:(Resolution and Definitions 3

Resolution 4

“Public Health” 5

“Public Health Services” Are Provided by the Government 6

“Public Health” Services Can be Mandatory 7

“Public Health” Aims at Overall Population Health 8

General Definitions of “Public Health” 9

“Public Health is not Private 15

“Genes”/”Gene Editing” 16

What are Genes? 17

What is Gene Editing? 18

Current Law on Germline Research 19

Human Genome/Germline 20

China Leads 21

Future 23

CISPR/9 24

Access 25

Pro 26

General Advantages 27

Virus Prevention 28

Sickle Cell 29

Germline Editing Solves Disease 30

“Public Health” Advantages/Justification 31

Answers to: Gene Editing Bad 32

Answers to: Gene Mutations Bad 33

Answers to: Genome Editing Not Natural 34

Answers to: Can’t Decide for Future Generations 35

Answers to: It’s Dangerous 36

Answers to: Designer Babies 37

Answers to: Public Health Violates Individual Liberties 38

Con 40

Disadvantages – General 42

Eugenics, Discrimination, Inequality 43

Shouldn’t Solve Inequality Through Public Health 44

Gene Editing Fails 49

Risks – General - 50

Germline Editing Bad 51

Risks 52

Answers to: Need to Stop Inherited Genetic Disease 53

General Pros & Cons 54

Books 57

# Resolution and Definitions

### Resolution

**Public health services should expand access to gene editing technologies**

## “Public Health”

### “Public Health Services” Are Provided by the Government

#### “Public health services” are provided by the government

Mark A. **Rothstein**, Herbert F. Boehl Chair of Law and Medicine and director of the Institute for Bioethics, Health Policy and Law at the University of Louisville, **2002**

[“Public Health Law, Society, And Ethics: Rethinking the Meaning of Public Health,” *Journal of Law, Medicine & Ethics* (30 J.L. Med. & Ethics 144), Summer, Available Online via Lexis-Nexis *// BATMAN*]

n9 Committee for the Study of the Future of Public Health, Institute of Medicine, The Future of Public Health (Washington, D.C.: National Academy Press, 1988): at 19.

**The IOM report also makes public health the responsibility of everyone, although it gives primacy to *government effort*s**: "The mission of public health is addressed by private organizations and individuals as well as by public agencies. But the governmental public health agency has a unique function: to see to it that vital elements are in place and that the mission is adequately addressed." n10 In contrast to this government-centered approach, a more expansive definition of public health cited in, but not necessarily endorsed by the IOM report is the following: "It's anything that affects the health of the community on a mass basis." n11 **Under such a view, efforts to improve access to health care as well as more general measures to prevent injury and illness and reduce morbidity and mortality, such as advice to use sunscreen and eat healthy foods, would be considered public health. I term this conception of public health the "population health as public health" model**.

### “Public Health” Services Can be Mandatory

#### “Public health” is collective efforts to ensure that the population is healthy

Dorothy Puzio, health care attorney 2003/4, Journal of Law & Health, An Overview of Public Health in the New Millennium: Individual Liberty vs. Public Safety, <http://engagedscholarship.csuohio.edu/jlh/vol18/iss2/3/>, DOA: 8-20-15, p. 173-4

**"Public health is what we, as a society, do collectively to assure the conditions for people to be healthy."** In the abstract, the vast majority of Americans believe in public health and support public health goals. More than three and a half decades ago, **this attitude prompted Congress to establish "a separate standard for coverage of children within Medicaid" in order to facilitate baby well-care.**

#### Public health requirements can intrude on civil liberties

Dorothy Puzio, health care attorney 2003/4, Journal of Law & Health, An Overview of Public Health in the New Millennium: Individual Liberty vs. Public Safety, <http://engagedscholarship.csuohio.edu/jlh/vol18/iss2/3/>, DOA: 8-20-15, p. 179-80

Adequately addressing **the identified weaknesses of the** United States' **public health system will involve some friction with individual rights. For example affording public health officials an expansion of authority, will, of necessity, intrude on the protection of civil liberties. More governmental power almost invariably corresponds to less individual liberty; "[i]t is not a new equation."**  Likewise, some of the most popular and commonly used public health measures around the world--namely quarantines, mandatory screening and immunization, and **health information sharing--all intrude upon civil liberties to one extent or another.**

#### “Public health” can trade-off with rights

Lawrence O. Gostin, professor of Public Health at Georgetown, and Johns Hopkins, Summer 2001, Journal of Law, Medicine, and Ethics, Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann, p. 131

Jonathan Mann viewed human rights as the conscience of public health. He was acutely aware that public health policies can, and do, infringe on human rights. For example, **a decision to compulsorily test, treat, or confine** a person with tuberculosis certainly **invades a sphere of autonomy or liberty. Similarly, surveillance and mandatory reporting invade a sphere of our privacy. It was for this reason that he worked on a "human rights impact assessment" to measure the human rights effects of public health policies.**

### “Public Health” Aims at Overall Population Health

#### “Public health” is aimed at the population’s overall health

Dorothy Puzio, health care attorney 2003/4, Journal of Law & Health, An Overview of Public Health in the New Millennium: Individual Liberty vs. Public Safety, <http://engagedscholarship.csuohio.edu/jlh/vol18/iss2/3/>, DOA: 8-20-15, p. 175-6

**Public health differs from traditional health care in several respects. Some of its distinguishing features include a focus on: "(1) the health and safety of *populations* rather than** . . . individual patients; (2) [the] ***prevention* of injury** and disease rather than treatment[;] . . . (3) [the] **relationship between *government* and the *communit****y* rather than physician and patient; and (4) services grounded on [sic] . . . *scientific methodologies* of public health (e.g. . . . *epidemiology*) rather than personal medical services." **The Institute of Medicine's definition of public health, set forth at the beginning of this article, reinforces these distinguishing characteristics by emphasizing a mutuality of obligation lying with the government and community as a whole, and focusing on increasing the incidence of conditions that facilitate healthy living as opposed to guaranteeing health itself.** People often fail to appreciate the benefits of public health, because the effects of prevention are usually invisible. However, a strong public health system is essential to the welfare of any society, and has accounted for approximately "twenty-five of the thirty years of increased life expectancy in the United States since the turn of the century." The importance of public health to American society has been underscored by the events of September 11th, which confirmed that terrorist attacks, with the potential for biological warfare, are very real threats.

### General Definitions of “Public Health”

#### Various definitions of “public health”

Lawrence O. Gostin, professor of Public Health at Georgetown, and Johns Hopkins, Summer 2001, Journal of Law, Medicine, and Ethics, Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann, p. 122

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|  |  |
| Definition | Society's obligation to assure the conditions for |
|  | people's health |
|  |  |
| Mission | To promote physical and mental health |
|  | To prevent disease, injury, and disability |
|  |  |
| Functions | To assemble and analyze community health needs |
|  | To develop policy informed through scientific |
|  | Knowledge |
|  | To assure the community by providing services |
|  | necessary for its health |
|  |  |
| Jurisdiction/Domain | Narrow focus--proximal risk factors |
|  | Broad focus--distal social structures (e.g., |
|  | discrimination, homelessness, socioeconomic status) |
|  |  |
| Expertise/Skills | Epidemiology and biostatistics |
|  | Education and communication |
|  | Leadership and politics |

ideal state of physical and mental health to a more concrete listing of public health practices. Charles-Edward A. Winslow, for example, defined public health as:

the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, [and] the organization of medical and nursing service for the early diagnosis and preventive treatment of disease. n5

More recent definitions focus on "positive health," emphasizing a person's complete well-being. n6 Definitions of positive health include at least four constructs: a healthy body, high quality personal relationships, a sense of purpose in life, and self-regard and resilience. n7

n5 C.A. Winslow, "The Untilled Fields of Public Health," *Science*, 9 (January 1920): 20-30, at 30.

n6 "Putting Public Health Back into Epidemiology," Editorial, *Lancet*, 350 (1997): 229.

n7 C.D. Ryff and B. Singer, "The Contours of Positive Health," *Psychological Inquiry*, 9 (1998): 1-28; J.W. Rowe and R.L. Kahn, *Successful Aging* (New York: Pantheon Books, 1998).

The Institute of Medicine, in its seminal report on the *Future of Public Health*, proposed one of the most influential contemporary definitions: "Public health is what we, as a society, do collectively to assure the conditions for people to be healthy." n8

n8 Institute of Medicine, *The Future of Public Health* (Washington, D.C.: National Academy Press, 1988): at 19.

The Institute's definition can be appreciated by examining its constituent parts. The emphasis on cooperative and mutually shared obligation ("we, as a society") reinforces that collective entities (e.g., governments and communities) take responsibility for healthy populations. Individuals can do a great deal to safeguard their health, particularly if they have the economic means to do so. They can purchase housing, clothing, food, and medical care. Each person can also behave in ways that promote health and safety by eating healthy foods, exercising, using safety equipment (e.g., seatbelts and motorcycle helmets), or refraining from smoking, using illicit drugs, or drinking alcoholic beverages excessively. Yet, there is a great deal that individuals cannot do to secure their health; to overcome whatever these barriers may be, individuals need to organize, work together, and share their resources. Acting alone, people cannot achieve environmental protection, hygiene and sanitation, clean air and surface water, uncontaminated food and drinking water, safe roads and products, and control of infectious disease. Each of these collective goods, and many more, is achievable only by organized and sustained community activities. n9

n9 L.O. Gostin, "Public Health Law in a New Century: Part I: Law as a Tool to Advance the Community's Health," *Journal of the American Medical Association*, 283 (2000): 2837-41.

The Institute of Medicine's definition also makes clear that even the most organized and socially conscious society cannot guarantee complete physical and mental well-being. There will always be a certain amount of injury and disease in the population that is beyond the reach of individuals or government. The role of public health, therefore, is to "assure the *conditions* for people to be healthy" (emphasis added). These conditions include a variety of educational, economic, social, and environmental factors that are necessary for good health. n10

n10 Institute of Medicine, *Health and Behavior: The Interplay of Cells, Self and Society* (Washington, D.C.: National Academy Press, forthcoming in 2001).

Most definitions share the premise that the subject of public health is the health of populations--rather than the health of individuals--and that this goal is reached by a generally high level of health throughout society, rather than the best possible health for a few. The field of public health is concerned with health promotion and disease prevention throughout society. Consequently, public health is less interested in clinical interactions between health-care professionals and patients, and more interested in devising broad strategies to prevent, or ameliorate, injury and disease.

Scholars and practitioners have long been conflicted about the "reach" or domain of public health. n11 Some prefer a narrow focus on the proximal risk factors for injury and disease. Under this perspective, public health should identify risks or harms and intervene to prevent or ameliorate them. This has been the traditional role of public health, exercising discrete powers such as surveillance, infectious disease controls (e.g., screening, vaccination, partner notification, and quarantine), and sanitary measures (e.g., safe food and drinking water).

n11 See G. Mooney, "Book Review," *Journal of Health Politics, Policy & Law*, 25 (2000): 775 (discussing the debate in Britain in the 1840s between non-physician Sir Edwin Chadwick, architect of a public health system focused on the water supply and sewage system, and Dr. William Alison, who emphasized lack of food, clothing, warmth, and adequate shelter as causes of disease).

Others prefer a broad focus on the societal, cultural, and economic foundations of health. Under this perspective, public health should be more concerned with the underlying conditions that are associated with poor health. n12 For instance, the field of public health is ultimately interested in the equitable distribution of social and economic resources because social status, race, and wealth are important determinants of health. n13 This inclusive direction for public health is gaining popularity; consider how many of the federal government's health objectives for 2010 seek a reduction in health disparities. n14 Public health researchers are also venturing into areas far from their traditional expertise, including violence, war, homelessness, and discrimination. n15

n12 I.H. Meyer and S. Schwartz, "Social Issues as Public Health: Promise and Peril," *American Journal of Public Health*, 90 (2000): 1189-91 (discussing the role of public health in addressing the "social ills rooted in distal social structures").

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### “Public Health is not Private

#### Definitions of “public health” that include “private care” are too broad

Lawrence O. Gostin, professor of Public Health at Georgetown, and Johns Hopkins, Summer 2001, Journal of Law, Medicine, and Ethics, Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann, p. 122

The problem with an expansive view is that public health--as a field, as a mandate--becomes limitless, as almost everything human beings undertake affects public health. By this account, **public and private activities across a wide spectrum are the work of public health. To many, this all-inclusive notion of public health is counterproductive. First, by defining itself so widely, the field lacks precision. Public health becomes an all-embracing enterprise bonded only by the common value of societal well-being. Second, by adopting such a broad array of behavioral, social, physical, and environmental interventions, it lacks a discrete expertise. The public health professions consequently incorporate a wide variety of disciplines (e.g., occupational health, health education, epidemiology, and nursing) with different skills and functions. Finally, by espousing controversial issues of economic redistribution and social restructuring, the field becomes highly political. While public health practitioners like to conceive of their field as a positivistic discipline that stresses the importance of science and technique, the field is, in reality, imbued with values and influenced by interest-group politics.**

## “Genes”/”Gene Editing”

### What are Genes?

#### Genes

Medicine.net, Medical Definition of Gene, https://www.medicinenet.com/script/main/art.asp?articlekey=3560

**Gene: The basic biological unit of heredity. A segment of deoxyribonucleic acid (DNA) needed to contribute to a function.** An official definition: According to the official Guidelines for Human Gene Nomenclature, **a gene is defined as "a DNA segment that contributes to phenotype/function. In the absence of demonstrated function a gene may be characterized by sequence, transcription or homology." DNA: Genes are composed of DNA,** a molecule in the memorable shape of a double helix, a spiral ladder. Each rung of the spiral ladder consists of two paired chemicals called bases. There are four types of bases. They are adenine (A), thymine (T), cytosine (C), and guanine (G). As indicated, each base is symbolized by the first letter of its name: A, T, C, and G. Certain bases always pair together (AT and GC). Different sequences of base pairs form coded messages. The gene: **A gene is a sequence (a string) of bases. It is made up of combinations of A, T, C, and G**. These unique combinations determine the gene's function, much as letters join together to form words. Each person has thousands of genes -- billions of base pairs of DNA or bits of information repeated in the nuclei of human cells --which determine individual characteristics (genetic traits). The chromosome: **Genes are arranged in precise arrays all along the length of 23 pairs of much larger structures: the chromosomes**. One chromosome in each pair comes from the mother and the other one from the father. The chromosomes in any particular pair look like each other, except in a boy. There is one pair of chromosomes, which usually settles the sex of the individual. This pair has two X chromosomes in females and one X and one Y chromosome in males. The X and Y chromosomes: These chromosomes -- the X and Y are always capitalized -- are the sex chromosomes. All the other chromosomes in the human chromosome complement are numbered from 1 to 22 and are called the autosomes (literally, the other chromosomes).

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

Remind me what genes are again?

**Genes are the biological templates the body uses to make the structural proteins and enzymes needed to build and maintain tissues and organs. They are made up of strands of genetic code, denoted by the letters G, C, T and A. Humans have about 20,000 genes bundled into 23 pairs of chromosomes all coiled up in the nucleus of nearly every cell in the body. Only about 1.5% of our genetic code, or genome, is made up of genes. Another 10% regulates them, ensuring that genes turn on and off in the right cells at the right time, for example**. The rest of our DNA is apparently useless. “The majority of our genome does nothing,” says Gerton Lunter, a geneticist at the University of Oxford. “It’s simply evolutionary detritus.”

What are all those Gs, Cs, Ts and As?

**The letters of the genetic code refer to the molecules guanine (G), cytosine (C), thymine (T) and adenine (A). In DNA, these molecules pair up: G with C and T with** A. These “base pairs” become the rungs of the familiar DNA double helix. It takes a lot of them to make a gene. The gene damaged in cystic fibrosis contains about 300,000 base pairs, while the one that is mutated in muscular dystrophy has about 2.5m base pairs, making it the largest gene in the human body. Each of us inherits about 60 new mutations from our parents, the majority coming from our father.

Encyclopedia Brittanica, August 22, 2018, <https://www.britannica.com/science/gene> Gene

**Gene, unit of hereditary information that occupies a fixed position (locus) on a chromosome. Genes achieve their effects by directing the synthesis of proteins. …. Genes are composed of deoxyribonucleic acid (DNA), except in some viruses, which have genes consisting of a closely related compound called ribonucleic acid (RNA). A DNA molecule is composed of two chains of nucleotides that wind about each other to resemble a twisted ladder**. The sides of the ladder are made up of sugars and phosphates, and the rungs are formed by bonded pairs of nitrogenous bases. These bases are adenine (A), guanine (G), cytosine (C), and thymine (T). An A on one chain bonds to a T on the other (thus forming an A–T ladder rung); similarly, a C on one chain bonds to a G on the other. If the bonds between the bases are broken, the two chains unwind, and free nucleotides within the cell attach themselves to the exposed bases of the now-separated chains. The free nucleotides line up along each chain according to the base-pairing rule—A bonds to T, C bonds to G. This process results in the creation of two identical DNA molecules from one original and is the method by which hereditary information is passed from one generation of cells to the next.

### What is Gene Editing?

#### Gene editing involves deleting part of a defective gene or repairing it

**Patronus Medical**, no date, <http://blog.patronusmedical.com/the-benefits-of-gene-editing> The Benefits of Gene Editing

In many cases, **genetic diseases occur when a mutation appears inside a cell**. Although researchers have been able to identify which cells the mutations occurred in, little could have been done to repair the defective genes. **Gene editing allows doctors to use specialized molecular tools to remove, repair or replace damaged genes with a healthy copy.** Although the technology is still a bit far off from being used regularly by medical professionals worldwide, **animal trials have been successful**. In fact, a team of Chinese scientists will be the first to test gene-edited cells in human patients this month. CRIPSR, or “clustered regularly interspaced short palindromic repeats,” is the most advanced and effective gene-editing technique being utilized by scientists. CRISPR is inexpensive, easy to use and precise. Gene modifications using CRISPR have extended from corn and rice to mice and pigs.

