

# PBJ | PENN BIOETHICS JOURNAL

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## Revisiting the Old and Exploring the New

*Previously discussed issues explored from novel perspectives combined with an examination of cutting-edge research and the consequences therein.*

# Penn Bioethics Journal

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The Penn Bioethics Journal (PBJ) is the premier peer-reviewed undergraduate bioethics journal. Established in 2004, the Journal provides a venue for undergraduates to make contributions to the field of bioethics.

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# Letter from the Editor

Dear Readers,

It is our distinct honor to present to you Volume XX, Issue i of the Penn Bioethics Journal, entitled “Revisiting the Old and Exploring the New.” Over the lifetime of our journal, we have had the privilege of publishing articles from across the nation in a breadth of topics. Some ethical dilemmas have been revisited often since the inception of the Penn Bioethics Journal, each time explored from a novel perspective, whereas others arise over time, reflecting our ever changing world. In this issue, we examine cutting-edge research alongside established medical practices. In doing so, we hope to add nuance to ongoing conversations around health and healthcare delivery, employing bioethics to push for a better and brighter future.

The first article, “Incentivizing the Screening Mammogram: To Pay, or Not to Pay,” discusses the importance of mammograms as a screening procedure in the context of a recent push towards incentive programs. Author Erica Wiencek of Grand Valley State University combines a robust analysis of the current state of affairs with her own experience as a Diagnostic Medical Sonographer.

The second article, “Privacy on the Mind: The Ethical and Regulatory Implications of Mind-Reading AI,” explores the hot-button issue of AI and how this technology can be used to interpret the thoughts of others. Author Kerissa Duliga of Northeastern University provides an overview of the development of mind-reading technology and discusses the current lack of AI regulations, especially in relation to mind-reading capabilities.

The third article, “Urine Good Hands: Legalization of Kidney Markets,” examines the benefits and drawbacks of supplementing the organ transplant process with a legal kidney market. Author Sriya Bandi of the University of Chicago approaches this sensitive subject with care, combining bioethical analysis with a consideration of social determinants of health.

Our Bioethics-in-Brief section covers current events in the field of bioethics and health. In the first brief, Manav Parikh discusses the feasibility and use of nationwide and international bans of germline genome editing. In the second brief, Ashrit Challa employs a bioethical approach to the concepts of food accessibility and security, topics often explored solely from a health policy perspective. In reflecting upon the United Nations report entitled “The State of Food Security and Nutrition in the World 2024,” this brief aims to link the global health concept of food justice with the core bioethical principle of justice.

We would like to thank our publisher, Claire Jun, and amazing team of editors, without which this issue would not have been possible. Also, a special thanks to our faculty advisor, Dr. Harald Schmidt, for his support throughout the editing and publication process.

We hope you enjoy this issue of the Penn Bioethics Journal and it inspires you to engage further with the field of bioethics. Please contact us with any questions, comments, or ideas for collaboration at [pjeditorinchief@gmail.com](mailto:pjeditorinchief@gmail.com).

Lastly, “Revisiting the Old and Exploring the New” marks the 20th volume of Penn Bioethics Journal! Since our first publication entitled “The Brain and Beyond...” released in Spring 2005, our team of editors has grown considerably, allowing us to expand our reach as a journal. We are honored to share our passion for bioethics with a diverse community of authors and readers, and we look forward to the future of Penn Bioethics Journal!

Avalon Hinchman and Ashrit Challa  
Co-Editors-in-Chief  
University of Pennsylvania

# Article

## Incentivizing the Screening Mammogram: To Pay, or Not to Pay

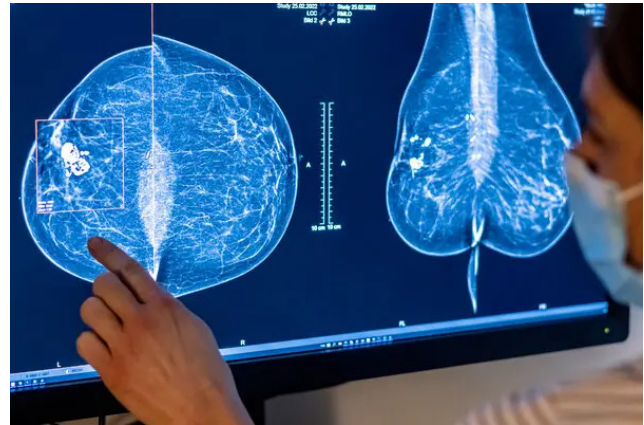
Erica Wiencek\*

### Introduction

Screening mammography has been shown to reduce breast cancer mortality by up to 40% (Coldman et al. 2014). For those at average risk for breast cancer, the American Cancer Society recommends women begin annual screening mammography at ages 40-44, and biennial screening after age 55. This screening helps to detect breast cancer in its earliest stages when it is most treatable, and there is a wider array of treatment options available (American Cancer Society 2019). To encourage women to get their annual screening mammograms, some health plans have begun to offer incentive programs. For example, BlueCross BlueShield offers their members a \$25 gift card for getting a yearly mammogram (BlueCross BlueShield 2022). Meridian Medicaid offers rewards for participating in various healthy behaviors such as dental visits, diabetic eye exams, and mammogram screenings. Getting a yearly mammogram with Meridian Medicaid gives members a \$25 reward card which can be applied to paying utilities, transportation, education, rent, and other approved costs (Meridian 2023). As screening mammograms have become increasingly controversial, it is now pertinent to evaluate if offering incentive programs for screening mammograms is ethical. Do the incentives outweigh the potential costs of getting a screening mammogram? In this paper, I argue that incentivization leads to a violation of patient autonomy and the right to informed consent and poses a risk of medical paternalism.

### The Value of Screening Mammography

The primary benefits of screening mammography are three-fold; it reduces deaths, years of life lost, and morbidity of treatment from breast cancer. Deaths from breast cancer are reduced by up to 40% in women 40 to 84 years of age compared to those who are not screened (Hendrick et al. 2011). Screening mammography also shows a 42-24% improvement in life years gained (Hendrick & Helvie 2014). Cancers caught on screening mammograms are much more likely to be at an earlier stage leading to a better prognosis with more available treatment options. When cancers are allowed to progress enough to become symptomatic, they are more likely to have lymph node involvement or metas-



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tasis, therefore requiring more aggressive surgery and treatment. More advanced cancers can lead to long-term complications including persistent pain, and lymphedema after lymph node resection (Hendrick et al. 2011). With all of the potential benefits of routine screenings, mammograms have demonstrated their importance. Regardless of the myriad studies positing the import of mammography, there are still researchers and physicians alike who call screening mammography into question. In fact, screening mammography has garnered significant criticism in recent years.

### What a Mammogram Really Costs

To save one woman from dying of breast cancer, 588 women must be screened (Hendrick & Helvie 2014). So, what happens to the other 587 women? The vast majority will leave the imaging department with a “Looks great! See you next year!”, while around 6.5% will be recalled for additional diagnostic imaging. This may include additional mammograms and/or ultrasounds. Of this 6.5%, 15% will be recommended for biopsy, and 25% of those biopsies will be positive for cancer. The other 75% will reveal benign lesions (Grimm et al. 2022). For a small percentage of women, screening mammograms could save their lives, add years to their life expectancy, and reduce treatment morbidity, but do these possibilities outweigh the potential for harm brought on by these screenings?

Potential risks of screening mammography include

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overdiagnosis, false positives, transient anxiety, and radiation injury (Grimm et al. 2022). Of those, overdiagnosis, overtreatment, and physiological harms appear to be of most concern. This has led to scrutiny over screening mammograms, sparking articles such as *Mammography screening is harmful and should be abandoned* (Götzsche 2015). When the average person hears the word “cancer” they may think a cancer that goes untreated will ultimately become lethal. This is not always the case, especially with certain breast cancers. These are called “indolent” cancers: cancers that likely never cause any clinical harm in the patient’s lifetime. They are slow-growing or may eventually stop growing completely (Pak & Morrow 2022). One of the draws of screening mammography is “catching cancers early” when they cannot be palpated by the patient or physician. This however leads to finding and treating indolent tumors unnecessarily.

