



## **Malignant: Cancer Politics and Policy**

HON 494/HSD 598  
Tuesdays, 3:00-5:45pm  
Sage Hall 141

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### **Synopsis**

We will examine cancer as a social, political, cultural, economic, literary, and historical construct. In other words, we will try to understand how the cluster of diseases we call cancer do what they do, from the molecular level through the individual to the social and political levels. This discussion-intensive course will center on how people react to cancer, why cancer research has long been a policy priority, and the role of science and policy in understanding and ameliorating its ravages. We will ask and answer questions such as: Why is cancer so feared? What is the role of cancer research? How are new medical technologies developed? What are the processes of commodification and exploitation in cancer treatments? What are the images and concepts that frame how we think about cancer? How do illnesses become “illnesses” and how do those illnesses become industries? Why is cancer treatment so expensive? Does it need to be? Together we will seek to better appreciate the complex ecosystem of cancer research and cancer care. Creatures in that ecosystem include individual patients and health professionals, abiding in a forest of nonprofit

organizations, research institutions, government agencies, and companies. We will look for answers and insight from science and technology studies, history, economics, sociology, and bioethics, as well as fiction, movies and personal narratives.

This is a mixed course for graduate and professional students (candidates for degrees in law, medicine, business, public policy, global health, sciences, social sciences, or humanities) and advanced honors undergraduates. It revolves around course readings and films that are discussed in class. At first, the structure will be set by the syllabus, but as the course progresses, students will take more responsibility for identifying topics, analyzing readings, and guiding discussion.

### **Assessment:**

The elements of the course are the readings and other materials, the weekly blogs, course discussion, and the group project (this year, a proposed exhibit), and a take-home final. The grade weighting is:

Blogs: 20%

Discussion and class participation: 25%

Short paper: 10%

Final project: 25%

Take-home final: 20%

### **Readings**

Readings, viewings and other homework are not separately graded, but they are essential to all the other elements in this course.

### **Blogs**

Weekly blogs have several purposes. First, they hold everyone accountable for the reading. Second, they greatly enrich the discussion. Classroom discussions are the beating heart of this course. Your blogs raise points warranting class discussion that each of you have picked up. Third, blogs encourage us to approach course material multiple times. By blogging in advance, you think about the material before class, and then come back to it again for discussion—and then come back yet again in the take-home final at the end of the semester.

The blogs will be due each week on Sunday at midnight (unless we indicate otherwise for that week). Pose a question based on the following week's readings and other materials, either at the beginning or end of your blog. The blogs are mainly a way to share what you have noticed, and to use that initial perception to guide discussion later in the week. That is, the blogs are written in advance of the discussions and after doing the readings. They should be short (a paragraph or two). Raise questions you want to see discussed, or make observations, or ask others what they thought of this person or that point or some feature that caught your attention.

### **Discussion and class participation**

This class demands respectful engagement with one another and with the texts. We recognize that it seems odd to *demand* participation, and yet, this seminar class will not function without your engagement. We want to hear what you think of the texts and the ideas. Some of them are very challenging; our class is a place for you to take (intellectual) risks, to ask questions, to share insights and respond to one another seriously and generously.

A note on readings: This class only meets once a week; **plan/expect to spend at least 6**

**hours outside of class reading, rereading, annotating, and preparing for each class meeting.** It is impossible to play catch up in this class, so plan ahead and finish the readings before you come to class.

### Short paper

About halfway through the semester, you will write a short four to five-page paper on one of the following themes:

- Pediatric leukemia and other childhood cancers went from uniformly fatal to often curable over several decades. Why *didn't* this happen with breast, colon, prostate, lung or other “adult” cancers? Will it now that we’re dissecting the genomic profiles and underlying biology of cancers?
- Cancer enjoys a privileged position in health policy and science policy. It has long commanded more money for research, more public attention than other disorders, and a disproportionate share of health care expenditures. Should it? Why or why not? Or
- Develop a 4-5 page treatment of what will become your final project, including at least part of the literature review.

This paper will be due November 7 at 5 p.m. Deposit your digital paper in the assignment section of the Blackboard site.

### Final project

The final project can be a paper, video, website, artwork, podcast, etc, on a topic of your choosing. The topic will be due Sept 22, the outline due Oct 9. You may work individually or in groups. More information is forthcoming.

### Final exam

This is truly a final *examination*. It is not a regurgitation of what you know, but instead a close inspection and recapitulation of the themes that have come up during the course. That is, it will center not on parroting back the facts we covered in the course, but rather on exploring the issues. The format will be two or three clusters of questions. You will address one question from each cluster. You will write **no more than three hours** total. You are free to talk to one another about the course themes and your thoughts, but the final examination is to be your own thoughts in your own words.

The Final Exam will take place in our regular classroom at our regular class time (3-5:45 p.m.) on December 8.

## Schedule of Readings

### 25 Aug Introduction to the course — Expectations, goals

Jain, L. 2013. *Malignant: How cancer becomes us* (Berkeley, CA: University of California Press), pp. 1-26.

