

Milken Institute School of Public Health

THE GEORGE WASHINGTON UNIVERSITY

Department of Health Policy and

HSML 6254, Spring 2018

Ethics in Health Services Management, 2 credit hours

Wednesday, 2:10-4:00pm, GWSPH 700B

Residential Graduate Course

Instructor

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Office Hours: By appointment. Please e-mail to schedule a meeting.

Course Description Advances in science and technology make ethics in the biomedical arena a continuing matter of concern for students, health professionals, and laypersons alike. This course offers an opportunity to investigate general and specific ethical questions and ethical decision making from both a personal and organizational perspective, including topics such as the right to health care, research with human subjects, reproductive technology, genetics, professional roles and responsibilities, and end-of-life issues. Such investigation requires exposure to complex questions and to varying attempts to address and resolve them. The course requires participation in group discussions, small-group projects, and independent critical writing.

Course Prerequisite(s): None

Course Competencies (corresponds to MHA competency grid)

1. Communication and Relationship Management – writing skills
2. Communication and Relationship Management – presentation skills
3. Communication and Relationship Management – working in teams
4. Business Skills and Knowledge – systems thinking
5. Professionalism – professional and managerial ethics
6. Healthcare Knowledge – standards and regulations

Course Learning Objectives – Upon completion of the course, students will be able to:	Meets Competency Number
• Describe basic ethical theories, traditions, and perspectives	# 1, 2, 3, and 5
• Participate in informed discussions, debate, and analytical writing regarding issues in ethics and health services management	# 1, 2, 3, 5, and 6
• Develop and exercise the capacity for ethical reasoning and critical writing	# 1, 2, 3, 4, and 5
• Develop positions on the topics discussed and be able to relate them to ethical theories, traditions, and perspectives	# 1, 2, 3, 4, and 5
• Identify ethical issues as well as varying approaches to resolving them in practical settings	# 1, 2, 3, 4, 5, and 6

Required Texts

(Readings should be completed before coming to class!)

Title	Author	Edition
Bioethics: Principles, Issues, and Cases ("Text")	Vaughn, L.	3d ed., Oxford University Press (2017)
Law, Science and Medicine ("Gostin") NOTE: Gostin readings are provided via links posted on Blackboard	Gostin, et al.	3d ed., Foundation Press (2005)
Supplemental Readings on Blackboard or distributed in class		

Methods of Instruction (check all that apply)

<input checked="" type="checkbox"/> Lectures	<input checked="" type="checkbox"/> Class and Small Group Discussions
<input checked="" type="checkbox"/> Case Studies	<input checked="" type="checkbox"/> Student Presentations
<input checked="" type="checkbox"/> Required Readings/Textbook	<input checked="" type="checkbox"/> Student-led Discussions
<input checked="" type="checkbox"/> Required Supplemental Readings	

Methods of Evaluation

Percent of Grade

Class Participation [Includes attendance, careful preparation, thoughtful contributions to discussion, and leadership in discussion question assignments]	30%
Individual Papers	35%
Small Group Project	35%

Students will be graded on their class participation, a small group assignment, and substantive writings.

Grading Scale and Standards

A: 94-100%	C+: 77-79%
A-: 90-93%	C: 73-76%
B+: 87-89%	C-: 70-72%
B: 84-86%	F: Below 70%
B-: 80-83%	

Workload:

In this course, you will be expected to spend approximately 4-6 hours per week in independent learning, which can include reviewing assigned material, preparing for class discussions, working on assignments, and group work. In addition, you will spend an average of 2 hours per week in direct instruction.

Class Policy: Expectations for individual contributions and acceptable levels of collaboration for assignments on which students may work together

Collaboration among students outside of class is strongly encouraged. Individual assignments must be written independently, although it is acceptable to seek the opinions of others on drafts. Group participation is required for the small group assignment (as described below). Comprehensive academic research in peer-reviewed sources and rigorous citation of all sources will be expected in all written work. These guidelines will be discussed in more detail in class.