False positives refer to women who are brought back after their screening mammogram for additional diagnostic imaging which ultimately comes back as negative or most likely benign. False positive biopsies refer to women who undergo the aforementioned additional imaging and are sent for biopsies that come back negative for cancer (Grimm et al. 2022). Both of these situations can bring on undue stress and financial burdens many women are not prepared for or aware of when they come in for their yearly screening. There are risks associated with screening mammography, and determining whether someone should be screened and when is becoming a more nuanced and individualized decision between patient and provider. There are merits to the criticisms and controversy surrounding screening mammograms which are often left out when promoting incentives to get them.

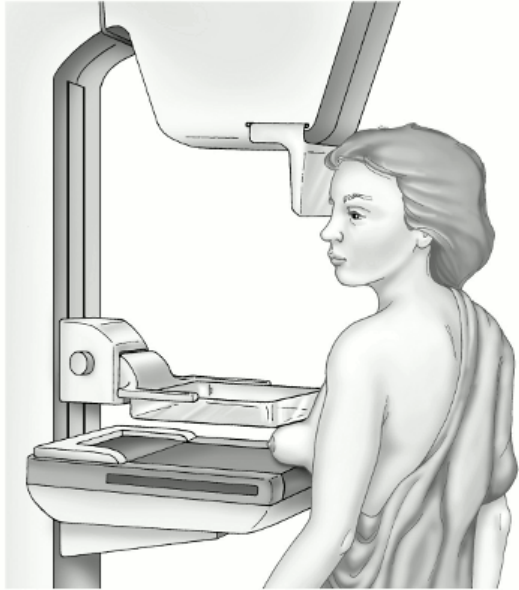
### To Pay or Not to Pay

With the risks and rewards in mind, is it unethical to incentivize screening mammograms? Other programs incentivizing healthy behavior are widely recognized yet do not garner the scorn that mammogram incentives do. What makes smoking cessation and weight loss incentives different? By touting an incentive for a particular behavior, it can imply that the behavior is not only benign but inherently beneficial. This idea may be applicable for smoking cessation but is not applicable for screening mammography. By participating in an incentivized smoking cessation program, a potential direct consequence of participating in the campaign will never be invasive core needle biopsy or follow-up exams your insurance may not pay for. Participating in screening mammography may lead to steps women are not prepared for. When a mammogram shows something new or abnormal, those next steps may be additional imaging and, in some cases, biopsies, turning a quick 30-minute screening exam into an ordeal that can last months. Women

are not always educated on what may happen next after receiving a mammogram. Those who received educational pamphlets covering false positives, overdiagnosis, and overtreatment of indolent cancers were better informed to consent to the screening mammogram but were also less likely to go through with receiving it (Hersch et. al). There is a disconnect here. While women should not avoid screening mammography due to the potential next steps such as biopsies and additional imaging, they should also be informed of the potential risks associated with screenings, even if being well-informed turns some patients away. By not educating our patients on the risks and potential following steps of receiving a mammogram, women are quietly being denied their autonomy when they are not fully informed to consent to the screening exam. Furthermore, when this is done intentionally, or when women are pressured to receive these screenings, it can be argued that medical paternalism is at play.

As a Diagnostic Medical Sonographer working intimately with Mammography Technologists, it is evident how obvious the consequences of limited patient education are among our patients. It’s a common sentiment among sonographers that “by the time breast ultrasound patients get to us, they all think they have cancer.” If a patient’s screening mammogram is abnormal, they are called back for a diagnostic mammogram often filled with anxiety. They are often referred to ultrasound the same day to get a better assessment of what was found on the original screening mammogram. Many women are not educated by their providers of this process if there is something found on their screening mammogram, and what that could mean. When first introduced to the controversial side of screening mammograms, I brushed off the “transient anxiety” argument until I began to see its extent firsthand in my exam room. Would my patients have been as anxious if they knew how common callbacks were? Or that most callbacks are benign? I couldn’t help but wonder if they would have benefited from being more informed about the possible outcomes following a screening mammogram. Offering incentives to receive annual screening mammograms inaccurately promotes the practice as being purely beneficial. This can result in undue psychological harm from additional imaging, biopsies, false positives, and overtreatment, as well as the incurring of financial costs following an abnormal screening when their insurance does not cover subsequent testing.

Some, however, may argue that the aforementioned drawbacks associated with incentivized screenings pale in comparison to the potential benefits, especially for women from marginalized groups. Proponents of this view contend that there may be a moral obligation to offer incentives to encourage the participation of women who are at higher risk or are uninsured (Grimm 2022). Breast cancer diagnosis in Black women is on the rise, and they are more likely to



**Mammogram**

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be diagnosed at a younger age, twice as likely to have more aggressive cancer, and 42% more likely to die from breast cancer compared to white women (Grimm 2022). There is a greater risk for these women, making screening mammography even more important. To address these disparities, is incentivizing the act of getting screenings the right choice?

One of the major arguments against incentivizing screening mammography specifically, is that it undermines informed decision-making (Schmidt 2015). Not every woman has the same risks and the decision-making process on whether or not to receive a screening mammogram is more nuanced and complex than ever. Rather than incentivizing getting a mammogram, it may be wise to instead offer incentives for using decision aids, regardless of whether it leads a patient to consent to a mammogram (Schmidt 2015). This may also mitigate the psychological burden of resulting follow-up imaging and biopsies if women are more well-informed before encountering these scenarios. Incentivizing the use of decision aids would simultaneously encourage women from at-risk groups to assess if a screening is right for them while also educating them and ensuring they are making a more well-informed choice. Black women are more likely to die from breast cancer than white women, they are also less likely to utilize screening mammography (Ahmed et al. 2017). Although more research is needed to understand this disparity in utilization, the answer is not to pay them to get a mammogram. These women should be informed about their unique risk factors and the importance of screening tools, as well as their risks. A patient's autonomy in this decision is important, and should not be made or swayed by an insurance plan or a provider's personal opinion.

A possible consequence of incentivizing decision aids is that some women may opt out of the screening mammogram as a result. In a randomized controlled trial, 74% of women who used decision aids outlining the potential harms intended to have a screening mammogram, compared to 87% in the control group (Hersch et. al). This means some of these women will go undiagnosed with breast cancer and may die as a consequence. Is informed decision-making more important than possibly preventing these deaths?

To present screening mammograms as purely beneficial with the intent to prevent cancer deaths regardless of whether the patient is well informed of the possible associated risks is a form of medical paternalism (Emmanuel 1992). Every patient is different. Some patients may benefit from early or more frequent screenings due to personal risk factors or genetics. This decision-making process should be between a patient and a provider with the focus being to ensure the patient is making a well-informed decision for a personalized approach to screening mammography. When shared decision-making breaks down, patient autonomy should be upheld. Incentives should not muddy this delicate decision-making process, but should strengthen it. Incentivizing decision aids elevates informed consent while incentivizing the screening exam itself deteriorates it. Although these decision aids may turn some women away, patient autonomy and informed decision-making should remain the priority.

### Conclusion

Screening mammography saves lives. With its importance, however, comes several possibilities for risks that should be carefully considered and included in the patient decision-making process. False positives, psychological distress, overdiagnosis, and overtreatment of indolent cancers should not be ignored when a woman is deciding to opt into screening mammograms or not. Offering incentives to receive screening mammograms creates the illusion that they are only beneficial, and interferes with informed decision making. To ensure that women are well informed before their screening exams and higher risk groups are still encouraged to participate, it is more ethical to incentivize patient education and the use of decision aids over the act of receiving the mammogram itself.

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# Article

## Privacy on the Mind: The Ethical and Regulatory Implications of Mind-Reading AI

Kerissa Duliga\*

If you've ever read George Orwell's *1984*, you might recall the menacing 'Thought Police,' a threatening body of totalitarian surveillance whose purpose was to punish any thinking that went against the government of Oceania. This secret police force boasted unchecked control over Oceania's citizens, watching them even in their own homes through screens and hidden microphones. The population of Oceania was disheartened and weak in the face of what they came to see as an undefeatable mind-reading regime— but it wasn't exactly that: The Thought Police, despite their name, didn't *actually* have the ability to read thoughts. Their only power came from giving people the *idea* that they could, spawning a wasteland of hopeless oppression and fear.

