

The Ethics of CRISPR-Cas9 Technology and its Socioeconomic Implications

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**Abstract**

CRISPR-Cas9 is a gene editing technology that allows scientists to target and alter specific DNA sequences. This paper explores the ethics of CRISPR-Cas9 technology and its socioeconomic implications. Selected based on influential publications, works, or community service, this paper features the insight of thought-leaders in the spheres of economics, bioethics, genetics, philosophy, ecology, public policy, and religion. Their perspectives, obtained via interviews, or in some cases, published works, cover topics from gene drives to agricultural applications and consider how the past and present may shape CRISPR-Cas9 development and innovation. Though offering differing perspectives and voicing varying concerns, those who expressed their opinions on gene editing shared some commonalities, such as advising caution in dealing with CRISPR-Cas9, acknowledging the potential implications it could have on society, and the consequences society could cause itself.

To increase engagement with CRISPR-Cas9, this paper seeks to provide a comprehensive review of CRISPR-Cas9 through its content and extensive use of footnotes. As the primary goal of this paper is to present perspectives, readers should form their own opinions of the science, and seek out other sources that both solidify and challenge their beliefs.

*Keywords:* CRISPR-Cas9, gene editing, agriculture, society, inequality, ethics, economics

## Introduction & Context

### Background

In 2018, He Jiankui, a Chinese researcher, shocked the world by announcing he had helped genetically engineer the DNA of twin babies to be immune to HIV. In doing so, he overrode several pre-existing ethical barriers and guidelines. In 2019, Jiankui was found guilty of conducting “illegal medical practices” and sentenced to 3 years in prison.<sup>1</sup>

Jiankui’s means were a technology called CRISPR. An acronym for Clustered Regularly Interspaced Short Palindromic Repeats, CRISPR is a genome editing technology that alters genes by cutting DNA to let natural DNA repair processes work in the targeted area. In the case of one of its more prominent technologies, CRISPR-Cas9, the technology accomplishes this using a Cas9 enzyme and guide RNA (gRNA).

### Complexity

Like any major development, the implications of CRISPR are not strictly confined to the medical or scientific world. Advancements concerning gene editing impact the spheres of economics, law, technology, religion, and ethics. Thus, several questions are raised, with the complexities of their relations within multiple fields making it difficult to arrive at a definitive answer. Where biotech startups push for and champion responsible and ethical development and use, what does “responsible and ethical” mean? With the rise of citizen scientists and biohackers, what role do these new stakeholders play, and in what ways can they help and hurt its responsible development?

Ultimately, the ethics of CRISPR technology will be determined by the people who use it and what they purpose it for. Thus, this raises questions regarding its regulation, and facilitates discussion concerning the need for intensive evaluation of implications before and alongside development.

### Applications

While initially discovered in 1987,<sup>2</sup> CRISPR made perhaps its first widespread, impactful impression on the broader public with Jiankui’s 2018 announcement. Since then, the technology has dominated press and media, solidifying its stature and confirming that CRISPR is here to stay.

Encompassing other technologies in addition to CRISPR-Cas9 (like CRISPR-Cas13, Cas3, and Cas10), CRISPR has many capabilities and much potential, including helping to transform modern medical and ecological practices through COVID-19 diagnostic tests,

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<sup>1</sup> [What CRISPR-baby prison sentences mean for research](#)

<sup>2</sup> [CRISPR History and Development for Genome Engineering](#)

investigation of therapies for beta thalassemia<sup>3</sup> and progeria, and even the revival of woolly mammoths.

First making its rounds within the academic spheres, CRISPR has slowly diffused down to the public sphere, but not without complication. Despite this passage, CRISPR still remains highly complex, with discussion largely circling among those within science or academia. Grappling with the complexity of CRISPR technology and the unique stakeholders it involves, both those involved directly with the science and those who are not should collaborate to forge the gap and facilitate the free-flow of meaningful discussion.

Though human tendency will likely stave off egregious advancements in gene editing for the foreseeable future, one must think of its implications currently instead of waiting for the “future” to arrive. After all, a few decades ago, cell phones were figments of science fiction and imagination. While it may be the technology of *tomorrow*, it is crucial to promote both research and development into the field as well as public engagement for there to be a *tomorrow*.

## Intention

As the influence and implications of CRISPR technology are not confined solely to one sphere, the purpose of this paper is to promote awareness among those from all backgrounds - whether within science, medicine, academia or other fields.

The intention here is to provide thought-provoking perspectives from a variety of backgrounds to inform readers of the diverse voices and implications involved with CRISPR Cas-9. Readers should, of course, review other sources of information in addition to this paper when forming opinions.

As this paper focuses mainly on CRISPR-Cas9, the terms CRISPR-Cas9 and CRISPR will be used interchangeably to refer to CRISPR-Cas9. Any other variations of CRISPR (Cas13, etc.) will be explicitly stated.

## Biology & Genetics

### CRISPR-Cas9 & COVID-19

Type the letters C, R, I, S, P, and R into Google, and approximately 16,300,000 results will pop up. From projected resurrections of woolly mammoths<sup>4</sup> to investigations of CRISPR-aided HIV cures,<sup>5</sup> CRISPR technologies are dominating the news, even recently scoring an appearance in the newsletter *Morning Brew*<sup>6</sup> with the startup Colossal. But perhaps one of its more current and influential ties are those with the COVID-19 pandemic. Though not involved

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<sup>3</sup> [CRISPR-Cas9 Gene Editing for Sickle Cell Disease and  \$\beta\$ -Thalassemia | NEJM](#)

<sup>4</sup> [Woolly Mammoth De-extinction Project & Process](#)

<sup>5</sup> [Excision's CRISPR gene editing therapy for HIV is heading into human testing after FDA clearance](#)

<sup>6</sup> [A biotech startup has raised millions to resurrect woolly mammoths](#)

directly with the mRNA vaccine itself, CRISPR aids as a diagnostic in COVID-19 tests, and the quick turnaround and adoption of COVID mRNA vaccines gives hope of a similar reception for CRISPR.

Lauded by Charles Wheelan, a Senior Lecturer and Policy Fellow at Dartmouth College, for “develop[ing] in record time, ultimately saving many lives,” how do COVID-19 mRNA<sup>7</sup> vaccines work? According to the Centers for Disease Control<sup>8</sup> (CDC), instead of delivering weakened or inactivated viruses like their conventional vaccine counterparts, mRNA vaccines “teach... cells how to make a protein - or even just a piece of a protein - that triggers an immune response inside our bodies.” Producing these antibodies, this pre-coached immune response protects vaccine recipients from severe consequences in the event they do contract COVID-19. Coining this as “the most amazing scientific achievement in [his] lifetime,” Wheelan is not the only one with this impression. Megan Hochstrasser, a Science Communicator at the Innovative Genomics Institute, terms the “programmability of RNA in the Moderna and Pfizer-BioNTech vaccines as exciting.” Showing “the public, as well as investors and governments how something new, mysterious, and hard to understand at first can have a really quick turnaround from concept to impact,” Hochstrasser ties mRNA vaccines to CRISPR-Cas9 technology, explaining that while CRISPR is not present in the vaccine itself, the identification abilities of gRNAs<sup>9</sup> in CRISPR has made it an excellent diagnostic for COVID tests. In fact, according to Robert Service in [New test detects coronavirus in just 5 minutes](#), a COVID-19 test developed by Jennifer Doudna<sup>10</sup> and her colleagues that uses CRISPR can “accurately identify a batch of five positive clinical samples with perfect accuracy in just 5 minutes per test,” a stark contrast to the “standard test [which] can take 1 day or more to return results.”

In contrast to this optimism, Jane Maienschein, Director of the Center for Biology and Society at Arizona State University, warns that “the current situation with COVID and the anxiety created around COVID vaccines has politicized them in ways that may carry over to CRISPR-Cas9 technology as a lightning rod.” Given society’s tendency to politicize issues to produce advantage,<sup>11</sup> she suggests that “people may extrapolate from one technology to another and confuse what they do and what it means,” advising that the path to acceptance won’t be easy.

### How does CRISPR-Cas9 work?

So how does CRISPR-Cas9 technology actually work? Involving two molecules (a Cas9 enzyme and gRNA) that introduce a change into DNA, the Cas9 enzyme functions as a pair of molecular scissors, snipping two DNA strands at specific locations in the genome to enable the

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<sup>7</sup> messenger RNA

<sup>8</sup> [Understanding mRNA COVID-19 Vaccines](#)

<sup>9</sup> guide RNA

<sup>10</sup> [Pioneers of revolutionary CRISPR gene editing win chemistry Nobel](#)

<sup>11</sup> [How An Industry Builds Political Advantage](#)

addition or removal of segments of DNA. From there, an RNA scaffold containing the gRNA<sup>12</sup> binds to a specific DNA sequence (the gRNA is designed to only bind to a specific sequence and contains bases that correspond to those of the target sequence). Guiding the Cas9 enzyme to the target genomic sequence, the gRNA ensures the Cas9 enzyme cuts at the correct point across both strands of DNA. Afterwards, CRISPR scientists let the organism's natural repair processes take over. In the case of a healthy cell, the organism's systems will recognize the DNA is damaged and proceed to repair it.

Scientists can use CRISPR's repair systems to insert changes to one or more genes in the area of interest, thus enabling both specificity and generalization. However, it still leaves room for error, such as off-target mutations,<sup>13</sup> emphasizing the need for further trials.

## History

### Asilomar

If CRISPR-Cas9 has such broad potential and impact, where was it five, ten years ago? How did we get here? In some ways, the groundwork began in 1975, when a group of biologists, lawyers and physicians gathered at the Asilomar Hotel and Conference Grounds in Pacific Grove, California to discuss the potential, implications, and guiding principles of recombinant DNA technology. A relatively new technology at the time, recombinant DNA technology might be representative to scientists in 1975 what CRISPR is to us today. A method that enabled scientists to engineer pieces of DNA “in a fashion that allows them to be copied, or replicated, in bacteria or yeast,” (Green<sup>14</sup>) this process is also known as DNA cloning, with the cloned DNA referred to as recombinant DNA. Establishing the foundation on which CRISPR-Cas9 would blossom, recombinant DNA technology also set a precedent of collaborative decision-making, guardrails, and caution.<sup>15</sup>

### CRISPR-Cas9, a Legacy Biotechnology?

With regards to molecular biology, Shirley Tilghman, President Emerita and Professor of Molecular Biology and Public Affairs at Princeton University, recalls “two technological revolutions” that occurred within her lifetime. The first, recombinant DNA, and the other, CRISPR, she asserts, have both had “dramatic impact[s] on... basic science, the kinds of questions that you can ask, and what [people are] going to be able to understand about the natural world.”

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<sup>12</sup> a small pre-designed RNA sequence

<sup>13</sup> where a change implemented at a specific location in the genome unintentionally causes an alteration at another location.