**Associated Press**, December 1, **2015**, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

While scientists have long been able to find defective genes, fixing them has been so cumbersome that it's slowed development of genetic therapies**. With gene editing, scientists home in on a piece of DNA and use molecular tools that act as scissors to snip that spot - deleting a defective gene, repairing it or replacing it. There are some older methods but a new tool called CRISPR-Cas9 has been adopted by laboratories worldwide because it's faster, cheaper, simple enough to use with minimal training, and allows altering of multiple genes simultaneously.**

### Current Law on Germline Research

Associated Press, December 1, 2015, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

Where you live determines if, or what kind of, research can be performed on embryos. Some countries, especially in Europe, ban germline research. Others, such as **China, have guidelines described as unenforceable. Britain allows basic lab research only. In the U.S., the NIH won't fund research involving germline editing but private funding is allowed.**

### Human Genome/Germline

#### Human eggs, sperm, embryos – human genome

Keren Weintraub, National Georgraphic, December, 2015, https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/ 5 Reasons Gene Editing Is Both Terrific and Terrifying

This week, a high-profile group of researchers, ethicists and advocates convened in Washington, D.C., to discuss the ethics of editing human genes. In particular, they're concerned about **changes to human eggs, sperm or embryos—known as the human germline.**

#### Editing the germline means the gene changes get passed down

Keren Weintraub, National Georgraphic, December, 2015, https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/ 5 Reasons Gene Editing Is Both Terrific and Terrifying

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### China Leads

#### China leads in gene editing

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

The race is on to get gene editing therapies into the clinic. A dozen or so Crispr-Cas9 trials are underway or planned, most led by Chinese researchers to combat various forms of cancer. One of the first launched in 2016, when doctors in Sichuan province gave edited immune cells to a patient with advanced lung cancer. More US and European trials are expected in the next few years.

### Embryo Editing Done in US

#### Embryo editing has been done in the US

Steve Connor is a freelance journalist based in the U.K. July 26, 2017, <https://www.technologyreview.com/s/608350/first-human-embryos-edited-in-us/> irst Human Embryos Edited in U.S.

The first known attempt at creating genetically modified human embryos in the United States has been carried out by a team of researchers in Portland, Oregon, MIT Technology Review has learned.

The effort, led by Shoukhrat Mitalipov of Oregon Health and Science University, involved changing the DNA of a large number of one-cell embryos with the gene-editing technique CRISPR, according to people familiar with the scientific results. Until now, American scientists have watched with a combination of awe, envy, and some alarm as scientists elsewhere were first to explore the controversial practice. To date, three previous reports of editing human embryos were all published by scientists in China. Now Mitalipov is believed to have broken new ground both in the number of embryos experimented upon and by demonstrating that it is possible to safely and efficiently correct defective genes that cause inherited diseases. Although none of the embryos were allowed to develop for more than a few days—and there was never any intention of implanting them into a womb—the experiments are a milestone on what may prove to be an inevitable journey toward the birth of the first genetically modified humans.

### Future

#### Future

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

What next?

Base editing

A gentler form a gene editing that doesn’t cut DNA into pieces, but instead uses chemical reactions to change the letters of the genetic code. It looks good so far. In 2017, researchers in China used base editing to mend mutations that cause a serious blood disorder called beta thalassemia in human embryos.

Gene drives

Engineered gene drives have the power to push particular genes through an entire population of organisms. For example, they could be used to make mosquitoes infertile and so reduce the burden of disease they spread. But the technology is highly controversial because it could have massive unintended ecological consequences.

Epigenome editing

Sometimes you don’t want to completely remove or replace a gene, but simply dampen down or ramp up its activity. Scientists are now working on Crispr tools to do this, giving them more control than ever before.

### CISPR/9

#### CRISPR/9 gene editing technique worked to edit a gene embryo

Keren Weintraub, National Georgraphic, December, 2015, <https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/> 5 Reasons Gene Editing Is Both Terrific and Terrifying

THE IDEA OF tinkering with the genes we pass to our children has long been the stuff of science fiction. **But scientists are rapidly solving the technological challenges, and expect such gene editing will soon be feasible. A three-year-old technique called CRISPR/Cas9 is so effective at cutting and adding genes that researchers all over the world have adopted it in their labs. Earlier this year, researchers in China edited genes in a nonviable human embryo to try to treat an inherited blood disease, and ended up with a lot of unintended—and potentially dangerous—changes.**

## Access

Google Definitions

"the ability, right, or permission to approach, enter, speak with, or use; admittance."

# Pro

## Disease Advantages

### Virus Prevention

#### Gene editing used to attack dangerous viruses

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

With gene editing, researchers have made seedless tomatoes, gluten-free wheat and mushrooms that don’t turn brown when old. Other branches of medicine have also seized on its potential. Companies working on next-generation antibiotics have developed otherwise harmless viruses that find and attack specific strains of bacteria that cause dangerous infections.

### Lots of Genetic Diseases

#### Gene errors are responsible for 5,000 inherited disorders

Antonio Regaldo, October 17, 2016, <https://www.technologyreview.com/s/602491/can-crispr-save-ben-dupree/> Technology Review Can CRISPR Save Ben Dupree?

Scientists know the gene errors responsible for around 5,000 inherited disorders, and sequencing labs discover some 300 more each year. Some are one-in-a-billion syndromes. Duchenne is at the other extreme; it is one of the most common inherited diseases, affecting 1 in 4,000 boys. Girls are affected rarely, and to a lesser degree.

### Sickle Cell

#### Gene editing can solve sickle cell

Associated Press, December 1, 2015, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

The biggest use so far is to rapidly engineer animals with human-like disorders for basic research, but promising gene-editing experiments make regular headlines. Much like a bone marrow transplant, researchers hope to use CRISPR for diseases like sickle cell, correcting the faulty gene in someone's own blood-producing cells rather than implanting donated ones.

### Hodgkins

#### Genetic modification can solve Hodgkins

David Warmflash is an astrobiologist, physician and science writer, September 12, 2016, <https://geneticliteracyproject.org/2016/09/12/will-use-gene-editing-treat-human-disease/> How will we use gene editing to treat human disease?

Huntington disease is a good example of what is called a dominant genetic condition. There also are certain familial forms of amyotrophic lateral sclerosis (ALS, Lou Gehrig disease) that are inherited with dominant genetics. Dominance means that just one abnormal gene copy, or allele, will cause a disease, even though the individual carries two alleles of every gene (one from mom and one from dad). Dominant conditions occur even when a person has a normal copy of the disease. On the other hand, recessive conditions require two abnormal alleles to produce disease, usually because lack of an enzyme due an abnormal allele is compensated by the normal allele.

This happens when the abnormal allele merely produces no enzyme, while amount of enzyme produced by the normal allele is adequate to the meet the cell’s needs. But there’s an abnormal gene for an enzyme in the membranes of the mitochondria—the power plants of the cell—that does worse than simply not make the enzyme. The enzyme is a powerful antioxidant called SOD1 (its gene is called ALS1) and molecules of the abnormal form clump together. It even causes normal versions of SOD1 to clump. This leads to ALS and since nerve cells are disrupted from the clumping, rather from a lack of functional SOD1 enzyme, it’s inherited with dominant genetics.

With Huntington’s disease, the reason for dominance is the presence of multiple copies of a genetic sequence within the abnormal allele, but in both Huntington’s disease and ALS a couple desiring children might have a pretty good rationale to opt for germ line editing. The basic strategy is this: embryos would be produced through in vitro fertilization (IVF), using the woman’s ova and the man’s sperm, the same method used for couples that are infertile.

The Huntington disease gene could then be edited out of any embryo that is to be implanted in the mother. Although a fertilized ovum begins as one cell, it immediately splits into a two-cell entity called a blastomere and is a multi-cell structure called a blastocyst when it is optimal for implantation in the uterus after around day 5. In this very early period of development, not only are there many cells, but the cells are changing and dividing rapidly, and gene editing technology would have to do its work (in this case replacing a Huntington gene) in the same way in every cell without disrupting the development process.

### Germline Editing Solves Disease General

#### Gene editing can solve genetic diseases

Antonio Regaldo, October 17, 2016, <https://www.technologyreview.com/s/602491/can-crispr-save-ben-dupree/> Technology Review Can CRISPR Save Ben Dupree?

Gene editing could be a way to erase such diseases, with a one-time, permanent alteration of a person’s DNA. It’s a step beyond conventional gene therapy—the 30-year-old idea of inserting entire replacement genes into a person’s cells, usually using a virus. That approach is impractical for some diseases. The gene for dystrophin, for instance, is too large to fit inside a virus, as CRISPR’s DNA-snipping proteins can. And sometimes a faulty gene that’s doing harm needs to be silenced, so adding a new one won’t help. CRISPR’s ability to delete and swap out genetic letters makes a huge new range of treatments possible. Some doctors are now calling CRISPR “gene therapy 2.0.”

To be sure, even gene therapy 1.0 has yet to fully arrive. After 30 years of research, scientists are still learning how to use viruses to move genetic instructions into a living person’s cells. Only two gene-replacement treatments for inherited disease have ever been approved, both in Europe. But Olson says he is convinced CRISPR is the most plausible way to stop Du­chenne. Early this year, he showed he could repair mutations in mice with muscular dystrophy after sending viruses stuffed with CRISPR ingredients into their veins. “A mouse is not a boy, but we think we know exactly what needs to be done,” says Olson. If it works, he adds, “this is a cure, not a treatment.”

#### Germline editing means no transfer of disease from one generation to the next

Associated Press, December 1, 2015, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

Altering genes in sperm, eggs or embryos can spread those changes to future generations, so-called germline engineering that might one day stop parents from passing inherited diseases to their children. Chinese scientists reported the first-known attempt to edit human embryos last spring, working with leftovers from fertility clinics that never could have developed into fetuses. They aimed to correct a deadly inherited gene, but uncovered problems that will require more research.

#### Gene editing can alter cancer cells

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

Today you can go online to any number of biological-supply companies and order your own CRISPR kit for as little as $130. The technique is being used in hundreds of labs across the U.S. and around the globe. At New York City's Memorial Sloan Kettering Cancer Center, cancer biologist Scott Lowe is developing therapies that turn on and off genes in tumor cells to make them easier for the immune system to destroy. Before CRISPR, figuring out what effect a particular gene had on cancer required breeding mice that lacked the gene to see how their cancers progressed or didn't--a months-long endeavor. "Now CRISPR makes it very easy in an afternoon to knock out a gene and study what effect it has on the tumor," Lowe says.

#### Gene editing has solved muscular dystrophy

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

Already, CRISPR is producing clear results in practically every corner of biology. Researchers have corrected the genetic defect in Duchenne muscular dystrophy in mice and deactivated 62 genes in pigs so that organs grown in the animals, such as heart valves and liver tissue, won't be rejected when scientists are ready to transplant them into people. In China, researchers report that they have accomplished in dogs, rabbits, goats and monkeys what human bodybuilders yearn for: a way to quickly build muscles to hulklike proportions. Also in China, plant scientists are editing out genes that make wheat susceptible to mildew, potentially leading to hardier crops.

#### CRISPR can reduce malaria

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

Malaria researchers are exploring a number of ways that CRISPR can be used to manipulate mosquitos to make them less likely to transmit the malady. (Since only females bite and spread the parasite, for example, they're editing in sterilizing changes so the females can't reproduce. Eventually, the hope goes, malaria will cease to be transmitted.)

## Environment Advantage

### Germline Editing Reduces Waste

#### CRISPR can reduce plastic waste

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

Some even see the technology as an answer to the growing problem of plastic waste. In Japan, scientists found a bacterium that can chew up the main element in landfill staples like plastic shopping bags--but very slowly. They're investigating ways to use CRISPR to rev up the plastic-degrading gene and turn such microbes into garbage-eating machines.

## “Public Health” Advantages/Justification

#### “Public health” intervention is justified when there is a risk of disease

Richard A. **Epstein**, James Parker Hall Distinguished Service Professor at the University of Chicago Law School, Peter and Kirsten Bedford Senior Fellow at the Hoover Institution at Stanford University, and Adjunct Scholar at the Cato Institute, **2003**

[“Let The Shoemaker Stick To His Last: A Defense Of The ‘Old’ Public Health,” *Perspectives in Biology and Medicine*, Volume 46, Number 3, Summer, Available Online to Subscribing Institutions via Project Muse *// BATMAN*]

This paper investigates the proper understanding of the discipline of public health. How far does it run and what does it encompass? Dealing with this question requires moving back and forth between the conception of public health that is internal to the public health discipline, and the conception of public health as it has been understood outside the public health field by historians and lawyers who are interested in defining the appropriate use and limitations of the state power of coercion. **The old public health established the principle that** [End Page S138] **epidemics offer strong reason for decisive public intervention, whether by quarantine, vaccination, or the creation of public sewers and waste disposal systems. Today, the new public health uses the term "epidemic" to justify state regulation to limit tobacco consumption or control obesity, even though these activities do not pose risks of communicable disease or any other form of recognizable externalities** (pace secondhand smoke) **to other individuals**. **For its part, the old public health tracks the idea of public goods in economics, namely, those non-excludable goods that cannot be supplied to one unless they are also given to another** (for the classical account, see Olson 1971). **It thus invokes an analogous concept for "public bads": those harms inflicted on others without their consent, as, for example, both communicable diseases and pollution. In contrast, the new public health covers matters of general public importance, including obesity, smoking, and genetic diseases**. My broad thesis is that **the "old" public health is superior to the new, whose broad (and meddlesome) definitions of public health help spur state actions—including the regulation of product and labor markets—that in all likelihood jeopardize the health of the very individuals the new public health seeks to protect. The new public health extends regulation into inappropriate areas, and thus saps the social resources and focus to deal with public health matters more narrowly construed**.

## Inequality Advantage

### Gene Editing inevitable

#### Germline editing is inevitable

Debra Mathews, PhD, is assistant director for science programs at the Johns Hopkins Berman Institute of Bioethics Stat News, 2015, Experts Debate: Arew we playing with fire when we edit human genes, https://www.statnews.com/2015/11/17/gene-editing-embryo-crispr/

That said, concerns over modifying the human germline are justiﬁed and deserve careful attention. I am part of the Hinxton Group 12 , a collaborative of international, interdisciplinary scholars, policymakers, journals, and funders focused on stem cells, ethics, and the law. In a September statement on human germline genetic modiﬁcation 13 , we said that there may be morally acceptable uses of this technology in human reproduction “given all safety, efﬁcacy and governance needs are met.” Before that happens, however, substantial societal discussion and debate will be needed.

Regardless of what we decide to do in the United States, germline gene editing for reproductive purposes will be done somewhere around the world. We can have this difﬁcult but deeply important conversation now and make proactive decisions about how to harness this science to achieve the beneﬁts we care most about, or we can wait until the decisions are made for us by others and we are forced to react. I believe that we need to engage the public, policymakers, and broader scientiﬁc community to weigh the potential beneﬁts and harms of human genome editing for research and human health instead of stopping all discussion, debate, and research.

#### Gene editing inevitable

Lydia Ramsey, November 7, 2017, <https://www.businessinsider.com/crispr-set-to-be-a-10-billion-market-by-2025-citi-2017-11> A revolutionary gene-editing technology is on track to be a $10 billion market by 2025

A revolutionary gene-editing tool will grow into a $10 billion market in 2025, according to a new report by Citi GPS.

CRISPR, short for "clustered regularly interspaced short palindromic repeats," is a revolutionary tool that allows researchers to go into a cell's DNA and modify a mutated part of the gene, a process known as gene editing. It's currently being used in research settings, and it has the potential to be used to treat diseases, enhance agriculture and livestock, and even modify human embryos.

"The shift to CRISPR genome editing and the rapid expansion of its use is expected to have a disruptive and far-reaching impact on multiple branches of science and medicine," Citi biotech analyst Yigal Nochomovitz wrote in the report.

Getting to a $10 billion market

The technology is still relatively new. CRISPR as it's being used today has only been around since 2012, and trials to see how the technology works in humans have yet to kick off here in the US, though human trials have begun in China. According to Citi's report, human trials in the US are expected to kick off in late 2017 or early 2018.

But there have been some promising developments, which led Nochomovitz to think that the technology would have a huge market potential in the next eight years, up from the less than $1 billion market size it has in 2017.

Nochomovitz said: "Currently the CRISPR market is small, with its main offerings dedicated to lab work and scientific research via research toolkits. However, the real economic potential of CRISPR lies with human therapeutics. With CRISPR-based therapeutics having already entered human trials last year in China, the first CRISPR-based medicine could reach the market in ~6 years or less."

"If CRISPR gene editing works in early test cases of human disease, the long-term upside for the technology could be much, much greater," Nochomovitz added.

By Citi's count, there has also been more than $300 million in venture funding for gene-editing startups, and the publicly traded companies in this space have a combined $3 billion+ market cap.

The line between altering traits for medical reasons and enhancement is “inherently blurry and subjective," she said, imagining fertility clinics that “offer the latest upgrades for your offspring” and even nationalistic rivalries among countries using the technology.

#### Already $1 billion invested in gene editing

Antonio Regaldo, October 17, 2016, <https://www.technologyreview.com/s/602491/can-crispr-save-ben-dupree/> Technology Review Can CRISPR Save Ben Dupree?

Among these possibilities, the chance to end the pain and suffering of people like Dupree is CRISPR’s most compelling, if still distant, promise. In early-stage lab experiments, academic scientists are showing that gene editing offers new ways to attack cancer, to knock out HIV and hepatitis infections, even to reverse blindness and deafness. Companies aren’t far behind. Three startups in the Boston area have already raised a combined $1 billion and partnered with some of the world’s biggest drug companies, like Bayer and Novartis. “None of us can anticipate where this technology will end up,” says Olson. “I’m operating under the premise that it will take us farther than we can imagine.”

### Only the Rich Can Access Now

#### Right now, only the wealthy will gain access

Jason Pontin, April 21, 2015, <https://www.technologyreview.com/s/536696/editing-human-dna/> EDITing Human DNA

As our biomedicine editor, Antonio Regalado, reports in this issue’s cover story, “Engineering the Perfect Baby,” experiments designed to correct the DNA in a woman’s egg or a man’s sperm, or to directly edit the DNA of an early-stage embryo using CRISPR, are already being carried out. Why not? One concern is that the technologies would not be widely available, at least at first. Their expense would mean only rich people would have perfect children.