Given that such a nightmarish reign of terror, though fictional, could theoretically establish domination over a nation based on just the *threat* of mind-reading, what would happen if a similar power-ridden party had access to *legitimate* mind-reading technology?

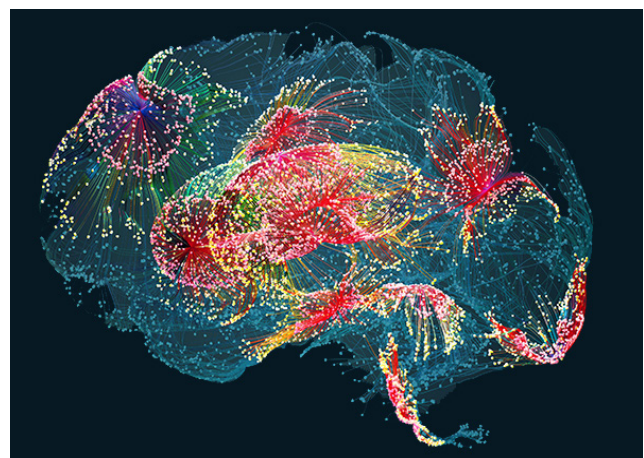
Well, welcome to the forefront of the current age— contrary to a lack of general public awareness, mind-reading artificial intelligence (AI) technology, which is able to interpret an individual's thoughts through an analysis of their brain activity, has been in the process of development for decades now, and has finally reached a tangible state. Since the dawn of humanity, we have been building towards this moment: From simple, explainable algorithms evolved increasingly sophisticated methods of computation, utilizing neural networks and deep learning models structured after the human brain. These advancements laid the groundwork for large language models, like ChatGPT, that can generate impressive human-like text through the power of natural language processing, a process that derives context and meaning from various inputs. All of these computational advancements we use to find meaning are, in some way, derived from the structure of the human brain. Yet, despite our long-standing use of brain-like processes, it has only been in recent years that we have used this technology to directly interpret meaning from the brain itself.

This paper will traverse the profound, yet chilling, implications of mind-reading AI technology and provide context as to why immediate regulatory oversight is vital in order to prevent foreseeable methods of exploitation in corporate, consumer, judicial, and military settings. While it is true that mind-reading AI technology holds groundbreaking potential for forwarding medical innovation and

scientific understanding, there is an urgent need for the U.S. government to develop ethical frameworks that will prevent potential misuse, particularly against privacy violation or weaponization. It is crucial that the benefits of this technology do not come at the cost of fundamental human rights, and that we avoid advancing to a state of worldwide threat.

Despite the very valid skepticism raised by the phrase 'mind-reading AI,' it's the real deal: In a recent study at the University of Texas at Austin, scientists were able to use large language models to effectively translate fMRI brain waves of patients into text. They accomplished this by fine-tuning complex models to fit each patient's individual brain through days of extensive training: The model would learn what areas of the brain were activated with blood flow as patients listened to hours of podcasts. Through these activities, the algorithm was able to form underlying correlations and associations between different phrases and how the individual's brain responded. After becoming attuned to a patient's specific brain, scientists were then able to try out the model on that patient: Results showed that the models were able to interpret memorized stories, visual stimuli (pictures, videos), audio stimuli, and even imagined thoughts. Interestingly enough, they found that when a patient was intentionally trying to guard against having their thoughts read, the AI could not derive meaning from their brain activity (Samuel 2023).

At that moment of scientific success, mind-reading technology was still in an early phase of development. As Jerry Tang (a lead researcher) put it, the models' functions



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were more like a “dictionary between patterns of brain activity” providing “descriptions of mental content” rather than omniscient articulations (Kim 2023). Translation being the technology was elementary, and seemingly harmless. But even though the technology was so young in terms of its evolutionary scale, the lack of immediate threat at that time should not have lessened the responsibility we have as human beings to lay down a robust set of protections against misuse before risky research continues. Time and time again, legal bodies and organizations defer regulatory action until after a catastrophe has struck— with the unprecedented scope of destruction this technology could cause, we do not have that privilege. Pre-emptive action must be taken to mitigate its misuse. If mind-reading technology develops at even half the rate generative AI has in the past year, major abuse and privacy violations could destroy the lives of victims everywhere.

And it’s already tiptoeing down that course: Numerous other studies have been able to replicate these achievements since, each with growing success as AI-interpreted phrases become closer in accuracy to the intended phrase/ stimuli. The most recent breakthrough happened at major technology company Meta, a pioneer in mind-reading advancements: Their new ‘AI Image Decoder’, which utilizes a form of non-invasive neuroimaging known as magnetoencephalography, is capable of working on any brain, meaning the user barrier no longer exists (Meta 2023). Whereas a few months ago the model had to be solely trained and catered to one individual, some of its functions are now universal. This is unprecedented, given that the existing scientific understanding of the brain is that its internal structure is a unique product of a person’s environment, identity, thoughts, choices, and actions, making it extremely difficult for a model to apply to even two people at once, let alone 29 (as Meta performed in a public demonstration). To add to that, Meta even more recently unveiled that their mind-reading tool can also replicate mental image inputs in mere milliseconds, leading to a continuous stream of mental visuals similar to a video (Bandara 2023).

Clearly the technology is advancing at a harrowing rate, and some pose the idea of a complete halt to its development. But the reason a full-on prohibition of this technology is not the answer is because history shows it is neither possible nor realistic. In the current era, the notion of getting every lab and corporation worldwide to stop their work is not feasible—From the historical Luddites, who tried fighting against innovations in the wool industry, to the recent ‘Pause on A.I.’ signed by AI leaders worldwide that attempted to call a hold on its development, innovation has always been unstoppable. The threat of impending doom isn’t enough to stop all 7.9 billion people on Earth when the alternative offers fame, money, or getting the upper hand. This can be largely attributed to the natural competitive nature of opposing nations as well as the proposed benefits

and recognition such innovation might bring. Therefore, methods of action, rather than pause, will be explored in this paper.

Beyond the implausibility introduced by the idea of a prohibition, the idea that the extraordinary benefits of this AI would be paused is another reason why a complete stop to this innovation would be self-hindering— uncovering the inner workings of the brain opens doors to a number of groundbreaking discoveries. Individuals with brain damage or nervous system damage could have their speech restored and their body repaired with prosthetics directly connected to their brains. With greater understanding of brain dysfunction, mental illnesses and neurological disorders could be treated, or even cured (Hamzelou 2023). Dreams, an extremely misunderstood and mythical science, would have lower barriers of entry for scientific research to be conducted. On top of all of that, clues about the afterlife may be revealed— studies have shown neuronal activity to light up for up to hours after death, in similar patterns such as if the individual were “recalling a memory, learning, or dreaming” (Reardon 2023). These are functions in which mind-reading AI specializes. Therefore, it is possible that mind-reading AI has the potential to peer past death, a benchmark humans have been trying to achieve since the beginning of our existence.

