

The Ethics of Scientific Research

description: This course will be a survey of the main ethical issues in scientific research. Topics to be covered include data fabrication, data falsification, plagiarism, conflicts of interest, data management, mentor and trainee responsibilities, collaborative research, authorship and publication, peer review, animal experimentation, and human experimentation.

class schedule: Mondays, 11:00–11:50, in 4011 Wescoe Hall
(enrollment code 63093 for BIOL 420 or 62466 for PHIL 500)

meeting with me and contacting me:

The location of my office is 3071 Wescoe Hall. I will have office hours on Wednesdays from 12:00 to 12:50 and on Thursdays from 11:00 to 11:50, but you should feel free to come by my office at any time. In rare cases I may have to ask you to come back at another time, but in general I will be happy to speak to you at your convenience. You are also quite welcome to make an appointment with me. To do so, please send me an email (my email address is my last name (no capitalization necessary), followed by '@ku.edu') with a list of some times when you are available, and I'll find a time when we're both available and write back to you. Please note that I tend to use email only for scheduling appointments and handling logistical matters, not for substantive discussions of course material.

requirements/grading:

Your final average will be determined by your scores on the following three course components.

<u>assignment</u>	<u>weight (percent)</u>
quizzes (typically not announced in advance)	50
papers (see more information below)	40
attendance and class participation	10

If you are taking this course for 1 credit, you will write two or three papers (your choice), and your two best papers will count for 20 percent each. If you are taking this course for 2 credits, you will write four or five papers (your choice), and your four best papers will count for 10 percent each.

papers:

basic information:

Each of your papers should be a maximum of 300 words long. Each paper should be on just one topic – that is, if you are writing a paper in a week for which there are multiple topics provided, write your paper on just one of the topics provided. Also, you cannot turn in more than one paper in any given week, unless one of them is on one of the special papers topics described below.

formatting your papers:

At the beginning of every paper, include at least the following identifying information: your name, the date when you are turning it in, its word count, and the number of the topic on which you are writing. Use left and right margins of at least 1.25 inches. Finally, make your text double-spaced or 1.5-spaced; I especially encourage the latter if it will enable you to fit your paper on one side of one sheet of paper.

stylistic expectations:

Every paper you turn in should be a finished, polished piece of writing. Additionally, it should be written as if intended for the general reader, not just for me or the members of this class.

due dates:

You must turn in at least half of your required papers by the end of February. Otherwise, you can choose the weeks in which you'll write your papers. Just be sure to start writing them soon enough in the semester to leave yourself time to write as many papers as you need (given the rule about not turning in more than one paper in any given week), as determined by the number of credits for which you are enrolled.

deadlines:

The deadline for each paper will be the beginning of the class period with which it is associated. This deadline will be strictly enforced: late papers' scores will be reduced by 25 percentage points for each full or partial day of lateness (with each "day" starting at 11 a.m.). Papers submitted in class, or shortly before, will be returned the next week. Papers turned in at least 24 hours early may be graded and returned in the associated class period rather than a week later.

formatting your files:

You can turn in your paper either in hard copy or by email. Acceptable formats for papers turned in by email include the formats associated with the extensions .pdf, .docx, .doc, and .rtf. Be sure that you save your file in one of these formats; do not save it in another format and then just change the extension to one of these. Versions of Microsoft Word capable of saving files in several of these formats are available on most, if not all, of the computers in KU's computer labs, and many other word processors than Microsoft Word are also capable of saving files in some of these formats. For example, you might find that you can use Google Docs rather than Microsoft Word, if that is more convenient for you.

special paper topic #1: The Lab:

Most of the paper topics are given below, in the schedule. The first three topics, however, are given in this part of the syllabus. The first topic is based on an interactive web video called *The Lab: Avoiding Research Misconduct*, from the Office of Research Integrity, of the U.S. Department of Health and Human Services. In this video, the user can take the perspective of any of four main characters in the story – a third-year graduate student, a postdoctoral student, a principal investigator, or a research administrator. The interactive aspect of the video is that the user is confronted with choice situations, makes decisions, and is shown how they turn out. Every character has several choice situations that occur in sequence. The paper topic for this video is as follows; also see the “Special paper topic additional instructions,” below:

