2020 National Bioethics Bowl Case Packet

Northeastern University
Boston, MA April 3-4 2020

*This packet contains fifteen cases, with three questions following each case. At the National Bioethics Bowl competition, only one of the three questions will be selected. Teams will only answer the single question read by the moderator during for each case. Not every case will be read in the competition.
Case 1: A Danger to Oneself

Jane is an 18-year-old girl diagnosed at age seven with Anorexia Nervosa (AN). She is now completing her senior year in high school. Jane is a strong student who wishes to pursue a premedical degree in college. She exercises every day and tightly controls her caloric intake. She is being treated for her AN at a large medical center by the adolescent health department. At the time of her last visit, two months ago, Jane was significantly malnourished and had severe osteoporosis (BMI 16; height 156cm, Wt. 39kg.). Her last bone scan showed significant deterioration in her long bones and spine, leaving her at greater risk for fractures. She refuses any treatment or referrals for counseling, thinking she can manage her eating disorder “on her own.”

At her last appointment, her providers informed her that she has dangerously worsening osteoporosis, and her heart function is a growing concern. Jane has had a good relationship with her adolescent medicine physician, who was able to convince her to continue to come to the hospital for monitoring of her bone health. Her physician holds out hope that she can influence Jane in the direction of treatment.

AN has the highest mortality of all psychiatric illnesses, with fatality rates ranging from 7-14%. Jane has a disease characterized by denial of illness. This is the case even in the presence of high intellectual achievement. Her parents describe her as “thinner than ever.” AN is not “cured,” but managed, and compelled treatment may or may not work; there isn’t definitive data proving one way or the other. What the data do show is that the earlier treatment is started, the more likely it is to be successful. While AN has the highest mortality rate of all psychiatric illnesses, it is difficult to predict when death will occur because some patients tolerate semi-starvation better than others.

The ethics consult service at the medical center has been called by adolescent medicine due to her refusing care. The medical team is worried about Jane’s wellbeing, saying she could die at any time from complications related to her disease. Jane’s parents would like the ethics consult team to make a recommendation that may be used in a legal proceeding to compel treatment. They have hired a lawyer to pursue power of attorney and a certification for commitment. The attorney met with Jane, and was unable to convince her to go willingly. A bid to declare her a danger to herself has not been possible because she refuses to see a psychiatrist.
The medical team seeks an ethics recommendation on what ethically permissible courses of action are available to them.

Questions:

1. Jane has just turned 18-years-old and is in the process of developing her autonomy. She has a scholarship to a four-year college, but still relies on her parents for financial and emotional support. Does her right to autonomy outweigh her family’s, physician’s, and society’s obligation to care for her if she cannot act in her best interests? We allow drug addicts, who do not act in their own best interests to make their own decisions; is this any different? Does having just turned 18 make an ethical difference, even if not a legal one?

2. Compelling treatment might damage the already strained relationship Jane has with her adolescent medicine physician. Currently, Jane is willing to come to the hospital for bone scans several times per year. Does the chance of putting her on a path towards cure outweigh the risk of driving her away from all treatment?

3. Hospital counsel has advised the ethics consult service that should Jane invoke it, the hospital will no longer be allowed to give her parents information on her condition; doing so would violate HIPAA. Does the legal requirement of HIPAA outweigh the parent’s right to know about their daughter’s health, in that they 1) continue to support her financially, and 2) are fighting to save her life.
Case 2: Best Interests and Parental Authority

The pediatric palliative care (PPC) and the heart and kidney unit (HKU) teams are considering withdrawal of the artificial nutrition and hydration (ANH) being used to maintain Brenda, a 6-month-old female with complex cardiac disease, devastating neurological injury, and ongoing pain. Brenda’s parents strenuously object.

Brenda is a 6-month-old female infant who has suffered diffuse neurological injury (8/10 severity) due to oxygen deprivation. Severe ischemia in all 4 limbs that has resulted in loss of both hands and both feet. Two significant iatrogenic factors contributed to Brenda’s current condition. The first is severe neurologic injury secondary to ECMO (extracorporeal membrane oxygenation) decannulation and subsequent cardiac arrest. This damage is diffused throughout the brain. Her ability to suck and swallow is doubted by her physicians, but unknown. The second is severe ischemia to all of her limbs following prolonged ECMO (related to inability to remove Brenda from bypass following surgery). Her hands and feet are reportedly not salvageable, but remain attached to advancing necrotized live tissue, forming transition zones on all four limbs.

The MRIs presented during the consult display extensive brain tissue loss throughout prefrontal and midbrain areas, leaving only the brainstem intact. The patient requires medication to prevent seizures, is blind, will likely be unable to exhibit motor control functions such as sitting, and has a high chance of being non-verbal. She may be able to hear.

Brenda’s parents believe no one can decide to “call her back to heaven” except God. They visit her daily, and are joined periodically by members of their church. Multiple family meetings have occurred in which the medical team attempts to convey the severity of Brenda’s condition. At the last family meeting the discussion became heated and the parents finally said, “As long as she has a heartbeat, that is enough for us.”

Nurses are asking to be reassigned in increasing numbers due to moral distress. Most think providing this care is wrong when there is no chance of benefit, but some support the parent’s right to decide, and are uncomfortable with withdrawal of ANH. The PPC and HKU attending physicians believe withdrawing ANH and redirecting the goals of care to palliation (comfort care) is the ethical course of action. They point out that as the body shuts down, food and liquids can be uncomfortable to ingest; Brenda will not “starve,” but rather her death will be peaceful and her suffering will end.
Unlike specific neurological injury, where other, undamaged regions of the brain can “take over” certain functionality, diffuse brain damage has no such remedy. While traumatic brain injuries can improve over time, anoxic brain damage does not. Brenda, while not meeting the criteria for brain death, will be unable to interact with the world in any meaningful way. As reported by Neurology, Brenda will never be able to develop the capacity for thought, or move intentionally, and is likely to be both nonverbal and unable to maintain her body positioning.

However, Brenda is capable of feeling pain, and the transition zones between live and necrotic tissue on all four limbs cause her significant pain and suffering. She is facing probable 4-limb debridement/amputation. The transition zones are being monitored, but daily wound care causes significant pain. Debridement of necrotized tissue on all four limbs will eventually be needed if efforts are made to preserve limb length. Wound care reports undetermined lengths of healthy tissue exist towards the centers of each limb. Artificial life-support could maintain her for an indefinite period of time—months to years.

