

The Council of Europe and the prohibition on human germline genome editing

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Comment on: **P Sykora & A Caplan**

See reply: **P Sykora & A Caplan**

In anticipation of the international conference to celebrate the 20th anniversary of the Convention on Human Rights and Biomedicine (the Oviedo Convention), Sykora and Caplan have “come out swinging” [1]. They insist that the Council of Europe should not reaffirm the Oviedo Convention, mainly because its Article 13 prohibits human germline genome modification [2].

According to Sykora and Caplan, the CRISPR/Cas9 genome “editing” system is more efficient and precise than previous technologies for making intentional modifications to the human genome which, in their view, justifies lifting the current ban. This opinion captures CRISPR euphoria, but fails to justify embracing human germline modification.

Sykora and Caplan explain the original ban on germline modification as motivated by concerns about safety and efficacy. This mischaracterizes the Convention, which is firmly rooted in the principles of human rights and dignity. The treaty’s full name bears this out: “Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine”. Further, comments on Article 13 in the Explanatory Report on the Convention highlight eugenic concerns (fears of misuse) and do not mention safety or efficacy [3]. Moreover, Article 13 is part of Chapter IV on the Human Genome and should not be read out of context, as Chapter IV expresses concerns (fears) about discrimination and eugenics. Neither human rights, human

dignity, nor ethics can be peremptorily reduced to safety and efficacy. A genetic intervention can be safe and efficacious, yet objectionable on other grounds. Finally, it is premature to hint at the safety and efficacy of the CRISPR/Cas9 system [4, preprint: 5].

Sykora and Caplan acknowledge the risk that eugenics will inform some uses of human germline modification, but they do not directly (or meaningfully) address this possibility and the attendant risks of discrimination and stigma. Rather, they deflect by pointing to the use of preimplantation genetic diagnosis (PGD) and the UK’s recent approval of human nuclear genome transfer (so-called mitochondrial replacement therapy) [6], both of which remain ethically controversial. To be sure, the use of these technologies shows that some are willing to select against children with (or at risk of) certain genetic diseases. The availability of these technologies, however, does not counter the concern that expansive definitions of “healthy”, “disease”, and “disability” will drive genetic selection resulting in harmful consequences. Nor does a willingness to use these technologies address the effects of commercialization, which have driven the proliferation of clinics that offer untested and unauthorized procedures advertised as stem cell “therapies” [7].

The opinion concludes its nonresponse to eugenics concerns by asserting that, “it is unethical to hold hostage patients with severe genetic diseases to fears of a distant dystopian future”. In addition to using an inapt metaphor, this statement assumes a right that does not exist—the right to have a genetically related child. It would be more accurate (and apt) to say

that calling on the Oviedo Convention “to recognize, permit and regulate” human germline modification is an attempt to highjack meaningful public engagement on possible future applications of germline modification in humans.

The Parliamentary Assembly of the Council of Europe has recently urged member states that have not yet ratified the Oviedo Convention to do so or, at a minimum, to introduce a ban on establishing a pregnancy with modified germ cells. The Parliamentary Assembly has also called on the Committee of Ministers to foster a broad and informed public debate. Maintaining the status quo while debate about the appropriateness of possible future applications of germline modification takes place is both logical and, more importantly, respectful of the public [8]. Such debate cannot occur while scientists and clinicians forge ahead with germline modifications and disregard the views, interests, and concerns of the many communities to whom germline modification matters. Public engagement is not a barrier to progress. It is the path to progress, especially if we are (slowly) able to achieve “broad societal consensus” [9]. The Oviedo Convention, as currently worded, prioritizes human rights and human dignity over scientific ambition and the technological imperative.

References

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