## Answers to: Gene Editing Bad

### Answers to: Gene Mutations Bad

#### Risk of a dangerous mutation from gene editing is low – and there are mutations all the time

Michael LePae, March 21, 2105, <https://geneticliteracyproject.org/2015/03/17/how-do-we-weigh-benefits-and-risks-of-human-gene-editing/> How do we weigh benefits and risks of human gene editing?

The trouble is, we don’t know yet if germline editing is dangerous. One of the points of trying it with human embryos is to find out. The main worry is so-called off-target mutations, that is, unintended changes to the genome. Studies that have been done with monkeys suggest the risk is low. The risk also has to be viewed in context: the DNA in our cells naturally mutates. Each of us is born with around 50 new mutations, the vast majority of which have no known effect.

### Answers to: Genome Editing Not Natural

#### We shouldn’t celebrate natural disease and death

John Harris is professor emeritus in science ethics at University of Manchester, August 2018, <https://www.nationalgeographic.com/magazine/2016/08/human-gene-editing-pro-con-opinions/> Pro and Con: Should Gene Editing Be Performed on Human Embryos?

Let’s start with the objection that embryo modification is unnatural, or amounts to playing God. This argument rests on the premise that natural is inherently good. But diseases are natural, and humans by the millions fall ill and die prematurely—all perfectly naturally. If we protected natural creatures and natural phenomena simply because they are natural, we would not be able to use antibiotics to kill bacteria or otherwise practice medicine, or combat drought, famine, or pestilence. The health care systems maintained by every developed nation can aptly be characterized as a part of what I have previously called “a comprehensive attempt to frustrate the course of nature.” What’s natural is neither good nor bad. Natural substances or natural therapies are only better that unnatural ones if the evidence supports such a conclusion

### Answers to: Can’t Decide for Future Generations

#### We decide for future generations all the time

John Harris is professor emeritus in science ethics at University of Manchester, August 2018, <https://www.nationalgeographic.com/magazine/2016/08/human-gene-editing-pro-con-opinions/> Pro and Con: Should Gene Editing Be Performed on Human Embryos?

The matter of consent has been raised by Francis Collins, director of the National Institutes of Health. “Ethical issues presented by altering the germline in a way that affects the next generation without their consent,” he has said, constitute “strong arguments against engaging in” gene editing. This makes no sense at all. We have literally no choice but to make decisions for future people without considering their consent. All parents do this all the time, either because the children are too young to consent, or because they do not yet exist. George Bernard Shaw and Isadora Duncan knew this. When, allegedly, she said to him “why don’t we make a baby together … with my looks and your brains it cannot fail” she was proposing a deliberate germline determining decision in the hope of affecting their future child. Shaw’s more sober response—“Yes but what if it has my looks and your brains!”—identifies a different possible, but from the child’s perspective equally non-consensual, outcome. Rightly, neither Shaw nor his possible partner thought their decision needed to wait for the consent of the resulting child.

### Answers to: It’s Dangerous

#### The status quo is dangerous

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

Finally, there’s the argument that modifying genomes is inherently dangerous because we can’t know all the ways it will affect the individual. But those who fear the risks of gene editing don’t take into account the inherent dangers in the “natural” way we reproduce. Two-thirds of human embryos fail to develop successfully, most of them within the first month of pregnancy. And every year, 7.9 million children—6 percent of total births worldwide—are born with a serious defect of genetic or partially genetic origin. Indeed so risky is unprotected sex that, had it been invented as a reproductive technology rather than found as part of our evolved biology, it is highly doubtful it would ever have been licensed for human use. Certainly we need to know as much as possible about the risks of gene-editing human embryos before such research can proceed. But when the suffering and death caused by such terrible single-gene disorders as cystic fibrosis and Huntington’s disease might be averted, the decision to delay such research should not be made lightly. Just as justice delayed is justice denied, so, too, therapy delayed is therapy denied. That denial costs human lives, day after day.

#### 1:25 kids born with a genetic disease

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

Much of the excitement around gene editing is fuelled by its potential to treat or prevent human diseases. There are thousands of genetic disorders that can be passed on from one generation to the next; many are serious and debilitating. They are not rare: one in 25 children is born with a genetic disease. Among the most common are cystic fibrosis, sickle cell anaemia and muscular dystrophy. Gene editing holds the promise of treating these disorders by rewriting the corrupt DNA in patients’ cells. But it can do far more than mend faulty genes. Gene editing has already been used to modify people’s immune cells to fight cancer or be resistant to HIV infection. It could also be used to fix defective genes in human embryos and so prevent babies from inheriting serious diseases. This is controversial because the genetic changes would affect their sperm or egg cells, meaning the genetic edits and any bad side effects could be passed on to future generations.

### Answers to: Designer Babies

#### Making designer babies way too complex; involves making thousands of genes

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

#### Engineering human embryos also raises the uneasy prospect of designer babies, where embryos are altered for social rather than medical reasons; to make a person taller or more intelligent, for example. Traits like these can involve thousands of genes, most of them unknown. So for the time being, designer babies are a distant prospect.

### Answers to: Unethical

#### We should always try to improve himself

Sara Karlin, February 16, 2016, <https://www.politico.com/story/2016/02/gene-editing-abortion-wars-219230> Gene editing: The next frontier in America’s abortion wars

“Gene editing of human embryos to eliminate disease should be considered to be ethically the same as using laser surgery to correct eye defects, or a surgeon operating on a baby to repair a congenital heart defect,” molecular geneticist Johnjoe McFadden wrote in The Guardian, supporting Britain's approval. “DNA is just another bit of our body that might go wrong.” The moral imperative of civilization is “to do our best” when pursuing scientific investigation, including the technology of gene editing, said John Harris, a bioethics professor at the University of Manchester.

### Answers to: Public Health Violates Individual Liberties

#### No link – we are just saying that gene editing services should be provided by public health authorities, not that public health authorities should require them

#### Individual rights can be limited to solve disease

The Harvard Crimson: Harvard University, February 4, 2015 Vaccines for All, <http://www.thecrimson.com/article/2015/2/5/harvard-staff-measles-vaccine/> DOA: 8-19-15

America was founded upon principles of individual rights: We believe that people should be allowed to live their lives as they see fit. At the same time, however, **individual freedoms must occasionally be limited, especially in situations where unabridged liberty may endanger the safety and welfare of the public. Vaccination against fatal diseases is one such case.**

#### Public health and rights can only exist with security

Dorothy Puzio, health care attorney 2003/4, Journal of Law & Health, An Overview of Public Health in the New Millennium: Individual Liberty vs. Public Safety, <http://engagedscholarship.csuohio.edu/jlh/vol18/iss2/3/>, DOA: 8-20-15, p. 192

Overall, Gostin's approach seems to advocate "a carefully constrained and narrowly delineated interventionist role for government" whenever intervention and civil liberties come into conflict. He does not think that public health and individual rights can always coexist. On the other hand, he also contends that **the exercise of civil liberties is only possible with security; therefore, almost paradoxically, some sacrifice of liberty must be made in order to gain it. After all, "individuals, acting alone, cannot safeguard their own health and safety, even with full access to the sophisticated technologies of modern science and medicine."**

#### People sacrifice their own interests for the common good and are willing to accept rights limitations

Dorothy Puzio, health care attorney 2003/4, Journal of Law & Health, An Overview of Public Health in the New Millennium: Individual Liberty vs. Public Safety, <http://engagedscholarship.csuohio.edu/jlh/vol18/iss2/3/>, DOA: 8-20-15, p. 186

Reviewing the tensions between public health and civil liberties inherent in quarantines, mandatory screening and immunization, and health information sharing, makes it clear that there is much to consider when balancing these values. It is difficult to predict how the American public would react to the implementation of these measures, with much depending on the context of the situation. On the one hand, **there are many historical examples of Americans sacrificing for the greater good in times of war, for example. Similarly, there are many limitations on individual rights that society has agreed to enforce in the name of public health, such as seat belt requirements.**

#### Individuals benefit from societal responsibility

Lawrence O. Gostin, professor of Public Health at Georgetown, and Johns Hopkins, Summer 2001, Journal of Law, Medicine, and Ethics, Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann, p. 120

Scholars in bioethics have demonstrated convincingly the power and importance of individual freedom. However, they have given insufficient attention to equally strong values of partnership, citizenship, and community. n26 **As members of a society in which we all share a common bond, we also have an obligation to protect and defend the community against threats to its health, safety, and security. Members of society owe a duty--one to another and to all--to promote the common good. A new public health ethic should advance the idea that individuals benefit from being part of a well-regulated society that reduces risks that all members share.**

#### Individuals cannot effectively respond to public health threats

Dorothy Puzio, health care attorney 2003/4, Journal of Law & Health, An Overview of Public Health in the New Millennium: Individual Liberty vs. Public Safety, <http://engagedscholarship.csuohio.edu/jlh/vol18/iss2/3/>, DOA: 8-20-15, p. 177-8

Although the pendulum has swung quite heavily in favor of individual rights in recent decades, "[m]any Americans have come to rethink the role of government and the importance of the public health safety system." n26 September 11th and the subsequent anthrax scare have illustrated the importance of rapidly detecting and reacting to the threats of bio-terrorism and infectious disease.27 Even more significantly, these disasters have made it clear that individuals acting alone cannot effectively protect against many public health threats to their well-being.

## Solvency/Workability

### Gene Editing Works

#### Few technological limits to gene editing

Center for Genetics and Society, <https://www.geneticsandsociety.org/internal-content/human-gene-editing-timeline-crispr-cover-stories> uman Gene Editing: A Timeline of CRISPR Cover Stories

Before that, though, some background: CRISPR is a molecule that can be programmed to target a specific sequence in a genome. It guides an enzyme, such as Cas9, to chop the code like tiny molecular scissors. Scientists began using Cas9 to cause “blunt end” breaks in DNA. This tends to initiate a jerry-rigged repair; the break is cobbled back together, incorporating small bits of available DNA or a repair template of other genetic material that scientists might add. A Cas9 repair is not always precise, but as the old saying goes, “a carpenter doesn’t blame his tools.” But researchers have since found Cpf1, another such enzyme, which hacks into double-stranded DNA and leaves a “sticky end” break that leaves one strand dangling off the end. This template allows for more precise gene edits. And in December, U.C. Berkeley scientists reported discovering yet more enzymes—CasX and CasY—which promise to make the technology even more versatile and exacting. In short, technical limitations are evaporating.

### CRISPR 2.0

#### CRISPR 2.0 solves

Emily Mullin, October 25, 2017, <https://www.technologyreview.com/s/609203/crispr-20-is-here-and-its-way-more-precise/> CRISPR 2.0 Is Here, and It’s Way More Precise

You’ve probably heard of the molecular scalpel CRISPR-Cas9, which can edit or delete whole genes. Now, scientists have developed a more precise version of the DNA-editing tool that can repair even smaller segments of a person’s genome.

In two studies published today, one in Nature and another in Science, researchers from the Broad Institute of MIT and Harvard describe a new way to edit DNA and RNA, called base editing. The approach could one day treat a range of inherited diseases, some of which currently have no treatment options.

The human genome contains six billion DNA letters, or chemical bases known as A, C, G and T. These letters pair off—A with T and C with G—to form DNA’s double helix. Base editing, which uses a modified version of CRISPR, is able to change a single one of these letters at a time without making breaks to DNA’s structure.

That’s useful because sometimes just one base pair in a long strand of DNA gets swapped, deleted, or inserted—a phenomenon called a point mutation. Point mutations make up 32,000 of the 50,000 changes in the human genome known to be associated with diseases.

In the Nature study, researchers led by David Liu, a Harvard chemistry professor and member of the Broad Institute, were able to change an A into a G. Such a change would address about half the 32,000 known point mutations that cause disease.

To do it, they modified CRISPR so that it would target just a single base. The editing tool was able to rearrange the atoms in an A so that it instead resembled a G, tricking cells into fixing the other DNA strand to complete the switch. As a result, an A-T base pair became a G-C one. The technique essentially rewrites errors in the genetic code instead of cutting and replacing whole chunks of DNA.

“Standard genome-editing methods, including the use of CRISPR-Cas9, make double-stranded breaks in DNA, which is especially useful when the goal is to insert or delete DNA bases,” Liu said on a conference call with journalists on Tuesday. “But when the goal is to simply fix a point mutation, base editing offers a more efficient and cleaner solution.”

Liu said base editing isn’t meant to be a replacement to traditional gene editing with CRISPR, but rather another option for altering the genome in an attempt to correct disease. If CRISPR is akin to a pair of scissors, base editing is more like a pencil, he said.

Learn more about the original functionality of CRISPR, which scientists have now modified for improved precision.

Previously, researchers had created base editors capable of making the opposite kind of swap—changing a G into an A. Substitutions of a G for an A in certain parts of the DNA represent about 15 percent of disease-associated point mutations. In September, Chinese researchers reported that they used one of these editing tools in an embryo to remove the genetic mutation that causes anemia.

Working in cells taken from patients, Liu and his colleagues used their base-editing tool to correct a point mutation that causes hereditary hemochromatosis, a disorder that causes the body to absorb too much iron from food. This excess iron can build up over time and cause liver cancer and other liver diseases, diabetes, heart disease, or joint disease.

Liu and his team also used the base editor in human cells to induce a mutation that suppresses sickle-cell anemia. In both studies, they detected virtually no off-target effects, or unwanted DNA insertions or deletions, which are a concern with the traditional way of using CRISPR to edit entire genes.

In the new Science study, Feng Zhang, of the Broad Institute and MIT, used a similar base-editing method to target individual letters in RNA, DNA’s chemical cousin. RNA naturally degrades in the body, so editing RNA wouldn’t result in a permanent change to a person’s genome.

Ross Wilson, of the Innovative Genomics Institute at the University of California, Berkeley, says base editing may eventually be a better way to treat some diseases. He says a single base pair is like a word in a paragraph of text. With conventional CRISPR technology, you would have to replace the whole paragraph.

“It’s a lot of DNA to move around,” he says. With base editing, you could just change the single word.

Liu says he’s hopeful that base editing of DNA and RNA could be used as complementary approaches for a “broad set of potential therapeutic applications.”

His lab is exploring base editing to fix blood disorders, neurological disorders, hereditary deafness, and hereditary blindness.

### CRISPR Works for Germline Editing

#### CRISPR can effectively edit the human germline

BOSTON COLLEGE LAW REVIEW, 2018, NOTE: THE PRICE TAG ON DESIGNER BABIES: MARKET SHARE LIABILITY, 59 B.C. L. Rev. 319, https://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=3618&context=bclr

The past few years--2015 in particular--have seen the emergence of simple, precise, and affordable DNA altering techniques. 6Link to the text of the note These techniques include the use of clustered regularly interspaced short palindromic repeats ("CRISPR") and the enzyme, protein-9 nuclease ("Cas9"). 7Link to the text of the note Using CRISPR-Cas9, scientists can effectively and efficiently alter the human germline. 8Link to the text of the note "Human germline editing" involves targeting DNA in human sperm, eggs, or embryos that is passed on to future generations through normal reproduction.

#### CRISPR technology is effective

BOSTON COLLEGE LAW REVIEW, 2018, NOTE: THE PRICE TAG ON DESIGNER BABIES: MARKET SHARE LIABILITY, 59 B.C. L. Rev. 319, https://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=3618&context=bclr

In an outpouring of recent experiments, the CRISPR-Cas9 methodology has enabled scientists to treat muscular dystrophy in mice, counteract drugresistance in insects, increase physical strength in dogs, generate virus-resistant pigs, and modify crops for greater protection

# Con

## Disadvantages – General

### Biological Weapons

#### Gene editing enables the development of deadly biological weapons

James Clapper, Director of National Intelligence, 2016, <https://www.armed-services.senate.gov/imo/media/doc/Clapper_02-09-16.pdf> Worldwide Threat Assessment of the

US Intelligence Community Research in genome editing conducted by countries with different regulatory or ethical standards than those of Western countries probably increases the risk of the creation of potentially harmful biological agents or products. Given the broad distribution, low cost, and accelerated pace of development of this dual-use technology, its deliberate or unintentional misuse might lead to far-reaching economic and national security implications. Advances in genome editing in 2015 have compelled groups of high-profile US and European biologists to question unregulated editing of the human germline (cells that are relevant for reproduction), which might create inheritable genetic changes. Nevertheless, researchers will probably continue to encounter challenges to achieve the desired outcome of their genome modifications, in part because of the technical limitations that are inherent in available genome editing systems

#### Mosquitos could be used to decimate a population

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

So, apparently, does the national-security establishment. CRISPR means that most microbes driving infectious diseases are just a few DNA edits away from becoming superstrains that could wipe out unprepared populations. That's the thinking that prompted Director of National Intelligence Clapper's classification of CRISPR as a weapon of mass destruction. With the tools easily bought online, it would be theoretically possible to engineer a killer mosquito that transmits a deadly disease, or a DNA-damaging virus, that could infect human cells and decimate the population.

### Terrorism

#### Terrorists or rogue states can get access to gene editing technologies

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

The potential is enormous, but to many, the risks are equally great. Even well-intentioned scientists don't understand all the possible downstream effects of unleashing altered organisms into the wild--including the human gene pool. The simplicity that makes CRISPR so powerful raises the possibility that terrorists or rogue states could deploy it as a weapon--a fear that led Director of National Intelligence James Clapper to include gene-editing methods like CRISPR on a list of mass-destruction threats earlier this year. But no matter the dangers, rewards or questions, this technology is being used now. Will scientists know what to do with it?

### Eugenics

#### Gene editing could lead to neo-eugenics

Center for Genetics and Society, <https://www.geneticsandsociety.org/internal-content/human-gene-editing-timeline-crispr-cover-stories> uman Gene Editing: A Timeline of CRISPR Cover Stories

CRISPR gene editing is a "dual use" technology. Harnessed to help consenting patients, it may fulfill the promise of "gene therapy" for a range of diseases. But deploying CRISPR to create human babies with re-engineered genetic traits could open the door to new forms of social inequality, discrimination, and conflict. Efforts to genetically "enhance" future humans could usher us into an era of neo-eugenics – dictated not by an authoritarian regime, but by the commercial markets and consumer dynamics that favor the already privileged.