Questions:

1. The medical teams have asked for an ethics recommendation. How do you weigh the two competing moral claims: parental authority to make decisions on behalf of their minor children, and the physician’s fiduciary duty to act in the best interests of her patient?
2. If the hospital administration stands behind the physicians, and the family were to go to the media, the negative publicity could deleteriously affect the hospital’s fundraising ability, which the nonprofit uses to provide free medical care to those who cannot afford it. Should the administration choose to support ending Brenda’s suffering without any portent of benefit at the risk of this potential damage to their mission to provide care to large numbers of children?
3. What is in Brenda’s best interests? Can death ever be said to be in one’s best interests?
Case 3: Captive Retirement

In 2015 the United States National Institutes of Health (NIH) stopped funding virtually all biomedical testing on chimpanzees, effectively ending government funded experimentation on this species of great apes in America. In the United States, much of the chimpanzee research involved giving the primates cancer, HIV and hepatitis, in an effort to advance therapies and cures; however, after years of research, the work was not proving fruitful. On top of that, many animal welfare and animal rights groups were voicing outrage over our closest genetic relatives enduring this form of captivity and experimentation, when only a small number of countries other than the U.S. continued biomedical research on chimpanzees. Currently, about half of the NIH laboratory chimpanzees still remain in captivity, while the rest have been moved to sanctuaries or, in some cases, zoos.

In 1993, Philosophers Peter Singer and Paola Cavalieri helped form an international organization of ethicists and scientists called the Great Ape Project, which sought to extend legal rights to all great apes. Similarly, attorney and animal rights activist Steven Wise, began suing on behalf of chimps in captivity for research and entertainment, arguing that animals with certain levels of ‘cognitive complexity’ (apes, elephants, dolphins and cetaceans) should be recognized as ‘legal persons’ rather than ‘legal things’. Wise, famed primatologist Jane Goodall, and other activists helped form the Nonhuman Rights Project (NhRP) which argues that cognitively complex animals should have ‘personhood’ and should have basic legal rights. Wise argues that these animals have autonomy, a theory of mind, and they should have ‘dignity rights’ - the right to not be killed, tortured, or imprisoned. Britain banned research on chimpanzees, orangutans and gorillas in the late 1990s, and New Zealand gave legal protection from experimentation to apes in 2000. Spanish Parliament approved ‘human rights’ for chimps in 2008. In 2010, the European Union banned all ape experimentation and certain forms of entertainment.

However, the retired chimps of American biomedical research could, of course, not be released into the wild, as most of them had never set foot outside of the lab, and many of them had special physical and psychological needs. According to ChimpCare, in 2017 there were still around

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2 https://www.projetogap.org.br/en/
3 https://www.nonhumanrights.org/who-we-are/
4 https://www.theguardian.com/world/2008/jun/26/humanrights.animalwelfare
547 chimps that were living in captivity inside research facilities in America. Chimp Haven and Project Chimps are the two primary havens for these retired chimps, but they do not have enough employees or funding for all retired U.S. research chimps.

Some chimps still held in captivity have been evaluated as too ill to risk being moved to a sanctuary. Housing these chimps in laboratories still costs tax-payer’s money. In 2019, the New York Times reported that all 44 chimps still held at a Lab in New Mexico were judged to be too ill to move to Chimp Haven – a private non-profit sanctuary that cares for over 200 chimps from retired NIH projects. Philosophist Dr. Lori Gruen argued that Chimp Haven has cared for chimps with the same ailments described by the New Mexico vets, and other activists are calling for the ill chimps’ health to be reviewed again, hoping they could be moved to sanctuaries. Currently, workers at Chimp Haven are given vasectomies to the males, and eventually plan to shut the sanctuaries down when all of the retired chimps pass away. However, some private companies have given their retired research chimps to non-AZA accredited zoos, sparking more controversies and backlash from animal welfare groups.

Questions:

1. What moral responsibility, if any, does the United States have in making sure these retired research chimps are moved to sanctuaries?
2. Do you think biomedical research should be banned on animals that display a certain level of ‘cognitive complexity’?
3. If the research on chimpanzees had yielded more positive results and potential benefits for humans, would it have been ethical to continue the experimentation on them?

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https://www.nonhumanrights.org/unlocking-the-cage/
Case 4: Charter Cities

In 2009, economist Paul Romer gave a TED talk where he introduced the world to the concept of charter cities. A charter city is governed by city law, instead of a larger government’s law. As Romer said: “A host country would provide land; a source country would provide residents; and a guarantor country would provide the assurance that the new city’s charter would be respected and enforced.” Romer theorized that you could treat cities like startups, with charters of new rules that aim to provide comparative advantages over nearby cities. For example, an entity could take an unoccupied piece of land in a developed country, apply a new set of rules to live by, and have people voluntarily populate the new city as they seek to find a better life. Hong Kong is a classic example of something akin to a charter city, where the old national rules no longer apply, and new rules are instituted for the citizens. Although Romer has tried to help found new charter cities in both Honduras and Madagascar, these endeavors have not yet found much success.

GrowthCorp (a fictional entity) is worth several hundred billion dollars, and is interested in improving humanity. They’ve decided to build a brand new charter city, which they hope to design with gloriously-optimized city-planning through statistical algorithms and machine learning. GrowthCorp believes that if they can create a wonderfully well-oiled city, it will grow to be one of the top ten largest cities in the world. Their perfect city would enable citizens to be their happiest, and would be a model for other charter cities looking to spring up elsewhere.

At the outset of the project, the GrowthCorp city planning team needs to pick some Key Performance Indicators (KPI’s) to optimize their design. Peter Drucker, the Austrian founder of modern management, popularized the phrase: “If you can’t measure it, you can’t improve it.” Jeremy Bentham, the father of modern utilitarianism, said that a perfect society would have an accurate measure of happiness called a “Util”.

In 2018, Tyler Cowen extended Bentham’s idea with his book Stubborn Attachments. Cowen made a moral case for maximizing a sustainable rate of economic growth. One of Cowen’s premises was that wealth enables human flourishing. Gross Domestic Product (GDP) has excellent correlation with indicators of human flourishing, both measurable and immeasurable. Cowen coined a new unit called “wealth-plus” to describe GDP plus immeasurable goods. Cowen also posited that “wealth-plus” grows exponentially over time. For example, money can be invested to make a good product and yield a return. Inventions can enable leisure, which can improve health.
and happiness, decrease disease, generate innovation, and so on. Cowen concludes that if the future population will vastly outnumber the present population, the best way to maximize happiness is to maximize the sustainable rate of economic growth. Cowen does include the caveat that growth-maximization should not violate human rights.