<sup>14</sup> [Recombinant DNA \(rDNA\)](#)

<sup>15</sup> [Asilomar moments: formative framings in recombinant DNA and solar climate engineering research | Philosophical Transactions of the Royal Society A: Mathematical, Physical and Engineering Sciences](#)



Sharing similar views, Eric Juengst, Professor of Social Medicine and of Genetics at the University of North Carolina at Chapel Hill, recounts the ‘origin story’ of CRISPR-Cas9. “It came out of left field [from a] study of strange patterns in the DNA of bacteria... in [the] salt flats in Spain,” he says, and is “a central tool for much in molecular biology and manipulating DNA.” Coining CRISPR-Cas9 as a “game changer” due to its precision, efficiency, and versatility, Juengst adds that “we’re only beginning to see the ways in which it’s going to be used, not simply with direct interventions into double stranded DNA, but all kinds of interesting epigenetic interventions and other RNA editing.”

In particular, Juengst believes CRISPR has its advantages over past biotechnologies like recombinant DNA technology and gene therapy - citing its precision and efficiency in placing transgenes “where you want them in the genome.” However, Juengst also emphasizes the importance of directing attention to both the off target and on target effects,<sup>16</sup> as, in his words, “there’s lots of strange things happening that’s CRISPR-related - mosaicism<sup>17</sup> and in mutations of various kinds.”

### Similar and Different

“As soon as CRISPR got discussed we were all visibly talking about it.” Contrasting the abilities of CRISPR-Cas9 and past biotechnologies, Maienschein asserts that while “other gene editing technologies were very slow [which gave scientists] time to think about what [they were] doing and what [it] mean[t], CRISPR-Cas9 allows [for a] much faster response... [and] for things to happen much more precisely.” What effect does this have? According to Maienschein, a faster response time results in “more incentive or pressure [for scientists] to think ahead of time” about what they’re doing, why they’re doing it, and what it might mean, translating to increased consideration of social and ethical issues.

However, from the stance of Diego Comín, a Professor of Economics at Dartmouth College, speed hasn’t always been the case with CRISPR. Arguing that “biotechnology was losing steam until the pandemic” in terms of public engagement and interest, Comín compares the rise of CRISPR-Cas9 in pandemic-era to that of AI<sup>18</sup> – believing another bump is in store for biotechnology in “both resources and potential breakthroughs.” From Comín’s perspective, these potential bumps, already in action courtesy of CRISPR’s ties to COVID-19, “are huge for a technology that was not really on [the non-geneticist’s] radar until basically a year and a half ago.”

Speaking of losing steam, Wheelan compares CRISPR-Cas9 to past technologies by alluding to the steamboat. Arguing that biotechnology like CRISPR-Cas9 is “radically different than [past technologies like the] steamboat because it is harder to envision its

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<sup>16</sup> [Analysis of off-target effects in CRISPR-based gene drives in the human malaria mosquito](#)

<sup>17</sup> Mosaicism is a condition that occurs when a multicellular organism has 2 or more genetically different cell lines.

<sup>18</sup> Artificial Intelligence

implications,” Wheelan asserts that while “nobody fully appreciated how the steamboat changed society<sup>19</sup>... [we are] now at a place where kinds of radically changing technology are more difficult to understand and appreciate.” In contrast to the general simplicity of the steamboat, Wheelan casts CRISPR-Cas9 as more complex, arguing that “as technology gets more complicated, it may be harder for the public to get its mind around [its] true costs, benefit, and potential,” which may lead to misinformation or intense, partisan debate.

### Looking Forward

In the eyes of Kimberly MacPherson, Executive Director of Health Management at the Haas School of Business and Faculty Program Director for Health Policy & Management at UC Berkeley’s School of Public Health, CRISPR-Cas9 “is too important... and unlikely to get fully sidelined.” But, she adds, “even stem cell [technology] got derailed for quite a while.” The reason for this uncertainty, MacPherson notes, is because “unlike other technologies, where [concern was mostly] about how to best bring [biotechnologies] into active use, managing [CRISPR-Cas9] involves different nuances, because [of its potential for] permanent impacts on germlines and other areas.” This difference, MacPherson observes, could present challenges for determining ethical and moral guardrails, already seen in the July WHO<sup>20</sup> report, which provided general recommendations on the use of CRISPR systems.<sup>21</sup>

Diving into more specifics, Richard Scotch, a Professor of Sociology, Public Policy, and Political Economy at the University of Texas at Dallas, considers CRISPR’s implications for diverse societies. In a sample society, he proposes, if it is “thought that people [who are] neurologically atypical should be cured, eliminated, or considered as ill,” could the same be assumed for height? “Is it appropriate to try to enhance [the] growth of children with short stature, not through CRISPR but through the use of growth hormones?” he asks. In reality, “we don’t know enough about the genetic code, or its limitations, to do this, from a cognitive and physical standpoint.” Nevertheless, Scotch asserts that “we need to accept and embrace these kinds of variation and not use the genome to prevent the birth of children with limitations.” Considering history, Juengst notes that with the “last 70 years involving some form of human enhancement, ranging from the option to [prevent] the birth of people with impairments... to other state or culturally mandated restrictions, the fear that has become established, in light of all horrors, including what happened with the Nazis in Germany, is not a trivial concern.”

Emphasizing Scotch’s points on the dangers of its implications, MacPherson acknowledges that while CRISPR-Cas9 is “a scientific breakthrough, it’s not one that... solely lives in the domain of those with high expertise and high-end technological equipment.” And this, she notes, opens a Pandora’s box of considerations.

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<sup>19</sup> And didn’t have to since it was relatively straightforward

<sup>20</sup> World Health Organization

<sup>21</sup> [Human genome editing: recommendations](#)

## Public Policy & Affairs

### Path to the Public

What contributed to today's widespread interest in CRISPR? Tilghman offers an explanation: "In the last... 20 years, [there] has been a far greater willingness on the part of both the scientific and medical professions to welcome in the points of view of patients and patient advocates." Considering this, Tilghman suggests "the growth of patient advocacy groups, like the breast cancer advocacy group that was influential in bringing attention to breast cancer," is doing the same for CRISPR-Cas9 as the "medical profession and the scientific workforce recogniz[es] the value of engaging with the public." Commending the change as healthy, she predicts that in terms of future growth, the increase in engagement "is an irreversible trend that will make science and medicine better."

With respect to "other subtractive therapies (ZFNs, TALENs), additive gene therapies, or integrases," George Church, Professor of Genetics at Harvard Medical School and Professor of Health Sciences and Technology at Harvard University and the Massachusetts Institute of Technology, argues that "it's not [entirely] clear exactly why," CRISPR-Cas9 in particular, "caught on." Acknowledging both its cool name and involvement of interesting people,<sup>22</sup> Church concedes that other forces likely factored into the equation, since the technology is "about four times less expensive and [possibly] a little bit easier to think about," with grasp of the topic mainly dependent on understanding "the Watson-Crick rules."

### Engaging the Public

"Every report that's come out since 2015 about gene editing has stressed the need for this widespread... engagement, [involving] not just global scientific stakeholders, but... the public... as well." Noting this, Juengst hints there may be more than what meets the eye. "My cynical side notices that a lot of times, this is the scientific community's way of pushing all the hard questions off to the public. *Well we, of course, have no skills or expertise in ethics or social issues, but the public should discuss that and come up with what they think the rules should be.*" This approach, Juengst says, "seems like a little bit of a cop-out, since if the scientists are going to be in this business,<sup>23</sup> they should probably take some responsibility for it."

On the other hand, Juengst offers, "there's just as much call for this engagement coming from the public. So the other side of the argument is that this kind of technology is important enough that the public should have a say in how it unfolds. And that's relatively unusual." So why this interest? MacPherson offers an explanation: "It's not just money generated in a cool new science. It actually affects people, affects physicians, affects patients, families, and the

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<sup>22</sup> Referring to Jennifer Doudna, 2020 Chemistry Nobel Laureate, MacPherson remarks, "the Nobel prize doesn't hurt."

<sup>23</sup> The business of developing biotechnology for application.

ecosystem.” In other words, CRISPR-Cas9 isn’t like the Met Gala<sup>24</sup> that seems so far removed from the ordinary person. It’s more like a (fictional) announcement by several of the leading mirror companies that they are discontinuing their normal line and replacing it with mirrors that feature touchscreens and digital assistants. *Well, you might ask, what data will the mirror store? Will the mirror have visual access into the room in which it is placed? Who will have access to the mirror’s data? Where will the discontinued mirrors go?* And as the average individual uses mirrors on a daily basis (car mirrors, bathroom mirrors, dance studios, etc.), it is not difficult to imagine the wealth of concerns that would arise.

### In the Public Eye

In addition to the public, stakeholders in the public eye can be key in effecting change. As the Faculty Program Director for Health Policy & Management at UC Berkeley’s School of Public Health, which sits next to IGI,<sup>25</sup> MacPherson is often a neighbor to CRISPR pioneer and 2020 Chemistry Nobel Laureate Jennifer Doudna, who she describes as “a true leader in the industry.” Regarding Doudna’s approach with CRISPR, MacPherson remarks on her “thoughtful [manner] when... speak[ing] about it and... posture that while we can do all kinds of things, it is important to consider what one *should* do.” This, in addition to her stress “on stakeholders mov[ing] forward together... in a way that is thoughtful and intentional,” according to MacPherson, creates an atmosphere of transparency and authenticity that evokes trust, setting an example for others to follow.

### Public Among Us

“The number one rule in science communication is to know your audience and to cater your message and what you’re doing specifically to that audience.” As a science communicator for IGI, Hochstrasser is in the business of knowing audiences. “In other words,” she says, “understanding what different audiences care about, what appeals to them, etc., is really important.” Asserting the need for policymakers to connect with the communities in which their proposals impact, Hochstrasser stresses the importance of “speak[ing] to different people before or while projects begin,” arguing that this approach can help scientists “gain insight” about their target audiences, which can “potentially direct the course of the project.”

That being said, developing *with* the public, instead of *for*, is not without its advantages. “I think a lot of the time, you can really, really benefit from hearing what people think about what you’re doing.” In the case of agriculture, Hochstrasser explains, say “you’re trying to [engineer] rice that grows much faster [and] has a higher yield. But then you actually talk to the rice farmers that you’re imagining buying this product, and they say, *oh, but you’re doing that in a variety of rice that I would never grow or what you’re doing is fundamentally against how I*

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<sup>24</sup> An annual fundraising gala that benefits the Metropolitan Museum of Art’s Costume Institute. Exclusive invitation is extended by Vogue’s Editor in Chief, Anna Wintour, to popular figures in the fields of sports, fashion, music, etc.

<sup>25</sup> Innovative Genomics Institute, University of California, Berkeley. Founded by Jennifer Doudna, who resides as its President.

