HUMANITIES 220 & SOCIOLOGY 220 "Health, Biomedicine, Culture, and Society" Spring 2022

Tuesdays and Thursdays, 9:30-10:50 am, in Lutkin Hall

Professor Steven Epstein Department of Sociology Northwestern University

Contact info:

Office phone: 847-491-5536

E-mail: <u>s-epstein@northwestern.edu</u>

Web page: http://www.sociology.northwestern.edu/people/faculty/core/steven-epstein.html

<u>Office hours this quarter (by appointment)</u>: For exact availability and to sign up for a slot in advance: <u>https://calendly.com/professor-epstein/office-hours</u>

A copy of this syllabus can be found on the Canvas site for the course: <u>https://canvas.northwestern.edu/courses/166011</u>

TA Contact Information:

Gabriela Kirk

gabrielakirk2022@u.northwestern.edu

Office hours: Tuesdays, 2:00-4:00 pm at the University Library Café

Gershwin Penn

gershwin.penn@u.northwestern.edu

Office hours: Wednesdays, 5:00-6:00 pm at the University Library Café; and Fridays, 9:00-10:00 am via Zoom

Wayne Rivera

wayne.rivera@northwestern.edu

Office hours: Thursdays, 11:15 am -12:15 pm via Zoom (or by appointment)

Section Information:

Section 60:	Tu 3:00-3:50 pm in Locy 303	TA: Gershwin Penn
Section 61:	Tu 5:00-5:50 pm in Kresge 2-343	TA: Gabriela Kirk
Section 62:	Tu 6:00-6:50 pm in Kresge 2-343	TA: Gabriela Kirk
Section 63:	We 9:00-9:50 am in Kresge 2-331	TA: Gershwin Penn
Section 64:	We 3:00-3:50 pm in Locy 303	TA: Wayne Rivera
Section 65:	We 4:00-4:50 pm in Locy 303	TA: Wayne Rivera

Summary:

Of all the products of modern science, medical care and treatment are among the most familiar and the most desirable. We all would like to see cures for diseases, affordable and accessible health care, ethical treatment of patients, and rapid dissemination of effective new drugs. Yet such outcomes are hard to achieve, and present-day medicine and health care are flashpoints for a bewildering array of controversies—many of them exacerbated by the global Covid-19 pandemic. Topics of controversy include:

- Whose interests should the health care system serve and how should it be organized?
- How trustworthy is the medical knowledge we rely on when confronted with the threat of illness?
- How can the ethical character of biomedical research best be ensured?
- How do we manage health risks in an uncertain world?
- How can health care be made affordable?
- Is it possible for the benefits of good health to be shared equitably across lines of social class, race, gender, and nation?
- What are the proper roles of health professionals, scientists, patients, activists, corporations, and the state in establishing medical, political, economic, and ethical priorities?

By providing a broad introduction to the domain of health and biomedicine, this course will take up such issues as matters of concern to all. We will analyze the cultural meanings associated with health and illness; the political debates surrounding health care, medical knowledge production, and medical decision-making; and the structure of the social institutions that comprise the health care industry. We will examine many problems with the current state of health and health care in the United States and also consider potential solutions.

The course is divided into three parts:

- We begin (Part One) with a **survey of the social meanings of health and illness**. We will investigate the social determinants of health and the stark inequalities in relation to health in the United States and around the world; the social processes of framing or constructing illness; the medicalization of life; and the cultural manifestations of biomedical risk and uncertainty.
- Next, in Part Two, we turn to the **social structuring of biomedical encounters**. We analyze the dynamics of the patient-provider relationship, the authority exercised by health professionals, issues of trust and mistrust in medicine, and the ethics and politics of medical research. We also consider how those domains have been changing, especially as a consequence of patient activism.

• Finally, in Part Three, we study the **structure of the health-care industry**, including the power of the pharmaceutical industry and the dynamics of profit-seeking within health care, the twin crises of access to care and cost of care, and the recent history of health care reform (including the implementation of and continuing controversy surrounding the Affordable Care Act). We examine alternative approaches to the organization of health care and consider both barriers to change and potential new directions.