With this fresh understanding of “wealth-plus”, the GrowthCorp city planning team believes that if they can craft an algorithm which optimizes economic growth, their city will be a paradise. Again, they can’t optimize or improve a design unless they quantify the parameters. They organize a team of civil engineers, economists, public servants, data scientists, machine learning engineers, and other various experts to quantify the parameters of the algorithm to maximize “wealth-plus” for their city.

However, several members of the team argue that it’s impossible to quantify every aspect of life. Not everything can be fully measured, and if measurement tools are applied, they yield a reduction of the original concept. For instance, can love, intimacy, happiness, or joy, actually be quantified? Is it possible to quantify the value of going to visit one’s grandmother, or holding her hand on her deathbed? If, in the search for petroleum, seismic surveys in a coastal area create booming vibrations which deafen whales and disrupt migration patterns, is it possible to quantify the negative impacts?

The team begins to debate about what is and isn’t able to be measured and quantified. Some argue for “carbon-taxes” which would tie an economic activity to its carbon footprint, and therefore make it quantifiable. Some argue that improvements in AI technology will allow humanity to continually “cast a wider net” of what they can measure, so that some day humanity literally can measure everything. Others take a softer approach, saying that machine learning can reach a “good enough” optimum value. Finally, some argue that there should be “sacred” areas of life, held separate from Market mechanisms, which offer value that will always be impossible to quantify.

Questions:

1. Machine learning is currently being used to create autonomous vehicles by quantifying things like speed, acceleration, location, and proximity. However, machine learning in this instance cannot capture immeasurables like the joy of driving, the protection of loved ones, or the
environmental impact of transportation. If machine learning generates “wealth plus”, but is unable to account for immeasurables, is it successful in increasing human flourishing?

2. At the scale of a society, does “wealth-plus” truly increase exponentially over time? For instance, at the individual scale, exponentially increasing wealth does not necessarily exponentially increase happiness, and could in fact reduce happiness.

3. It’s plausible that hardship in life can lead to profound growth in the future. A forest fire might be temporarily devastating, but ultimately beneficial for a habitat in the long term. Is it possible for GrowthCorp to ethically apply this concept to their algorithm (either intentionally or unintentionally through “unknown” parameters)?
Case 5: China’s DNA Surveillance

On December 3, 2019, Yves Moreau, a biologist and writer for Nature published an essay - “Crackdown on Genomic Surveillance” - calling for intervention on the Chinese government’s practices of buying DNA-profiling technology and using it to perform human-rights abuses. It states that China’s police are using a national DNA database along with cameras and facial scanners to monitor the minority Uyghur Muslim population in China’s western province, Xinjiang. Moreau noted that US, UK, and EU-based companies are the largest suppliers of DNA-surveillance technologies. He also specifically called out Thermo Fischer Scientific, a company based in Massachusetts, for selling products to and working with the Chinese Ministry of Justice and the People’s Public Security University of China in their initiatives to surveil the Uyghurs and to “build a population-scale database for DNA, fingerprint, face and voice information in a major Chinese city.” The company did eventually end their relationship with China after two years of public outrage and political pressure. A lobbyist for Thermo Fisher responded to Moreau’s article arguing that that universal DNA databases are “inevitable” and the only thing stopping them from being implemented in western countries are public parliamentary processes and the influences of protests. Moreau warns that “the use of DNA for state-level surveillance could become the norm in many countries.”

Moreau calls for updated legislature on identification processes, citing the fact that legislation has passed for fingerprint sensors, but no for the more advanced and invasive facial and DNA recognition technologies. Moreau studied 529 articles, including 40 published by three leading forensic journals, and found that Uyghurs and Tibetans were 30 to 40 times more frequently studied than the Han majority1 in China, relative to population size.2 Previous reports, including one by the New York Times in April of 2019, had stated that China’s use of facial recognition to monitor the Uyghurs was the first known time a government had intentionally used artificial intelligence for racial profiling. The expanding network of Chinese cameras is integrated with facial recognition capabilities exclusively for Uyghurs and keeps track of their activity for review. Technology had previously been used to monitor the Xinjiang province which most


Uyghurs reside in, but it is being expanded to monitor the wealthier Uyghurs in coastal eastern cities.³

Another Time’s article details Tahir Imin’s experience as a Uyghur in a Beijing airport, where he is brought aside for a ‘free health check’, one where his face is scanned, blood is taken, and his voice is recorded, but his heart is not checked and his weight not taken. The Chinese government is forcing Uyghurs into ‘re-education’ camps, and this racial profiling will be used to track down any Uyghurs who resist.

Genetic material was provided by Kenneth Kidd, a prominent geneticist at Yale University, and technology would be used from the aforementioned Thermo Fisher Scientific. Although Kidd willingly gave these samples to the Chinese government, he claims to be unaware of its intended use. The Chinese government has taken advantage of the public database of genetic information, much of it from the United States, and in turn, they have provided the database with Uyghur DNA. The global scientific community is under scrutiny for allowing this exchange to occur, and many researchers from top universities are calling for this initiative to be closed off from the Chinese government.⁴

On Tuesday, December 3, 2019, the US House of Representatives voted nearly unanimously on a bill condemning China’s treatment of ethnic minorities. Many scientists have expressed their worry that the DNA research, in particular, violates the worldwide scientific rules regarding consent. It is nearly impossible for scientists to guarantee that the Uyghurs involved in this study gave their blood samples willingly.⁵

Questions:

1. What steps are researchers morally obligated to take (if any) to make sure their research in this area can’t be used for the purpose of government surveillance?
2. What uses of DNA research should be considered morally acceptable?
3. Are private corporations morally obligated to take steps to make sure their products can’t be used in ways they would find morally unacceptable?