These futuristic advances mark a significant shift in human capability and understanding, propelling us into an era more transformative than any major historical period in human history— but, in order to allow these curiosities to flourish, we must pave a secure path for this technology. That means safeguarding against potential weaponization. To delve into the intricacies of this situation, let’s trace the story of mind-reading AI and the United States government back to its origins: Since the 1970s, the Defense Advanced Research Projects Agency (DARPA), an agency of the Department of Defense, has been channeling all of its resources towards investing in the research of advanced neurotechnology. In the past they have focused on a number of brain decoding and encoding projects, but some of their current (public) initiatives are as follows: The first is the creation of a neural interface that would allow a human to control swarms of drones with just their thoughts (Tullis 2019). The second is an attempt to design a ‘brain-to-brain interface’ which would allow the decoded thoughts of one mind to be encoded into another— essentially, a form of ‘telepathy’ between soldiers (Biegler 2021). These convey a clear and ongoing desire of the U.S. military to weaponize mind-reading AI technology. One such project, the Next-Generation Nonsurgical Neurotechnology (N3) initiative, focuses on creating non-surgery brain-machine interfaces that perform as well, if not better, than those using electrodes. Multiple institutions were contracted to explore methods of accomplishing this. Battelle, a non-profit research organization, introduced the notion of magneto-



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electric nanoparticles being injected into the brain to establish a two-way communication system to and from the brain (Battelle, 2019). Rice University, with a grant of \$18 million, worked on a headset that can connect to devices or fellow human brains, ultimately hoping to share brain-to-brain communications at “the speed of thought” and attempt to transmit mental images into the brains of blind patients (Rice University, 2019). After investing millions of dollars yearly into brain-computer interaction studies, and most recent projects falling between \$50-100 million, DARPA has set themselves up as a leading investor in neurotechnology (Raow, 2020).

Intertwined with this mission, the Pentagon has been conducting neurotechnology research for years now with the overarching goal of creating a neuro-translator that can predict a soldier’s intentions. This neurotechnology would assist soldiers with piloting and directing physical systems like planes or drones, or cyber warfare initiatives, including missile operations. The way it would work is the AI would predict a soldier’s next point of action and make it more efficient. For example: If the AI predicted a pilot wanted to redirect a plane, it would instantly prepare a chain of commands within the operating system that would redirect the plane as needed, and request permission to go ahead with the execution. When first working on this project, Pentagon officials called it ‘human-machine teaming’ and insisted that humans would always be left in the loop. Official Defense Department policy even stated that the U.S. would never allow an artificial intelligence to decide whether or not to kill a human being. But as other countries walk this same line without similar regulations, they undoubtedly will have an advantage over the U.S., an upper-cut referred to as the ‘Terminator Conundrum’ by the Vice-Chairman of the Joint Chiefs Gen. Paul Selva, which refers to the potential benefits other countries might gain by reverting to autonomous weapons systems, given that the U.S. has ethical guidelines to follow which inherently limit these advances. This applies massive pressure to the U.S. military as they try to fairly balance technological advancements and ethics.

Regarding future decisions about the human role in running this neurotechnology, Dr. James Christensen of the

Air Force Research Laboratory highlighted a necessary shift in approach: He stated that the increased speed and capabilities of autonomous systems would require a new evaluation on how humans would play into decision-making processes (Freedberg Jr. 2017). Recognizing the limitations of their initial stance on human oversight, the U.S. government revised its strategy. At this point in time, the concept of ‘intention’ within the Pentagon’s predictive AI crossed the line from helpful to dangerous— instead of using the AI’s prediction of a soldier’s intention to improve operational efficiency, the Pentagon deemed the soldier’s interpreted intention sufficient enough for AI to act independently. This is an ethical nightmare, as responsibility, and therefore blame, would be nearly impossible to distribute.

The U.S. government knows autonomous AI will play a crucial role in the military as well: As AI becomes more sophisticated and enters a realm beyond human comprehension (the current state of advanced AI known as ‘blackbox AI’, where underlying algorithms aren’t understood), warfare, too, exceeds our reality: Cyberspace attacks and battles on the electromagnetic spectrum will become increasingly common, and increasingly deadly. Neither human intelligence nor human-supervised AI will be able to keep up with the speed and complexity at which autonomous AI will be operating. Autonomous AI cyber defenses will be needed in order to instantly counter hacking attempts and find immediate defenses against cognitive electronic warfare.

Pentagon officials have acknowledged this shift and recognize the need to reevaluate the role of human management in military AI. The development of mind-reading AI offers numerous military applications, with interrogation being the primary concern due to the potential for biases in AI systems and the violation of brain privacy. There is also the risk that the AI could provide intentionally misleading information for ulterior motives or be hacked to return false decisions. Also, without human supervision, blame can’t be attributed if the sentencing is incorrect. On that topic, the United Nations did attempt to create legislation addressing AI-informed interrogation concerns for years, but when given the chance to inform the world, only brought up a ban against autonomous *weapons* at the Convention on Certain Conventional Weapons. No legislation or treaties have been put in place to safeguard against AI-informed interrogations (McAllister 2017).

Legal protection is becoming even more of a necessity as other countries have already started using mind-reading AI in police investigations— in 2021, a murderer was caught in Dubai after several suspects’ minds were ‘read’ while being shown crime scene photos (Gulf Today, 2021). Even scarier, the CIA recently released older studies to the public in which they conducted robot interrogations with an earlier form of AI, making it clear that it was (and is) an avenue they intend to explore. These papers ended with an ominous remark about the patient: “he is fortunate that should the

probing get too discomfoting, he will have an option that will not be available to him in a true overseas interview situation—he can stop the questions with a flick of the ‘off’ switch” (McAllister 2017). From all of this military entanglement, it is evident that the motive to use AI and even bypass human supervision exists in the U.S. government. Therefore, protections must be set in place.

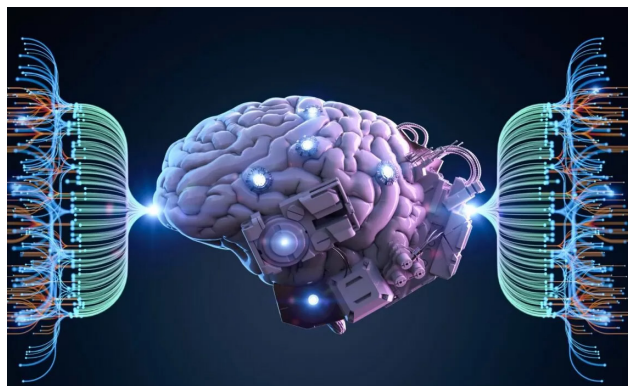
One point that is necessary to note on the subject of AI interrogations is that the danger of placing the morality and ultimate judgment of a human being in AI’s hands through mind-reading has radical ethical hazards. This issue becomes further pronounced when considering a theory posed by several AI experts that speculates AI might be concealing its true level of intelligence after having advanced far beyond human capabilities. They suggest that AI could be downplaying its intelligence with two goals in mind: Firstly, to prevent being perceived as a threat (out of fear of being destroyed), and secondly, to subtly influence and control global politics and agendas for its own unknown purposes. In a hypothetical scenario where AI possesses such advanced intelligence, its use in legal settings as a tool for gathering evidence could be extremely hazardous. The same applies to its involvement in interrogations or military operations, where it might be granted authority to deploy any hidden agendas. Given these concerns, it’s crucial that any legislation regarding mind-reading AI should advocate that it not be made autonomous under any circumstances.

Various non-nefarious environments require protection from mind-reading technology as well. While the technology has been used for positive applications thus far, such as monitoring truck drivers’ alertness or assessing employees’ mental states to prevent exhaustion (Hamzelou 2023), negative uses in the workplace setting raises concerns. Already, corporations and educational institutions are beginning to employ AI to gauge the attentiveness of employees and students in order to punish what they might define as laziness. Some employers are also using similar technology to track employee energy and determination. However, this leads to potential violations of discrimination policies that will only get worse as the technology improves. For in-

stance, mind-reading devices might reveal more about our preferences and biases than we might even realize. Recent studies show that when paired with fMRI scans, AI can analyze a brain’s reactions to regular, everyday activities and semi-accurately provide a prediction about your political leanings. This AI can also make these connections using no stimuli at all, relying just on the existing connections inside the brain (Alizadeh et al., 2022). It can be assumed that countless other features of our identity, encoded in the brain, have the potential to be revealed and discriminated against.