#### Parents could edit out dark skin or homosexuality

Sara Karlin, February 16, 2016, <https://www.politico.com/story/2016/02/gene-editing-abortion-wars-219230> Gene editing: The next frontier in America’s abortion wars

Groups that favor abortion rights, including the Center for Genetics and Society, support embryonic stem cell research and basic research on gene editing on principle. They see the potential to alleviate suffering from genetic diseases but favor using the technology in adults only. If used in embryos, they worry the technology might further inequalities and bring greater harm to those on society's margins, including the disabled, minorities and gay people.

That’s because some parents might want to use the tool to “prevent or cure” things like dark skin or homosexuality, “instead of looking for social changes to make people see each other as more equal,” said Darnovsky.

#### Gene engineering will promote inequality, discrimination, genetics

Marcy Darnovsky, August 2016, Dranovsky is executive director of the Center for Genetics and Society, <https://www.nationalgeographic.com/magazine/2016/08/human-gene-editing-pro-con-opinions/> Con: Do Not Open the Door to Editing Genes in Future Humans

In opening the door to one kind of germline modification, we are likely opening it to all kinds. Permitting human germline gene editing for any reason would likely lead to its escape from regulatory limits, to its adoption for enhancement purposes, and to the emergence of a market-based eugenics that would exacerbate already existing discrimination, inequality, and conflict. We need not and should not risk these outcomes.

#### Gene editing means eugenics

Fraser Nelson, April 2016, <https://www.spectator.co.uk/2016/04/the-return-of-eugenics/> The Spectator, The Return of Eugenics,

It’s comforting now to think of eugenics as an evil that sprang from the blackness of Nazi hearts. We’re familiar with the argument: some men are born great, some as weaklings, and both pass the traits on to their children. So to improve society, the logic goes, we must encourage the best to breed and do what we can to stop the stupid, sick and malign from passing on their defective genes. This was taken to a genocidal extreme by Hitler, but the intellectual foundations were laid in England. And the idea is now making a startling comeback.

A hundred years ago the eugenic mission involved a handful of crude tools: bribing the ‘right’ people to have larger families, sterilising the weakest. Now stunning advances in science are creating options early eugenicists could only dream about. Today’s IVF technology already allows us to screen embryos for inherited diseases such as cystic fibrosis. But soon parents will be able to check for all manner of traits, from hair colour to character, and choose their ‘perfect’ child.

The era of designer babies, long portrayed by dystopian novelists and screenwriters, is fast arriving. According to Hank Greely, a Stanford professor in law and biosciences, the next couple of generations may be the last to accept pot luck with procreation. Doing so, he adds, may soon be seen as downright irresponsible. In his forthcoming book The End of Sex, he explains a brave new world in which mothers will be given a menu with various biological options. But even he shies away from the word that sums all this up. For Professor Greely, and almost all of those in the new bioscience, eugenics is never mentioned, as if to avoid admitting that history has swung full circle.

The word ‘eugenics’ was coined in 1883 by Francis Galton, a polymath who invented fingerprinting and many of the techniques of modern statistical research. He started with a hunch: that so many great men come from the same families because genius is hereditary. Fascinated by the evolutionary arguments of his cousin Charles Darwin, he wondered whether advances in health care and welfare had sullied the national gene pool because they allowed more of the sick and disabled not just to survive but to lead normal family lives. He went off to collect data, and came back with his theory of eugenics.

This was hailed not as a theory but as a discovery — a new science of human life, with laws as immutable as Newton’s. A race of gifted men could be created, he said, ‘as surely as we can propagate idiots by mating cretins’

Some of the most revered names in British history lapped this up. As Home Secretary, Churchill wrote to the Prime Minister urging him to do more to stop the “multiplication of the unfit”. Darwin himself would come to fear that “if the prudent avoid marriage whilst the reckless marry, inferior members tend to supplant the better members of society”.

By 1908, a Royal Commission conveyed the grave news that there were 150,000 ‘feeble-minded’ people in Britain. So what was to be done with them? As one reformer put it: “They must be acknowledged dependents of the State…but with complete and permanent loss of all civil rights – including not only the franchise but civil freedom and fatherhood”. This was William Beveridge, founder of the welfare state.

A report in The Times conveyed, matter-of-factly, the substance of a lecture given to the Eugenics Society following survey of the people of Devon by a Dr Grunby.

As to imbeciles, he said there was only one thing to do with them: exterminate them as they arose. He put forward the suggestion on purely humanitarian grounds.

Eugenics came to stand for modernity: to believe in it was to declare one’s belief in science and rationalism, to be liberated from religious qualms. Some of the most revered names in English history lapped all of this up. The Bishop of Birmingham called for sterilisation. Bertrand Russell looked forward to a eugenic era driven by science, not religion. ‘We may perhaps assume that, if people grow less superstitious, government will acquire the right to sterilise those who are not considered desirable as parents,’ he argued in 1924.

When a Sterilisation Bill was brought before Parliament in 1931 it had the backing of social workers, dozens of local authorities and the medical and scientific establishment. It was defeated, but the agenda continued. The Nuremberg Trials established that the Nazis (latecomers to all this) carried out some 400,000 compulsory sterilisations — a figure so horrific it has eclipsed the 60,000 in Sweden and a similar number in the United States. The idea of a biological divide between the fit and the unfit was no Nazi invention. It was the conventional wisdom of the developed world.

And this is the problem. Because we forget how badly Britain fell for eugenics, we fail to recognise the basic arguments of eugenics when they reappear — which they are now doing with remarkable regularity.

Consider Adam Perkins, a lecturer at King’s College London, who has published a study echoing the Royal Commission’s attempt to quantify the feeble-minded. The group he aims to study are the ‘employment-resistant’: those disposed to a life on welfare as a result of genetic predispositions and having grown up in workless homes. With Galtonesque precision, he estimates some 98,040 ‘extra’ people were ‘created by the welfare state’ over 15 years due to a rise in welfare spending. They represent an ‘ever-greater burden on the more functional citizens’.

In 1938, Germans were shown a poster of a cripple and invited to be angry about the costs of caring for him (60,000 Reichmarks). Dr Perkins tries a softer version of this general idea, calculating the £12,000-a-head annual cost of the new British untermensch — not just in welfare, but the crimes they will probably commit. His remedy? That Cameron’s government restricts welfare, so that claimants have fewer children. A perfect eugenic solution.

There is nothing monstrous about Dr Perkins, himself a former welfare claimant, nor anything very original about his book. He simply joins the dots of recent academic research and spells out what others won’t. His footnotes show the growing academic pedigree of the new eugenics: work has been done to identify genes relating to alcoholism, criminality, sporting success, even premature ejaculation. Extrapolations are now made about how far the quality of human stock worldwide has been eroded by health care and welfare.

In academia, the word ‘eugenics’ may be controversial but the idea is not. To Professor Julian Savulescu, editor-in-chief of the Journal of Medical Ethics, the ability to apply ‘rational design’ to humanity, through gene editing, offers a chance to improve the human stock — one baby at a time. ‘When it comes to screening out personality flaws such as potential alcoholism, psychopathy and disposition to violence,’ he said a while ago, ‘you could argue that people have a moral obligation to select ethically better children’.

Meanwhile, the scientific pursuit of ‘ethically better children’ is advancing rapidly. Since Louise Brown was conceived in a laboratory 38 years ago — the world’s first IVF baby — the treatment has become mainstream, sought by 100 women a day in Britain. Developments in IVF mean that, today, several embryos can be fertilised and screened for diseases, with the winner implanted in the uterus. The next step was taken last year, when Chinese scientists succeeded in modifying the genes of a fertilised embryo. It was rather messy: they attempted to treat 86 non-viable embryos, and failed in most cases. So they abandoned the experiment, saying a 100 per cent success rate is needed when dealing in human life.

This — the genetic modification of human embryos — is what causes the concern. But here, and at each point in the new eugenics, you can argue: where is the moral problem? There are no deaths, no sterilisations, no abortions: just a scientifically guided conception. The potential avoidance of disease, to the betterment of humanity. So who could complain?

One answer came four months ago, when 150 scientists and academics called for a complete shutdown of human gene editing. In a letter released before a summit in Washington DC, they argued that the technology would ‘open the door to an era of high-tech consumer eugenics’, with affluent parents choosing the best qualities and creating a new form of genetically modified human. To these scientists, the complex issue boils down to a simple point: ‘We must not engineer the genes we pass on to our descendants.’

Such concerns cannot be heard from the British government, which recently helped to build the Francis Crick Institute, a new nerve centre for biomedical research. A few weeks ago, the institute was given authorisation to begin a new, controversial gene-editing technique known as CRISPR-Cas9. To supporters, this is proof of Britain’s position at the cutting edge of research. To critics, it is proof that Britain (one of the few countries that does not ban the use of fertilised human embryos in experiments) is again rushing headlong into eugenic science with minimal debate.

On the rare occasions the matter is raised in Parliament, ministers say that they do not support eugenics. But, as Chris Patten has pointed out in the Lords, that is a meaningless statement if there is no attempt to define the term. To David Galton, who has written more about the subject than any British academic, the definition is simple. If you use science to make the best of genes handed down to the next generation, that’s eugenics: ‘Sweeping the word under the carpet or sanitising it with another name merely conceals the appalling abuses that have occurred in the past and may lull people into a false sense of security.’

The idea of consumer eugenics is no futurist fantasy. Already, sperm banks boast about screening for everything from autism to red hair. £12,000 buys you the chance to choose which embryo to implant. And £400 buys sperm-sorting, the better to conceive a boy (or a girl). And even in the slums of India, women desperate for a boy will pay for ante-natal screening to identify — and abort — girls. It doesn’t take government to pursue eugenics: parents will do it themselves.

The Francis Crick Institute says its gene-editing research has nothing to do with eugenics; even British law prohibits pregnancies from gene-edited embryos, and its researchers plan to destroy them after seven days. Instead, it aims to learn about the role of genes in miscarriage. But if its research improves gene-editing technology, less scrupulous scientists can make use of that. This is why scholars like Robert Pollack, a professor at Columbia University, want a moratorium on of germ-line DNA modification. ‘Imagine that, many years hence, there are two sorts of people: those who carry the messy inheritance of their ancestors, and those whose ancestors had the resources to clean up their germ cells before IVF.’ So you end up with two types of humans: the genetically tidy rich and everyone else.

The experiments being carried out in London are worrying, he says, precisely because the British have such a good success rate. ‘It is not failure, but success, that concerns me,’ says Professor Pollack. ‘And for that concern, there are few venues more troubling than the Crick Institute — it is as likely as any place in the world to do this without making any distracting, avoidable mistakes.’

So some 130 years after Britain gave the world the idea of perfecting humanity, we are once again at the cutting edge of this troubled science. For good or ill, eugenics is back.

## Risks-Mutations

### “Off Target”

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#### The wrong gene could be accidentally cut

Associated Press, December 1, 2015, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

Safety is a key question because gene editing isn't always precise enough; there's the possibility of accidentally cutting DNA that's similar to the real target.

#### Gene editing can be “off target” increasing disease risks

BOSTON COLLEGE LAW REVIEW, 2018, NOTE: THE PRICE TAG ON DESIGNER BABIES: MARKET SHARE LIABILITY, 59 B.C. L. Rev. 319, https://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=3618&context=bclr

Nonetheless, CRISPR-Cas9 is not a magic bullet. 13Link to the text of the note According to Dr. Keith Joung, a renowned pathologist at the Massachusetts General Hospital and Harvard Medical School, more research is needed to reduce off-target gene editing before CRISPR-Cas9 can be used in clinical applications. 14Link to the text of the note "Off-targets" occur when the splicing enzyme matches the designated sequence to the wrong gene causing potentially disastrous side-effects. 15Link to the text of the note For instance, an off-target impact may result in creating a higher likelihood of a future cancer diagnosis. 16Link to the text of the note While scientists remain hopeful that they will be able to more accurately assess the risk of unintended editing through advancing technology, the effects remain unclear for now. 17Link to the text of the note Off-target gene altering may create unintended and uncertain changes in a gene pool that could last for generations.

#### Some genetic weaknesses may functional genetic strengths in other areas

Jim Kozubek, January 9, 2017, Time, <http://time.com/4626571/crispr-gene-modification-evolution/> How Gene Editing Could Ruin Human Evolution

Furthermore, genetic variants that predispose us to risk or supposed weaknesses are precisely the same ones that turn out to have small fitness advantages (they make us better at numbers, more sensitive, alter concentration…). This is one reason I am a “neurodiversity advocate.” Evolution works at the margins, and it does so through trade-offs: Often, you don’t get an advantage without risking a disadvantage. This is not trivial.

#### “Harmful” versions may contribute to important increases in genetic diversity

Jim Kozubek, January 9, 2017, Time, <http://time.com/4626571/crispr-gene-modification-evolution/> How Gene Editing Could Ruin Human Evolution

n 1966, Richard Lewontin and John Hubby proposed the idea of “balancing selection,” which suggests that harmful versions of genes, known as alleles, can remain in the population to contribute to genetic diversity. These versions can be useful in the case when individuals have one copy of the rare version of the gene and a copy of a more common, surefire form (this makes the individual “heterozygous”). The infamous APOE4 variant, the single strongest risk variant for late-onset Alzheimer’s disease, remains at 15% frequency in the population—one reason is that it may also up Vitamin D. A variation in a gene called COMT can increase dopamine levels by four-fold in the frontal cortex, which can increase concentration—perhaps helpful if you have one copy, though it makes you more prone to being jittery if you have two copies (which 5% of us do).

#### Some mutations that cause disease also strengthen the immune system

Jim Kozubek, January 9, 2017, Time, <http://time.com/4626571/crispr-gene-modification-evolution/> How Gene Editing Could Ruin Human Evolution

Even some variants that are highly compromising stick around by piggy-backing on other useful genes that are under natural selection. Last year, Tobias Lenz, a scientist at the Max-Planck Institute for Evolutionary Biology in Germany, reported that a region of the genome called the major histocompatibility complex, which creates an immune system component that detects an array of infections, is littered with mutations. Many of these mutations also associate with human diseases, cancer, autoimmune disease and schizophrenia. The advantage of altering immune system genes, then, may come with a tradeoff of removing genes that are “hitchhiking” nearby and dispose an associated risk for cancer or neuropsychiatric disorders. Losing the bad can mean losing the good, too.

#### There are no superior genes

Jim Kozubek, January 9, 2017, Time, <http://time.com/4626571/crispr-gene-modification-evolution/> How Gene Editing Could Ruin Human Evolution

There are no superior genes. Genes have a long and layered history, and they often have three or four unrelated functions, which balance against each other under selection. Those risky variants that can, in the right scenario, say, make us better at numbers are actually helpful to remain in the population in low frequencies. Indeed, versions of hundreds of genes that predispose us to psychiatric risks remain in the population at stable rates, while autism spectrum disorder and schizophrenia each occur at about one percent—hinting at a tradeoff of risk for advantage.

#### Altering genes can alter the psyche

Jim Kozubek, January 9, 2017, Time, <http://time.com/4626571/crispr-gene-modification-evolution/> How Gene Editing Could Ruin Human Evolution

In his 2015 book NeuroTribes, Steve Silberman argued against “framing autism as a contemporary aberration,” instead suggesting it had roots in “very old genes that are shared widely in the general population while being concentrated more in certain families than in others. Whatever autism is, it is not a unique product of modern civilization. It is a strange gift from our deep past, passed down through millions of years of evolution.”

In 1995, Arnold Ludwig reported a 77 percent rate of psychiatric disorders in eminent fiction writers. The link between creativity and madness is an old debate—but there are plausible theories for how this works. One in the scientific literature is that subclinical traits—which we often characterize as schizotypal or psychoticism—or even psychological traits like “openness to experience” enable people to perform better on measures of creativity. However, if these tendencies become overly pronounced in the cases of severe mental illness, the aptitude for productivity and creativity plummet—a concept broadly referred to as the “inverted U.” In effect, mild amounts of stress and disorientation can contribute to outside-of-the-box thinking, but a full spiral into a psychotic episode results in a rapid decline in insight.

As Steven Pinker told me, “There are several possible explanations of why the trait of openness to experience could be an individual adaptation. As with any trait that varies among individuals, there is the challenge of explaining why it does not take a single, optimal value in all members of the species. Among the possibilities are that it’s the result of mutations that have not been weeded out yet; that different values are adaptive in different kinds of environments; and that it’s frequency-dependent: it’s only adaptive when it’s not too common.”

But thousands of genetic variants do indeed add up to influence psychiatric risk. That these variants stay in the human population at small frequencies also suggests that they may conceal a fitness benefit in some genetic backgrounds, for some people—one reason we should not be so quick to clip snippets of code out of our genomes. Some of those with psychiatric risk—Carrie Fisher, David Foster Wallace, Kurt Cobain—turn out to illuminate reality in ways those inside the normal curve cannot. They demonstrate the limits of the human condition, mthe ultimate failure to achieve any security and the impossibility of control. That we could do any better than that through biotechnology is unlikely; that we should want to is at best dubious and, at worst, morally questionable. “Blessed be the meek, for they shall inherit the earth.”

We’ve known for a long time the folly of genetic determinism: 30,000 genes cannot model 100,000,000,000,000 (a hundred trillion) synaptic connections in the brain. We also know that chronic stress and limiting social and economic factors are critically important to health, including cancer rates, cardiovascular and mental health, as articulated through well-known phenomena such as the “Glasgow effect.” Yet the NIMH has taken the position to only fund research that entails a “neuro-signature,” which conveniently supports a drugmaker model and ignores the context of conditions. We are investing billions into data, yet every day I walked to work in Cambridge, I walked past “methadone mile,” where there are plenty of homeless people suffering from panic and schizophrenia, without adequate resources—save for a half-million-dollar toilet. The promise that we can use gene modification, or even data, to eliminate psychiatric disorders is a fool’s errand. Chronic stress matters. And genetic risk variants remain in the population because they’re advantageous to certain people, given the right genetic background or conditions. Those risk variants are speculating—evolution, always and forever, takes chances.

