

Perspective

Commoning genomic solidarity to improve global health equality

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This article underlines two key asynchronies between prevailing governing logic and expanding practices in somatic human genome editing that are hindering an effective and orderly translation of the new technology into public good. The first is a “genomic sovereignty” framing adopted by a number of non-Western countries that may exacerbate data biases in global research and that directs policy attention away from the necessary structural changes required to achieve non-discriminatory and equitable genomic healthcare. The other is a global deficiency in attending to “science at large”: the challenge of regulating new assemblages of societal interests that advocate controversial or experimental research, often outside of conventional institutions and aided by “policy shopping.” Both issues point to the fact that genomic research does not represent a well-defined scientific commons but rather a domain that requires active “commoning,” with the aim of fostering genomic solidarity that coordinates responsible research within and across national boundaries.

INTRODUCTION

Somatic human genome editing seems to paradoxically bear promises that are both within reach and beyond reach. The excitement brought by genomic research can be demonstrated by numbers. The global gene therapy market accounted for 5.6 billion USD in 2022 and is expected to reach 49.3 billion USD by 2032.¹ Such quick expansion is both due to increasing social needs for therapy and an increasing government recognition of gene therapy as a strategic area for scientific growth and for public health. The development of CRISPR-based somatic human genome editing has further opened up possible treatments to a wide range of genetic and acquired diseases and disorders. The global CRISPR market size was valued at 2,480.95 million USD in 2022 and is expected to expand at a compound annual growth rate of 34.05%.² Yet, there is also an increasing concern that gene therapies might further exacerbate global health inequalities and benefit only “a privileged few.”³ This is not only because of their typical jaw-dropping million-dollar-per-treatment price tag but also because a persistent underrepresentation of people of color in genome databases means that treatments derived from them are leaving communities in the Global South behind.⁴ Furthermore, it is also a field filled with hyperbole, ambition, and a plethora of startups with varying degrees of scientific and ethical credibility.

While pricing and intellectual property regimes have been much discussed in relation to realizing gene therapy’s promise to improve health,^{5,6} this article aims to underline two less-discussed hurdles to a fair and accountable development of genomic research globally. The first is a “genomic sovereignty” framing adopted by a number of non-Western countries, which was conceived as a policy instrument to protect domestic

research competitiveness and benefit sharing against global capitalism. However, as experiences from Mexico and China suggest, it often paradoxically undermines rather than protects the public good in an era of data-driven research, for it adds obstacles to diversifying genome databases. Furthermore, the nationalist rhetoric distracts attention from necessary infrastructure and capacity building within the nation-state. What is needed is genomic solidarity that sees genetic differences not as reasons for an us/them distinction or exclusion but as generators of inclusion and collaboration, that is, as an incentive to necessitate inclusive and reciprocal collaborations between different communities and social groups. The other underexplored governance gap is a global deficiency in attending to “science at large.” This refers to the challenge of regulating new assemblages of societal interests that advocate controversial or experimental genomic research, often outside of conventional institutions and aided by “policy shopping” in developing countries. As the article demonstrates, in some cases, scientific frontiers have become sites for new forms of social activism, creating new socio-ethical concerns and novel forms of research ventures that transcend the scope of traditional regulations. Both issues point to the fact that genomic research does not represent a well-defined scientific commons but rather a domain that requires active “commoning”^{7,8} with the aim of fostering genomic solidarity that coordinates responsible research within and across national boundaries.

GENOMIC SOLIDARITY, NOT GENOMIC SOVEREIGNTY

Genomic sovereignty was a concept first proposed by Mexican legislators with specific concerns over national human genetic resources by foreign entities.⁹ In 2008, Mexico amended its



General Health Act, which is also known as the Genomic Sovereignty Act.¹⁰ It stipulates that the Mexican genome had to be primarily studied “by and for Mexicans”¹¹ and precludes DNA samples from being taken out of the country without Mexico being part of the project or without government approvals. Similar technonationalism¹² can be seen in discussions in Africa,¹³ Brazil,¹⁴ and India.¹⁵ More recently, China’s Biosecurity Law promulgated in 2020 claimed the governance of human genetic resources as part of China’s national sovereignty and underlined human genetic resource governance as a matter of national security.¹⁶ In 2022, China’s Ministry of Science and Technology publicized the *Detailed Implementing Rules for Regulation on Administration of Human Genetic Resources*, which amounts to a *de facto* “ban” on the use of Chinese human genetic resources abroad.¹⁷

