

Fall 2020

HSS 404-H01: Human Subjects - The History of Experimenting on Humans

Rosanna Dent

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HSS 404 H01: Human Subjects The History of Experimenting on Humans

Class Time & location Tuesdays and Thursdays, 16:00-17:20
Synchronous, Online on WebEx

Instructor Rosanna Dent
Pronouns she/her/hers
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Office <https://njit.webex.com/meet/rdent>
Office Hours Tuesday 17:30-18:30; Thursday 14:00-15:00 and by appointment.
Please sign up on my [Google Cal](#) to assure a spot.

Overview From pharmaceuticals to AI algorithms to notions of “the human mind” or “human nature,” our experiences and perceptions of the world around us are profoundly shaped by research conducted on people. This senior seminar explores the history of human subjects research. From the early twentieth century to the present we will ask, how and why have people been studied? How have ethical norms developed and changed medical and social research? And how have those who participated, willingly and unwillingly, experienced research? We will focus on issues of power, race, gender, disability, sexuality, geography, and economy to appreciate the ongoing influence of these histories on social and medical realities in the present.

Prerequisites HUM 102 and one from among HUM 211, HUM 212 and HIST 213 or their equivalents, all with a grade of C or better. Completion of either the LIT/HIST/PHIL/STS or Open Elective in Humanities and Social Science, with a grade of C or better.

Course Goals Students who successfully complete this course will be able to:

- Raise pertinent questions regarding the political and social implications of human subjects research;
- Identify and summarize the main idea and key arguments of a textual source;
- Critically evaluate a source (whether primary or secondary), situating it in its historical context and interpreting its broader relevance for historical thinking;
- Communicate these summaries, questions, and analyses in clear written and oral form;
- Demonstrate information literacy through the use of appropriate source material and the ability to cite properly.

Required Texts	All readings will be available online on Canvas.
WebEx Class Meetings	<p>Our class will meet synchronously at our scheduled time through WebEx. In-class participation matters, and we will make it as interactive as possible given the medium. I also recognize we are living in uncertain times. I will take attendance so I can follow-up with students who miss class. I will also make and post recordings of class to Canvas.</p> <p>Please mute yourselves when not speaking. Sharing video is strongly encouraged if bandwidth permits as it will provide us with more visual cues and a better sense of who we are thinking with. For privacy concerns, this guide explains how to put up a virtual background in WebEx.</p> <p>Classroom recordings of students are educational records under the Family Educational Rights and Privacy Act (FERPA), the U.S. federal law that governs access to educational records. Both instructor and students must provide notification if any part of online sessions are to be recorded, and such recordings cannot be circulated outside the course.</p>
Academic Integrity	<p>NJIT’s policy is as follows: “Academic Integrity is the cornerstone of higher education and is central to the ideals of this course and the university. Cheating is strictly prohibited and devalues the degree that you are working on. As a member of the NJIT community, it is your responsibility to protect your educational investment by knowing and following the academic code of integrity policy that is found at: http://www5.njit.edu/policies/sites/policies/files/academic-integrity-code.pdf.</p> <p>Please note that it is my professional obligation and responsibility to report any academic misconduct to the Dean of Students Office. Any student found in violation of the code by cheating, plagiarizing or using any online software inappropriately will result in disciplinary action. This may include a failing grade of F, and/or suspension or dismissal from the university. If you have any questions about the code of Academic Integrity, please contact the Dean of Students Office at dos@njit.edu.”</p> <p>Most importantly, you are here to learn, grow, practice, make mistakes, exchange ideas, take risks, debate, discuss, and so on. Academic integrity is about being committed to these learning processes and taking responsibility for your own learning. I am here to answer questions and help with this process. If in doubt, ask.</p>

**Citation
Expectations**

Scholars communicate their intellectual connections through citation. This is a **generative practice** that allows you to join a broader conversation with those you read and those who read you. It is also a way to **credit others** for their work.