The use of RWE to achieve several commercial and strategic objectives, including value-based contracting, regulatory submissions, and clinical trial design is expanding.

That, of course, is the hope of companies including Editas Medicine, which Joung cofounded, CRISPR Therapeutics, Caribou Biosciences, and Sangamo BioSciences, which all presented at the ASH workshop.

Related: They’re going to CRISPR people. What could possibly go wrong?

Off-target effects occur because of how CRISPR works. It has two parts. RNA makes a beeline for the site in a genome specified by the RNA’s string of nucleotides, and an enzyme cuts the genome there. Trouble is, more than one site in a genome can have the same string of nucleotides. Scientists might address CRISPR to the genome version of 123 Main Street, aiming for 123 Main on chromosome 9, only to find CRISPR has instead gone to 123 Main on chromosome 14.

In one example Joung showed, CRISPR is supposed to edit a gene called VEGFA (which stimulates production of blood vessels, including those used by cancerous tumors) on chromosome 6. But, studies show, this CRISPR can also hit genes on virtually every one of the other 22 human chromosomes. The same is true for CRISPRs aimed at other genes. Although each CRISPR has zero to a dozen or so “known” off-target sites (where “known” means predicted by those web-based algorithms), Joung said, there can be as many as 150 “novel” off-target sites, meaning scientists had no idea those errors were possible.

CRISPR is a tool that acts as a microscopic pair of scissors with the ability to slice DNA.

DOM SMITH/STAT

One reason for concern about off-target effects is that genome-editing might disable a tumor-suppressor gene or activate a cancer-causing one. It might also allow pieces of two different chromosomes to get together, a phenomenon called translocation, which is the cause of chronic myeloid leukemia, among other problems.

Many researchers, including those planning clinical trials, are using web-based algorithms to predict which regions of the genome might get accidentally CRISPR’d. They include the scientists whose proposal to use CRISPR in patients was the first to be approved by an NIH committee. When scientists assure regulators that they looked for off-target effects in CRISPR’d cells growing in lab dishes, what they usually mean is that they looked for CRISPR’ing of genes that the algorithms flagged.

As a result, off-target effects might be occurring but, because scientists are doing the equivalent of the drunk searching for their lost keys only under the lamppost, they’re not being found.

Related: Federal panel approves first use of CRISPR in humans

One little-appreciated feature of CRISPR’s DNA-cutting enzyme is that it doesn’t stop at one. Even if the enzyme cuts its intended target, the risk of off-target cutting remains. The enzyme “still has energy to bind with off-target sites,” Joung said, so “it can still cleave those sites.”

Scientists from some of the leading genome-editing companies said they are confident they will be able to minimize off-target CRISPR’ing, by picking “high-quality” guide RNAs, among other methods. While “bad” RNAs hit as many as 152 wrong targets, studies show, good ones hit only one, and the algorithms “capture most of” the potential off-target effects, said Dr. Bill Lundberg, chief scientific officer of CRISPR Therapeutics. Still, he conceded, “At the end of the day we’re taking a cell where we can’t predict a priori where the edit has happened.”

Scientists have recently recognized another reason to worry about off-target effects: No two people’s genomes are identical. Off-target-identifying methods, which are based on a composite or “reference” human genome, might indicate that there are no stretches of DNA that CRISPR can mistakenly snip. But because of random mutations and genetic variations, some patients might have additional “123 Main Street”s, attracting CRISPR and its DNA-cutting enzyme where they’re not supposed to go.

“There are a significant percent of sites, more than I would have thought,” where that might happen, said Joung, “and it varies by ethnic group.”

Said Andrew May, chief scientific officer of Caribou: “There is going to have to be some consideration of that” as genome-editors try to bring CRISPR to patients.

#### Large risk of off-target results

BOSTON COLLEGE LAW REVIEW, 2018, NOTE: THE PRICE TAG ON DESIGNER BABIES: MARKET SHARE LIABILITY, 59 B.C. L. Rev. 319, https://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=3618&context=bclr

As CRISPR-Cas9 techniques advance, off-target consequences for individuals and subsequent generations are of immense concern. 74Link to the text of the note In a 2013 study on Duchenne muscular dystrophy ("DMD"), which results from a genetic mutation on the X chromosome and causes muscle deterioration, Dr. Eric Olson successfully treated DMD afflicted mice by editing their genome using CRISPR-Cas9. 75Link to the text of the note Although off-target consequences were rare in that specific experiment, Dr. Olson acknowledged that CRISPR genome editing can unintentionally cause lifelong changes to an organism's DNA. 76Link to the text of the note Many scientists worry that treating a human with DMD using CRISPR-Cas9 technology may lead to generations of unforeseen and possibly irreparable harm--such as removing someone's protective gene for cancer. 77Link to the text of the note Thus, scientists worry that human manipulation of the genome may lead to long-term negative impacts on the gene pool itself. In the first reported human germline genetic modification, Chinese researchers replaced the gene for a blood disorder called ?-thalassaemia in twenty-eight out of seventy-one non-viable embryos. 79Link to the text of the note In the process, they caused unwanted alterations in other parts of the genome. 80Link to the text of the note In subsequent research, Chinese researchers attempted to insert a mutated gene into the germline to create HIV resistance and were successful in a mere four out of twenty-six non-viable embryos and again, caused unwanted mutations.

Notably, even if scientists can precisely edit the targeted gene, unintended causal reactions may still ensue. 82Link to the text of the note This is because genes that increase the risk for some diseases may actually decrease the risk for others. 83Link to the text of the note For instance, if a genetic company targets someone's CCR5 gene, which increases the risk for contracting West Nile, removal of the gene will also rid her of an important protection from HIV. 84Link to the text of the note Likewise, altering someone's MC1R gene in order to produce vibrant red hair can also increase her risk of melanoma. 85Link to the text of the note In one study, geneticists who modified a mouse's gene in order to protect against tumors ] also had the unintended effect of causing the mouse to age prematurely, complete with osteoporosis, decreased life-span, and organ deterioration. 86Link to the text of the note Even if perfectly executed, human disruption of genes may have unintended and poorly--if at all--traceable consequences for generations. 87Link to the text of the note

#### Off target accidents are more likely than beneficial treatments

Sharon Begley, July 18, 2016, <https://www.statnews.com/2016/07/18/crispr-off-target-effects/> Do CRISPR enthusiasts have their head in the sand about the safety of gene editing?

ASHINGTON — At scientific meetings on genome-editing, you’d expect researchers to show pretty slides of the ribbony 3-D structure of the CRISPR-Cas9 molecules neatly snipping out disease-causing genes in order to, everyone hopes, cure illnesses from cancer to muscular dystrophy. Less expected: slides of someone kneeling on a beach with his head in the sand.

Yet that is what Dr. J. Keith Joung of Massachusetts General Hospital showed at the American Society of Hematology’s workshop on genome-editing last week in Washington. While the 150 experts from industry, academia, the National Institutes of Health, and the Food and Drug Administration were upbeat about the possibility of using genome-editing to treat and even cure sickle cell disease, leukemia, HIV/AIDS, and other blood disorders, there was a skunk at the picnic: an emerging concern that some enthusiastic CRISPR-ers are ignoring growing evidence that CRISPR might inadvertently alter regions of the genome other than the intended ones.

“In the early days of this field, algorithms were generated to predict off-target effects and [made] available on the web,” Joung said. Further research has shown, however, that such algorithms, including one from MIT and one called E-CRISP, “miss a fair number” of off-target effects. “These tools are used in a lot of papers, but they really aren’t very good at predicting where there will be off-target effects,” he said. “We think we can get off-target effects to less than 1 percent, but we need to do better,” especially if genome-editing is to be safely used to treat patients.

#### Technology isn’t safe yet

Sara Karlin, February 16, 2016, <https://www.politico.com/story/2016/02/gene-editing-abortion-wars-219230> Gene editing: The next frontier in America’s abortion wars

“We should improve on human nature “if we can, when we can, by ways that are safe enough,” he said. But given the state of research, much of the scientific establishment opposes gene manipulation in a human embryo. Currently, the risks are much greater than the potential benefits, said NIH’s policy chief, Kathy Hudson. While the technology is “very precise, it also makes errors and those errors can be catastrophic,” she said. “A small percentage of catastrophic errors in humans doesn’t really pass the test.” Many biotechnology companies, including CRISPR Therapeutics, and pharma giants like Novartis, have made it clear they are not pursuing gene editing of human embryos at this time.

#### There is no particular way a gene is supposed to be

Jim Kozubek, January 9, 2017, Time, <http://time.com/4626571/crispr-gene-modification-evolution/> How Gene Editing Could Ruin Human Evolution

Second, scientists tend to think of men as machines, genes as their broken parts and variations in life as problems to be solved—aberrations outside the normal curve. This assumes there is a right way for genes to be. In reality, Darwin showed us that evolution does not progress toward an ideal model or a more perfect form, but instead is a work of tinkering toward adaptation in local niches. Nowhere in nature does it say how a gene should function.

### Scientists Will use Risky Experiments

#### CRISPR is feasible, but scientists will engage in risky experiments

BOSTON COLLEGE LAW REVIEW, 2018, NOTE: THE PRICE TAG ON DESIGNER BABIES: MARKET SHARE LIABILITY, 59 B.C. L. Rev. 319, <https://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=3618&context=bclr>, p. 328-9

large concern with gene editing is that companies will exploit CRISPRCas9 to perform risky experiments since it is cheap, simple, and yields high rewards. 71Link to the text of the note Sir Venki Ramakrishnan, the 2009 Nobel prize winner in chemistry, echoes the fears of many in the scientific community that "once a technology is feasible, we may well regulate it, but someone somewhere may start using it in ways we consider unethical." 72Link to the text of the note With such technology at their fingertips, companies may strive to remain ahead of competitors by racing to patent lucrative applications of CRISPR-Cas9 to the human germline and clinically apply the technology before it is thoroughly tested. 73

## Germline Editing Bad

### Germline Editing Bad – Future Generations

#### Future generations can’t consent to gene editing, negative side effects could manifest in future generations

Associated Press, December 1, 2015, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

Germline engineering "has been viewed almost universally as a line that should not be crossed," National Institutes of Health Director Francis Collins said at the time. After all, future generations couldn't consent, and any long-term negative effects might not become apparent for years. There's also concern about babies designed for better intellect, athleticism or appearance rather than to prevent disease.

#### Human germline editing could alter future generations in ways that could threaten health

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

By the end of the lively debate, the 13 scientists, ethicists and lawyers at the summit agreed that using CRISPR to modify human reproductive cells, so called germ-line changes, that would result in pregnancy or treatments in people, should not be attempted by scientists for the time being.

A Quarter of the World's Adults Don't Get Enough Exercise, Study Says

Their position was based on the reality that precise as CRISPR is, the technique still isn't perfect. Even more uncertain, the group said, were the long-term consequences of altering genomes. Snipping out a disease-causing gene might treat the ailment, but evolution makes it clear that any change in genes or characteristics in a living thing may affect its ability to survive and reproduce in other ways down the line. It's well established, for example, that the mutation responsible for sickle-cell anemia also tends to protect people from developing malaria. What other risk-benefit balances would this kind of genetic editing disturb?

#### Too much is unknown to apply it to the germline

Gang Bao, Stat News, 2015, Experts Debate: Are w we playing with fire when we edit human genes, <https://www.statnews.com/2015/11/17/gene-editing-embryo-crispr/>, Gang Bao, PhD, is professor of bioengineering at Rice University in Houston, where he directs the Nanomedicine Center for Nucleoprotein Machines. Bao’s work focuses on gene-editing treatments for sickle cell disease.

Gene editing potentially holds great promise, and equally great peril. Today, there are too many unknowns about this technique to apply it to the germline of humans and other species. Think of the CRISPR-Cas9 gene editing technique as a nanoscissors. Put some of these nanoscissors into a cell and they will make cuts near the gene defects you want to alter, which can then be replaced by a properly functioning gene segment. But the nanoscissors can also cut other genes in a somewhat unpredictable fashion. This could change the function of a gene responsible for keeping a cell from becoming cancerous, for example, or causing other diseases. CRISPR studies by year and country These unwanted edits are called off-target effects. Even if on-target gene editing is accurate, the off-target effects could inﬂuence the function of many genes, possibly posing serious health problems. In the germline, off-target effects might persist for generations and could lead to long-term changes in the genome. Until we know the full consequences of gene editing, it would be a huge mistake to use it to modify the germline.

## Should Ban

### Germline Editing Should Be Banned

#### Germline editing should be banned

Center for Genetics and Society, November 2015, <https://www.geneticsandsociety.org/internal-content/open-letter-calls-prohibition-reproductive-human-germline-modification?id=8999> Open Letter Calls for Prohibition on Reproductive Human Germline Modificati

Recent developments in gene editing have generated worldwide attention. Like so many powerful new technologies, gene editing holds potential for both great benefit and great harm.

Those signing this letter represent a broad spectrum of scholars, scientists, health practitioners, public interest advocates, and others, with a wide range of opinions on many questions involving the uses of gene editing. All of us agree, however, about one of its potential applications: We must not engineer the genes we pass on to our descendants.

The implementation of heritable human genetic modification – often referred to as the creation of “genetically modified humans” or “designer babies” – could irrevocably alter the nature of the human species and society.

Gene editing may hold some promise for somatic gene therapy (aimed at treating impaired tissues in a fully formed person). However, there is no medical justification for modifying human embryos or gametes in an effort to alter the genes of a future child. Parents who wish to have children unaffected by genetic diseases can almost always accomplish this through other methods, including conventional embryo screening and selection procedures. While screening future children also raises significant ethical implications, it is far safer than experimentally manipulating the DNA of germ cells to produce genetically modified babies, and has less potential for widespread societal disruption.

Experiments with human germline intervention could lead to miscarriage, maternal injury, and stillbirth. Genetically modified children who seem healthy at birth could develop serious problems later in life, some perhaps introduced by purported enhancements. Other harmful consequences of germline modification might only present themselves in subsequent generations. Such outcomes would represent individual tragedies; they could also trigger social backlash against beneficial uses of genetic technologies.

Some suggest that germline modification be allowed for therapeutic purposes but not for “enhancement.” But the distinction between these applications is subjective and would be difficult or impossible to implement as policy. Permitting germline intervention for any intended purpose would open the door to an era of high-tech consumer eugenics in which affluent parents seek to choose socially preferred qualities for their children. At a time when economic inequality is surging worldwide, heritable genetic modification could inscribe new forms of inequality and discrimination onto the human genome.

For these reasons, several dozen countries, including most of those with highly developed biotechnology sectors, have explicitly banned human germline modification. The Council of Europe’s binding 1997 Convention on Human Rights and Biomedicine also prohibits it. Numerous opinion surveys show that the great majority of Americans and others worldwide believe that heritable genetic modification should be prohibited.

While we are encouraged by efforts on the part of scientific bodies to move the process of deliberation about acceptable uses of gene editing forward, we are concerned that much of the focus has been on technical issues of safety (implying that if it were safe it would be acceptable), rather than on broader ethical and social implications. We strongly believe that the National Academies’ initiative and international meeting should be considered a very early step of a broadly inclusive program of public discussion. Any recommendations emerging from the meeting or the initiative should make this clear.

In sum, there is no justification for, and many arguments against, human germline modification for reproductive purposes. We call for a prohibition on such germline modification and a robust and broadly inclusive discussion on the socially responsible uses of this and other emerging genetic technologies.

Sincerely,

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#### Gene base editing can solve disease

James Gallagher, 9-28, 17, <https://www.bbc.com/news/health-41386849> DNA surgery on embryos removes disease

The potentially life-threatening blood disorder beta-thalassemia is caused by a change to a single base in the genetic code - known as a point mutation.

The team in China edited it back. They scanned DNA for the error then converted a G to an A, correcting the fault. Junjiu Huang, one of the researchers, told the BBC News website: "We are the first to demonstrate the feasibility of curing genetic disease in human embryos by base editor system." ADVERTISEMENT He said their study opens new avenues for treating patients and preventing babies being born with beta-thalassemia, "and even other inherited diseases". The experiments were performed in tissues taken from a patient with the blood disorder and in human embryos made through cloning. Genetics revolution Base editing is an advance on a form of gene-editing known as Crispr, that is already revolutionising science. Crispr breaks DNA. When the body tries to repair the break, it deactivates a set of instructions called a gene. It is also an opportunity to insert new genetic information. Human embryos edited to stop disease UK scientists edit DNA of human embryos Base editing works on the DNA bases themselves to convert one into another. Prof David Liu, who pioneered base editing at Harvard University, describes the approach as "chemical surgery". He says the technique is more efficient and has fewer unwanted side-effects than Crispr. He told the BBC: "About two-thirds of known human genetic variants associated with disease are point mutations. "So base editing has the potential to directly correct, or reproduce for research purposes, many pathogenic [mutations]." Image copyrightGETTY IMAGES The research group at Sun Yat-sen University in Guangzhou hit the headlines before when they were the first to use Crispr on human embryos. Prof Robin Lovell-Badge, from the Francis Crick Institute in London, described parts of their latest study as "ingenious". But he also questioned why they did not do more animal research before jumping to human embryos and said the rules on embryo research in other countries would have been "more exacting". The study, published in Protein and Cell, is the latest example of the rapidly growing ability of scientists to manipulate human DNA. It is provoking deep ethical and societal debate about what is and is not acceptable in efforts to prevent disease. Prof Lovell-Badge said these approaches are unlikely to be used clinically anytime soon. "There would need to be far more debate, covering the ethics, and how these approaches should be regulated. "And in many countries, including China, there needs to be more robust mechanisms established for regulation, oversight, and long-term follow-up."