1. Go to the website for this video (<http://ori.hhs.gov/thelab>), go through the video as one of the four characters, and answer these questions:
 - a. What was the role of the character that you went through the video as – third-year graduate student, postdoctoral student, principal investigator, or research administrator?
 - b. What were the main ethical or professional lessons that the video sought to convey about proper behavior and decision-making for a person in that role?
 - c. How would you evaluate this video, either in terms of the substance of the lessons it conveys or in terms of its overall design and execution as a tool for teaching the ethics of scientific research?

special paper topic #2: The Research Clinic:

The second paper topic is based on an interactive web video called *The Research Clinic*, from the Office of Research Integrity, of the U.S. Department of Health and Human Services. In this video, the user can take the perspective of any of four main characters in the story – a principal investigator, a clinical research coordinator, a research assistant, or an institutional review board (IRB) chair. The interactive aspect of the video is that the user is confronted with choice situations, makes decisions, and is shown how they turn out. Every character has several choice situations that occur in sequence. The paper topic for this video is as follows; also see the “Special paper topic additional instructions,” below:

2. Go to the website for this video (<http://ori.hhs.gov/theresearchclinic>), go through the video as one of the four characters, and answer these questions:
 - a. What was the role of the character that you went through the video as –principal investigator, clinical research coordinator, research assistant, or institutional review board (IRB) chair?
 - b. What were the main ethical or professional lessons that the video sought to convey about proper behavior and decision-making for a person in that role?
 - c. How would you evaluate this video, either in terms of the substance of the lessons it conveys or in terms of its overall design and execution as a tool for teaching the ethics of scientific research?

special paper topic #3: The Immortal Life of Henrietta Lacks:

You might have read this best-selling book by Rebecca Skloot. (If you have not, a description of it is provided at the end of this syllabus, in the “Additional Resources” section.) If you have read it, and would like to write about it for one of your short papers, you are welcome to do so, by answering the following question (which is based on one of the reading-group questions listed in the back of the book, or at least some editions of the book). Your answer to this question should not only reflect your own opinion but also draw on at least three different pages from the book and/or other sources (and you must cite the pages and/or sources that you draw on, of course). Finally, note that this question has two parts (a and b); your paper should also have two parts (labeled ‘a.’ and ‘b.’). The two parts of your paper do not have to be of equal length – the part of your paper responding to one part of the question may be shorter or longer than the part of your paper responding to the other part of the question.

3. (a) Victor McKusick directed Susan Hsu to contact Henrietta’s children for blood samples to further HeLa research. Were their efforts to get these blood samples ethical? Why or why not? (b) Consider the case of John Moore and David Golde, in which the Supreme Court of California ruled that when tissues are removed from your body, you no longer own them. What were the court’s reasons for reaching this decision? Do you agree with it? Why or why not?

special paper topic additional instructions:

To give you more latitude to write papers on these three topics, the paper rules, for these three topics only, are modified as follows:

1. The length limit of 300 words is extended to 500 words. (You are not required to write a longer paper, however – the additional length is just an option.)
2. You can turn in a paper on any of these topics in any week, even a week in which you are also turning in a paper on some other topic. (Papers on these topics will be accepted until the latest of the due dates for the other paper topics. Since the video for topic 1 or the video for topic 2 could be unavailable for some reason later in the semester, do not count on being able to write a paper on those topics at the last minute.)

attendance and class participation:

If you have to miss class, let me know. You should miss class when you are ill and might infect others. If you have a contagious illness, please protect your classmates from the risk of catching it from you. Absences in such circumstances will be excused and there will be no adverse effect on your grade.

Good class participation consists of offering intelligent, relevant, and helpful comments and questions. You should be an active discussant and should feel free to introduce your own perspective and concerns into the discussion; at the same time, however, you should not think that more participation is always better. Ideal class participation involves not only being willing and able to contribute; it also involves being respectful of others’ time and interests, being aware of what concerns are already under discussion and unresolved at any particular point, and being aware of those occasions when a particular topic or thread that interests you would be more appropriately pursued later or outside of class.

standing policies:

my grading scale:

At the end of the course, I'll give you a grade between A and F. The grades A, B, C, and D are given specific interpretations in KU's University Senate Rules and Regulations, which I adhere to. Article 2 of those rules and regulations – "Academic Work and Its Evaluation" – contains a section called "The Grading System" (at <http://policy.ku.edu/governance/USRR#art2sect2>), which says that an A should be given for achievement of outstanding quality, a B for achievement of high quality, a C for achievement of acceptable quality, and a D for achievement that is minimally passing, but of less than acceptable quality.

