**STARTING THE CONVERSATION: CRISPR’S ROLE IN INDIA**

Abstract: The applications of gene editing technologies such as CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats) have developed significantly in recent years. Several countries have taken stances on the regulation of such technology, however India has not. There is a need for such a development as India’s regulatory, sociocultural, and economic landscape is unique. First, we discuss the uncertainty regarding India’s legal and professional capacity to ethically and efficaciously regulate CRISPR technology. Then, we discuss the possibility that CRISPR could be misused to feed certain sociocultural norms such as preferences for fair skin and sex determination. Given these previous concerns, we posit the question; where on the priority list does CRISPR stand in the context of public health in India?

**PERSPECTIVE:**

Late in 2018, the world stood in disbelief as a Chinese scientist reportedly created two genetically engineered human beings using CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats) gene-editing technology [1]. This development, which was merely a morally challenging thought experiment not so long ago, has led to a host of ethical debates in the scientific community. On a global front, the technology has been growing faster than our ability to reach any sort of moral consensus on its use and regulation. The successful genetic modification of human embryos, and now, human beings, have fueled apprehensions that this technology could one day be used to design and pick babies with certain designer character traits. Would it be ethical for parents to customize a baby that could run like Usain Bolt and sing like Beyoncé? While experts discredit these specific applications as being unlikely in the near future, the ability to control for less complex and highly heritable traits, such as skin color and gender, are not [2].

In response to these scientific advancements countries across the globe have put forth certain restrictions on gene editing. India has not created a framework for regulating clinical trials using CRISPR technology. However, what is clear is that translating these discussions into public discourse is of imminent need. Private companies have already sought to explore the commercial potential of such technology in India and they will surely march forward in due time [3]. Scientists have been calling for the quick development of regulatory guidelines and the country is poised to capitalize on this impactful new technology. However, doing so prematurely could have unintended consequences. In India’s unique sociocultural and professional environment, concerns go beyond science, to the existing regulatory infrastructure and sociocultural landscape. These raise worthy considerations in using such a technology, which when considered within the context of the country’s existing medical burdens, begs the question; to what extent should gene-editing even hold priority in Indian medicine?

Based on the management of scientific technology in the past, it is uncertain whether or not the current regulatory landscape in India would be capable of regulating the prowess of such an immensely powerful technology in a safe and ethical manner. Past developments in genetic technology have been mishandled, demonstrating the capacity (or lack thereof) of India’s regulatory organizations. For example, take the development of genetically modified crops. While the permissibility of these was still being debated in parliament, they were being illegally and prematurely sown in Gujarat in spades, due to their perceived profitability [2]. This was largely due to corrupt practices in Indian regulatory agencies. Corruption within such organizations is so rampant that India’s medical administration is ranked as one of the most corrupt in the world [4]. The Medical Council of India (MCI) and the Indian Medical Association (IMA) have faced countless scandal regarding bribes for the establishment of ventures and even entire institutions. Efforts to hold them accountable through the legal systems have been null and void due to the backlog of cases and only a small fraction of prosecutions have resulted in legal consequences [5]. Therefore, there is little discouragement against the misuse and manipulation of medical technology for personal or commercial gain. The extensive growth of black markets for human organs and counterfeit medicine in India is testament to this statement. India’s black market for organs is one of the largest in the world, with hospital administrators, doctors, and even law enforcement officials regularly caught for the procurement and sale of black market organs [6]. This paints an alarming picture of the state of regulation with regards to medical services in India. Given the impact and intergenerational effects of gene editing technologies, poor regulation in this respect could have devastating consequences. Therefore, even if efficacious and ethical guidelines can be developed, it would be uncertain as to whether or not they can be properly enforced as things stand. As medical technology becomes more pervasive and powerful, the need to address India’s poor regulatory capacity rises as well. Not addressing a system of poorly enforced professional and legal mandates first, before taking on such technological responsibility would be unethical.