## Ethical Problems

#### Ethical problems with gene editing

Francis S. Collins, MD, is the director of the National Institutes of Health. (The opinion expressed is the author’s, and should not be taken as the ofﬁcial position of the US government.), Stat News, 2015, Experts Debate: Arew we playing with fire when we edit human genes, https://www.statnews.com/2015/11/17/gene-editing-embryo-crispr/

The ethical arguments against human germline engineering are signiﬁcant. A most compelling one is that medical research should always seek to balance beneﬁts and risks, with individuals who are participating in research giving fully informed consent. But the individuals whose lives are potentially affected by germline manipulation could extend many generations into the future. They can’t give consent to having their genomes altered from what nature would have made possible.

There’s also a concern about human hubris. Who gets to decide what’s an improvement on the genome?

Many of the scenarios being discussed aren’t about correcting a disorder caused by misspelling of a single gene. For that, preimplantation genetic diagnosis already offers a practical and much less ethically challenging option for most couples seeking to avoid the birth of a child with a serious genetic disorder. Instead, futurists dream about changing traits that someone decides could be improved, such as intelligence, height, or risk of some common chronic illness. All of those are complex multigene situations in which the environment plays critical roles, and no single genetic change would be expected to have much beneﬁt.

Evolution has been working toward optimizing the human genome for 3.85 billion years. Do we really think that some small group of human genome tinkerers could do better without all sorts of unintended consequences?

There are also issues of equity and justice. Who would have access to this kind of human germline engineering? Do we want to accept the scenario that only those with ﬁnancial resources get to “improve” the genomes of their children?

A more subtle but signiﬁcant concern is whether the application of germline manipulation would change our view of the value of human life. If genomes are being altered to suit parents’ preferences, do children become more like commodities than precious gifts?

If there was a truly compelling argument that only human germline engineering could alleviate the suffering of many people, then I would say we might consider trying it under closely controlled circumstances. But the fact that there is a profound paucity of compelling cases, and that the ethical counterarguments are so signiﬁcant, makes me conclude that the balance of the debate leans overwhelmingly against human germline engineering.

#### 

## Too Soon – Need More Study

#### Need to better understand the risks of germline editing

George Church, PhD, is professor of genetics at Harvard Medical School and is also afﬁliated with the Wyss Institute, Broad Institute, and MIT Media Lab, Stat News, 2015, Experts Debate: Arew we playing with fire when we edit human genes, https://www.statnews.com/2015/11/17/gene-editing-embryo-crispr/

Many of the two thousand or so gene therapies, including precise gene editing, being tested in clinical trials around the world today are already curing patients, and some are being approved for general use. As with all new therapies, we need to pay great attention to the effectiveness, safety, reversibility, and cost of gene editing. In some cases, genetic counseling is more effective than gene therapy, but in other cases, both parents carry only the high risk genetic types, or do not want to harm embryos, and so they might choose gene therapy of somatic or germ cells.

The effectiveness of gene editing can depend on age. To cure some types of blindness, it may need to be performed in a young child. Other disorders might require gene editing even earlier, just as some surgeries need to be performed on children in the womb. Doing gene editing in sperm or egg cells can greatly improve both the safety and effectiveness of the procedure. One potential problem with gene editing is the occurrence of “off-target” mutations that can affect the treated cell in possibly unpredictable ways. Correcting a problem in liver or retinal cells may require gene editing in millions of cells. Even if the risk of off-target mutations is low, with so many cells involved the chance of it happening is not insubstantial. Gene editing in a single sperm or egg cell, could lower the risk of off-target mutations by a million-fold.

Although I believe that germline gene editing may soon be of great value, we need to better understand and manage the risks that could arise before moving forward with it, as we do with all new medical technologies. That is why I joined 17 other investigators calling for a moratorium 2 on the clinical use of germline gene editing while diverse groups of citizens examine emerging data on this technology and evaluate its risks and rewards.

#### Risks

Eleonore Pauwels is a scholar with the Science and Technology Innovation Program at the Wilson Center in Washington, D.C., where she conducts research and writes about the governance of genomics technologies, 2015, Experts Debate: Arew we playing with fire when we edit human genes, https://www.statnews.com/2015/11/17/gene-editing-embryo-crispr/

For the public to fully understand the potential of germline gene editing — and the risks it poses — scientists, writers, and policymakers must change how they talk about this new technology. Metaphors saturate scientiﬁc conversations. They can simplify or confuse new technologies like gene editing. Gene editing opponents offer up dystopian nightmare scenarios, such as wealthy parents choosing attributes for their “designer” babies. Some turn a complex biological procedure into a sci-ﬁ story, as seen in references about “editing humanity.” Those who support gene editing often describe it as molecular scissors that cut out harmful DNA sequences on a chromosome and thus “edit out” disease. They sometimes use the image of a red pen, or the “undo” function on a computer, only applied to the book of life. These images make the gene editing process seem easier and cleaner than it really is, and assume a control over our germline we have not yet mastered. This reinforces the hype and glosses over the potential for off-target edits, which can create unintended mutations in the genome. Talk of designer babies draws attention away from the more realistic risks associated with gene editing applications in non-humans. Scientists can already modify the genome of disease-carrying insects. But few calls have been made for research into what genetically modiﬁed mosquitos released into a Florida swamp might do to the ecosystem. If we are lucky, gene editing may someday contribute to treating certain cancers and inherited diseases. Until then, we must not let the story get ahead of the facts.

#### We need to study the technology more before we make it accessible

Ian Sample, May 23, 2016, <https://www.theguardian.com/science/2016/may/24/genetic-engineering-humans-great-potential-nobel-winner> The Guardian, Genetic engineering of humans has great potential, says Nobel winner

In a wide-ranging interview with the Guardian, Ramakrishnan, said the risks and benefits of the procedure, which would create the first genetically modified humans if given the green light, should be thrashed out in discussions that involve people from all walks of life. “It’s definitely a major step, there’s no getting around that. That’s why it’s important to really slow down and not rush any decisions,” he said. “What we need is a diverse and transparent group of people to really come together and get to grips with how do we go about using this tool and are there red lines. They may well decide there are red lines we shouldn’t cross.

“The concern I have is the same as with any other technology, which is that once a technology is feasible, we may well regulate it, but someone somewhere may start using it in ways we consider unethical,” he added. At a landmark meeting in Washington DC in December, scientists decided not to impose their own global ban on modifying human embryos destined to become people, but stated that to do so would be unacceptable given the unknown risks today. If proved safe, the therapy could potentially prevent devastating conditions from being passed on. It might also be used to reduce people’s risk of diseases such as cancer and dementia. On Tuesday, the Royal Society publishes a document on the more familiar area of GM crops. According to , half of the UK population do not feel well informed about GM crops, and a further 6% have never heard of them. The document lists common questions raised about GM crops, and provides answers from a group of experts convened by the society. “We wanted to provide the background and facts about some of the most important questions people have on GM crops,” Ramakrishnan said.

## Shouldn’t Solve Inequality Through Public Health

#### Trying to solve inequality through public health is totalitarian

Mark A. **Hall**, Fred D. and Elizabeth L. Turnage Professor of Law at Wake Forest University School of Law and School of Medicine and Associate in Management at the Babcock School of Management, **2003**

[“The Scope and Limits of Public Health Law,” *Perspectives in Biology and Medicine*, Volume 46, Number 3, Summer, Available Online to Subscribing Institutions via Project Muse *// BATMAN*]

**Beyond the public health arena, there are other good reasons for the government to pursue the more general aims of education, taxation, regulation, and redistribution, but these are broader social and economic policies or they belong to legal realms other than health. Public health advocates can be commended for calling our attention to the health implications of social disparities, but health promotion should not be the primary objective of corrective measures. The main reason to make social inequities an issue of public health authority, rather than simply public health analysis, is to invoke the highly paternalistic, absolutist, ends-oriented thinking associated with public health law. Viewed from a public health perspective, nothing short of totalitarian communism would thoroughly satisfy someone who takes literally the idea that social and economic justice is a primary driver of the "public's health," as that phrase is understood by law. It isn't enough to confer equal rights or equal opportunities; nothing short of achieving the desired results—equal welfare—will abate the threat to public health. Obviously, reformers would never be allowed to go this far, but the fact that this extremism is the logical extension of the social determinant argument shows that public health advocates seriously overstep their bounds when they call on government to address broad economic and political conditions as public health problems, rather than as more general efforts to improve overall social equality and well-being, including health as a component of well-being**. [End Page S208]

#### The terminal impact is nazism, stalinism, and slavery.

Lynne **Henderson**, Professor of Law at the Indiana University School of Law at Bloomington, **1991**

[“Authoritarianism and the Rule of Law,” *Indiana Law Journal* (66 Ind. L.J. 379), Spring, Available Online via Lexis-Nexis *// BATMAN*]

**Substantive authoritarianism means opposition to the "liberal" values of tolerance of ambiguity and difference, insistence on obedience to rules, insistence on conformity, and use of coercion and punishment to ensure that obedience. Frequently associated with xenophobic nationalism or ethnocentrism,** n18 **authoritarianism in the substantive sense is premised on a suspicious and distrustful view of human nature and is frequently linked, both on a personal and political level, to racism, anti-semitism and patriarchy.** n19 **Substantive authoritarianism oppresses in the name of order and control. This form of authoritarianism may reach the extreme level it did in Nazi Germany and Stalinist Russia or appear in milder forms, as it did during the McCarthy era in the United States, when, as a result of fear, hatred and extreme nationalism, the government, with private and judicial support, used law to persecute and punish citizens for being "un-American."** n20

Authoritarianism need not be based only in active coercion and oppression of disfavored groups by government. **The government may also allow authoritarianism to flourish by omission – by permitting other institutions or persons to coerce and oppress others in the interest of maintaining control. Thus, much of the history of slavery in the United States could be characterized as government authoritarianism by omission in the interests** [\*383] **of maintaining order and national and party unity.** n21 Other examples include the government largely ignoring oppression of and violence against African-American women, n22 and a long history of governmental tolerance of private oppression of women and children through violence. n23

#### Their approach “healthaffies” social problems

Ilan H. **Meyer**, Deputy Chair for Master of Public Health Programs and Associate Professor of Clinical Sociomedical Sciences at Columbia University’s Joseph L. Mailman School of Public Health, **and** Sharon B. **Schwartz**, Associate Professor of Clinical Epidemiology at Columbia University’s Joseph L. Mailman School of Public Health, **2000**

[“Social Issues As Public Health: Promise And Peril,” *American Journal of Public Health*, Volume 90, Issue 8, August, Available Online to Subscribing Institutions via Academic Search Elite, p. 1189 *// BATMAN*]

Along with the promise of this approach, however, is considerable peril that deserves discussion. We are concerned that **the study of social and economic factors in public health may have unintended consequences that, paradoxically, serve to preserve disparities rather than eliminate them**.10 **This can occur because public health research transports social issues into the health domain, where they are examined through the narrow prism of health relevance instead of within their political, social, and economic contexts. We refer to this as the "public healthification" of social problems**, akin to the "medicalization"11 and "healthism"12 that have

#### This approach inevitably leaves social problems unaddressed

Ilan H. **Meyer**, Deputy Chair for Master of Public Health Programs and Associate Professor of Clinical Sociomedical Sciences at Columbia University’s Joseph L. Mailman School of Public Health, **and** Sharon B. **Schwartz**, Associate Professor of Clinical Epidemiology at Columbia University’s Joseph L. Mailman School of Public Health, **2000**

[“Social Issues As Public Health: Promise And Peril,” *American Journal of Public Health*, Volume 90, Issue 8, August, Available Online to Subscribing Institutions via Academic Search Elite, p. 1189-1190 *// BATMAN*]

**As social problems are refracted through the public health prism, their scope is narrowed. This narrowing is due to the mismatch between the theories, methods, and values of public** [end page 1189] **health research and the broader political and socioeconomic factors that characterize social problems. We discuss 3 perils posed by the broad approach to public health: a focus on the individual, the institutionalization of research paradigms and findings, and the valuation of social problems by their health consequences**. We illustrate this process with the recent history of public health research on homelessness.

#### To solve social problems, we have to treat them as social problems, not as health problems

Ilan H. **Meyer**, Deputy Chair for Master of Public Health Programs and Associate Professor of Clinical Sociomedical Sciences at Columbia University’s Joseph L. Mailman School of Public Health, **and** Sharon B. **Schwartz**, Associate Professor of Clinical Epidemiology at Columbia University’s Joseph L. Mailman School of Public Health, **2000**

[“Social Issues As Public Health: Promise And Peril,” *American Journal of Public Health*, Volume 90, Issue 8, August, Available Online to Subscribing Institutions via Academic Search Elite, p. 1190 *// BATMAN*]

**Another peril of studying social problems in public health is that they become institutionalized as public health problems. Once a social problem is established as a health problem, a research paradigm develops, following a scientific method** (e.g., the epidemiologic study of risk factors for homelessness). **Soon a large body of literature is created, with its language, common assumptions, methods, and sets of legitimate constructs.**16 **Thus, a linguistic category "the homeless" was constructed, and "facts" about risk factors for homelessness became widely accepted. In the process, the research question and its method of investigation were validated and institutionalized. This body of literature created the need for further research** (recommended by most articles on the topic) **and elicited governmental resources in the form of research grants and contracts. This scientific discourse established homelessness as a public health research question. Solutions are now sought from within this discourse**.

**But**, as described above, **public health research findings pointed to individual-level solutions. Such solutions are palatable to, and indeed supportive of, the social structures and forces that many agree produced the problem in the first place. Even as governmental policies that reduced availability of housing for the poor have been claimed to be the culprit, public health has produced a body of knowledge that, by documenting individual responsibility for homelessness, may be used to absolve the government of its responsibility**.17 **Thus, in establishing homelessness as a public health problem, public health researchers may have unintentionally reduced the possibility of remedying the problem by addressing the core structural factors—those that lie within the larger public-policy and socioeconomic domains. The peril is that remedies may be sought within a public health framework, from a narrow clinical or even biomedical perspective. Such clinical interventions may help subgroups among the homeless but not reduce the magnitude of the problem**.18,19

#### The Pro’s approach diverts away from social problems

Ilan H. **Meyer**, Deputy Chair for Master of Public Health Programs and Associate Professor of Clinical Sociomedical Sciences at Columbia University’s Joseph L. Mailman School of Public Health, **and** Sharon B. **Schwartz**, Associate Professor of Clinical Epidemiology at Columbia University’s Joseph L. Mailman School of Public Health, **2000**

[“Social Issues As Public Health: Promise And Peril,” *American Journal of Public Health*, Volume 90, Issue 8, August, Available Online to Subscribing Institutions via Academic Search Elite, p. 1190 *// BATMAN*]

**In practice, despite the conceptual understanding of the role of structural causes of homelessness, homelessness has been studied as if it were a disease, an outcome defined as residing in the individual. The tools used in public health research for examining individual variation in disease led to the identification of individual rather than structural factors in the etiology of homelessness**.14 **Research highlighted individual characteristics as risk factors for homelessness, including sociodemographic characteristics** (e.g., age, gender, ethnicity), **psychiatric and substance use disorders** (e.g., schizophrenia, alcoholism), **and disruptive family and childhood experiences** (e.g., foster care and group home placements) (see, for example, the review by Susser et al.15). **The structural factors often asserted to be distal causes of homelessness**, and cited by Breakey as the impetus for broadening the scope of public health research,9 **were left largely unexamined. Thus, the promise held in examining upstream causes of health problems was broken. Instead of addressing fundamental social causes, public health researchers highlighted individual characteristics that serve to obscure rather than illuminate the social and economic causes of homelessness**.

#### It gauges the importance of an issue by its health outcomes – homelessness becomes bad only insofar as it harms public health.

Ilan H. **Meyer**, Deputy Chair for Master of Public Health Programs and Associate Professor of Clinical Sociomedical Sciences at Columbia University’s Joseph L. Mailman School of Public Health, **and** Sharon B. **Schwartz**, Associate Professor of Clinical Epidemiology at Columbia University’s Joseph L. Mailman School of Public Health, **2000**

[“Social Issues As Public Health: Promise And Peril,” *American Journal of Public Health*, Volume 90, Issue 8, August, Available Online to Subscribing Institutions via Academic Search Elite, p. 1190 *// BATMAN*]

Perhaps **the most serious peril in the transportation of social problems into the public health arena is that health outcomes become the evidence for and definition of the wrongfulness of social problems. In this way, research results are used as a moral battleground. Public healthification implies that homelessness is problematic because it is a health-related problem. But would homelessness divorced from its health impact be any less troubling? In a wealthy country, the sight of people living in subways and in shelters is evidence of a wrong that needs no further justification for action. Similarly, should an argument against inequality be dependent on research findings that document the negative health outcomes of inequality? Is discrimination any less unjust if it does not lead to adverse health outcomes?** We think **this is a perilous stance**.

#### Homelessness is just an example – our evidence applies to other social issues, too.

Ilan H. **Meyer**, Deputy Chair for Master of Public Health Programs and Associate Professor of Clinical Sociomedical Sciences at Columbia University’s Joseph L. Mailman School of Public Health, **and** Sharon B. **Schwartz**, Associate Professor of Clinical Epidemiology at Columbia University’s Joseph L. Mailman School of Public Health, **2000**

[“Social Issues As Public Health: Promise And Peril,” *American Journal of Public Health*, Volume 90, Issue 8, August, Available Online to Subscribing Institutions via Academic Search Elite, p. 1190 *// BATMAN*]

**We have used homelessness as an example of the potential unintended consequences of examining social problems through a health prism. But our concerns are not limited to homelessness. A public health focus on violence, war, discrimination, or inequality caries the same risks. In each case, public healthification may inadvertently lead to a focus on the individual, institutionalization of the problem as a public health research problem, and valuation of the social and moral import of the problem solely by its health consequences**.

## Gene Editing Fails

### General Gene Editing Failure

#### Gene editing can fail

Ian Sample, January 25, 2018, The Guardian, Gene editing – and what it really means to rewrite the code of lifehttps://www.theguardian.com/science/2018/jan/15/gene-editing-and-what-it-really-means-to-rewrite-the-code-of-life

Modern gene editing is quite precise but it is not perfect. The procedure can be a bit hit and miss, reaching some cells but not others. Even when Crispr gets where it is needed, the edits can differ from cell to cell, for example mending two copies of a mutated gene in one cell, but only one copy in another. For some genetic diseases this may not matter, but it may if a single mutated gene causes the disorder. Another common problem happens when edits are made at the wrong place in the genome. There can be hundreds of these “off-target” edits that can be dangerous if they disrupt healthy genes or crucial regulatory DNA.

