

# Empowering Indigenous Knowledge in Deliberations on Gene Editing in the Wild

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## Abstract

Proposals to release genetically engineered organisms in the wild raise complex ethical issues related to their safe and equitable implementation. While there is broad agreement that community and public engagement is vital to decision-making in this context, more discussion is needed about who should be engaged in such activities, and in what ways. This article identifies Indigenous Peoples as key stakeholders in decisions about gene-editing in the wild and argues that engagement activities need not only include Indigenous Peoples, but be designed, conducted, and analyzed in ways that confront longstanding power imbalances that dismiss Indigenous expertise. We offer specific recommendations to guide deliberative activities to not only be inclusive of Indigenous Peoples but empower their diverse, situated knowledges. We call on those committed to the inclusive design of broad public deliberation to pursue strategies that shift dominant power dynamics to include Indigenous communities in more meaningful ways.

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## Introduction

The advent of genome editing tools such as CRISPR/Cas9 (clustered regularly interspaced short palindromic repeats/associated protein Cas 9) are enabling new possibilities in the genetic modification of insects and other wild organisms. While genetic engineering techniques have been used to suppress populations of disease-vectoring insects like mosquitoes for over a decade (e.g., Oxitec's *Aedes aegypti* technology), emerging genetic engineering technologies make it possible do so more rapidly than ever before<sup>1</sup>. Scientists can now theoretically push genetic modifications that cause population decline or crash (e.g., via infertility or biased sex-ratios<sup>2</sup>) through entire populations of organisms with unprecedented speed and efficacy. As such, genetic engineering may provide a powerful strategy to intervene in a number of challenges including vector-borne disease (e.g., malaria, Zika, chikungunya, Lyme)

and invasive species or pest control (e.g., management of rodents or insects threatening ecological biodiversity or crop health).

However, proposals to introduce genetically engineered organisms into the wild raise complex considerations about the processes that should guide their safe and ethical use. It is impossible to know for sure how technologies not yet tested outside the laboratory will affect natural ecosystems. How should risk assessment be performed given this high degree of uncertainty? Whose notions of risk and benefit shape these processes? Some genetic engineering technologies have the potential to significantly and irreversibly impact shared environments. Who should ultimately decide whether they are released in the wild? Decisions about the development and deployment of these technologies are invariably complex and value laden.

Given these vexing ethical issues, there is broad agreement that some form of community and public engagement will be necessary to guide decisions about the release of genetically engineered organisms in the wild. Some recommendations call for the engagement of local community stakeholders who would be directly impacted by the use of a given genetic engineering technology (e.g., residents of geographic regions where a genetically engineered organism is proposed for release), while others suggest that broader publics ought to be engaged, given the high stakes associated with technologies that may forever change our shared environment<sup>1,3</sup>. While there has been some acknowledgment that it is important to engage groups historically excluded from decision-making about research and technology-development that has impacted them<sup>4,5</sup>, more discussion is needed about specific ways to pursue the meaningful inclusion of such groups.

This article argues that Indigenous Peoples should be involved as key stakeholders in decisions to release genetically engineered organisms in the wild. We add to a growing

conversation<sup>1,4,6-11</sup> about the importance of engaging Indigenous Peoples in this context, and argue that engagement must go beyond the mere inclusion of Indigenous Peoples to ensure that the design, conduct, and analysis of those activities actively confronts and subverts power imbalances that marginalize Indigenous ways of knowing. After introducing power as a generative framework for the design and conduct of deliberative activities related to gene editing in the wild, we discuss why Indigenous Peoples represent vital stakeholders in those activities. Finally, we offer specific recommendations to guide deliberative activities to not only be inclusive of Indigenous Peoples but empower their diverse, situated knowledges. While our discussion focuses specifically on Indigenous Peoples, our recommendations may have broader relevance to other key stakeholder groups who have historically been excluded from conventional deliberation processes for gene editing in the wild, such as marginalized communities in the Global South.

