

Bioethics: Regulating Right and Wrong (PHIL 209A)
Syllabus, Spring 2016
MW 9:30-10:20; Tydings 2106 and Friday Discussion

Instructor: Kelsey Gipe Skinner 1121 kgipe@umd.edu Office hours: Wed. 1:15-3:15pm	Teaching Assistant: Javiera Perez-Gomez Skinner 1108A jmpg@umd.edu Office hours: Tu/Th 10:30-11:30am
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Bioethicists help to formulate ethical guidelines for medical professionals and the public. These guidelines answer questions such as the following: When life-saving health resources are scarce, how should we decide who gets them? If drug trials in the developing world are beneficial to patients who consent to participate, may we conclude that the trials are ethical, even if the same research would be forbidden in the US? Should patients be able to receive physician assisted suicide? If so, what should be the conditions on eligibility? What rules should govern the release of incidental findings to subjects of genetic and genomic research?

Ethical guidelines pertinent to questions like these can be found in documents such as the World Medical Association's "Declaration of Helsinki" and the World Health Organization's "Guiding Principles on Human Cell, Tissue, and Organ Transplantation." Such guidelines often change over time as a result, for example, of the emergence of new technologies or the discovery of morally problematic dimensions of longstanding practices. This course involves students in the project of constructing and defending ethical rules for four particularly dynamic domains in medicine and health: research ethics, allocation of scarce resources, physician assisted suicide, and challenges in genetic and genomic research.

By the end of this course students can expect to be able to:

- Select and critically evaluate literature relevant to the practice of bioethics in the four domains of research ethics, allocation of scarce resources, physician assisted suicide, and challenges in genetic and genomic research.
- Apply, in a way authentic to the practice of bioethics, its methods, including that of constructing moral arguments, to produce an amendment to actual or proposed ethical rules in one of these domains.
- Critique, revise, and refine such an amendment in the way bioethicists do.
- With the help of visual aids, effectively communicate in an oral presentation a proposal for a change to actual or recommended ethical guidelines in these domains.
- Collaborate with others in order to construct a plausible proposal for such a change.
- Demonstrate an ability to grasp and criticize moral arguments regarding research ethics, allocation of scarce resources, physician assisted suicide, and challenges in genetic and genomic research.
- Demonstrate familiarity and facility with fundamental concepts in bioethics, especially

concepts salient to these four domains.

Texts:

All readings are available as PDF files on the ELMS site for this course. (Login at <http://www.elms.umd.edu/>.) There is no textbook. Scheduled readings might change as the course progresses. Changes will be announced. Please consult ELMS regularly **and make sure your Canvas settings enable you to receive announcements.**

Discussion sections:

They are an integral part of this course. You are expected to attend them.

Requirements:

Three exams, two short papers, one group paper/presentation, and participation.

exam 1	on research ethics	15% of grade	Feb. 22
exam 2	on allocation of scarce, life-saving resources	15% of grade	March 23
final	on physician assisted suicide and on challenges in genetic and genomic research	20% of grade	May 18
2 short papers	on material from 2 different parts of course, including one that is the focus of your group paper/presentation	15% of grade	Turn in paper on two of these dates: Feb. 17, March 9, April 18, May 2
group paper/presentation	on material from one part of course	25% of grade	Present on one of the dates specified in the schedule
effective participation	in own group project and critique of others' projects	10% of grade	Based on peer evaluation of performance in own group project and instructor evaluation of performance in critique of others' projects

Regarding exams:

Approximately 5 days before each exam, I will hand out a list of questions. The questions will require you to summarize, compare, and criticize central ethical arguments or positions defended in readings for the particular part of the course the exam addresses (e.g., the questions handed out before the final will have to do with readings on organ donation/sales and on human enhancement). The actual exam will consist of questions I select from that list. Exams will be open book. But you will not be permitted to use notes. You will be permitted to

make up a missed exam only if you provide me with a university-approved excuse for your absence.

Short papers:

You are required to turn in a short paper (300-600 words) on two of the four dates: Feb. 17, March 9, April 18, May 2. You must turn in one short paper devoted to material in the same part of the course as your group paper/presentation. You should think of this paper as a preliminary step towards successful completion of the group project. In each short paper, you must summarize and criticize an *ethical* position or argument manifest in one of our readings in that particular section of the course. So, for example, if you turn in a short paper on research ethics, you might criticize an ethical position taken in the Declaration of Helsinki. Late papers will be accepted, but they will be penalized 1 full grade per day they are late. Only a university-approved excuse will free you from this penalty.

