

TOPICS IN BIOMEDICAL ETHICS: CAPACITY AND CONSENT
Winter 2019
Syllabus (Draft 1/4/2019)

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Course Description: We will take on a number of challenging ethical questions that all concern, in one way or another, the ideas of autonomy and informed consent in health care and medical research settings. We will begin by exploring **the history and rationales** for the principle of Informed Consent that forms a centerpiece of medical practice in the United States and around the world today. Next we will turn three different areas of medical practice, policy, and research in which autonomy and informed consent have been thought to be threatened in some way:

- **Consent and Compensation.** Payment for human organs sales, payment for participation in clinical trials, and payment for surrogacy have all targeted by the objection that they are in tension with truly autonomous and informed consent. For each case, we will evaluate different answers to the questions of whether payment should be allowed or required in any of these areas, and whether payment is consistent with Informed Consent.
- **Autonomy and Nudges.** We will then turn to a set of questions about the moral permissibility of so-called “nudges” in medical contexts. For example, if making organ donation a matter of opting *out* rather than opting *in* makes an enormous difference to the number of organ donors, should we allow this policy practice? Does it conflict with autonomous decision-making?
- **Consent and Population-Level Interventions.** Some medical interventions, like adding fluoride to water systems, are neither “opt in” or “opt out”. Does this sort of wide-spread policy threaten autonomous decision-making? Similarly, large-scale species level genetic interventions (some made possible by recent research on gene drives) raise questions about what consent could possibly look like in such cases.

Finally, we will conclude by addressing an issue that concerns autonomy and consent at different stages of a person’s life by looking at the case of **Advance Directives**, in which persons at an earlier time specify in official documents how they would like to be treated later if incapacitated in various ways.

Course Readings: All course readings are available through the class website.

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| 1/7 | Introduction |
| 1/9 | Informed Consent: History and Rationale Nuremburg Code, Belmont Report |
| 1/11 | Informed Consent: Fabian Freyenhagen, “Personal Autonomy and Mental Capacity” |

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| 1/14 | Informed Consent and Autonomy: Nomi Arpaly, "Which Autonomy?" |
| 1/16 | Informed Consent and Rationales: Nir Eyal, "Informed Consent" |
| 1/18 | Noxious Markets? Deborah Satz, <i>Why Some Things Should Not Be for Sale</i> chapter 3 |
| 1/21 | Martin Luther King Day |
| 1/23 | Noxious Markets? Deborah Satz, <i>Why Some Things Should Not Be for Sale</i> chapter 4 |
| 1/25 | Organ Sales Deborah Satz, <i>Why Some Things Should Not Be for Sale</i> chapter 9 |
| 1/28 | Research Subject Payments Collin O'Neill, "Consent in Clinical Research" |
| 1/30 | Research Subject Payments Trudo Lemmons and Carl Elliot, "Guinea Pigs on the Payroll" |
| 2/1 | Research Subject Payments Alan Wertheimer and Franklin Miller, "Payment for Research Participation: A Coercive Offer?" |
| 2/4 | Research Subject Payments Tricia Phillips, "Exploitation in Payment to Research Subjects" |
| 2/6 | Surrogacy Deborah Satz, <i>Why Some Things Should Not Be for Sale</i> chapter |
| 2/8 | Autonomy and Nudges Richard Thaler and Cass Sunstein, <i>Nudge</i> excerpts |
| 2/11 | Midterm |
| 2/13 | Autonomy and Nudges Richard Thaler and Cass Sunstein, <i>Nudge</i> (excerpt) |
| 2/15 | Nudging and Organ Donation Thaler and Sunstein, <i>Nudge</i> (excerpt) |
| 2/18 | Presidents Day |
| 2/20 | Nudging and Health Maintenance Alex Rajczi, "Liberalism and Public Health Ethics" |
| 2/22 | Nudging, Informed Consent, Procedures, and Clinical Trials Schlomo Cohen, "Nudging and Informed Consent" |
| 2/25 | Nudging, Informed Consent, Procedures, and Clinical Trials Eric Chwang, "Consent's Been Framed" |
| 2/27 | Consent and Population Level Interventions James Childress, Ruth Faden et al., "Public Health Ethics: Mapping the Terrain" |
| 3/1 | Consent and Population Level Interventions: Case Study-Gene Drives Arthur Caplan et al, "No Time to Waste-The Ethical Challenges Created by CRISPR" |
| 3/4 | Autonomy and Advance Directives Ronald Dworkin, <i>Life's Dominion</i> (excerpt) |
| 3/6 | Advance Directives Rebecca Dresser, "Dworkin on Dementia: Elegant Theory, Questionable Policy" |
| 3/8 | Advance Directives Allen Buchanan, "Advance Directives and the Personal Identity Problem" |
| 3/11 | Advance Directives Agnieszka Jaworska, "Respecting the Margins of Agency..." |
| 3/13 | Advance Directives Agnieszka Jaworska, "Respecting the Margins of Agency..." |
| 3/15 | Conclusion |

Course Requirements:

- Midterm (25%) (2/11)
- Paper (25%) (due: 2/27)
- Take-home Final, uploaded to Turnitin on the TritonEd site (40%)
- Weekly In-Class Quizzes (10%) (Top 6 out of 8 will count)

Please note: Late assignments will not be accepted without a valid excuse and supporting documentation, given in advance if at all possible.

Policies:

- If OSD accommodations are needed, please notify me as soon as possible during the first week of class.
- Laptops, phones and other electronic devices may not be used in class **except by permission of the instructor.**
- The Academic Honor Code must be observed in this course.
- If you find yourself needing help with any aspect of the course, or would simply like to explore some ideas further, please don't hesitate to see me in office hours or make an appointment to talk.
- Please note that the policies and reading schedule described above are subject to **minor change.**