For many non-Western societies, invoking genomic sovereignty is a necessary (and belated) correction to historical oppression and a collective resistance to ongoing global capitalist exploitation. Indeed, developed countries have largely benefitted from imposing various forms of (Western-based) monopoly as a global scientific and commercial norm. It should be reminded that the wound created by the coloniality of power in the advancement of the biosciences, especially bioprospecting, is a not-so-distant collective memory for many non-Western societies. Bioprospecting, also referred to as biopiracy, involves the exploitation of biological resources and knowledge belonging to a specific community by external researchers with the aim of generating commercial benefits, such as pharmaceutical and medical products. Lack of informed consent, unfair benefit sharing, irreversible environmental degradation, and violation of human rights and indigenous culture are just some of the widely acknowledged historical harms that have been caused.¹⁸ Take China, a current global power in genome research, as an example. In the 1990s, a series of exploitative medical research endeavors conducted by Western entities in China gained notoriety as the “Gene War of the Century.”¹⁹ One prominent scandal involved Professor Xiping Xu from Harvard University, who collected tens of thousands of blood samples from illiterate peasants in Anhui province without proper informed consent.²⁰ In the early 2010s, Monsanto’s partnership with India’s major seed company, Mahyco, in developing genetically modified eggplant, Bt brinjal, also raised allegations of biopiracy and infringement of indigenous knowledge.²¹ As the worry of continuous bioprospecting looms, many Global South countries have adopted firmer stands on genomic sovereignty¹³ to counteract what Juan Camilo Cajigas termed the “biocoloniality of power,” an exploitation of genetic resources under Western-dominant capitalist logic.²² While the United Nations’s 1993 adoption of Convention on Biological Diversity (CBD) affirms the states’ right to control genetic resources and associated traditional knowledge as part of national sovereignty, the CBD applies to environmental protection and does not pertain to human genetic resources. The “sovereign right” framing to human genetic material and data, as we’ve seen in countries such as Mexico and China, was intended to be an extension of the core principles underlined by the CBD that affirms self-determination, fair benefit sharing, and sustainable development.

However, as demonstrated below, the invocation of genomic sovereignty in major late-developing countries has often been effectively reduced to a centralized restriction of the circulation and sharing of biomaterial and bio-data across national jurisdictions. By overly relying on limiting access, such policy approaches do not offer an alternative to either enhance domestic research capacity or to promote public well-being or fairer benefit sharing. Rather, they replicate a similar hegemonic rationale and exert a form of state-led biocoloniality over managing genetic resources. As biomedical research increasingly relies on data-driven approaches, genomic sovereignty as such may perversely exacerbate global health disparities and impede the scientific progress of non-Western nations. What is needed is to de-link from a “us/them” nationalist framing of genomic sovereignty and to re-link national genetic research policy with genomic solidarity: that is, to promote collaborative and inclusive genomics research and a non-discriminatory culture that can improve health outcomes to diverse communities.