Group paper/presentations:

In discussion sections, students will be divided into groups of 4 or 5 students. Each group will work on a project focused on one part (and only one part) of the course. Each group will draft a paper (1,000-2,000) words regarding one of the areas explored in the course. In particular:

- Papers regarding Part 1 (research ethics) must propose, explain, and justify a significant departure from an ethical position contained in the Declaration of Helsinki or the WHO's "Ethical considerations for use of unregistered interventions for Ebola viral disease."
- Papers regarding Part 2 (allocation of scarce, life-saving resources) must propose, explain, and justify a significant departure from cost-effectiveness-based prioritization of health resource allocation or Persad, Wertheimer, and Emanuel's "Principles for Allocation of Scarce Medical Interventions."
- Papers regarding Part 3 (physician assisted suicide) must propose, explain, and justify a significant departure from an ethical position in Dworkin et al.'s "Assisted Suicide: The Philosophers' Brief" or Eijnden and Martinovici's "Neonatal euthanasia: A claim for an immoral law."
- Papers regarding Part 4 (challenges in genetic and genomic testing) must either propose, explain, and justify an ethical departure from one of the models of consent put forward in Applebaum et al.'s "Models of Consent to Return of Incidental Findings in Genomic Research" (this may **not** just amount to one of the criticisms Applebaum et al. discuss) or propose and defend a set of conditions for an improved model of consent to return of incidental findings in genomic research.

Each group will give a 20-minute PowerPoint-style presentation, based on its draft paper, in discussion section. Other students in the section will pose questions regarding the presentation. Based on this feedback, as well as feedback from the instructor(s), students will revise their drafts. Final versions of group papers will be due 11 days after group presentations (at the beginning of lecture on Tuesday).

Academic integrity:

The University of Maryland Honor Pledge reads: "I pledge on my honor that I have not given or received any unauthorized assistance on this assignment/examination." The Pledge statement should be handwritten and signed on the front of your papers and exams. Students who fail to write and sign the Pledge will be asked to confer with the instructor. The Code of Academic Integrity identifies four types of academic dishonesty: cheating, fabrication, facilitating academic dishonesty, and plagiarism. It is your responsibility to understand what constitutes dishonesty of these four types. Please consult the Code of Academic Integrity <http://www.president.umd.edu/policies/iii100a.html> or speak with the instructor if you would like any further clarification (e.g., on what constitutes plagiarism). Incidents of academic dishonesty will be taken very seriously. Any cases of it will be forwarded to the Student Honor Council.

Policy on Electronic Devices

No use of electronic devices (e.g., computers, phones, tablets) will be permitted in class, unless a documented disability renders their use necessary.

Grading:

Your final grade will depend on the percentage you earn of the total points possible in the class: A+: 97-100; A: 94-96; A-: 90-93; B+: 87-89; B: 84-86; B-: 80-83; C+: 77-79; C: 74-76; C-: 70-73; D+: 67-69; D: 64-66; D-: 60-63. **There will be no opportunities for extra credit.** Failure to complete an assignment will result in your receiving no points (a zero) for that assignment.

Policy on Medically Necessitated Absence from Class

- I will accept as an excused absence a self-signed note from a student who has missed a single class session, attesting to the date of an injury/illness. The note must contain an acknowledgement by the student that the information is true and correct and that providing false information is prohibited under Code of Student Conduct.
- A student who experiences a prolonged absence, namely, either three or more class sessions consecutively, four or more sessions non-consecutively, or an injury/illness preventing participation in a Major Scheduled Grading Event is required to provide written documentation of the illness from the Health Center or an outside health care provider, verifying the dates of treatment and the time period during which the student was unable to meet academic responsibilities.
- Major Scheduled Grading Events will be: exams and group presentations.

Copyright notice: Class lectures and other materials are copyrighted and they may not be reproduced for anything other than personal use without written permission from the instructor.

Emergency protocol: If the university is closed for an extended period of time, instruction will continue via Canvas.

This syllabus is subject to change: Students will be notified in advance of important changes that could affect grading, assignments, etc.

Religious Observances: You will not be penalized for any absence that results from religious observance. However, it is your responsibility to notify the instructor within the first 3 weeks of class regarding any religious observance absence(s) for the entire semester.