Class Policy: Attendance, Participation, and Discussion

Class attendance is mandatory. Class discussions showing careful preparation, rigorous thought, and an informed understanding of the subject matter will be an integral part of the learning process. *Please read and analyze all of the assigned materials before class to facilitate discussions.* All students will be expected to participate actively in class discussions. Students will also be expected occasionally to lead

discussion on discussion question assignments. **Absences will only be excused in extraordinary circumstances and must be discussed with me prior to class.**

Ethics is a demanding discipline that requires students to think critically and utilize high-level analytical skills regarding complex issues. The discipline requires such mastery not only in well-articulated written work, but also in thoughtful discussions between and among students and instructors. Receiving full points for participation is not simply a matter of showing up and turning work in on time. Outstanding participation grades require truly thoughtful, insightful, and well-argued contributions and leadership in class that demonstrate a high level of mastery of the course material.

Class Policy: Use of laptop computers/Internet/mobile phones/tablets/electronic devices. Laptop computers/tablets may be used in class only for taking notes with wifi disabled. The Internet, mobile phones, or any other electronic communication device should not be used during class except in the case of an emergency. The instructor reserves the right to ban the use of electronic devices altogether if these guidelines are not followed.

Class Policy: Assignments.

- **Class Participation. Regular attendance at lectures and discussions, constructive participation, and 1-2 proposed written discussion questions posted on the class blog 24 hours in advance of class. 30%**
- **Individual Papers. Each week, students will turn in either a reflection paper or a short institutional policy memorandum. 35%** The papers will take the following form:
 - **2-3 pages of “reflection”** that demonstrate your engagement with the assigned readings for that week and reflection on the issues at hand. The reflection papers should be typed, double-spaced, in 12-point font with 1-inch margins, should include your name and page numbers, and are **due before class in the week the papers are due**. Instructor will provide more details regarding expectations for this assignment.
 - **A 2-3 page memorandum** briefly presenting the issues raised in the assigned readings for that week and recommending institutional policy regarding those issues for a health care delivery organization. The memoranda should be typed, double-spaced, in 12-point font with 1-inch margins, should include your name and page numbers, and are **due before class in the week the papers are due**. Instructor will provide more details regarding expectations for this assignment.
- **Group Case Analysis/Presentations.** Small groups will write and analyze a case based upon professional or personal experience (or from the literature) that contains both administrative and ethics issues. The group presentations will occur in class on **Wednesday, April 25, 2018** and written analyses will be due at the same time. Instructor will provide more details regarding expectations for this assignment. **35%**

Class Policy: Late Work

Students must meet the due dates for all assignments. **Extensions will be granted only in extraordinary circumstances and must be discussed with the professor in advance of the due date.** Grades for unexcused late assignments will be reduced one step for each day the assignment is late (A to A-, B+ to B, etc.).

Class Policy: Make-up Work

Any student who experiences significant family or personal illness or emergency after the final withdrawal date and is unable to complete course work should ask the instructor for an incomplete for the course. Each case will be managed on an individual basis.

University Policy on Religious Holidays

- Students should notify faculty during the first week of the semester of their intention to be absent from class on their day(s) of religious observance.

- Faculty should extend to these students the courtesy of absence without penalty on such occasions, including permission to make up examinations.
- Faculty who intend to observe a religious holiday should arrange at the beginning of the semester to reschedule missed classes or to make other provisions for their course-related activities.

Blackboard

Blackboard will be used for posting course files and assignments and for communicating with the class. You are already enrolled for this course on Blackboard if you have completed registration for the course. It is your responsibility to periodically check the course site (log in at <http://blackboard.gwu.edu/> Using your gwu.edu address) for updates to the syllabus/readings.

