

LETTER TO EDITOR / CARTA AL EDITOR

Global divisions of health; bioethical principles, practices and regulations on human genome editing and stem cell research in Latin America.

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Recent genetic technologies have uncovered the urgent need for global governance of health that can guarantee an ethical consensus on human genome editing and stem cell research. Although the majority of gene-transfer trials have been located in the Americas and Europe, the regulation of human somatic cell genome editing is generally limited in Latin America and largely informed by ethical concerns about genetically modified plants and animals, biopiracy, biosecurity, and use of stem cells for clinical care. Few jurisdictions in the region (i.e., Chile, Panama, Ecuador, and Colombia) have explicitly addressed somatic genome editing. Jurisdictions often address concerns regarding the use of new biotechnologies (i.e., CRISPR-Cas9) for human "enhancement" purposes rather than the prevention or cure of serious medical conditions¹.

Cases such as the 'CRISPR babies' allow us to foresee some of the most pressing ethical concerns. On November 25th, 2018, a Chinese scientist He Jiankui announced the birth of the world's first genetically engineered children, prompting a general condemnation of his actions for contravening an international scientific moratorium on all modifications of the germline nuclear genome for clinical application in human reproduction. The case of the 'CRISPR babies' has uncovered some of the potential implications of global governance of health that shapes but is also deeply dependent on national contexts. His action highlighted the need for a serious discussion about the uneven effects of the making of knowledge and technology on developed and developing countries. For instance, several scientists from top universities in the US were aware of He Jiankui's work and have been widely criticized for their silence². As Sleeboom-Faulkner³ suggests, when looking at stem cell interventions, 'idealized notions of ethics are not feasible for many stem cell scientists in low-and middle-income countries.'

To some extent, the absence of a robust regulation or clear ethical guidelines in Latin America has been the result of a general lack of consensus among scientific and non-scientific communities regarding human nature or the moral status of embryos. However, little or no regulation, in practice, means permissiveness^{4,5}. The fact that some technologies (e.g., genome transfer technologies) are being applied in countries such as Mexico to evade US rules frames the urgency of discussing global divisions relating to bioethical principles, practices and regulations⁶. The region must start consolidating multidisciplinary networks to consolidate consensus on the ethics of human genome editing and stem cell research, we must assess the implications of a geographical and discursive distance between those places where bioethical frameworks are produced (global north) and those where the actual practice of human genome editing (research and trials) could be potentially happening. We must learn from the few countries with jurisdictions in Latin America that have explicitly addressed somatic genome editing (i.e., Mexico, Panamá, Ecuador, and Chile) and assess the basic conditions for regulatory frameworks to flourish in the region and for a consensus that would care for the wellbeing of its population.

Current racialized aspects of health might complicate even further bioethical discussions in the region. For instance, the technoscientific entity of the 'Mexican genome' is being re-branded with pan-ethnic labels such as 'Latin American,' 'Latino,' and in some cases 'Hispanic.' These flexible categorizations seem to follow a commercial logic in which the intended size of the market influences whether the findings or benefits of clinical applications are presented as targeted at national or regional populations, or in the case of Latinos/Hispanics, as ambiguous populations that are hard to delimit⁷. In this context, current racialized notions of risk predisposition



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linked to genetic ancestry⁸, might have implications that go beyond national borders, and that must be discussed alongside bioethical frameworks on human genome editing and stem cell research. Admixture populations are often presented as sites were racialized and medically interesting gene variants can be found, making them relevant sites for research, especially when ethical controls are minimal and this might reinforce the racialization of disease⁹. Countries of the South must not be seen as places where research and trials can take place that would be ethically impossible or difficult in the North. Similarly, southern populations must not be seen as less important in a human sense or less deserving of ethical care.

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