

BIOTECHNOLOGY

Global citizen deliberation on genome editing

Global governance can be informed by a deliberative assembly composed of lay citizens

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Genome editing technologies provide vast possibilities for societal benefit, but also substantial risks and ethical challenges. Governance and regulation of such technologies have not kept pace in a systematic or internationally consistent manner, leaving a complex, uneven, and incomplete web of national and international regulation (1). How countries choose to regulate these emergent technologies matters not just locally, but globally, because the implications of technological developments do not stop at national boundaries. Practices deemed unacceptable in one country may find a more permissive home in another: not necessarily through national policy choice, but owing to a persistent national legal and regulatory void that enables “ethics dumping” (2)—for example, if those wanting to edit genes to “perfect” humans seek countries with little governance capacity. Just as human rights are generally recognized as a matter of global concern, so too should technologies that may impinge on the question of what it means to be human. Here we show how, as the global governance vacuum is filled, deliberation by a global citizens’ assembly should play a role, for legitimate and effective governance.

INCLUSIVE PARTICIPATION

Calls for inclusive participation are common among those concerned with the technology and its governance (3), when it comes to applications in humans, food, agriculture, and environmental conservation (4). International organizations such as the World Health Organization (WHO), the United Nations Educational, Scientific and Cultural Organization, and the Organization for Economic

Co-operation and Development; science bodies such as the U.S. National Academies of Sciences, Engineering, and Medicine (5) and the UK-based Nuffield Council on Bioethics; and many others have joined the call. The WHO’s Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Gene Editing is exploring public engagement at various scales (6), involving a registry of genome editing trials, dissemination of scientific findings translated into many languages, consultation with a broad range of stakeholders from around the world through videoconference seminars or web-based dialogue, and collaboration with other international organizations and nongovernmental organizations (NGOs). This is a call for action, but not a design for how to act in a way that involves citizens, still less at the crucial global level.

In 2018, the international Association for Responsible Research and Innovation in Genome Editing (ARRIGE) was created, aiming to bring civil society into the discussion (7). But civil society is not the same as the citizenry, and to date ARRIGE has only got as far as a website, open meetings, and international expert meetings. Others have called for monitoring and learning that would involve experts, scholars, policy-makers, and organizations (8). However important they may be, such initiatives do not fully address the practicalities and specifics that would enable meaningful participation of citizens from around the world. We propose a crucial, complementary effort, which would involve global public deliberation to explore the science and its implications, beginning with a global citizens’ assembly.

There is already vast experience with citizen deliberation at local and national levels, on complex issues including those involving scientific and technological risk accompa-

nying potential benefits. Relevant models include citizens’ assemblies, citizens’ juries, deliberative polls, and consensus conferences (9). They can be game-changers: Citizens’ assemblies on same-sex marriage, abortion, and climate change in Ireland led to changes not just in law but to the texture of Irish politics—overturning the presupposition that some obstacles to reform were immutable. Currently there is no experience with global citizens’ forums [globally oriented multicountry exercises such as World Wide Views (10) have citizens deliberate only with fellow-nationals]. The challenge to consider complex issues in multiple languages is formidable, but Europe-wide forums such as Europolis have demonstrated the success of simultaneous translation.

GLOBAL CITIZENS ASSEMBLY

How would a global citizens’ deliberation be constituted? We propose a citizens’ assembly model (rather than any of its smaller alternatives, such as citizens’ juries) that would at a minimum be composed of 100 people. Participants would be recruited throughout the world. Stratified random sampling would yield a broad spread in terms of nationality, cultures, level of education, age, income, religion, and gender. Care would be needed to protect the integrity of sampling from political interference, and in some places, it might be necessary to argue for the legitimacy of stratified random sampling (as opposed to, say, selecting only elders). Increasing the size beyond 100 could promote representativeness, though increase logistical challenges.

Participants could, where possible, be recruited from nationally organized forums (themselves with members recruited through stratified random sampling) on specific aspects of genome editing. This offers the advantage that citizens would join the global process with considerable knowledge and experience. A hundred or more citizens would bring to bear all kinds of relevant local knowledge and different worldviews. They would meet over a week or more, hear presentations from experts and advocates, deliberate among themselves in small groups (each of which would have a facilitator) then in plenary session, and produce a report that summarized key concerns and recommendations. There would be an advisory committee with members from relevant interests and expert communities, ensuring that participants receive balanced information.

