

SOCIOLOGY OF ILLNESS: THE NORMAL AND PATHOLOGICAL THROUGH
THE LENS OF GENETICS

Instructor: Santiago J. Molina, santiagomolina@northwestern.edu

Seminar: Monday and Wednesday 11:00-12:20pm in University Hall 112

Office Hours: Mondays 3:00pm-4:30pm (<https://www.wejoinin.com/santiagomolina>)

I. SUMMARY AND GOALS

This course surveys a variety of topics in the sociology of illness and social studies of science and threads them together with a common goal: to unpack the entanglements of society with the science of human genetics and biomedicine. Through the readings, students will engage with themes that are central to sociological thought: identity, knowledge, power, categorization, race, politics, etc. albeit in the context of science and illness. By the end of the course students will be able to sharply interrogate two sides of the relationship between science and society: a) how social and political conditions shape the production of claims about the genetic basis of illness and difference; and b) vice-versa, how claims about the genetic basis of illness and difference can affect social and political conditions.

Since the mid-Twentieth century, scientists' understanding of the molecular basis of human biology has grown exponentially. Correspondingly, this knowledge has trickled out into the public sphere. Today, the relevance of this knowledge to modern societies is reflected in record sales of personal genetic tests, holiday package discounts for DNA ancestry services, the normalization of pre-natal genetic screening and the emergence of a flourishing industry for preserving human tissue samples and genetic data for commercial, clinical, and criminological uses. Additionally, the advent of new tools in genetic engineering has put more pressure on societies to engage in public discussions about how to ensure that scientific research is conducted ethically, that the safety risks of new technology are mitigated and that the products of this research reach the communities that most stand to benefit.

However, many of the issues that arise from these technologies are not entirely new. Instead, Western societies have been obsessed with the idea that a person's characteristics are passed down to their children and that wealth, status, and group membership is tied to your bloodline. Additionally, since the industrial revolution, both states and individual actors have produced a swath of eugenic policies aimed at "improving" the nation or "alleviating" poverty. On a more personal level, *who we are* has always had at least something to do with our bodies, whether it's our height, skin color, ability, health, sex or gender. This course will take up simultaneously historical and deeply personal dimensions of these issues.

While much of the scholarship we will consider is broadly sociological, some of it is drawn from other fields, and part of the goal of the course is to show what is gained when we think about health and illness from an interdisciplinary perspective. Students with majors in African American studies, Asian American studies, anthropology, communication studies, critical theory, history, film and media studies, Latina and Latino studies, as well as from biological science, biomedical engineering, biotechnology and biochemical engineering, premed and the integrated science program are welcome.

II. ASSIGNMENTS AND GRADING

<p>a) Participation. You are expected to come to class having done the readings and prepared to actively discuss, compare, and critique the readings with your peers. Both active <i>listening</i> and <i>contributing</i> are required for participation. Meeting with the instructor for one-on-one office hours during the first three weeks of instruction is required for full participaiton.</p>	<p>20%</p>
<p>b) 4 response memos. (300-500 words) Here you should aim to: summarize the argument in one of the readings; reflect on the readings in relation to your own experience, ask clarifying questions and connect the readings (from any week) to each other. Along with the Reading Guide, these are meant to help you keep on track with the readings and to prepare you for doing a literature review for your midterm. Deadlines for each memo are set throughout the semester on <u>X, X, X, and X</u>. Response memos must be submitted to Canvas by Sunday 10:30pm.</p>	<p>20%</p>
<p>c) Midterm paper. (4-5 pages double spaced) Halfway through the course, students will identify a particular phenotype they think is interesting. It could anything from a disease (like hemophilia or diabetes), a behavior (aggressiveness for example), or an attribute (like height or skin color). For the midterm you must find one original scientific research article on your chosen phenotype, summarize the article, and then apply concepts from at least two of the readings to analyze this article sociologically. Students will have to justify their choice of phenotype and connect it to at least three of the readings. (Due <u>XXXXX</u>)</p>	<p>25%</p>
<p>e) Final take home essays. Consist of three short essay questions around the readings and applying course concepts to an empirical cases. (Due <u>XXXX</u>)</p>	<p>35%</p>