Any words taken directly from a written source (assigned reading, website, book, article...) or from another individual (interview, podcast, youtube...) must be in quotation marks and cited. ALWAYS. I will work with you to learn how to do this. This matters a lot, both to **avoid plagiarism** and to **learn how research works**.

In this class we will use Chicago Manual of Style format for citations. Davida Scharf is an expert researcher and our librarian for the History Department. Online research guides, office hours or other help:
<http://researchguides.njit.edu/scharf>.

**Disability
Services**

Students who have special needs should contact NJIT's Student Disability Services to help procure accommodations in completing coursework. The center can be found at <http://www.njit.edu/counseling/services/disabilities.php>.

**University
Education in
Pandemic
Times**

Even if we may be more used to online interactions, social distancing, and life-through-masks than a few months ago, these are still stressful and uncertain times. We are facing many serious issues that will impact different members of our class differently, including COVID-19, but also racism, state violence, climate change, and a highly charged political climate. Part of what we will do in this class is learn about the historical roots of many of the problems we now face.

For some of us this is the first semester that we have studied (or taught) in the online format, so there will be a steep learning curve. Please be compassionate to others who may be facing different challenges from you. Make an extra effort to get to know your classmates. Read, discuss, and work together if you can.

If you are struggling with the course for whatever reason, please contact me. I may be able to help. I want you to succeed and will help you do so. I also strongly encourage students to seek support in different forms, including from the Center for Counseling and Psychological Services, and Health Services depending on the challenge.

Furthermore, I urge any student who faces challenges securing food or housing and believes this may affect their learning to contact the Dean of Students. And let me know if you're comfortable doing so, because there are ways I may be able to help.

Note: I reserve the right to make changes to the syllabus that I deem necessary.

Assignments and Grading

Submission: All assignments should be submitted electronically through Canvas. Only the following file types are accepted: pdf, doc, docx. (I.e. Google docs are not accepted – make a pdf.) Please prepare all assignments in Times New Roman, size 12 font, with 1-inch margins, double spaced.

Late Submissions: Assignments in this course are scaffolded towards the completion of an independent work of research. I encourage you to meet deadlines so that you can get timely feedback and build on drafts to learn more from the work. Assignments (other than reading responses and presentations – see below) may lose up to one grade for every day late (A to A-, A- to B+).

Golden Ticket: Life can be complicated. All students have one “Golden Ticket,” which can be used for a no-questions-asked 3-day extension on one major assignment. Simply **indicate at the top of the first page** that you are using your Golden Ticket, and you will not be marked down. If you use this on a rough draft, it is STILL your responsibility to give timely peer edits.

Exceptional Circumstances: If there are pressing issues affecting your ability to complete class work, please get in touch with me as early as possible. I also strongly encourage you to reach out proactively to the Dean of Students’ office.

Participation	(45%)	Grading Scale
Reading Responses (30%)		A= 90 to 100
In-class work (15%)		B+= 88 to 89
Research Paper	(55%)	B= 80 to 87
Proposal (15%)		C+= 78 to 79
Rough draft and peer editing (15%)		C= 70 to 77
Final draft (25%)		D= 60 to 69
		F= 59 to 0

Participation (45%)

Participation is central to your success in this course and includes speaking, listening, and demonstrating careful completion of all assigned reading. Full participation in this class includes:

- (a) All students will be required to post a **response to the readings** on the canvas discussion board by 5pm on **Monday** of each week. I will post a prompt and guidelines for the response each week by Thursday at 8pm. These responses should be approximately 300 words and should demonstrate comprehension and analytical thinking. Late responses will receive half credit. Reading responses will be graded based on how fully they meet the directions, and how thoughtful and thought provoking they are. Students can drop their two lowest response grades. (30% of final grade.)
- (b) **In-class participation** can take many forms, such as speaking during full-class discussion, group work and leadership during class activities, pre-prepared questions or comments, in-class writing assignments, among other options. You must be present to participate. If you tend to be shy or quiet in class I encourage you to talk to me about it early in the semester. (15% of final grade.)
- (c) All students **must attend office hours** or meet with me by appointment during the first six weeks of the semester.