Existing studies have highlighted at least three significant ways in which genomic sovereignty exacerbates global health disparities. First, excessive restrictions or bureaucratic hurdles in sharing genetic data in the name of genomic sovereignty worsen existing underrepresentation of non-white populations, which has already impeded the realization of genomic medicine as a global public good. The value of biological materials, cells, genes, and tissues has never been purely limited to being in and of themselves. Yet, as biomedical research has become more akin to information science,²³ the manifestation of scientific capital in biomedical data becomes more reliant on its circulation and in its utility, rather than in the physical possession of biological material itself. The radical shift on how “value” is identified and realized in genomic materials is best exemplified by the United Kingdom’s long-term plan, Genome UK: The Future of Health Care,²⁴ set out in 2020. In contrast to the data restriction approach adopted by many Global South countries in the name of genomic sovereignty, Genome UK and associated policy papers^{25,26} considered that an easily accessible high-quality genomic dataset is critical to reinforce the United Kingdom’s global presence and influence. The UK Biobank provides “non-preferential access” to researchers in different countries, undertaking health-related research that is for the public good.²⁴ As of 2020, the UK Biobank has approved over 12,000 registrations from researchers based in over 1,500 institutes in 68 countries.²⁴ In fact, 80% of data access applications it receives come from outside the United Kingdom. To be sure, this is not lofty charitable data sharing but is deeply rooted in ensuring long-term national scientific competitiveness. The socio-economic rationale behind “mak[ing] the UK the best place in the world to access genomic data for research” is not difficult to comprehend.²⁴ If the UK’s genomic dataset becomes the core of the world’s cutting-edge life sciences, then the British people will naturally be the most direct beneficiaries of the subsequent medical knowledge and clinical application. It will also help to establish a new norm: “new genomics-based treatments to be sold globally from a UK base.”²⁶ It should be noted that transnational data sharing is not so straightforward. This is partly due to infrastructural and legal issues that are required for safe and responsible data transfer and sharing. But it also due to an

evolving understanding of the value and importance of sharing. The UK example underlines a shift in policy rationale that effective *sharing* of well-curated genetic material and data *globally* has become critical to securing future competitiveness and public welfare.

In contrast, there are worries that the genomic sovereignty framing has made it more difficult to incorporate data from non-white populations into global genetic research and further alienates non-Western bioscientific communities from international collaboration and publication.²⁷ For example, statistics compiled by Deloitte suggested that between 2016 and 2020, while the number of international studies with a Chinese component and corresponding human genetic resource applications have steadily increased, China's approval rate has steadily declined.²⁸ In Mexico too, the sovereignty framing in genetic data sharing has been criticized as incompatible with the needs of contemporary clinical and pharmaceutical research.¹⁰ This approach has hindered opportunities for domestic researchers to engage in international collaborations, limiting their ability to stay abreast of advancements in the field.¹¹

In fact, many have pointed out that the genomic sovereignty discourse is often employed by the state to capture the economic promise of the life sciences rather than being driven by equality and social justice concerns to protect all population groups within the country.²⁹ For example, although India has a much more decentralized governing framework when compared to Mexico and China,^{30,31} an us/them framing in its national ethical framework remains to be problematic. India's latest Ethical Guidelines for Biomedical and Health Research Involving Participants¹⁵ promulgated in 2017 upheld the "principle of maximization of benefit" rather than "benefit sharing" as its central principle. An article in the *Indian Journal of Medical Ethics* further criticized that concerns for distributive justice remained "mainly or only related to international collaborations," while when it comes to domestic research, the language on benefit sharing is "often quite noncommittal."³²

Second and related, this leads to a further concern that was cogently put forward by researchers at Mexico's National Institute of Genomic Medicine. That is, the preoccupation with sovereignty against "the 'others' extracting and exploiting" local human genetic resources has the potential to divert the nation-state's attention away from the fundamental inquiry into the necessary regulatory and technical infrastructures that are needed for responsible sharing to take place.¹¹ For example, in India, as in Brazil,³³ both regulatory and technical hurdles remain for domestic data sharing. In the absence of a standardized publicly accessible database, Indian researchers often find "different hospitals and laboratories adopt different terminologies to record a disease or a health condition and use different reference ranges,"³⁴ which make finding links and cross-comparing genetic information very difficult.³⁴ As I detailed elsewhere,³⁵ in China too, policy makers are more interested in "safekeeping" of human genetic resources rather than the responsible usage of them. There is also a visible segregation of regional biobanks, where there is low willingness and low capability for data sharing across institutions. The associated duplication of investments and low sample utility rate further negate public good. In other words, true genetic sovereignty

cannot be exercised as a purely outward-looking policy mechanism aimed at restricting foreign access. The assertion of sovereignty requires serious examination and investment in domestic capacity building. For genetic research to serve public health and promote social equity, effective and responsible sharing of genetic data across *and* within a country are both needed.