III. COURSE MECHANICS

Academic Integrity. Much of your learning in this class will come from the contributions and ideas of your classmates through discussion; in this respect, collaboration is encouraged. However, remember to give credit where credit is due, and know that in your papers and tests it is *your own* ideas we need to hear about. Note that plagiarism is not limited to stealing an entire paper. Using quotes without properly citing them or using ideas without acknowledging their source also constitute plagiarism. Any form of cheating and plagiarism will lead to zero on the assignment and to disciplinary action. For specific guidelines on citation and Northwestern policies on plagiarism, please refer to <https://libguides.northwestern.edu/c.php?g=114869&p=748726>

Cell Phone Policy. Cell phones should be turned off or in airplane mode. No checking messages or receiving calls during section, except in cases of extreme personal urgency. Please let me know at the beginning of section if you think this situation might apply to you.

Content Warning. The readings and discussion in this course deal with deep personal and historical social issues that may contain material that is startling, upsetting, and/or difficult to process. This includes medical violence, oppression, personal stigma, psychiatric distress, settler-colonialism, stereotypes, systemic racism and white supremacy. Engaging with this content openly and directly requires honest, transparent, and just community agreements below. Please contact me or come to office hours to talk about specific issues that might arise.

Community Agreements the Course.

1. Be respectful of others.
2. Do not interrupt another student while they are speaking. (Persistent interrupting can lead to percent loss in your participation grade)
3. We may be discussing controversial social issues in this class. In debate, listen to the other person's argument, and respond to their points. Try to understand where the other person is coming from, even if you fundamentally disagree with their position.
4. Do not make personal attacks or make fun of anyone's argument.
5. Do not dominate discussion; let others speak.
6. Our goal is to include everyone in discussion. So, if you reference an outside author, please take time to explain to the other students what the author's argument is, and how it's relevant to the current readings and discussion. If you do bring outside material you should know it well enough to explain it to us. This way, we can *teach* each other, rather than exclude each other. To make discussions as participatory as possible (and welcoming to students coming from multiple disciplines), I discourage "namedropping" and "-ism-dropping."
7. These same rules apply to me and I intend to work by them. If I do interrupt someone or break these rules, call me out on it. Please. I hope to learn from our conversations just as much as you do.
8. Any other suggestions and feedback about how the seminar is run, in-seminar activities, preferences and questions are welcomed.

COVID-19. The course will abide by Northwestern's current public health and safety guidelines as they change. If you show any COVID-19 symptoms please stay home, get tested, and be mindful of your community. Please email me and I will do my best to accommodate by providing slides and lecture notes.

Disabled Students Program and Special Accommodations. Any student requesting accommodations related to a disability or other condition is required to register with AccessibleNU (accessiblenu@northwestern.edu; 847-467-5530) and provide professors with an accommodation notification from AccessibleNU, preferably within the first two weeks of class. All information will remain confidential.

Email Policy. If you email me during the week, I will do my best to get back to you within 24 hours, except on weekends or administrative holidays.

Late Assignments Policy. Except under unusual circumstances, late assignments will be marked down. Late final papers may not even be accepted at all, if they arrive too late for me to grade them. If you know *ahead of time* that there is going to be a problem with the assignment dates, you should let me know ahead of time, but *no* retroactive excuses will be accepted. Please compare deadlines for assignments from this course with those of your other classes to anticipate significant conflict, for example if you have an exam the same day your midterm is due. I will arrange to accept late assignments in cases of medical or personal emergency. If you have a separate scheduling conflict with assignments from another class, important events, etc. you should request an extension as soon as possible [at least 7 days prior to assignment due date].

Social Media and Copyright. This syllabus and all PowerPoint presentations for this course are copyright 2021 by Santiago Molina. Please do not post any materials related to the course on the internet without the permission of the instructor. This includes sites such as “Course Hero.” Students are also prohibited from selling (or being paid for taking) notes during this course to or by any person or commercial firm without the express written permission of Santiago Molina. No audio or video recordings of class are permitted without the instructor’s permission/consent.