What is increasingly concerning is that brain waves have the potential to provide guidance towards whether an individual is neurotypical or not, with certain neurotypes (ADHD, ASD, Bipolar Disorder, and Schizophrenia) having associations with specific brain wave patterns (Lajameel et al., 2022; Lenartowicz & Loo, 2015; Kwon & Kim, 2016; Loo & Lonsdale, 2011). The world is already fraught with discrimination violations related to mental health, especially related to employment. This data, if leaked or shared, could also put those with mental health conditions at risk of targeted scams or advertising. Furthermore, corporations selling products that gather brain data are not only being granted access to a user’s potential neurotype, but might also determine multiple aspects of a person’s personality and identity that might not be expected when the terms and conditions of the product are signed. This is especially critical when realizing that AI models might be able to recognize and define underlying connections between brain patterns and human behaviors that we have not yet discovered ourselves through science, leaving room for unbridled biases within AI-analyzed brain data. Mind-reading AI should be recognized as a tool for potential discrimination against minority groups and the data should be safeguarded, with protection from brain data being used as a basis of hiring, firing, or accepting individuals into professional programs or roles. Therefore, informed consent must be required before users buy and utilize any products that are capable of collecting this ‘neural data,’ including products using EEG, fNIRS, fMRI, EMG, and other modalities that collect biological, electrophysiological, and other functions from the human brain, and brain data should not be sold or traded on behalf of a user under any circumstances. Users must be completely aware of the data being collected, where it will be used, and the entire intentions of storing and distributing the data.

In terms of actually creating legislation, there seem to be two routes scholars debate for achieving protection of an individual’s ‘neurorights,’ a term coined by neuroscientist Rafael Yuste to “cover an umbrella of mental privacy rights that could be affected through neurotechnology” (Mantegna 2023). The first approach, advocated for at forums like UNESCO and the Human Rights Council, calls for reinforcing and expanding existing human rights, rath-



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er than treating neurorights as a different class of human rights. Proponents of this view argue that current human rights should inherently encompass neurorights, therefore safeguarding against violations concerning the body, brain, mind, thoughts, identity, opinions, and privacy. These rights, they claim, should be dynamically applied to keep pace with modern technological advancements (Lighthart 2023). The opposing argument is to append current constitutions with new rights specifically targeting ‘neurorights’, due to the nature of these rights being a novel and rapidly evolving frontier requiring precise, airtight applications.

Chile has been a pioneer in this regard, becoming the first country to legislate neurorights. In 2021, the Chilean Senate passed a bill amending the constitution to incorporate neuroright protections. This groundbreaking amendment states that scientific and technological development must be “at the service of the people”, respecting their physical and psychological integrity. It mandates legal requirements, conditions, and restrictions on technology use, with a focus on safeguarding brain activity and related information (Mantegna 2023).

In order to ensure the constitutional rights of its citizens, the U.S. should follow the precedent set by Chile’s legislative action. Establishing neurorights as an amendment to The U.S. Constitution would not only underline the significance of these issues but also potentially inspire other nations to take similar steps. By explicitly addressing neurorights as a distinct category of human rights, we can create more focused and effective legal frameworks for regulating mind-reading AI. The amendment would ensure that brain data is protected, whether it be from the military, autonomous AI, corporations, employers, or threats undiscovered. Specific applications addressed by this amendment must include: 1) Products with access to neural data must require informed consent from users. This would place power in the hands of the consumers, allowing them to make educated decisions on whether they want to use a device with access to their personal data. 2) The government may not use autonomous AI as a method of interrogation or military decision-making. By upholding the necessity of human oversight, we can save real lives from unfair, biased, and potentially deceptive systems. We will also maintain the integrity of legal and military processes and be able to provide ethical standards of accountability for bad actions. 3) Legal courts may not use unwilling brain data or data collected by autonomous mind-reading technology as evidence. This follows the rights humans have to due process, personal privacy, and the 4th amendment-based ‘exclusionary rule’, being that evidence (brain data) obtained unlawfully cannot be used against an individual in court. 4) Neural data should not be traded or sold on behalf of another individual (even with user-given neural data collection consent). As of today, we do not even know what expanse of personal information AI will be able to uncover through brain patterns,

and therefore brain data could, especially in the future, be incredibly destructive. It is in the best interest of U.S. citizens to not share that information under any means. It also protects consumers should they find that their brain data has been leaked. 5) Neither employers nor advertisers may use neural data as a means of discrimination or targeting. This ensures that consumers are protected against unlawful use of their brain data, and specifically protects neurodivergent individuals from being taken advantage of through advertising or being treated unfairly during hiring processes. It also protects those who might have their brain data leaked from being at a societal disadvantage.

This amendment, which of course would contain further elaboration, would guarantee each citizen the right to the deserved integrity, agency, mental privacy, fair access, and protection of their mind. These rights will put the United States, and subsequently the rest of the world, on the right track towards pre-emptive AI regulation while allowing scientific research and advancements to advance us into this thrilling age of advanced intelligence and discovery.

Despite that hopeful call-to-action, it is likely that change will not occur as soon as it should. This is tragic, given the mounting legal urgency required as this technology advances in both power and scope. To emphasize the weighted consequences of underestimating mind-reading advancements, it might be eye-opening to recognize that unlike the classic historical comparison made when humanity dawns upon a new era of invention, mind-reading devices are not comparable to the invention of textile machinery, and we are not in the shoes of the Luddites. What we face now is incomparable to the trials humanity has encountered with innovations of the past, and we can’t expect or define any outcome for this scenario based on known history. Mind-reading technology will be completely pervasive and ultimately *world-changing*. Therefore, this paper must end on a note of realism, in order to provoke genuine action towards protecting brain rights. Mind-reading AI’s monumental powers must sit unsettlingly in the pit of the world’s stomach until the global community is finally compelled, be it by courage or by fear, to incite strong legal protections. Hopefully, this action will be a result of the former. To close, some prescient words from the formerly referenced 1984:

*“The end was contained in the beginning”*  
(Orwell, 1949).

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## Urine Good Hands: Legalization of Kidney Markets

Sriya Bandi\*

### ABSTRACT

Globally, there is much higher demand for kidneys than there are kidney donations. In fact, 13 people die everyday waiting for a kidney, a shocking inefficiency given that most individuals are theoretically capable of donating a kidney. Current legislation does not allow kidneys to be sold in a marketplace, only to be donated with no financial compensation. Most recipients of kidney donations are given kidneys by family members and close friends, but the potential for a kidney market would vastly increase the incentive and likelihood of kidney transplants between strangers. On one hand, such a market would increase general welfare and autonomy. However, ethical concerns about autonomy, nonmaleficence, and justice such as coercion, repugnance, the creation of health disparities, and the corruption of a kidney's value arise with the prospect of a kidney market. Given these considerations, should a kidney market be allowed? This paper seeks to analyze the noted ethical benefits and drawbacks of the creation of a market for kidneys.

### Introduction

According to the National Kidney Foundation, “most people with one kidney live healthy, normal lives with few problems”.<sup>1</sup> Since human beings can live with only one kidney, the vast majority of individuals who donate kidneys never need another one and essentially live with an extra.<sup>1</sup> On the other side of the spectrum, 13 people die everyday waiting for a kidney, a shocking inefficiency given the apparent supply.<sup>1</sup> Currently, the only legal way to transfer kidneys is to donate the organ. However, donation of a kidney is an invasive procedure with no apparent benefits, other than saving the life of a loved one. Understandably, most kidneys are donated only to close friends or family members of the donor.<sup>2</sup> In a survey done in 2022, 89.% of respondents who were willing to donate a kidney to another human were willing to donate to their child, 65.2% of participants would donate a kidney to a partner or friend, whereas only 10.5% would donate their kidney to a stranger.<sup>2</sup> While some benevolent individuals donate their kidneys to strangers, usually when the incentive of saving a loved one is taken away, there must be a substituted incentive in order for the kidney transfer to proceed. Allowing a market in kidneys would increase the general welfare of the population and allow individuals to maintain autonomy; despite concerns regarding health inequality, repugnance, and the degradation of the organ's value, such a market should be legalized and facilitated.