1 Sept Mukherjee, S. 2010. *Emperor of all Maladies: A biography of cancer*. New York: Scribner, Part One (pp. 1-104).

8 Sept Mukherjee, S. 2010. *Emperor of all Maladies: A biography of cancer*. New York: Scribner, Part Two (pp. 107-190).

### Cancer: Politics of Research and Philanthropy

15 Sept Excerpts from: Sulik, G. 2012. *Pink Ribbon Blues*. New York: Oxford Univ. Press.  
Mukherjee, S. 2010. *Emperor of All Maladies*, pp. 393-448.  
Brawley, O. and P. Goldberg. 2012. *How We Do Harm: A Doctor Breaks Rank About Being Sick in America*. New York: St. Marten's Griffin, pp. 257-284.  
Batt, S. "Who Pays the Piper?: Industry Funding of Patient Advocacy Groups" In Rochon Ford, A., and D. Saibil. (Eds). 2009. *The Push to Prescribe*. Toronto, ON: Women's Press/Canadian Scholars' Press, pp. 67-89.

### Metaphors and Imagery of Cancer

22 Sept Stacey, J. 1997. *Teratologies: A Cultural Study of Cancer*. London: Routledge, pp. 1-29.  
Jain, L. "Cancer Butch." *Cultural Anthropology* 2007; 2: 501-538.  
Sontag, S. 1990. *Illness as Metaphor and AIDS and Its Metaphors*. New York: Doubleday, pp. 3-87.

**Assignment:** Find an image you think represents cancer. Bring a copy to present to the class.

**Deadline:** Topic of final project due in class. Describe in 200 words what topic or idea you'd like to explore in your final project.

### Cancer Narratives

29 Sept Choose your own adventure (in cancer memoirs):  
Read one of: *Death Be Not Proud* (John Gunther), *A Whole New Life* (Reynolds Price), *Eating Pomegranates* (Sarah Gabriel) or another of your choice (check with one of us in advance).

### Palliative Care

6 Oct Bach, P. "The Day I Started Lying to Ruth." *New York Magazine*, 6 May 2014. Available online at <http://nymag.com/news/features/cancer-peter-bach-2014-5/>.  
Teague, M. "The Friend." *Esquire*, 10 May 2015. Available online at <http://www.esquire.com/lifestyle/a34905/matthew-teague-wife-cancer-essay/>

**Deadline:** Outline of final project due in class. Sketch out your plan for your final project in a two-page draft. Include 4-5 key citations.

**13 Oct**            **Fall Break — No class**

**Pediatric cancer history, policy, and narrative**

20 Oct            Green, John. 2012. *The Fault in Our Stars*. New York: Dutton Books.  
Simone, J. and J. Lyons. “The Evolution of Cancer Care for Children and Adults.” *Journal of Clinical Oncology* 1998; 16 (9): 2904-2905.

**22 Oct**            **Screening of the film “I Want So Much to Live”** (Genentech).  
*Cottonwood 103, 7-9 p.m.* Catered by Curry Corner (we hope; if not, still food).  
Feel free to invite friends.

**Behind the Scenes in Cancer Care and Research**

27 Oct            *Part I: HeLa Cells and Their Legacy*  
Skloot, R. 2010. *The Immortal Life of Henrietta Lacks*. New York: Broadway.  
Hudson, K. and F. Collins. “Family Matters.” *Nature* 2013; 500 (8 Aug): 141-142.  
Skloot, R. “The Immortal Life of Henrietta Lacks, the Sequel.” *New York Times*,  
March 23, 2013.

*Part II:*  
Discussion of the film “I Want So Much to Live”

**Numbers and the Work They Do**

3 Nov            Woodward, K. “Statistical Panic.” *differences: A Journal of Feminist Cultural Studies* 1999; 11(2): 177-203.  
Sarangi, S., et al. “‘Relatively Speaking’: Relativisation of genetic risk in counseling for predictive genetic testing.” *Health, Risk & Society* 2003; 5(2): 155-170.  
Jolie, A. “My Medical Choice.” *New York Times* 2013 (14 May), A25.  
<http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html>  
Jolie Pitt, A. “Angelina Jolie Pitt: Diary of a Surgery,” *New York Times* 24 March 2015.  
Jain, L. 2013. *Malignant: How Cancer Becomes Us*. Chapter 5: The Mortality Effect (pp. 115-127).

**The Business of Cancer**

10 Nov            **Part I: Case Study: Myriad Genetics**  
Baldwin, A.L., and R. Cook-Deegan. “Constructing narratives of heroism and villainy: case study of Myriad’s BRACAnalysis® compared to Genentech’s Herceptin®.” *Genome Medicine* 2013; 5(8): 1-14.  
Conley, J., R. Cook-Deegan and G. Lazaro-Muñoz, “Myriad after *Myriad*: The Proprietary Data Dilemma,” *North Carolina Journal of Law and Technology* 15 (June): 597-637 (2014).  
Material selected from the September 15 investor call for Myriad Genetics. Will be posted when it is available.

**Part II: Regulatory and Business Aspects**  
DiMassi, JA, “The Economics of New Cancer Drug Development: Metrics and

Trends,” presentation 28 October 2014.

