



## Gene Editing Communication Must Center Marginalized Communities

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COMMENTARY



## Gene Editing Communication Must Center Marginalized Communities

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Many prospective CRISPR/Cas9's breakthroughs – from treating sickle cell disease (Stein, 2019), to developing climate-change resistant crops (Molteni, 2019), to curbing the transmission of mosquito-borne illnesses (Prabhune, 2019) – will disproportionately impact marginalized communities, including racial and ethnic minorities, individuals with disabilities, and people living in poverty around the world.

Gene editing research is predominantly (Siwo, 2018) done in Western and economically-developed countries, and is unfortunately – like most scientific research – not very inclusive of marginalized communities. For example, there is a lot of CRISPR research on malaria – a disease that predominantly impacts sub-Saharan Africa – but researchers from that region are underrepresented in the field. The lack of sub-Saharan African scientists in malaria CRISPR research is problematic because local perspectives and cultural understandings are likely missing from the way research is being done, how current investigators are engaging with affected communities, how applications of the technology are being designed, and how the implications of the research are being discussed. This type of skew contributes to health disparities, unequal access to gene editing technologies and their benefits, and perpetuates the exclusion of marginalized communities and individuals.

Just like gene editing research, communication about gene editing is also done from predominantly Western (and mostly White) perspectives. This raises important questions for environmental – and more broadly, science – communication researchers and practitioners. How does one engage and partner with marginalized groups to explore and address the multiple complex scientific, ethical, and legal issues related to gene editing? Given science's history of colonialism, oppression, and exploitation (Roy, 2018) (e.g. eugenics, nuclear testing in the Marshall Islands, contraceptive trials in Puerto Rico), how can one foster trust and transparency with marginalized communities? How can gene editing communication be made more inclusive and equitable? How does one avoid perpetuating disparities?

To address these urgent questions, the field of environmental communication will need to reframe its approaches. To put it simply, inclusion and equity need to become priorities, not afterthoughts.

### Prioritize inclusion and equity by centering marginalized communities

Centering marginalized communities means literally that – shifting the practices and power dynamics that have kept these communities in the margins and putting them at the center of gene editing communication efforts. To do this, communicators must continuously grow their awareness of historical injustices and disparities, and of the context and culture of these communities. Centering marginalized communities also means moving away from trite assumptions and narratives about marginalized individuals. From media to textbooks, the stories of people from marginalized identities are rarely seen or heard, and when they are, they are often told from a deficit

perspective. Other times, marginalized groups are portrayed as monolithic or one dimensional, perpetuating erroneous stereotypes and biases.

For example, although previous literature suggests that there are more Māori (the indigenous Polynesian people of New Zealand) who oppose genetically modified (GM) products, a recent pilot study (Hudson et al., 2019) indicates that GM products with clear community or environmental benefits are viewed more positively by Māori people. The study also showed that Māori cultural concepts and values influence whether or not members of the community oppose gene editing research and its agricultural applications. All of this underscores the importance of community engagement, of understanding historical perspectives, disparities and injustices, and of culturally-responsive approaches. Also, it stresses the need for more research to understand how the practices, beliefs, previous knowledge and experiences, and values of marginalized individuals influence how they engage with, perceive, and understand gene editing.

To center marginalized communities, researchers and practitioners must also consider who the messenger is, what they are saying and how, and in turn how that might impact perceptions. In the gene editing documentary “Human Nature” (n.d.) (produced by some of my colleagues at iBiology and focused on the CRISPR/Cas9 system), one of the main characters is David Sanchez, an African American teenager with sickle cell disease. In the film, David vividly describes his pain by closing and opening his arms in a slow, pulsing manner, saying “This hurts. You are having a sickle cell crisis.” David dispels the perception that he might wish he didn’t have sickle cell disease. “I don’t think I’d be me if I didn’t have sickle cell,” he poignantly says. Hearing David, in his own voice, without any mediators or narrators throughout the film centers his perspective as a Black kid with sickle cell. It also offers a stark reminder that although marginalized individuals have voices, they are infrequently given a platform to raise them.

