INTRODUCTION TO BIO ETHICS

Dr. Elena Rosca
Ashesi University, Ghana

Additional materials by Paul Stoddard,
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**One example:**
How Artificial Intelligence helps medicine
- Diagnosing diseases and reading images.
- Developing drugs faster.
- Personalizing treatment.
- Short [article](#)
Bioethics - deals with ethical issues related to advances in biology and medicine.

The field received much attention in 1960s in the US in connection with the civil rights movement and women’s rights movement. Patients raised concerns that they have rights:

- The right to know what disease they have
- The right to make choices about their treatment

Here is a link to the NY state hospital patients’ bill of rights.
The Hippocratic Oath

• Oldest written copy is dated @AD 275, but the actual oath probably pre-dated Hippocrates.
• Includes the promise to “do no harm or injustice” and to keep patient information confidential. (Remember the Google motto, “Don’t be evil”?)
• Modern codes of medical ethics are evolved from it.
• Some US medical schools still use it or a variation of it.
Bioethics and Research

Tuskegee Syphilis Study
• A study conducted between 1932 to 1972 by the US Public Health Service and CDC which enrolled black men to study syphilis
• 600 men (399 with syphilis and 201 without)
• No informed consent
• Patients were told they were being treated for “bad blood” (encompasses syphilis, anemia and fatigue)
• Treatment was withheld from some patients so researchers could track the disease
• Outrage in 1972 caused the study to be cancelled and the creation of the Office of Human Research Protections.
• President Clinton formally apologized in 1997

Questions about medical research and drug development
• Is it ok to test drugs on animals? Which animals?
• Should a researcher who has a financial investment in a drug’s development be allowed to do research on its safety?
Who should get COVID vaccines first?

Governments throughout the world debated this last year (and still are).
• Doctors and nurses
• Hospital workers
• Food preparation and delivery
• Essential workers, teachers
• Political leaders
• Military personnel
• Prisoners, guards
• Vulnerable people
Who do you think should get vaccines first?

Wired article – every US state and territory must develop their own plan. However, the CDC has issued a 57 page “interim playbook” to help them (p. 14 lists critical populations).

The Cybersecurity and Infrastructure Security Agency identifies additional Critical Infrastructure Workers (see page 6). It includes elections personnel.
Poll – answers are anonymous.
Who should get vaccines first?

WHO (World Health Organization) says it’s inequitable that wealthy countries are getting COVID boosters while poorer countries haven’t gotten their first doses. 70% of all vaccines have been administered in just 10 countries. (VOA News)

Director-general Tedros Adhanom Ghebreyesus says it would be more useful in curbing the pandemic if boosters were sent to poorer countries. (Nature)
Ethical questions related to the pandemic

Unvaccinated COVID patients are more expensive to treat when they get sick. They are straining the resources of hospitals, doctors and nurses. This is preventing patients who need treatment for other diseases from getting what they need.

• Should vaccinated patients get priority over unvaccinated?
• Is it ethical for governments to force people to be vaccinated?

Similar issue: Is it ok to give a liver transplant to an alcoholic? No - liver transplant recipients must be free of alcohol for at least 6 months. NPR story on this (5 minutes).
Hofstede’s cultural dimensions theory explained in [Wikipedia](https://en.wikipedia.org)

One of the dimensions is individualism-collectivism.

The USA is at the individualistic end of this dimension, China is at the other end.

Does that mean one country is more ethical than the other? Or “better” than the other? How do we define “better”?

Freakonomics - The Pros and Cons of America’s (Extreme) Individualism ([Ep. 470](https://freakonomics.com/episodes/individualism-vs-collectivism/))

Vaccines are a classic case of Individualism vs Collectivism

Valuing a human life

Recall the utilitarian approach to ethics. Can we measure the value of a human life in dollars? Governments, economists, and insurance companies sometimes want to measure this.

There are economists who attempt to measure VSL (Value of a Statistical Life). Wired article on the subject.
Medical treatment costs

- Advancing medical technology is driving up costs.
- Studies show that most medical costs are incurred in the last few months of a person’s life.
- Does this make sense?

Recommended book: Being Mortal by Atul Gawande
Genetic testing (aka DNA testing)

The cost of genetic testing has fallen in recent years (less than $100 for some tests).