What would a global citizens’ assembly do? Like any such body, it would need an initial charge: possibly, “Should there be global principles for the regulation of genome editing technologies?” Assuming

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the assembly felt there ought to be such principles (rather than defer to national variety), it would then consider their content. There is generally a place for universal principles in global governance, even if they are implemented nationally. Think of the Sustainable Development Goals, applying universally, implemented nationally. The assembly would not address the local content of applications, such as gene editing research involving human embryos in the United Kingdom. Although we cannot predict what principles the assembly would highlight, one might specify from whom and in what terms co-design of field trials (with participation by those who stand to either gain or lose) is needed in light of the risk that wealthy actors may use developing countries as sites for the field testing of technologies (such as gene drive technology to kill pests). Another might be genome editing justice: How should we think about the allocation of scarce resources given that some applications may benefit a small number of the relatively wealthy (for example, gene drives for Lyme disease) whereas others may benefit large numbers of the poor (for example, gene drives for malaria)?

The citizens' assembly would not legislate; its report would have no standing in international law. However, for good reasons that the assembly would make public, it should help shape what happens next. The idea is to inspire a more effective response in global institutions [notably, the UN Food and Agriculture Organization (FAO) and the WHO], national governments, civil society, and the private sector. The report would be a first draft of informed global public opinion regarding genome editing. Here, public opinion can be defined not in terms of unreflective mass responses to survey questions, but as a provisional and dynamic outcome of inclusive and competent public discourse supported by evidence-based science that connects to public values.

Who should fund and organize the assembly? Funding should come from independent bodies with no material stake in the technology. International organizations such as the WHO and FAO would be appropriate, as would foundations. National (and European Union) research councils could contribute on the grounds of social scientific research questions, including testing the deliberative capacities of the global citizenry. We can be more specific about organizations that have the necessary capacity, neutrality, and experience in running citizen deliberation. A consortium under construction includes Missions Publiques and the Danish Board of Technology (both of which have run large multinational processes), Involve (UK), the ECAST (Expert

and Citizen Assessment of Science and Technology) network of academics and practitioners (U.S.), and institutes such as the Centre for Deliberative Democracy and Global Governance at the University of Canberra, and School of Population and Public Health at the University of British Columbia. This networked expertise puts the consortium in a position to make precise and implement what others have only called for in very general terms.

What kind of influence should the assembly seek? A citizens' assembly that met immediately prior to, say, global negotiations organized by the United Nations would be in a good position to influence those negotiations (think of the public consultations that preceded negotiation of the Sustainable Development Goals in 2015). But deliberative democracy requires larger publics to be active, so equally important is the role of the assembly in stimulating broader informed participation. Its activities and conclusions would be witnessed, publicized, and amplified through documentary film, social media, and the more traditional media. This suggests that appropriate timing would be early in the life of the issue's presence on the global agenda.

THREE ESSENTIAL REASONS

There are three essential reasons why a global citizens' assembly on genome editing would be a good idea. The first concerns the legitimacy of any collective decisions in global governance. Public confidence in technologies and their application can be secured by public participation in decisions about the regulation of those technologies. At the global level, legitimacy cannot be secured through elected representation, which is unavailable. There is increasing awareness of the benefits of linking citizen deliberations to wider public debate as a way of facilitating conditions for the public to come to terms with the issue and create trust with experts and decision-makers (11). Evidence shows that nonparticipants can more readily trust their deliberating fellow-citizens than politicians. For issues that are not yet on the public radar, citizens' assemblies provide mechanisms for anticipating considered public responses that would only otherwise occur well after implementation of technologies, when public outcry can be costly and disruptive (12).

The second reason concerns the current disconnect between expertise and public values (13). As it stands, public views on genome editing (whether applied to humans, animals, or plants) are generally not well formed, mainly owing to the novelty and highly technical nature of the issues involved. Those who do have well-considered views



are often highly knowledgeable, but knowledge does not imply a warrant to make value judgments for a broader public, or impose framings of issues on a public that might be amenable to competing frames. Sometimes those with considered views are perceived as embedded in specific interests (be it as health care professionals, scientists, corporations, or activists) and accompanying framings that may constrain their ability to reflect on broad public interests. Good deliberation remedies this disconnect through productive integration of scientific knowledge, lay knowledge, and public values, meaning that specialists can learn about broader publics, and publics can learn about expert framings. Two decades of national-level experience on complex risk-related issues shows that citizens' forums are an effective vehicle for this vital integration of science and society. Citizens' forums can also help develop public values on distinctive issues such as genome editing, where opinions and framings have yet to solidify, thus further contributing to anticipatory governance. Without such values, it is not obvious what public need the technology would be serving.

