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OPINION

## Advances in genetic engineering test democracy's capacity for good decisionmaking

Local community input is not adequately sought out, and issues of social justice and equity are largely ignored.

By Natalie Kofler and Riley Taitingfong Updated November 9, 2020, 5:00 a.m.



An Aedes aegypti mosquito, known to carry the Zika virus. Sometime next year, genetically modified mosquitoes will be released in the Florida Keys in an effort to combat persistent insect-borne diseases such as dengue fever and the Zika virus. The plan,

This year has tested our ability as Americans to address collective challenges. From the wildfires of the Pacific Northwest to hurricanes in the Gulf of Mexico and the ongoing impacts of COVID-19 on lives across the country, we are reminded, over and over, that solutions too narrow in scope, too ignorant of history, and too dismissive of communities will fail. The effects of these failures — disproportionate impacts of COVID-19 and the climate crisis on communities of color — tend to fall on those left out of the decision-making process, the already structurally disenfranchised and disempowered.

This country's failure to address the coronavirus pandemic is an example of a US history peppered with narrowly framed decisions that resulted in danger and death. <a href="Navajo">Navajo</a>
<a href="Navajo">Nation</a>
is still living with the adverse health and environmental impacts of Cold War-era government decisions to mine for uranium without local community consent. Black Americans still carry multigenerational trauma from the <a href="Tuskegee Syphilis Study">Tuskegee Syphilis Study</a>, where American researchers intentionally withheld medical treatment from hundreds of non-consenting Black men to study disease progression. When decisions that impact the environment and public health don't empower communities, human rights violations follow.</a>

New advances in genetic engineering and their application for environmental conservation and public health are further testing our democracy's capacity for good decision-making. With minimal public input, the Environmental Protection Agency recently approved the release of genetically modified mosquitoes in Florida and Texas. An application for the planting of GM American Chestnut trees, engineered to reproduce and spread in the wild, is currently under review by the US Department of Agriculture. And even more complex and powerful genetic technologies intended for environmental release are in the research pipeline.

Gene drives may be the most impactful and controversial of these technologies. Gene drives are genetically engineered plants and animals designed to force expression of a

desired genetic trait in a wild population. When released into the environment, just a few gene-drive organisms can override natural selection to spread a genetic modification through a species and potentially change it forever. The oceanic release of gene-drive corals, for example, could spread heat resiliency to protect reefs from rising sea temperatures. Release of gene-drive mosquitoes that spread infertility could eliminate the transmission of mosquito-borne diseases in the United States, such as the Zika virus and dengue fever; gene drives to suppress malaria have already been developed in labs.

But these potential benefits could easily be overshadowed by unintended consequences. Without thoughtful oversight, gene drives could disrupt ecosystems, cause food webs to collapse, increase disease virulence, and further disenfranchise cultures and communities.

US regulatory agencies charged with overseeing gene drives <u>define a good decision</u> as one that is safe (the technology isn't likely to harm human and environmental health) and effective (the technology does what it's designed to do). In addition to misgivings about who gets to decide what constitutes safety and efficacy, we have concerns about this narrow definition of a good decision. Aside from public comment periods, <u>local</u> <u>community input is not adequately sought out</u> and issues of social justice and equity are largely ignored. This is unacceptable for a technology with the capacity to forever change our shared environments.

Here are four ways decision-making about gene drives could be improved:

• Diverse experts must be empowered. Gene drives and their interactions in the environment are complex. Rigorous scientific data are needed to inform decisions, as are experts with a deep understanding of the human and nonhuman communities where release would occur. In addition to geneticists, vector biologists, and ecologists, a parent whose child has been developmentally impacted by Zika is an expert. Indigenous peoples with generations of experience of sustainably fishing their local waters and reef systems are experts. The best solutions will be those developed in collaboration with communities

facing the challenge meant to be solved. To ensure everyone's safety, their inputs must be included and valued.

• Consent isn't enough. Gaining consent from communities that could be impacted by a gene-drive release will be crucial, but consent should be the bare minimum for a good decision. Today's consent mechanisms, such as the Common Rule and Institutional Review Boards, are born out of histories of harm and misconduct (e.g., <a href="Tuskegee">Tuskegee</a>, <a href="Willowbrook">Willowbrook</a>, the <a href="San Antonio Contraceptive Study">San Antonio Contraceptive Study</a>). But these important safeguards emphasize individual bodies and lack procedures that protect the rights and welfare of communities, the environment, and the interdependent relations among them.

Gene-drive decisions must go beyond narrow goals of obtaining consent and instead seek to build trust and reciprocal relations among technologists, regulatory agents, and affected communities. This means going beyond public comment periods to treating communities as partners and seeking input in decision-making.

• Reckon with history or it will be repeated. Centuries of racist and colonial practices have not only contributed to today's environmental and public health crises — such as impacts of deforestation on zoonotic disease transmission, pollution-induced degradation of marine ecosystems in low-lying atolls, or in East Boston, a designated Environmental Justice Population, where Logan Airport already controls half of the land and the electric company Eversource now seeks to site a new substation — they have also all but ensured that those least responsible for these issues will feel their impacts the most. Relationships cannot be built without an understanding of the historic and ongoing injustices faced by members of impacted communities. This calls for an open and critical assessment of our complicity in racist and colonial structures by virtue of the institutions we work in and the lands we live on.

For example, most Americans don't know about the unsavory links between the founding fathers of environmental conservation and the <u>eugenics movement</u>. Gifford Pinchot, the first head of the nation's first National Conservation Commission, for example, also

served as a delegate to the first and second International Eugenics Congress. Efforts in the early parts of the 20th century to keep the American wilderness "pristine" were interwoven with pseudoscientific ideas of genetic purity, white supremacy, and racial segregation — this way of valuing nature still influences who can access American wild spaces and natural places today.

• Put your money where your mouth is. Numerous governmental agencies, technology developers, academics, and NGOs have called for more community involvement in gene drive decisions. But without meaningful investments, this can't happen because our institutions don't have the infrastructure or capacity to sustain open and inclusive decision-making. As millions of dollars are being invested in technology development, equal resources are needed to support collective oversight. Those investments are needed immediately.

In calling for collective oversight and community empowerment, we fully expect our recommendations to be labeled as too idealistic by those firmly rooted in the status quo. Good. Because if ever there were a time to imagine a more ideal, democratic future, it's now. Gene drives may or may not be part of this future, but better decision-making processes absolutely must be.

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