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A global observatory for gene editing

Sheila Jasanoff and **J. Benjamin Hurlbut** call for an international network of scholars and organizations to support a new kind of conversation.

In August 2017, scientists reported that they had used the gene-editing tool CRISPR-Cas9 to correct a mutation in viable human embryos. The work is just one of countless applications of the technique, with which scientists hope to alter plants, animals and humans.

The value of most applications of the technology has barely been exposed to public review. Unless these editorial aspirations are more inclusively debated, well-intentioned research could move humanity closer to a future it has not assented to and might not want.

Over the past three years, leading scientists have called for global deliberation on the possible effects of gene editing on the human future¹. In our view, the discussions that have taken place fall far short of the expansive, cosmopolitan conversation that is needed.

DOWN FROM THE SUMMIT

An important milestone was the International Summit on Human Gene Editing, held in Washington DC in December 2015. Organizers called for an international forum to seek "broad societal consensus" on the norms that should guide research².

Nobel laureate David Baltimore began the summit by invoking the 1975 Asilomar meeting on recombinant DNA research³: "In 1975, as today, we believed it was prudent to consider the implications of a remarkable achievement in science. And then, as now, we recognized we had a responsibility to include a broad community in our discussions."

Asilomar is often remembered as a model of successful self-regulation that affirmed **>**

science's autonomy and the principle of responsible research. Yet at the 2015 summit, as at Asilomar, the questions asked, the forms of expertise called upon, and the definition of stakes for science and human life were all shaped by those communities most aggressively advancing the research.

The summit brought together a more diverse and international group than is typical of meetings on the implications of scientific research. But the discussion still focused on predictions about what genome editing will be able to do in the near term and what its biological risks are, even though it raises issues that clearly transcend immediate concerns for health and safety. Moreover, the meeting format offered little opportunity for deeper listening or learning.

Instead, it encouraged an all-too-common pattern⁴. Discussion split into two camps: scientific experts explored technical issues, whereas scholars who study science and society addressed questions about the possible disruption to social norms. The two camps did not inform each other.

To break out of this bifurcation between the 'science' and the 'ethics', methods must be found to get people to engage substantively with each other. In our view, an entirely new type of infrastructure is needed to promote a richer, more complex conversation — one that does not originate from scientific research agendas but that instead invites multiple viewpoints.

We advocate the establishment of a global observatory for gene editing, as a crucial step to determining how the potential of science can be better steered by the values and priorities of society. This would be an international network of scholars and organizations similar to those established for human rights and climate change. The network would be dedicated to gathering information from dispersed sources, bringing to the fore perspectives that are often overlooked, and promoting exchange across disciplinary and cultural divides.

ALTERNATIVE VISION

In seeking new models, it is worth recalling a little-known meeting held at Airlie House in Warrenton, Virginia in April 1976 — a counterpoint to Asilomar's narrow, expert-dominated approach. There, about 50 participants debated whether a new social contract was needed between society and science⁵. Half of the group were scientists; the rest were lawyers, public-interest advocates, philosophers, journalists and congressional staff members.

At that gathering, the philosopher Stephen Toulmin declared that science was facing the equivalent of the Protestant Reformation that splintered Europe 500 years ago. "People are tired of being shut out of science's ecclesiastical courts and are demanding to be let in," he said. Hans Jonas, another philosopher, was more blunt. "Scientific inquiry", he said, "demands untrammeled freedom for itself."⁶

Today, a reformation of the contract between science and society is even more overdue, but the institutional barriers are even more entrenched. Certainly in relation to gene editing, there has been much more advice from experts than acknowledgement of the limits of such expertise.

In April 2017, we gathered three dozen social scientists, ethicists, religious thinkers, legal scholars, scientists and representatives of national and international ethics bodies at Harvard University in Cambridge, Massachusetts. We discussed how to enable a different kind of conversation about the variety of techniques with which scientists can edit living systems.

We did not start with the usual question of what science is ready to achieve. Instead, we took a step back and asked to what extent existing scientific and political institutions are capable of initiating the forms of deliberation demanded by the prospect of editing life. We explored the rights and responsibilities of scientific experts, policymakers, publics and scholars in such processes. And we asked what is needed — in terms of representation and deliberation — for a genuinely broad societal consensus on gene editing.

We agreed on the need for a coordinated

"Free enquiry, the lifeblood of science, does not mean untrammelled freedom to do anything." d for a coordinated international effort to gather and analyse salient information on what is already being done to integrate perspectives from science and society. That effort would bring to light diver-

gent ideas about what is at stake in protecting the integrity of life, human and non-human, against unwarranted intrusion from new and emerging technologies.

We identified the need for a forum to promote sustained international, interdisciplinary and cosmopolitan reflection on several key considerations: what questions should be asked, whose views must be heard, what imbalances of power should be made visible, and what diversity of views exist globally.

We agreed that more crosstalk is needed between people representing different disciplines, political cultures and normative frameworks — so that approaches currently taken for granted can be tested and recalibrated in the light of alternative and dissenting perspectives. A new global forum, grounded in a commitment to hospitality and friendship towards unfamiliar, possibly upsetting ways of thought, would encourage people to build a rapport and so begin to engage more meaningfully with one another. To these ends, the global observatory we imagine would fulfil three functions.