### **Power as a framework for deliberative design**

In its 2016 consensus report on an emerging genetic engineering technology known as gene drive, the National Academies of Science, Engineering, and Medicine (NASEM) defines engagement as: “Seeking and facilitating the sharing and exchange of knowledge, perspectives, and preferences between or among groups who often have differences in *expertise, power, and values*<sup>1</sup>” (emphasis added). The report offers ample discussion about the importance of engaging multiple forms of expertise and values. It notes that community insight and knowledge may contribute pragmatically to more robust approaches to gene drive development and governance, or ensure that tasks such as risk assessment adequately account for community or culturally specific perspectives on what constitutes a risk or benefit. However, there is limited discussion devoted to the *power imbalances* that emerge among stakeholders in the conduct of genetic

engineering research, development, and deployment, such as power differentials inherent to the institution of science, perpetuated across geopolitical divisions, or constraining marginalized communities' capacity to inform decision-making.

For instance, scientists working to develop genetic engineering technologies commonly express positive intentions to leverage their work to help people in the Global South (formerly known as the 'developing world') or island nations, as these geographic regions experience disproportionate impacts of several issues that genetic engineering technologies seek to address, such as vector-borne disease, climate change linked issues with invasive species or pest control, and food security<sup>12</sup>. However, the vast majority of scientists, ethicists, and philanthropic or corporate funders central to the development of genetic engineering technologies are in the Global North, aiming to trial and eventually implement these technologies in the Global South.

Thus, when deliberative activities seek to include Indigenous or Global South communities, they must be conscious of the power differentials undergirding those relations and how they might influence the dynamics of a deliberative activity. In the broadest sense, this necessitates cognizance of global histories of imperialism, including the role that science has played in facilitating the various forms of colonialism that have emerged from imperialism, and their negative impacts on Indigenous Peoples and local communities<sup>13</sup>. Another facet of power imbalance to consider is that of a scientist or other stakeholder backed by a relative wealth of monetary resources and institutional support approaching a smaller, historically marginalized community that may live under a dominant settler colonial structure, and how this affects their power to directly impact decision-making.

Such local and global power imbalances (as well as heterogeneity of different community stakeholder groups) also influence how different groups of people understand and experience

harm, making it critical to engage Indigenous Peoples in a way that empowers them to define what is deemed risk, benefit, and harm through their local epistemologies and lifeways. It is imperative for Western-trained scientists and ethicists to reflect upon the presumptions underlying their own perceptions of risk and benefit: for instance, the reliance on definitions of harm that manifest in physical and measurable ways on human and ecological health. In seeking to minimize the continued perpetuation of harm across historic and ongoing power differentials, we suggest that researchers adopt a more holistic and inclusive conceptualization of harm that includes cultural, emotional, psychological, and socioeconomic aspects. Acknowledging the inseparability of Indigenous wellbeing from ecological health and stewardship practices, it is evident that the loss of land, knowledge, and traditional practice represent significant forms of harm to these communities.

### **Indigenous Peoples as key stakeholders in decisions to genetically engineer the wild**

#### Indigenous knowledge

There are at least 476 million people who identify as Indigenous around the world<sup>14</sup>. While Indigenous Peoples comprise around 6% of the global population, it is estimated that their ancestral lands encompass more than one-quarter of Earth's surface<sup>15</sup>, and as much as 80% of Earth's remaining biodiversity<sup>16</sup>. Having stewarded this biodiversity for millennia, Indigenous Peoples around the world have cultivated sophisticated knowledge systems spanning agriculture, aquaculture, forestry, celestial navigation, and much more. Sustained over many generations through a variety of oral traditions and ceremonial practices, these knowledge systems are distinct from Western perspectives as they draw on embodied, experiential knowledge derived in close relation to the natural world<sup>17</sup>.

Indigenous knowledges are as diverse and heterogeneous as the communities who steward them, and live not only in the written word but in embodied forms like speech, storytelling, songs, and chants. Diné scholars Tsosie and Claw aptly describe Indigenous ways of knowing as *knowledge that endures*, affirming the empirical quality of knowledge created and continuously substantiated through countless trials over time<sup>18</sup>. Indeed, Indigenous Peoples and knowledge have also endured generations of suppression by colonial and settler colonial structures seeking to disconnect them from their lands and ways of relating to them.