The potential for misuse in an Indian context is heightened by a number of sociocultural factors intrinsic to the subcontinent as well. For example, take the all too familiar preference for fair skin in Indian society. The pervasiveness of general concern over skin color is reflected in consumer markets, with the Indian population having spent over $500 million on ‘fairness’ products in 2014 [7]. This sociocultural obsession translates into discrimination against darker skin tones in the professional sphere. In 2012, close to 70% of the surveyed population preferred partners of fairer complexion, and furthermore, many industries including film, hospitality and aviation are marred with cases of active hiring discrimination against applicants with darker complexions [8,9]. To what extent might these preferences take form in healthcare markets when consumers are given tools to manipulate such characteristics?

One of the sociocultural elements that perhaps merits the greatest consideration is one that the Indian medical profession has been grappling with for centuries. Preferences for male children drive some of the most severe ethical breaches amongst the medical profession. In fact, fairly recent technological advances have been shown to empower such preferences, contributing to the vastly skewed sex ratios observed in many Indian states [10]. The normal sex ratio observed for children is 952 girls per 1000 boys, yet in states such as Haryana it remains as low as 830:1000, and states like Punjab, Delhi, Bihar, Gujarat, Andhra Pradesh and Madhya Pradesh all fall significantly short of the mark [11]. According to public health scholars, the increased availability of ultrasound machines in rural areas coupled with poor to no regulation of sex determination laws are some of the driving factors behind these skewed ratios [12]. This is a worrisome trend that results in adverse effects to the Indian population as a whole, the effects of which have been extensively studied. From an economic perspective, according to a report by McKinsey & Co., India’s GDP could be 60% higher in 2025 if women played the same role in the workforce as men [13]. While there is no doubt that other factors (sexism in the work force, systematic patriarchy, etc.) also contribute to an unequal workforce, skewed sex ratios are not an insignificant driving factor. From a social standpoint, empirical studies have also linked skewed sex ratios to the increased likelihood of violent sexual crimes, specifically human trafficking and sexual abuse [13]. Efficacious and ethical regulation of CRISPR technology must take these factors into considerations.

Given the unique sociocultural, economic and regulatory landscape of India, we must also ask to what degree we are willing to allocate resources towards the development and application of technologies like CRISPR. Furthermore, to what extent might gene-editing technology further pre-existing injustice and inequality? It is unlikely that the substantial proportion of Indians who live in poverty, 363 million to be exact, would be the direct beneficiaries of CRISPR [14]. In a country where the top 1% is responsible for 73% of the country’s wealth and 60% of women do not have access to hospital care when giving birth, can we justify further reallocating valuable and limited resources that will likely benefit only the wealthy few? [15,16]. Should we also not be even more cautious if this technology could one day lead to cognitive or physical genetic enhancement for its beneficiaries? As the Western world gears up to allocate resources towards the development and application of CRISPR technology, we feel developing countries like India must bear caution. A technology should have an evidenced and favorable risk/benefit ratio in order to justify a higher prioritization of resources. Approximately 423,000 Indians die from tuberculosis, 205,000 die from malaria and 105,000 die from diarrhea each year, to name only a few [17,18,19]. Interventions that are effective and cost effective exist, and these should take priority.

The promises of gene-editing technologies are discussed and disseminated to great degrees, and with good reason. They represent very real, tangible opportunities at positively impacting the lives of certain patients with certain diseases. However, it is important not to generalize this potential across societies and nations, but to recognize that each country is unique and has its own narrative. The sociocultural factors discussed above have been weaved together with medical practice in India for decades, despite best attempts at regulation. Understanding that a technology with such great potential for unethical use requires more caution than optimism, regulatory efforts going forward must stop to consider these issues in depth.

If India is to pursue advancements in gene-editing technology, it is important that they not conform to the laws of other countries, rather, it is crucial that rules and regulations are created that take into account India’s unique professional and sociocultural landscape, and furthermore, their capacity for ensuring that such a technology is handled responsibly and ethically.

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