### Blood Donor Treatment Solvency Answers

#### Blood order treatment experiments have not worked

Fiona McDonald, February 9, 2016, <https://www.sciencealert.com/10-things-you-need-to-know-about-the-uk-s-decision-to-allow-genetic-modification-of-human-embryos> 10 Things You Need to Know About The UK Allowing Genetic Modification of Human Embryos

Last April, Chinese scientists admitted to tweaking the genes of 28 embryos to try to prevent a deadly blood disorder. They encountered serious challenges in their research, and said the technology has a long way to go before it can be used to treat disease in humans.

### HIV Solvency Answers

#### Attempts to control HIV have failed

AKshat Rathi, April 9, 2016, <https://qz.com/658537/chinese-researchers-have-genetically-modified-human-embryos-yet-again/> Chinese researchers have genetically modified human embryos—yet again

The technology in question is called CRISPR, and it allows researchers to make genetic modifications with greater precision than ever before. In 2015, Chinese researchers used CRISPR to target genes responsible for a blood disorder called β-thalassaemia. They were only able to replace the defective gene in 28 out 71 embryos. Worse still, it left a slew of unintended changes in other parts of the genome.

In the latest attempt, researchers at Guangzhou Medical University have gone a step ahead. Instead of trying to correct mutations that could cause disease, they used CRISPR technology to insert a genetic mutation which might offer resistance against HIV.

The mutation was targeted in the CCR5 gene, which is responsible for producing a protein that HIV uses to latch on, enter, and infect a human immune cell. If the CCR5 gene were mutated, the logic goes, the HIV virus would not be able to infect—and thus the mutation would confer resistance to the disease.

The researchers report in the Journal of Assisted Reproduction and Genetics that they were successfully inserted the mutated gene in four out of 26 embryos. And, even in the successful cases, not all copies of the CCR5 gene were modified. In other cases mutations were caused that weren’t intended.

#### Gene editing could alter the environment

Associated Press, December 1, 2015, <http://www.foxnews.com/health/2015/12/01/potential-benefits-and-ethical-implications-gene-editing.html> The potential benefits and ethical implications of gene editing

Human gene editing aside, there are environmental concerns, too. Experiments are under way to force genetic changes to spread rapidly through populations of animals and plants - changes that could wipe out invasive species or disease-carrying insects. A California team reported a first step last week, hatching malaria-resistant mosquitoes that could easily spread their new protective gene to their offspring.

### Risks

#### Too risky now

Keren Weintraub, National Georgraphic, December, 2015, https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/ 5 Reasons Gene Editing Is Both Terrific and Terrifying

The organizing committee ended the discussion by issuing a statement saying that “it would be irresponsible to proceed with any clinical use of germline editing” until more safety and effectiveness research can be done, risks and benefits weighed, and a social consensus reached. The group called for regulatory oversight of use in people, and concluded that “as scientific knowledge advances and societal views evolve, the clinical use of germline editing should be revisited on a regular basis.”

In Washington, scientists and ethicists talked about science, ethics, human rights, government relations and Aldous Huxley’s futuristic 1932 novel Brave New World, offering five basic reasons that gene editing is exciting—but scary:

## Answers to Pro Arguments

### Answers to: Need to Stop Inherited Genetic Disease

#### Inherited genetic disease can be stopped through other methods

Marcy Darnovsky, August 2016, Dranovsky is executive director of the Center for Genetics and Society, <https://www.nationalgeographic.com/magazine/2016/08/human-gene-editing-pro-con-opinions/> Con: Do Not Open the Door to Editing Genes in Future Humans

Beyond technical issues are profound social and political questions. Would germline gene editing be justifiable, in spite of the risks, for parents who might transmit an inherited disease? It’s certainly not necessary. Parents can have children unaffected by the disease they have or carry by using third-party eggs or sperm, an increasingly common way to form families. Some heterosexual couples may hesitate to use this option because they want a child who is not just spared a deleterious gene in their lineage, but is also genetically related to both of them. They can do that too, with the embryo screening technique called pre-implantation genetic diagnosis (PGD), a widely available procedure used in conjunction with in vitro fertilization.

PGD itself raises social and ethical concerns about what kind of traits should be selected or de-selected. These questions are particularly important from a disability rights perspective (which means they’re important for all of us). But screening embryos for disease is far safer for resulting children than engineering new traits with germline gene editing would be. Yet this existing alternative is often omitted from accounts of the controversy about gene editing for reproduction.

# Plant/Animal Editing Links

### General Links to Plant/Animal Editing

#### Advances gene editing technologies such as CRISPR can be applied to all life, including animals and plants

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

This research would be significant enough all on its own. Niakan, a 38-year-old Ph.D. from UCLA, is trying to override nature's selections, instead generating an outcome that she has designed. But what's truly remarkable is that her work represents just one front of a broad revolution in genetics sparked by the technique called CRISPR-Cas9. Just four years old, this discovery is transforming research into how to treat disease, what we eat and how we'll generate electricity, fuel our cars and even save endangered species. Experts believe that CRISPR can be used to reprogram the cells not just in humans but also in plants, insects--practically any piece of DNA on the planet. On June 2, a scientist at MIT and Harvard's Broad Institute announced the development of a related CRISPR technique that can edit RNA, which is responsible for regulation and expression of genes. If DNA is the genetic alphabet, RNA spells actual words. In plain terms, that means the already vast possibilities for CRISPR got even bigger….. alk to any biologist, geneticist or botanist right now and you will hear a level of excitement that comes only from the emergence of something truly groundbreaking. If the evolution from giant mainframes to personal computers forever changed technology, CRISPR promises to do something similar for genetics--democratizing the power to improve on nature for scientists at nearly all levels of expertise in practically every field. There have been other techniques for altering DNA, but those were expensive and complicated. CRISPR is neither. "It's a game changer," says David Baltimore, a Nobel laureate for his discoveries in viral cancer genetics.

### Reduced Species Extinction

#### CRISPR can reduce the number of endangered species

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

Even endangered species might be getting the CRISPR treatment. George Church, a professor of genetics at Harvard Medical School, is exploring the possibility of saving the Asian elephant by giving it an entirely new habitat in the relatively human-conflict-free tundra of Siberia. What he hopes will keep the species alive are genes from the extinct woolly mammoth. "It dawned on me that this could be possibly the most exciting part of a new conservation strategy where the goal is not so much to bring back extinct species but to enliven the ecosystem and help endangered species," says Church.

### Mosquitos

#### Gene editing allows the editing of mosquito genes, solving deadly diseases

Michael Specter, August 2016, National Georgraphic, <https://www.nationalgeographic.com/magazine/2016/08/dna-crispr-gene-editing-science-ethics/> How the DNA Revolution Is Changing Us

IF YOU TOOK a glance around Anthony James’s office, it wouldn’t be hard to guess what he does for a living. The walls are covered with drawings of mosquitoes. Mosquito books line the shelves.

Hanging next to his desk is a banner with renderings of one particular species—Aedes aegypti—in every stage of development, from egg to pupa to fully grown, enlarged to sizes that would even make fans of Jurassic Park blanch. His license plates have a single word on them: AEDES.

“I have been obsessed with mosquitoes for 30 years,” says James, a molecular geneticist at the University of California, Irvine.

There are approximately 3,500 species of mosquito, but James pays attention to just a few, each of which ranks among the deadliest creatures on Earth. They include Anopheles gambiae, which transmits the malaria parasite that kills hundreds of thousands of people each year. For much of his career, however, James has focused on Aedes. Historians believe the mosquito arrived in the New World on slave ships from Africa in the 17th century, bringing with it yellow fever, which has killed millions of people. Today the mosquito also carries dengue fever, which infects as many as 400 million people a year, as well as such increasingly threatening pathogens as chikungunya, West Nile virus, and Zika.

Picture of mosquito full of cow blood under microscope in lab

Cow blood engorges an exposed mosquito’s gut in Anthony James’s lab. Versions of the species carrying Zika and dengue fever can be manipulated with CRISPR so that they give birth to sterile offspring, below.

DAVID LIITTSCHWAGER

Picture of mosquito larvae with unedited genes in laboratory at University of California, Irvine

Picture of mosquito larvae with edited genes in laboratory at University of California, Irvine

Mosquito larvae in the laboratory of Anthony James at the University of California, Irvine pay witness to how a dreaded disease might be stopped. Both are Anopheles stephensi, a major carrier of the malaria parasite in urban Asia. Using a technique called CRISPR, James has edited a gene in the larva on the right so… Read More

DAVID LIITTSCHWAGER

In a widening outbreak that began last year in Brazil, Zika appears to have caused a variety of neurological disorders, including a rare defect called microcephaly, where babies are born with abnormally small heads and underdeveloped brains.

The goal of James’s lab, and of his career, has been to find a way to manipulate mosquito genes so that the insects can no longer spread such diseases. Until recently, it has been a long, lonely, and largely theoretical road. But by combining a revolutionary new technology called CRISPR-Cas9 with a natural system known as a gene drive, theory is rapidly becoming reality.

CRISPR places an entirely new kind of power into human hands. For the first time, scientists can quickly and precisely alter, delete, and rearrange the DNA of nearly any living organism, including us. In the past three years, the technology has transformed biology. Working with animal models, researchers in laboratories around the world have already used CRISPR to correct major genetic flaws, including the mutations responsible for muscular dystrophy, cystic fibrosis, and one form of hepatitis. Recently several teams have deployed CRISPR in an attempt to eliminate HIV from the DNA of human cells. The results have been only partially successful, but many scientists remain convinced that the technology may contribute to a cure for AIDS.

In experiments, scientists have also used CRISPR to rid pigs of the viruses that prevent their organs from being transplanted into humans. Ecologists are exploring ways for the technology to help protect endangered species. Moreover, plant biologists, working with a wide variety of crops, have embarked on efforts to delete genes that attract pests. That way, by relying on biology rather than on chemicals, CRISPR could help reduce our dependence on toxic pesticides.

No scientific discovery of the past century holds more promise—or raises more troubling ethical questions. Most provocatively, if CRISPR were used to edit a human embryo’s germ line—cells that contain genetic material that can be inherited by the next generation—either to correct a genetic flaw or to enhance a desired trait, the change would then pass to that person’s children, and their children, in perpetuity. The full implications of changes that profound are difficult, if not impossible, to foresee.

“This is a remarkable technology, with many great uses. But if you are going to do anything as fateful as rewriting the germ line, you’d better be able to tell me there is a strong reason to do it,” said Eric Lander, who is director of the Broad Institute of Harvard and MIT and who served as leader of the Human Genome Project. “And you’d better be able to say that society made a choice to do this—that unless there’s broad agreement, it is not going to happen.”

Picture of worker holding a CRISPR-modified long-tailed macaque in a Kunming, China, laboratory

Zhou Yin of the Yunnan Key Laboratory of Primate Biomedical Research in Kunming, China, shows off a young long-tailed macaque raised from a CRISPR-modified embryo. Dozens of other… Read More

No discovery of the past century holds more promise—or raises more troubling ethical questions.

“Scientists do not have standing to answer these questions,” Lander told me. “And I am not sure who does.”

CRISPR-Cas9 has two components. The first is an enzyme—Cas9—that functions as a cellular scalpel to cut DNA. (In nature, bacteria use it to sever and disarm the genetic code of invading viruses.) The other consists of an RNA guide that leads the scalpel to the precise nucleotides—the chemical letters of DNA—it has been sent to cut. (Researchers rarely include the term “Cas9” in conversation, or the inelegant terminology that CRISPR stands for: “clustered regularly interspaced short palindromic repeats.”)

The guide’s accuracy is uncanny; scientists can dispatch a synthetic replacement part to any location in a genome made of billions of nucleotides. When it reaches its destination, the Cas9 enzyme snips out the unwanted DNA sequence. To patch the break, the cell inserts the chain of nucleotides that has been delivered in the CRISPR package.

By the time the Zika outbreak in Puerto Rico comes to an end, the U.S. Centers for Disease Control and Prevention estimates that, based on patterns of other mosquito-borne illnesses, at least a quarter of the 3.5 million people in Puerto Rico may contract Zika. That means thousands of pregnant women are likely to become infected.

Currently the only truly effective response to Zika would involve bathing the island in insecticide. James and others say that editing mosquitoes with CRISPR—and using a gene drive to make those changes permanent—offers a far better approach.

Picture of a genetically altered salmon and a non-genetically altered salmon on silver table

Scientists used conventional genetic engineering to add genetic material from two other fish species to create the AquAdvantage Atlantic salmon (top), which can reach market size twice as fast as its… Read More

Gene drives have the power to override the traditional rules of inheritance. Ordinarily the progeny of any sexually reproductive animal receives one copy of a gene from each parent. Some genes, however, are “selfish”: Evolution has bestowed on them a better than 50 percent chance of being inherited. Theoretically, scientists could combine CRISPR with a gene drive to alter the genetic code of a species by attaching a desired DNA sequence onto such a favored gene before releasing the animals to mate naturally. Together the tools could force almost any genetic trait through a population.

Last year, in a study published in the Proceedings of the National Academy of Sciences, James used CRISPR to engineer a version of Anopheles mosquitoes that makes them incapable of spreading the malaria parasite. “We added a small package of genes that allows the mosquitoes to function as they always have,” he explained. “Except for one slight change.” That change prevents the deadly parasite from being transmitted by the mosquitoes.

HOW TO HACK DNA

Learn—and visualize—how CRISPR technology works in this animated graphic video.

“I’d been laboring in obscurity for decades. Not anymore, though—the phone hasn’t stopped ringing for weeks,” James said, nodding at a sheaf of messages on his desk.

Combating the Ae. aegypti mosquito, which carries so many different pathogens, would require a slightly different approach. “What you would need to do,” he told me, “is engineer a gene drive that makes the insects sterile. It doesn’t make sense to build a mosquito resistant to Zika if it could still transmit dengue and other diseases.”

To fight off dengue, James and his colleagues have designed CRISPR packages that could simply delete a natural gene from the wild parent and replace it with a version that would confer sterility in the offspring. If enough of those mosquitoes were released to mate, in a few generations (which typically last just two or three weeks each) entire species would carry the engineered version.

James is acutely aware that releasing a mutation designed to spread quickly through a wild population could have unanticipated consequences that might not be easy to reverse. “There are certainly risks associated with releasing insects that you have edited in a lab,” he said. “But I believe the dangers of not doing it are far greater.”

t has been more than 40 years since scientists discovered how to cut nucleotides from the genes of one organism and paste them into the genes of another to introduce desired traits. Molecular biologists were thrilled by the possibilities this practice, referred to as recombinant DNA, opened for their research. From the start, however, scientists also realized that if they could transfer DNA between species, they might inadvertently shift viruses and other pathogens too. That could cause unanticipated diseases, for which there would be no natural protection, treatment, or cure.

This possibility frightened no one more than the scientists themselves. In 1975, molecular biologists from around the world gathered at the Asilomar Conference Grounds, along California’s central coast, to discuss the challenges presented by this new technology. The group emerged from the meeting having agreed to a series of safeguards, including levels of laboratory security that escalated along with the potential risks posed by the experiments.

It soon became clear that the protections seemed to work and that the possible benefits were enormous. Genetic engineering began to improve the lives of millions. Diabetics, for example, could count on steady supplies of genetically engineered insulin, made in the lab by placing human insulin genes into bacteria and then growing it in giant vats. Genetically engineered crops, yielding more and resisting herbicides and insects, began to transform much of the world’s agricultural landscape.

Spreading

the Cure

Most genes in a species have a one-in-two chance of being inherited by each offspring. But with the advent of CRISPR and a controversial technique called engineered gene drive, scientists are beating those odds in the lab. An alteration that makes a mosquito resistant to malaria, for example, can be engineered to be inherited by all its offspring.

ALTERED

Yet while genetically engineered medicine has been widely accepted, crops produced in a similar fashion have not, despite scores of studies showing that such products are no more dangerous to eat than any other food. As the furor over the labeling of GMOs (genetically modified organisms) demonstrates, it doesn’t matter whether a product is safe if people refuse to eat it.

CRISPR may provide a way out of this scientific and cultural quagmire. From the beginning of the recombinant era, the definitions of the word “transgenic” and the term “GMO” have been based on the practice of combining in a laboratory the DNA of species that could never mate in nature. But scientists hope that using CRISPR to alter DNA could appease the opposition. It gives researchers the ability to redesign specific genes without having to introduce DNA from another species.

Golden rice, for example, is a GMO engineered to contain genes necessary to produce vitamin A in the edible part of the grain—something that doesn’t happen naturally in rice plants. Each year up to half a million children in the developing world go blind for lack of vitamin A—but anti-GMO activists have interfered with research and prevented any commercial production of the rice. With CRISPR, scientists could almost certainly achieve the same result simply by altering genes that are already active in rice plants.

Scientists in Japan have used CRISPR to extend the life of tomatoes by turning off genes that control ripening. By deleting all three copies of one wheat gene, Caixia Gao and her team at the Chinese Academy of Sciences in Beijing have created a strain that is resistant to powdery mildew.

Picture of a specialist collecting eggs from a woman using a needle in Chicago, Illinois

Chicago-based reproductive specialist (and Bulls fan) Ilan Tur-Kaspa collects a patient’s eggs using a needle and ultrasound for guidance. Screening embryos for genetic diseases prior to in vitro fertilization… Read More

Picture of a five-day-old blastocyst, which can be screened for diseases

Picture of kid walking with his parents next to a body of water

Both of Jack’s parents are carriers of a defective gene that imparts a 25 percent chance that their children will develop cystic fibrosis. Jack, 16 months old, is also a carrier but will never suffer from the illness. Embryos (like the five-day-old blastocyst shown here) were screened to select ones free of the disease before… Read More

DAVID LIITTSCHWAGER (LEFT)

Without regulation, the tremendous potential of this revolution could be overshadowed by fear.