## Drug Pricing

17 Nov

Conti, R.M., Fein, A.J., and S.S. Bhatta. “In Spending On And Use Of Oral Oncologics, First Quarter 2006 Through Third Quarter 2011.” *Health Affairs* 2014; 33:1721-1727.

Experts in Chronic Myeloid Leukemia, “The Price of Drugs for Chronic Myeloid Leukemia: A Reflection of the Unsustainable Prices of Cancer Drugs: From the Perspective of a Large Group of CML Experts,” *Blood* 2013 (May 30): 121(22):4439-42. doi: 10.1182/blood-2013-03-490003, available at: <http://www.ncbi.nlm.nih.gov/pubmed/23620577>.

Memorial Sloan-Kettering Cancer Center website on cancer drug pricing: <http://www.mskcc.org/research/health-policy-outcomes/cost-drugs>

Tefferi, A., et al. “In Support of Patient-Driven Initiative and Petition to Lower the High Price of Cancer Drugs.” *Mayo Clinic Proceedings* 2015 (August); 90(8): 996–1000.

Chhatwal J, Mathiesen M, and Kantarjian H: “Are High Drug Prices for Hematologic Malignancies Justified? A Critical Review,” *Cancer* (1 Oct) 2015 **121**: 3372-3379.

Whalen, J. “Doctors Object to High Cancer-Drug Prices.” *Wall Street Journal* 23 July 2015. Available online at: <http://www.wsj.com/articles/doctors-object-to-high-cancer-drug-prices-1437624060>

## Tobacco Politics

24 Nov

Mukherjee, *Emperor of All Maladies*, pp. 235-275.

Brandt, A.M., “Inventing Conflict of Interest: A History of Tobacco Industry Tactics,” *American Journal of Public Health* 2012 (January); 102(1): 63-71.

Proctor R.N., “Should medical historians be working for the tobacco industry?” *Lancet* 2004; 363: 1174–75.

1 Dec

**Last day of class**

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## Policies

Attendance: Daily attendance is required. Each student is allowed one absence, with no explanation necessary. Additional absences will negatively affect your final grade (e.g., taking you from a B to a B-). The instructor reserves the right to fail those who miss twenty percent of the class meetings or more for any reason.

Penalty for late assignments: *Late assignments are not accepted.*

Regrading policy: If you think the grade we gave you on an assignment is wrong, you may submit it to be regraded. It must be resubmitted within one week, with a paragraph explanation as to why you think our assessment was incorrect and why the paper or project deserves a different grade. Please refer to our grading rubric when making your case and remember that grades are earned, not given.

Electronic devices: You are welcome to use a laptop or tablet in class if you are referencing relevant readings. Do not use the laptop or tablet to check e-mail or Facebook or shop for shoes because that will significantly affect your overall participation grade. (It will affect your grade for the worse, just to be clear). Our preference is no use of phones or laptops except one designated online connection that is kept active for checking facts or references. If we have exercises that entail web searches, then we will make that explicit.

A note on content: We will be exploring sensitive subjects in this class, concerning death and illness, health and well-being, art and nudity, and the nature of charity. If you are uncomfortable with any of the topics, please schedule an appointment to speak with one of us, and we will discuss possible accommodations.

Unless you are otherwise instructed, all assignments are to be submitted to Blackboard via dropbox, which simplifies time-stamping and ensures fairness, and hard copies directly to the Instructors.

Reading assignments are to be completed in advance. You must come to class prepared and ready to participate in discussion. Please bear in mind that theoretical literature often must be read two or three times to achieve comprehension.

At ASU, we work very hard to promote a campus environment that is safe and conducive to learning and university-related business. Interfering with the peaceful conduct of university-related business or activities or remaining on campus grounds after a request to leave may be considered a crime. If someone is being disruptive, we reserve the right to ask them to stop, and if that does not resolve the problem, to eject that person from class.

Students with permanent or temporary disabilities who would like to discuss course requirements and accommodations are asked to see the instructors within the first week of class. Any athletes or others with school-related special scheduling needs should feel free to approach us.

The syllabus is a contract between the student and the teachers. If you come back for the second class, you agree to abide by the terms we have laid out in the syllabus. While we reserve the right to make small changes to the reading schedule, policies or due dates, we agree to not make any significant changes to the syllabus without consulting the class.

## **Academic Integrity**

If you submit work that is not your own, you will be fully disciplined in accordance with university policies. Cheating, plagiarism, or other forms of academic dishonesty are strictly forbidden and will result in a failing grade for the assignment, the class, and disciplinary action with the Dean. It is your responsibility to be aware of, understand, and adhere to the rules and regulations of Barrett, The Honors College and Arizona State University. If you have questions about this, raise them with one of us. The art of scholarship is weaving together ideas from others in useful and distinctive ways.

The general rules are these: do not claim someone else's work as your own. If you are using someone else's concepts, cite them. If you cite a fact, then trace it to its primary source and cite that (not the *New York Times* reporter who was also just using it or the review article that cited it). If you are using that person's reporting on it or the review article that cited it, make that distinction and tell us where to find the quote (including page number).