Students with Disabilities: The University of Maryland is committed to providing appropriate accommodations for students with disabilities. Students with a documented disability should inform the instructors within the add-drop period if academic accommodations are needed. To obtain an Accommodation Letter prepared by Disability Support Service (DSS), a division of the University Counseling Center, please call 301-314-7682, e-mail dissup@umd.edu, or visit the Shoemaker Building for more information.

Readings: All readings will be made available on the Canvas site for this course.

Schedule:

(Readings might be altered as the course progresses. If there are any changes, they will be announced.)

Jan. 25	[Snow Day : No Class]
Part I	Research Ethics
Jan. 27	Introduction
Feb. 1	Jones, "The Tuskegee Syphilis Experiment"; Annas and Grodin, "The Nuremberg Code"; Jonas, "Philosophical Reflections on Experimenting with Human Subjects"
Feb. 3	Declaration of Helsinki; Porter and Koski "Regulations for the Protection of Humans in Research in the United States" 156-159; Hawkins, "Brief Background to Clinical Research Ethics"
Feb. 8	Mellow and Wolf, "The Havasupai Indian Tribe Case"; Truog et al., "Is Informed Consent Always Necessary for Randomized, Controlled Trials?"
Feb. 10	Lurie and Wolfe, "Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries"
Friday, Feb. 13	presentations on research ethics
Feb. 16	Hawkins, "Case Studies: The Havrix Trial and the Surfaxin Trial"
Feb. 18 Short Paper Accepted	WHO: "Ethical considerations for use of unregistered interventions for Ebola viral disease"; Rid and Emanuel: "Ethical considerations of experimental interventions in the Ebola outbreak"
Friday, Feb 20	presentations on research ethics
Feb. 23	exam 1: on research ethics
Part II	Allocation of Scarce Life-Saving Resources Allocation of Scarce Life-Saving Resources
Feb. 25	Alexander, "They Decide Who Lives, Who Dies" Truog, "Four Babies and Three Machines: Rationing at the Bedside."
March 1	Bognar and Hirose: <i>The Ethics of Health Care Rationing</i> , Chapters 2 and 3
March 3	Harris, "QALYfying the Value of Life"
March 8	Singer et al., "Double Jeopardy and the Use of QALYs in Health Care Allocation"
March 10 Short Paper Accepted	Kamm: "Aggregation, Allocating Scarce Resources, and the Disabled" You are responsible only for 148-169.
Friday, March 11	presentations on resource allocation
Spring Break	
March 22	Persad, Wertheimer, Emanuel: "Principles for Allocation of Scarce Medical Interventions"
March 24	exam 2: on resource allocation
Friday, March 25	presentations on resource allocation

Part III	Physician Assisted Suicide
March 29	Dworkin et al., "Assisted Suicide: The Philosophers' Brief"
March 31	McMahan: "Killing, Letting Die, and Withdrawing Aid"
April 5	Brock: "Voluntary Active Euthanasia"
April 7	Van der Heide: "End-of-Life Practices in the Netherlands under the Euthanasia Act" ; Bilsen et al., "Medical End-of-Life Practices under the Euthanasia Law in Belgium"
Friday, April 8	presentations on physician assisted suicide
April 12	"Oregon's Death with Dignity Act"
April 14	Hartocollis: "Hard Choice for a Comfortable Death: Sedation"
Friday, April 15	presentations on physician assisted suicide
April 19 Short Paper Accepted	Eijnden & Martinovici: "Neonatal Euthanasia: A claim for an immoral law"
Part IV	Challenges in Genetic and Genomic Research
April 21	Green et al., "Charting a course for genomic medicine from base pairs to bedside" ; Cho: "Understanding Incidental Findings in the Context of Genetics and Genomics"
April 26	McGuire et al., "Research ethics and the challenge of whole-genome sequencing" ; Lunshof et al., "From genetic privacy to open consent"
April 28	Applebaum et al., "Models of Consent to Return of Incidental Findings in Genomic Research"
Friday, April 29	presentations on challenges in genetic & genomic research
May 3 Short Paper Accepted	Deschenes et al., "Human genetic research, DNA banking and consent: a question of 'form'?"
May 5	<i>Pediatrics</i> 2013: "Ethical and Policy Issues in Genetic Testing and Screening of Children"
Friday, May 6	presentations on challenges in genetic & genomic research
May 10	review for final
May 13 8-10:00 AM	final exam