## Embrace co-creation

Co-creation is a collaborative and participatory process that allows different interested parties to contribute their knowledge, experiences, and perspectives to inform the design and implementation of a project. Co-creation approaches like community-based participatory research and integrated knowledge translation (Jull et al., 2017) are being successfully leveraged in areas like public health (Simonds et al., 2013), informal science education (Bevan et al., 2018), and genomics research (Claw et al., 2018).

One example of how co-creation is being utilized in gene editing is the work of the non-profit organization Target Malaria (n.d.). They are partnering and engaging with communities in Africa (Hartley et al., 2019) to use gene editing technologies for malaria control. One tenet of their work is that researchers and practitioners must move away from thinking about community engagement “as the right thing to do or as a way to secure public acceptance.” Rather, researchers and practitioners should collaborate with marginalized communities in ways that value the communities’ knowledge, experiences, and culture. Researchers and practitioners should approach engagement with a recognition that these communities have agency and diverse types of knowledge that can enrich the research, application and communication of gene editing. By embracing co-creation (Thizy et al., 2019), communication researchers and practitioners can create opportunities for meaningful engagement, genuine inclusion and build trust with marginalized groups. One additional benefit of co-creation is that it could help uproot the deficit model that persists in communication.

## Funding should center inclusion and equity

Reports from both the National Academies of Science, Engineering and Medicine (NASEM, 2017) and the American Academy of Arts and Sciences (Nisbet & Nisbet, 2019) have underscored the need for investing in research in the communication of gene editing. However, I believe that funders (e.g. federal agencies, non-profit organizations, philanthropic foundations, academic institutions) will need to go

further than this. Centering inclusion and equity is hard work that requires much more than good will. It requires that organizations and individuals have the capacity, skills, and resources to do so. And that requires money. Thus, funders will also need play an important role in catalyzing a shift towards centering inclusion and equity in the research and practice of gene editing communication.

To center equity and inclusion, funders will likely need to rethink their programs and criteria themselves. Chicago Beyond's Guidebook "Why Am I Always Being Researched?" (2018) has excellent resources to help communities, researchers, and funders establish more equitable partnerships. Some of their recommendations for funders include asking questions like: How can you ensure the research produces something of real value to the community? Who defines that value? How could you include researchers from communities being researched? For example, if a funder is supporting a project to investigate perceptions of deaf people about the use of CRISPR to treat deafness (Mullin, 2017), are deaf researchers participating in the project? How? If no, why not?

Some examples of philanthropy and government funded projects focused on knowledge-building and fostering science communication partnerships that intentionally center equity and inclusion have emerged over the past few years (e.g. Inclusive Science Communication [n.d.], Civic Science Fellowship [Rita Allen Civic Science, n.d.]). These projects are promising early steps, but more investments that are focused specifically on gene editing will be necessary given the complex scientific, ethical, and legal issues surrounding gene editing and how fast technologies like CRISPR are moving.

## Conclusion

Gene editing has the potential to address some of the biggest healthcare, agricultural and environmental challenges of our times. However, if this new CRISPR-driven gene editing revolution follows a path similar to previous scientific revolutions, its benefits and burdens will be unevenly distributed. To ensure that the disparities and injustices of the past are not repeated, then the gene editing research and communication communities must reframe its approaches to center marginalized populations. Everyone in gene editing must be willing to do the hard work of promoting equity and inclusion. By now you have probably noticed that I have purposefully de-emphasized diversity, because simply increasing the numerical representation or participation of individuals from groups that have been historically marginalized is not enough to promote equity and inclusion. Diversity does not equal equity and inclusion and needs to stop being co-opted as an equivalent.

The gene editing research and communication communities must work to constantly raise our (and I am including myself as a scientist and communicator) awareness of inequities and inequalities and cultural responsiveness. We must seek to move away from trite assumptions and narratives, and listen to new perspectives with empathy. We must all recognize that for far too long, the knowledge and agency of marginalized communities has been overlooked and undervalued. We can no longer afford to do that or stay silent and complicit. All of us must be willing to raise important questions not only about access to the technology itself and the equitability of its applications, but about access to information and equitability in who participates in making decisions regarding gene editing. For CRISPR/Cas9 to fulfill its revolutionary potential equitably and inclusively, gene editing communication must center marginalized communities.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

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