

Life/Death | Health/Justice (WST 395)

Professor Lisa Diedrich

Fall 2022 | TuTh 11:30-12:50 pm

Office hours: Tu 4:30-5:30 & W 2:30-4:30 or by appointment

Please email to schedule an appointment

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One thing that can be said for an eight-month course of cancer treatment: it is highly educational. I am learning to suffer.

—Prof. Vivian Bearing in Margaret Edson's *Wit*

In fact, the Hmong view of health care seemed to me to be precisely the opposite of the prevailing American one, in which the practice of medicine has fissioned into smaller and smaller subspecialties, with less and less truck between bailiwicks. The Hmong carried holism to its ultima Thule. As my web of cross-references grew more and more thickly interlaced, I concluded that the Hmong preoccupation with medical issues was nothing less than a preoccupation with life. (And death. And life after death.)

—Anne Fadiman, *The Spirit Catches You and You Fall Down*

To me, disability is not a monolith, nor is it a clear-cut binary of disabled and nondisabled. Disability is mutable and ever-evolving. Disability is both apparent and nonapparent. Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural, and biological. Being visible and claiming a disabled identity brings risks as much as it brings pride.

—Alice Wong, *Disability Visibility*

I conceive of care as the way someone comes to matter and the corresponding ethics of attending to the other who matters.

—Lisa Stevenson, *Life Beside Itself*

In this course, we will explore big questions about life and death and health and justice. We will investigate these questions through several case studies, moving from experiences of ill and disabled bodies in the world to the way global events and structures affect those experiences, and back again. Our first series of case studies will look at various relationships within the institution of medicine: between doctors and patients, patients and nurses, doctors and nurses, etc. As we analyze these relationships, we will consider the way knowledge, power, and choice gets expressed in and through these relationships. Our second series of case studies will expand out from specific relationships within medicine to larger global events and structures that affect the health of peoples throughout the world, historically and in the present. In the most general terms, we are interested in being, doing, and becoming in relation to illness and disability experiences and events, therapeutic thought and practices, and clinical and caring institutions and spaces. We will explore biopolitical issues, including the social determinants of health and structural violence, to address why some people are at greater risk for illness and premature death than others. We will also explore disability justice as a practice of care. Some of our organizing questions for the semester include: Why and how are illness and disability political? What factors impact health? What constitutes good care? How can we improve access and deliver better care?

Learning Outcomes

This course fulfills the Stony Brook Curriculum (SBC) requirements DIV/GLO/SBS+. Upon completion of this course, students should be able to demonstrate proficiency in the following skills:

1. Identify how knowledge, power, and choice operate in healthcare settings. Give examples of structures that limit the agency of ill people and their caregivers, as well as effective strategies and models of good care and healthcare delivery.
2. Analyze scientific, medical, political, and aesthetic responses to illness and health inequities.
3. Investigate and critique how different media present stories about health, illness, disability, and healthcare.
4. Use a variety of methods (including discourse analysis, annotation, visual cultural analysis, and interviewing) to analyze different experiences and events of illness.
5. Enhance group communication skills through discussions, small-group work, presentations, and debates.

Required texts that you will need to purchase or borrow:

- Edson, Margaret. *Wit* (New York: Faber and Faber, 1999).
- Fadiman, Anne. *The Spirit Catches You and You Fall Down* (New York: Farrar, Straus and Giroux, 1998).
- Stevenson, Lisa. *Life Beside Itself: Imagining Care in the Canadian Arctic* (Berkeley: University of California Press, 2014).
- Alice Wong, ed. *Disability Visibility: First-Person Stories from the Twenty-first Century* (New York: Vintage, 2020).

Films:

- *Wit* (Mike Nichols, 2001; 99 minutes). (<https://vimeo.com/328690172>)
- *All About My Mother* (Pedro Almodovar, 1999; 105 minutes)

Course Delivery Mode and Structure:

This course meets in person but will have some asynchronous components using Blackboard. For the week of November 15 and 17, we will not meet in person. That week students will participate in an online annotation exercise.

Classroom etiquette: A good classroom atmosphere depends on the behavior of both the instructor and the students. So, we need to respect each other and be courteous to each other.

Laptops: I permit the use of laptops for notetaking and to consult electronic versions of reading materials. Using your laptop for other things during class time is not allowed—searching the web, checking social media, etc. is distracting to you and others!

