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Building Capacity for a Global Genome Editing Observatory: Institutional Design

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A new infrastructure is urgently needed at the global level to facilitate exchange on key issues concerning genome editing. We advocate the establishment of a global observatory to serve as a center for international, interdisciplinary, and cosmopolitan reflection. This article is the second of a two-part series.

Genome editing and other technologies capable of altering human heredity raise profound questions for ethical deliberation. Calling for a broad societal consensus is not enough: steps must be taken to invite, support, and facilitate cosmopolitan dialogue [1] to ground expert advice and inform policymaking.

We advocate the development of an infrastructure whose purpose is not to supply policy advice but to make deliberation more robust and inclusive [2]. Its central function would be to expand the range of questions that need to be addressed by making visible the diversity of moral perspectives represented within the global human community. A new protocol will be necessary to bring into view perspectives that have been overlooked or dismissed by expert bodies in scientifically leading nation states and professional societies.

Terms of Deliberation

Key to the success of all deliberation is basic agreement on shared questions. There is a well-documented tendency in bioethical debates to render the questions surrounding ethically challenging technologies more tractable by narrowing their scope and translating them into language that seems to admit straightforward technical solutions [3]. With regard to human germline genome editing, many existing forums have tended to simplify debate by first addressing questions of risk and benefit, as if they can be resolved independently of more expansive ethical debate.

Thus, questions of the safety, reliability, and risk of unintended consequences such as off-target effects have tended to take precedence over questions that are not scientifically grounded but are no less fundamental, such as questions of human integrity, rights, and dignity. Such a constricted framing misses the central purpose of ethical inquiry – how to understand and safeguard the moral worth of life, both human and non-human, in the face of advancing technological capabilities.

Questions about how to govern genome editing are moral, religious, social, political and legal, as well as scientific and medical. Discourses and vocabularies to engage with these questions have developed in disciplines and practices outside and independent of science and technology – for example human rights, individual decisional autonomy, dignity, diversity, disability studies, and resilience. All of these discourses have a legitimate place in guiding expert deliberations and informing public ethical judgment. For example, the 29 countries that have signed and ratified the Oviedo Convention [4] are already committed to evaluating applications of biology and medicine in the frameworks of human rights and human dignity. Furthermore, failure to attend to the interrelation of technical and ethical dimensions neglects the ways in which CRISPR science itself is embedded within pre-existing economic, legal, and social structures. Treating science as if it is independent of these contexts produces insufficiently deep, reflective, or inclusive approaches to policy.

If there is to be any consensus about the acceptability of particular applications, that agreement must be grounded in prior consensus about what questions need to be asked, in what terms, involving which parties, and drawing upon what range of technical and moral perspectives. The quality of ethical judgment depends on answers to these questions about the basic parameters of deliberation that precede and structure judgments. Deliberation is compromised if it is forced to focus too soon on binary judgments of the pros and cons of particular applications of human germline genome editing. Indeed, consensus may mean a temporary agreement to slow or stop some types of research unless and until such questions have been debated in sufficiently cosmopolitan forums.

Deliberation must be grounded in ways of framing problems that do not unfairly privilege particular ways of talking and thinking while others that are less familiar or institutionally powerful are prematurely silenced. Insofar as stakes and stakeholders are chosen without providing adequate space for contesting or refining initial framings, deliberation will become exclusionary and the appearance of consensus will be misleading. If, for instance, current editing capabilities are conceived as mere incremental extensions of medicine's existing repertoire, then their eugenic or ecological implications will be sidelined as being too far in the future to worry about. The resulting debate would inhibit the potential for robust ethical judgments about what notions of human-ness deserve to be protected, and what this, in turn, means for the purposes of biomedicine. By contrast, inviting – and enhancing – deliberation that makes room for diverse, even discordant, moral positions, and does not shy away from broad questions of human integrity, rights, and dignity, would lay stronger foundations for dealing with both present and future challenges.

Cosmopolitan Ethics and Capacity Building

Our ignorance of each other remains one of the greatest challenges to achieving international reflection and exchange, cosmopolitan ethical deliberation, and ultimately a broad societal consensus. Declarations of scientific globalism notwithstanding, we lack the infrastructures necessary to survey what the human community as a whole takes to be valuable, virtuous, and inviolable about its own condition, and to calibrate scientific and technological projects accordingly.

There is significant variation in how societies currently approach ethical evaluation and governance of biotechnology. These differences are reflected in the institutional frameworks and forums that structure public debate, the oversight mechanisms and processes for evaluating research, and the analytic vocabularies that are brought to bear on bioethical judgments [5]. Academic disciplines bring their own problems of narrowing, often concealing profound value differences beneath expert languages of supposed universal validity. Nevertheless, diversity of thought and practice should not be seen as an impediment to consensus building; neither should this diversity be tamed through exclusion. Instead, such diversity is a rich repository of human wisdom and experience, and it must be judiciously mined for deliberation to be robust, consensus to be genuine, and resulting policies to be legitimate. Societies can learn much from one another, and building forums for full-blown engagement and exchange among diverse cultures and disciplines is therefore a necessity for responsibly governing biotechnology.

