

SCIENTIFIC AMERICAN®

<https://blogs.scientificamerican.com/observations/human-genome-editing-who-gets-to-decide/>



[Observations](#)

Human Genome Editing: Who Gets to Decide?

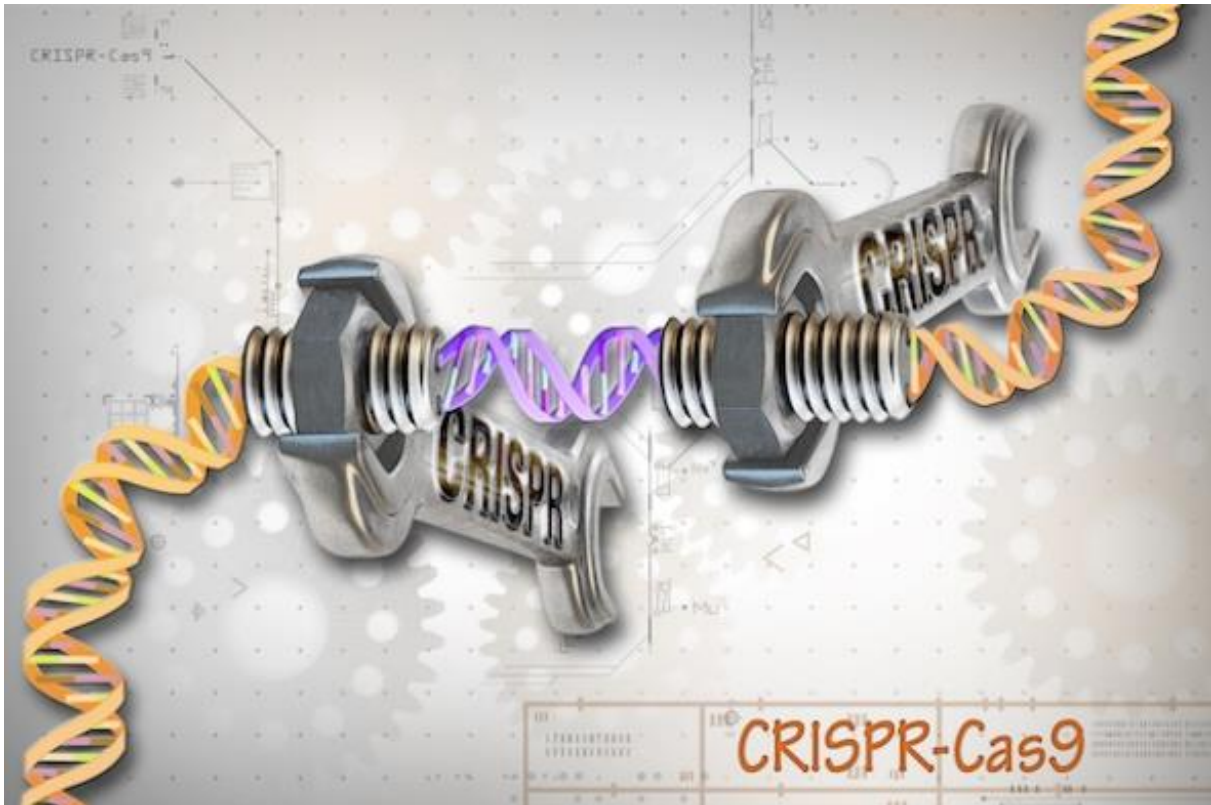
A report from the National Academies says scientists alone can't make the call—they must engage with the broader public

Dietram A. Scheufele

Dietram A. Scheufele, Ph.D. is the John E. Ross Professor & Vilas Distinguished Achievement Professor in the University of Wisconsin-Madison Department of Life Sciences Communication

David Beier

David Beier, J.D. is Managing Director at Bay City Capital in San Francisco



Credit: [Ernesto del Aguila III, NHGRI Wikimedia](#)

Meaningful public debate seems almost impossible in an era of political bubbles isolating us one from another and facts becoming a matter of opinion. Unfortunately, our political culture is crumbling just as rapid scientific breakthroughs confront us with some of the most serious moral, ethical and policy questions of our age.