*view nature and how I think of the world, I would never use that product.”* While knowing these things prior to starting “can save you a lot of investment,” she notes, “more importantly, it can save you time – where you can redirect things so that you’re actually making something that people want and that will benefit them.” If development policies effectively incorporate flexibility and a willingness to shift course based on public input, Hochstrasser argues, developers can save time and funds that could potentially be lost down an unfavorable avenue.

### A Policy of Transparency

“I do think we can run into some of the same issues that people ran into with GMO<sup>26</sup> technology if we’re not careful. There needs to be transparency, you can’t hide information; you shouldn’t avoid telling people what you’re doing until you secretly release a product.” Alluding to the approach<sup>27</sup> applied with the GMO revolution that often kept decisions “hidden and in corporate conversation only,” Hochstrasser warns against reutilizing this policy, citing past “shutdowns by hyper regulation or public sentiment or people burning down fields of crops in protest,” as motivating reasons.

Primarily, Hochstrasser explains, transparent policies are perhaps “most important when someone wants to release something into the environment.” As “a lot of these use cases, such as releasing a gene drive<sup>28</sup> mosquito into a particular region, are very specific,” she notes, “it’s [challenging] to think about how to approach it globally... but any developer who’s in that situation should be [aware] about what’s potentially going to happen, what they think the environmental impacts could be, [and] what could go wrong in that case.”

### Nantucket

In June of 2019, Kevin Esvelt, Assistant Professor of Media Arts and Sciences at MIT’s<sup>29</sup> Media Lab, traveled to Nantucket Island to deliver a proposal to its residents. Aware of Nantucket’s prevalence<sup>30</sup> of Lyme disease, which primarily spread through ticks that latched onto the fur of white mice that roamed the island, Esvelt approached the issue by suggesting a gene drive. Through this method, he proposed, fifty thousand mice, genetically modified with an immunization against Lyme, would be released onto the island. The goal was that the mice would mate with the native population, with the immunized gene spreading through the mice population until all of the Nantucket mice were immunized against Lyme. The absence of mice

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<sup>26</sup> Genetically Modified Organisms

<sup>27</sup> [Public views on GMOs: deconstructing the myths](#)

<sup>28</sup> A spread of a heritable gene through a population at a rate faster than would occur naturally by Mendelian genetics. Aided by genome engineering technology, such as CRISPR-Cas9.

<sup>29</sup> Massachusetts Institute of Technology

<sup>30</sup> [Nantucket Infectious Disease Report](#)

as major carriers, in addition to decreasing Nantucket's Lyme affliction by 90 percent,<sup>31</sup> held the possibility of curing ticks who bit the vaccinated mice of Lyme itself.

While the science is fascinating, Esvelt's approach is what caught the eye of many. In atypical academic fashion, he declared a policy of honesty and transparency, posting extensive materials to a page<sup>32</sup> dedicated to the project on his lab website. A stark contrast from the usual route most scientists take, Tilghman commends Esvelt's approach of "engaging with the population of Nantucket" as "a great example of how a scientist is trying to use... cutting edge technology" but in a way that is considerate of community concerns. Wearing what Michael Specter in *The New Yorker* terms as "a neon badge... [of] political opposition to corporate science," Tilghman notes that Esvelt in particular would "not... do anything without [the] full endorsement and enthusiasm" of the residents of Nantucket.

The question that remains, however, is whether or not Esvelt's community engagement approach sets a precedent and standard for science and academia. According to James Collins, Virginia M. Ullman Professor of Natural History and the Environment at Arizona State University, there is no true way to tell, though there are individuals in the field thinking about questions similar to Esvelt's. "*What would it mean to have communities involved? How do you get the communities involved? Who does the choosing? Who gets included or excluded? What would it mean to reach a decision - is the decision a consequence of vote, does it have to be a majority, should it be a super majority?*" Regarding the legacy of Esvelt's Nantucket as a whole, however, Collins notes that Nantucket "has its own context, within which Kevin Esvelt in particular is working there with them" that may be a challenging precedent to follow. "It's one thing to say that, in principle, [community engagement] is a good thing," he says. "It's another thing to put it into practice."

### Ways and Means

Echoing Collins, Church emphasizes the importance of "broad discussion," simultaneously noting that "it's not clear that [this is] easy to engage." While "there are plenty of people [who] are interested," he explains, "most of them are ethicists, experts in bioethics, and/or editing." In contrast, Church says, the interest of "the average person is not [as] accessible." Likewise, Maienschein believes conducting this discourse with CRISPR in particular can be challenging. "Public engagement should be honest and open, [and] should allow different answers than expected." But with CRISPR, she says, public discussions engaging the broad public "often haven't been very deep" when measured to conversations within higher ranks in academia with CRISPR and other topics. "Compared to discussions around recombinant DNA [technology] which were fairly broad and fairly deep, we just haven't seen that same kind of engagement here."

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<sup>31</sup> [OF MICE & MEN](#)

<sup>32</sup> [Updates < Mice Against Ticks - Preventing tick-borne disease by permanently immunizing mice — MIT Media Lab](#)

One way that scientists are currently working to improve public access and engagement, according to Church, includes working with “screenwriters and other writers to help reach a broader audience.” Stressing the importance of inviting the public into conversations, Church explains that one of his outreach initiatives involves “working with writers for popular entertainment venues to embed knowledge” about CRISPR in movies. Another option he entertains is to apply this approach in documentaries, though he admits this method “tend[s] to typically reach a lot fewer people, and [engages viewers] that [the science] might have reached anyway.” An advantage to embedding elements of CRISPR in movies and films, Church argues, is that this medium “can reach tens of millions of people.” However, he adds, “whether [audiences will] take away a lot of science, rather than a few buzzwords is unclear... it’s by no means comprehensive.”

### Reinventing Levelset

Due to the complexity of biotechnologies and the diversity of the field, guidelines that create the *comfort zone* for stem cell technology may not apply for others, like CRISPR. Framing general understanding as “levelset,” MacPherson asserts that “in a way, [both the public and scientists] have to kind of reinvent levelset.” Because of this, it can be particularly challenging for the public to see reason to keep up with these rapid ‘updates,’ especially with CRISPR. With each development, she says, both scientists and the public have to say, “*Okay, the world’s changed again, we can now do interesting new things, but we have to do them in a way that honors that there’s a pre-existing system. How do we do this?*”

### Biohackers

#### Hacking Biology

According to Oxford Languages, biohacking is “the activity of exploiting genetic material experimentally without regard to accepted ethical standards, or for criminal purposes.” Yet, the field of biohacking is much more nuanced. Emerging as a ‘wild-card’ stakeholder, where do biohackers fit in?

#### A Seat at the Table

“It’s one thing for the advocates for the public to want to have a voice at the table,” Juengst says. “It’s another thing to want to have a license to do the research on themselves or by themselves, without any kind of oversight.” Juengst could be referring to an incident where biohacker Josiah Zayner injected CRISPR DNA into his arm.<sup>33</sup> Or when the late biohacker Aaron Traywick injected himself with a homemade Herpes vaccine.<sup>34</sup> Or maybe the time when French teenager Adrien Locatelli injected himself with passages from the Qur’an and Bible,

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<sup>33</sup> [True Story: I Injected Myself With a CRISPR Genetic Enhancement – The Antisense](#)

<sup>34</sup> [Biomed CEO Injects Himself with DIY Herpes Vaccine — Why That’s Not a Good Idea](#)

translated into DNA sequences meant to modify proteins.<sup>35</sup> Regardless, Juengst argues that those operating outside of the standard academic and scientific traditions lack structured environments. With this lack of protocol, he says, there is a lot more room for individual pursuits, which can lead to dangerous and potentially life-threatening ventures.

Agreeing with Juengst's assertions, David Magnus, Thomas A. Raffin Professor of Medicine and Biomedical Ethics at Stanford University and Director of the Stanford Center for Biomedical Ethics, believes that as biohacking claims its place as a stakeholder, biohackers should acknowledge the responsibility that it brings. "There needs to be broad discussion both with the public and with other people in the field," he says, "and a general consensus that the field is ready for that [particular] innovation beforehand."

### Me and My Friends

"When people talk about biohackers," Magnus notes, "they don't usually just mean themselves. They often mean *and my friends*, or other people who are willing to have [the biohacker(s)] do this to them. That is highly problematic." *Why?* Magnus cites concerns "that biohackers [who are] technologists, but... not clinicians... are not steeped in the institutionalized clinical research enterprise." This, he asserts, can produce "a very naive view about how easy it is to go from something that just seems like it should work,<sup>36</sup> to things that actually work."

"In the early days of gene therapy in the early 1990s," Magnus explains, "all the gene therapy developers were like, *I can't believe they're making us do clinical trials when we have the cure for cancer. And this is going to work - the HSC gene therapy system<sup>37</sup> is going to cure glioblastoma and other kinds of tumors. I can't believe they're making us do clinical trials.* Well guess what, it didn't work. People couldn't believe it didn't work. So they kept doing trials over and over and over again, and failing before they finally realized, oh, what do you know, humans aren't mice. It works great in mice,<sup>38</sup> but it doesn't work in humans.<sup>39</sup> We can cure cancer a million ways, ways that never work in humans." And so, Magnus notes, "I do worry that that naiveté leads people to think, *well, this is just a great idea. Let me try this and do this for my friends, and do this for the people.* And that's great," he concedes, "until they die. And then the idea that somehow they're indemnified by the fact that they sort of went in and said it was okay is not going to work." This concern and underestimation of CRISPR's implications, Magnus argues, is why "we need [thorough], randomized trials to really answer questions."

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<sup>35</sup> [Biohacker injects himself with DNA made from Bible, Koran verses](#)

<sup>36</sup> [Biohacker Injects DIY Herpes Vaccine on Facebook Live](#)

<sup>37</sup> [Implications of hematopoietic stem cells heterogeneity for gene therapies | Gene Therapy](#)

<sup>38</sup> [Introduction of new genetic material into pluripotent haematopoietic stem cells of the mouse](#)

<sup>39</sup> [REPORT AND RECOMMENDATIONS OF THE PANEL TO ASSESS THE NIH INVESTMENT IN RESEARCH ON GENE THERAPY Executive Summary of Findings a](#)



### Defining Community Engagement

“A biohacker in a garage [who] is going to make his own version of a gene drive for mosquitos is not community engagement.” Referencing Esvelt’s approach on Nantucket, Magnus continues. “It’s having townhall meetings with the people who live on the island where you’re conducting your field trials with, whether it’s with mice or mosquitoes, all of which has happened, and doing that thoroughly so that you don’t have researchers saying *this is for the best so the risks are reasonable*.”

“If there’s dual use implications of research,” he advises, “we should be talking to *those* people about that, who are essentially unwittingly making a bet about what’s going to happen. When you think about some of the mosquito field trials with gene drives to eliminate mosquitoes, well, *what about the people who live where all those field trials are taking place?* That’s when you have to have community engagement townhall meetings and get people together. *That’s* community engagement.”