Western science is a significant site of this suppression. In spite of the fact that many basic Western technologies and medicines are sourced from Indigenous cultures and traditions throughout history<sup>19</sup>, Indigenous expertise is often minimized and dismissed by Western science. Given that Indigenous knowledge does not follow Western conventions of separating the empirical and objective from the sacred, intuitive, or spiritual, it is often perceived as incompatible with Western conceptions of rationality, earning derision from those who perceive tradition as outdated, unscientific, or primitive<sup>20</sup>. However, there is growing recognition of the degree to which this dismissal of Indigenous knowledge has had deleterious effects not only for Indigenous communities, but for the ecological health of our planet at large. For instance, to manage rampant wildfires in California, government officials are partnering with tribes to revitalize cultural burning practices previously outlawed under state and federal policy -- the banning of which has contributed to the unprecedented size of today's fires to begin with<sup>21</sup>.

All around the world, biologists, conservationists, ecologists, and government officials are partnering with Indigenous Peoples to provide insights into the intractable issues of climate change, deforestation, species extinction, and ecosystem degradation<sup>22</sup>. As we look to technological solutions like genetic engineering to aid in the management of issues that will

intensify on a warming planet (e.g., neglected tropical disease, ecological degradation), we must actively support Indigenous and Global South communities to guide technology-development and look critically at the degree to which dismissal of Indigenous knowledge has created these issues in the first place. While Western science offers valuable knowledge about navigating these issues, we would be remiss to not consider the robust knowledge cultivated in Indigenous and Global South communities.

### Indigenous self-determination

As long as there is intention to release genetically engineered organisms directly onto Indigenous territories, or there is risk that those organisms may spread into those territories and affect ecologies they steward, Indigenous Peoples must be involved in the oversight and decision-making regarding genetic engineering technologies. Because considerable uncertainty remains about how gene editing technologies might impact wild ecosystems, and whether those impacts will be reversible or truly confinable to a given geographic space, we argue that any decision to gene edit the wild poses risk to Indigenous lands and thus necessitates inclusion of Indigenous stakeholders. Excluding this key stakeholder group from these processes would not only decrease the likelihood of authorization or acceptance of the technology by these communities-- it would represent a violation of Indigenous rights to determine the use of their lands.

The inherent rights of Indigenous Peoples to self-determination are communicated in several pieces of international law and policy, such as the International Labour Organization Conventions 107<sup>23</sup> and 169<sup>24</sup>, and the United Nations Declaration on the Rights of Indigenous Peoples<sup>25</sup>. UNDRIP affirms that “Indigenous peoples have the right to maintain and strengthen their distinctive spiritual relationship with their traditionally owned or otherwise occupied and

used lands, territories, waters and coastal seas and other resources ...” and that “States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free and informed consent prior to the approval of any project affecting their lands or territories and other resources...”. The United Nations (UN) has also discussed the potential application of free, prior and informed consent (FPIC) specifically to genetic engineering<sup>6</sup>, and scholars have explored the possibility of extending the ethical principles of FPIC to ecological editing in order to respect Indigenous rights to autonomy and self-determination<sup>7</sup>. However, in the absence of clear guidelines or policy to ensure that Indigenous self-determination is respected, the onus is on researchers and the institutions with which they are affiliated to commit to practices that do not intentionally or unintentionally exclude Indigenous stakeholders.

Engagement activities that support Indigenous self-determination will go beyond ensuring that Indigenous Peoples or communities are merely present or equally represented to identify whether the qualities of the engagement are truly inclusive of Indigenous expertise, values, and perspectives. In the realm of deliberation, scholars have noted that deliberative activities including Indigenous and settler participants may surface culturally distinct or even incommensurate viewpoints given differing empirical beliefs, norms, or epistemic procedures among these groups <sup>26</sup>. Inclusion of diverse cultural perspectives in a deliberation may serve as a valuable resource for reflexive thinking and collective problem-solving<sup>27,28</sup>. However, the hegemony of certain cultural perspectives may foreclose the meaningful inclusion of non-dominant knowledge or expertise.