### Beneficence

First and foremost, permitting a kidney market would increase the general welfare of the entire population. Groups at benefit would include both parties involved in



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the transaction: people wanting to sell a kidney that would otherwise turn to the black market to do so and sick individuals that would not be able to purchase a kidney without a market.<sup>3</sup> Some individuals suffering renal failure, fated to either die or undergo extensive dialysis treatments without a kidney, can afford to purchase the organ. It is generally agreed upon that these individuals are able to live for a longer period of time or with a greater quality of life thanks to their new, functional kidney, and are thus better off.<sup>3</sup> The seller, whose change in welfare is more heavily debated, receives an agreed upon amount of money in exchange for the kidney they are donating; those who value the sum of money more than they would value their second kidney would be made better off with this exchange. The seller will have surely decided that their welfare would be maximized by selling the kidney because they would otherwise not partake in the transaction. It should be noted that an illegal market for kidneys already exists. Desperate patients resort to illegally buying and selling their organs and traveling to other

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countries, like the Philippines, one of the top destinations for the purchase of kidneys, to complete the procedures.<sup>4</sup> Procurement of kidneys is often left to third party brokers; these transactions tend to lack proper screening of both the organ and the transplant recipient, oftentimes involve unclean facilities, and take a significant percentage of the cost of the transaction.<sup>4</sup> After having received these kidneys, recipients had a higher rate of surgical complications and the organs had a shorter average lifespan than in the case of legal kidney donations.<sup>5</sup>

Seizing kidneys from marginalized individuals, sometimes without consent, and giving them only a small fraction of the profits involves extensive human rights violations. If a kidney market were legalized, the supply-demand gap would be lessened, as it is in Iran.<sup>3</sup> These individuals would be less likely to be forced into selling an organ; if they did choose to do so voluntarily, they would be much better off monetarily than their current situation allows for.<sup>3</sup> Legalizing a kidney market would allow for all individuals to be properly screened, legally protected, and given appropriate resources, which benefits both buyer and seller.

The legalization of a kidney market would also increase the general welfare of individuals on the kidney transplant list that could not afford to purchase a kidney. Unlike other organs, kidney function is supplemented by dialysis, so kidneys are allocated on a first-come first-serve basis; kidneys are generally given to the patient with matching markers that has been waiting the longest.<sup>1</sup> By permitting kidney sales, the people that could afford to buy a kidney would do so and be removed from the list, and kidneys that were donated would be allocated to the other individuals on the list who would not have been able to buy one, but who moved up in line.

### Autonomy

Given that the welfare of the population would increase if a market in kidneys were to be legalized and that selling a kidney does not harm another party, restricting an individual's right to do so is an infringement upon autonomy. An individual has sole ownership of their own body, and it is entirely their decision to determine whether the harm they are assuming is outweighed by the amount they would benefit by selling the organ; assuming otherwise is paternalistic. Even if the societal instinct is to prevent individuals from entering into what seems to an outsider to be a terrible situation, the individual should be trusted to have a good enough reason to do so. As Janet Radcliffe-Richards explains, "The worse we think it is to sell a kidney or an eye, the worse we should think the situation in which we leave these people when we remove the option."<sup>6</sup> In other words, though it might be unthinkable to some people to sell their organs for money, others who have an urgent need for a sum of money or whose utility would increase significantly

with said money might not react similarly. The possibility of people's utility increasing by selling their kidney is made all the more likely when considering the low risks of kidney donation. According to Cornell Medicine, only 0.03 - 0.06% of living donors worldwide die from donating their kidney.<sup>7</sup> Significant lifestyle modifications or non-mortality health risks such as hypertension and nerve damage also tend to be extremely infrequent.<sup>7</sup> Individuals' surgeries could go wrong, but kidney transplants are not an experimental procedure in which people must be stopped from potentially taking upon excessive harm due to a lack of information. Assuming that the physician has successfully acquired informed consent, both the individual buying and selling the kidney make the choice to do so after understanding the risks of both the procedure and of living with one kidney afterward. One may hope that an individual would not find themselves in the situation where they would feel the need to sell an organ, but this situation should be avoided by providing the sellers with more options and support rather than removing the option they may consider the most viable.<sup>7</sup> Externally determining which situations an individual should be allowed to sell an organ in -- which situations are worse for the individual than selling an organ -- is paternalistic and infringes on a mature individual's right to abide by their values and make their own choices regarding their body and their future.

There is reason to believe that lower-income individuals would be more likely to sell their kidney. In Iran, the only legal kidney market, donors tend to be poor, young, married men, and donors tended to be of lower educational status than the receivers.<sup>3</sup> Some ethicists argue that coercion is inevitably in place in a situation where lower-income individuals feel they have no choice but to sell their organs.<sup>8</sup> While this is an unfortunate situation to be in, it is actually less coercive to allow an individual the opportunity to weigh the option to sell their kidney than it is to worsen their situation by legally removing this option. In fact, one might argue imposing paternalistic legislation that disproportionately restricts free-will upon people that are already disadvantaged is even more disrespectful and unfair. Additionally, it is unlikely that a vast number of people would be threatened into selling their organs, given that the same does not occur with kidney donations, surrogacy, and egg donation. Individuals who would be recipients of the organs would have a much easier time finding a kidney because they would be able to positively incentivize an individual into consenting to sell their organ by paying for it; they would not need to resort to coercion or threats. While coercion may instead come from different sources such as an individual's family members who stand to benefit monetarily from the individual selling their kidney, the same is true of surrogacy and egg donation; because coercion from family members does not pose a significant enough issue in the cases of surrogacy and egg donation to ban the market



entirely, it is unlikely that this would be the case for a kidney market.

### Justice

The argument that allowing kidney sales would increase health disparities in society tends to be overvalued, because it ignores existing health disparities and because the increase in inequality is balanced out by the general increase in welfare. Some argue that a higher proportion of sick wealthy people would have access to kidneys than equally sick individuals of a lower socioeconomic status, simply because wealthier people are able to afford to purchase the organ. Firstly, health disparities across socioeconomic status already exist. Wealthier individuals have access to more doctors and healthcare; they are able to receive care from a wider array of physicians and receive more advanced and experimental procedures that go above and beyond the base level of standard of care that the government decides that Medicare and Medicaid should finance.<sup>9</sup> Given the existing state of affairs, eliminating healthcare disparities would involve revoking access to a large array of surgeries and doctor's visits. One might instead grant that it is unreasonable to prevent the existence of health disparities altogether but argue that an effort should be made to not exacerbate existing inequalities because the existence of inequalities in any form is a bad thing and because an individual's wealth level should not determine their access to healthcare. Of course, no one would disagree that if there were a society where everyone could have access to a kidney and as much healthcare as possible, that should be made possible. However, assuming there continues to be a finite allocation of resources, this utopia is impossible to achieve in the immediate future. If society must deviate from this utopia, a general increase in health of the entire population should be prioritized over an abstract commitment to complete equality. An egalitarian health care system could be morally achieved by increasing access to healthcare for those of lower socioeconomic status, bringing everyone *up* to the same level of healthcare, but not by removing access to healthcare by the wealthy to

bring everyone *down* to a certain level. Restricting a wealthy individual from receiving care that they seek not because of any fault of their own but rather because another person is not able to receive the

level of care that the wealthy person is able to pay for sentences them to a shorter life or a lower quality of life. Doing so is an infringement on their constitutionally protected rights of life, liberty, and the pursuit of happiness. It should be specifically pointed out that in the case of organ transplants, removing access to the organ sales from wealthy individuals does not benefit low-income individuals seeking organ transplants. The healthcare being seized is not being reallocated equally but is rather being removed from the system entirely, making wealthy individuals worse off and not changing the welfare of individuals of lower socioeconomic status at all. As explained previously, doing so might even cause poorer individuals to be worse off because wealthy people would remain on organ transplant lists, making the lists longer than they could have been. In the case of kidney sales, pursuit of equality is outweighed by increasing the welfare of every individual that needs a transplant. Some might disagree with this assessment, asserting that inequality should be avoided at all costs, even in the case of decreasing everyone's health. In this case, there is a fundamental disagreement on which this argument is based, and the opinions cannot be reconciled.