### By the Rules

With “the extent [to which] Zayner and his friends can help push along the debate, educate the public, [and] get public voices represented in the debates,” Juengst comments, “that’s great. But I think if they want to play with the global community, they will need to rein themselves in a bit too, and play by the rules.” *By the rules* seems to be a popular sentiment in discussion, echoing the call for responsible and ethical development. Joining Juengst’s perspective, MacPherson describes “a gentleman who was trying to biohack guard dogs<sup>40</sup> to make them glow with the bioluminescence of certain starfish... [who] thought glowing security attack dogs would be a good thing to do.” This individual, she notes, “was some guy in Tennessee doing this in his back porch... [who had] some science knowledge but no controls - at least not what [scientists] would consider proper scientific environments, with guardrails and peer review and a regulatory path.” This particular engagement with the science, MacPherson notes, adds several more levels to the ethics debate for everyone involved to consider. “This is just free rein.”

“But how do you root out and stop practices that we might disagree with?” Since disagreement is based on subjective judgement, MacPherson believes finding a solution won’t be clear cut. “This also puts you at a cultural issue,” she says. “While some people might find biohacking perfectly fine... others are going to be morally and religiously offended.” Furthermore, she asserts, that at a time “when we can’t even agree on simplistic public health mechanisms like vaccination and masking, the idea that we are going to create an easy, easily accessible and agreed-upon framework for CRISPR seems incredibly out of our reach,” arguing that society will likely “revert to using what we know how to do in similar situations.”

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<sup>40</sup> [Meet the guy biohacking puppies to make them glow in the dark](#)

MacPherson also argues that the level of feasibility poses a challenge. “The ability to control [the regulation of CRISPR] will be more difficult, because it’s going to be easier to replicate the scientific activity in small level and undetectable lab environments.” As opposed to that of “regenerative medicine like growing bone and cartilage... [that requires] much more expensive equipment or gene sequencing,” MacPherson warns of those who sell unregulated kits or advertise ‘miracle cures.’<sup>41</sup>

“While the idea of democratizing science in the way that biohackers and other citizen scientists are pushing for has appeal,” Magnus advises there is good reason for concern. These guidelines and restrictions, he says, “are things that [scientists and the public have] developed over time... to at least have the floor in place.” With the prevalence of biohackers “who are outside the traditional academic structures [and] lack a lot of those pieces in place,” it increases the likelihood of having “higher variance in terms of behavioral norms, which is likely to cause problems.”

## Bioethics & Ethics

### A Blank Slate

A reason for the large emphasis on intention and execution with CRISPR, MacPherson asserts, is because “the technology itself is neither good nor bad.” As CRISPR acts as a vessel, a means to an end, the stakeholders involved - scientists, the public, and anyone else - ultimately share varying degrees of responsibility in the outcome, whether intended or accidental.

Because of this, MacPherson believes CRISPR’s potential for a “more democratized approach” has pros and cons. “I think [it] provokes a different conversation about the technology than what we might hear about in other domains.” Included in this, she notes, is the concept that “just because we can do something doesn’t mean we should do it.”

### Defining *Responsible and Ethical*

Whenever new technologies are introduced or make their passage from the private to public sectors, the phrase “responsible and ethical development” is often paraded around. Complex terminology aside, what does *responsible and ethical* actually mean?

According to Magnus, it means that “if the research is going to actually impact certain populations, you go to those populations who are going to be impacted and find ways of engaging with those people to find out how they look at things, and how they look at the research.” A model that was used by Esvelt, Hochstrasser shares a similar perspective. “Responsible development of any CRISPR technology or product, be it in health or agriculture, means thinking very deliberately before you even begin a project about what your goals are and why those are your goals, why you’re doing what you’re doing, and how what you’re doing

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<sup>41</sup> [Mail-Order CRISPR Kits Allow Absolutely Anyone to Hack DNA](#)

could impact people.” With this, she says, it is crucial to “make sure that you’re [not just] thinking about people in your community, that look like you [or] that you’re friends with, but [about] people anywhere in every community.”

Acknowledging that this can be “an uncomfortable model for most researchers and scientists” to pursue, Hochstrasser encourages this approach to not only save investment and time, but to make an intentional impact as well.

### Germline v Somatic

“I think that we need to consider carefully the applications of CRISPR to both somatic and germline editing,” Peter Singer, Ira W. DeCamp Professor of Bioethics in the University Center for Human Values at Princeton University, asserts. “Obviously, the first and perhaps less controversial applications will be somatic editing to try to assist people with genetic diseases. But,” he adds, “I would not absolutely rule out germline editing. It does need more careful thought and reflection. But I don’t think that there’s any kind of absolute ethical barrier to using it once we can be sure that we know what we’re doing and that we will produce the results that are desired.”

What Singer refers to as *somatic* and *germline* gene editing are both feasible with CRISPR. Somatic editing, which only affects targeted cells of the person the procedure is performed in, is seen as more “safe.” On the other hand, germline editing, which affects all cells of the person, including sperm and egg cells, is seen as more unpredictable, as this causes changes to the “germline” - that is, the children of that person. While CRISPR-mediated gene therapies are already in place for somatic<sup>42</sup> editing, wariness still lingers around involving the germline. With *Skinner v. Oklahoma*<sup>43</sup> (1942) and *Buck v Bell*<sup>44</sup> (1927) not far behind in history, many worry that germline editing will provide a slippery slope and enable a reemergence of eugenic practices.

Maienschein agrees that we need to think carefully about both somatic and germline editing. “Most bioethicists make assumptions that editing somatic cells will not affect germ cells,” she says, “but this is not true. Germ cells can regenerate under some conditions, even after being genetically engineered.” Since “the germline is not insulated from the effects of the somatic cells, nor from the effects of engineered somatic cells,” Maienschein argues that discussions need to consider all aspects and implications of the technology as its facets are often interconnected.

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<sup>42</sup> [A CRISPR focus on attitudes and beliefs toward somatic genome editing from stakeholders within the sickle cell disease community | Genetics in Medicine](#)

<sup>43</sup> [SKINNER v. STATE OF OKLAHOMA ex rel. WILLIAMSON, Atty. Gen. of Oklahoma.](#)

<sup>44</sup> [Virginia Eugenics](#)

### A Wolf in Sheep's Clothing

“I am concerned about what people might claim and do under the guise of something like CRISPR.” A situation that has occurred with stem cell clinics,<sup>45</sup> MacPherson explains “a very extreme case of a company<sup>46</sup> that managed not to kill anybody, but really harmed... people by giving [them] contaminated stem cells.” With these stem cell clinics, MacPherson believes “there’s a really interesting parallel” with CRISPR. “These clinics, if you google them, you can find them. There’s probably one in your neighborhood that you can go to, and they’re basically violating policies, not necessarily laws, but they’re not doing what they’re supposed to be doing. And the FDA could completely shut them down if it had the bandwidth, but the problem is there. It seems like they’re sort of playing whack-a-mole... a company closes its doors but then reopens under another name.” This functionality, MacPherson says, puts people at risk and “misrepresents stem cell science [in a way that] can potentially harm people,” which is not a possibility out of reason for CRISPR with the spread of misinformation, biohacking kits, and politicization of science.

### Ground Zero

The lowest level of social responsibility, Magnus asserts, “is to be in accord with regulatory requirements, which ha[ve] some ethics behind them. For example, if you’re... developing new CRISPR technologies and human applications, which would take the form of clinics, you need to meet all the regulatory requirements for human subjects research. When you’re doing research and doing trials, you have to make sure that the risks are minimized as far as possible, that you have adequate informed consent from the research participants in the studies, and that you have an equitable selection of subjects.” This, Magnus, argues, “is the floor” for responsible science. “Beyond that,” he says, “are issues that play out at several different levels.”

In order to do this, he explains, “there needs to be mechanisms and ways of making sure that researchers, when they’re thinking about their research, don’t just think of meeting... the requirements that the IRB is going to set out.” In particular, Magnus asserts, researchers and scientists “need to think about the downstream impacts on other people, including issues of dual use, other impacts on different populations and subpopulations, issues of how it may impact equity,” and more variables unique to their situation.

For those interested in participating in research, Hochstrasser advises the importance of “understand[ing] the risks that are involved... if you’re considering participating in a clinical trial or trying a new therapy.” This, she believes, includes “not just see[ing] a splashy headline about a miracle cure,” but thinking more deeply about its implications - “like, *my health is on the line here. This is very serious.*” Similarly, Magnus emphasizes the importance of transparency

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<sup>45</sup> [US stem cell clinics boomed while FDA paused crackdown](#)

<sup>46</sup> [‘Dr. Death’ Team Has New Podcast About Stem Cell Industry: ‘Bad Batch’](#)

and understanding for researchers. “It is very important during phase one trials that [they] don’t inadvertently convey benefit.” Asserting “the challenge between the fact that there’s likely to be greater hype (and hence higher expectations of benefit on the part of patients)” and accounting for unintended consequences, Magnus offers gene therapy trials<sup>47</sup> as an example. “Nobody benefited for decades... and we learned a lot that made it possible to someday be able to do more. But people thought they were... going to be magically cured from cancer... by the gene therapy.” With “some of the same concerns aris[ing] with stem cell trials,” Magnus warns that “we additionally run the risk of [miscommunication] with CRISPR trials that have been starting to move forward, at least in the somatic realm,” which discolors policies of transparency and may seriously harm stakeholders.

Overall, Singer believes that all stakeholders “should consider the consequences of what [they]’re doing.” Arguing for a more holistic approach, Singer says those involved “should try to decide whether those consequences are on the whole, good or bad, for *all* of those affected,” in order to effect intentional and beneficial progress. “There’s nothing guaranteed,” Hochstrasser adds, advising that a policy of transparency, with both peaks and ruts, is the healthiest approach in terms of public relations and accountability.

### In Theory

As a father himself, Comín weighs on the issue of genetic modification with CRISPR-Cas9 in practice. “Gene modification is something permanent. Making decisions on behalf of somebody else has ethical considerations, [and implies] that we shouldn’t allow people to choose anything they want on behalf of children. [There are] situations... where decisions even for therapeutics are granted because there is benefit for [the] individual whose genes are going to be modified.”

On the other hand, he yields, there are “other modifications [that] may not be the best for children,” such as those predetermined by parents without input by the children. In a world where “life is easier taller than shorter, and... parents [can manipulate height], if the children grow up and decide they are too tall for their taste [and are] unhappy,” Comín believes the children should have a right to complain” because their genes were modified without their consent.

But, say “you ignore [the] interpersonal element,” Comín proposes. “Suppose all [of] the members of one family are perfectly aligned... the same entity, and there are genetic alteration[s] that in principle [are held], on objective grounds, [to] make life easier: being taller or having a more symmetric face, something that maybe the labor market has valued positively.” In this case, he argues “there is [a] second consideration of ethics that needs to be taken into account when deciding. [A] government or institution [might] forbid this type of intervention because... [the] extent [to which] these... modifications” are pursued and secured is not a length everybody can

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<sup>47</sup> [National Advisory Council for Human Genome Research - Summary of Meeting](#)

“afford, [which] can tilt the playing field... and make society more unequal in a way. Those who have access *can* change [the] playing field so their children do better than the rest.”