Wellbeing and Mental Health. This is just a class. Please prioritize your wellbeing. This means, at a very baseline, sleeping and eating are more important than keeping up with the class. Students can find useful resources for safety and security, academic support, and mental and physical health and wellbeing at the NUhelp website (<https://www.northwestern.edu/nuhelp/>) and on the NUhelp app (<https://www.northwestern.edu/nuhelp/get-help/nuhelp-app-features.html>). Please make use and explore the wealth of support available to you through <https://www.northwestern.edu/wellness/>.

IV. SCHEDULE OF READINGS AND ASSIGNMENTS

Monday 1/3. Introduction to Course: Unpacking science and society. (11 pages)

keywords: heritability, medicalization, biomedicalization, genetic determinism

Duster, T. (1996). The prism of heritability and the sociology of knowledge. in *Naked Science: Anthropological Inquiry Into Boundaries, Power, and Knowledge*. Routledge. pp. 119--130

CNN (2009) Blame genetics for bad driving, study finds:

<http://www.cnn.com/2009/TECH/science/10/29/bad.driver.gene/index.html?s=PM:TECH>

Wednesday 1/5. Biomedicalization (26 pages)

Clarke, A. E., & Shim, J. (2011). "Medicalization and biomedicalization revisited: technoscience and transformations of health, illness and American medicine." In *Handbook of the sociology of health, illness, and healing* (pp. 173-199). Springer New York.

Monday 1/10. Stigmatization and genetic determinism I. (53 pages)

keywords: biomedicalization, geneticization theory, attribution theory, inherent, interaction

Goffman, E. (2009). "Ch.1 Stigma and Social Identity" (pp. 1-40) and "Ch.4 The Self and Its Other" (pp.126-139) in *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

Wednesday 1/12. Stigmatization and genetic determinism II. (15 pages)

Sociology in Practice: During this class we will also discuss how to conduct an organized search of existing literature and how to navigate digital and library collections.

Phelan, J. C. (2005). Geneticization of Deviant Behavior and Consequences for Stigma: The Case of Mental Illness*. *Journal of Health and Social Behavior*, 46(4), 307-322.

Film Suggestion: *Gattaca* (1997)

Monday 1/17. Disability and the Normal Body

Wilson J. (2002) Ch.5 "(Re)Writing the Genetic Body-Text Disability, Textuality, and the Human Genome Project" (pp. 87-78) in Davis, L. ed. *The Disability Studies Reader*, Routledge: NY

Frederick, A. (2017). Risky Mothers and the Normalcy Project: Women with Disabilities Negotiate Scientific Motherhood. *Gender & Society*, 31(1), 74-95.

Film Suggestion: *Fixed – The Science/Fiction of Human Enhancement* (2013)

Wednesday 1/19. Theories of biological discourse. (53 pages)

keywords: discourse, technologies of reproduction, technology of self

Canguilhem, G. (1991). "Introduction to the Problem," (pp.321-325) "Normality and Normativity" (pp.351-357, 369-378) in *The Normal and the Pathological*. NY: Zone Books.

Foucault, M. (1988). Technologies of the self. In *Technologies of the self: A seminar with Michel Foucault* (pp. 16-49).

Monday 1/24. Making people: how categories work. (67 pages)

keywords: looping effects, classification struggles, self-knowledge

Hacking, I. (1986). "Making up people" in *Historical Ontology* (pp. 222-236).

Navon, D., & Eyal, G. (2016). "Looping genomes: Diagnostic change and the genetic makeup of the autism population." *American Journal of Sociology*, 121(5), 1416-1471.

Park, A. (2017) "How Much of Autism is Genetic?" *TIME*. [Available online at <http://time.com/4956316/how-much-of-autism-is-genetic/>]

Wednesday 1/27. Biopolitics (42 pages)

Keywords: biopolitics, biopower, scientia sexualis, ethopolitics

Foucault, Michel (1984) *The History of Sexuality: Vol. 1 An Introduction*, Random House: NY. (pp. 57-73, 115-127 **only**)

Rose, N. (2001). "The politics of life itself." *Theory, culture & society*, 18(6), 1-30.