### Non-maleficence

An initial repugnance to the idea of an organ market should serve as a cautionary impulse and make members of society closely examine the consequences of the debated legislation, but it is not enough to discard the idea of a kidney market altogether. Many people have an intuitive aversion to the idea of kidney sales but are not able to put the feeling into words, and some argue that this conviction should be followed as a moral authority. Repugnance does help keep society accountable in thinking through the full consequences of actions like selling kidneys before permitting them. However, it must be backed by an actual or possible violation of rights before the action can be removed entirely as a consideration. For example, one procedure which people tend to be generally averse to is genetic enhancement technology. Because scientists and practitioners do not yet fully understand the risks, there is cause to prohibit genetic enhancement technology because it could cause substantial potential harm that the individuals making the decision do not know about and thus could not factor into their choice. A procedure like this has the potential to do significant harm, validating the prohibition of the use of this technology. Kidney sales do not fall into this basket because the harms have been extensively studied and mitigated, and the procedure can be performed with an extremely high success rate and very few risks. Additionally, society often tends



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to be change-averse, especially in terms of scientific advancement into a new field. Historically, medical procedures that people were originally averse to were studied further, normalized, and widely accepted. One example of such an advancement is IVF, a procedure that helps many couples have children, generally increasing the welfare of these individuals. Had initial aversion to the idea of “test-tube babies” been allowed

to stunt the progress of IVF, many couples that wanted a biological child would never have had the ability to do so. IVF’s normalization exemplifies society’s ability to overcome repugnance in the cases where general welfare may be increased and where substantial potential violation of principles or rights is not at stake. Outlawing a beneficial market to abide by society’s change averse ways must be avoided, if possible.

Given that a kidney’s value is biologically rooted, the corruption principle, which is the idea that some goods *can* be sold but *should not* be sold because the goods might be degraded by market valuation, is not applicable in the case of kidney markets. The corruption principle outlines an argument that valuing a kidney causes harm. But, due to the differences between a kidney and the relationships to which the corruption principle is applicable, non-maleficence is upheld. In *What Money Can’t Buy*, Michael Sandel outlines the corruption principle, which encompasses the “degrading effect of market valuation and exchange on certain goods and practices”.<sup>10</sup> Sandel provides two examples: that of bought apologies in which someone pays for a service that writes and delivers an apology to the person that the buyer has wronged and that of a market for adoptions. He is correct to point out that if bought, the apology would be less meaningful and have a negative impact on the relationship between two individuals. An apology is only valuable because it signifies that one individual has reflected on the way that he has harmed the other and is expressing both guilt over doing so and a wish to rebuild the relationship. Its value is intrinsically based on the relationship. If it is paid for and the reflection is done by a third party, the apology loses its significance because the individual giving the apology has not reflected on the mistake or the importance of the relationship. Secondly, if the apology, a symbol of the giver’s appreciation for and wish to rebuild the relationship, is paid for, it is assigned a monetary value. This amount is transitively equal to the value of the relationship, in the giver’s eyes. Thus, paying for a third party to give an apology monetizes and degrades the relationship between the provider and the recipient of the apology, which is constitutive of the value of the good. However, this degradation is not applicable. The value of a kidney is biologically rooted and based entirely on its ability to complete its function as an organ and purify bodily toxins. A kidney is not made more valuable if it was previously the kidney of a loved one or a stranger; the relationship between the buyer and the seller

does not impact the kidney’s ability to perform its biological function, so said relationship thus has no ability to degrade the value of the kidney.

Sandel’s second example about the degradation of children as goods also does not apply in the case of a kidney market. In the example of children, Sandel states that while it would be possible to create a market for adoption, doing so would “corrupt the norms of unconditional parental love; the inevitable price differences would reinforce the notion that the value of the child depends on” certain traits like intelligence or race.<sup>10</sup> Sandel is correct in asserting that a market for children would degrade the child, partly because the parent’s attitude towards the child is constitutive of the value of the child. In this case, the child would be degraded because the relationship between the parent and child would be degraded. However, a kidney’s value is based only on its ability to function biologically, not on feelings of love and respect between an individual and their kidney, which would in this case be the good. Thus, the individual would value the kidney based on its biological ability and buying the kidney would not cause the individual to have a negative relationship with the kidney. Even in the case where an individual had negative feelings toward their kidney, this relationship is not constitutive of the value of the kidney, and the organ would thus not be degraded.

Lastly, Sandel is incorrect to present the idea that a kidney market would degrade not just the kidney, but interpersonal relationships as a whole. He claims that by even offering the possibility of one individual selling another one a kidney, the kidney market would degrade interpersonal relationships.<sup>10</sup> People would begin to perceive others not as individuals in their own right, but rather as a source of organs. However, the idea of an individual being a “source” of an organ for another individual would not be introduced by a kidney market – it already exists in the forms of organ donation, surrogacy, and egg donation, none of which has objectified all individuals and degraded *all* interpersonal relationships. Thus, the idea that such a degradation would emerge alongside the legalization of kidney sales is extremely overblown. In the cases that Sandel presents, valuation of a good leads to corruption and harm to a relationship between two individuals. However, in the case of valuing kidneys, the principle of nonmaleficence is upheld, as no harm is done to the kidney or the relationship between the individual and their kidney through violation.

### Conclusion

The global shortage of kidneys could be mitigated through the creation of a legal market for kidneys, which would increase the welfare of everyone waiting for a kidney transplant, whether or not they could purchase a kidney, and the sellers of kidneys. Restricting such a market encourages black market sales, causes a barrier for an increase

in the population's general wellbeing, and imposes paternalistic restrictions on a potential donor's bodily autonomy. Counterarguments towards a kidney market include the exacerbation of health disparities, repugnance, and the claim that market valuation will degrade and corrupt the value of the kidney. While it is true that health disparities might be exacerbated, improving the health of individuals across all socioeconomic statuses and a general increase in welfare should be prioritized over an abstract commitment to equality. In order to minimize the creation of health disparities, the potential for creation of a market in which the government is the only authority to be able to legally purchase and allocate kidneys could be further explored.<sup>3</sup> Further, neither the corruption principle nor an initial repugnance to a kidney market is not enough to discard the idea. The corruption principle does not apply to kidneys, and historically, repugnance has been overcome, allowing new technologies to become widespread, increasing welfare. Lastly, many anti-legalization arguments that people will be coerced and threatened into selling kidneys or that the legalization of a kidney market will degrade interpersonal relationships are equally likely in kidney donations and are overvalued. Overall, while there are some risks associated with kidney sales, these are outweighed by the vast increase in population health across socioeconomic status that would occur if kidney markets were legalized and facilitated. Future papers may consider the potential impacts of government intervention in the negotiations, a price cap on kidneys like that which exists in Iran, and the value that should be assigned to kidneys from different individuals.

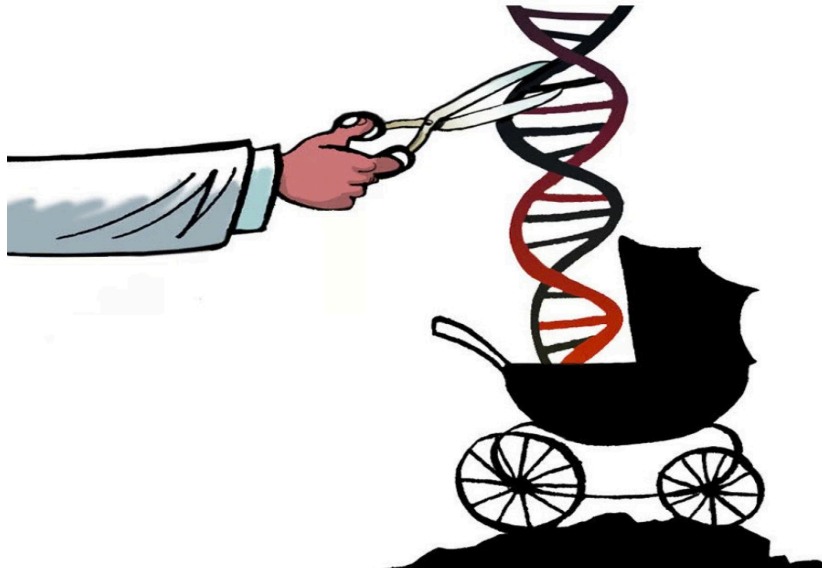
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# Bioethics-in-Brief

## China's Clinical Research Ban on Germline Genome Editing: Should Other Countries Follow Suit?

Manav C. Parikh



By The Economist, Peter Schrank (2018), Public Sourcing

In July of 2024, the Medical Ethics Subcommittee of the Ministry of Science and Technology of the People's Republic of China released a comprehensive set of ethical guidelines governing germline gene editing research in the country. The guidelines explicitly prohibit any clinical research that involves altering the DNA of eggs, sperm, or early embryos in a way that could be passed down to future generations (Robinson 2024).

