## **Sociology 476:**

# "Sociology of Health, Illness, and Biomedicine" Spring 2023

Mondays, 9:30-12:20, in Parkes 222

Professor Steven Epstein Department of Sociology Northwestern University

#### **Contact info**

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#### Office hours this quarter (by appointment)

For exact availability (both in-person and via Zoom) and to sign up for a slot in advance: https://calendly.com/professor-epstein

A copy of this syllabus can be found on the Canvas site for the course.

Direct link: <a href="https://canvas.northwestern.edu/courses/189529">https://canvas.northwestern.edu/courses/189529</a>

#### **Summary:**

This course will introduce and explore central topics in the sociology of health, illness, and biomedicine. At the same time, it will show how that field has been redefined and reinvigorated by science and technology studies. We will seek to understand health, health care, and biomedicine through attention to multiple domains: the work sites in which health professionals interact with one another, with their tools, and with their clients; the research settings where medical knowledge and technologies are generated; the cultural arenas within which ideas of health and disease circulate; the market relations that produce health care as a commodity; the institutions and practices that transform social inequalities into health disparities; the social movements that challenge the authority of experts; and the bodies and selves that experience and are remade by illness.

Needless to say, in a course with nine sessions, the assigned reading is a small subset of relevant literature, and we will be leaving out many classics as well as many important recent works. The selected readings are intended to introduce key themes as well as to provide instructive examples of different theoretical perspectives and methodologies. I will be posting on Canvas a separate list of recommendations for further reading. This list should be helpful to you as you work on your papers for the course; it should also provide resources for students who seek to develop a more thoroughgoing expertise in the sociology of health, illness, and biomedicine. The list will also contain recommendations about relevant journals in the field.

Although many of the themes we will address have a long history, the emphasis will be on developments of the last several decades. The course focuses largely (but not completely) on the United States, though we will try along the way to consider global and transnational contexts. While the majority of the scholarship we will consider is sociological (broadly construed), some of it is drawn from other fields. Students from other disciplines are very welcome.

### **Course Requirements:**

Your grade for the quarter will be based on participation (25%) and a final paper (75%). Participation has three components: attendance, engagement in class discussions, and preparation of discussion questions. More specifically:

- 1) Students (including auditors) are expected to **attend** the seminar regularly and **contribute** actively to our discussions.
- 2) In addition, each student will be asked to circulate **discussion questions** in advance of two class meetings during the quarter. (Auditors are asked to do this once.) Students will sign up for specific weeks at the first meeting of the seminar. These questions must be distributed to all participants in the seminar by **noon on the day before class**. Please use Canvas to email the questions as a Word file to all students in the class.

Ideally, the questions should help frame the seminar discussion by asking about key arguments and concepts, juxtaposing and comparing readings, thinking about the theoretical perspectives as well as the methods employed, raising concerns, and beginning the process of articulating critiques. Keep in mind that the goal is to facilitate discussion (not to stump the audience).

Please come up with **two or three questions per reading**, for at least three of the readings for the week. Please **number your questions in a single sequence** (to make it easier to refer to them in class), and please take the time to spell authors' names and terms correctly.

Everyone should read and think about the distributed discussion questions before class. I will try to make sure we address as many of them as possible during the seminar meeting. In addition, the students who prepare questions for the week should take responsibility to help bring us back to those questions during the discussion.

3) Students taking the course for credit must submit a **paper** (around 20 double-spaced pages in length, *not including* references) by **10 am on Monday, June 5**. Please submit the paper as a Word file sent by email attachment to <u>s-epstein@northestern.edu</u>. I will do all my grading on the email attachment and then email it back to you.

I am relatively open about directions in which you might take your paper, provided that you get my approval for your topic as described below. Your paper may be empirical with a theoretical framing, or it may take the form of a critical review of the literature. In either case, the paper <u>must</u> draw explicitly on course materials but <u>must</u> also extend beyond course readings. (You may find the list of recommended readings helpful for the latter purpose.)

