

## **Navigating the Future in a Sea of CRISPR Uncertainty: Contemplating Map Essentials**

**June 26, 2019**

### **Who gets a voice in the imagining?**

#### ***Opening Words***

Adapted from Marge Piercy

#### *Councils*

We must sit down and reason together.

Perhaps we should sit in the dark. In the dark we could utter our feelings.

In the dark we could propose and describe and suggest.

In the dark we could not see who speaks and only the words would say what they say.

No one would speak more than twice. No one would speak less than once.

Thus saying what we feel and what we want, what we fear for ourselves and each other in the dark.

Perhaps we could begin to listen.

We have thought about imagining the future, especially a human future, in the context of possibilities offered by CRISPR technology for editing the human germline, and gene editing limited to non-germline human cells. At this point in our conversations we recognize the different questions raised by enhancement versus medical therapies, and the potential of CRISPR on one hand to ease human suffering, but on the other to increase social disparities. We know that scientists and ethicists have raised concerns about CRISPR technology, and there has been a call for a moratorium on gene editing experiments designed to alter heritable traits in human babies. In addition to safety and medical necessity issues, the national academies and the individual scientists who suggested the moratorium argued that altering

heritable traits in human babies should not take place unless “there is broad societal consensus about the appropriateness of the proposed application.” This last point speaks directly to the question we are contemplating this morning, as we imagine the future- “Who gets a voice in the imagining?”

Are we ever likely to reach a broad societal consensus on the appropriateness of a proposed application of CRISPR to the human germline? I doubt that in this country we can ever reach a consensus about whether or not any experimental testing with human embryos should be permissible, regardless of the funding source, and whether or not the goal is a viable pregnancy. But that reality doesn’t excuse us from working to insure that the public has a place at the imagining table, but how to reach people’s attention on this topic and invite their “informed” input? I used to, and still do, worry a lot about the “informed” part of that question, but these days I find myself thinking more and more about the “invitation” part.

I am involved in an education research project to develop curriculum for high school biology teachers in Alabama that will be used to help them teach evolution. Just two years ago these teachers could have avoided the topic altogether, but a change in Alabama state standards means the expectation now is that high school students will learn about evolution. There are places in this country, and Alabama is not the only one, where it is still possible to graduate from high school without having had the opportunity to learn about evolution, usually because the community believes it is a threat to their religious beliefs.

My contribution to the curriculum are lesson plans that help teachers to acknowledge the students’ concerns before they begin their science instruction,

essentially guiding teachers on how to spend a few class periods creating a safe space to discuss what is a culturally controversial topic while protecting the integrity of the science classroom. Three to four weeks later the hope is that the students will understand evolution from a scientific perspective, even if they don't accept it. For the science education community this is a contentious idea, whether the goal of instruction should be an understanding of evolution or an acceptance of evolution, you might assume that the first should lead to the second, but it doesn't always.

*Should a community that doubts the validity of evolution have a voice at the CRISPR imagining table? How informed can their understanding of genetics or the timeframe of evolution by natural selection be? One of the biggest lessons I have taken from my work in science education research is that reaching a place of mutual trust and respect is just as important as striving for science literacy, and maybe more important.*

While I was observing a classroom in one Alabama community, I had the opportunity to hear student responses to this question posed by their teacher, "Why do you think some people don't want you to learn about evolution?" I have heard a question like this addressed to students many times before, in Alabama classrooms and other classrooms around the country. Previously student responses included some version of "evolution conflicts with my religious beliefs." But in this Alabama class, not a single student mentioned a concern about a conflict with their religious beliefs. Instead many of them talked about a conspiracy by the US government to keep them from learning about evolution, because if they learned about it they

would know the truth about some diseases, and the truth was that medical cures exist, but in order for doctors to keep making money they are hiding the truth. Can anyone guess where in Alabama I was? Driving back to the hotel after the classroom visit we passed a sign for the “Tuskegee Airmen museum,” then it all made sense. Starting in 1923 and continuing for 40 years, 600 black men in Tuskegee were recruited for a study about the natural course of syphilis, without their informed consent, and as part of the study the proper treatment needed to cure their illness was withheld from them. *Who gets a voice at the imagining table matters, our whole view of a situation can be shifted when we switch lenses, for example, from those of a middle aged, highly educated white women scientist and education researcher (with an interest in Science and Religion) to that of a black teenage high school student in Tuskegee Alabama.* Think about this in the context of making decisions about CRISPR gene editing, especially altering the human germline.