Academic Integrity

All Milken Institute School of Public Health Students are required to complete two (separate) online activities regarding academic integrity -- the GW Academic Integrity Activity and the Identifying and Avoiding Plagiarism Activity. Both activities must be completed within 2 weeks of starting your coursework at Milken Institute School of Public Health. - See more at: <https://publichealth.gwu.edu/integrity#sthash.FIIRdO5H.dpuf>

Academic dishonesty is defined as cheating of any kind, including misrepresenting one's own work, taking credit for the work of others without crediting them and without appropriate authorization, and the fabrication of information. Common examples of academically dishonest behavior include, but are not limited to, the following: cheating; fabrication; plagiarism; falsification and forgery of University academic documents; facilitating academic dishonesty. For the remainder of the code, see <https://studentconduct.gwu.edu/code-academic-integrity>. **There will be no exceptions to this policy.**

NOTE: Please type out and sign the following honor pledge at the end of each assignment:

“On my honor as a student of the George Washington University, I have neither given nor received assistance on this assignment.

[Signed: Your name]”

Support for Students Outside the Classroom

Disabilities Support Services (DSS)

Any student who may need an accommodation based on the potential impact of a disability, should contact the Disability Support Services office at 202.994.8250 in the Rome Hall, Suite 102, to establish eligibility and to coordinate reasonable accommodations. For additional information please refer to: <https://disabilitysupport.gwu.edu/>

Mental Health Services- 202-994-5300

The University's Mental Health Services offers 24/7 assistance and referral to address students' personal, social, career, and study skills problems. Services for students include: crisis and emergency mental health consultations, confidential assessment, counseling services (individual and small group), and referrals. <https://counselingcenter.gwu.edu/>

Adverse Weather/Class Cancellation

In the advent of inclement weather or any other emergency, the Milken Institute School of Public Health will follow the decision of the University. Call the University hotline at 202.994.5050 or check the Human Resources status button at <http://hr.gwu.edu/adverse-weather-conditions-and-emergency-situations>. In the event of class cancellation, we will email you about rescheduling, assignments due, etc.

Emergency Preparedness and Response Procedures

The University has asked all faculty to inform students of these procedures, prepared by the GW Office of Public Safety and Emergency Management in collaboration with the Office of the Executive Vice President for Academic Affairs.

To Report an Emergency or Suspicious Activity

Call the University Police Department at 202-994-6111 (Foggy Bottom) or 202-242-6111 (Mount Vernon).

Shelter in Place – General Guidance

Although it is unlikely that we will ever need to shelter in place, it is helpful to know what to do just in case. No matter where you are, the basic steps of shelter in place will generally remain the same.

- If you are inside, stay where you are unless the building you are in is affected. If it is affected, you should evacuate. If you are outdoors, proceed into the closest building or follow instructions from emergency personnel on the scene.
- Locate an interior room to shelter inside. If possible, it should be above ground level and have the fewest number of windows. If sheltering in a room with windows, move away from the windows. If there is a large group of people inside a particular building, several rooms may be necessary.
- Shut and lock all windows (for a tighter seal) and close exterior doors.
- Turn off air conditioners, heaters, and fans. Close vents to ventilation systems as you are able. (University staff will turn off ventilation systems as quickly as possible).
- Make a list of the people with you and ask someone to call the list in to UPD so they know where you are sheltering and who is with you. If only students are present, one of the students should call in the list.
- Await further instructions. If possible, visit GW Campus Advisories for incident updates (<http://CampusAdvisories.gwu.edu>) or call the GW Information Line 202-994-5050.
- Make yourself comfortable and look after one other. You will get word as soon as it is safe to come out.

Evacuation

An evacuation will be considered if the building we are in is affected or we must move to a location of greater safety. We will always evacuate if the fire alarm sounds. In the event of an evacuation, please gather your personal belongings quickly (purse, keys, GWorld card, etc.) and proceed to the nearest exit. Every classroom has a map at the door designating both the shortest egress and an alternate egress. Anyone who is physically unable to walk down the stairs should wait in the stairwell, *behind the closed doors*. Firemen will check the stairwells upon entering the building.