Third, a nationalist rationale in genomic research may reinforce ethnic and racial discrimination within a nation-state.^{14,36,37} It runs the risk of replacing old colonial marginalization with new forms of state-led biocoloniality, which perpetuates disparities in access to healthcare or encourages new medical inequalities. For example, while sickle cell disease is not race limited, discrepancies in how marginalized groups are treated within the health system in Brazil meant that Afro-Brazilians with sickle cell disease need to invoke racial distinctions to claim health rights.^{14,38} What's more important, existing policy and social discriminations, if left unattended, can distort the conception of research priority or place certain social groups at undue risk. For example, Jiankui He's illegal CRISPR baby clinical trial between 2017 and 2018 was not merely a situation where a brazen researcher deceived patients into undertaking unnecessary risks. The pervasive social stigma experienced by HIV carriers in China and the policy precluding HIV-positive couples from accessing IVF treatments were also critical factors that contributed to the HIV-positive couples' perception that the potential risks were "worthwhile." This further underlines the need for nation states to reconsider the limits of current genomic sovereignty framing and the necessity of cultivating genomic solidarity beyond a nationalist lens.

In summary, in data-driven genomic research, promoting responsible sharing and usage of genetic data is a pre-requisite for effective and fair development of medical advancement that promotes public well-being globally.³⁹ Across the world, researchers are forming bottom-up initiatives to correct data bias with better visibility and circulation of diverse dataset. This includes national initiatives, such as the Brazilian Initiative on Precision Medicine (BIPMed), a coalition of five research centers in Brazil dedicated to facilitate genomic data sharing of under-represented populations.³³ It also includes transnational efforts, such as the Global Alliance for Genomics and Health (GA4GH)³⁹ that advocates a "federated approach" to data management and data transfer across institutions or countries.

Nation states, especially those in the Global South, have a significant gatekeeping role to play to make sure that the collection, curation, and sharing of data are ethical and effective and that sensible benefit sharing is enforced, sensitive to cultural differences. The task is immensely challenging, as it needs to both learn the lessons from historical biocoloniality and be attentive to shifting practices of genomic research. As this section demonstrates, the implementations of genomic sovereignty in several non-Western nations are often effectively reduced to a misguided limitation of knowledge and data circulation, which perversely impedes their scientific capacity building and impairs the realization of potential health benefits. This is because the notion of genomic sovereignty, as practiced by these states, does not confront but rather perpetuates the traditional logic of biocoloniality, which subjugates human and natural resources as possessions of a hegemonic authority. Instead, the attention

should be put on genomic solidarity that sees genetic traits not as bases for discrimination (exclusion) but as generators of solidarity (inclusion), that is, as an incentive to necessitate inclusive and reciprocal collaborations between individuals, communities, and populations and between “competing but ultimately compatible interests.”^{40,41} Thus, in contemporary genomic research, true sovereignty comes not from exclusive control of human genetic resources but from the capacity to coordinate responsible and effective management of these resources for the social good.

COMMONING THE SCIENCE AT LARGE

What further invalidates a traditional top-down sovereign approach to govern contemporary genomic research is that science is at large.¹⁹ That is, a growing variety of incentives and societal resources are facilitating cutting-edge biomedical research to be carried out beyond traditional institutional science. It is well documented in previous empirical studies that life scientists may actively “shop for” socio-political environments that can accommodate their research agenda globally, which turns permissive regulatory regimes (or a lack of regulations) into new forms of (scientific and financially) profitable “regulatory capital.”⁴² What further adds to this complexity, as explained in this section, is that genomic research has become a site for new forms of social activism that mobilizes actors and socio-scientific resources transnationally. Their impact often transcends conventional boundaries of public-private categorizations. Thus, good governance of genomic research can no longer be conceived merely within a nation-state framework. This is not a problem unique to non-Western countries but a shared problem globally. However, it further underlines the fact that good governance of genomic research can no longer be conceived through a nation-state lens. National interest is a priority to any country in the world, regardless of their positions in the Global South or the Global North. But no country can be an island in developing contemporary science, for people, ideas, and technical know-hows travel. Not only is sovereign thinking out of sync with how genomic research is organized, but as this section advances the argument further, we need a more fundamental re-thinking of *how* to govern in the face of new forms of research activities. To borrow the wisdom of Elinor Ostrom, we need to recognize that the “scientific commons” is no longer a given, with identifiable stakeholders and a predictable range of strategies and practices. Rather it is a domain that sparks social, political, and technical possibilities at large and thus requires a regulatory humility of *commoning*,^{7,8} that is, a continuous evolution of a shared stewardship through engaging and coordinating with new actors and emerging interests.

