

The politics of gene editing: How to handle a post-CRISPR world

Alex Pearlman

Journalist, Bioethics at King's College London

@lexikon1

Who am I?



90.9 wbur
BOSTON'S NPR® NEWS STATION

NewScientist

The Boston Globe



ALJAZEERA

What am I talking about?



CRISPR-Cas9

Let's start with a thought experiment

More Convenient

Would you like to be engineered to be able to go without sleep for days?

Better

What about the idea of giving everyone a little boost in empathy? Make the world a better place?

What is our responsibility?

Isn't it our moral duty to have the best possible children with the best possible chance at living their best life?

Faster

Would you like the ability to perform 50% better, physically, than other humans?

Smarter

Feeling like you could do with some tweaking when it comes to a gene for intelligence?

A little bit of history on regulations

US

Stem Cells -- Banned under Bush.

Saved (kind of) by Obama.

Private IVF clinics -- Unregulated.

Mitochondrial Donation -- Approved by an ethics board, rejected by the FDA.

UK

Stem Cells -- Legal. And regulation goes way beyond US.

Private IVF -- Regulated by HFEA.

Mitochondrial Donation -- Going forward with pregnancies soon.

Where we are now

China Has Launched the First-Ever CRISPR Gene-Editing Trial in Humans

CRISPR: gene editing is just the beginning

The real power of the biological tool lies in exploring how genomes work.

**GENE
EDITING
WILL
TRANSFORM
CANCER
TREATMENT**

Obama's Science Advisors Are Worried About Future CRISPR Terrorism

Monsanto licenses CRISPR technology to modify crops

Genetic editing is like playing God - and what's wrong with that?

Don't edit the human germ line

What's the difference between genetic engineering and eugenics?

Jennifer Lopez could bring CRISPR to primetime

US next in line to test CRISPR gene editing technology on human cells

Federal panel approves first test of CRISPR editing in humans

U.S. Public Wary of Biomedical Technologies to 'Enhance' Human Abilities

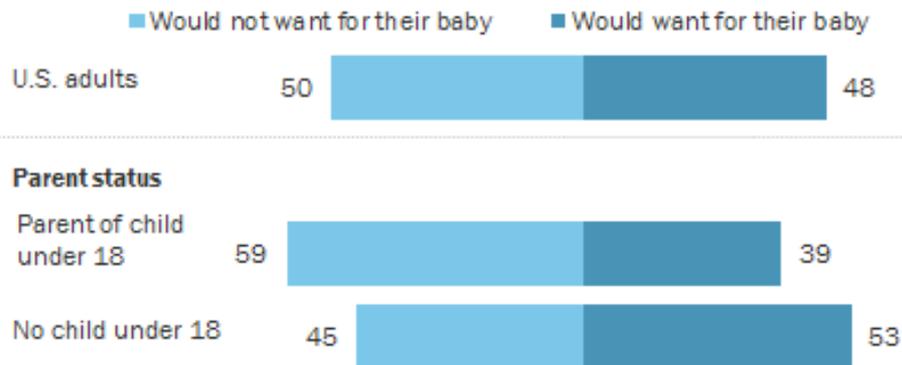
Americans are more worried than enthusiastic about using gene editing, brain chip implants and synthetic blood to change human capabilities

Where we are now

- 42% had never heard of gene editing, but of those who had, 57% were in favor of it
- Trend lines fall along religious divides
- Only 28% overall say that gene editing to cure disease is morally acceptable

Public closely divided over whether they would want gene editing to reduce their baby's risk of disease

% of U.S. adults who say the possibility of gene editing to give healthy babies a much reduced risk of serious diseases is something they would/would not want for their baby



Note: Respondents who did not give an answer are not shown. "Definitely" would/would not want and "probably" would/would not want responses combined.

Source: Survey of U.S. adults conducted March 2-28, 2016.