How to Be Successful in this Course: As the instructor, my focus is to help you do well in this course. I want to make sure you have every opportunity to learn and to

achieve a satisfactory experience engaging with your classmates and exploring new ideas and ways to think about life and death and health and justice. Here are some tips for the successful completion of the course:

1. **Read the syllabus carefully and check it frequently.** Keep track of when assignments are due and be aware of when there is more (and less!) reading.
2. **Keep up with the readings, films, and other materials for the course. Be an active reader, viewer, and listener!** Bring the current readings to each session and be ready to discuss those readings with questions, comments, and criticisms. Some of the readings will be difficult: spend time reading carefully and thinking critically about what you have read! One way to engage in discussion is to bring up specific passages in the text that are interesting, confusing, provocative, etc. Take notes during class. I also recommend that you use the questions posted on Blackboard to help you engage with the material and join in discussion.
3. **Complete all the assignments.** Please be sure to sign up at the beginning of the semester for your blog post. Students have a choice for their final project and will submit a proposal in advance. It's important to be aware of deadlines and plan for your assignments.

Blackboard: This class is on Blackboard (<http://blackboard.stonybrook.edu>), and students are expected to consult Blackboard regularly for updates on readings and assignments. I will post questions on the readings on Blackboard and will also email students through Blackboard with reminders and follow up from class discussions. We will utilize the Blackboard Discussion Board feature for our blogging, commenting, and sharing activities, as well as for our annotation exercise. Make sure that the email listed for you on Blackboard is the one you use, and if you need assistance with Blackboard, contact helpme@stonybrook.edu or call 631-632-9602.

Email: It is your responsibility to make sure that you read your email in your official University email account. To schedule a meeting during office hours, please email me first. If you use Blackboard's **email tool** from the course site, it will automatically include your full name, course name and section when you send me an email. **Please allow between 24-48 hours for an email reply.** Your Stony Brook University email must be used for all University-related communications. All instructor correspondence will be sent to your SBU email account. **Plan on checking your SBU email account regularly for course-related messages.** To log in to Stony Brook Google Mail, go to <http://www.stonybrook.edu/mycloud> and sign in with your NetID and password. If you need technical assistance, please contact Client Support at [\(631\) 632-9800](tel:631-632-9800) or supportteam@stonybrook.edu.

Student Accessibility Support Center Statement: If you have a physical, psychological, medical, or learning disability that may impact your course work, please contact the Student Accessibility Support Center, 128 ECC Building, (631) 632-6748, or at sasc@stonybrook.edu. They will determine with you what accommodations are necessary and appropriate. All information and documentation are confidential.

Students who require assistance during emergency evacuation are encouraged to discuss their needs with their professors and the Student Accessibility Support Center. For procedures and information go to the following website: <https://ehs.stonybrook.edu/programs/fire-safety/emergency-evacuation/evacuation-guide-people-physical-disabilities> and search Fire Safety and Evacuation and Disabilities.

Critical Incident Management: Stony Brook University expects students to respect the rights, privileges, and property of other people. Faculty are required to report to the Office of Student Conduct and Community Standards any disruptive behavior that interrupts their ability to teach, compromises the safety of the learning environment, or inhibits students' ability to learn.

Academic Integrity: Do not plagiarize, which is defined as “to take and use as one’s own the thoughts, writings, or inventions of another” (*The Oxford English Dictionary*). This means you have plagiarized if, for example: you copy part or all of another student’s paper, use another student’s paper from another class or semester, or if you download part or all of your paper from the internet and claim it as your own, or if you copy from a book and do not quote or cite the author. I take plagiarism very seriously. If you plagiarize, you will be turned in to Academic Judiciary. If you are confused about what constitutes plagiarism, come talk to me about it.

University statement on Academic Integrity: Each student must pursue their academic goals honestly and be personally accountable for all submitted work. Representing another person's work as your own is always wrong. Any suspected instance of academic dishonesty will be reported to the Academic Judiciary. For more comprehensive information on academic integrity, including categories of academic dishonesty, please refer to the academic judiciary website at <http://www.stonybrook.edu/uaa/academicjudiciary/>

Course Evaluations: Each semester Stony Brook University asks students to provide feedback on their courses and instructors through an online course evaluation system. Feedback from course evaluations helps me determine what texts, assignments, pedagogical practices work well or not. Course evaluations also help our department continue to deliver a rigorous, exciting, and comprehensive curriculum in Women’s, Gender, and Sexuality Studies that prepares students for a diverse range of career and graduate and professional school options.