- Once you have evacuated the building, proceed to our primary rendezvous location: the courtyard area between the GW Hospital and Ross Hall. In the event that this location is unavailable, we will meet on the ground level of Science and Engineering Hall (SHE) (800 22nd Street NW). From our rendezvous location, we will await instructions to re-enter the School.
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Alert DC

Alert DC provides free notification by e-mail or text message during an emergency. Visit GW Campus Advisories for a link and instructions on how to sign up for alerts pertaining to GW. If you receive an Alert DC notification during class, you are encouraged to share the information immediately.

GW Alert

GW Alert provides popup notification to desktop and laptop computers during an emergency. In the event that we receive an alert to the computer in our classroom, we will follow the instructions given. You are also encouraged to download this application to your personal computer. Visit GW Campus Advisories to learn how.

Additional Information

Additional information about emergency preparedness and response at GW or the University's operating status can be found on GW Campus Advisories (<http://CampusAdvisories.gwu.edu>) or by calling the GW Information Line at 202-994-5050.

Session Outline	
Session 1	Wednesday/January 17
COURSE REVIEW/INTRODUCTION Introduction to Ethics	
Session 2	Wednesday/Jan. 24
MORAL REASONING IN BIOETHICS BIOETHICS AND MORAL THEORY Required Readings: Text, Chapters 1 and 2 Assignments: <ol style="list-style-type: none">1. Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.2. 2-3 pp. reflection paper that demonstrates your engagement with the assigned readings and reflection on the issues at hand due prior to class.	
Session 3	Wednesday/Jan. 31
PATERNALISM AND PATIENT AUTONOMY/TRUTH-TELLING AND CONFIDENTIALITY Required Readings: Text, Chapters 3 & 4 Assignments: <ol style="list-style-type: none">1. Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.2. 2-3 pp. reflection paper that demonstrates your engagement with the assigned readings and reflection on the issues at hand due prior to class.	

Session 4

Wednesday/Feb. 7

INFORMED CONSENT

Required Readings: Text, Chapter 5

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. reflection paper that demonstrates your engagement with the assigned readings and reflection on the issues at hand due prior to class.**

Session 5

Wednesday/Feb. 14

Defining Death

- a. Introduction to legal cases in bioethics.
- b. Legal/Medical/Ethical definitions of death.

Required Readings:

- 1) *State v. Guess*, 244 Conn. 761, 715 A.2d 643 (1998), plus notes, Gostin, pp. 976-981
- 2) Karen Grandstrand Gervais, *Advancing the Definition of Death: A Philosophical Essay*, plus notes, Gostin pp. 981-991
- 3) Curfman, G., Morrissey, S., & Drazen, J. (2008). Cardiac transplantation in infants. *The New England Journal Of Medicine*, 359(7), 749-750.
- 4) Boucek, M. M., Mashburn, C., Dunn, S. M., Frizell, R., Edwards, L., Pietra, B., & Campbell, D. (2008). Pediatric heart transplantation after declaration of cardiocirculatory death. *The New England Journal Of Medicine*, 359(7), 709-714.
- 5) Truog, R., & Miller, F. (2008). The dead donor rule and organ transplantation. *The New England Journal Of Medicine*, 359(7), 674-675.
- 6) Bernat, J. (2008). The boundaries of organ donation after circulatory death. *The New England Journal Of Medicine*, 359(7), 669-671.
- 7) Veatch, R. M. (2008). Donating hearts after cardiac death--reversing the irreversible. *The New England Journal Of Medicine*, 359(7), 672-673.
- 8) Kevin G. Munjal, Stephen P. Wall, Lewis R. Goldfrank, Alexander Gilbert, Bradley J. Kaufman, and Nancy N. Dubler, on behalf of the New York City uDCDD Study Group, "A Rationale in Support of Uncontrolled Donation after Circulatory Determination of Death," *Hastings Center Report*, 43, no. 1 (2013): 19-26.
- 9) Magnus, D. C., Wilfond, B. S., & Caplan, A. L. (2014). Accepting brain death. *The New England Journal Of Medicine*, 370(10), 891-894.