Framing this in terms of job accessibility, Comín envisions a scene where two people apply for a job, with only one receiving the job offer. Maybe the reason “why you g[ot the] job, to some extent,” he chances, “is because [your] parents could afford to make genetic alterations to a feature of your persona that would make your performance better at [the] expense of making mine worse.” As a result, he explains, gene editing for superficial traits, such as height or phenotypic features, “could potentially be forbidden on grounds of [improving equality in] society.” This is a “very different type of ethical consideration” than previously encountered, Comín admits. It “is not like me having different perceptions of my children [or] me not being allowed to make genetic alterations because [other people] may not agree with those.” This is “more about [my] dynasty being [more] advantage[d] than [the] rest of [the] dynasties because [mine has] superior knowledge, resources, or access to [the] technology [that] gives benefit[s] to my dynasty.”

“But you might think,” Juengst concedes, there “might be cool additions to your children, like... enhancing their immune system to resist viruses... COVID, for example, [and] give them their vaccinations right in their genome. Or [to] give them other abilities.” And though we could talk about “the road to genetic enhancement,” Juengst notes that there are many more “better reasons for using CRISPR... [which] makes the whole prospect... sensitive from a social and ethical point of view, because those are the uses that everybody is concerned about.” How one “would regulate th[e]se kinds of interventions,” Juengst asserts, “isn’t clear... particularly when they’re conducted in the world of infertility medicine - private practice of infertility medicine - in different countries with different regulations.”

## Disability Policy & Ethics

### Caution

A thought-leader in disability studies, Rosemarie Garland-Thomson, Professor of English and Co-Director of the Disability Studies Initiative at Emory University, believes a concept termed “velvet eugenics,” underlies certain medical and scientific practices today. Translating to “good genes,” in [Project MUSE - How We Got to CRISPR: The Dilemma of Being Human](#), she asserts that eugenics harnesses “the modern spirit of progress and improvement that promise[s] to make a better future citizenry by producing the supposedly “best” kind of people.” Visible throughout history with events such as the Nazi eugenics of WWII or the 1927 Supreme Court case *Buck V Bell*,<sup>48</sup> Garland-Thomson and Sandy Sufian, Professor of Disability and Human Development at University of Illinois Chicago, argue in [The Dark Side of CRISPR](#) that eugenic thinking can appear in many forms. With “velvet eugenics,” they say, “violence and inequality

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<sup>48</sup> Deemed the forced sterilization of people labeled as “feebleminded” as constitutional.

[are hidden] behind claims of patient autonomy and... a veil of voluntary consent,” an occurrence which is just as dangerous and harmful as visible eugenics, if not more. Due to its “laissez-faire commercialism,” Garland-Thomson and Sufian note that “velvet eugenics seems like common sense” to some, raising concerns for those within the disability community. With the arrival of technology like CRISPR-Cas9, they note concerns “that the use of these “genetic scissors” will, in the future, cut people like [them] out of existence without others even noticing.” Despite its portrayal “as authoritative and reliably predictive knowledge,” Garland-Thomson and Sufian argue that “genetics, at its very best, can only predict a broad range of outcomes,” as off-and-on-target effects are still possible as unintended consequences. Paired with “the cultural impulse t[hat] assumes that people with genetic variations are in a constant state of suffering,” a viewpoint that is both damaging and patronizing, they warn of the potential “commercialized medical technology [holds to] produc[e] a culture of reprognetics that carries out... velvet eugenics,” advising caution for all those involved and the need for those affected by the technology, such as the disability community, to be invited and included in discussion.

Singer also believes caution is needed. “Obviously, discrimination against people with disabilities in employment, for example, or in housing, where the disabilities do not prevent them [from] performing adequately in the employment that's being offered, is wrong.” But, he argues, considering disability in the context of risk analysis and management, “the suggestion that it's better to avoid having disabilities oneself, and that it's reasonable for parents to avoid wishing to have a child with a disability,” would not be considered by him to be “ableist in a pejorative sense,” and should not necessitate nixing CRISPR technology altogether.

### Lessons from History

Analyzing the past, Juengst believes “there’s always a danger of repeating history,” noting that “we don’t seem to learn very well from history as human beings, [which is] something that the world needs to be alert to.” And while Juengst doesn’t believe there would be “forced gene editing on a population basis,” he acknowledges “a subtler form of pressure” that could influence parents to pursue this form of gene editing. There might be “a cultural endorsement,” he offers, “that if you’re a responsible parent... you would want to give your child every advantage, and you would want to ensure that they have all [of] their genetic risks addressed.” This endorsement would imply that “whatever advantages [science] can give them through enhancements at the [time would be] the right parental move.” With this pressure, Juengst chances, “even in relatively open [and free] societies where people get to make their own choices,” genetic alteration will likely be “the direction people will choose,” which can “begin to look very much like the eugenics movement.” Supported by “an idea of what a better version of humanity would look like,” and encouragement “to take... families in that direction,” Juengst warns that eugenic undertones and thinking often precedes slippery slopes that can be enabled through technologies such as CRISPR.

### Misconceptions

“I think as [I] hope most academics would say, it’s not a simple choice. I think we know that genetic and inherited factors are important... [but] I would also say there is an important aspect... [of] how societies impact and accommodate” people with disabilities, Scotch muses. The “medical model [uses] an essentialist approach to impairment, [labeling it as a] biological phenomenon [that] can’t be altered much and that has consequences.” On the other hand, he says, the “social model say[s the] sphere is the interaction [in which] impairment plays. Handicap or not, this creates problems for some: [in a] society where no one reads, a reading impairment isn’t a problem for really anybody, [but] in a society like ours where any labor involves being able to read texts and manipulate things in an abstract way, say manufacturing, it is a real problem.” Framing the perception of disabilities within a social and cultural context, Scotch emphasizes the subjectivity of what different societies and groups define as *positive* or *negative*.

Scotch further explores this through a wheelchair accessibility scenario. “We might think about people who use wheelchairs... [While] narrow bathrooms and stalls don’t prevent you from walking,” this, coupled with the environment one may be in, he notes, presents challenges that may not prevent completion of action but severely increase its difficulty. The limitation in this case is the ease of motion, “not performing necessary functions,” Scotch says, “so context is as important as the impairment itself. And that shifts with what’s going on in society and people’s assumptions about what is ‘normal’... So in that context, trying to alter people genetically based on... what is good (associated with a high ‘quality’ life) or allows people to be productive, is often contingent on assumptions on quality of life or productivity that may not always be correct or are grounded in stereotypes.”

### Opportunity Does Not Imply Obligation

“There is [an] assumption that anyone who can [genetically enhance their child] should do it, and if you don’t do it, you’re not a good parent.” Emphasizing what he argues to be a harmful belief, Scotch asserts that fostering “a society that accepts variability and differences [and] does not try to prevent people who are different” from being is important.” There is “some concern,” he says, that “if there is a potential for limiting some of these differences, there is a potential for withdrawal of support. Say we could prevent cognitive impairment, then [some people might] say *well if we can prevent it, why should we provide for education or medical services for someone born with a preventable condition?*”

Decisions like these are “often made in ignorance of [the] quality of life of those with disabilities,” Scotch asserts. Take “financial gatekeepers and the biomedical world,” he hazards. “If a care company would allow funds to be used for certain procedures but not others based on what is... financially beneficial for the company, we may see decisions about enhancement made on [the] basis of cost benefits for the funders of health care... Back in the 90s in the state of



Oregon,<sup>49</sup> they wanted to expand the number of people signed up for Medicaid, because only half of low income people [had signed up].” Based on a public opinion survey, he says, “they decided they would only pay for certain kinds of procedures... [in] acute care: heart attacks [and] other kinds of medical procedures... Medicaid was on the verge of providing coverage to more people but [would exclude] those with chronic illness.” Though this was “challenged in court and overturned,” Scotch notes that it’s “scary [for] some people [because while you] can’t spend everything on healthcare... there is a concern that enhancement potential might be used as rationale for restricting access to necessary care for people whose lives are somehow devalued by some kind of social conscience.”

### In Conversation

The mission of nonprofits like IGI is to make genome editing tools affordable and accessible. But the question remains about *if* and *how* it should be accessible, in certain regards. Especially with the development of technologies like CRISPR-Cas9, where there is much excitement around its potential to combat diseases, biotechnology policy has the possibility of implicating attitudes towards those with disabilities or differences that may already be painted with eugenic undertones. At Cold Spring Harbor Laboratory’s 2021 conference in Genome Engineering: CRISPR Frontiers, Jennifer Doudna, 2020 Chemistry Nobel Laureate and Professor of Biochemistry & Molecular Biology at UC Berkeley, addressed this. Expressing hope that “CRISPR will become a widely accessible technology,” Doudna, who heads IGI as well, admits that there still remains uncertainty on how to ensure stakeholders are included in spaces to voice their concerns. “Making sure the science and technological applications continue at a timely pace and in a responsible manner... when CRISPR-Cas9 is moving as fast as it is,” Doudna says, can be challenging. However, she notes that venturing out of the ‘comfort zones’ to have these types of conversations is necessary in order to facilitate the thoughtful development of CRISPR.

“Frankly, I think all of us have a responsibility to participate in the conversation,” Doudna says, echoing earlier sentiments asserted by Hochstrasser. In this way, Doudna believes, if we “communicate about what we’re doing, why [we’re doing it], and how we can ensure appropriate regulation” transparently and intentionally, science and public involvement can progress together. Emphasizing this approach, she hopes organizations like IGI as well as advocacy figures can decrease the conversation gap “without, hopefully, impinging on the pace of the science that we all believe in so strongly.”

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<sup>49</sup> [Oregon Lists Illnesses by Priority To See Who Gets Medicaid Care \(Published 1990\)](#)

## Religious Ethics

### Perspectives in Judaism

“Any kind of genetic research, medical procedure, [or] genetic manipulation that can preclude and fix some kind of genetic or medical defect, even if that is done in utero, would certainly be permissible according to Biblical ethics and Jewish law,” says Rabbi Michael Kushnick, a Rabbi at Anshai Torah in Dallas. “We’re all created in the image of God... [which means] our doctors and scientists who are [using] this type of technology are endowed [by God] with the knowledge and skill set to be able to improve our world... and improve the life of a child.”