Course Policies

Late Work: All assignments have due dates outlined in the schedule below. If, for some reason, you cannot meet a particular deadline, you will have the option of turning in late assignments for partial credit. Please contact me by email if you cannot meet a deadline, so we can discuss when and how you can complete the assignment.

Religious Observances: If you have religious observances that conflict with scheduled assignments, please contact me at least one week beforehand so we can plan an alternative schedule for you to complete any class activity or assignment you missed.

Understand When You May Drop This Course: It is your responsibility to understand when you need to consider [withdrawing from a course](#). Refer to the [Stony Brook Academic Schedule](#) for dates and deadlines for registration.

Incomplete Policy: Under emergency/special circumstances, you may petition for an incomplete grade. Circumstances must be documented and significant enough to merit an incomplete. If you need to request an incomplete for this course, contact me for approval as far in advance as possible.

Course Materials and Copyright Statement: Course material accessed from Blackboard, SB Connect, SB Capture or a Stony Brook Course website is for the exclusive use of students who are currently enrolled in the course. Content from these systems cannot be reused or distributed without written permission of the instructor and/or the copyright holder. Duplication of materials protected by copyright, without permission of the copyright holder is a violation of the Federal copyright law, as well as a violation of Stony Brook's Academic Integrity.

Student resources

Academic and Major Advising: Have questions about choosing the right course? Contact an advisor today. Phone and emails vary-please see website for additional contact information; website: <https://www.stonybrook.edu/for-students/academic-advising/>

Interested in becoming a WGSS major or minor?

Email me or visit the WGSS website: <https://www.stonybrook.edu/commcms/wgss/>

Academic Success and Tutoring Center (ASTC): The ASTC provides free academic support services for all undergraduate students, including one-on-one tutoring, small group tutoring, academic success coaching, and public speaking seminars. Learn more about these services and additional campus resources at www.stonybrook.edu/tutoring.

Further Resources: Another helpful resource for students who need any kind of help while at Stony Brook (academic, financial, health, etc.) is the "For Students" section linked from the Stony Brook homepage: <http://www.stonybrook.edu/for-students>

Counseling and Psychological Services: CAPS staff are available by phone, day or night. <http://studentaffairs.stonybrook.edu/caps/>

SBU Libraries: access to and help in using databases, ebooks, and other sources for your research.

- Research Guides and Tutorials: <http://guides.library.stonybrook.edu/>
- Getting Help: <https://library.stonybrook.edu/research/ask-a-librarian/>

Writing Center: Writers of all skill levels and at any stage of the writing process are invited to make appointments at the Writing Center. Writers can bring in anything they're working on, be it a creative piece, a personal statement, or a paper for class. Tutors will help writers brainstorm, organize, focus, and develop their written work.

The Writing Center aims to meet all writers' needs, but in the interest of helping writers rather than helping papers, we do not function as an editing service. Tutors may choose to address some grammar and punctuation issues, but only at advanced stages of the writing process. When we do address sentence-level concerns, we discuss fundamental concepts as opposed to making editorial corrections. Make an appointment at: <https://sunysb.mywconline.com>

Questions? Feel free to contact me to discuss the course at any point during the semester. Make an appointment to meet with me, send me an email, or see me after class.

Keep the conversation going, use our course hashtag: #LDHJ22. I will use this hashtag on Twitter to post articles and commentary related to course themes. Students are encouraged to do the same on Twitter and other social media. Some other hashtags to explore to get you started: #CripTheVote, #AccessIsLove, #DisabilityJustice, #IllnessPolitics, #LongCOVID. If you come across a new hashtag relevant to the class, please share on the Sharing Discussion Board thread.

Course Schedule (+ links for some readings)

Aug 23: Welcome and introductions to Life/Death | Health/Justice
Read the syllabus carefully before class!

The practices of caring and curing: Doctor/patient and nurse/patient relationships



[Image description: Screen grab from the film *Wit*. The camera looks down from the ceiling of Dr. Bearing's hospital room. She lies unconscious on her bed at the center of the shot. Her nurse Susie leans over her and holds her head gently in her hands.]

Aug 25: Film screening (in class)—*Wit* (Please also read the play script)
Review questions to guide you as you watch the film and read the play script

Aug 30: *Wit* cont.—discussion of film and play

Sep 1: *Wit* cont.—discussion of film and play

The practices of curing and caring: “Epilepsy” or “the spirit catches you and you fall down”

Sep 6: *The Spirit Catches You and You Fall Down*, pp. 1-59

Sep 8: *The Spirit Catches You*, pp. 60-139

Sep 13: *The Spirit Catches You*, pp. 140-224

Sep 15: *The Spirit Catches You*, pp. 225-288

The practices of medical ethics: Organ donation and the “new death”

Sep. 20: Margaret Lock, “Displacing Suffering: The Reconstruction of Death in North America and Japan,” *Daedalus* Vol. 125, No. 1 (Winter, 1996), 207-244.