Although in practice your paper may be a "first stab" at something you will develop in greater detail later (for example, a second-year paper, special field paper, or dissertation prospectus), it should stand on its own and not read like a rough draft. The paper should articulate an identifiable argument. (That is, even a paper that is just outlining a future research project should still have a thesis statement up front. If you have any questions about this, I advise you to talk to me about it.) In addition, the paper should be addressed to a general academic reader and should not assume a reader who attended the class. (It should not reference class discussions or refer informally to "the articles we read for this seminar").

Please proofread carefully and pay close attention to matters of style, grammar, syntax, and organization. (If your paper has a lot of careless errors and does not seem to have been proofread adequately, I will send it back to you.) The paper should include a title and should be broken into sections with headings. Use parenthetical citations for quotes and references to other texts. List all such texts in your bibliography. (You may use any standard bibliographic style, as long as you are consistent.) Please double-space and use a standard font and margins.

You must get my **approval of your proposed topic** for the paper by emailing me a written description by no later than Friday, April 21 (1-2 paragraphs plus a short reference list). Please send the proposal as an email attachment. If your paper will be thematically similar to, or will have any overlap in actual content with, any other paper you have written in the past or are writing this quarter, please also provide a clear description of the overlap as well as an explanation of how your paper for this class will differ. Such overlap is not necessarily a problem, but we need to come to a clear understanding about it in advance.

In addition, every student **must attend my office hours** at least once—either before or very soon after the submission of the topic—to discuss the paper. (I have scheduled some additional office hours during the weeks of April 17 and April 24 to facilitate these meetings.)

If you later want to change your topic, you must request my approval. Please send me a new description in that case.

#### **Course Mechanics:**

- I encourage you to keep me posted about any issues you may be experiencing that might impact your attendance at, participation in, or work for the seminar. Students can find useful resources for safety and security, academic support, and mental and physical health and wellbeing at the NUhelp website (<a href="https://www.northwestern.edu/nuhelp/">https://www.northwestern.edu/nuhelp/</a>) and on the NUhelp app (<a href="https://www.northwestern.edu/nuhelp/get-help/nuhelp-app-features.html">https://www.northwestern.edu/nuhelp/get-help/nuhelp-app-features.html</a>). The following link for graduate students may also be helpful: <a href="https://www.northwestern.edu/hr/benefits/work-life/view-benefits-by-audience.html#Graduate-Students">https://www.northwestern.edu/hr/benefits/work-life/view-benefits-by-audience.html#Graduate-Students</a>.
- ♦ We will follow all announced <u>health and safety guidelines</u> with regard to Covid. Masks are not currently required. Those who wish to wear masks are very welcome to do so. (I continue to wear a mask indoors.)
- ♦ This course will make use of the "Canvas" course management system. The direct link for this course is <a href="https://canvas.northwestern.edu/courses/189529">https://canvas.northwestern.edu/courses/189529</a>. Students are responsible for logging in, checking regularly for posted announcements, and obtaining readings and assignments from the site.
- ♦ This syllabus and schedule are **subject to change** in the event of unforeseen circumstances. Announcements of changes will be posted on Canvas and emailed to students.
- ♦ Important course **announcements** may also be sent to students' registered campus email addresses. You are responsible for monitoring those email accounts.