What letter grade I give you will depend on the final average of the scores you get on the various assignments in the course. I'll use the following scale to convert your final average to a letter grade. (For an explanation of how I arrived at these numbers, see the "Plus/Minus Grading" document on my website.)

<u>final average</u>	<u>letter grade</u>
93.50 and above	A
90.00 through 93.49	A–
86.50 through 89.99	B+
83.50 through 86.49	B
80.00 through 83.49	B–
76.50 through 79.99	C+
73.50 through 76.49	C
70.00 through 73.49	C–
66.50 through 69.99	D+
63.50 through 66.49	D
60.00 through 63.49	D–
59.99 and below	F

Many (if not all) assignments will be graded numerically, rather than with letter grades, and you can also use this scale to interpret the numerical scores you get in this course during the semester.

disability accommodation:

If you have a disability for which you may be requesting special services or accommodations for this course, be sure to contact the Academic Achievement and Access Center (AAAC), at 22 Strong Hall or at 864-2620 (V/TTY), if you have not already done so, and give me a letter from that office documenting the accommodations to which you are entitled. Please also see me privately, at your earliest convenience, so that I can be aware of your situation and can begin to prepare the appropriate accommodations in advance of receiving that letter. For more information, see <http://access.ku.edu>.

academic misconduct:

I take academic misconduct, especially cheating on tests and plagiarizing papers, extremely seriously, and am generally disposed to impose the harshest available penalties when it occurs. KU's policy on academic integrity is in article 2, section 6 of the University Senate Rules and Regulations (<http://policy.ku.edu/governance/USRR#art2sect6>).

commercial note-taking:

Pursuant to the Provost's Statement on Commercial Note-Taking Ventures (<http://policy.ku.edu/provost/commercial-note-taking>), commercial note-taking is not permitted in this course. Lecture notes may be taken for personal use, for the purpose of mastering the course material, but may not be sold to any person or entity in any form. Any student engaged in or contributing to the commercial exchange of notes or course materials will be subject to discipline, including academic misconduct charges. This policy does not prohibit note-taking provided by a student volunteer for a student with a disability, as a reasonable disability accommodation.

course materials and resources:

textbook:

ORI Introduction to the Responsible Conduct of Research, updated edition, by Nicholas H. Steneck (Office of Research Integrity, Department of Health and Human Services, 2007)

I have asked the KU bookstore to stock this book; and as of the writing of this syllabus, it is available for purchase at the U.S. Government Bookstore, at

<http://bookstore.gpo.gov/products/sku/017-023-00214-7>

and can be downloaded as a PDF file from

<http://ori.hhs.gov/sites/default/files/rcrintro.pdf>

Also, I have put that PDF file in the “Course Documents” section of the course Blackboard site.

course materials on the web:

Some course documents, including this syllabus, will be available on the website for the course, the URL of which is

<http://www.benegg.net/courses/esr8>

(If you don't want to type in this whole thing, you can stop after 'net' – at which point you'll be at my personal website – and then follow the links to the website for this particular course.)

Most of the readings mentioned below – every one for which URLs are not provided (and many for which they are) – will be provided on the course Blackboard site. The ones provided there are marked below with '(Bb)'.

email distribution list:

I've set up an email distribution list for the course. In general, I'll try to mention everything important (whether substantive or procedural) in class. But at times, I may use the email distribution list to send you information that you will be responsible for having or acting on, so it is your responsibility to make sure that you read mail that I send to this list. You can do this by making sure that you (1) check the email account that goes with the email address that you have on record with KU and (2) are registered for the course (because this list is updated every night to reflect current enrollment, taking account of drops and adds).

I've had the list set up so that not only I, but also you, can use it, so that you can communicate with everyone in the class (including me) whenever you have a reason to do so. Here is its address:

phil500_etc{62466_etc}sp17@ku.edu

Note that sending a message to this address is not sufficient for KU's distribution-list service to send that message to everyone on the distribution list. The message must also come from an approved account or, at least, an approved “From:” address. This could be relevant if you send the message from an email account other than the one you have in KU's Outlook system. For more information about this issue, see section 1 of the following web page:

<http://technology.ku.edu/how-use-ku-group-lists-distribute-email>.

