digital pedagogy, see

audio & slides of Gonzalo Bacigalupe, talking about "The impact of the new social media on public health research", <http://sicw.wikispaces.com/ISHS09>

MIT OpenCourseWare
<http://ocw.mit.edu>

WGS.693 Gender, Race, and the Complexities of Science and Technology: A Problem-Based Learning Experiment

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