- ♦ Students who wish to count this course toward the **Gender & Sexuality Studies graduate certificate** should meet with me at the beginning of the quarter to discuss how they intend to emphasize themes related to gender and sexuality. We will need to document the plan and send it to the Director of Graduate Studies in GSS.
- ♦ My **office hours** are by appointment, and I will offer both in-person and Zoom options. Please sign up to see me using this link: <a href="https://calendly.com/professor-epstein">https://calendly.com/professor-epstein</a> (being sure to select the correct set of options, depending on whether you want to meet in-person or via Zoom). Please sign up at least one hour in advance. For Zoom meetings, I will follow up with a link.
- ♦ All required course readings are available as PDF downloads from Canvas. Please always bring readings with you to class (either as printouts or in electronic form).
- ♦ Attendance is required, and we will use a discussion format. Typically, I will make an introductory presentation at the beginning of class. (I will post the PowerPoint afterward on Canvas. However, these PowerPoints are not meant to stand alone and may not be comprehensible to anyone who was not in class.) The discussion that follows should be grounded in the reading, and it's taken for granted that everyone had done the reading carefully. We will also be guided by the discussion questions that students have prepared and distributed in advance (see above). To make discussions as participatory as possible (and welcoming to students coming from multiple disciplines), I discourage "namedropping" and "-ism-dropping," unless you take the time to explain the reference to the thinker or school.
- ♦ I discourage **incompletes**, because in my experience they are rarely in students' long-term best interests (and often just the opposite). That said, please be in touch with me promptly to discuss unanticipated circumstances as they arise.
- 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. I keep all such information confidential.
- ◆ I am committed to very strict enforcement of university regulations concerning academic integrity. I report to campus authorities all suspected violations of the policy (including suspicion of cheating, plagiarism, fabrication, obtaining an unfair advantage, and aiding and abetting dishonesty). Please take the time to familiarize yourself with the university's policy on academic integrity (<a href="http://www.northwestern.edu/uacc/">http://www.northwestern.edu/uacc/</a>) as well as The Graduate School's policy and procedures (<a href="https://www.tgs.northwestern.edu/academic-policies-procedures/policies/academic-integrity.html">https://www.tgs.northwestern.edu/academic-policies-procedures/policies/academic-integrity.html</a>), and I urge you to speak with me if you have any questions.
- ♦ This syllabus and all PowerPoint presentations for this course are copyright 2023 by Steven Epstein. 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 Professor Epstein. No **audio or video recordings** of class are permitted without the instructor's permission.

#### **Schedule of Readings and Assignments:**

- <u>Tue</u>, March 28 (Session 1): Sociology of Health, Illness, and Biomedicine: Possible Goals, Agendas, Boundaries, and Definitions
  - Rosich, Katherine J., and Janet R. Hankin. 2010. "Executive Summary: What Do We Know? Key Findings from 50 Years of Medical Sociology." *Journal of Health and Social Behavior* 51: S1-S9.
  - Rose, Nikolas. 2001. "The Politics of Life Itself." Theory, Culture & Society 18: 1-30.
  - Timmermans, Stefan, and Steven Haas. 2008. "Towards A Sociology of Disease." *Sociology of Health and Illness* 30: 659-76.
  - Lakoff, Andrew. 2015. "Global Health Security and the Pathogenic Imaginary." Pp. 300-320 in *Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power*, edited by Sheila Jasanoff and Sang-Hyun Kim. Chicago: University of Chicago Press.
- Mon, April 3 (Session 2): Social Conditions, Health Disparities, and the Framing of Illness
  - Klinenberg, Eric. 1999. "Denaturalizing Disaster: A Social Autopsy of the 1995 Chicago Heat Wave." *Theory and Society* 28: 239-95. [Please focus on pp. 239-56, 272-76, and 282-84.]
  - Epstein, Steven. 2007. *Inclusion: The Politics of Difference in Medical Research*. Chicago: University of Chicago Press. Pp. 1-16 ("Introduction: Health Research and the Remaking of Common Sense").
  - Farber, Reya. 2023. "Don't Think that We Die from AIDS': Invisibilised Uncertainty and Global Transgender Health." *Sociology of Health & Illness* 45: 196-212.
  - Aronowitz, Robert. 2008. "Framing Disease: An Underappreciated Mechanism for the Social Patterning of Health." *Social Science & Medicine* 67: 1-9.
  - Wailoo, Keith. 2020. "Spectacles of Difference: The Racial Scripting of Epidemic Disparities." *Bulletin of History of Medicine* 94: 602-625.
- MON, APRIL 10 (SESSION 3): THE CHANGING TERRAIN OF THE MEDICAL
  - Conrad, Peter. 2005. "The Shifting Engines of Medicalization." *Journal of Health and Social Behavior* 46: 3-14.