Let me supply one example from the work of Tracy Trothen , an ethicist and co-chair of the American Academy of Religion’s “Human Enhancement and Transhumanism Group.” Here is what she has to say about the possibility of altering the human germline to achieve a moral enhancement of individuals:

“My beginning point is the claim that all life is sacred and interdependent. This claim is consistent with most religions... Several religions, including Christianity, underscore the duty to improve ourselves and others, making the world more just. Theologians with a stated commitment to the disadvantaged or marginalized prioritize social justice, as do I. *Systematic power imbalances affect each person’s experiences in particular ways, giving*

*rise to perspectives that are shaped by privilege and disempowerment. A just approach to moral bio-enhancement requires the consideration of perspectives from the margins.” (Religion and Human Enhancement p. 245)*

As one example of how power imbalances might impact decisions about moral enhancement she considers excessive pride, noting that this is usually identified as a vice, so should we bioengineer human embryos to remove it? Not necessarily, she reminds us that pride is a greater temptation for the more privileged whereas, “Many women and other marginalized people need more pride leading to a greater claim of their voice.” Her point is that what is a vice depends on whose eyes we are looking through. Before we start making decisions about enhancing virtues or removing vices, assuming (and it’s a big assumption) that these were realistic applications for CRISPR technology, our invitation to the imagining table needs to include those who ordinarily might not be invited. This means that scientific literacy is not necessarily the criteria that out ranks all others. We know it can be challenging to bring new voices to the table, but what do we risk if we don’t?

Who gets a voice in the imagining? *What about those who can never speak for themselves, at least not using human language? Up to now my comments have focused on CRISPR and humans, but I have said next to nothing about the rest of nature, other than to agree with John Haught that our universe, all of it and not just humans, is unfinished and part of an ongoing transformation. Considering the rest of nature, or if you prefer, creation, what does CRISPR technology offer in terms of a tool for humans, in Haught’s words, to extend “the creativity of the cosmic process”? Here is*

*a reminder of some of the ways we have already “inserted ourselves into the creativity of evolution” (as reported by Jim Kozubek in his 2018 book *Modern Prometheus*):*

-CRISPR has been used to fix recessive kidney disease in inbred Dalmatians, to create super-strong beagles, cows without horns, and miniature pet pigs, to disable immune altering genes in pigs so that their organs can be used for human transplant and to change the color pattern in butterfly wings.

According to bioethicist Hank Greely, one of two non-scientists present at that first meeting Doudna called to discuss developing CRISPR technology, “our accelerating ability to alter non-human germlines” is *the* topic that deserves more discussion. In March 2015, Greely had this to say in his own editorial:

“To me, the biggest likely change in our world from CRISPR-Cas9 and other genomic editing methods won’t be in humans but in the non-humans we use the methods to modify. As it gets cheaper and easier to modify genomes, non-human genomes offer freedom from a lot of regulation, liability, and political controversy, while offering plenty of opportunities to improve the world, become famous, or make money – with combinations of all of the above. ... In fact, on the same day Science published the moratorium call on-line, it published on-line an article on one very successful “gene drive” system, using CRISPR-Cas9, that could spread a chosen genetic variant very quickly through an entire population [*or even an entire species*]. It is these kinds of uses of genomic engineering that could reshape the biosphere.”  
(Stanford Law School)

In what new ways might we soon reshape the biosphere? Non-human germlines, specifically those of mice and mosquitoes are being altered to stop Lyme disease and to stop the spread of the Zika virus and malaria, -certainly these experiments hold great promise to ease human suffering. Currently these experiments are taking place in secured labs, but if and when these CRISPR modified organisms are released into the wild what unforeseen effects on the environment might also be unleashed? Is there a cost to our creativity?

We know the answer to that last question, it goes by the name “the Anthropocene”, the name proposed for a new geological epoch that recognizes the scale of human influence on the planet. Humans have already changed the Earth’s climate, biodiversity, land usage, and the geochemistry of it’s atmosphere and oceans. The non-human life we have impacted by these changes didn’t have a voice in the decisions that got us to where we are now, and they won’t have a voice in how we decide to use CRISPR in the future. If they did, they might begin by questioning our agricultural and domestication processes. And therein lies an irony, I think, when it comes to CRISPR technology.

If we mark the beginning of the Anthropocene as a few thousand years after the rise of agriculture, then it took Homo sapiens about 8,000 years to have the impact on the planet we see today. CRISPR research is currently going on with almost all of the crops we regularly eat. In the next few years we can expect to see crops genetically engineered with CRISPR for increased productivity and disease resistance. Given our growing population numbers and decreasing land availability, the use of CRISPR technology in agriculture could be a much needed tool to combat

world hunger and perhaps even reverse some of the unintended consequences of agriculture and animal domestication that threaten Earth's biodiversity .

But in first world countries, one roadblock might be a public suspicious of CRISPR engineered crops in the same way they are of genetically modified organisms, GMOs. Scientists need to extend an invitation to a diverse public for a transparent and respectful discussion about imagining the use of CRISPR in agriculture and soon. Failure to do so could come at the cost of lost public trust in the technology. New agricultural processes, one of the areas where CRISPR might make an immediate impact that has benefits for human and non-human life, could be overly regulated at the demand of a public that was never included in the imagining conversation.

Our answer to *the* question "Who gets a voice in the imagining?" probably reflects our answer to the question "Who do we trust?" *Expanding trust is hard work, the evolution education research community is coming around to the idea that inviting and listening needs to come before informing. Maybe that can work for CRISPR public engagement too.*

***Closing Words*** Adapted from Verna Myers

Diversity is being invited to the party; inclusion is being asked to dance.

As we imagine a CRISPR future, let's make sure we have a variety of dance partners.

So let it be. Amen.