Course Requirements:

Your grade for the quarter will be calculated on the basis of the following four requirements:

1. A **take-home short essay (4-5 pages)** that will focus on the material in Part One of the course (**25%** of the grade). The assignment will be distributed and discussed in class (and posted on Canvas) on Thursday, April 14, and it is **due by 9:00 am on Monday, April 25**. You must submit it electronically on Canvas via "TurnItIn" (see below). Your essay will be graded directly on Canvas, and a marked-up and graded version will be made available to you through Canvas around May 3.

2. A closed-book, **in-class midterm** on **Tuesday**, **May 10**, covering all material in Parts One and Two of the course (**25%**). On the midterm, I will ask you to provide 2-3 sentence definitions of terms and concepts that have been covered in lectures and readings. In some cases, I will also ask you to give an example. To help you prepare, I will provide a longer list of possible terms and concepts one week in advance, out of which I will ultimately choose 12. You will write in a blue book that I will provide—no notes, books, or electronic devices are permitted. The graded midterm will be returned to you in class around May 19.

3. A **take-home final** covering the entire course but emphasizing Parts Two and Three (**40%**). The final will consist of two essays, each 4-5 pages in length. The essay questions will be posted Friday, May 27 by 9:00 am, and the final will be **due no later than 9:00 am on Monday, June 6**. (You are welcome to submit the final earlier.) You must submit it electronically on Canvas via "TurnItIn" (see below). Your essays will be graded directly on Canvas, and marked-up versions will be made available to you through Canvas around June 13.

4. Section attendance and participation (10%). Your TA will explain how the section grade is determined, but regular attendance in section is a basic component. Your participation grade will be made available to you on Canvas around June 13.

Course Mechanics and Policies:

Please read the following list of items carefully. Along with providing basic information, this section also serves as <u>fair warning</u> of my classroom policies and expectations:

- The past two years of disruption from Covid have affected all of us, though in many different ways. As we continue to adjust to changing circumstances, I encourage you to keep me or your TA posted about any issues you may be experiencing that might impact your attendance at, participation in, or work for this course. Students can find useful resources for safety and security, academic support, and mental and physical health and wellbeing at the NUhelp website (<u>https://www.northwestern.edu/nuhelp/</u>) and on the NUhelp app (<u>https://www.northwestern.edu/nuhelp/get-help/nuhelp-app-features.html</u>).
- We will follow all announced <u>Covid procedures</u>. As of this writing, **masks** will not be required in the classroom in Spring quarter. However, "the University strongly recommends masking in areas where distancing is not possible." Furthermore, members of the campus community have been asked "to be conscientious of each other and honor individual requests where possible." With these guidelines in mind, I ask each of you to make an informed decision about mask use based on your own needs, judgments, and preferences. You should not hesitate to wear a mask if that makes you feel safer or more comfortable.
- Humanities 220 / Sociology 220 is one single course, listed in two different ways. There are no differences in terms of requirements, assignments, possibilities to fulfill distribution requirements, or anything else.
- This course will make use of the **Canvas** course management system. The direct link for this course is <u>https://canvas.northwestern.edu/courses/166011</u>. Students are responsible for logging in, checking regularly for posted announcements, and obtaining readings and assignments from the site.
- Important course **announcements** may also be sent to students' registered campus email addresses. You are responsible for monitoring those email accounts.
- Unless you are directed to do so by me or your TA, please do not use Canvas to send broadcast announcements to the rest of the class. If you have material that you think should be shared, please ask me or your TA to distribute it.
- ♦ You are welcome and encouraged to sign up to see me during my office hours using this link: <u>https://calendly.com/professor-epstein/office-hours</u>. Please sign up in advance. The sign-up webpage will indicate which slots are in person and which are via Zoom. Also, please note that my office is on the second floor of a building without an elevator. Any student for whom stairs pose difficulties may email me to work out an alternative.