According to Kushnick, “it can be for the benefit of a child and for the benefit of the family... [to use technology] to some degree” to combat diseases or genetic disorders, with emphasis on restraint. Specifically, he says, “many Jews, especially... of Ashkenazi descent<sup>50</sup>... [may] carry genetically transmitted alterations [in their genome, like] Tay Sachs disease.” Often, “when both partners may be a carrier for one of these [genetic] mutations [and are of Ashkenazi descent,] ... [it is practice] to go get tested to know if [couples are] both carriers for one of these diseases.” With “carriers of a fragile X or of Tay Sachs... there are [already] ways to ensure that [couples] have a healthy child through genetic testing of the embryo and things like that,” says Kushnick. “And so, I’m all for [using CRISPR-Cas9 in this way] to do our best to try to provide a healthy child.” Rabbi Howard Wolk, retired Rabbi at Shaare Tefilla and current Community Chaplain at Jewish Family Service of Greater Dallas, agrees with Kushnick’s sentiments. “If we can preclude a future generation from inheriting [genetic diseases like Tay Sachs] then I think it’d be looked at as a laudable thing to do.”

“Religiously, where I think it gets inappropriate is, we don’t want to be playing the hand of God,” Kushnick asserts. “I don’t think it’s appropriate to choose the sex of the child or the hair color of a child, or *I want my child to try to be over six feet tall*, or whatever the case may be. I think it’s a strict limit, *no, we’re not going there in any of those cases*.” While “there is still a holiness in procreation and conception,” he argues, “if we have the ability to ensure a child... doesn’t struggle with things that we have the ability to change, then I think there’s some important things with that.” Enhancing life, Kushnick believes, is a practice that is already in use with procedures like open heart surgery and organ transplants. “Most of society has become very comfortable with giving somebody a lung transplant or a heart transplant or whatever the case may be,” he says. “If we didn’t do that, then that individual would die.”

Another “caution that’s... been raised in literature,” Wolk says, is “the phrase *designer babies*.” A term<sup>51</sup> used to refer to the augmentation or alteration of non-essential features, such as intelligence or phenotypic elements, Wolk believes it functions as a “stop sign,” or a reminder

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<sup>50</sup> Jews who come from Eastern Europe.

<sup>51</sup> [Paul Knoepfler: The ethical dilemma of designer babies](#)

that “we [those involved] don’t want this branch of scientific and medical development to develop to the point that it becomes something... that separates people from society.” But, Wolk counters, “anything new is fraught with questions that have to be asked. People ask, *are you going too far? What are the limitations? Are we going to need that in our governmental limitations? Will the science field itself police themselves?*” These questions, Wolk asserts, “were asked going back 30 years or so when the so-called test tube babies were first born,” and demonstrates how “raising the questions and respond[ing] to them from an ethical standpoint” are prerequisites to “people see[ing] the benefit, whether it’s [with] CRISPR or anything else.”

In order to do this, Wolk proposes, with “every step along the way in scientific and medical advancement, there has to be caution.” Following the Torah, he says, “one of the directives to human beings is to act divine... [and] imitate the ways of God.” The caution in this, Wolk asserts, is to “realiz[e] every step of the way that [though] we may try to act godlike, we are in fact, not God... that we are created beings [and] not creators.” And so, Wolk believes, “any kind of advance should remind us of how awesome the Almighty is, that he created the potential in human beings to bring about this kind of advance.”

According to Kushnick, “an obligation in Judaism... call[ed] *pikuach nefesh*” provides a guiding principle. Meaning to save the life and individual, Kushnick says that in Jewish tradition, “saving an individual is the highest commandment, overrid[ing] everything else in the world.” This action, Wolk offers, can be seen in the case of eliminating disease with “develop[ing] vaccinations against COVID-19... [which is] acting godlike, but not playing God.” With CRISPR’s capacities for germline and somatic editing, *pikuach nefesh*, for Kushnick, outlines an “obligation... because *nefesh* provides for saving life and overrides, but all other qualities of choosing hair color, sex, etc. is out of bounds.”

### Perspectives in Christianity

“It can be a slippery slope for a lot of Christians to what extent should be used to modify genes and things to that nature,” says Andrew Kim, a Teaching Pastor at Global Harvest Church in Dallas. “I think that has always been a challenge - [historically,] Christians have always been lagging in accepting things when they became the norm.” For example, he asserts, in the “medieval times they were resistant to science because it seemed to go against the Bible. In that way today, though Christians would embrace it to a certain extent, there are even Christians today who don’t accept evolution.” Considering the wide variance of beliefs within the branches of Christianity, Kim believes that “once we frame technology in the right perspective, it can be very beneficial,” and that “if lives can be saved with [CRISPR], we [Christians] would embrace it, to an extent.”

A way to do this, Kim hazards, is to “understand [that] the way the world exists [today] is not the way God created the world to be.” Citing Genesis 3 in the Christian Bible, which “describes sin entering the world and affecting everything,” Kim explains that from a Christian perspective, sin “is the reason for tsunamis, cancer, etc.” According to Kim, “if we understand

the framework that it is a broken world, and [that] he (God) wants it to look better than it is today... Christians should be [wanting] to do whatever they can to reverse the effects of sin.” Why? Kim asserts that in Christian tradition, Christians are “called to be a salt and a light to slow down [sin-induced] things like poverty and hunger.” This, Kim notes, isn’t to say Christians should “approach it with a savior syndrome,” but rather that they should “use available resources to [remediate the effects of sin,] like help the poor or those who are hungry.” From this calling, Kim believes there shouldn’t be “too much issue on why [it] also doesn’t transfer to the medical field [where it] could help diseases or kids in [disadvantaged areas] for hunger, disease, and poverty.”

In regards to social impairment, Kim believes policy-making should honor voices of the community. “CRISPR’s capabilities involve being able to reverse some of the effects of diseases and genetic mutations. For children who [have physical or social impairment] like Down Syndrome who don’t want to change anything, I think that’s great.” Explaining how in Christian tradition, God uses impairment to bring people closer to him, Kim emphasizes that Christians “are called to find the purpose and good for suffering.”

Acknowledging Christian doctrines that are not in favor of abortions, Kim notes that Christians may be in support of CRISPR due to its capabilities to alleviate some of the motivating factors for abortion. “I think a part of abortion is economics - a baby with a physical or developmental disability may require more resources and specialized care than a neurotypical baby, and in this way, may place potential parents who are not stable financially in a tough situation with medical bills, etc.” To this, Kim explains that since “abortion is [often] a symptom of the root problem... if CRISPR technology can help alleviate the medical expenses by giving [potential parents] a better way or not having to make the choice of aborting for financial reasons,” it could potentially see support from Christian individuals and organizations.

However, in regard to its broad use, Kim asserts that in alignment with Christian beliefs, “CRISPR should be used in the approach of leveling the playing field, like to help alleviate the condition of someone living with a chronic medical condition, but not to provide advantages.”

### Perspectives in Islam

“From an Islamic standpoint, the therapeutic application of CRISPR-Cas9 for germline editing may be permissible if the safety and efficacy concerns are resolved and if the principles of Maqasid al-Shari’a are fulfilled,” Nimah Alsomali and Ghaiath Hussein discuss in [CRISPR-Cas9 and He Jiankui's Case: an Islamic Bioethics Review using Maqasid al-Shari'a and Qawaid Fighiyyah](#). Asserting that “in its simplest form... Islamic law is meant to achieve five necessities (primary needs) (ḍarūriyyāt) in the essence that they are needed to maintain good quality of life,” Alsomali and Hussein state that the “Shari’a aims to increase the benefits for both the community and individual... [and] aims to protect these benefits and to facilitate an enhanced quality of human life.”

As “CRISPR-Cas9 methodology... lead[s] to a modification of... genetic materials and subsequently to alterations in God’s creation,” Alsomali and Hussein note that CRISPR could be “prohibited in Islam.” However, they argue that CRISPR’s applications within “medical purposes... are considered to be essential changes... [as] Muslims are permitted to undergo plastic surgery in order to return organs to their normal function. Thus... so long as it is used to treat severe genetic disease... the CRISPR-Cas9 tool can be considered as acceptable technology from the Islamic point of view.”

In addition, Alsomali and Hussein observe that “the preservation of human life is one of the most significant objectives of Islamic Shari’a... [as] verses of the Holy Quran... state that *if anyone saves a life, it will be as though he had saved the lives of the whole humanity.* (Qur’an 5:32)”

However, they assert, in accordance with “the third objective of Maqasid al Shari’a, which is the protection of progeny... any modification of the genes that might lead to possible harm to future offspring would be impermissible,” therefore nulling prospects of germline editing. Citing “another ethical issue with respect to germline gene editing [as] informed consent,” they note that it would be “impossible to obtain consent from the next (unborn) generation.”

While CRISPR may be permissible in certain respects for the preservation of life, Alsomali and Hussein argue that human enhancement is not included in these provisions. As “most Islamic scholars believe that human is created in their best form (Qur’an 10:5),” they note, “any enhancements that increase the human capabilities [would be] considered to be unlawful according to the Shari’a purposes and principles.” In addition, as the concept of enhancement “may include increasing the power and capacity of selected individuals beyond what has been previously limited by nature... [doing so] might violate objectives related to wealth because it may lead to the exacerbation of social inequalities.”

Overall, Alsomali and Hussein observe that with regards to permissible CRISPR procedures, intention is the best determiner of its ethicality under Islamic law. “The first principle of intention (al umūr bi maqāṣidihā)... defines the purpose behind any action and states that deeds are judged by intentions,” they assert. Emphasizing the precise evaluation of “the purpose underlying the use of CRISPR-Cas9,” they state that as the primary maxim of “the principle of injury (Ḍarar)... is that no harm should be inflicted (al ḍarar yuzāl),” as long as procedures followed the “sub-maxims under this principle... that any harm that might result from treatment should be minimized (harm is relieved as possible) (al ḍarar yudfa’u bi qadr al imkān) and an individual should not harm others or be harmed by others (yjb ‘an la yadura alshakhs al akhar ‘aw yadura bih al akharun),” CRISPR procedures would be supported by Islamic law.

Ultimately, “using the principle of necessity (Ḍarūra)” to guide decision, Alsomali and Hussein assert that one could state that utilizing this technique is necessary in order to prevent harm, notably in cases where there are no alternatives (necessity legalizes the prohibited) (al

ḍarūrāt tubīḥ u al maḥḍūrāt) and refer to alternatives when the required is difficult.” Therefore, they state, following the aforementioned guidelines and instructions of Islamic teachings, if a CRISPR-aided procedure is deemed as permissible in accordance with Islamic law, “scientists should discuss all alternatives, including their safety and availability, in order to justify their selection of CRISPR-Cas9 gene editing as [the] optimal therapy.”

### Defending CRISPR

“The Hebrew Bible, the Old Testament... teaches us that the most important thing we can be doing as human beings is to protect and save life,” says Kushnick. Defending the potential of CRISPR for good, he asks, “when somebody has a heart attack, do you go in and tell them to go to a doctor, and possibly go to the operating room to have open heart surgery? Because in that case, they’re stopping the human heart... cutting it open and repairing whatever needs to be repaired, and then restarting the heart.” This is the same case with transplants he says, which involves “taking an organ from another God-given body and putting it into another body so that person lives a longer, healthier life.”