- Clarke, Adele E., Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman. 2003. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." *American Sociological Review* 68: 161-94.
- Moreira, Tiago. 2006. "Sleep, Health and the Dynamics of Biomedicine." *Social Science & Medicine* 63: 54-63.
- Barker, Kristin K. 2014. "Mindfulness Meditation: Do-It-Yourself Medicalization of Every Moment." *Social Science & Medicine* 106: 168-176.
- Morse, Jaimie. 2019. "Legal Mobilization in Medicine: Nurses, Rape Kits, and the Emergence of Forensic Nursing in the United States since the 1970s." *Social Science & Medicine* 222: 323-34.
- MON, APRIL 17 (SESSION 4): CONSTRUCTING MEDICAL OBJECTS AND SUBJECTS
  - Hirschauer, Stefan. 1991. "The Manufacture of Bodies in Surgery." *Social Studies of Science* 21: 279-319.
  - Menon, Alka. 2017. "Reconstructing Race and Gender in American Cosmetic Surgery." *Ethnic and Racial Studies* 40: 597-616.
  - Roichman, Maayan. 2022. "Becoming a Complementary Health Practitioner: The Construction of Alternative Medical Knowledge." *Health* 26: 302-318.
  - Benjamin, Ruha. 2017. "Cultura Obscura: Race, Power, and 'Culture Talk' in the Health Sciences." *American Journal of Law and Medicine* 43: 225-238.
  - Navon, Daniel. 2019. *Mobilizing Mutations: Human Genetics in the Age of Patient Advocacy*. Chicago: University of Chicago Press. Pp. 1-13 and 239-274 ("Introduction: From New Mutations to New Kinds of People" (excerpt); Ch. 7: "Remaking the Normal versus the Pathological in Genetic Medicine").
- \*\*REMINDER: PAPER TOPICS DUE FRIDAY, APRIL 21
- MON, APR 24 (SESSION 5): RISK, PREPAREDNESS, AND RESPONSIBILITY
  - Lakoff, Andrew. 2017. *Unprepared: Global Health in a Time of Emergency*. Oakland, CA: University of California Press. Pp. 13-66 (Chapter 1: "A Continuous State of Readiness"; Chapter 2: "The Generic Biological Threat").
  - Mamo, Laura, Amber Nelson, and Aleia Clark. 2010. "Producing and Protecting Risky Girlhoods." In *Three Shots at Prevention: The HPV Vaccine and the Politics of Medicine's Simple Solutions*, edited by Keith Wailoo, Julie Livingston, Steven