- This syllabus, schedule, and modalities of instruction (in-person, via Zoom, etc.) are subject to change in the event of unforeseen circumstances. Announcements of changes will be posted on Canvas and emailed to students.
- No books are assigned for this course. All **course readings** are available for **download** from the Canvas site in the form of PDFs. I encourage you to bring readings with you to class, either as printouts or on your laptops or tablets. Note that some PDFs appear sideways when viewed in Adobe Acrobat. They will print fine as is, but to read them on screen, select "Rotate View" from the "View" menu.
- Over the course of the quarter, your **grades** will become accessible to you on Canvas. Please let your TA know immediately if there are any recording errors.

Your grades on Canvas will take the form of numerical scores (not percentages, even if Canvas displays a percent sign). For each assignment, you can convert your numerical score to a letter grade equivalent by using the following key:

97-100 A+ 93-96 A 90-92 A-87-90 B+ Etc.

Similarly, your participation grade is a score, not a percentage. Therefore, if you are a great participant, you should expect to receive a 93 to 96, because that corresponds to an A. (You are not likely to get 100, because that would be a high A+.)

Your **overall course grade** will be calculated simply by multiplying each numerical score by its respective weight (for example, 0.25 for the midterm), summing up the results, rounding up or down to the *nearest* whole number, and then converting to the letter grade equivalent.

- Students are responsible for all material presented in readings, lectures, and sections. My lectures will almost always include material not covered in the reading. **Class attendance** is required for both lectures and sections, and attendance will be taken formally at sections. While I will post my PowerPoints on Canvas, these are not intended to be comprehensive, and often they will not make complete sense by themselves. Students are expected to attend class in order to learn the course material.
- I also fully expect that students will be not just physically present in the classroom but also mentally present (that is, conscious and not otherwise occupied—even intermittently—with email, texting, social media, computer games, shopping, or other online activities).

You may bring **technology** to the lecture hall as long as you can handle it responsibly and respectfully. Laptops and tablets should be used for note-taking or other class-related purposes only. I also urge you to consider evidence that indicates many students learn

better when they take notes by hand (because the act of writing forces them to think about the ideas) and that the distracting effects of technology interfere with long-term retention of information. (See <u>https://www.insidehighered.com/news/2018/07/27/class-cellphone-and-laptop-use-lowers-exam-scores-new-study-shows</u>.)

- Come to class having *already read* the readings for that day, and be prepared to **participate**! Please do ask questions and offer opinions! Discussion in lecture is heartily encouraged—and of course, in sections as well. Disagreement with the instructor, the TA, or fellow students is fine, as long as you are polite and patient in how you go about it. That is, I am open to a wide range of views, but I insist on our always showing respect for one another.
- I am granting every student a 24-hour "extension bank" that can be used up over the course of the quarter if needed for the take-home essay or the take-home final. For example, if you turn in your take-home essay three hours late, then you still have 21 hours "in the bank" that you can use for the take-home final if necessary. (This does not apply to the midterm, which must be taken at the scheduled time.)

If you exceed your allotted 24 hours for the take-home essay, it will be marked down except in unusual circumstances. But it is still to your advantage to submit the take-home essay late rather than never. In the case of the take-home final, however, we cannot accept papers beyond the 24-hour extension bank period because of the limited time available for grading during exam week before final grades must be submitted to the registrar.

Please note that there is no excuse for failing to keep **electronic backups** of your data (for example, on flash drives, external hard drives, "cloud" storage sites, or other computers) in case your primary computer fails or your hard drive crashes.