In November of 2018, He Jiankui, a Chinese scientist, revealed to the world that he had created the first genetically modified babies. Two twins, Lulu and Nana, were claimed to be resistant to the virus HIV, which interferes with the way the body fights infections. In his experimentation, He removed the CCR5 protein that the HIV virus uses to infect the human body. This, in effect, created two humans who were highly resistant to the HIV virus. When He presented his research at a conference, he was met with skepticism, outrage, and concern. Many scientists called He reckless and irresponsible because this experimentation was done without comprehensive knowledge of how CRISPR works and its potential for error.

In the United States, several studies and clinical trials have been approved for the use of CRISPR in humans. A clinical trial is currently being done at the University of Pennsylvania with CRISPR to treat cancer patients. Immune cells are being removed from 18 people with cancer and then edited using CRISPR before being implanted back into the patients. Additional approved studies involving the use of CRISPR include potential treatments for genetic disorders like sickle cell anemia and beta thalassemia. These studies all involve removing cells from the patient for modification and reimplantation. However, another study using CRISPR to try to correct a form of inheritable blindness is attempting to do so within the human body without isolating cells for modification.

Somatic genetic therapy seeks to treat and prevent existing diseases in “mutant” genes that decrease a person’s quality of life. Parkinson’s, cystic fibrosis, and sickle cell anemia are all diseases that scientists are working on treating and preventing with gene therapy. The clinical trials that have been approved thus far arguably fall into the realm of therapy rather than

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enhancement, treating “mutant” genes or disorders that affect “normal” function rather than enhancing a person’s capacities beyond that of a typical human. However, some have wondered whether in the future CRISPR might be used not only to alter traits associated with disease, but also to alter non-disease related traits.

Opponents of genetic enhancement and germline editing point out that it may increase inequality if only wealthy parents are able to afford genetic editing. Furthermore, some also object to the value judgments they see as inherent to changing the traits of their offspring.

Questions:

1. How, if at all, should we distinguish treatment from enhancement in the context of gene editing? If this distinction should be made, how should we use it to make decisions about when to use gene editing?
2. If possible, should parents edit the genes of their children? What moral considerations should go into making this decision for one’s child?
3. What, if anything, makes the studies being done now at UPenn morally superior to He’s experiment that caused outrage in the scientific community? Should He’s experiment have been condemned?
Case 7: Ectogenesis

Life, as we know it, begins in the womb of the mother. Imagine, however, a world where mothers no longer have to carry their fetus, a world where fetuses can grow outside of a mother’s womb – a world with artificial wombs. This idea is known as ectogenesis, or the development of an embryo outside of the body. Discussed since the 1920s, experimentation began in the 1980s with various types of animals. The most famous experiment was done in 2017 by the Children’s Hospital of Philadelphia. Researchers were able to sustain a baby lamb during a period of development. It was calculated to be equivalent to about 23 to 24 weeks’ gestation of a human fetus.

One of the purposes of this new technology would be to assist the thousands of babies born extremely prematurely. Of those babies who survive, many are more likely to develop an array of chronic health issues. Having this incubator-like device to replicate the environment of the womb would allow doctors to closely monitor fetuses at risk for premature development and cater to their needs in order to grow into healthy children. In addition, according to the CDC, about seven hundred women die each year of pregnancy complications, so having the option of developing their child in an external womb may be able to reduce this number.

The possibility of ectogenesis also complicates the debate about abortion. Some think that this new technology could put an end to the abortion debate. Ectogenesis provides the possibility of a woman putting her fetus into an artificial womb as opposed to terminating her pregnancy. Perhaps this option could satisfy both sides of the debate: a woman could decide to end her pregnancy and a fetus’ life would be preserved.

Even with all of the benefits that ectogenesis can bring, there are many areas of concern. This artificial womb has the potential to change the parent-child dynamic. Some mothers experience maternal bonding beginning with pregnancy. Some argue that that this bonding helps the mother understand and more efficiently respond to the needs of her child.

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11 https://www.merriam-webster.com/dictionary/ectogenesis
12 https://metro.co.uk/2019/05/14/human-babies-born-using-an-artificial-womb-possible-in-a-decade-8156458/
14 https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-relatedmortality.htm
16 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3838467/
17 https://www.sciencedaily.com/terms/maternal_bond.htm
Questions:

1. In principle, is there anything morally problematic with ectogenesis?
2. If it became possible for fetuses to grow in an artificial womb should physicians be required to offer this option to women thinking of having an abortion?
3. If ecotgenesis did effect the maternal bonding that a mother experiences with her fetus/child is this a reasons against it? How strong of a reason?
Case 8: Genetically Modified Crops

Food labels bearing the words “Verified non-GMO”, “GMO-free” are ubiquitous at the supermarket. Consumers are drawn toward non-GMO foods because they often worry about the safety of genetically modified foods. That being said, GM crops dominate the world of industrial agriculture, representing anywhere from 80 to 98 percent of crops like soy, cotton, and maize grown in the United States.\(^1\) The results, in terms of yield and shear efficiency, are quite evident - GM technology adoption has reduced chemical pesticide use by 37%, increased crop yields by 22%, and increased farmer profits by 68%\(^2\). However, the laws surrounding the largest biotech companies and their genetically modified crops are controversial.

GMO’s, specifically the modified DNA in the original genes, are protected under US patent law, where plant and utility patents last for 15 to 20 years. However, the protections from “infringement” that patents provide have been contested by a number of farmers. In 1999, Indiana farmer Vernon Hugh Bowman purchased GM seeds from the large biotech firm Monsanto.\(^3\) Bowman saved a portion of the second-generation seeds from the first harvest to be planted in the next season. When Monsanto examined Bowman’s planting activities, they found traces of the patented genetic modifications in his crops, they sued for copyright infringement. The case reached the Supreme Court, where unanimously the justices ruled that “using the seed to grow a crop and then harvesting those seeds for future use constitutes creating copies of a patented item”, and therefore violates patent law.\(^4\) Cases like this, whether it be the seeds are obtained through genetically cross-contaminated crops or even cleaned, have resulted in lawsuits and court cases on the basis of violating the patent agreements. And in nearly all of them, the court tends to rule in favor of companies like Monsanto.

The underlying reason for defending the patent rights given to biotech companies like Monsanto is clear: allowing developers of these genetically modified products to have the first chance to commercialize and profit from their technology. Creating a single new trait in a crop costs hundreds of millions of dollars and can take several years out of the patent’s window of protection, so the existence of patents is vital to ensure that the field continues to develop.

