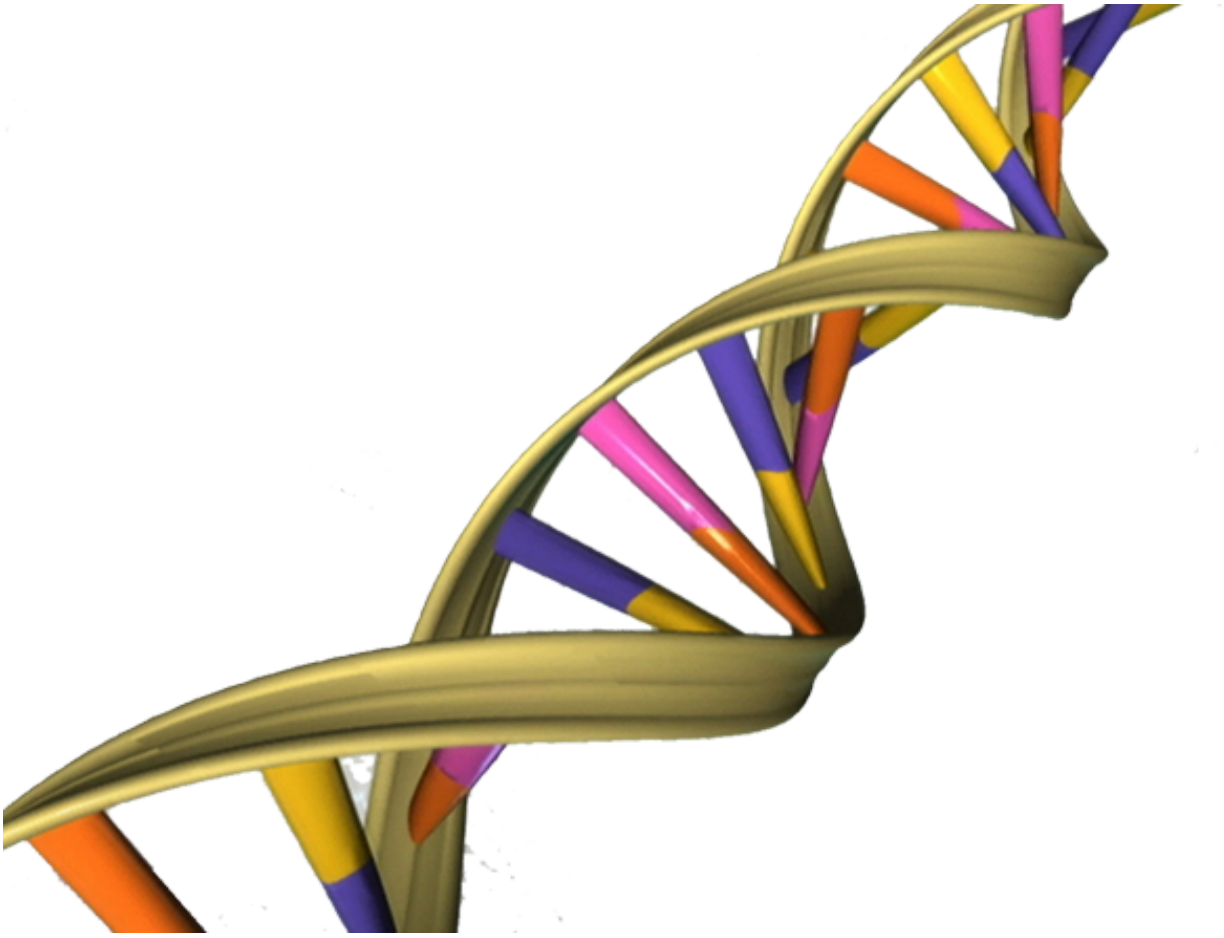
Guidelines for human genome editing

January 21 2016



A depiction of the double helical structure of DNA. Its four coding units (A, T, C, G) are color-coded in pink, orange, purple and yellow. Credit: NHGRI

Human genome editing for both research and therapy is progressing, raising ethical questions among scientists around the world.

On the one hand, technical advances could enable doctors to modify germline genes - those contained in sperm and eggs - to prevent offspring from developing devastating genetic diseases. At the same time, the potential for gene editing to alter human inheritance also alarms many scientists, prompting some to argue that germline editing should be prohibited indefinitely.

As countries around the world seek to craft policy frameworks governing the powerful new genetic editing tool, policy makers need to determine "thresholds of acceptability" for using the technology, according to three researchers from the Centre of Genomics and Policy at McGill University.

Rosario Isasi, Erika Kleiderman and Bartha Maria Knoppers suggest in a 'Perspectives' article in *Science* magazine that policy makers could be guided by the model that has served to develop policies governing pre-implantation genetic diagnosis after in vitro fertilization.

Pre-implantation genetic diagnosis (PGD), used to identify genetic conditions in embryos and prevent certain diseases from being passed on to the child, "was first regarded as highly controversial and now is mainly governed within the general biomedical research context," the researchers write. Many countries allow genetic testing in pre-implantation embryos, subject to medically determined requirements such as the gravity of the genetic condition and a substantial risk of occurrence.

Robust approach

While the PGD model is still "relatively flawed and contentious," they argue that it represents "a robust approach to regulation" in the thresholds it is delineating for medical determinations and substantial risk of occurrence.

"Many questions still remain to be addressed," with regard to genome editing, the researchers add. For example: Are there potential defensible uses for genome editing so as to select, or de-select certain human traits? Are there any thresholds for non-medical interventions?

Still, they conclude, "Public acceptance may change as the benefits of genome editing emerge for disease prevention. Eventually, as we move from research to the clinic, the collective sum of individual decisions could constitute a de facto policy."

More information: "Editing policy to fit the genome?" by R. Isasi; E. Kleiderman; B.M. Knoppers, DOI: 10.1126/science.aad6778

Provided by McGill University