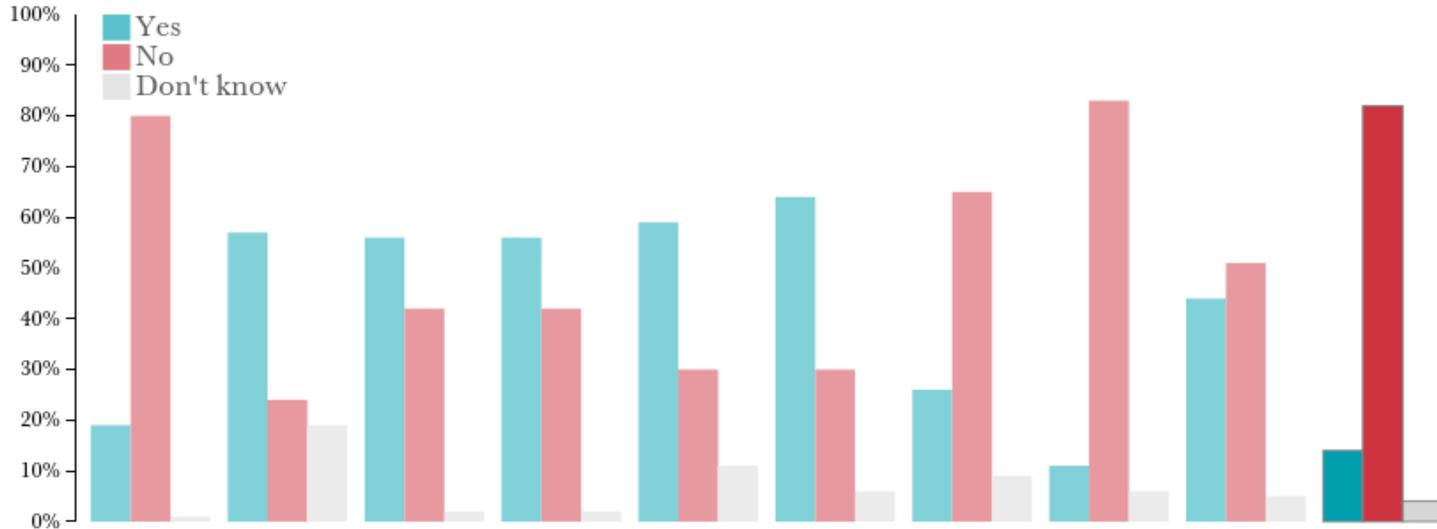
"U.S. Public Wary of Biomedical Technologies to 'Enhance' Human Abilities"