- All written work for the course must be **typed**, **double-spaced**, using a standard font and 1-inch margins on all sides.
- 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 me with an accommodation notification from AccessibleNU, preferably within the first two weeks of class. All information will remain confidential.
- A course on health issues almost inevitably includes material that will upset some students, particularly if they or people close to them have confronted health challenges. Please keep this possibility in mind and be forewarned.
- ♦ I am committed to strict enforcement of university regulations concerning academic integrity, which means <u>I report ALL suspected violations</u> of the policy (including suspicion of cheating, plagiarism, fabrication, obtaining an unfair advantage, unauthorized collaboration, and aiding and abetting academic dishonesty) to the Assistant Dean for Academic Integrity, who then carries out a formal investigation. It is your

responsibility to familiarize yourself with the <u>university's policy on</u> academic integrity. See the <u>WCAS website</u> on academic integrity and <u>Academic Integrity: A Basic Guide</u> for more information.

Examples of plagiarism include but are not limited to: directly copying work written by another person without an appropriate citation; modifying a few words written by someone else, but otherwise presenting another person's ideas as if they were your own without appropriate citations; and using information from the internet without appropriate citation even if that information has no identifiable author (such as information from a Wikipedia page). In addition, while I encourage students to collaborate when studying or learning course material, it should be clear that **no collaboration** is permitted on written work or exams, and any collaboration in those cases constitutes academic dishonesty.

If you have any questions about what constitutes plagiarism or academic dishonesty, please ask me! <u>Confirmed violations of academic integrity will result in both an</u> <u>administrative penalty and an academic penalty</u>. The administrative penalty, assigned by university officials, typically is **suspension** for one quarter; any such suspension becomes part of your record, which is made available on request to potential employers and graduate school admissions committees. The academic penalty is assigned by the instructor, and my own policy in almost every case is to assign a **failing grade FOR THE ENTIRE COURSE**.

- This course makes use of **Turnitin**, a software product that compares your work against other texts in its database in order to safeguard academic integrity. Students agree that by taking this course all required papers may be subject to submission for textual similarity review to Turnitin.com for the detection of plagiarism. All submitted papers will be included as source documents in the Turnitin.com reference database solely for the purpose of detecting plagiarism of such papers. Use of the Turnitin.com service is subject to the Usage Policy posted on the Turnitin.com site. Please contact me if you have any questions about Turnitin.
- Please be respectful of those around you. At the beginning of class, make sure your **cell phone** is turned off or set to vibrate. And please don't chat with other students during class. In addition, arriving late, leaving early, and walking in and out of class are distracting to those around you. Obviously they are sometimes unavoidable. But I'd appreciate your keeping them to a minimum.
- This syllabus and all lectures and PowerPoint presentations for this course are copyright 2022 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:

WEEK 1

**No section meetings this week

THU, MAR 31: INTRODUCTION

Please read pp. 3-9 of the syllabus carefully before coming to class.

WEEK 2

**Sections begin meeting this week

PART ONE: Social Meanings of Health and Illness

TUE, APR 5: SOCIAL DETERMINANTS OF HEALTH AND THE PROBLEM OF HEALTH DISPARITIES

- Koh, Howard K., Arnand K. Parekh, and John J. Park. 2019. "Confronting the Rise and Fall of U.S. Life Expectancy." *JAMA* 322 (26 November): 1963-65.
- Lavizzo-Mourey, Risa J., Richard E. Besser, and David R. Williams. 2021.
 "Understanding and Mitigating Health Inequities—Past, Current, and Future Directions." *New England Journal of Medicine* 384 (6 May): 1681-84.
- Maani, Nason, and Sandro Galea. 2020. "The Role of Physicians in Addressing Social Determinants of Health." *JAMA* (online 3 Apr): E1-E2.

THU, APR 7: HEALTH DISPARITIES (CONT.)

- Shattuck-Heidorn, Heather, Meredith W. Reiches, and Sarah S. Richardson. 2020. "What's Really Behind the Gender Gap in Covid-19 Deaths?" New York Times, 24 June.
- Neimark, Jill. 2022. "Can an Equation to Help Determine Kidney Health Be Racist?" *Undark*, 19 January, <u>https://undark.org/2022/01/19/can-an-equation-to-help-determine-kidney-health-be-racist/</u>.