First, it would serve as a clearing house. It would consolidate and make universally accessible the global range of ethical and policy responses to genome editing and related technologies. These responses would include relevant literature, and position statements from civil-society groups, especially from the global south. The network would also report on activities and outputs of formal bioethics bodies, such as the Nuffield Council on Bioethics in the United Kingdom or the German Ethics Council, professional societies such as the American Society for Reproductive Medicine, and intergovernmental agencies, such as the Council of Europe and the World Health Organization.

Second, the observatory would enable the tracking and analysis of significant conceptual developments, tensions and emerging areas of consensus around gene editing. It would broaden the focus beyond the technical pros and cons of gene editing to a richer range of questions and concerns that tend to be overlooked.

Studies of the social dynamics of international collaborations — from setting research agendas to the allocation of intellectual-property rights — could help to reveal the hidden power imbalances in science that are likely to influence who benefits from gene-editing research, as well as who does not. Likewise, the material gathered in the global observatory would give us a more detailed view of the biological futures people actually want for themselves and their societies. For instance, it could shed light on differing perceptions of social and biological relationships, such as ideas of disability and disease, across cultures.

Third, the observatory would serve as a vehicle for convening periodic meetings, and seeding international discussion informed by insights drawn from data collection and analysis.

To be effective in all three dimensions identified, those involved must reject the rhetoric of a competitive race in international science. The fixation on 'winning' should be replaced with deeper reflection on the purposes of technological change⁷. Analysis of the contexts in which the narrative of winners and losers emerges should itself be part of the work of the observatory, as should its effects on the course of scientific research.

REFRAMING THE QUESTIONS

If successful, the observatory we propose would alter the way problems are framed and expand the idea of a "broad societal consensus".

In current bioethical debates, there is a tendency to fall back on the framings that those at the frontiers of research find most straightforward and digestible. This move



The International Summit on Human Gene Editing was held in Washington DC in 2015.

comes at great cost. If the ethical stakes of human germline genome editing are limited to questions of physical safety, for example, then the technical evaluation of particular biological endpoints (for instance, off-target effects) might offer sufficient answers⁸. But such a focus short-circuits the central question of how to care for and value human life, individually, societally and in relation to other forms of life on Earth.

Likewise, the goals of consensus must go beyond merely agreeing on whether particular applications of genome editing are acceptable or unacceptable. Deliberation is insufficient if the conversation is too quickly boxed into judgements of the pros and cons, risks and benefits, the permissibility or impermissibility of germline genome editing, and so on.

Such an approach neglects important background questions — who sits at the table, what questions and concerns are sidelined, and what power asymmetries are shaping the terms of debate. When it comes to shaping the future of humanity, those neglected issues are just as important as the concerns of people poised to radically remake it. Indeed, consensus might even mean agreeing not to proceed with some research until a more equitable approach to setting the terms of debate is achieved⁹.

Cosmopolitanism, in styles of thought and in cultural intelligence, is not merely an aspiration for the proposed observatory; it should be integral to the network's way of working. Success will ultimately depend on whether those leading the initiative have the skill and sensitivity to manage crossdisciplinary and cross-cultural conversations, and are backed by the knowledge and networks needed to sustain an infrastructure that facilitates these conversations.

LOOKING AHEAD

The observatory would not seek to engage in a race against science. Its purpose is more to engender robust, sustained conversation about the limits and directions of research. The pace of current research might well bring about some near-term interventions that humanity has not consented to, such as the creation of an edited child. Far from rendering international deliberation moot, such a step would only underscore the need for meaningful cosmopolitan thinking.

Our hope is that the observatory would begin to shift entrenched habits of thought beyond those directly influencing geneediting research. Indeed, because the issues that the observatory would illuminate reach far beyond narrow questions about particular technologies and associated risks and benefits, its work should enrich and deepen debate around biotechnology more broadly.

All too often, scientists and others have tended to circumscribe debate about human genetic engineering on the premise that, until the technical capability does exist, it is not necessary to address difficult questions about whether such interventions in human life are desirable¹⁰. For example, even as scientists are applying gene editing to human embryos in the lab, the argument that the technology is too risky for clinical use serves as an excuse to delay the hard work of thinking through the technology's wider ramifications.

These tendencies to delimit and delay debate leave exploratory research largely unquestioned. The effect is that scientific developments, once they are realised, seem to have been inevitable and outside our control, even though they are the products of scientists' choices. Questions of value then seem largely reactive, even futile.

Thus, a big challenge will be to ensure that entry cards to the observatory are not dictated by dominant cultural views about what constitutes relevant moral or technical competence. Profound and long-standing traditions of moral reflection risk being excluded when they do not conform to Western ideas of academic bioethics. But as the Intergovernmental Panel on Climate Change discovered through its climate assessment exercises, formal scientific training cannot be the only criterion by which to decide whose voices should be heard in an inclusive global forum. Equally, care must be taken to ensure that participation is not preferentially given to those who are the most vocal or most polarized on the issues.

Free enquiry, the lifeblood of science, does not mean untrammelled freedom to do anything. Society's unwritten contract with science guarantees scientific autonomy in exchange for a research enterprise that is in the service of, and calibrated to, society's diverse conceptions of the good. As the dark histories of eugenics and abusive research on human subjects remind us, it is at our peril that we leave the human future to be adjudicated in biotechnology's own "ecclesiastical courts".

It is time to invite in voices and concerns that are currently inaudible to those in centres of biological innovation, and to draw on the full richness of humanity's moral imagination. An international, interdisciplinary observatory would be an important step in this direction.

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