Final Paper (55%)

Final Paper Topic Brainstorm (ungraded) (due Sep. 17)

Proposal (rough draft) (ungraded) (due Oct. 8)

Proposal (15%) (due Oct. 22)

Rough draft and peer editing (15%) (due Nov 19 & 22)

Final draft (25%) (due Dec. 14)

The final paper for this course will be an 8-10 page historical study of a case within human subjects research. You can focus on a single study, an institution, a legal case, a category of research, or any topic you can explore using quality primary and secondary sources.

Proposal (due Thur. Oct. 22, 11:59pm)

The paper proposal will help you prepare to write your final papers. For this assignment, you will explain your topic, identify the primary and secondary sources that you plan to use and how you plan to use them, and sketch out what you think your argument might be. You will also provide a correctly formatted annotated bibliography of sources. **(15%)**

Rough draft and peer editing (due Thur., Nov. 19 and Sun, Nov. 22)

Writing improves dramatically with multiple drafts and thoughtful feedback. You will be responsible for working with two classmates to peer edit well developed rough drafts of your final papers. This will be graded on the basis of (a) having a rough draft of at least 9 pages on time; (b) giving careful feedback to your peers. We will discuss and practice effective peer editing in class, and you will turn in your edits on your partners' paper. **(15%)**

Schedule of Topics and Assigned Readings

Reading Response for the readings are due on MONDAY of the week listed

<p>Week 1</p> <p>Tues, Sep. 1</p> <p>Thurs, Sep. 3</p>	<p>Introduction</p> <p>**no responses required, readings due in class on Thursday**</p> <p>Secondary Sources: TallBear, Kim. 2014. "Standing With and Speaking as Faith: A Feminist-Indigenous Approach to Inquiry." <i>Journal of Research Practice</i> 10 (2): Article N17. Campbell, Nancy D., and Laura Stark. 2015. "Making up 'Vulnerable' People: Human Subjects and the Subjective Experience of Medical Experiment." <i>Social History of Medicine</i> 28 (4): 825–48. https://doi.org/10.1093/shm/hkv031. (831-845 Optional.)</p> <p><i>Course Introduction</i></p> <p><i>Defining Human Subjects</i></p>
<p>Week 2</p> <p>Tues, Sep. 8</p> <p>Thurs, Sep. 10</p>	<p>Bioethicizing the Subject</p> <p>Primary Sources: The Nuremberg Code The Helsinki Declaration National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research." Health, Education, and Welfare: Washington, DC: U.S. Government Printing Office, 1979.</p> <p>**No Class – Monday Schedule**</p> <p><i>Beyond Bioethics</i></p> <p>NOTE: Tuesday September 8th is the last day to add or drop a course.</p>
<p>Week 3</p>	<p>Soldiers and Prisoners</p> <p>Secondary Sources: Comfort, Nathaniel. 2009. "The Prisoner as Model Organism: Malaria Research at Stateville Penitentiary." <i>Studies in History and Philosophy of Biological and Biomedical Sciences</i> 40 (3): 190–203. https://doi.org/10.1016/j.shpsc.2009.06.007. Moreno, Jonathan. 2004[1997]. "Convenient and Captive Populations" [abridged] in Ezekiel J. Emanuel et al, eds. <i>Ethical and Regulatory Aspects of Clinical Research: Readings and Commentary</i> Baltimore: Johns Hopkins University Press, 258-262. Roelcke, Volker. 2004. "Nazi Medicine and Research on Human Beings." <i>The Lancet</i> 364 (December): 6–7. https://doi.org/10.1016/S0140-6736(04)17619-8.</p> <p>Primary Source: Kor, Eva Mozes. 2017. "I Survived the Holocaust Twin Experiments" BuzzFeed. https://www.youtube.com/watch?v=gdgPAetNY5U. Accessed 17 January 2020.</p>