WEEK 3

TUE, APR 12: FRAMING ILLNESS

- Brown, Phil. 2008. "Naming and Framing: The Social Construction of Diagnosis and Illness." Pp. 82 and 86-103 **only** in *Perspectives in Medical Sociology*, 4th ed., edited by P. Brown. Prospect Heights, IL: Waveland Press.
- Taylor, Rosemary C.R. 2013. "The Politics of Securing Borders and the Identities of Disease." *Sociology of Health & Illness* 35 (2): 241-54.

THU, APR 14: FRAMING EPIDEMICS

**Take-home essay assignment distributed and discussed in class

- Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press. Pp. 47-78 (Chapter 1: "The Nature of a New Threat").
- Wailoo, Keith. 2020. "Spectacles of Difference: The Racial Scripting of Epidemic Disparities." *Bulletin of History of Medicine* 94 (4): 602-25.

WEEK 4

TUE, APR 19: MEDICALIZATION

- Conrad, Peter. 2005. "The Shifting Engines of Medicalization." *Journal of Health and Social Behavior* 46: 3-14.
- Loe, Meika. 2004. *The Rise of Viagra: How the Little Blue Pill Changed Sex in America*. New York: New York University Press. Pp. 29-61 (Chapter 2: "The Rise of Erectile Dysfunction").

THU, APR 21: CULTURES OF RISK AND RESPONSIBILITY

- Fosket, Jennifer Ruth. 2010. "Breast Cancer Risk as Disease: Biomedicalizing Risk." Pp. 331-52 in *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, edited by A. E. Clarke, L. Mamo, J. R. Fosket, J. R. Fishman and J. K. Shim. Durham, NC: Duke University Press.
- Lupton, Deborah. 2012. "M-Health and Health Promotion: The Digital Cyborg and Surveillance Society." *Social Theory & Health* 10: 229–44.

PART TWO: Patients and Professionals: The Politics of Authority and the Dynamics of Trust and Mistrust

WEEK 5

MON, APR 25: ****TAKE-HOME ESSAYS** DUE BY 9:00 AM ON CANVAS

TUE, APR 26: THE PATIENT-PROVIDER RELATIONSHIP

Hum/Sociol 220 Syllabus (Epstein, Spring 2022 - Page 12

- Lella, Joseph W., and Dorothy Pawluch. 1988. "Medical Students and the Cadaver in Social and Cultural Context." Pp. 125-35 in *Biomedicine Examined*, edited by M. Lock and D. R. Gordon. Dordrecht: Kluwer.
- Timmermans, Stefan. 2020. "The Engaged Patient: Changes in Patient-Doctor Communication." *Journal of Health and Social Behavior* 61 (3): 259-73.

THU, APR 28: TRUST AND MISTRUST

- Blendon, Robert J., John M. Benson, and Joachim O. Hero. 2014. "Public Trust in Physicians—U.S. Medicine in International Perspective." *New England Journal* of Medicine 371 (17): 1570-72.
- Reich, Jennifer A. 2016. *Calling the Shots: Why Parents Reject Vaccines*. New York: New York University Press. Pp. 67-96 (Chapter 2: "Parents as Experts").
- Alba, Davey, and Sheera Frenkel. 2021. "Calls Grow to Discipline Doctors Spreading Virus Misinformation." New York Times, 27 August. <u>https://www.nytimes.com/2021/08/27/technology/doctors-virusmisinformation.html</u>.

WEEK 6

TUE, MAY 3: THE ETHICS AND POLITICS OF MEDICAL RESEARCH

******Midterm discussed in class, and list of possible terms and concepts posted on Canvas

- Jones, David S., Christine Grady, and Susan E. Lederer. 2016. "'Ethics and Clinical Research': The 50th Anniversary of Beecher's Bombshell." *New England Journal of Medicine* 374: 2393-98.
- Brandt, Allan M. 1978. "Racism and Research: The Case of the Tuskegee Syphilis Study." *Hastings Center Report* 8: 21-29.
- Warren, Rueben C., Lachlan Forrow, David Augustin Hodge, Sr., and Robert D. Truog. 2020. "Trustworthiness before Trust: Covid-19 Vaccine Trials and the Black Community." *New England Journal of Medicine* 383, no. 22 (26 November): e121(1)-(3).