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

Withholding and Withdrawal of Life-Sustaining Treatment

- a. Decision-making competence.
- b. Surrogate decision-making.
- c. The “right” to die.
- d. Legal standards of review.

Required Readings:

- 1) *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990), plus notes, Gostin, pp. 1001-1017
- 2) The Multi-Society Task Force on PVS (1994). Medical Aspects of the Persistent Vegetative State *New England Journal Of Medicine*, 330, 1572-1579, plus correction, *New England Journal Of Medicine*, 333, 130
- 3) *In re Conroy*, plus notes, Gostin, pp. 1072-1081
- 4) Gostin, L.O. (2005). Ethics, the Constitution, and the dying process: the case of Theresa Marie Schiavo. *Journal of the American Medical Association*, 293(19): 2403-7.
- 5) Vegetative Patient Shows Signs of Awareness, Study Says, *The New York Times*, September 7, 2006
- 6) Spontaneous Movements Often Occur After Brain Death, *Science Daily*, Jan. 13, 2000
- 7) Wilkinson, D. J. (2011). A Life Worth Giving? The Threshold for Permissible Withdrawal of Life Support From Disabled Newborn Infants. *American Journal Of Bioethics*, 11(2), 20-32.
- 8) Pew Research Center. Living to 120 and beyond: Americans' views on aging, medical advance, and radical life extension. Washington, DC 2013.
- 9) Fewing, R., Kirk, T. W., & Meisel, A. (2014). A Fading Decision. *Hastings Center Report*, 44(3), 14-16.

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

Euthanasia and Physician-Assisted Suicide

- a. Euthanasia v. physician-assisted suicide: Legal distinctions.
- b. Statutory Law.
- c. Evolution of common law regarding the "right" to die and physician-assisted suicide.
- d. Euthanasia v. physician-assisted suicide: Ethical/moral distinctions.
- e. The role of trade organizations/medical societies.
- f. Policy v. law v. ethics/morals.

Required readings:

- 2) Gostin, L.O. (1997). Health law and ethics. Deciding life and death in the courtroom: from Quinlan to Cruzan, Glucksberg, and Vacco -- a brief history and analysis of constitutional protection of the 'right to die'. *Journal of The American Medical Association*, 278(18), 1523-1528.
- 3) Gostin, L.O. (2006). Physician-assisted suicide: a legitimate medical practice? *Journal of The American Medical Association*, 295(16), 1941-1943.
- 4) *Washington v. Glucksberg*, 521 U.S. 702 (1997), and *Vacco v. Quill*, 521 U.S. 793 (1997), Gostin pp. 1035- 1050
- 5) The Oregon Death with Dignity Act, Gostin, pp. 1050-1055
- 6) Current Annual Report on Oregon's Death with Dignity Act
- 7) Robinson, J. (2010). Baxter and the return of physician-assisted suicide. *Hastings Center Report*, 40(6), 15-17.
- 8) A piece of my mind. It's over, Debbie. (1988). *Journal of The American Medical Association*, 259(2), 272.
- 9) Quill, T. (1991). Death and dignity. A case of individualized decision making. *The New England Journal Of Medicine*, 324(10), 691-694.
- 10) Rachels, J. *Active and Passive Euthanasia*, plus notes, Gostin, pp. 1059-1062
- 11) Emanuel, E. J. (2016). Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. *Journal of The American Medical Association*, 316(1), 79-90.
- 12) American Medical Association, Council on Ethical and Judicial Affairs, Policies (Excerpt)

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

Maternal-Fetal Relations/Assisted Reproduction

- a. Ethical/social debates regarding maternal-fetal relations.
- b. Autonomous decision-making
- c. The meaning and interpretation of parental rights.
- d. Surrogate motherhood.
- e. Assisted reproduction

Required readings:

- 1) *In re A.C.*, 573 A.2d 1235 (D.C. 1990) (Excerpt)
- 2) *In re: Baby Boy Doe, A Fetus*, 260 Ill.App.3d 392, 198 Ill.Dec. 267, 632 N.E.2d 326 (1997), plus notes, Gostin, pp. 1226-1236
- 3) Rhoden, N. K. (1987). Cesareans and samaritans. *The Journal of Law, Medicine & Ethics*, 15, 118–125. (Excerpt)
- 4) Cantor, J. (2012). Court-ordered care--a complication of pregnancy to avoid. *The New England Journal Of Medicine*, 366(24), 2237-2240.
- 5) *Davis v. Davis*, 842 S.W.2d 588 (TN 1992), *cert. denied*, 507 U.S. 911, plus note, Gostin, pp. 1115- 1124
- 6) *In re Baby M*, 109 N.J. 396, 537 A.2d 1227 (1988), plus note, Gostin, pp. 1188-1198
- 7) Notes, Gostin, pp. 1209-1213
- 8) Purdy, L. M. (1989). Surrogate mothering: exploitation or empowerment?. *Bioethics*, 3,18–34. (Excerpt)
- 9) Cohen, I., & Adashi, E. (2013). Made-to-order embryos for sale--a brave new world?. *The New England Journal Of Medicine*, 368(26), 2517-2519.
- 10) Hookway, James. (2014). Thailand targets surrogacy practices amid scandals; government threatens to close door on major international hub for infertile couples. *Wall Street Journal* (Online), Aug 27, 2014.
- 11) Macer, D. (2014). Ethical conditions for transnational gestational surrogacy in Asia. *American Journal Of Bioethics*, 14(5), 1-2.

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

WEDNESDAY, MARCH 14: SPRING BREAK (NO CLASS)

Stem Cells & Cloning

- a. Review of bioethics advisory commissions' recommendations regarding cloning and research involving embryonic, induced pluripotent, and adult stem cells.
- b. Discussion of proper role of advisory commissions in public policy-making.
- c. Discussion of ethical/legal/policy debates regarding cloning and research involving stem cells.

Required Readings:

- 1) National Bioethics Advisory Commission, Cloning Human Beings, Executive Summary
- 2) Childress, J.F. (1997). The challenges of public ethics: reflections on NBAC's report. *Hastings Center Report*, 27(5), 9-11
- 3) President's Council on Bioethics, Human Cloning and Human Dignity, plus notes, Gostin, pp. 1213- 1222
- 4) Fletcher, J.C. (2000). The National Bioethics Advisory Commission's report on stem cell research: a review. *ASBH Exchange*.
- 5) Bush Vetoes Measure on Stem Cell Research, The New York Times, June 21, 2007
- 6) Executive Order 13505, March 9, 2009, Removing Barriers to Responsible Scientific Research Involving Human Stem Cells
- 7) 2009 Guidelines on Human Stem Cell Research. In *Stem Cell Information* [World Wide Web site]. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services, 2011.
- 8) Davis, D.S. (2013). Not with a bang, but a whimper: *Sherley v. Sebelius*. *Hastings Center Report* 43(1), 17-18.
- 9) Stein, R. Scientists report possibly crucial advance in human embryonic stem cell research, The Washington Post, Oct. 5, 2011
- 10) Baker, M. Stem Cells Made by Cloning Adult Humans, *Nature*, April 28, 2014.
- 11) With three first-in-human trials, therapeutic stem cell science takes a bold step, *ScienceDaily* (October 20, 2014).

Assignments:

- 1. Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
- 2. 2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

Genetics

- a. Discussion of ethical/moral/legal issues raised by advances in genetics.
- b. Discussion of privacy implications and recent legislation involving genetics.
- c. Discussion of ethics cases in genetics.