Tues, Sep. 15	<i>Total Institutions</i>
Thurs, Sep. 17	<i>Virtual Library Visit (TBC)</i> **Final Paper Topic Brainstorm Due**
Week 4	Finding and Citing Sources
Tues, Sep. 22	<i>Bibliographies</i>
Thurs, Sep. 24	<i>Guided Research Session (TBC)</i>
Week 5	Patients
	<p>Secondary Sources:</p> <p>Owens, Deirdre Cooper. 2017. <i>Medical Bondage: Race, Gender, and the Origins of American Gynecology</i>. Athens, GA: University of Georgia Press, 1-15, and excerpts from Ch 2. (The rest of Chapter 2 is optional.)</p> <p>Reverby, Susan. 2009. <i>Examining Tuskegee: The Infamous Syphilis Study and Its Legacy</i>. Chapel Hill: The University of North Carolina Press. (Selections)</p> <p>Primary Sources:</p> <p>Sims, J. Marion. 1894. <i>The Story of My Life</i>. New York: D. Appleton and Company. Hathi Trust. http://hdl.handle.net/2027/hvd.hc1hb9, 226-246.</p> <p>Visit the National Archives website and find one primary source to bring to class. https://catalog.archives.gov/search?q=Tuskegee%20Study</p>
Tues, Sep. 29	<i>The Origins of Gynecology</i>
Thurs, Oct. 1	<i>The Syphilis Study and Its Legacy</i>
Week 6	Indigenous Peoples part I
	No Assigned Reading: Work on Proposal
Tues, Oct. 6	<i>Yanomamö: A Multidisciplinary Study</i>
Thurs, Oct. 8	<i>Peer Editing</i> **Proposal Rough Draft Due in Class**

<p>Week 7</p> <p>Tues, Oct. 13</p> <p>Thurs, Oct. 15</p>	<p>Indigenous Peoples part II</p> <p>Primary Source: Chagnon, Napoleon. 1988. "Life Histories, Blood Revenge, and Warfare in a Tribal Population." <i>Science</i> 239 (4843): 985–92. https://doi.org/10.1126/science.239.4843.985. Cunha, Manuela Carneiro da. 1998. "Letter to the AAA Ethics Committee." <i>Anthropology Newsletter</i>. 30(3): 3. Chagnon, Napoleon. 1989. "Reply." <i>Anthropology Newsletter</i>. 30(3): 3-4. Kopenawa, Davi, and Bruce Albert. 2013. <i>The Falling Sky: Words of a Yanomami Shaman</i>. Translated by Nicholas Elliott and Alison Dundy. Cambridge, Massachusetts: Belknap Press. (Selection).</p> <p>Optional Secondary Sources: Borofsky, Rob, Bruce Albert, Raymond Hames, Kim Hill, and Lêda Leitão Martins. 2005. <i>Yanomami: The Fierce Controversy and What We Can Learn from It</i>. Berkeley: University of California Press, 3-34, 61-71.</p> <p><i>Gender, Violence, Politics</i></p> <p><i>Anthropology and the Limits of Institutionalized Ethics</i></p>
<p>Week 8</p> <p>Tues, Oct. 20</p> <p>Thurs, Oct. 22</p>	<p>Twins</p> <p>Secondary Sources: Lindee, M. Susan. 2005. "Two Peas in a Pod: Twin Science and the Rise of Human Behavior Genetics," in <i>ibid. Moments of Truth in Genetic Medicine</i>. Baltimore: Johns Hopkins University Press, 120-155.</p> <p><i>Two Peas</i></p> <p><i>Three Identical Strangers</i> **Proposal Final Draft Due at 11:59pm**</p>
<p>Week 9</p> <p>Tues, Oct. 27</p> <p>Thurs, Oct. 29</p>	<p>Individual Research Meetings (No Class Meetings)</p> <p>You are required to sign up for a meeting with Prof Dent on her Google Calendar to discuss your proposal one-on-one.</p> <p>No Class Meeting</p> <p>No Class Meeting</p>