[Image description: Screen grab from Pedro Almodóvar's film *All About My Mother*. Manuela reacts in anguish as two doctors give her the news that her son Esteban is brain dead.]

Sep 22: Film screening: *All About My Mother*

Sep 27: *All About My Mother* cont. and discussion

Sep 29: *All About My Mother* discussion

Structure and agency: Doing disability Justice

Oct 4: *Disability Visibility* selections [Alice Wong, Introduction; Harriet McBryde Johnson, "Unspeakable Conversations"; Talila A. Lewis, "For Ki'tay D. Davidson, Who Loves Us"]

Oct 6: *Disability Visibility* selections [Jen Deeringwater, "The Erasure of Indigenous People in Chronic Illness; Jillian Weise, "Common Cyborg"; Ricardo T. Thornton, Sr., "We Can't Go Back"; Sandy Ho, "Canfei to Canji: The Freedom of Being Loud"]

Oct 11: Fall Break—No class

Oct 13: *Disability Visibility* selections [A.H. Reaume, "Why My Novel is Dedicated to My Disabled Friend Maddy"; Alice Sheppard, "So. Not. Broken"; Britney Wilson, "On NYC's Paratransit, Fighting for Safety, Respect, and Human Dignity"; Lateef McLeod, "Gaining Power through Communication Access"]

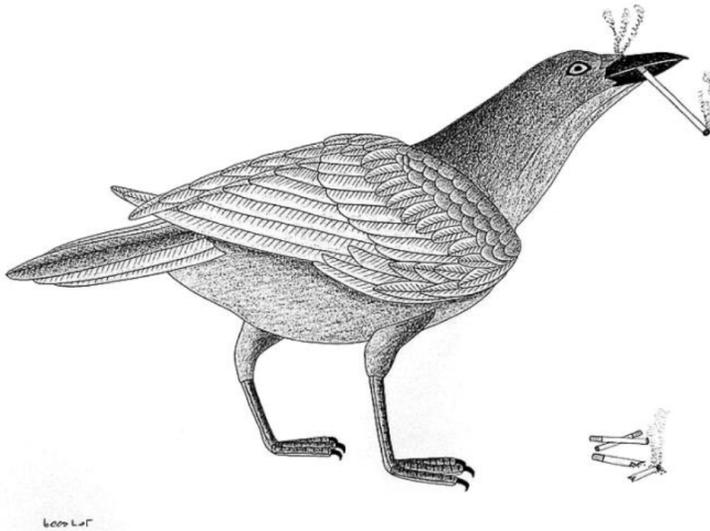
Oct 18: *Disability Visibility* selections [Patty Berne, "To Survive Climate Catastrophe, Look to Queer and Disabled Folks; Harriet Tubman Collective, "Disability Solidarity: Completing the 'Vision for Black Lives'"; Leah Lakshmi Piepzna-Samarasinha, "Still Dreaming Wild Disability Justice Dreams at the End of the World"; Stacey Milbern, "On

the Ancestral Plane: Crip Hand-Me-Downs and the Legacy of Our Movements”; s.e. smith, “The Beauty of Spaces Created for and by Disabled People”]

Oct 20: *Disability Visibility* cont.
Final project proposal due

Structure and agency: Imagining care

Oct 25: *Life Beside Itself*, Introduction and Chapter 1, pp. 1-46



[Image description: Drawing of a raven smoking a cigarette with several cigarette butts at the raven’s feet. This drawing is included in Lisa Stevenson’s book *Life Beside Itself*. The drawing is by artist Kavavaow Mannomee, *Untitled (Raven Smoking)*, 2007, colored pencil and ink.]