Required readings:

- 1) Gostin: Decoding the Structure of Life, Gostin, pp. 6-11; Katskee v. Blue Cross/Blue Shield, 245 Neb. 808, 515 N.W.2d 645 (1994), plus notes, Gostin, pp. 25-28; Genetic Enhancement, Gostin, pp. 39-46
- 2) Hudson, K., Holohan, M., & Collins, F. (2008). Keeping pace with the times--the Genetic Information Nondiscrimination Act of 2008. *The New England Journal Of Medicine*, 358(25), 2661-2663.
- 3) Genetics and Public Policy Center, The Genetic Information Nondiscrimination Act
- 4) Genetics and Public Policy Center, Information on The Genetic Information Nondiscrimination Act
- 5) Donley, et al. (2012). Prenatal whole genome sequencing: just because we can, should we? *Hastings Center Report*, 42(4), 28-40.
- 6) Parens, E., Appelbaum, P., & Chung, W. (2013). Incidental findings in the era of whole genome sequencing. *Hastings Center Report*, 43(4), 16-19.
- 7) Conley, J. (2013). Myriad, finally: Supreme Court surprises by not surprising. *Genomics Law Report*.
- 8) Presidential Commission for the Study of Bioethical Issues, Privacy and Progress in Whole Genome Sequencing, Executive Summary.
- 9) Belluck, P. In Breakthrough, Scientists Edit a Dangerous Mutation From Genes in Human Embryos. *The New York Times* (Aug. 2, 2017).
- 10) Cha, A.E. FDA cracks down on company marketing 'three-parent' babies. *Washington Post* (Aug. 8, 2017).
- 11) The National Academy of Sciences and National Academy of Medicine, Committee on Human Gene Editing: Scientific, Medical, and Ethical Considerations. *Human Genome Editing: Science, Ethics, and Governance*, Executive Summary

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

Research with Human Subjects

- a. The evolution of human subjects research policy
- b. The Nazi Experiments
- c. Tuskegee
- d. Informed consent in research trials
- e. Guidelines for international research trials
- f. Case studies in research with human subjects

Required Readings:

- 1) Overview and the Nazi War Crimes Trials, plus notes, Gostin, pp. 871-885
- 2) Henry Beecher, *Ethics and Clinical Research*, plus notes, Gostin, pp. 886-890
- 3) Testimony of Fred Gray, plus notes, Gostin, pp. 890-894
- 4) Patricia King, *The Dangers of Difference*, Gostin, pp. 894-898
- 5) *Government Regulations*, Gostin, pp. 904-907
- 6) Department of Health and Human Services, Regulations on Protection of Human Subjects, plus notes, Gostin, pp. 907-914
- 7) U.S. Department of Health and Human Services (Jan. 18, 2017), Final rule enhances protections for research participants, modernizes oversight system, available at: <https://www.hhs.gov/about/news/2017/01/18/final-rule-enhances-protections-research-participants-modernizes-oversight-system.html>
- 8) Federal Policy for the Protection of Human Subjects, Final Rule, Executive Summary, 82 Fed. Reg. 7149 (Jan. 19, 2017)
- 9) CIOMS, International Ethical Guidelines for Biomedical Research Involving Human Subjects, plus notes, Gostin, pp. 918-924
- 10) Lurie, P., & Wolfe, S. M. (1997). Unethical trials of interventions to reduce perinatal transmission of the human immunodeficiency virus in developing countries. *The New England Journal Of Medicine*, 337(12), 853-856.
- 11) Angell, M. (1997). The ethics of clinical research in the Third World. *The New England Journal Of Medicine*, 337(12), 847-849.
- 12) Levine, R. J. (1998). Editorial: The 'Best Proven Therapeutic Method' Standard in Clinical Trials in Technologically Developing Countries. *IRB: Ethics and Human Research*, 20(1), 5-9.
- 13) Bloom, B. R. (1998). The Highest Attainable Standard: Ethical Issues in AIDS Vaccines. *Science*, 279(5348), 186-188.
- 14) Lynch, H. (2012). Ethical Evasion Or Happenstance And Hubris? *Hastings Center Report*, 42(2), 30-38.
- 15) Hudson, K.L., & Collins, F.S. (2013). Family matters. *Nature*, 500(7461), 141-142

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. memorandum that briefly presents the issues raised in the assigned readings and recommends institutional policy for a health care delivery organization.**