Schedule:

Introduction

January 23 introduction to course

reading before class:

(none)

in-class handouts:

Robert Service, “A Dark Tale Behind Two Retractions”
(*Science* vol. 326, no. 5960 [December 18, 2009], pp. 1610–1611;
<http://dx.doi.org/10.1126/science.326.5960.1610>) (Bb)

Nancy E. Levinger and Ellen R. Fisher, “Responsible Researchers Required”
(*Science* vol. 327, no. 5968 [February 19, 2010], pp. 957–958;
<http://dx.doi.org/10.1126/science.327.5968.957-b>) (Bb)

January 30 introduction to research ethics

reading before class:

Steneck, introduction to part I, “Shared Values” (pp. 2–3)

Steneck, chapter 1, “Rules of the Road” (pp. 4–17)

Steneck, part V, “Safe Driving and Responsible Research” (pp. 158–164)

Steneck, chapter 2, “Research Misconduct” (pp. 18–29)

University of Kansas University Senate Rules and Regulations article IX, “Guidelines for Dealing with Allegations of Scholarly Misconduct,” section 1, “General Provisions” (<http://policy.ku.edu/governance/USRR#art9sect1>)

paper topics:

4. In the introduction to part I and then again in part V, Steneck singles out the values of honesty, accuracy, efficiency, and impartiality. What is the difference between honesty and accuracy? Is it possible to fall short with regard to one of these values while effectively fulfilling the other?
5. In chapter 2, Steneck notes that a particular institution’s definition of research misconduct may include practices other than fabrication, falsification, and plagiarism (pp. 23–24). In looking at KU’s definition of scholarly misconduct in light of Steneck’s remarks, is it a narrow definition of scholarly misconduct or a broad one? In your opinion, what aspects of KU’s definition of scholarly misconduct are commendable or objectionable?

in-class handouts:

C. K. Gunsalus, “How to Blow the Whistle and Still Have a Career Afterwards” (*Science and Engineering Ethics* vol. 4, no. 1 [March 1998], pp. 51–64; <http://dx.doi.org/10.1007/s11948-998-0007-0>) (Bb)

Fabrication, Falsification, and Plagiarism

February 6

reading before class:

Charlotte Bronson, “What is Plagiarism?” (*Bioethics in Brief* vol. 1, no. 2 [November 1999], http://www.biotech.iastate.edu/publications/bioethics_outreach/Bioethics_in_Brief/nov_99.html) (Bb)

paper topic:

6. In the plagiarism exercise by Charlotte Bronson, which of the eight statements do you think is (a) the worst failure to give proper credit, (b) the best instance of giving proper credit, and (c) the most debatable case? Explain your reasons in all three cases – that is, identify the characteristics of the statement that make it a good answer for category a, b, or c.

in-class video:

Mark S. Frankel, American Association for the Advancement of Science, “Noah’s Dilemma”

in-class handouts:

Donald Kennedy, “Editorial Retraction” (of articles about cloning of stem cells) (*Science* vol. 311, no. 5759 [January 20, 2006], p. 335; <http://dx.doi.org/10.1126/science.1124926>) (Bb)

Mike Rossner and Kenneth M. Yamada, “What’s in a Picture? The Temptation of Image Manipulation” (*The Journal of Cell Biology*, vol. 166, no. 1 [July 5, 2004], pp. 11–15; <http://dx.doi.org/10.1083/jcb.200406019>) (Bb)

John Dahlberg, “Findings of Research Misconduct” (case of Gerald Lushington) (*Federal Register* vol. 76, no. 247 [December 23, 2011], pp. 80371–80372) (Bb)

John Dahlberg, “Findings of Research Misconduct” (case of Mahesh Visvanathan) (*Federal Register* vol. 77, no. 1 [January 3, 2012], p. 125) (Bb)

Eugenie Samuel Reich, “US Authorities Crack Down on Plagiarism” (*Nature*, January 11, 2012; <http://dx.doi.org/10.1038/nature.2012.9776>) (Bb)

Conflicts of Interest

February 13 overview

reading before class:

Steneck, introduction to part II, “Planning Research” (pp. 32–33)

Steneck, chapter 5, “Conflicts of Interest” (pp. 66–81)

Paul Basken, “Ethicists Prod NIH to Spend Money Investigating Conflicts of Interest” (*Chronicle of Higher Education*, November 17, 2009) (Bb)

Jocelyn Kaiser, “Lowering the Boom on Financial Conflicts” (*Science* vol. 328, no. 5982 [May 28, 2010], p. 1091; <http://dx.doi.org/10.1126/science.328.5982.1091>) (Bb)