A deliberative activity that does not allow Indigenous Peoples to express their situated expertise, or that devalues those inputs, will amount to exclusion regardless of their presence.

While we believe there are opportunities at every stage of a deliberative activity (i.e., design, recruitment, conduct, analysis of outputs) to meaningfully include Indigenous Peoples and knowledges, we argue this cannot be done without a direct confrontation of the historic and ongoing power imbalances that are relevant to genetic engineering, and how those may be reified in deliberative spaces. Put another way, without critical reflection on the broader social, political, and economic contexts in which genetic engineering technologies would be deployed, deliberative activities may reify the very inequities they are meant to overturn.

### **Recommendations for Facilitating Empowering Deliberation with Indigenous Peoples**

How might Indigenous ways of knowing be similar and different to the epistemology of a western scientific framework? How do we design specific deliberative processes that facilitate mutual understanding with Indigenous Peoples and subvert the traditional power differentials underlying normative deliberation spaces? These are core questions to consider when seeking to facilitate empowering deliberation on gene editing in the wild with Indigenous peoples. The meaningful engagement of Indigenous Peoples in these processes is vital to respecting Indigenous self-determination, and, when treated as an opportunity for mutual dialogue and relationship-building, deliberation may also help to align scientific research and development to Indigenous priorities.

Drawing upon our personal experiences working with Indigenous Peoples and cross-disciplinary ideas participatory design, psychology, education, development, global public health, performance studies, and cultural anthropology, we offer the following recommendations to foster a deliberation process that longitudinally recognizes and cultivates Indigenous ways of knowing<sup>29-36</sup>. While we have derived these recommendations specifically to address the inclusion

of Indigenous communities, we invite readers to consider how certain recommendations may have import for the inclusion of other key stakeholder groups whose knowledge and lifeways may be excluded under dominant or normative modes of deliberation.

## **Establishing Relations and Recruitment**

Deliberative activities encompass important recruitment questions, such as who to involve and how to ensure the equal representation of diverse groups. Organizers may seek ways to boost the attendance of typically underrepresented groups so they are equally represented, or perhaps even overrepresented, in a given deliberative activity. However, we recognize that representation alone cannot ensure the meaningful engagement of underrepresented groups including Indigenous Peoples. We invite an approach that seeks to establish relations with local Indigenous communities, and defers to community preferences in navigating questions related to recruitment (see Table 1).

To begin discussion of establishing relations with Indigenous Peoples, we would like to build upon the concept of “reflexivity,” which the 2016 NASEM gene drive report defines as “creating opportunities for reflexive thinking to clarify one’s beliefs and understandings, reflect upon and revise one’s opinions, and gain insight into how different interests and values are situated in conversations about how to proceed”<sup>1</sup>. In relation to the recommendations we offer below, each stage of the deliberation process must be grounded in reflexivity of the researcher. At the stage of establishing relations, engaging in reflexivity could take the form of the researchers making time to learn about the historical and current sociopolitical issues occurring in the community they would like to work with, asking communities if there are certain shared values that can be met through a partnership, and understanding that actively inviting Indigenous

Peoples to deliberate on environmental gene editing technologies may not yield specific outputs that can be easily translated into the framework of Western science (see Box 1 for examples of reflexive questions to guide gene editing research). Furthermore, it will be helpful for researchers to learn more about how Indigenous Peoples have been historically harmed or exploited through certain scientific research projects<sup>37,38</sup>, and how these negative experiences necessitate creating a non-confrontational space for Indigenous communities to refuse engaging in deliberation activities if they believe a partnership could impose harm or constrain limited time and resources.

With these important considerations in mind, there are still many Indigenous Peoples who will likely be interested in sharing their perspectives to guide environmental gene editing technologies. When establishing relations with Indigenous collaborators, practitioners will ideally find community leaders or representatives to work closely with and cultivate opportunities for co-design and collaborative decision-making about what the relationship will look like, such as by establishing shared expectations surrounding time, labor, compensation, and potential outputs. We recommend deference to collaborator input on established, culturally-variant processes for deliberation, such as decisions on who to include in deliberative activities and how to conduct them. Finally, practitioners should aim to build enduring relationships with Indigenous communities that are not contingent upon successful future development or deployment of the technologies deliberated upon.