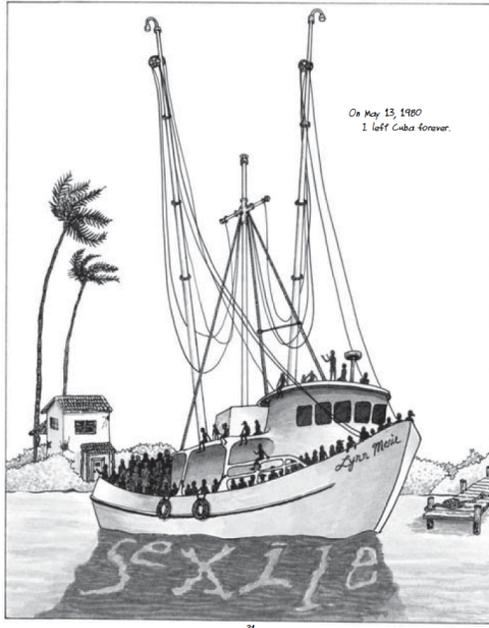
Oct 27: *Life Beside Itself*, Chapter 2, pp. 49-73

Nov 1: *Life Beside Itself*, Chapters 3 and 4, pp. 75-126

Drawing HIV/AIDS and COVID-19: Graphic medicine

Nov 3: Jaime Cortez, *Sexile*

Nov 8: Jaime Cortez, *Sexile*



[Image description: Full page from Jaime Cortez’s graphic narrative *Sexile*. A boat called the *Lynn Marie* crowded with people leaves a dock in Cuba heading for Florida. The words *sexile* is written in the water under the boat, suggesting the water as conveyance towards a new experience of sexuality and exile.]

Nov 10: Hillary Chute, “Can Comics Save Your Life?” *Public Books* (August 21, 2020).
<https://www.publicbooks.org/can-comics-save-your-life/>

Please also explore the COVID-19 Comics page on the Graphic Medicine website:
<https://www.graphicmedicine.org/covid-19-comics/>

Nov 15 and 17: we will not meet in person, but students will participate in an asynchronous annotation exercise on Blackboard. Students will select a comic to annotate from the COVID-19 Comics page on the Graphic Medicine website: <https://www.graphicmedicine.org/covid-19-comics/>. Post a comic and annotation before midnight on Thursday, November 17. Read your classmates’ annotations and post at least one comment before 6pm on Sunday, November 20. Be prepared to discuss your annotations in class on Tuesday, November 22.

Living with and Documenting COVID-19 in real time

Nov 22: COVID-19 comics annotation exercise in-class discussion

Nov 24: Thanksgiving—No class

What is the time of COVID-19?**Nov 29:**

1. Merlin Chowkwanyun and Adolph Reed, Jr., “Racial Health Disparities and Covid-19—Caution and Context,” *The New England Journal of Medicine*.

https://www.nejm.org/doi/10.1056/NEJMp2012910?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%20pubmed

2. Amy Maxmen, “Inequality’s Deadly Toll,” *Nature* (28 April 2021).

<https://www.nature.com/immersive/d41586-021-00943-x/index.html>

Dec 1: Ed Yong, “COVID-19 Can Last for Several Months,” *The Atlantic*, June 4, 2020.

Accessed at: <https://www.theatlantic.com/health/archive/2020/06/covid-19-coronavirus-longterm-symptoms-months/612679/> and wrap up!

Dec 9: Final projects due on Blackboard before midnight**Course Requirements**

I. Blogging (50 points total): This assignment is multi-faceted and has 3 components: posting, commenting, and sharing. Students will write and post a blog entry (200-250 words each—posted on the Discussion Board site on Blackboard), in which you discuss the readings assigned for one of the days in the week ahead. Students will also comment at least twice on a post by a classmate and share at least once a news article or other item they have come across outside the class that relates to the themes of the class.

Blog posts (25 points):

Students will sign up for a blog post at the beginning of the semester. Blog posts should be 250-300 words and include:

- 1) A succinct summary of the text
- 2) A thoughtful analysis and assessment. Some questions to consider in your analysis: What are the author’s main arguments? Do you agree or disagree with them and why? How does the material relate to course themes and to earlier class discussions? What new concepts or terms are introduced? What do you find interesting and/or confusing about these terms and concepts?
- 3) At least two discussion questions that will help generate a conversation about the reading.
- 4) Respond to comments on your post.

Blogs should be posted before 6 p.m. on the Sunday before the text is discussed—feel free to post earlier than this. Late submissions will be penalized.

Comments (3x5 points): Students are also expected to comment (50-100 words) on three posts by classmates. (This is the minimum requirement. You should feel free to engage more!) Comments are due before 6pm on Mondays. Your comments should be analytical and thoughtful, not simply “I agree with so and so” but why you

agree/disagree. You should also try to read as many blog entries by your classmates as possible—this will help you understand the readings better—different people notice and focus on different things. We learn more from each other than we do on our own.