<p>Week 10</p> <p>Tues, Nov. 3</p> <p>Thurs, Nov. 5</p>	<p>Activists</p> <p>Nelson, Alondra. 2013. "As American as Cherry Pie: Contesting the Biologization of Violence" in <i>ibid. Body and Soul: The Black Panther Party and the Fight against Medical Discrimination</i>. Reprint Edition. Minneapolis: University Of Minnesota Press, 153-180.</p> <p>Epstein, Steven. 2007. "Sex Difference and the New Politics of Women's Health." In <i>ibid., Inclusion: The Politics of Difference in Medical Research</i>. Chicago: University Of Chicago Press.</p> <p>Optional: Epstein, Steven. "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials." <i>Science, Technology & Human Values</i> 20, no. 4 (October 1, 1995): 408–437.</p> <p>Primary Sources (TBD)</p> <p><i>Opposing Research</i></p> <p><i>Demanding Research</i></p>
<p>Week 11</p> <p>Tues, Nov. 10</p> <p>Thurs, Nov. 12</p>	<p>Naïve Bodies</p> <p>Petryna, Adriana. 2009. <i>When Experiments Travel: Clinical Trials and the Global Search for Human Subjects</i>. Princeton: Princeton University Press, 89-138.</p> <p>Crane, Johanna Tayloe. 2013. "Chapter Four: Research and Development" in <i>ibid. Scrambling for Africa: AIDS, Expertise, and the Rise of American Global Health Science</i>. Ithaca: Cornell University Press, 109-144.</p> <p>Cooper, Melinda, and Catherine Waldby. 2014. "Chapter Seven: Speculative Economies, Contingent Bodies: Transnational Trials in China and India." In <i>ibid, Clinical Labor: Tissue Donors and Research Subjects in the Global Bioeconomy</i>. Durham: Duke University Press, 159-194.</p> <p><i>Offshoring Clinical Trials</i></p> <p><i>"Opportunities" Abroad</i></p> <p>NOTE: Monday Nov. 9th is the last day to withdraw from a course.</p>
<p>Week 12</p>	<p>Oversees Subjects</p> <p>Secondary Sources:</p> <p>Biruk, Crystal. 2018. "Clean Data, Messy Gifts: Soap-for-Information Transactions in the Field" in <i>ibid. Cooking Data: Culture and Politics in an African Research World</i>. Durham: Duke University Press Books, 100-128.</p> <p>Geissler, P. Wenzel, Ann Kelly, Babatunde Imoukhuede, and Robert Pool. 2008. "'He Is Now Like a Brother, I Can Even Give Him Some Blood': Relational Ethics and Material Exchanges in a Malaria Vaccine 'Trial Community' in the Gambia." <i>Social Science and Medicine</i> 67 (5): 696–707. https://doi.org/10.1016/j.socscimed.2008.02.004.</p>

Tues, Nov. 17	<i>Gifts and Kinship</i>
Thurs, Nov. 19	<i>Peer Editing</i> **Rough Drafts of Research Papers Due**
Week 13	Data Secondary Sources: Radin, Joanna. 2017. "Digital Natives': How Medical and Indigenous Histories Matter for Big Data." <i>Osiris</i> 32 (1): 43–64. https://doi.org/10.1086/693853 . Primary Sources (TBD)
Tues, Nov. 24	<i>AI and Experimental Subjects</i>
Thurs, Nov. 26	<i>Thanksgiving Holiday</i> **no class meeting**
Week 14	Writing Workshops
Tues, Dec. 1	<i>Structure</i>
Thurs, Dec. 3	<i>Evidence</i>
Week 15	Writing Workshops
Tues, Dec. 8	<i>Prose</i>
Thurs, Dec.10	<i>Course Wrap up</i>
Mon, Dec. 14	**FINAL Research Papers Due**