2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4218791/
3. https://www.oyez.org/cases/2012/11-796
Innovation, unfortunately, would likely cease, if it were not profitable to continue research into new crops.

However, advocates for non-GMO groups claim that the patents on genetically modified crops are contrary to the principles and traditions of farming and agriculture. Dave Murphy, Executive Director and founder of Food Democracy Now, says that “The Court’s decision to give Monsanto the power to control the future harvest of America’s family farmers and our county’s food supply is deeply troubling, immoral and a very bad sign for the future of our nation’s food”. GM crop patents, from this perspective, prey on farmers’ ability to reduce costs by saving and reusing crops.

The world population has risen to over 7 and a half billion people, and is only expected to continue its exponential rise in the future. Conventional methods of agriculture simply cannot keep pace with the rapid growth in population; GM crops seem to be the only way to fill the gap in production. As genetically-modified plants and foods become more and more necessary, the morality of the “monopolies” that biotech companies have with current patent law comes into question. If GMO’s are indeed the cornerstone of a well-fed populace in the future, can the precedent of companies having far-reaching patent protections continue?

Questions:

1.) Should the government enforce patent laws for GMO crops?
2.) What, if any, limits should there be on the patents for GMO seeds?
3.) What’s the moral justification for intellectual property rights?

Case 9: Language Preservation

Ricky Duvall, a man who grew up in Lyons Switch, Oklahoma, speaks Cherokee as his first language. Everyone in his family and community speak Cherokee. But everyone in his kindergarten spoke English, and his teacher didn’t allow him to speak his first language. Things become worse when he could not play with other children because of a language barrier. To join in other students and follow the rules, he started to use English as often as possible -- first at school, then at home, and eventually everywhere… As a result, he lost his first language. Sad, cases like Duvall’s to a lot of people in the US, and all over the world. And that is how we are losing many languages.

There are approximately 7,111 languages spoken today. However, among these languages, 40% of them are endangered, and only 23 languages account for more than half the world’s population. In the trend of globalization, big languages such as English, Spanish, and Mandarin Chinese are more widely accepted by people, while at the same time those indigenous languages are largely abandoned by speakers in order to join the modern world. One language dies out every two weeks.

There seem to be three major causes of the growing language loss: 1) a language used by more people in the world is more convenient for communication and means more opportunities; 2) some languages can be privileged in some countries, so by speaking these privileged languages people may have more confidence; 3) not every language has a writing system: most languages only have a speaking system, which is a disadvantageous because it’s harder for speakers to teach the next generation these languages. Many dying languages are indigenous ones because of things happened in the past such as invasion, and things happening today such as globalization. Language preservation ensures the preservation of cultural identity since the language(s) we speak largely shape(s) whom we think we are. The living of a language also means whether the cultural heritage from ancestors, material or nonmaterial, can be remembered by the world.

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25 Ethnologue, “How many languages are there in the world?” https://www.ethnologue.com/guides/how-many-languages
26 Ethnologue, “What is the most spoken language?” https://www.ethnologue.com/guides/most-spoken-languages
understanding language is vital to the research of human cognition. Through understanding the inner structure of a language, people speaking different languages generate different concepts and worldviews and those languages work differently in our minds. The loss of languages will prevent us from seeing the full picture of cognition.  

Languages also help people to know more about the world because they can reflect the physical environment of where it is mainly spoken. For speakers of many indigenous languages, their languages are the best way to know about the native ecosystem and topography because they have special vocabularies and expressions that do not exist in other languages. Endangered languages also have more specified taxonomies of flora and fauna than what is known to Western science. For example, the tribe of Haunóo in Philippine has forty expressions for types of soil. Common remedies we know, such as aspirin and ipecac, are informed by indigenous peoples. Without these languages, valuable knowledge might be lost.

“However, there are several objections to small language preservation.” The government has to spend a great deal of money to preserve language. For Example, education and publications in these languages must be supported to ensure that the language is passed down through each generation. Kenan Malik, a British writer and broadcaster, considered the preservation of small languages as “irrational.” According to him, although the loss of languages is the loss of culture, cultural forms are lost all the time. Also, if people want to learn a minority language, it is their job to find the source, but not the government’s burden. “Language is the only absolutely true democracy. It’s not what professors of linguistics or academics or journalists say, but what people do,” said Philip Howard, a veteran word-watcher and Times columnist agreeing that languages are in the hands of people, not politicians, “[i]t’s very romantic to try and save a language but nonsense.” If people really want to preserve their languages, they will do that. Language is just a tool for a group of humans to communicate. If the tool is not as convenient as another one, then why should we always keep it?  

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29 Judith Thurman, “A loss for words: can a dying language be saved? Mar. 23, 2015, https://www.newyorker.com/magazine/2015/03/30/a-loss-for-words
Questions:

1. Does the outcomes and benefits brought by the investment of language preservation make it worth doing for government?
2. Should only use effective languages to communicate or pay more attention to small languages for cultural preservation?
3. Since there are still many languages not found and documented by linguists, but they do exist, is there a good way to save all languages, known and unknown?
Case 10: Leaderboards

Leaderboards are notoriously tricky to design well. One example of a leaderboard is the New York Time Best Seller list. There are cases where publishers have “hacked” the New York Times Bestsellers list and gotten a small-time author on it by playing the system. The NYT Bestsellers list is influenced by sales numbers and pre-orders, so some publishers will use a lump-sum of money to pre-order 10,000 copies of their book, boost the numbers, and then re-sell their own books.

Another example of a leaderboard are the Apple top Podcasts list. In the early days, this list was sorted by an algorithm which scored podcasts by number of daily downloads. By trial and error, some small-time podcasters discovered the sorting metric, and purchased click-farms to have thousands of fake downloads per day, giving them easy exposure to the top of the popular list.

Companies creating sorting algorithms are constantly adjusting their parameters to prevent users from gaming the system. If people can figure out what’s measured and what’s rewarded, they will optimize for it. “Search Engine Optimization” was a career born out of the early days of the internet to help websites show up at the top of Google or other search engine queries.

These days, trending news, social media feeds, and even advertisements are sorted and shown to you using complex algorithms (instead of sorted by date, or other simple metrics). Even in multiplayer video-game matchmaking, players of various skill levels are sorted by an algorithm, and then the game system matches players with similar skill levels.