A paradox of the current governing approach is that while governments continue to inject new impetus toward public-private partnership and societal investment in genomic research, ethical oversights of these new forms of research enterprises significantly lag behind.⁶ In China, there has been a national push for academics to engage with the industry and private ventures in research and innovation, including the life sciences.⁴³ The vision set out by Genome UK also emphasizes the cultivation of “a vibrant startup economy” that facilitates entrepreneurship and

industry-charity-government partnership.²⁴ A 2020 study shows that in the United States, 36% of gene therapy trials were funded solely by industry.⁴⁴ However, one often overlooked fact is that the composition of “industry” or “startups” is increasingly fluid. They may consist of new entrants who have limited professional training or experience in either the life sciences or in business, or both. Crowdfunding, for example, has become an alternative way to quickly amass social resources to do science. For example, as of the end of 2021, a nonprofit organization, the Alliance for Cancer Gene Therapy, started to accept donations in cryptocurrency to support cancer cell and gene therapy initiatives. Yet, this was not the first time that Bitcoin was featured in supporting genomic research. In early 2019, a couple of months after Jiankui He’s CRISPR baby scandal was widely denounced by the mainstream scientific community, a 29-year-old programmer and a former biotech company lab scientist in Texas together set up a designer baby startup to experiment with human germline genetic engineering funded by Bitcoin, outsourcing preparatory lab research to Ukraine.⁴⁵

In other words, science is “at large” for it receives growing support from diverse sources that transcend the traditional confines of academia, industry, and the private sector, as well as national boundaries. It directly challenges conventional hierarchies of research and regulation. In April 2023, journalist Elizabeth Carr, who was the first American IVF baby, joined a startup, offering unproven genetic testing to score the quality of IVF embryos.⁴⁶ Against the concerns of “consumer eugenics,” Carr considers it a matter of individual choice, “If you have moral objections to the test or you don’t agree with it, don’t use it.” Yet for other startups, the development and promotion of gene therapy can be seen as a form of activism, challenging existing epistemological and socio-economic regimes. Since 2018, there have been number of grassroots initiatives to develop copycat gene therapies for the masses,⁴⁷ defying regulators such as the FDA.⁴⁸ As a co-founder of one nonprofit research lab put it, “It’s about disrupting the narrative”⁴⁸ and to contest the hierarchy of probables dictated by existing capitalist knowledge production. More recently, a Delaware biotech startup called Minicircle has been taking advantage of Honduras’ “innovation-friendly” regulation to recruit participants for a clinical trial of DIY gene therapy, in the name of countering the big pharma system to develop affordable drugs for everyone.⁴⁹ This has the potential to turn its host city Próspera into the latest hub for medical tourism.

Instead of dismissing these grassroots initiatives as outliers, or as deviant from what “should be,” the expanding number of these activities and their potential impact on public health and social values require us to comprehend the landscape of genomic research with a fresh pair of eyes. While many have rightly pointed out that these private ventures bear many characteristics of previous unproven experimental stem cell therapies,⁴⁹ the critical element of socio-political activism (to varying degrees) embedded in these enterprises make them distinctly different from conventional policy shopping. It simultaneously creates hope and adds risk to vulnerable social groups. This is of course not to say that *all* social ventures of genomic research are activism oriented. Some have made the helpful distinction between a “first-generation innovation” or

proprietary innovation, which is mainly driven by profit seeking and problem solving, and a “second generation of innovation,” which builds on broadened societal financial and technical contributions and consequently has attached wider social values to research.⁵⁰ It is more accurate to say most biomedical projects are driven by a mixture of the first-generation proprietary innovation with the second generation of innovation.