Paul Basken, “Obama Tightens Rules on Financial Conflicts of Interest in Science” (*Chronicle of Higher Education*, August 23, 2011) (Bb)

paper topics:

7. Would any of the career paths you are considering be likely to confront you with conflicts of interest? How might you deal with them in order to avoid acting unethically?
8. Can you think of an example (not from a case discussed in this course) in which a person acted in disregard of a conflict of interest? How would you evaluate that person’s behavior in light of the considerations discussed in this chapter?
9. Disclosing one’s conflict of interest is generally seen as the most important step to take in order to appropriately deal with a conflict of interest when it cannot be avoided beforehand. Why is this considered important? What is accomplished by such disclosure?

February 20 cases

reading before class:

Daniel E. Koshland, Jr., “Editorial: Conflict of Interest Policy” (*Science* vol. 257, no. 5070 [July 31, 1992], p. 595; <http://dx.doi.org/10.1126/science.1496363>; also <http://www.jstor.org/stable/2877451>) (Bb)

Marcia Barinaga, “Confusion on the Cutting Edge” (*Science* vol. 257, no. 5070 [July 31, 1992], pp. 616–619; <http://dx.doi.org/10.1126/science.1496372>; also <http://www.jstor.org/stable/2877472>) (Bb)

Eliot Marshall, “When Does Intellectual Passion Become Conflict of Interest?” (*Science* vol. 257, no. 5070 [July 31, 1992], pp. 620–624; <http://dx.doi.org/10.1126/science.1496373>; also <http://www.jstor.org/stable/2877473>) (Bb)

“Conflicting Views: The Readers Respond”
(*Science* vol. 257, no. 5070 [July 31, 1992], p. 625; included after last page of Marshall article) (Bb)

“*Science* /AAAS Authorship Form and Statement of Conflicts of Interest”
(<http://www.sciencemag.org/site/feature/contribinfo/prep/coi.pdf>) (Bb)

paper topics:

10. Barinaga’s article describes some of the early conflict-of-interest issues that journals faced. What were the main issues that journals had to make policies to deal with?
11. Marshall’s article describes three cases of possible intellectual conflict of interest. Are any of the cases ones in which the researcher has such a strong commitment to his view that his objectivity is in doubt?
12. Choose question(s) 1, 2, 3, and/or 4 from the survey “Conflicting Views: The Readers Respond,” state what your answer would be, and explain why you would choose it over the other possible answers.
13. How has *Science* magazine’s handling of conflicts of interest changed between 1992 and the present? (You might discuss changes in policy and/or changes in information gathering.)

Data Management

February 27

reading before class:

Steneck, introduction to part III, “Conducting Research” (pp. 84–85)

Steneck, chapter 6, “Data Management Practices” (pp. 86–101)

Ralph J. Cicerone, “Ensuring Integrity in Science”
(*Science* vol. 327, no. 5966 [February 5, 2010], p. 624;
<http://dx.doi.org/10.1126/science.1187612>) (Bb)

paper topics:

14. When research at a university is funded by a federal grant, who typically owns the data thereby generated – the institution or the individual researcher(s)? What are the advantages and disadvantages of this arrangement?
15. On p. 87, Steneck presents a case study that ends with three questions. Answer these questions.
16. What are the main reasons for storing some data for as long as is feasible, and what are the main circumstances in which one might need to be sure to destroy some data within a specified period of time?

in-class video:

Mark S. Frankel, American Association for the Advancement of Science,
“Of Mice and Mendoza”

Mentor and Trainee Responsibilities

March 6

reading before class:

Steneck, chapter 7, “Mentor and Trainee Responsibilities” (pp. 102–115)

Michael Price, “Young Researchers Deserve More Support, Reviewers Say”
[*Science* vol. 336, no. 6088 [June 22, 2012], pp. 1489–1490;
<http://dx.doi.org/10.1126/science.336.6088.1489>] (Bb)

Adil E. Shamoo and David B. Resnik, *Responsible Conduct of Research*, 2nd ed.,
“Cases for Discussion,” pp. 78–79 (Bb)

paper topics:

17. Steneck presents several questions on p. 113. Answer question no. 2: “What are the qualities of a good mentor? A good trainee?”
18. Price describes two reports’ recommendations for changes to the way the U.S. government provides financial support for doctoral training. What are the most important of these recommendations? If they are implemented, what are the most important possible benefits and what are the most important possible costs or harms?
19. Shamoo and Resnik present four cases for discussion. Pick one of them and answer the question(s) stated at the end of it.