However, companies are trying to push the leaderboard system even further. For instance, one company has designed a bicycling app allowing users to track their biking history and compete against other users. The company has experimented with pitting users against users who are just slightly better than them, in order to motivate them to work harder. Then, intermittently, the company will match the users against other users who are worse than them, in order to allow them to feel accomplishment. The bicycling app isn’t just sorting users by skill, they’re matching users based on a value system the company chose.

Organ transplant waiting lists are another type of “leaderboard” that have historically been highly scrutinized for their fairness. The United Network for Organ Sharing (UNOS) manages the USA’s organ transplant system under a federal government contract, and they allow people to apply and be on wait lists at multiple centers simultaneously. This system meant that extremely
wealthy people with the resources to travel quickly could apply to many transplant centers across the country. In 2009, Steve Jobs was able to obtain a liver transplant at a hospital over 2000 miles away from his home. Since it is such a costly endeavor to be approved on more that one list, wealthy individuals tend to have an advantage over those with the most medical need.

Organ Donation Reform has the potential to save lives and money by reducing inefficiencies in how organs are matched to the needy, as well as by reducing how many organs go to waste. However, the method for reform is still under heavy debate. Currently, UNOS sorts their list of recipients based on several factors: physical compatibility between donor and recipient, the health of the recipient, and the length of time the recipient has been on the list. These factors are designed to optimize maximizing a recipient’s “need” (i.e., those who have the highest need get first pick). However, “need” is a qualitative value. “health” is also difficult to parse out into quantitative values. Organ Donation Reform might involve unifying many thousands of donation centers’ lists into one giant federal list. Of course, donation centers would need to add data about location and organ supply. Many hospitals are already using computer vision and machine learning to quantify “health” with various parameters. If more patients in need of organs have data generated by machine learning, how will this impact the fairness of organ transplant waiting lists?

Questions:

1. In one sense, leaderboard sorting algorithms must be kept secret to prevent people from gaming the system. In another sense, the opacity of leaderboard algorithms leads to people not having true checks and balances against unfairness. Are curators of leaderboards ethically obligated to explain how their sorting algorithm works, at any level?
2. Currently, there are many thousands of organ waiting lists across the nation because most clinics maintain their own lists. If federal regulations changed to mandate a single, central waiting list organized by UNOS, what would happen if different hospitals disagreed on how to quantify “health” metrics?

3. Certain types of machine learning techniques are “black box”, meaning even the programmers and data scientists can’t understand how they work—they just generate an output. Further, students have proven that it can be fairly easy to trick machine learning if you can figure out the decision thresholds. On the other hand, some machine learning computer vision algorithms have been shown to be more accurate than humans at recognizing things like cancer. Should machine learning be allowed in the sorting / matchmaking process of organ donor lists, or is it too risky that people would find easier ways to unfairly game the system?
Case 11: Native Care

The Indian Health Service (IHS), officially established in 1955, is a federal agency responsible for providing health services to Native Americans and Alaskan Natives. A relationship between Indian tribes and the federal government led to the creation of the agency. The federal government promised to take care of Native American’s health when it signed treaties through which tribe members gave up most of their land.

According to the IHS official government website, “This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Order…The IHS provides a comprehensive health service delivery system for approximately 2.2 million American Indians and Alaskan natives who belong to 573 federally recognized tribes.”

Even though the IHS seeks to provide high-quality health services for its native people, the life expectancy of Native Americans is approximately 20 years shorter than the national average. According to a report by NPR, health programs for Native Americans are chronically underfunded. NPR contributor Eric Whitney writes, “Congress has long failed to allocate enough money to meet Native American health needs. In 2016 it set the Indian Health Service budget at $4.8 billion. Spread across the US population of 3.7 million American Indians and Alaska Natives, that's $1,297 per person. That compares to $6,973 per inmate in the federal prison system.”

In addition to the problem of underfunding, one quarter of Native Americans reported feeling discriminated against when going to a doctor or health clinic. Accusations of discrimination are due, in part, to the fact that outside of IHS providers, hospitals in the private sector do not see many native patients. Another contributing factor to the small number of native patients at non-IHS hospitals is the fact that many Native Americans are uninsured and unable to afford insurance. Whitney also writes, “The IHS isn’t insurance. It’s more like the Veterans Administration, running clinics and hospitals where its members can get care. But the IHS is far smaller than the VA.”

When the IHS cannot provide appropriate operations or surgeries, Native Americans often find themselves getting denied and/or having to wait long periods of time (sometimes years) on the approval for follow-up care.

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33 https://www.ihs.gov/aboutihs/
34 https://www.npr.org/sections/health-shots/2017/12/12/569910574/native-americans-feel-invisible-in-u-s-health-care-system
The Trump administration has pledged to make the IHS more effective. Although the president’s inaugural budget (proposal for 2018) included $300 million dollar cuts to the agency, the administration reversed this proposal a year later and asked congress to provide an increase from $5 billion dollars in spending to $5.4 billion.\(^{35}\)

The administration’s pick to lead the IHS has also been controversial. Reporter Andrew Siddons writes, “On Feb. 21, the administration said its pick to lead IHS was no longer in the running for the job. Robert Weaver, a health insurance consultant with ties to Oklahoma’s Quapaw tribe, was nominated for director in October. But he was dogged by questions about whether he was qualified to lead an agency whose leaders typically have backgrounds in medicine or hospital administration, and his chances of winning Senate confirmation seemed troubled.”\(^3\) Whether or not the pick is qualified for the position, the proposed $4-billion-dollar boost in funding is not enough to fix the problems within the IHS, according to Oklahoma Republican Rep. Tom Cole. In 2019, the IHS budget increased to 5.8 billion dollars.


\(^{36}\) Image source: National Center for Biotechnology Information
Questions:

1. Is it ethical to segregate health care services for Native Americans, or do you think that it follows from the treaty described in the case that Native Americans should be able to visit and receive care at any hospital of their choosing?
2. What improvements could be made to help Native Americans feel less discriminated against when receiving medical care?
3. Beyond funding concerns, what interventions are needed to improve the health and health services of Native Americans?
Case 12: Organizational Ethics in the Emergency Department

Susan is a 67-year-old woman suffering from advanced metastatic breast cancer. She was diagnosed with cancer seven years ago. She is a health-conscious person, and the cancer was detected early and treated aggressively with surgical tumor removal followed by adjuvant chemotherapy. Due to early detection and aggressive intervention, Susan was able to battle her cancer into remission. Having fought through many months of fatigue, nausea, cramping, vomiting, and pain, Susan worked hard to improve her health. She felt things were looking up, but 18 months later, the cancer returned. Susan elected to fight it aggressively again, maintaining her positive attitude. Her tumors were more aggressive, but repeated rounds of chemotherapy and radiation sent the cancer into remission once again.