Shares (2 x 5 points): Please share with the class twice during the semester an article or some other item of relevance to the themes of the class (e.g., a news story, feature article, academic article, film or book review, comic, hashtag or conversation on social media, etc.). You will briefly summarize what you share (50-100 words): tell the class how this connects with our readings and discussions (be specific). For example, does it offer a story or situation that demonstrates a key concept or theme we have discussed in class? Does it offer a different perspective on the experience of illness, disability, and/or care?

2. Annotation as method of visual analysis Blackboard exercise (20 points):

During the week of November 15 and 17, students will annotate a comic chosen from the COVID-19 Comics page on the Graphic Medicine website:

<https://www.graphicmedicine.org/covid-19-comics/>. Tell us what is happening in the comic you have chosen. Describe the comic in detail, emphasizing what it shows and how it shows it (content and form). Interpret the significance of the comic in relation to themes we have discussed this semester. Provide at least one discussion question that will help generate a conversation about COVID-19 comics. **Students will post their notes and interpretations on Blackboard before midnight on Thursday, November 17. Please also comment on two other posts before 6pm on Sunday, November 20.**

How to annotate: Generally, we annotate by writing directly on a text or image. Because our discussion will be virtual not in-person, students are not required to write directly on the image. What you will do is a two-part process—note taking and interpretation. First, you will study the image carefully. You will take notes on what you see and feel as you look at the image. This is descriptive work. Describe the image in detail. These notes do not need to be full sentences or paragraphs. You will want to look and look again. That is, don't simply look and take notes in one sitting, but spend time studying, then do something else for a period of time (sleep on it, go for a walk, watch a film, listen to music), and return later to look again.

After you feel like you have fully annotated or described the image, then give us some thoughts on what ideas or feelings the image is attempting to show. In a short paragraph (3 or 4 sentences), interpret the image. Key concepts from the course and other course materials will help you do this interpretative analysis.

You will post both your notes on and your interpretation of the image. Once you have posted your own notes and interpretation, you will be able to see what other members of the group have posted. You will want to comment and respond to 2 other posts.

Grade rubric for asynchronous annotation exercise (20 points):

- Notes (8 points)—How detailed is your description of the image?

- Interpretation (8 points)—Your notes should help you analyze and interpret the image. How insightful/creative/original is your interpretation?
- Comments (4 points)—Your comments should be analytical and thoughtful, not simply “I agree with so and so” but why you agree/disagree.

3. Documenting COVID-19 final project (30 points): three options—choose one!

1. Interview: Students will conduct a 30-minute interview with a person about their experiences with COVID-19. You may interview someone you know (including family members) or someone you don't already know but who has a particular experience of the pandemic that you would like to learn about. Students will transcribe the interview and write a 2-page reaction to the interview process.

2. Comic: Students will create a comic about COVID-19. This could document a personal experience or that of someone you know; it could be the experiences of healthcare or other essential workers; about how and why the virus spreads and how to slow the spread; or about the racial, sexual, and class politics of COVID-19. The comic must be at least 4 panels. Students will write a 2-page artist's statement discussing their comic.

3. Public health or illness politics poster or meme: Students will create their own public health or illness politics graphic poster or meme. Students will write a 2-page artist's statement discussing their poster or meme.

Project proposals (1-page) are due on Blackboard on October 20 before midnight. Proposals are worth up to 5 points towards the total 30 points. Please explain which project you intend to do, along with a rationale for your project. For the interview project, you will explain who you are interviewing and why, and submit 10 questions that will help frame your interview. For the comics project, describe the experience your comic will document and explain why you think this experience is important to document in this form. For the public health or illness politics poster or meme, describe the message that you want to communicate and why and how you plan to do so.

Final projects will be turned in on Blackboard on December 9 before midnight.



[Image description: Photograph of a **RESIST/COVID TAKE 6!** billboard on the wall of a brick building in Syracuse, New York. **RESIST/COVID TAKE 6** is an initiative launched by artist Carrie Mae Weems. This billboard includes three separate posters with black and white photos above statements in all caps and red letters on white background. From left to right: a photo of three black women in a line with distance between them above the words “**PLEASE KEEP YOUR DISTANCE.**”; a photo of the Empire State Building at night above the words “**CLOSED UNTIL FURTHER NOTICE!**”; and a photo of a group of three men and three women stylishly dressed and holding hands above the words “**DON’T WORRY. WE’LL HOLD HANDS AGAIN.**” The **RESIST COVID/TAKE 6!** logo with an iconic rendering of the COVID virus in red is under each of the three photos on the right.]