Farmers have been adjusting genes in single species—by crossbreeding them—for thousands of years. CRISPR simply offers a more precise way to do the same thing. In some countries, including Germany, Sweden, and Argentina, regulators have made a distinction between GMOs and editing with tools such as CRISPR. There have been signs that the U.S. Food and Drug Administration might follow suit, which could make CRISPR-created products more readily available and easily regulated than any other form of genetically modified food or drug. Whether the public will take advantage of them remains to be seen.

The potential for CRISPR research to improve human medicine would be hard to overstate. The technology has already transformed cancer research by making it easier to engineer tumor cells in the laboratory, then test various drugs to see which can stop them from growing. Soon doctors may be able to use CRISPR to treat some diseases directly.

Stem cells taken from people with hemophilia, for example, could be edited outside of the body to correct the genetic flaw that causes the disease, and then the normal cells could be inserted to repopulate a patient’s bloodstream.

In the next two years we may see an even more dramatic medical advance. There are 120,000 Americans on waiting lists to receive organ transplants, and there will never be enough for all of them. Thousands of people die every year before reaching the top of the list. Hundreds of thousands never even meet the criteria to be placed on the list.

For years, scientists have searched for a way to use animal organs to ease the donor shortage. Pigs have long been considered the mammal of choice, in part because their organs are similar in size to ours. But a pig’s genome is riddled with viruses called PERVs (porcine endogenous retroviruses), which are similar to the virus that causes AIDS and have been shown to be capable of infecting human cells. No regulatory agency would permit transplants with infected organs. And until recently, nobody has been able to rid the pig of its retroviruses.

Now, by using CRISPR to edit the genome in pig organs, researchers seem well on their way to solving that problem. A group led by George Church, a professor at Harvard Medical School and MIT, used the tool to remove all 62 occurrences of PERV genes from a pig’s kidney cell. It was the first time that so many cellular changes had been orchestrated into a genome at once.

Picture of researchers working with lungs and heart of a gene-altered pig in Maryland

Researchers handle the lungs and heart removed from a gene-altered pig in the lab of Lars Burdorf at the University of Maryland School of Medicine, which has been developing and testing animal… Read More

Human blood filters through pig lungs in the lab of Lars Burdorf at the University of Maryland. Thousands of people die every year for lack of transplantable human organs. Scientists are experimenting with… Read More

When the scientists mixed those edited cells with human cells in a laboratory, none of the human cells became infected. The team also modified, in another set of pig cells, 20 genes that are known to cause reactions in the human immune system. That too would be a critical part of making this kind of transplant work.

Church has now cloned those cells and begun growing them in pig embryos. He expects to start primate trials within a year or two. If the organs function properly and are not rejected by the animals’ immune systems, the next step would be human trials. Church told me he thinks this could happen in as few as 18 months, adding that for many people the alternative to the risk of the trial would surely be death.

Church has always wanted to find a way to provide transplants for people who aren’t considered healthy enough to receive them. “The closest thing we have to death panels in this country are the decisions made about who gets transplants,” he said. “A lot of these decisions are being made based on what else is wrong with you. Many people are rejected because they have infectious diseases or problems with substance abuse—a whole host of reasons. And the conceit is that these people would not benefit from a transplant. But of course they would benefit. And if you had an abundance of organs, you could do it for everyone.”

The black-footed ferret is one of the most endangered mammals in North America. Twice in the past 50 years, wildlife ecologists assumed that the animals, which were once plentiful throughout the Great Plains, had gone extinct. They came close; every black-footed ferret alive today descends from one of seven ancestors discovered in 1981 on a cattle ranch near Meeteetse, Wyoming.

But the ferrets, inbred for generations, lack genetic diversity, which makes it harder for any species to survive.

“The ferrets are a classic example of an entire species that could be saved by genomic technology,” said Ryan Phelan of the group Revive & Restore, which is coordinating efforts to apply genomics to conservation. Working with Oliver Ryder at the San Diego Frozen Zoo, Phelan and her colleagues are attempting to increase the diversity of the ferrets by introducing more variable DNA into their genomes from two specimens preserved 30 years ago.

Phelan’s work can address two immediate and interlocking threats. The first is lack of food: Prairie dogs, the ferrets’ main prey, have been decimated by sylvatic plague, which is caused by the same bacterium that gives rise to bubonic plague in humans. And the plague is also fatal to the ferrets themselves, which become infected by eating prairie dogs that have died of the disease. A vaccine against human plague developed in the 1990s appears to provide lifelong immunity in ferrets. Teams from the Fish and Wildlife Service have captured, vaccinated, and released as many of the ferrets (a few hundred exist in the wild) as they can. But such a ferret-by-ferret approach cannot protect the species.

A more sophisticated solution has been proposed by Kevin Esvelt, an assistant professor at the MIT Media Lab, who developed some of the CRISPR and gene drive technology with Church. Esvelt describes his work as sculpting evolution. “All you need to do is provide resistance,” he explained—by encoding antibodies generated by vaccination and then editing them into the ferrets’ DNA.

Photo of scientist holding a petri dish of a plant edited to resist disease

Scientist Caixia Gao holds a petri dish of bread wheat whose genome she’s edited to resist powdery mildew, a severe crop disease. This technology could boost yields for the millions of people who depend… Read More

Picture of old trees in a Virginia forest

Picture of a person tending a plant at State University of New York

American chestnut trees blanketed much of the eastern U.S. until an invasive fungus all but wiped them out in the early 20th century—a tragedy visible in a Virginia forest (left). William Powell of the State University of New York College of Environmental Science and Forestry and colleagues (including Kristen… Read More

LIBRARY OF CONGRESS (LEFT)

With gene drives and CRISPR

we now have a power over species of all kinds that we never thought possible.

HANK GREELY, DIRECTOR OF STANFORD’S CENTER FOR LAW AND THE BIOSCIENCES

Esvelt believes a similar approach could not only help the ferrets resist plague but could also help eradicate Lyme disease, which is caused by a bacterium transmitted by ticks that commonly feed on white-footed mice.

If resistance to Lyme could be edited into the mice’s DNA with CRISPR and spread through the wild population, the disease might be reduced or eliminated with little visible ecological impact. Esvelt and Church, however, both feel strongly that no such experiment should be attempted without public participation and unless the scientists who carry it out have developed a reversal system, a kind of antidote. Should the original edits have unforeseen ecological consequences, they could drive the antidote through a population to cancel them out.

Black-footed ferrets are hardly the only endangered animals that could be saved through a CRISPR gene drive. The avian population of Hawaii is rapidly disappearing, largely because of a type of malaria that infects birds. Before whalers brought mosquitoes in the early 19th century, birds in the Hawaiian Islands had no exposure to the diseases that mosquitoes carry, and therefore no immunity. Now only 42 of more than a hundred species of birds endemic to Hawaii remain, and three-quarters of those are listed as endangered. The American Bird Conservancy has referred to Hawaii as “the bird extinction capital of the world.” Avian malaria is not the only threat to what remains of Hawaii’s native birds, but if it cannot be stopped—and gene editing seems to be the best way to do that—they will likely all disappear.

Jack Newman is a former chief science officer at Amyris, which pioneered development of a synthetic form of artemisinin, the only genuinely effective drug available to treat malaria in humans. Now he focuses much of his attention on eliminating mosquito-borne disease in birds. The only current method of protecting birds from malaria is to kill the mosquitoes by spreading powerful chemicals over an enormous region. Even that is only partially successful.

“In order to kill a mosquito,” Newman says, “the insecticide actually has to touch it.” Many of these insects live and breed deep in the hollows of trees or in the recessed crags of rock faces. To reach them with insecticides almost certainly would require poisoning much of the natural life in Hawaii’s rain forests. But gene editing, which would result in sterile mosquitoes, could help save the birds without destroying their surroundings. “Using genetics to save these species is just an incredibly targeted way to address a variety of environmental ills,” Newman says. “Avian malaria is destroying the wildlife of Hawaii, and there is a way to stop it. Are we really willing to just sit there and watch?”

In February of this year, U.S. Director of National Intelligence James Clapper warned in his annual report to the Senate that technologies like CRISPR ought to be regarded as possible weapons of mass destruction. Many scientists considered the comments unfounded, or at least a bit extreme. There are easier ways for terrorists to attack people than to conjure up new crop plagues or deadly viruses.

Nevertheless, it would be shortsighted to pretend that the possibility for harm (including, and perhaps especially, accidental harm) does not exist with these new molecular tools. The scientists most responsible for advances like CRISPR agree that when we begin to tinker with the genetic heritage of other species, not to mention our own, it may not be easy, or even possible, to turn back.

“What are the unintended consequences of genome editing?” asked Jennifer Doudna, as we spoke in her office at the University of California, Berkeley, where she is professor of chemistry and molecular biology. In 2012, Doudna and her French colleague Emmanuelle Charpentier were the first to demonstrate that scientists could use CRISPR to edit purified DNA in lab dishes. “I don’t know that we know enough about the human genome, or maybe any other genome, to fully answer that question. But people will use the technology whether we know enough about it or not.”

The more rapidly science propels humanity forward, the more frightening it seems. This has always been true. Do-it-yourself biology is already a reality; soon it will almost certainly be possible to experiment with a CRISPR kit in the same way that previous generations of garage-based tinkerers played with ham radios or rudimentary computers. It makes sense to be apprehensive about the prospect of amateurs using tools that can alter the fundamental genetics of plants and animals.

But the benefits of these tools are also real, and so are the risks of ignoring them. Mosquitoes cause immense agony throughout the world every year, and eradicating malaria or another disease they carry would rank among medicine’s greatest achievements. Although it is clearly too soon to contemplate using CRISPR in viable human embryos, there are other ways of editing the human germ line that could cure diseases without changing the genetic lineage of our species.

Children born with Tay-Sachs disease, for instance, lack a critical enzyme necessary for the body to metabolize a fatty waste substance found in the brain. The disease is very rare and occurs only when both parents transmit their defective version of the gene to a child. With CRISPR it would be easy to treat one parent’s contribution—say, the father’s sperm—to ensure that the child did not receive two copies of the faulty gene. Such an intervention would clearly save lives and reduce the chance of recurrence of the disease. A similar outcome can be achieved already through in vitro fertilization: Implanting an embryo free of the defective gene ensures that the child won’t pass the disorder on to a future generation.

When faced with risks that are hard to evaluate, we have a strong tendency to choose inaction. But with millions of lives at stake, inaction presents its own kind of danger. Last December scientists from around the world met in Washington to discuss the difficult ethics of these choices. More discussions are planned. There will never be simple answers, but without any regulatory guidance—and there is none yet for editing human DNA—the tremendous potential of this revolution could be overshadowed by fear.

“With gene drives and CRISPR we now have a power over species of all kinds that we never thought possible,” says Hank Greely, director of Stanford’s Center for Law and the Biosciences. “The potential good we can do is immense. But we need to acknowledge that we are dealing with a fundamentally new kind of power, and figure out a way to make sure we use it wisely. We are not currently equipped to do that, and we have no time to lose.”

### Biofuels Links

#### CRISPR can be applied to plant sciences and improve biofuels

Alice Park, June 23, 2016, <http://time.com/4379503/crispr-scientists-edit-dna/> A New Technique That Lets Scientists Edit DNA Is Transforming Science—and Raising Difficult Questions

So while Niakan moves forward with her work, scientists around the world are exploring other ways to deploy this powerful new tool. At the University of California, Riverside, a team is reprogramming a yeast strain to convert sugars into the components of biofuels. A plant pathologist at Pennsylvania State University has created a mushroom that doesn't brown. At Temple University in Philadelphia, scientists have used CRISPR to successfully excise HIV from human cells in a lab--and in living animals infected with the virus. Scientists envision creating cows that make more milk, tomatoes that don't taste like water and--that stuff of science fiction--the ability to bring back extinct species. In July, the National Institutes of Health (NIH) will issue recommendations on the first bid to test a CRISPR-based medical treatment, on people with myeloma, by taking out their blood cells and revving up their cancer-fighting genes with CRISPR and then returning the newly edited disease-free cells.

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# General Pros & Cons

#### Five pros and cons

Keren Weintraub, National Georgraphic, December, 2015, https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/ 5 Reasons Gene Editing Is Both Terrific and Terrifying

In Washington, scientists and ethicists talked about science, ethics, human rights, government relations and Aldous Huxley’s futuristic 1932 novel Brave New World, offering five basic reasons that gene editing is exciting—but scary:

1. Curing disease

By eliminating genes that cause disease, doctors could treat a wide range of illnesses, from heart disease to Alzheimer’s.

Scientific challenges remain, such as making sure that the right gene—and only the right gene—gets changed. But gene therapy is now being used to treat eye disease, and early trials suggest that it may be able to treat the blood disorders beta thalassemia and sickle cell anemia, said Fyodor Urnov of Sangamo BioSciences, a leader in blood disease research.

Even for this seemingly noble cause, there are moral challenges: namely, which conditions to treat. And not everyone necessarily wants to be “cured.”

To some people labeled with disabilities, “editing may be more akin to getting pushed through a shredding machine,” said Ruha Benjamin, an African-American Studies and bioethics professor at Princeton University.

2. Stopping inherited disease in its tracks

Diseases that are passed down in families, like Huntington's and Tay-Sachs, might one day be simply snipped out of the family line.

Though we can already screen for some genetic diseases and avoid them using in vitro fertilization, new CRISPR methods could potentially make much more complex edits. Harvard Medical School geneticist George Church recently showed that with the new CRISPR methods, he could edit 60 embryonic pig genes simultaneously. This may be harder in people, though, and since we don’t know the full roles of most of our genes, we can’t know the risks involved in editing them.

People who carry a genetic risk for Alzheimer’s might some day be able to benefit from new efforts to change genes.

Rudolf Jaenisch, a stem cell biologist at MIT and the Whitehead Institute, raised another ethical concern: Is it morally acceptable to edit the genes of healthy children in the hopes of preventing unhealthy ones? In his research on mouse embryos, he’s found that he can’t edit the genes of diseased mice without also affecting the genes of mice that would otherwise be healthy.

In trying to prevent a genetic mutation in sick children, doctors would have to introduce a gene mutation into healthy ones. Such a mutation would carry forward into the human population, and no one knows whether it would have an unintended effect.

3. Creating a better you

Keren Weintraub, National Georgraphic, December, 2015, https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/ 5 Reasons Gene Editing Is Both Terrific and Terrifying

Theoretically, gene editing could also be used to make so-called designer babies. Traits governed by a small number of genes would be the most straightforward to manipulate, such as muscularity, eye color, height, and memory, said George Daley, a stem cell biologist at Harvard Medical School.

Editing genes for more complex traits like intelligence would be more difficult or impossible. “You don’t know what else you’re going to get,” Sheldon Krimsy of Tufts University, who writes about science and ethics, said in an interview. “The genome is an ecosystem. Everything is in some kind of balance. You try to maximize one quality and you may affect another one.”

What's more, if a change is introduced into the human population, and can be inherited, it could be hard to remove—and won't stay put in a particular community or country.

Unlike curing disease, genetic enhancement would be morally reprehensible, said Marcy Darnovsky, who heads the nonprofit Center for Genetics and Society.

She worries that parents will feel pressured to “improve” their kids and that wealthy families will have greater access than poor ones. “There would be fertility clinics vying to sell the latest upgrades." And parents might be pressured to ‘give their child the best start in life.’

4. Saving endangered species

Keren Weintraub, National Georgraphic, December, 2015, https://news.nationalgeographic.com/2015/12/151203-gene-editing-terrific-terrifying-science/ 5 Reasons Gene Editing Is Both Terrific and Terrifying

The same technology used to edit human genes can be used on animals. This could mean protecting a species like the Tasmanian devil, now endangered by an infectious cancer, or engineering the East Coast's chestnut trees to resist the chestnut blight that has devastated their growth.

“We’re faced with the sixth great mass extinction," Gary Roemer, a wildlife ecologist at New Mexico State University, said in an interview, "and this allows us to avert or perhaps just postpone the decline of certain species.”

On the other hand, he and others were horrified at the possibility that someone might use gene editing as justification for putting off a species rescue “because we can always solve the problem later.”

"We’re faced with the sixth great mass extinction." —Ecologist Gary Roemer

“I’m very much against that kind of arrogance,” said Stuart Pimm, the Doris Duke professor of Conservation Ecology at Duke University. “We should be good stewards. We should look after biodiversity.”

5. Resurrecting extinct species

Gene editing could even be used to bring back extinct species, or at least parts of them, for example by mixing genes from extinct species back into existing ones. A group called The Long Now Foundation supports these scientific efforts, and hopes first to bring back the passenger pigeon and then the wooly mammoth.

De-extinction could also resurrect traits lost to commercial breeding, like the great natural taste of tomatoes, bioethicists, R. Alta Charo of the University of Wisconsin-Madison, and Henry Greely of Stanford, wrote in a paper published Wednesday.

But, they write, somewhat tongue-in-cheek, gene editing could also be used to blend or make new species “on a whim” or for commercial or artistic purposes. “Why should we not expect dwarf elephants, giant guinea pigs, or genetically tamed tigers? Or—dare we wonder—the billionaire who decides to give his 12-year-old daughter a real unicorn for her birthday?”

# Books

[**A Crack in Creation**](https://www.theguardian.com/books/2017/jun/17/a-crack-in-creation-by-jennifer-doudna-and-samuel-sternberg-review)**:** Gene Editing and the Unthinkable Power to Control Evolution by Jennifer Doudna and Samuel H. Sternberg

[**The Gene: An Intimate History**](https://www.theguardian.com/books/2016/jun/06/the-gene-an-intimate-history-siddhartha-mukherjee-review)by Siddhartha Mukherjee

[**The Epigenetics Revolution:**](https://www.theguardian.com/books/2011/aug/19/epigenetics-revolution-nessa-carey-review) How Modern Biology is Rewriting our Understanding of Genetics, Disease and Inheritance by Nessa Carey

[**Modern Prometheus: Editing the Human Genome with Crispr-Cas9**](https://www.guardianbookshop.com/modern-prometheus.html) by Jim Kozubek