That was four years ago, and since that time, Susan’s immune system has remained compromised. She suffered other lasting effects of aggressive cancer treatment, as well. For example, peripheral neuropathy has caused her constant pain that is only partially managed by strong opioid therapies, which themselves induce fatigue, nausea, and constipation. The neuropathy makes walking difficult, and Susan is exhausted by the smallest exertions. She has worked diligently to rebuild her health, always more upbeat than it would seem possible for someone who suffers as she does.

Two years ago, the cancer returned. Despite all attempts at treatment, it has become much more virulent. It has metastasized and spread into Susan’s liver, lungs and lymph nodes. Susan’s oncologist indicates that while the five-year survival rate for stage 4 breast cancer is approximately 20-25 percent, Susan has no realistic chance of either another remission, or surviving to the five-year mark. Even if she did, her chronic pain, neuropathy, and fatigue would continue to worsen; she will likely become bed bound as the cancer spreads to her bones.

During her initial fight with cancer seven years ago, Susan discussed the matter with her husband and made a living will specifying that she does not want aggressive life-sustaining treatment if there is no possibility of, if not cure, at least remission. All her life, Susan exercised, ate well, and enjoyed being physical—spending time outside in her garden, hiking, and travelling. With the onset of the neuropathy and chronic pain (following her first relapse), she could no longer do those things. Having lived with that for four years, she gathered her family together and explained that while she loved her life and her family, she had lost many of the things that made
life enjoyable, and the progressive loss of function and debilitating pain degraded her quality of life further still. Her family agreed to support her decision to complete a MOLST form (Massachusetts Medical Orders for Life-Sustaining Treatment) which made explicit her desire not to be either resuscitated or kept alive using artificial means of life support. The MOLST form was completed and signed by her physician. Susan’s family honored her wishes by ensuring her oncologist had made the form part of her electronic medical record and posted a copy on her kitchen bulletin board should EMTs be called to her home.

Susan has just been brought to the emergency department following a suicide attempt. Her living will states that she refuses both CPR and artificial life-sustaining treatment. However, Massachusetts law requires physicians to attempt to revive patients who have attempted suicide, since many suffer from mental health problems that once treated, relieve their desire to end their lives. But, Susan is known to the hospital staff. She does not have any mental health problems, and has been suffering terribly from a fatal disease. Unwanted medical care constitutes battery. Consent to medical treatment for competent adults is a foundational principle of biomedical ethics. However, suicide has been called “a permanent solution to a temporary problem,” and the state has an interest in protecting the lives of those with mental illness who attempt to take their own lives.

Questions:

1. As the clinical ethicist on call when Susan is brought to the emergency department, you are asked by the attending physician whether or not the MOLST form should be honored in light of this being a suicide attempt.
2. Is this issue most appropriately handled by the clinical ethicist, or the risk manager?
3. If the risk manager states that Susan must be revived and aggressive life-sustaining measures used, do you alter your ethics case note to support the decision?
Case 13: Ultra-Personalized Medicine

The New England Journal of Medicine has identified the first known custom treatment for a disease of genetic origin. The drug is called Milasen, and it is named for a young girl named Mila Makovec. Mila has a condition called Batten’s disease, a rapidly progressing and fatal neurological disease that is recessive, meaning both of her parents must give her the mutated gene for the disease. Upon inspection of her genetic code, researchers found that Mila only had one mutated gene, and the other gene was located on an extraneous piece of DNA, leading to the scrambling of an important protein. Dr. Timothy Yu of Boston Children’s Hospital proposed that a custom piece of RNA could block the effects of the extraneous DNA, however, this drug would be extremely costly. Mila’s mother used money from her foundation along with $3 million from a GoFundMe campaign to pay for the drug, which was cleared by the FDA and given to Mila via spinal tap starting in January of 2018. Mila may be too old to fully recover from Batten’s disease, but her mother says she hopes that personalized medicine might help any younger children with a rare disease. Personalized medicines for rare genetic diseases are very new, in fact of the over 7 thousand known rare diseases (below 1 in 2 million), less than 10 percent have an F.D.A.-approved treatment. Milasen is a new step forward in personalized medicine, deemed ultra-personalized medicine, because it is designed for a single patient.

The only other instance of medicine being personalized for a single patient is CAR-T cancer therapy, although these therapies are not drugs like Milasen. CAR-T therapy is one of the forefronts of immunotherapy. CAR-T cell therapy has primarily been used in clinical trials for patients with advanced blood cancers. It has been deemed a “living drug” because the therapies rely on T-cells to orchestrate an immune response to the pathogenic cancer cells. T-cells must be drawn from each individual patient and genetically engineered with receptors to target an antigen on the tumor cells. CAR-T treatments, until recently, were seen as ‘boutique therapy by researchers because of their high cost and small, defined patient groups. However, the CAR-T therapy field has grown quite a lot in the past 5 years has brought a new enthusiasm about the treatment. However, the cost is still an issue, with a single treatment costing as much as $375,000 and

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Medicare only covering costs in FDA-evaluated healthcare facilities. The next step forward in CAR-T therapy is de-ultra-individualizing care by creating off-the-shelf therapies derived from healthy donors.

Ultra-personalized, or precision, medicine is said to be the next frontier in medicine. We are presently in the era of pharmacogenomics, creating drugs based on clinical outcomes and patient responses to drugs. In the future, medicine will not be tailored from a group of people and then given to the masses, instead medicine will be personalized for each person, taking into account everything from their lifestyle to their genome.

While precision medicine may be the way of the future, in the era of pharmacogenomics the individual research is costly and time-consuming. With this new frontier, the job of the clinician conflicts with the job of the clinical researcher. The clinician’s goal is to maximize an individual patient’s health, but a clinical researcher’s goal is to produce research that is useful to all of society. The healthcare industry, a large as it is, is truthfully overwhelmed when it comes to the amount of resources available. With limited resources, as of now, it is impossible to make custom drugs available to everyone. Is it ethical to ask a clinical researcher, who is meant to work to benefit the common good over the individual, to dedicate scarce resources to benefit the individual over the common good? Wealth inequality is also a factor, with custom drugs only being financially attainable by the rich elite, in Mila’s case her mother’s successful foundation. The FDA must also answer the question of how it is going to clear drugs for personal use if the only person they can use for clinical trials is the patient the drug is designed for.