Similarly, from a Christian perspective, Kim notes that as a society, “we have already embraced a lot of things that modify a person’s life to help fight against diseases.” However, Kim says that “there is a very small sect within Christianity that doesn’t believe in science [or] using things God did not create naturally to extend their lives and improve its quality, a big part of [which includes] science, medicine, and technology.” To this, Kim says if people are “against CRISPR on these grounds,” there needs to be consistency, and the same “should [apply] for chemotherapy, surgery, [and] any other artificial medical procedures. There “should be consistency,” he says. Similar to CRISPR technology, “if a loved one needs surgery, would you do it to keep them alive, even if the pacemaker is artificially put inside of a person?”

### Economics & Finance

#### In the Arena

“There’s barely a biology laboratory in this country and in most developed parts of the world that are not using CRISPR in one way or another.” Expanding upon the fascination of CRISPR by scientists and non alike, what Tilghman remarks on is no ordinary feat. Due to its growing popularity and the efforts of scientists to increase engagement rates, CRISPR is on the trajectory to becoming a widely discussed name, which may be valuable for investors eyeing the next big thing. Move over NFTs,<sup>52</sup> CRISPR is on the rise.<sup>53</sup>

Speaking of which, Singer, who’s enjoyed some of the spotlight after *The Guardian* labeled him as the world’s most dangerous man in an article succinctly titled *The Most*

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<sup>52</sup> NFTs: Non Fungible tokens.

<sup>53</sup> [NFTs: Why The Next Big Thing In The Digital Economy Is A Cash Cow For The IRS](#)

*Dangerous Man in the World*,<sup>54</sup> endorses the value of investing in CRISPR as well. “I am aware,” he says, “of things like the use of CRISPR to [develop] plants that will be better suited to changing climatic conditions.” As an advocate for clean eating and veganism himself, this, Singer predicts, will see lots of attention because of climate change. With fellow Princeton professor Syukuro Manabe<sup>55</sup> winning the Nobel Prize in physics for his work with mapping and predicting climate change, climate change is a little more than on the global radar right now. In other words, Singer says, “the potential is huge.”

### Wallet Dash

“I fully expect it to be a very frothy, high income competition,” asserts MacPherson. Interested in the different tactics investors might take<sup>56</sup> to secure competitive advantage, she notes that “where and how different countries and entities will play off of competitive opportunities... will be an attractive thing” for investors to explain to their stakeholders.

On the pathway, “what we really are trying to do,” Magnus says, “is to build scaffolding in different ways to get researchers, as they’re developing the research, to not just think in terms of IRB regulations.” In addition, he asserts the importance of thinking about the “downstream applications and [providing access to] systematic tools for how to think about those things, so that they can think about [it] early on.” Within this thoughtful development, according to Magnus, one should ask, “*Is this a good idea? Should I do research? What are the issues around it? How am I going to conduct the research? How can I mitigate the problems? How can I build things into the design of the research as we’re moving forward, to avoid and mitigate some of those kinds of issues?*”

This consistent awareness and engagement with communities, Magnus believes, is “the last big stage we’re heading towards,” which “is far from where we are now.” But, he says, if a scientist, group, or company were to “hit it there, [where development] was actually conducted... in an ethically appropriate way, ***I would grab my wallet*** - because how much do they know about what that means? How many resources do they have access to, to really cash that [ethically-minded development] out?” Returning to discussion of IRB regulations, Magnus remarks, “Oh, [you] got IRB approval? That’s the bare minimum floor.”

Regarding wallet dashes, Comín asserts that “in general, the value of medical technologies that are related to genetics and genetic modifications has become even more evident with the pandemic due to the RNA vaccines.” Just by glancing at “evaluations of new and old companies that use new technologies,” he says, it is apparent that “their market values - [in] stock markets like ANSA or in counter-markets - are huge... [the] multiples of earnings they are trading for is just mind blowing.” What will be especially appealing for investors, he says, is

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<sup>54</sup> [The most dangerous man in the world | Life and style](#)

<sup>55</sup> [Princeton's Syukuro Manabe receives Nobel Prize in physics](#)

<sup>56</sup> [CRSP Stock: Ethical Concerns Will Likely Dog CRISPR Therapeutics Stock](#)

“that there is going to be plenty of capital (cheap money) to find innovation in these particular areas.” In addition, Comín believes “the push for biotech innovation in the coming decades may change the allocation of capital equity to private equity,” remarking that “biotechnology is changing the game.”

Tilghman, in contrast, argues “that the market for CRISPR technology treatments is going to be... on a broad spectrum,” with high costs of production and distribution still reigning over certain fields. Speaking on rare diseases, she says that because “there are a relatively small number of [potential] patients,” CRISPR-related treatments are likely “to remain very expensive, simply because of the way in which biotech companies do their calculations - the smaller the population, the greater the cost.” In contrast, with “common diseases like cancer... where CRISPR is being used right now,” Tilghman believes “it is likely to see real reductions in cost.” Due to the number of prospective patients within this particular market, she says, “it is very likely that [affordability] pressures... will play out and the price will come down dramatically, over time.” But, she advises, “it still won’t be cheap. It’s not a pill. It’s not something that you can just pop in your mouth, like a generic drug.”

### Wallet Crash & Backlash

According to Comín, “at the beginning, [technology] is always expensive.” Alluding to the early days of genome sequencing, he notes that “25 years ago when [scientists] were developing ways to code DNA, it was extremely expensive, required very slow computers, and... huge teams of people to read the DNA of one person.” A contrast to today, where he says gene sequencing “is extremely cheap, [with] many companies [able to] do it very quickly for low prices.” Comín believes the same accelerated process is likewise in store for CRISPR, which down the road, he predicts, “will [make treatments] very cheap and affordable for people.”

However, Hochstrasser believes there are more nuances involved. Asserting what she terms as “a cynical take,” Hochstrasser argues that “unless there are incentives in place for people to try to make things affordable or accessible, it won’t happen.” Citing “concerns about how expensive [treatments] are going to be if profit is the goal,” she notes that “it’s not necessarily easy to snap your fingers and say, *okay, it cost me \$2 million to make this drug, but I’ll give it to you for \$10 because that’s affordable for you.*” And right now, Hochstrasser says, biotechnologies like CRISPR are “just inherently very expensive. It’s not simply the fact that a company wants to make money<sup>57</sup> – there are really high costs to doing these intensive manipulations.” Alluding to gene therapies, which are further along in development, she remarks that “being FDA approved, they’ve gone through the whole clinical trials process” and are being

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<sup>57</sup> [Paying for CRISPR Cures: The Economics of Genetic Therapies](#)



marketed at “really high prices.” In gene therapies, according to Hochstrasser, “really high prices”<sup>58</sup> means in the “\$0.5–2 million dollars per treatment.”<sup>59</sup>

But with “the uses and market for biotechnologies [having existed] for a long time,” where people have “always been willing to pay money to correct... life-threatening genetic mutations,” Comín believes “what is new [is that] now we have the technology to do it.” Noting that CRISPR introduces a “highly personalized version of medical treatment” that involves “taking cells out of an individual patient, modifying those cells, and re-introducing those cells back into the patient,” Tilghman expands on Comín’s ideas, asserting that “the minute... individual treatments of that kind... are introduced into medical practice, it means that the cost is going to escalate.” Though excited about CRISPR’s prospects with “correct[ing] the defect in sickle cell, [which] is such a critical unmet medical need,” Tilghman acknowledges that “it’s going to be very, very expensive in the beginning.”

To offset the expense of treatment, Wheelan believes that in the United States, “health insurance... will ultimately determine the price [of] services.” Noting that high initial costs are “true of all healthcare products... [and] is an age-old problem with any technology that has huge startup costs,” he argues that “the real battle will be getting insurance... to cover it.” Another thing to consider, Wheelan argues, is the practice where “technologies are [often] offered [at] cheaper [prices] to poorer countries because they have a lower willingness/ability to pay,” in what he terms as “classic price discrimination.” Observable through “HIV/AIDS drugs, [where] there is no way sub-Saharan African countries could pay the prices being charged in the US,” Wheelan notes that with this approach, “someone has to pay high prices for companies to be able to recoup investment costs,” asserting that “if poorer countries are charged less, as is economically and morally sensible, there may be a backlash among wealthier countries [who are] being charged more.”

### Targeting Accessibility

“There’s no indication right now that [CRISPR] is going to be distinct in terms of pricing and accessibility,” says Hochstrasser. “So assembling people [to] think about [issues] in a holistic way is going to be necessary.” An example from the science side, she says, is how oftentimes, scientists will “use viruses to deliver genes to cells that [are] in need of correction.” This method, she says, is “really expensive, because it’s difficult to produce enough virus to dose actual human beings.” Actively working to decrease costs on part of patients, Hochstrasser says IGI is “exploring... non-viral delivery strategies, because that could potentially change things” in terms of accessibility for those who need treatment.

Another way to lower cost is to change the aim from profit to ‘people,’ says Hochstrasser. Considering issues not only “from the science and technical side,” but also “the

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<sup>58</sup> [Bluebird talks in Germany may be bad omen for gene therapy in Europe](#)

<sup>59</sup> [Gene therapies offer breakthrough results but extraordinary costs](#)

social side,” according to Hochstrasser, IGI was “one of the first groups to develop a therapy for sickle cell disease using CRISPR.” One out of approximately “five groups... doing this simultaneously,” IGI is taking a different approach as “the only [group] so far that is strictly nonprofit,” an approach which, according to Hochstrasser, emphasizes the patient over profit.

## Agriculture & Ecology

### A Welcome Curveball

“CRISPR throws a welcome curveball into the GMO debate - it can do very different things from GMO technology – and a lot of people sort of view it as a second chance at genetically engineering crops,” says Hochstrasser.

But exactly how it plays into the GMO debate is the remaining question.<sup>60</sup> “The anti GMO movement, which has been underway for 30 years now, has always objected to the introduction of foreign DNA into a plant or an animal,” Tilghman explains. “What CRISPR is now raising the possibility [of is] that you can in fact improve upon stocks of both plants. The only question that I think every country is going to have to decide is, does the fact that CRISPR’s... modifications... [do] not involve any kind of foreign DNA... change people’s attitudes towards GMOs? Or does their objection to GMOs go deeper than the initial objection, which is [that] you’re introducing foreign DNA?”

According to Collins, the CRISPR curveball “opens up the door to many more kinds of genetically modified organisms, because it circumvents the principle criticisms... namely the introduction of foreign genes” of the anti-GMO movement. Similarly, Singer, as a veganism activist, notes that CRISPR “at least reduces the clear division between GMO and conventional breeding as a middle position, which could be more acceptable by anti-GMO advocates.” However, Collins asserts that this also “opens the door... to the criticism... that you’ve got this genetic construct that must be limited in the way in which it’s applied.”