- Epstein and Robert Aronowitz, 121-45. Baltimore, MD: Johns Hopkins University Press.
- Pienaar, Kiran, and Alan Petersen. 2022. "Searching for Diagnostic Certainty, Governing Risk: Patients' Ambivalent Experiences of Medical Testing." *Sociology of Health & Illness* 44: 25-40.
- Reich, Jennifer A. 2014. "Neoliberal Mothering and Vaccine Refusal: Imagined Gated Communities and the Privilege of Choice." *Gender & Society* 28: 679-704.
- Mon, May 1 (Session 6): Professional Authority, Medical Encounters, and Illness Identities
  - Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York: Basic Books. Pp. 3-29 ("Introduction: The Social Origins of Professional Sovereignty").
  - Epstein, Steven, and Stefan Timmermans. 2021. "From Medicine to Health: The Proliferation and Diversification of Cultural Authority." *Journal of Health and Social Behavior* 62 (3): 240-254.
  - Lupton, Deborah, and Annemarie Jutel. 2015. "It's Like Having a Physician in Your Pocket!': A Critical Analysis of Self-Diagnosis Smartphone Apps." *Social Science & Medicine* 133: 128-135.
  - Stivers, Tanya, and Stefan Timmermans. 2020. "Medical Authority under Siege: How Clinicians Transform Patient Resistance into Acceptance." *Journal of Health and Social Behavior* 61: 60-78.
  - Barker, Kristin. 2002. "Self-Help Literature and the Making of an Illness Identity: The Case of Fibromyalgia Syndrome (FMS)." *Social Problems* 49: 279-300.
- Mon, May 8 (Session 7): Evidence, Classification, and Standardization in Medicine
  - Fletcher, Isabel. 2013. "Defining an Epidemic: The Body Mass Index in British and US Obesity Research 1960–2000." *Sociology of Health & Illness* 20: 1-16.
  - Rondini, Ashley C., and Rachel H. Kowalsky. 2021. "First Do No Harm': Clinical Practice Guidelines, Mesolevel Structural Racism, and Medicine's Epistemological Reckoning." *Social Science & Medicine* 279 (113968): 1-6.
  - Epstein, Steven. 2022. *The Quest for Sexual Health: How an Elusive Ideal Has Transformed Science, Politics, and Everyday Life*. Chicago: University of Chicago Press. Pp. 136-165 ("Chapter 5: Diagnostic Reform and Human Rights in the ICD: Classifying Sexual Health").

- Milan, Stefania. 2020. "Techno-Solutionism and the Standard Human in the Making of the COVID-19 Pandemic." *Big Data & Society* July-Dec: 1-7.
- Merz, Sibille. 2021. "Global Trials, Local Bodies: Negotiating Difference and Sameness in Indian For-Profit Clinical Trials." *Science, Technology, & Human Values* 46: 882-905.
- MON, MAY 15 (SESSION 8): HEALTH ACTIVISM: BODIES, EXPERTISE, AND BIOCITIZENSHIP
  - Epstein, Steven. 1995. "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials," *Science, Technology & Human Values* 20: 408-437.
  - Nelson, Alondra. 2011. *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination*. Minneapolis: University of Minnesota Press. 115-152 (Chapter 4: "Spin Doctors: The Politics of Sickle Cell Anemia").
  - Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior Altman. 2004. "Embodied Health Movements: New Approaches to Social Movements in Health." *Sociology of Health & Illness* 26: 50-80.
  - Lorway, Robert. 2020. "Experimental Entanglements: Surveillance Science, Sex Worker Activism, and Evidentiary Politics in Kenya." *Medical Anthropology Quarterly* 34: 398-419.
  - Underman, Kelly, and Paige L. Sweet. 2022. "Counter-Clinical Spaces." *Sociological Forum* 37: 155-176.
- Mon, May 22 (Session 9): Political Economy of Health and Health Care
  - Fisher, Jill A. 2015. "Feeding and Bleeding: The Institutional Banalization of Risk to Healthy Volunteers in Phase I Pharmaceutical Clinical Trials." *Science, Technology, & Human Values* 40: 199-226.
  - Kenny, Katherine E. 2015. "The Biopolitics of Global Health: Life and Death in Neoliberal Time." *Journal of Sociology* 51: 9-27.
  - Decoteau, Claire Laurier, and Cal Lee Garrett. 2022. "Disease Surveillance Infrastructure and the Economisation of Public Health." *Sociology of Health & Illness* 44: 1251-1269.
  - Bharti, Nishtha, and Sergio Sismondo. 2022. "Political Prescriptions: Three Pandemic Stories." *Social Studies of Science*. Online ahead of print, 14 September. https://doi.org/https://doi.org/10.1177/0162243922112.

\*\*REMINDER: Papers due by 10 am on Monday, June 5 (by email attachment).