### **Design of deliberation**

The design of deliberative activities involves questions about what the deliberation will look like, includes a location for deliberation, and materials needed to conduct the deliberative activity. We emphasize the need to consider the power dynamics associated with particular

places and suggest a partnership approach to identify strategies that will increase access to Indigenous participants. We also recommend a holistic approach to background materials that will be presented to deliberation. In particular, we call for materials to situate the genetic engineering technology(ies) of interest within the broader social, political, and economic contexts that they would be deployed (see Table 2).

In acknowledgement of the diversity of Indigenous Peoples and their cultures, practitioners should draw upon a strengths-based approach to participatory action research<sup>32</sup>, and pursue place-based<sup>39</sup> and collaborative design of deliberation process rather than a standardized approach across different communities of Indigenous Peoples. Practitioners should invite Indigenous collaborators to lead decision-making on where to conduct a deliberative activity and the logistical concerns surrounding accessibility of such activities. Although it may be more convenient for researchers to hold deliberation activities on university campuses, researchers should take time to learn about the historical trauma that may be associated with certain places like universities, as some of these sites may be associated with harm through their association with historical mistreatment of Indigenous Peoples or unethical treatment of ancestral remains. Some communities may prefer or be willing to host deliberative activities in their own spaces, and it would be helpful for researchers to support such activities through additional resources, time, and research personnel.

In publicizing the deliberative activities, researchers should work with Indigenous collaborators to co-design materials for presentation to the broader Indigenous community in a way that situates the technology into local contexts: this could include mention of specific aspects of local culture and history that are relevant to deliberation about gene-editing. Beyond asking questions about how to best to communicate facts about the technology, it is imperative to

consider questions like: What information should deliberants have access to so they can understand the broader contexts in which the proposed gene-editing technologies would be deployed? What forms of knowledge are deliberants likely to draw upon during these deliberations (i.e., cultural narrative, song, spiritual, personal experience), and what specific strategies can be incorporated into design of activities ensure that diverse forms of knowledge are accounted for in the deliberative space? How can we create a culture of collaborative problem solving early in the deliberation process so that Indigenous Peoples feel respected and supported in sharing context for existing health and environmental issues that the technology seeks to contend with? How do we create equal time and space to center existing Indigenous technologies and approaches that may already contend with issue at hand and continue viewing these approaches as plausible options in addition to the technology being deliberated?

### **Facilitation of deliberation**

Facilitation involves the conduct of the deliberation. This raises questions about how the deliberative activity will open and sustain discussion and how participants will be asked to engage with materials and with each other. We recommend a participatory orientation to deliberation that values collective learning and co-design of outputs, and we call for an approach to facilitation grounded in reflexivity, empathy, and active listening (see Table 3).

Following the previous discussion of fostering a culture of collaborative problem solving, practitioners should consider providing equal time and space for scientists and community members during the beginning of deliberation activities to share important information about the collaboration and issue at hand. Such information could include overviews of each stakeholder involved in the collaboration, the origins of the specific environmental or public health issue the technology seeks to address, and existing or emerging technological and non-technological

approaches to mitigating these issues through broader stewardship of the local environment. For instance, Indigenous community partners may wish to discuss their kinship relations or guardianship responsibilities to particular ecosystems or species, factors threatening those relationships, and the types of interventions most appropriate to explore in various contexts.

During the deliberation activity, it is crucial to cultivate an environment built on listening and sharing instead of one-way dissemination or the use of persuasion and urgency narratives. Framing dialogue around Indigenous wellbeing rather than pure deliberation of the technology at hand could be a helpful strategy for surfacing how potential technology development and deployment may interact with wellbeing in nuanced and culturally specific ways. Examples include consideration of the material conditions under which the technology will potentially be produced and tested, the history and significance of the land such technologies will potentially be trialed on, and culturally diverse perspectives on how gene editing in the wild could yield particular risk, benefit, and harm in a specific regional context. Collectively producing a dynamic document detailing the dialogue arising from activities aimed at surfacing Indigenous concepts of harm, risk, benefit can offer a productive strategy of deliberation for both community members and practitioners.