And there is a real urgency. Scientific breakthroughs surrounding human gene editing, for instance, have moved medical treatments that seemed science fiction just a few years ago within scientists' reach. Today, tools like CRISPR/Cas9 allow making modifications to the human genome in ways that are more efficient and safer than ever before. And the science emerges rapidly, constantly offering new venues for treating what used to be incurable diseases.

The idea of editing the human genome raises questions that science alone cannot answer. What are the ethical and moral boundaries of the human race editing its own genome? Who will have access to many of the potentially expensive medical treatments resulting from this new area of research? And where is the line between treating serious disease and enhancing humans beyond what society considers "normal?"

None of these questions have simple or obvious answers. What is needed are broad societal discussions, not just about the scientific risks and benefits, but also about the moral, political, and societal complexities surrounding human genome editing.

Even though the scientific community cannot provide definitive answers to some of these moral or political questions, meaningful public debate is impossible if it is not based on the best available science and accurate facts. We in the scientific community therefore have a special obligation to fully engage with a broader public—both about the science of human gene editing and on the societal concerns that may arise from its applications.

As members of the National Academy of Science and National Academy of Medicine study committee that recently released its [final report on human genome editing](#), we were tasked to offer opinions about the future direction and medical promise of breakthroughs in biology. We looked intensely through public hearings here and abroad—as well through a literature review—for diverse voices on the moral, regulatory and ethical issues associated with multiple uses of these technologies. Our conclusions point to the hopes and perils these breakthroughs offer.

We all recognized that none of us could or should speak for the larger public. A central theme throughout our report was the need for the key decision makers in science—both private and government—to commit to a robust, systemic, substantive and ongoing public dialog. The Genome Editing report was a step along that road, but it is not the final destination.

Some mechanisms for engagement are already in place, especially including when it comes to the approval of clinical trials within existing regulatory frameworks. But the need for broad public debate will likely emerge from questions that fall outside of the regulatory realm and deal with areas where science raises value-based or moral concerns.

For the scientific community, this will sometimes mean going beyond their comfort zone and engaging with a wide variety of audiences on questions of faith, morality, and values. It also means that the reason for the scientific community to engage in these debates is not to convince people of particular viewpoints or to promote this new technology. Instead, what all public engagement efforts should have in common is a commitment to listening to and respecting the voices of others, including ones from audiences less versed in the details or facts of the subject matter. And listening can start long before the engagement itself, using public opinion surveys, focus groups, and a host of other tools.

The broader scientific community also has a responsibility to engage as educators to offer facts to help inform the debate, particularly if faced with groups who intentionally misrepresent or ignore the best available science and facts that underline it. Scientists need to understand that a majority of citizens who may express concerns about human gene editing or its applications are neither ignorant nor wrong.

Policy choices for most citizens involve weighing different societal, political, moral, and scientific risks and benefits. It is very likely that some will agree with scientists that a technology like human gene editing is “safe” and still oppose it on moral or religious grounds. The relative weight we as citizens put on any risk or benefit depends on social contexts, including class or economic status, on media portrayals, and on personal value systems, to name just a few. All of those factors shape how we each recalculate our mental algorithms as new information about risks or benefits emerges.

Public engagement on human gene editing is not a box that we need to check before proceeding with potentially controversial applications. It is an ongoing process that will help science *and* society understand and navigate the societal, political and moral complexities that will emerge as CRISPR and other scientific breakthroughs continue to innovate medicine and many other areas of our lives.

In sum, the time for science policy setting being done exclusively by scientists is over, and when ethical and moral issues (like genome editing) arise the era of full public engagement has begun.

The views expressed are those of the author(s) and are not necessarily those of Scientific