The third reason concerns the generation of a much-needed kind of considered input into governmental decisions, about detailed applications no less than broad questions about whether or not to pursue the technology. Aside from introducing previously marginalized perspectives, evidence shows that a well-designed process involving lay citizens can bring reflective judgment to bear in a way that stakeholders, activists, and politicians may not (because they are too invested in advocacy). In a jury trial, we trust lay jurors to reach a reflective judgment based on what they hear from advocates on both sides of a case. Similarly, citizens' forums can effectively judge the merits of different sides.



In Oregon, the Citizens' Initiative Review provides considered assessment of the best arguments for and against referendum measures (such as one on labeling of genetically modified food) which are often not the arguments that advocates for both sides stress. We might expect scientists and ethicists also to be better than stakeholders, activists, and politicians when it comes to reflective judgment. But though we might expect scientists to be good at reflecting on scientific values, their role gives them no special insight on the public interest. Ethicists are professionally capable when it comes to moral principles—but these are not necessarily the same as public values. Citizens' forums also prove good at creatively identifying courses of action that meet the main concerns of different sides.

A global citizens' assembly would not replicate existing international consultations. The pattern of self-appointed representation from global civil society (dominated by NGOs from wealthy countries) is highly incomplete, especially in representing the marginalized and poor. Random selection yields more cognitive diversity than self-appointment. This diversity can be harnessed in deliberative interaction to yield epistemic problem-solving gains. Interacting NGOs and organized interests usually produce compromise; interacting citizens are more likely to produce reasoned outcomes whose typically high level of agreement on content can be open to far-reaching options (see the 2020 French Convention Citoyenne pour le Climat). Deliberating citizens can find ways around impasses bedeviling experts and advocates, as demonstrated for solar geoengineering governance in a process organized by the Consortium for Science, Policy and Outcomes in 2018. Any persistent disagreement will illuminate contextual and cultural differences.

The three reasons will hold to the degree the citizens' assembly is well designed, drawing on evidence about what works and what doesn't. Fortunately there is an extensive body of empirical research to draw upon: on the impact of different facilitation styles on equality of participation; on the best way to generate principles to govern interaction within the assembly; on the optimal number of deliberating citizens in small groups; on the time (normally at least 2 or 3 days) needed for citizens to learn, reflect, clarify disagreements, and crystallize preferences; on the best way to conduct stratified random sampling; on the importance of gravitas in inducing selected citizens to accept invitations to participate; on the importance of citizens' perception of the impact of the forum; and on the most appropriate form of the final report (notably the degree to which it should contain reasons rather than simply conclusions or votes) (14).

Critics of public engagement worry that it can be used subtly to build support for existing policies by not challenging dominant framings. In health policy, citizens' forums have been designed and introduced to address such criticisms, by enabling deeper scrutiny of the implications of scientific findings, by broadening the kind of rationales for action that can be contemplated, by scrutinizing the meaning of the public interest, by being more inclusive of different forms of reasoning, and by avoiding overly narrow framings of issues (15). Citizens' forum conclusions can contravene existing government policy; on genome editing, there is currently something of a policy void, so it is not obvious what a dominant policy framing is to begin with. Still, organizers and facilitators should take care that powerful framings (such as the idea that technical expertise is more important than local knowledge) are

not taken as given, and are open to challenge. Worries about lack of impact can be assuaged by fostering strong connections with relevant governmental bodies in advance of the deliberative process.

MORE THAN JUST "CHECKING THE BOX"

What are the limitations? A global citizens' assembly would in the first instance offer a snapshot, only dealing with the issues as presented by the state of the science at one time. However, it would be possible to re-convene global assemblies periodically (with different citizen participants) to refine or reconsider principles. A more continuous conversation, which could include how principles identified by the citizens' assembly should apply, or might need to be re-thought in light of subsequent scientific developments, could be supplied elsewhere (8). Our proposal could also be joined to any more authoritative international institutions that develop, as well as to subsequent national deliberative processes.

A global citizens' assembly should do much more than simply check a "public participation" box. It would be the beginning of more effective global public deliberation, not its end, informing wider publics as much as the process of decision-making. If the global community is serious about public participation on genome editing, it is time to move beyond the rhetoric. Robust, legitimate, democratic, and effective action drawing on lessons from existing practice is possible, and it is time to move in this direction. ■

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