Collaborative Research

March 13

reading before class:

Steneck, chapter 8, “Collaborative Research” (pp. 116–127)

paper topics:

20. When a collaborative research project is beginning, what are some of the terms of the collaboration that should be agreed upon in advance?
21. What does Steneck mean when he writes, “when there are choices about appropriate action, select the most demanding option” (p. 123)? Using an example, explain this principle and show how it can be applied in practice.

in-class video:

Mark S. Frankel, American Association for the Advancement of Science,
“The Whole Truth”

March 20: no class (spring break)

Authorship and Publication

March 27

reading before class:

Steneck, introduction to part IV, “Reporting and Reviewing Research” (pp. 130–131)

Steneck, chapter 9, “Authorship and Publication” (pp. 132–145)

Philip Greenland and Phil B. Fontanarosa, “Ending Honorary Authorship”
(*Science* vol. 337, no. 6098 [August 31, 2012], p. 1019;
<http://dx.doi.org/10.1126/science.1224988>) (Bb)

Tom Jefferson, “Redundant Publication in Biomedical Sciences: Scientific
Misconduct or Necessity?” (*Science and Engineering Ethics* vol. 4, no. 2 [June 1998],
pp. 135–140; <http://dx.doi.org/10.1007/s11948-998-0043-9>) (Bb)

paper topics:

22. Why is it important whether someone is listed as an author of a paper or not?
23. What are the main forms of “redundant publication” that Jefferson discusses?
What are the ethical problems with these forms of redundant publication? Are
the ethical problems the same, and equally serious, for all of these forms of
redundant publication?

Peer Review

April 3

reading before class:

Steneck, chapter 10, “Peer Review” (pp. 146–157)

paper topics:

24. Steneck presents several questions on p. 155. Answer question no. 3: “Should
peer review be anonymous?”
25. On p. 147, Steneck presents a case study that ends with three questions. Answer
these questions.

in-class video:

Mark S. Frankel, American Association for the Advancement of Science,
“Only a Bridge”

Animal Experimentation

April 10 overview

reading before class:

Steneck, chapter 4, “The Welfare of Laboratory Animals” (pp. 50–65)

Paul Gazda, “I Was an Animal Experimenter” (*The New York Times*, April 15, 2015;
<https://opinionator.blogs.nytimes.com/2015/04/18/i-was-an-animal-experimenter/>) (Bb)

Jocelyn Kaiser, “An End to U.S. Chimp Research”
(*Science* vol. 350, no. 6264 [November 27, 2015], p. 1013;
<http://dx.doi.org/10.1126/science.350.6264.1013>) (Bb)

paper topics:

26. What is the scientific rationale for using animals in research? Why do some people object to using animals in research? How do you believe the reasons for and against can appropriately be weighed against each other in order to arrive at sound policies concerning this issue?
27. Steneck presents several questions on p. 63. Answer question no. 1: “Should all animals in research be treated the same or are there reasons to treat some animals differently than others?”

April 17 a philosophical perspective

reading before class:

Peter Singer, “All Animals Are Equal” (*Philosophic Exchange* vol. 1, no. 5
[Summer 1974], pp. 103–116) (Bb)

paper topics:

28. What does Singer mean by the claim (in the title of his paper) “All animals are equal”? (For example, does he mean that all animals are equally intelligent, or anything like that?) Does his view imply the immorality of all animal experimentation, or might it allow for some animal experimentation?
29. Singer criticizes both a perspective he calls “speciesism” and several views and practices that he regards as reflecting speciesism. Is he right that speciesism is unjustifiable, and is he right that it is reflected in many common views and practices?