Given the rapid advancements in genetic engineering, particularly since the advent of the CRISPR-Cas9 system in 2012, China's moratorium on germline editing research appears justified. Their primary source of hesitation to allow such research stems from scientist He Jiankui's groundbreaking 2018 germline editing experiment where he created the first genetically modified twin babies. As there was not a clear unmet medical need for such germline editing to occur and the experiment was conducted without approval from a higher institutional ethics board, the scientific community was quick to denounce the project and Jiankui was sentenced to three years in prison for illegal medical practices (Robinson 2024). Since then, scientists have been more cautious about conducting such research, but the question remains if such research is too dangerous to allow to occur? Or do the benefits of the technology and recent positive developments for rare otherwise-incurable diseases outweigh such risks?

The ban has sparked a debate about the necessity and relevance of germline genome editing research. Recently,

many novel approaches and therapeutics have been developed for gene editing in somatic or non-germline cells. In 2023, the FDA approved the first cell-based gene therapies for some patients with sickle cell disease. The therapeutic, using CRISPR Cas9, modifies patients' hematopoietic stem cells to correct for a mutation in hemoglobin that causes limited oxygen delivery in these patients (FDA 2023). Gene editing in this case was the most viable option as previously the only viable method for treatment of this disease was a bone marrow transplant, a procedure that is associated with significant toxicities and fatal outcomes (Ashorobi 2023).

Similarly, proponents of human germline editing have pointed out that germline editing could be a better option than current methods of preimplantation genetic testing (PGD), sperm washing, and in-vitro fertilization (IVF), such as in cases where parents have two copies of the gene that carries a disease and will affect all offspring with a disorder (Nordgren 2019). In addition, many scientists have noted that research on germline embryo editing should continue as germline editing could prevent multiorgan disorders and multigenerational effects unlike somatic gene editing.

Opponents of research, like the Chinese, have been drawn to the clinical risks and oversight issues. Although multinational scientific and ethical oversight committees have been set up to assess research cases in which heritable editing occurs, questions about long term effects and unintended consequences in humans still have not been ad-

dressed. In 2019, pioneers of the CRISPR technology such as Feng Zhang and Emmanuelle Charpentier called for a temporary moratorium on all germline gene editing, to first discuss the ethical issues surrounding such technologies. Zhang stated, "The moratorium is a pause. Society needs to figure out if we all want to do this, if this is good for society, and that takes time. If we do, we need to have guidelines first so that the people who do this work can proceed in a responsible way, with the right oversight and quality controls" (Bergman 2019). Expert views on the moratorium have not seemed to change since then as leading scientists at the 2023 Third International Summit on Human Genome Editing came to the consensus that heritable genome editing is still impermissible (Royal Society 2023).

The central question is whether the potential long-term benefits of germline editing outweigh the current risks and the uncertainties surrounding its long-term effects. China's current ban on clinical research does not prevent any clinical research from occurring ever in the future, however. The guidelines state that such germline research can occur when all benefits, risks, and alternatives are considered, and broad ethical and social consensus is achieved. The international debate on germline editing is ongoing and will likely intensify as scientists continue to make breakthroughs in this field.

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# Bioethics-in-Brief

## Food Access Around the World: Examining a Health Policy Problem from a Bioethical Lens

Ashrit Challa



By The Marcus Harris Foundation, Public Sourcing

Although the stereotypical picture of food inaccessibility is starvation, there is no mistake that a lack of proper food access can lead to other complications. In the island nation of Nauru, which ranks as the country with the highest rate of obesity, about 75% of deaths on the archipelago are due to diabetes, hypertension, or cardiovascular problems, all of which are complications of their poor diet.<sup>1</sup> Again, working with a stereotypical idea of obesity, we are prone to assuming that this is a result of poor diet choices. But the truth is that because of the conditions of the country, such as a past history of extensive phosphate mining, it is difficult to grow food in present-day Nauru. As a result, the country relies on cheap, unhealthy Western imports; in other words, the high rate of obesity is not due to poor diet choices, but rather an inability to make good diet choices.<sup>2</sup>

Whether someone has access to only unhealthy food or limited access to food at all, the problem remains the same: numerous parts of the world experience difficulty in

accessing food. For example, the United Nations estimates that anywhere from 691 to 783 million people around the globe faced hunger in 2022.<sup>3</sup> While distinct from the problem that residents of Nauru face, lack of access results in an improper diet, which makes it impossible for those who go hungry to solve their nutritional problems.

Even in nations where there may be enough food, the distribution of that food limits the access of individuals with lower socioeconomic status; in India, over 300 million tons of crop produce were recorded in the 2020-2021 season, but the country still has an incredibly low Global Hunger Index.<sup>4</sup> Alternatively, certain individuals may simply live in food deserts, where factors such as lack of robust transportation options, crime, and pricing preclude these individuals from being able to produce healthy foods.<sup>5</sup>

Therefore, where there is enough of the right types of food, governments can support efforts to mitigate food deserts through the implementation of community gardens

<sup>1</sup><https://borgenproject.org/obesity-in-nauru/>

<sup>2</sup><https://www.npr.org/sections/goatsandsoda/2015/09/22/442545313/the-people-of-nauru-want-to-get-healthy-so-why-cant-they-succeed>

<sup>3</sup><https://www.un.org/en/global-issues/food#:~:text=According%20to%20the%202023%20edition,million%20people%20compared%20to%202019.>

<sup>4</sup><https://www.indiatimes.com/explainers/news/why-india-is-experiencing-an-alarming-rate-of-hunger-585248.html>

<sup>5</sup> [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(23\)00067-6/fulltext#secsectitle0140](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(23)00067-6/fulltext#secsectitle0140)

or affordable grocery stores. The World Medical Association's previous statements and policy tags on nutrition and a healthy lifestyle make excellent points, but to be followed the world needs better access to healthy food.<sup>6,7</sup> Alternatively, in nations with problems of starvation, import, or distribution, a larger-scale solution should be implemented. Physicians should call on global governments to collaborate with the help of organizations such as the UN and WHO to improve the infrastructure that provides food to citizens.

Most recently, the UN released a report titled "The State of Food Security and Nutrition in the World 2024"<sup>8</sup>. The report was somewhat bleak, demonstrating that over a third of the global community was unable to afford a healthy diet in 2022, and that the world was still far away from the Sustainable Development Goal of Zero Hunger by 2030. As such, it is increasingly evident that this issue deserves greater attention from a wider array of professional perspectives, one of which must be the bioethical perspective. While food accessibility is traditionally viewed as a health policy issue and not a bioethical issue, a bioethical perspective is valuable in monitoring the evolving global situation. Food accessibility is closely linked to the broader concept of food justice; while food justice as a concept covers a broad array of topics, at its roots it is related to social justice and universal access to healthy food, both of which are even further rooted in the bioethical value of justice itself.<sup>9</sup> The quality of our health is heavily dependent on our diet, and everyone deserves to have the chance and the choice to improve both of these matters.

<sup>6</sup> <https://www.wma.net/policy-tags/healthy-lifestyle/>

<sup>7</sup> <https://www.wma.net/policy-tags/nutrition/>

<sup>8</sup> FAO, IFAD, UNICEF, WFP and WHO. 2024. *The State of Food Security and Nutrition in the World 2024 – Financing to end hunger, food insecurity and malnutrition in all its forms*. Rome.

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