Distributive Justice and the Allocation of Health Care Resources

- a. Theories of justice
- b. Legal rights and human rights
- c. Justice and health reform
- d. Rationing
- e. Futile Care
- f. Macroallocation & Microallocation
- g. Case study: Oregon Medicaid

Required Readings:

- 1) Social Justice, Gostin, pp. 633-636
- 2) Fried, C. (1976). Equality and rights in medical care, *Hastings Center Report*, 6(1), 29-34.
- 3) Daniels, N. (1985). *Just health care / Norman Daniels*. Cambridge [Cambridgeshire]; New York: Cambridge University Press, 1985, pp. 6-7.
- 4) President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Securing Access to Health Care: A Report on the Ethical Implications of Differences in the Availability of Health Services, Vol. 1. Washington, D.C.: U.S. Government Printing Office, 1983. (Excerpt)
- 5) Mariner, W. K., Glantz, L. H., & Annas, G. J. (2012). Reframing federalism - the Affordable Care Act (and broccoli) in the Supreme Court. *The New England Journal Of Medicine*, 367(12), 1154-1158.
- 6) Jost, T.S. (2012). A mutual aid society? *Hastings Center Report*, 42(5), 14-16.
- 7) *In re: Baby K*, 16 F.3d 590 (4th Cir. 1994), plus notes. (Excerpt)
- 8) Oberlander, J. (2007). Health reform interrupted: the unraveling of the Oregon Health Plan. *Health Affairs*, 26(1), w96-w105.
- 9) Callahan, D. (1991). Ethics and priority setting in Oregon. *Health Affairs (Project Hope)*, 10(2), 78-87.
- 10) Brown, L. (1991). The national politics of Oregon's rationing plan. *Health Affairs (Project Hope)*, 10(2), 28-51.
- 11) Alakeson, V. (2008). Why Oregon went wrong. *BMJ: British Medical Journal*, 337a2044.
- 12) Donaldson, C., Bate, A., Brambleby, P., & Waldner, H. (2008). Moving forward on rationing: an economic view. *BMJ: British Medical Journal*, 337a1872.

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. reflection paper that demonstrates your engagement with the assigned readings and reflection on the issues at hand due prior to class.**

Session 13**Wednesday/April 18**Public Health Ethics

- a. Ethical principles in population health
- b. Similarities/differences between public health ethics and bioethics
- c. Practical ethics: case studies

Required readings:

- 1) Childress, J., Faden, R., Gaare, R., Gostin, L., Kahn, J., Bonnie, R., Kass, N., Mastroianni, A., Moreno, J., & Nieburg, P. (2002). Public health ethics: mapping the terrain. *Journal of Law, Medicine & Ethics*, 30(2),170-8.
- 2) Callahan, D., & Jennings, B. (2002). Ethics and public health: forging a strong relationship. *American Journal of Public Health*, 92(2), 169-76.
- 3) Kass, N. (2001). An ethics framework for public health. *American Journal of Public Health*, 91(11), 1776-82.
- 4) Baum, N., Gollust, S., Goold, S., & Jacobson, P. (2007). Looking ahead: addressing ethical challenges in public health practice. *Journal of Law, Medicine & Ethics*, 35(4), 657-667.
- 5) Bayer, R., & Fairchild, A. (2004). The genesis of public health ethics. *Bioethics*, 18(6), 473-492.
- 6) Kuehn, B. (2016). Pediatrician Sees Long Road Ahead for Flint after Lead Poisoning Crisis, *Journal of the American Medical Association*, 315(10), 967-969.
- 7) Sharfstein, J. (2016). JAMA Forum: Flint, Michigan and the Failure of Public Agencies, February 17, 2016.

Assignments:

1. **Post discussion question based on the readings on the class blog 24 hours prior to class. Be prepared to lead class conversation on the question.**
2. **2-3 pp. reflection paper that demonstrates your engagement with the assigned readings and reflection on the issues at hand due prior to class.**

Session 14**Wednesday/April 25**

Final Case Presentations

Assignment: Case Analyses due in class