PEW RESEARCH CENTER

Therapy vs. Enhancement

STAT-Harvard Poll on Genetic Editing, Testing, and Therapy

Based on a telephone poll of 1,000 US adults conducted January 13 - 17, 2016



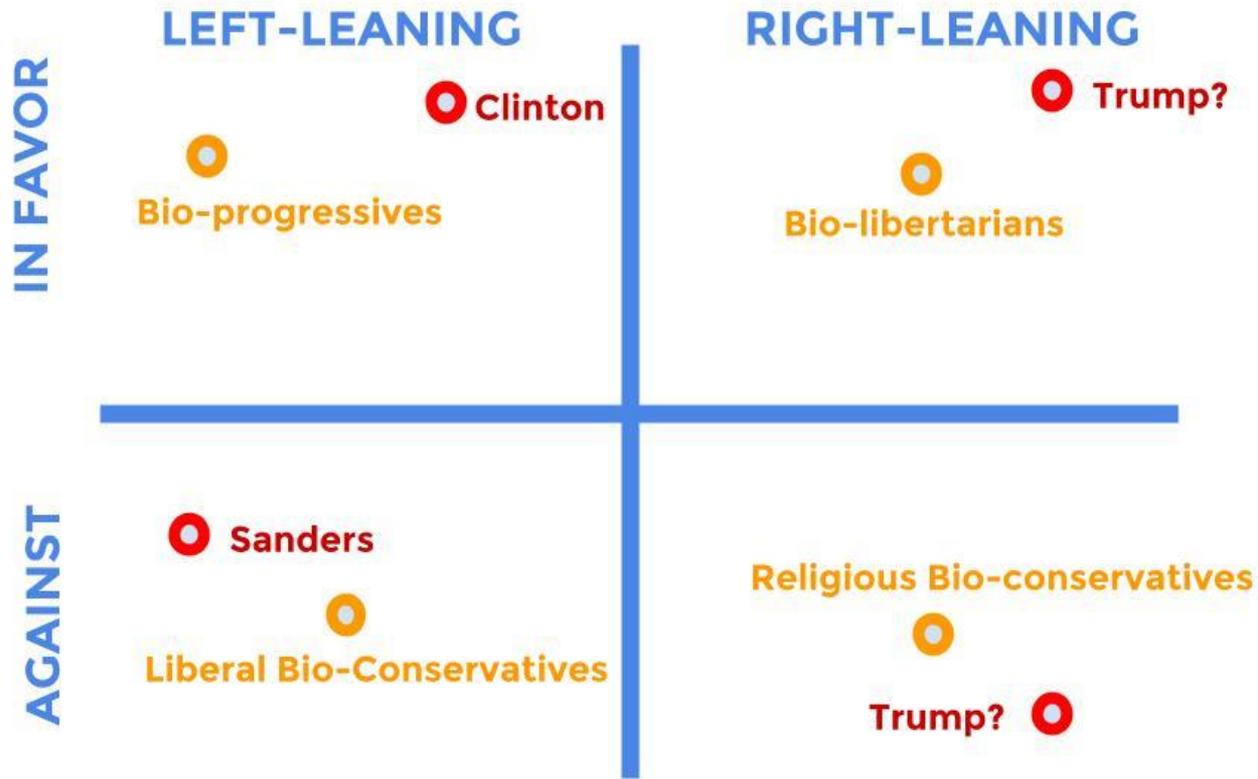
Do you think the federal government should fund scientific research on changing the genes of unborn babies that aims to improve their characteristics such as intelligence or physical traits such as athletic ability or appearance?

Yes: 14%, No: 82%, Don't know: 4%

Therapy vs. Enhancement

Nevertheless, a clear overall pattern emerges from the polling results. The public's views are largely in line with the conclusions of the organizing committee of the recent NAS summit. Most of the public favors gene therapy for clinical use in patients with serious diseases. The majority do not support gene editing in human embryos or germline cells, but the level of opposition varies depending on its goals. Of course, public opinion could change over time as discussions of these issues continue to evolve and as more is learned about the implications and safety of gene-editing technologies.

The BioPolitics Grid



The BioPolitics Grid



comment reply *AMA: I'm Zoltan Istvan, a transhumanist US Presidential Candidate. Ask me anything!!*

↑ from [Zoltan_Istvan](#) via [/r/Futurology](#) sent 29 days ago

Hey Zolt. Wondering if you can talk a little bit about your thoughts on regulating human enhancement through gene editing methods such as CRISPR. I know as a libertarian-leaning person, you are against agency regulation in general, however, do you feel there is a place for a regulatory agency outside or parallel to the FDA to oversee safety and efficacy of human enhancement and germline modification? Thanks! - AP.

On this, I just really don't think we need regulation. I think the greater concern is that China goes full speed ahead with genetic editing and America gets left behind and we dance around whether it's a good idea--and then shortly after a new generation of Chinese babies are born with better genetic intelligence than everyone else (posing a serious national security and cultural issue). I say embrace it. We don't need a new agency for gene editing.

[context](#) [full comments](#) (242) [report](#) [block user](#) [mark unread](#) [reply](#)

The BioPolitics Grid



<https://www.youtube.com/watch?v=3GPqfG1VQ9U&feature=youtu.be>

The BioPolitics Grid

“My worry is asymmetrical access to gene editing will create further divides between socioeconomic classes.”

“I would want to see legislation that bans "cosmetic" gene editing in embryos.”

“...the state's obligation, if any, is to facilitate that those who want/need the therapy get it. That approval should have nothing to do with the inheritability of the gene edit.... The concern about equality is only relevant to the therapeutic category - if we ban it because it doesn't work or isn't safe, then equity is irrelevant.”