Questions:
1. Is it morally justified use of clinical researchers’ time to devote their time to ultra-personalized drugs?

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42 Gameiro et. al, "Precision Medicine: Changing the way we think about healthcare” Clinics (Sao Paulo). November 23, 2018. [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6251254/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6251254/)

2. Is it just that only the very wealthy will have access to ultra-personalized medicine?
3. Should the FDA revise its clinical rules to suit ultra-personalized medicine?
Case 14: Savior Sibling

In the early 1990s, Molly Nash was born with Fanconi anemia, a rare disease that results in the decreased production of blood cells. Only a toddler, her bone marrow started to fail. When a bone marrow donor couldn’t be found, it seemed hope was lost. That is, until Dr. John Wagner, director of the Division of Hematology-Oncology and Blood and Marrow Transplantation at the University of Minnesota, stepped in. Using a procedure that increases egg production, embryos could be genetically diagnosed before implantation and then born as an ideal match through in vitro fertilisation (IVF). Lisa and Josh Nash, Molly’s parents, decided to have a baby that was selected to match Molly's bone marrow perfectly. Lisa conceived a son, Adam, and immediately after his birth, doctors used the blood of the umbilical cord to give Molly a life-saving transfusion.

Most parents are willing to do anything to keep their child safe: "It was my baby and you know what, I was going to take care of her no matter what she had," Lisa Nash once said. The benefits of preimplantation genetic diagnosis (PGD) can be very high. Parents can screen for known genetic diseases or conditions, preventing unhealthy embryos from being implanted. This can decrease the risk of having a child who will inherit a disease from a parent. And, as in the Nash’s case, it can be used to screen for genetic matches. However, this procedure does not come without risks. Using IVF-PGD, there is only a 54% delivery rate. Further, tests cannot check for every type of disorder and disease; it does not guarantee that a healthy child will be born. Finally, there is always the risk of false negatives.

The Nash’s case is highly controversial, and there are others like it. Starting in the 90’s, cases like theirs have been subjected to much media attention. It even inspired the popular book-turned-movie “My Sister’s Keeper” by Jodi Picoult. Some opponents argue that the procedure is a slippery slope toward “designer babies,” where parents screen for traits such as athletic ability, skin, eye, hair color, height, or intelligence to create the so-called perfect child. There is also a fear of having children not only to collect bone marrow, but to harvest organs.

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Other opponents argue that having a child intended to save a sibling places an undue burden on the new child. The thought that one was brought into the world to provide bone marrow, an organ, or blood for a sick sibling may be a difficult existential weight. The child must live with the fact that he/she is alive to save a sibling.

At the end of the day, what really matters is that the child is loved and cared for. Dr. Paul Billings, a board member of the Council for Responsible Genetics, said: "On the one hand this could theoretically commodify children, but on the other hand there is no evidence that children conceived this way are loved any less. As long as this family loves the child, then we should stay out of their business."47

Questions:

1. Is it morally permissible to have a child to save the life of another? Should doctors offer this option to parents? Why or why not?

2. At what point should the line between parental power and bodily autonomy be drawn? Should parents be able to make the decision for a child to give away biological parts of themselves, even before they are capable of understanding what that means? Explain.

3. Under what conditions, if any, is it ethical to screen embryos for specific traits? Which traits are deemed permissible?

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Case 15: Three-Person Babies

On April 9, 2019, Greek doctors were able to successfully use a controversial method of in vitro fertilization (IVF) which allowed a woman to give birth to a healthy baby boy. What made this particular instance of IVF so remarkable was that the baby boy carried the DNA of three people.

The 32-year-old Greek mother had tried, unsuccessfully, to have a baby through IVF several times before. The new technique was developed for women for whom IVF did not work and for women concerned about passing on mitochondrial genetic diseases to their children. This technique, known as the ‘spindle transfer,’ involves taking the sperm of a man and the genetic material of the mother but also removing the mother’s unhealthy mitochondria (which has its own unique DNA). Then the mother’s mitochondrial DNA is replaced with a healthy donor’s mitochondria. Thus, this new method of IVF results in a child with three three people’s DNA – the mother’s DNA, the father’s DNA, and the mitochondrial DNA of a donor. The mitochondrial donation is small, relative to the genetic material provided by the sperm and the egg, but nevertheless, this form of IVF results in a human who possesses the DNA of three unique individuals (although only two people’s phenotypes).

Some critics of the spindle method, however, feel that the technique should be banned for infertility cases and only used when genetic diseases are trying to be prevented. These critics feel that their has not been enough research done on the potential health risks to the child. Despite the controversy, the Greek doctors working on the project say that there are 24 other women taking part in the trial and eight embryos ready to be implanted.

2018 also marked another breakthrough for IVF. In October of 2018, a lesbian couple residing in Texas, Ashleigh and Bliss Coulter, made history by giving birth to a baby where one partner carried the child in the first stages of embryonic development and then the egg was later transferred to the other partner who eventually carried the child to term. Samantha Allen of The Daily Beast writes, “In this case, Bliss was the “egg source,” meaning that the eggs were harvested from her and inseminated using donor sperm. But then… rather than incubating the eggs outside of the body, Bliss “carried the embryo development for five days” inside her vagina using a small

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50 https://www.thedailybeast.com/these-lesbians-just-made-history-by-both-carrying-their-baby
medical device called an INVOcell capsule.” This form of IVF is actually less expensive than the ‘traditional’ method.

Questions:

1. Morally speaking, is donating DNA any different than donating blood, organs, or tissue, or do you think there is a morally significant difference? If so, why? If not, why not?
2. If the spindle transfer provided a gay or lesbian couple the opportunity to have offspring with both partners’ DNA (although one of the partners would only be contributing mitochondrial DNA) would this be ethical, or should this method should be reserved to prevent genetic diseases?
3. Do you view any of the new forms of IVF described in the case as unethical? What are the potential benefits and problems you foresee for these methods described in the case?

51 https://www.thedailybeast.com/these-lesbians-just-made-history-by-both-carrying-their-baby