## **Output and Analysis**

Outputs refer to the documents, texts, or other materials generated from the deliberative activity. Conventional outputs may include meeting notes or reports that distill key insights from the deliberation, and they may be public-facing and/or disseminated to specific stakeholder groups involved in decision-making about gene-editing such as regulators, risk assessors, or policymakers. We invite an approach to outputs grounded in participatory design and epistemic

flexibility. Deliberants should not only inform what information is represented in outputs, but also the form those outputs take. We call on organizers of deliberative activities to consider how outputs might take diverse, multimodal forms beyond conventional written reports. Finally, we call on those charged with analyzing and distilling information from deliberation into an output to practice reflexivity, remaining mindful of the ways in which their own cultural biases or interpretive frames may impact their participation in this task (see Table 4).

Practitioners can ask their collaborators what forms of outputs would be most accessible to the community at large and representative of the dialogues that took place. Researchers can consider including visual metaphors or diagrams that documenting collective understandings from deliberative activities, such as by using a red/green/yellow light system to categorize the status of consensus on different viewpoints arising from deliberation activities. Other avenues to explore include the use of social media to share updates and open space for additional dialogue, jargon-free language, audiovisual recordings of both the deliberative activity and future decision-making activities in which the outputs of the deliberative activity with Indigenous Peoples were consulted (i.e., policymaker meetings, internal lab meetings, institutional meetings in regards to the gene editing in the wild), physically or digitally accessible materials, and providing outputs in the local language or with closed captioning.

Beyond simply sharing outputs with involved communities, practitioners may also consider creative approaches to facilitating ongoing deliberation in ways that are synergistic with the values and objectives of involved communities. For example, this could involve working with Indigenous youth interested in the sciences to conduct audio interviews with elders in their community on cultural perspectives regarding the environmental or public health issue the technology seeks to address or potential use of environmental gene editing technologies.

Practitioners could also explore funding a local Indigenous performing arts group to create a participatory public skit on a nuanced cultural viewpoint unearthed during the deliberation process. Outputs can also offer provide future remote opportunities for Indigenous Peoples to continue engaging with deliberations between in-person deliberation activities, such as through online or social-media based forums, online multimedia storytelling projects, voicemail, or leaving questions and notes at a collaborative public installation commissioned specifically to foster dialogue in relation to salient themes discussed during deliberative activities.

Practitioners should focus on creating deliberation outputs *with* communities rather than *for* them. Practitioners should identify ways to involve community partners to iteratively refine of outputs and inform the processes and avenues through which such deliberations are incorporated into decision-making. Before sharing any outputs publicly or with policymakers, it is important to iteratively seek feedback and approval from deliberants and collaborators. By creating open channels of communication to keep communities in the loop on post-deliberation activities, offering opportunities to provide more input, and sharing updates about how deliberation is shaping the decision-making process, practitioners can remain accountable to their community partners.

## Conclusion

Significant and unprecedented advancements in gene editing technologies are well underway. If the potential benefits of these technologies are to be realized, scientists, researchers, regulators, and ethicists must first grapple with ethical and political stakes of their implementation in the wild. While many recognize the necessity of community and public engagement to the collective navigation and deliberation of these ethical issues, more discussion

is needed on the ways to engage specific stakeholder groups. In this article, we argued that Indigenous Peoples must be involved as key stakeholders in gene drive research given their inherent rights to self-determination, and offered a set recommendations to guide broad public deliberation involving Indigenous communities. While the recommendations offered are neither comprehensive nor universal, they invite continued consideration of how deliberative activities can be designed to empower the dynamic, historied, place-based knowledges of Indigenous Peoples. We call on those committed to the inclusive design of broad public deliberation about genetically engineering the wild to critically reflect on the normative orientation of deliberative activities, and pursue strategies that de-center dominant Western approaches to deliberation. Given the complexity of genetic engineering technologies (and the problems they seek to address), we believe the most generative and just outcomes will arise from those activities that exercise epistemic humility and invite the meaningful engagement of Indigenous knowledges.

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