Reasons for genetic testing
• Medical – diagnosis or risk prediction for conditions; customizing treatment
• Determining paternity
• Animals and plants – selective breeding
• Ancestry research (3-minute video)
Genetic testing - continued

Ethical Concerns

• Health insurance could be denied because of genetic risk for some diseases. In the US, the Genetic Information Nondiscrimination Act prohibits this.
• Direct to Consumer tests are being used for health risk determination for some conditions. These can be misinterpreted without professional guidance. Medical DNA tests sometimes require counseling – do you really want to know if you are likely to get Alzheimer's disease?
• Law enforcement – direct evidence for some crimes; using Ancestry data to solve old crimes. A US Supreme Court decision allows collection of DNA evidence. Question – who owns this data?
• Israel uses it to determine if some people are eligible to immigrate to Israel.
• Ancestry research - surprises sometimes upset families
CRISPR

Clustered Regularly Interspaced Short Palindromic Repeats

TED talk by Jennifer Doudna, co-inventor of the technology for editing DNA. (2015, 16 minutes)

Benefits
• Some scientists think CRISPR can help where antibiotics are failing.
• Current research for fighting cancer
• Can be used to grow human organs in pigs (for transplant)
• Gates Foundation is researching how to eliminate malaria by editing DNA of mosquitoes
Ethical concerns
- Could editing for desirable things cause unintended consequences? Many traits are complex, involving lots of genes.
- What impact would it have on society if lots of people are edited?
- In 2018 Chinese scientist Dr. He Jiankui edited the genes of twin baby girls using CRISPR to make them resistant to HIV and other diseases. This violated international ethical guidelines. He eventually was fined and sent to jail. China also created regulations.
## CRISPR - What would happen to future generations?

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Somatic genes (not inherited)</th>
<th>Germline genes (inherited)</th>
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<tbody>
<tr>
<td>Medicine</td>
<td></td>
<td>Curing future generations (ex. Sickle cell anemia)</td>
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| Enhancement | Plastic surgery | “Designer babies” |

Diagram is from the VOX Netflix show called “Explained”
BCI - Brain Computer Interface

Video (1 minute)
Video from The Economist (8 minutes)

Who’s doing it?
- Neuralink Corporation – an Elon Musk company
- CTRL-Labs is working on controlling devices mentally
- Kernel.com – Bryan Johnson says BCI is the most consequential technology in the history of mankind.
- Wired article on ‘Neurograins’
- “Facebook is building tech to read your mind. The ethical implications are staggering.” (Vox article)

Ethical concerns
- Who owns your brain data?
- Could your mind be read without your consent? Mind reading research.
- Intelligence enhancement - Who gets it first?
Biotecnology

Advanced prosthetics
Who should get them?
• Rich vs poor?
• Political leaders?
• Olympic athletes?
Yuval Noah Harari, author of *Homo Deus: A Brief History of Tomorrow*, is concerned that advances in Brain-Computer-Interface, genetic engineering (using CRISPR), enhanced prosthetics and other new technologies will enable some people to become “super-human”.

Who? Those who can afford it.

He says the current wealth gap could split humanity into 2 separate species - those who can pay to become super-human, and those who can’t.
Other Bioethics concerns

• How an Algorithm Blocked Kidney Transplants to Black Patients – Wired 10-26-2020
  Notice that this was a design mistake made by humans. The algorithm did what it was told to do.

• Theranos - really a business ethics case. Elizabeth Holmes and Ramesh Balwani trials delayed to August 31, 2021 and January, 2022. Theranos had many respected people on it’s Board, including George Schultz, Henry Kissinger, General James Mattis, and several Senators.
• Award-winning author and medical ethicist Harriet A. Washington wrote the book, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. The product of years of prodigious research into medical journals and experimental reports long undisturbed, *Medical Apartheid* reveals the hidden underbelly of scientific research and makes possible, for the first time, an understanding of the roots of the African American health deficit.

• *System Error: Where Big Tech Went Wrong and How We Can Reboot* written by Rob Reich, Mehran Sahami and Jeremy M. Weinstein. Mentioned by CLS member Bob Hamlyn.