THU MAY 5: PATIENT GROUPS AND HEALTH MOVEMENTS

Epstein, Steven. 2000. "Democracy, Expertise, and AIDS Treatment Activism." Pp. 15-32 in *Science, Technology, and Democracy*, edited by D. Kleinman. Albany: State University of New York Press.

Conrad, Peter, Julia Bandini, and Alexandria Vasquez. 2016. "Illness and the Internet:

From Private to Public Experience." *Health* 20: 22-32.

WEEK 7

TUE, MAY 10: ****IN-CLASS MIDTERM**

No books, notes, or electronic devices. Blue books provided.

PART THREE: The Structure of the Health Care Industry and the Crises of Health Care

Thu, May 12: The "Medical-Industrial Complex" and the Politics of "Big Pharma"

Fugh-Berman, Adriane, and Shahram Ahari. 2007. "Following the Script: How Drug Reps Make Friends and Influence Doctors." *PLoS Medicine* 4: 621-25.

Dumit, Joseph. 2012. Drugs for Life: How Pharmaceutical Companies Define Our Health. Durham, NC: Duke University Press, 55-85 (Chapter 2: "Pharmaceutical Witnessing and Direct-to-Consumer Advertising").

WEEK 8

TUE, MAY 17: THE U.S. HEALTH CARE SYSTEM: CRISES OF ACCESS AND COST

- Schneider, Eric C., and David Squires. 2017. "From Last to First: Could the U.S. Health Care System Become the Best in the World?" *New England Journal of Medicine* 377: 901-904.
- Weitz, Rose. 2019. *The Sociology of Health, Illness, and Health Care: A Critical Approach, 8th Ed.* Boston: Cengage. Pp. 170-94 (Chapter 8: "Health Care in the United States").

Thu, May 19: Alternative Systems

Weitz, Rose. 2019. *The Sociology of Health, Illness, and Health Care: A Critical Approach, 8th Ed.* Boston: Cengage. Pp. 195-220 (Chapter 9: "Health Care Around the Globe").

WEEK 9

TUE, MAY 24: HISTORIES AND POLITICS OF HEALTH CARE REFORM

Quadagno, Jill. 2014. "Right-Wing Conspiracy? Socialist Plot? The Origins of the Patient Protection and Affordable Care Act." *Journal of Health Politics, Policy and Law* 39: 35-56.

- Marmor, Theodore, and Jonathan Oberlander. 2011. "The Patchwork: Health Reform, American Style." *Social Science & Medicine* 72: 125-28.
- Connors, Elenora E., and Lawrence O. Gostin. 2010. "Health Care Reform—A Historic Moment in US Social Policy." *JAMA* 303: 2521-22.

Thu, May 26: Beyond the Affordable Care Act

- Morone, James A. 2020. "Diminishing Democracy in Health Policy: Partisanship, the Courts, and the End of Health Politics as We Knew It." *Journal of Health Politics, Policy and Law* 45 (5): 757-69.
- Tufekci, Zeynep. 2021. "What Happens after the Worst of the Pandemic Is Behind Us?" New York Times, 18 November. https://www.nytimes.com/2021/11/18/opinion/covid-winter-risk.html.

FRI, MAY 27: **TAKE-HOME FINAL EXAM ASSIGNMENT POSTED BY 9:00 AM

WEEK 10 & READING WEEK

TUE, MAY 31: REVIEW OF FINAL EXAM AND GENERAL Q&A (*VIA ZOOM*)

****Optional section meetings this week: Review sessions**

EXAM WEEK

MON, JUN 6: ****TAKE-HOME FINAL EXAM DUE** BY 9:00 AM ON CANVAS