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Gene editing – a collective responsibility

EDITORIAL

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In principle, we can now edit the genes of the entire plant and animal kingdom, eradicate genetic diseases and directly influence the evolution of mankind. Research and educational institutions must assume responsibility for the responsible use of the technology.

CRISPR (clustered regularly-interspaced short palindromic repeats) technology enables rapid, cost-effective, precision editing of DNA, and has taken the medical research community by storm (1). Never before have we been able to

replace specific parts of DNA so effectively, down to individual bases. Point mutations can be corrected. Specific genes can be turned on and off. Our imagination is the only limit (1).

If we replace individual genes or polymorphisms in germ cells prior to fertilisation, we can prevent serious hereditary diseases. Just a few years ago, the idea of trying to do that was inconceivable. Then came the news in October 2018 that a young Chinese researcher with a PhD and postdoc from the USA, He Jiankui, had for the first time edited the genes of human embryos (twins) (2, 3). It was recently reported that a scientist in Russia is planning something similar (4). Are we in the process of opening Pandora's box? Yes, without any doubt.

Scientists currently appear to agree that CRISPR babies represent an irresponsible experiment. Philosophers and religious leaders argue that modifying the genes of embryos is morally unacceptable. At the same time, we see growing acceptance for some modifications that prevent serious diseases, still without knowing the full consequences. If we accept individual cases, could we be creeping towards a new norm of "designer babies"?

Norway, like the USA, risks training researchers who take the technology back with them to countries with deficient ethical standards, regulation and enforcement. As an influential research nation, we cannot take our responsibility lightly.

We believe targeted research training, particularly with humanistic methods, and thematic dialogue among research communities, philosophers and ethicists, also in public fora, are crucial for counteracting the undesirable use of new technology. The training of many PhD students includes only a small obligatory course in research ethics. We believe we must encourage researchers to a greater degree to make normative evaluations of their research projects. We can use the Responsible Research and Innovation approach (RRI) to prepare this necessary groundwork. RRI entails constant reflection over the possible consequences of all aspects of the research, and involving different stakeholders from the very start (user participation). Specialists in this approach should be more directly involved in research communities to aid and guide reflection and discussion. These discussions should also regularly be aired publicly in order to be taken up at a higher societal level when needed. RRI expertise is currently found, for example, at the universities of Bergen and Oslo, the Norwegian University of Science and Technology (NTNU), and Oslo Metropolitan University (OsloMet).

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Those who authorise funding should require that Responsible Research and Innovation form a part of the research projects, as the Norwegian Research Council already does for some programmes like the Centre for Digital Life in the BIOTEK2021 programme. This applies in particular where researchers employ methods and technologies with a strong potential for misuse, or with unknown long-term consequences. However, there are no requirements at

present for how Responsible Research and Innovation should be practised. In some cases, such requirements are basically an add-on to a biotechnology project; in others the approach is integrated into the actual research questions and methods. Some of the differences in practice are attributable to different trainings and different cultures and practices within the research communities.

At the same time, we need training with specific requirements in the principles of Responsible Research and Innovation to ensure that the approach is well integrated and serves to sustain high quality projects.

We researchers clearly have an individual responsibility. At the same time, we believe that our research institutions have the primary responsibility for ensuring a responsible path of development, for example by establishing fora that pave the way for constant, conscious reflection on their own research, and by demanding more dialogue extending beyond the laboratory corridors.

Institutions must make sure to instil ethical reflection in the very DNA of their researchers. The question is whether this will be a more difficult job than making CRISPR babies.

LITERATURE

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