“I think if we ban it it will just be pushed more into the streets and be more "high tech, low life" cyberpunk and dangerous wetware hacking. People will go to other countries or seek out underground labs...”

“China: that's my argument”

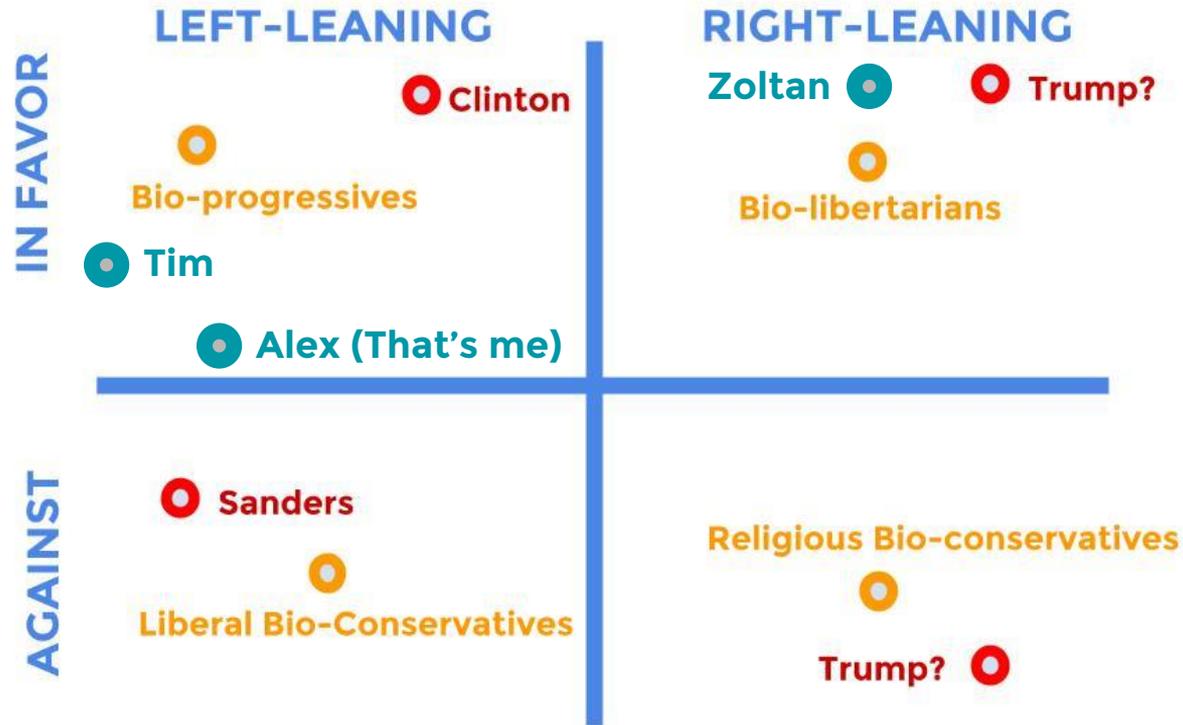
“Regulate for safety if a case can be made that this is somehow unsafe, with the understanding that the consumer of this tech should be free to make their own risk reward assessments (vs having the nanny state make overly conservative ones).”

“The possibility to eradicate disease or create immunities - to genuinely help all of humanity - are epic. Which means we have to do it.”

A company could try to patent a new human they created and own a new species of people. How far would that ownership go?”

“If I had the choice now to have it fixed ohhh hell yes I would! It's holding me back from my life!”

The BioPolitics Grid



What's next? Four future thoughts

- **More public engagement**
Education, and a media apparatus that actually functions
- **Commonsense policy: bring in a multi-stakeholder, intersectional cohort to discuss these issues.**
Many voices need to be heard, especially those from the biohacking, feminist, racial justice and disability rights communities
Look at non-human applications as well
- **Let the experts be experts, but let them be informed by public opinion.**
We live in a democracy
- **Keep an eye on the social justice issue**
The thing we hear so much about is fear of “1% designer babies”

Thank you