The implication for science governance is that as conducting genomic research becomes a vehicle for social activism, conventional attributions, such as “developmentalism,” “lack of oversight,” or “ethics dumping” as reasons for allowing these transnational “outliers” may no longer be a sufficient diagnosis of the situation. More importantly, dismissing this growing number of new players who are outside of traditional colonies of expertise and authorities who are outside of traditional realms of research and industry as unimportant outliers or as threats may be counterproductive.⁵¹ This is not to deny that institutional scientists remain the main driver for research breakthroughs nor to discount professional expertise. But this is to highlight that these new transnationally resourced and networked players’ work nevertheless shapes how emerging science is perceived and received by the public. Science is at large in the sense of socio-technical imaginations being at large, accompanied with a proliferation of societal capacities to indicate, if not actualize, those imaginations. A particular challenge of keeping the global development of genomic research in order is thus to understand and coordinate these diverse visions. This requires more than nation-to-nation dialogues or the harmonization of institutional rules, as cutting-edge science is increasingly supported by an intersection of different social spheres.

As such, ushering in more regulations and demanding compliance from diverse new actors in the science commons may not be effective. Rather we need to take a step back and recognize that instead of a relatively cohesive professional community, the frontier of genomic research constitutes fragmented, disjointed, even intentionally subversive initiatives promoted by practitioners of diverse professional and social membership. Although these new disjointed initiatives vary in their scientific impact, they nonetheless have a normalizing influence over the social perceptions of emerging science, as well as research practices. If we are serious about genomic research being a shared resource to achieve improved life quality for all, then we first need a commoning of the field of genetic research among conventional and new players,^{51,52} that is, to cultivate a sense of shared stewardship and responsibility to manage, curate, and develop such a resource. Commoning is quintessentially about widening meaningful dialogues horizontally. Institutions both in the Global North and in the Global South can facilitate the quality of such horizontal dialogues. For example, in addition to an emphasis of STEM (science, technology engineering, and mathematics) education, there could also be a corresponding emphasis on ELSI (ethical, legal, and social issues) education, not just for the scientific professionals but for the general public. This may appear to be a trivial point, but higher ethics and policy literacy may be a most effective line of defense against unproven experimental therapies or other forms of research exploitation. In addition, as genomic research is increasingly entangled with societal enterprise and an expanding scope of public involvement, public

ELSI literacy should be as important as scientific literacy. While it may be impossible to reach a societal “consensus” on how genomic research should forge ahead, an informed society may help to cultivate a sense of genomic solidarity or what Bernard Stigeler calls “care-ful” thinking,⁵³ that is, the imperative “to think in order to care” that will be essential to guide global coordination of responsible research.

CONCLUDING WORDS

Genomic research lies at the core of national bioeconomies and is a strategic area for national scientific competitiveness. There is an increasing shared recognition of the moral imperative to accelerate global access to the benefit that somatic human genome editing holds.⁵⁴ However, there is also an imperative to re-tune governing visions as to be in sync with the fast-expanding field. The well-worn nationalist approach to human genetic resources should be replaced by fostering collective stewardship and cultivating broader social alliances across and *within* a nation-state. As this article argues, instead of a sovereign thinking that sees foreign access as the primary concern, more emphasis should be put on enabling genetic solidarity through fair and quality data sharing. For non-Western countries, upgrading domestic infrastructure and developing standards that enable fair sharing are more effective than blocking access in securing future competitiveness and public well-being. A simple nationalist us/them framing is also losing touch with the reality that genomic research has become a site for social activism aimed at transcending (scientific and socio-political) boundaries. Emerging research practices outside of conventional research institutions and the new questions they’ve already evoked urge us to re-comprehend how socio-technical imaginaries are translated into collective actions. What is needed may not necessarily be *more* vertical top-down regulatory scrutiny but more horizontal commoning—that is, multi-level dialogues and coordination that incorporate rather than simply discipline different societal interests. Global health equality cannot be achieved merely through scientific aspirations or guarded by sovereign claims. Rather it requires the commoning of diverse social interests, be they foreign or domestic, and the vision to encourage solidarity and collaboration beyond national or institutional boundaries.

SUPPLEMENTAL INFORMATION

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DECLARATION OF INTERESTS

The author declares no competing interests.

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