Human Experimentation

April 24 overview

reading before class:

Tuskegee University, “About the USPHS Syphilis Study”
(http://www.tuskegee.edu/about_us/centers_of_excellence/bioethics_center/about_the_usphs_syphilis_study.aspx) (Bb)

Steneck, chapter 3, “The Protection of Human Subjects” (pp. 34–49)

paper topics:

30. The exposure of the Tuskegee syphilis study led to the development of many of the guidelines for experimentation on humans that Steneck describes. What were the ethical shortcomings of the Tuskegee syphilis study, and how do the guidelines that Steneck describes address those shortcomings?
31. Steneck presents several questions on p. 47. Answer question no. 4: “What other principles could be used for evaluating the ethics of human subjects besides respect for persons, beneficence, and justice?”
32. Steneck presents several questions on p. 47. Answer question no. 5: “Should subjects be allowed to enroll in experiments that either promise no direct benefit to them or cannot provide them with the opportunity to withdraw completely?”
33. On p. 46, Steneck describes an experiment in which researchers assessed the benefits of a common surgical procedure used to relieve arthritis pain. Based on Steneck’s description of the experiment, do you believe it was ethical? In your opinion, does the justifiability of the experiment depend on its apparently having successfully shown that the medical community had been mistaken about the benefits of the commonly performed procedure?
34. On p. 35, Steneck presents a case study that ends with three questions. Answer these questions.

in-class video:

clips from *Extreme Measures* (directed by Michael Apted, 1996)

May 1 current issues

reading before class:

Patrick Monahan, “Human embryo research confronts ethical ‘rule’ ”
(*Science* vol. 352, no. 6286 [May 6, 2016], p. 640;
<http://dx.doi.org/10.1126/science.352.6286.640>) (Bb)

Jocelyn Kaiser, “Researchers decry consent proposal”
(*Science* vol. 352, no. 6288 [May 20, 2016], pp. 878–879;
<http://dx.doi.org/10.1126/science.352.6288.878>) (Bb)

paper topics:

35. What are the ethical issues at stake in the debate over revising the so-called 14-day rule in order to allow further research on human embryos, and how do you evaluate the relative strengths of the competing reasons on the two sides of this debate?
36. What are the ethical issues at stake in the debate over requiring researchers to obtain patients' consent in order to use tissue samples for research, and how do you evaluate the relative strengths of the competing reasons on the two sides of this debate?

end-of-semester information:

The papers and quizzes are the only written assignments in the course. There is no final exam.

If you would like to retrieve any work that you have turned in, but have not yet had returned to you, please retrieve it by May 31, 2018. After that date, I may discard unclaimed work from this semester.

Additional Resources:

The Island, a 2005 movie directed by Michael Bay and starring Scarlett Johansson and Ewan McGregor. Internet Movie Database summary: "A man goes on the run after he discovers that he is actually a "harvestable being", and is being kept as a source of replacement parts, along with others, in a Utopian facility."

Never Let Me Go, a 2005 novel by Kazuo Ishiguro. See summary of movie, below.

Never Let Me Go, a 2010 movie based on the novel, directed by Mark Romanek, and starring Keira Knightley and Carey Mulligan. Internet Movie Database summary: "As children, Ruth, Kathy and Tommy, spend their childhood at a seemingly idyllic English boarding school. As they grow into young adults, they find that they have to come to terms with the strength of the love they feel for each other, while preparing themselves for the haunting reality that awaits them."

The Immortal Life of Henrietta Lacks, by Rebecca Skloot (Crown, 2010). From Amazon.com: "Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor Southern tobacco farmer who worked the same land as her slave ancestors, yet her cells—taken without her knowledge—became one of the most important tools in medicine. The first "immortal" human cells grown in culture, they are still alive today, though she has been dead for more than sixty years. If you could pile all HeLa cells ever grown onto a scale, they'd weigh more than 50 million metric tons—as much as a hundred Empire State Buildings. HeLa cells were vital for developing the polio vaccine; uncovered secrets of cancer, viruses, and the atom bomb's effects; helped lead to important advances like in vitro fertilization, cloning, and gene mapping; and have been bought and sold by the billions. . . . Now Rebecca Skloot takes us on an extraordinary journey, from the "colored" ward of Johns Hopkins Hospital in the 1950s to stark white laboratories with freezers full of HeLa cells; from Henrietta's small, dying hometown of Clover, Virginia—a land of wooden slave quarters, faith healings, and voodoo—to East Baltimore today, where her children and grandchildren live and struggle with the legacy of her cells."

Behind Closed Doors: IRBs and the Making of Ethical Research, by Laura Stark (University of Chicago Press, 2012). From Amazon.com: “Although the subject of federally mandated Institutional Review Boards (IRBs) has been extensively debated, we actually do not know much about what takes place when they convene. The story of how IRBs work today is a story about their past as well as their present, and *Behind Closed Doors* is the first book to meld firsthand observations of IRB meetings with the history of how rules for the treatment of human subjects were formalized in the United States in the decades after World War II.”