Page, Eric (2010) "Scientists Find 'Liberal Gene,' *NBC San Diego* [Available online at <https://www.nbcsandiego.com/news/weird/Scientists-May-Have-IDd-Liberal-Gen-105917218.html>]

Monday 1/31. Human genetics, identity, and ethnoracial classification I. (44 pages)

keywords: social construction, political identity, groups, naturalization, reinscription

TallBear, Kim. "Genomic articulations of indigeneity." *Social Studies of Science* 43, no. 4 (2013): 509-533.

Duster, T. (2015). A post-genomic surprise. The molecular reinscription of race in science, law and medicine. *The British Journal of Sociology*, 66(1), 1-27.

Wednesday 2/2. Human genetics, identity and ethnoracial classification II. (45 pages)

keywords: purification, hybridization, admixture

Panofsky, A., & Donovan, J. (2019). Genetic ancestry testing among white nationalists: From identity repair to citizen science. *Social Studies of Science*.

Liu, Jennifer A. (2010) "Making Taiwanese (Stem Cells)" (p.239-257) in *Asian Biotech: Ethics and Communities of Fate* edited by Aihwa Ong and Nancy N. Chen. Duke University Press

Ball, et. al. (2013) *Ancestry.com Ethnicity Estimate White Paper*

Monday 2/7. Politics of knowledge and national ancestry I. (11 pages) –
ASSIGNMENT DUE

keywords: bionation, imagined community, mestizaje

Frickel, Scott, and Kelly Moore. 2006. "Prospects and Challenges for a New Political Sociology of Science." In *The New Political Sociology of Science: Institutions, Networks, and Power*. Madison: University of Wisconsin Press. Pp. 3-14 **only**.

Film Suggestion: *DNA Dreams* (2015) <https://www.youtube.com/watch?v=1dVv5RMwzuo>

Wednesday 2.9. Politics of knowledge and national ancestry II. (47 pages)

Kent, M., García-Deister, V., López-Beltrán, C., Santos, R. V., Schwartz-Marín, E., & Wade, P. (2015). "Building the genomic nation: 'Homo Brasilis' and the 'Genoma Mexicano' in comparative cultural perspective." *Social studies of science*, 45(6), 839-861.

Sung, Wen-Ching (2010) "Chinese DNA: Genomics and Bionation," (pp. 263-288) in *Asian Biotech: Ethics and Communities of Fate* edited by Aihwa Ong and Nancy N. Chen. Duke University Press

Monday 2/14. Social movements and "molecular" diseases I. (51 pages)

keywords: sites of legitimacy, sickling discourses, sociality of distrust, uncertainty, organized ambivalence

Nelson, A. (2011). "Ch.4 Spin Doctors: The Politics of Sickle Cell Anemia" (pp.115-152) in *Body and soul: The Black Panther Party and the fight against medical discrimination*. U of Minnesota Press.

Benjamin, R. (2011). "Organized ambivalence: when sickle cell disease and stem cell research converge." *Ethnicity & health*, 16(4-5), 447-463.

Wednesday 2/16. Social movements and “molecular” diseases II.

Sociology in Practice: We will discuss strategies for shaping a research paper and narrowing an empirical research question.

Navon, D. (2018) *Mobilizing Mutations* (selections TBD).

Monday 2/21. Social construction of biotechnology (~36 pages)

Winner, L. (1980). Do artifacts have politics?. *Daedalus*, 121-136.

Colyvas, J. A. (2007). Factory, hazard, and contamination: The use of metaphor in the commercialization of recombinant DNA. *Minerva*, 143-159.

Molina, S. (n/a) “Metaphors of Nature: What is CRISPR-Cas9?” *brief presentation*

Film Suggestion: *Jurassic Park* (1993)

Wednesday 2/23.

Duster, Troy (2018) Welcome, Freshmen: DNA Swabs, Please. 259-263 in *Beyond Bioethics*, Editors Marcy Darnofsky and Osagie Obasogie, University of California Press

Monday 2/28.

Wednesday 3/2.

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