At present, many pressures are pushing in precisely the opposite direction. Most visible are the actions of individual scientists pressing forward with controversial research [6] without regard to significant public uncertainty over which technological genies should be set free or for what purposes. In addition, groups of national or disciplinary experts – culturally parochial by definition – are speaking as if on behalf of humanity as a whole simply because they possess what is seen as authoritative institutional backing and appropriate technical expertise [7,8]. Deliberation on the future of human-ness must be far more outwardly directed, inviting approaches that contextualize, problematize, and demand humility from the would-be editors of our common future.

Only by ensuring adequate breadth and depth of deliberation, at a pace that encourages reflection rather than instant reaction, can our societies cultivate a sufficiently capacious understanding of the purposes and ends of human lives to guide future scientific and technological development. To achieve this we must reject the idea that there is a competitive race toward predetermined technological goals that leaves no time for deliberation about where we ought to be headed.

A Protocol for Public Engagement

Although many policy-focused efforts related to human genome editing are underway, these are not grounded in what we have defined as a cosmopolitan ethic [1]. Calls for public engagement notwithstanding [7,9], public dialogue and engagement exercises are typically insufficient to the task: they are often one-shot affairs that are commissioned for highly specific purposes [10]. A forum is urgently needed for more sustained, iterative, and inclusive revisiting at the global level of key questions surrounding genome editing and related technologies.

For these reasons, we advocate the establishment of a new infrastructure for cosmopolitan deliberation: a global observatory. Its purpose would not be to define universal principles or forge consensus (Box 1), but – more humbly – to serve as a center for international, interdisciplinary, and cosmopolitan reflection on the progress of thinking on these issues around the world. The observatory would (i) gather and make visible the global range of ethical and policy responses to genome editing, (ii) provide substantive analysis of conceptual developments, tensions, and areas of consensus, and (iii) serve as a forum for convening periodic discussions, focusing in particular on important questions that have otherwise been neglected and actors whose voices might otherwise be inaudible.

We need to make room for voices and concerns that have gone largely unheard when debates are driven by the imperative of speed at the frontiers of biological

Box 1. How Prior Summits and Meetings Differ from the Envisaged Observatory on Human Genome Editing

A comprehensive picture of ethical and policy engagement with genome editing around the world would be of great value for informing and enhancing international, national, and local efforts. No such accounting yet exists. Many expert bodies have explored the implications of human gene editing over the past 5 years, but none have adequately assessed – nor have the capacity to assess – the range of views held around the world. Nevertheless, most have positioned themselves as *advisory*: offering judgments about what is at stake and what resolutions to ethical and policy uncertainties are appropriate for all of humanity. These judgments have taken a variety of forms, for instance, prioritizing consensus [11,12], focusing on harmonization as essential for international markets [13], or providing moral principles to guide future work [9,14,15] (www.coe.int/en/web/bioethics/news/-/asset_publisher/DcE9CvEiHMnp/content/gene-editing). By contrast, the global observatory proposed here would not dictate the terms of deliberation nor prescribe particular courses of action, but would serve as a forum for gathering and analyzing international experiences in ethical deliberation. Its aim would be to deepen conversations, engender fruitful exchange and discussion, facilitate mutual understanding and respect, and identify and foreground salient but sidelined issues.

International efforts to date have generally convened groups of experts who represent only very particular and culturally parochial (even if influential) approaches: scientific characterizations of technological risks and potential benefits, bioethical constructions of salient ethical implications, or social scientific modes of representing public attitudes and anxieties. Moreover, civil society and citizens have typically come together in separate forums, often drawing upon different framings and moral vocabularies.

Instead of seeking to resolve what forms of expertise deserve a seat at the table, the observatory would approach that question in a spirit of open-minded dialogue. Participants in the proposed global observatory would be cross-cultural and cross-institutional, and would include significant voices from the global South and well as the North. In addition, it would be essential to include interdisciplinary expertise – because what constitutes relevant expertise is itself a matter of disagreement that warrants serious deliberation. By inviting perspectives from a disciplinarily and culturally diverse group of participants at regular intervals, it would seek to cultivate rapport, foster engagement, and generate more cosmopolitan – and therefore more powerful – understandings of what is at stake in respecting and safeguarding human life.

research. Those neglected voices are no less important for shaping the human future than the voices of those who are already positioned to radically remake it.

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