Regardless, Wheelan argues, CRISPR has “enormous value with changing environments and its ability to change crops and modify them to specific temperature tolerances, as well as [against] diseases.”<sup>61</sup> Echoing Wheelan’s sentiments, Hochstrasser notes that “with climate change, people are starting to realize that we’re in desperate territory, and we need to be taking any tool into consideration and tackling [global warming] from all sides.” So maybe, she muses, “we’ll have a more hopeful outlook for [CRISPR] edited crops than GMO crops.”

### Engineering for Consumption

“I don’t think GMOs were really discussed in the most transparent way they could have been,” Hochstrasser remarks. “When you’re a scientist, you’re just thinking, *oh, I can make this*

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<sup>60</sup> [CRISPR screens in plants: approaches, guidelines, and future prospects](#)

<sup>61</sup> [A CRISPR path to a sustainable planet](#)

*crop better. I can make this healthier, I can make it withstand climate change, I can do all of these things. You don't want the public to be like, oh, you engineered my food, I don't want that, and have that ruin all of your goals, right?"* To combat this, instead of proceeding with obscurity, Hochstrasser asserts, "if we talk about [CRISPR and agriculture] in a more open way," things might be different.

Engineering for consumption<sup>62</sup> is not without benefits either, Tilghman notes. The acceptance of CRISPR by developing nations could "radically change the ability to feed their populations," which, she says, has "not been possible, mainly because those countries are recognizing that they would not be able to sell any of their crops in Europe if they were to use GMO technology." This barrier, Tilghman argues, "has had a tremendously negative impact on the ability to develop drought resistant crops, to develop saltwater resistant crops, to develop crops that have [added] nutrients that [would help] people who are living... under semi-starvation conditions."

### The Battlefield

So why the barrier? "Initially, [GMOs] were a threat to the European economy," Magnus explains. "To have an American monopoly, Monsanto, being the one pushing [genetically modified] seeds on them," was not favorable agriculturally or economically. This, he notes, brought about "a convenient way to fundraise for 'forces of nature' conservancies like Greenpeace, who... fairly reasonabl[y]... exploited the moment." While Greenpeace "wasn't completely anti-GMO and... broad[ly] accept[ed] things like bacteria [to] make human insulin, which is a very unnatural transgenic... and has a huge health benefit," he says, this demeanor changed with "a GMO called golden rice. Capable of saving a million people a year that, due to vitamin A deficiency, go blind and die within a year," Magnus believes that "it's ethically unacceptable to block [a crop like that], as long as you can show safety and efficacy." To ensure this, he says, "Greenpeace would demand field trials, which [is something] everybody wanted." But when "people would do field trials," he notes, "affiliates of Greenpeace would send in thugs to destroy the fields." This, he says, "assuming it's what it seems to be at face value... would be considered unethical."

Another thing, Magnus says, is that "the public debate is motivated mostly by how much people trust the regulatory institutions. If you actually look at trauma related to these studies [in the early] media accounts of GMOs in Europe, it was much more positive than in the US. And yet it came crashing down very suddenly. *So why did Europe turn so much against GMOs?*" Magnus argues that the answer is BSE,<sup>63</sup> commonly referred to as Mad Cow Disease. "Right when BSE hit, all of their food regulators told the public *there's nothing here, there's no problem, there's nothing to worry about.* And it turned out, they were lying - people got very

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<sup>62</sup> [CRISPR/Cas systems: opportunities and challenges for crop breeding](#)

<sup>63</sup> Bovine spongiform encephalopathy

sick from Mad Cow Disease and died - and people lost faith in the regulatory system.” Even though BSE and GMOs “are not conceptually linked,” Magnus says, “it really had a big impact. So if regulators fail, even in areas that are seen as related to food but have nothing whatsoever to do with GMOs, if people lose confidence in our regulators to keep our food supply safe,” Magnus predicts that there will “be huge opposition to using CRISPR or anything else.”

Considering Greenpeace and others, Church says there are “a number of groups that [he] would like to think went too far,” suggesting “CRISPR might provide... a face-saving way of moving forward... by allowing conversation to go to point mutations, rather than transgenics.” But eventually and hopefully, he adds, “this will also include transgenics, because they’re not fundamentally flawed. It really should be based on outcome.”

### Gene Drives Deciphered

First proposed as universal gene drive systems, according to Collins, “once genetic material [was] introduced into the population and released into the environment, then in principle, it c[ould] spread through the entire population.” Through this species, he explains, the genetic material “would keep moving through the population until natural selection would forestall [its] progress.” If this occurred in a population that was “small enough,” or, for example, with “genes encoding the development of one sex preferentially over another in a bisexual species,” Collins says “the gene drive system could move through in a way that could possibly cause extinction.”

Recently, however, Collins notes a movement of “focus [towards] the development of... gene drives that can be limited in some way,” in order to prevent outcomes such as displacement or extinction, emphasizing “the involvement of communities [a]s an important feature” of intentional gene drives. “Because the release of these organisms has its most proximate effect on those individuals near to the organisms that are going to be altered,” he explains, in order to have maximum positive impact, scientists and organizations need to involve communities, the definition of which, he asserts, involves different levels – “from those individuals closest to where the release might be done, to those individuals who have a vested interest but are quite removed from where the release is being done.”

In engaging with these groups, Collins says, scientists and companies need to think about “*what would it mean to have communities involved? How do you get the communities involved? Who does the choosing? Who gets included? Excluded? What would it mean to reach a decision? Is a decision a consequence of vote? Does it have to be a majority? Should it be a super majority?*” By posing these questions, Collins hopes those facilitating research will consider more critically other stakeholders and how CRISPR implicates them.

### Raising a Mammoth

Aided by CRISPR technology, in September of 2021, biotech startup Colossal announced their venture into the past: using mammoth DNA to help endangered elephants and Arctic

ecosystems. With the goal of integrating mammoth DNA into the genome of Asian elephants to increase their resistance to Arctic climate conditions, Colossal hopes the mammoth-elephant hybrid's reoccupation of the Siberian tundra will help offset the positive feedback loop that facilitates the thawing of permafrost.<sup>64</sup> Led by Harvard Medical School's George Church and serial tech entrepreneur Ben Lamm, Colossal has acquired more than \$15 million in funding in its initial seed round.

Describing Colossal's venture as "fascinating," Collins warns that "the likelihood of it working is... complex," and that we are "a long way from understanding what... the ecological implications of releasing genetically modified organisms... might look like." And so, acknowledging that while it is "fascinating biology," Collins says he is "very, very skeptical [that]... we'll ever get to actually having a woolly mammoth that's going to be released on the steppes of Central Asia." But who knows, he says. "In terms of breakthroughs, [it] might be possible... [and] lead to something closer to a woolly mammoth in terms of the phenotype." However, at the moment, Collins believes "it's just too far of a reach in terms of the science, at least as far as what we know right now," especially considering the "environmental risks that go along with the use of [the] technology and its release into natural ecosystems."

## Final Thoughts

### A Different Reality

"It's the differences in this debate, as opposed to earlier episodes, like the emergence of gene therapy in the 90s or the debate over the possibility of human cloning later in the early 2000s... [that is CRISPR's] major unique factor," Juengst argues. Along with the fact that "it can be done everywhere and is being done [practically] everywhere," and to begin, individuals "don't need a lot of scientific infrastructure," Juengst believes an interesting situation has been created. "You can't just have a conference of American scientists, like they did in the 70s, to decide what the rules should be on recombinant DNA research. [Now], you've really got to reach around the world, because so much work is going on globally... to address [these issues] from a broader health perspective."

### The Twitter Effect

While innovation in biotechnology "has been happening for decades," MacPherson asserts, "the pandemic experience has shaped my reality mindset about how powerful disinformation is. If we can't get people to unhook from that misinformation cycle in the face of a global pandemic, where people are dying every day," she asks, "what's the playout for CRISPR? People won't have trust that it won't get misused. In fact, they'll exploit the ability just to do it for their own ends. And the question is, how big of a piece of it will that be? It's not on

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<sup>64</sup> [The Context: Resurrecting the Woolly Mammoth](#)

the menu right now, because we're too consumed with [CRISPR and the pandemic]. But it will come back for sure. We haven't finished that dialogue at all."

Echoing MacPherson's sentiments, Tilghman believes there is reason to be concerned about "stakeholders in policy discussions [who] misrepresent the science." That is to say, those "who take a very adversarial point of view, but do so from a factually wrong position." Offering the anti-Vax movement as an example, Tilghman explains how "a group of people who misrepresented scientific work... and dug their heels in... have influenced a lot of people in this country and around the world to refuse the COVID vaccine and put themselves in real harm," adding that the dissemination of misinformation "can happen quickly because social media has allowed... [it to] influence people in a way" that is efficient, effective, and impactful.<sup>65</sup>

### Ethically-Minded

According to Collins, there is a growing number of scientists who are considering other stakeholders when it comes to the implications of particular sciences. "One of the things that struck me in a very positive light, as far as the development of CRISPR is concerned... relative to the environmental implications of the deliberate release of GMOs, is the degree to which practitioners from the very beginning were interested in what the ethical implications might be of this particular work." Especially concerning "the application of CRISPR in the area of developing engineered gene drives that could be proposed to be released into the environment," Collins lauds the work of individuals "such as George Church or Kevin Esvelt," who he says, "for the purpose of diminishing population sizes, changing the sex ratios of populations, [and] introducing new genes into populations... really have been interested in getting the wider community involved - both scientists as well as non-scientists - in making decisions about the use of [CRISPR]."

### He's Impact

What to make of Jiankui He? For Tilghman, "he was so strongly vilified, not just by the scientific establishment but by the Chinese government as well," that his work has become "a cautionary tale." This, Tilghman believes, sets an example that warns scientists of treading down the same path and promotes the transparency and observation of guidelines that He lacked.

But to Magnus, ensuring this will take more effort. "If you look at the very basics of regulatory research - ethics, basics, and these innovation requirements - you can see how badly, for example, Dr. He in China who produced CRISPR babies, failed to meet almost any of those standards. The risks were not minimized in relation to the benefits, because there were less risky procedures that could have produced the same outcomes - arguably, the benefits did not outweigh the risks." This faulty risk assessment, Magnus asserts, in addition to the "community consensus at the time that... the field wasn't ready yet," were either misunderstood or ignored, or

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<sup>65</sup> [A Dozen Misguided Influencers Spread Most of the Anti-Vaccination Content on Social Media](#)

both, something that Magnus argues should not have been possible and will take the combined efforts of the public and researchers to remedy.

### **99 Cent Gene**

CRISPR-Cas9 as a technology, Tilghman says, “has enormous potential and a lot of hype. And you wouldn’t be writing this report if it weren’t being broadly discussed and anticipated. I think this is one of the cases where it probably deserves the hype.” Among this, Comín chances, in the future, “maybe the same way you pay 99 cents and get access to a song in iTunes, you can pay 5 dollars and get a gene modified.” Who knows.

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