My body, my genes

Biohackers want to alter their own DNA with the gene-editing technique CRISPR. Should we stop them, asks Alex Pearlman

GENE editing is entering the mainstream. CRISPR, a cheap and easy technique for making precise changes to DNA, has got researchers around the world racing to trial its use in treating a host of human diseases.

But this race is not confined to the lab. Last month, Josiah Zayner, a biochemist who once worked for NASA, became the first person known to have edited his own genes with CRISPR. During a lecture about human genetic engineering that was streamed live on Facebook, Zayner whipped out a vial of edited DNA and a syringe, then injected himself. Now, following in his footsteps, other biohackers are getting ready to take the plunge and tinker with their own genes.

Away from the strict controls of formal science, this self-experimentation might seem dangerously reckless. But if people are allowed to modify their own body through cosmetic surgery, tattoos and other augmentations, should a person’s own genome really be off limits?

Zayner’s experiment was intended to boost his strength by removing the gene for myostatin, which regulates muscle growth. A similar experiment in 2015 showed that this works in beagles whose genomes were edited at the embryo stage. He injected himself with a copy of his own DNA that had been edited using CRISPR to remove the gene.

Robin Lovell-Badge, a leading CRISPR researcher at the Francis Crick Institute in London, says Zayner’s experiment was “foolish” and could have unintended consequences, including tissue damage, cell death, or an immune response that attacks his own muscles.

“Will allowing broad access to CRISPR risk creating a group of ‘superhumans’ with enhanced abilities?”

“He’s got a very large ego and he wants to make his muscles the same size as his ego, maybe,” says Lovell-Badge.

A single injection is unlikely to cause a lasting change, but Zayner’s stunt shows that it is possible for individuals to use the gene-editing technology. The general consensus is that a course of two or three injections per week for a few months is required to see a permanent alteration.

That may happen soon. Zayner has created a kit that is for sale through his company, The Odin, in Oakland, California, which will allow others to replicate his work. Rich Lee, a biohacker in Utah who is colour-blind, says he wants to use Zayner’s kit to not only cure his colour blindness, but take his eyesight to the next level. He wants to see into the ultraviolet spectrum, a rare genetic mutation called tetrachromacy that is sometimes found in women.

Another biohacker, David Ishee from Mississippi, whose previous attempts to use CRISPR in dogs were shut down by the US Food and Drug Administration (FDA), also intends to boost his muscle mass. He won’t be using CRISPR, but will inject an extra copy of the gene for follistatin into his cells. Where myostatin inhibits muscle growth, follistatin increases muscle mass and has been linked with accelerating metabolism.

These biohackers believe it is a basic human right to access and edit one’s own genome. “I am of the opinion that your genome is your own,” says Ishee. “I think that it is important that people have the ability to choose what kind of gene expression they want for themselves.”

This ethos of “my body, my choice” is used to underpin arguments for health, reproductive and disability rights, but should it extend to the right to edit our own genes? What about the potential unintended effects of using untested technology? And will allowing broad access to CRISPR risk creating a group of “superhumans” with enhanced senses and abilities?

These are some of the many issues that have plagued scientists and ethicists for years. Recent papers from the US National Academies and the Nuffield Council on Bioethics in the UK have attempted to grapple with these questions, including whether there is a moral difference between gene editing for medical therapy versus enhancing ordinary abilities.

John Harris, a bioethicist at the University of Manchester, UK, who has written about human enhancement since the 1980s, does not believe there is a significant difference. He thinks the biohackers could help move the arguments along and hasten the safe use of CRISPR in humans.
Bizarrely, because The Odin’s kits are not technically drugs, and Zayner is not attempting to actually practice medicine on anyone or market a medical device, the FDA will not yet regulate at-home genome editing. At the moment, self-experimentation is not illegal and so DIY CRISPR resides in a legal grey area in the US and UK. That isn’t true everywhere. In Germany, which clamps down on anything that carries even the slightest whiff of eugenics, the kits set off alarm bells with officials in Bavaria earlier this year and were banned from use in homes and schools.

Within the regulatory debate, it is also important to note that most biohackers aren’t intending to hack anyone other than themselves – but they are keen to help others do it at home, and sharing information transparently is tantamount. It is their version of peer-review, mostly conducted on forums and social media.

“I’m definitely going to be collecting a lot of data and sharing it,” says Ishee. “My goal is to put everything out there. There is some probability that it won’t work, right? But maybe the next guy gets it right.”

And what if “the next guy” is a future Olympic medallist? The World Anti-Doping Agency (WADA) announced last month that it would ban all forms of gene therapy or gene doping from international competitive sports from 2018. However, it’s unlikely that international testers will be able to detect most forms of gene editing, and with all the free-flowing information about various experimental enhancements, it seems even less likely that WADA will be able to enforce this ban. “WADA is a joke,” says Ishee.

Günes Taylor, who also works with CRISPR at the Francis Crick Institute in London, says she is conflicted by these home-brew experiments.

“Part of me is, like, ‘that is so awesome’... but it won’t work,” she says, insisting it will be more difficult than the biohackers think. “CRISPR has been sold as a cure-all... but actually getting it to do the thing that you want it to do successfully is more complicated.”

Taylor thinks there could be scientific benefits to monitoring how biohackers modify their bodies, giving us more information about how CRISPR works in humans, but the potential for harm means this would be unethical, and DIY experiments should be more heavily regulated.

But biohackers think the trouble is worth the risk, and there is no ethical reason they shouldn’t be allowed to use their own bodies to try to push science forward.

Perhaps instead of trying to take experiments away from the DIY community, we need to accept that we stand on the cusp of significant changes to the human genome – because they are going to do it anyway.

“We have this knee-jerk reaction that your genetics should always be up to chance, that there shouldn’t be a choice,” Ishee says. “But I don’t think that’s true or right. If the technology exists to give you the choice, you may as well make it.”

The question now is how to make sure genome editing is safe and accessible to use for the wider public, who may not fully understand the risks of self-experimentation. Lovell-Badge says he supports the biohacker community, and has attended their meet-ups, but they must be responsible and acknowledge possible consequences of spreading CRISPR widely, or face a crackdown. “It’s very hard to write regulations which allow people to play around with science in their garage,” he says.