

Stocktaking and recommendations for action: the BBAW's fourth gene technology report

In the new gene technology report, the interdisciplinary working group of the Berlin-Brandenburg Academy of Sciences (BBAW) takes stock of gene technology developments in Germany during the past few decades, and discusses the societal, legal and ethical challenges associated with these technologies in the future. The report is highly topical due to the controversy surrounding the ruling of the European Court of Justice on CRISPR/Cas9 genome editing and reports that the first children whose DNA has been altered using gene editing have been born in China.

Cover of the fourth gene technology report, 2018.

© Nomos Verlag, Baden-Baden

The fourth gene technology report presented on 29th October 2018 was originally conceived as the final gene technology report by the interdisciplinary working group (IAG) 'Gene Technology Report' of the Berlin-Brandenburg Academy of Sciences. However, in view of the unrestrained dynamic developments in genetic engineering and their far-reaching consequences for society that are both controversial and hard to predict, the eleven members of

the IAG have agreed to continue critically examining genetic engineering in the future and deriving conclusions and recommendations for action from this. After the group's first three gene technology reports published in 2005, 2009 and 2015 that focused on the current state of research and application, economic use and the ethical, legal and social implications of genetic engineering, the fourth gene technology report, according to its editors "serves to take stock of work of the past 18 years, and reflect on the long-term monitoring of genetic engineering while affording a glimpse into the future".

The IAG Gene Technology Report research group comprises renowned experts from the fields of medicine, natural sciences, social sciences, law, ethics and philosophy who are studying and analysing the six core genetic engineering topics of stem cell research, epigenetics, genetic diagnostics and gene therapy as well as green genetic engineering and synthetic biology from their respective perspectives. As the biochemist Ferdinand Hucho emphasised when presenting the report, the group's interdisciplinary approach is unbiased, independent of particular interests and intended to provide an impartial and objective framework for public discourse on genetic engineering in Germany.

The IAG has published critical surveys on each of these core topics or thematic fields in recent years. The comprehensive report that is now available summarizes a number of socially relevant topics (so-called problem areas) from scientific, social, economic and ethical points of view. Most of these problem areas simultaneously feed into several core topics (see Figure). Suitable indicators have been derived from many different, mostly publicly accessible databases in order to shed light on available information. As statistical parameters, these indicators enable the quantitative description of some problem areas that cannot otherwise be directly measured and compared. For example, the achievement of research objectives and the positioning of Germany as a research location can be illustrated by the number of international articles on the IAG topics as well as the funding measures by the German federal government, the German Research Foundation and the European Union.

Genetic engineering problem areas. Grey-shaded problem areas are relevant to three or more topics covered by the gene technology report; white areas are relevant to one or two topics.

© Marx-Stölting, L./Könninger, p. (2018): Problemfelder der Gentechnologien gestern und heute. In: Hucho, F. et al.: Vierter Gentechnologiebericht, Nomos, Baden-Baden.

Legal obstacles and recommendations for action

The report carries particular weight because of its well-balanced, well-founded and detailed recommendations for action on the problems and risks associated with genetic engineering. The recommendations refer to the areas of research and application in various thematic fields that will be specifically funded in the future in Germany, where public awareness of the status and possibilities of research needs to be improved and where monitoring by supervisory and regulatory authorities is necessary. The IAG experts emphasize the incomplete, inconsistent or even constitutionally unjustified provisions in the Embryo Protection Act and the Stem Cell Act that require revision. One can only hope that the BBAW's gene technology report,

and in particular their recommendations for action, will be consulted by decision-makers in science, research and health policy in Germany who are involved in this issue.

When the report was presented on 29th October, the discussion mainly focused on genome editing and its potential applications in gene therapy, drug development, plant breeding, but also in the development of animal research models, biomaterials and biofuels. Bernd Müller-Röber, IAG member and president of the Association of Biology, Biosciences and Biomedicine in Germany, emphasized that major efforts should be made to pursue the German Federal Ministry of Research and Education's initiative on the further development of existing genome-editing technologies and the cultivation of crops. In an open letter to the Federal Minister of Research, Anja Karliczek and her colleague in the Ministry of Agriculture, Julia Klöckner, Müller-Röber and 130 other renowned scientists call for the ruling of the European Court of Justice not to be taken as the last word on the issue and for the definition of genetically modified organisms used in the old EU Directive 2001/18/EC to which the ruling refers to be at least updated to take scientific progress into account.

With regard to the genome editing of stem cells, the IAG gene technology report recommends consistent, long-term research, "as new opportunities for patient-specific therapy and drug development for previously untreatable diseases can be expected. At the same time, the safety and risk aspects of possible applications of genome editing should be thoroughly researched, since this is the only way that professional assessment and consideration of the opportunities and risks can take place. In contrast, germ line interventions using genome editing that have potential effects on a developing human being need to be avoided now and in the future."

Back in 2015, the BBAW published a joint statement with other German Academies of Sciences, including the German Academy of Science and Engineering acatech and the German Research Foundation, calling for an international moratorium "on all types of artificial germline intervention in humans through which changes in the genome can be passed on to offspring, [...] open questions need to be discussed critically and transparently, the benefits and potential risks of the methods need to be evaluated and recommendations for future regulations need to be developed."

Pandora's box

Chancen und Grenzen des genome editing (2015)

© Leopoldina

On 26th November 2018, the sensational news from China that two genetically edited babies had been born in the southern city of Shenzhen spread round the globe; researchers had used CRISPR-Cas9 to alter the genes of the babies' CCR5 receptor, a mutation that confers resistance to HIV during early embryonic development. There is no independent confirmation of the allegations made by the Chinese medical doctor He Jiankui from the Southern University of Science.

Moreover, He has not yet published the results. Yet the news alone caused dismay and provoked fierce criticism worldwide. The fear is that protections against abusive genetic manipulation that various parties have attempted to implement are starting to crumble. The French scientist Emmanuelle Charpentiers, who was awarded the Leibniz Prize for the development of the CEISPR/Cas9 technology and is now at the Max Planck Institute for Infection Biology in Berlin, has expressed genuine concern that the researcher has "crossed a red line mainly because he has ignored the concerns of the international science community regarding the safety of germline interventions." Along with a group of 122 scientists in China and around the world, Feng Zhang, a Chinese neuroscientist at the Board Institute and co-developer of CRISPR-based genome editing, has appealed for China to swiftly put regulations and controls in place as He's experiments have opened Pandora's box. Perhaps there is a chance for it to be closed again in time.

References:

Vierter Gentechnologiebericht. Bilanzierung einer Hochtechnologie. Editor: Ferdinand Hucho, Julia Diekämper, Heiner Fangerau, Boris Fehse, Jürgen Hampel, Kristian Köchy, Sabine Könniger, Lilian Marx-Stölting, Bernd Müller-Röber, Jens Reich, Hannah Schickl, Jochen Taupitz, Jörn Walter, Martin Zenke, Martin Korte (Spokesperson). Nomos Verlag, Baden-Baden 2018. Open Access, accessible at: www.nomos-elibrary.de/10.5771/9783845293790

The opportunities and limits of genome editing. Joint statement of the German Research Foundation, the National Academy of Sciences Leopoldina, acatech – German Academy of Science and Engineering and the Union of the German Academies of Sciences. (2015, 30 pages, ISBN: 978-3-8047-3493-7)

Article

10-Jan-2019

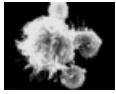
Dr. Ernst-Dieter Jarasch

© BIOPRO Baden-Württemberg GmbH

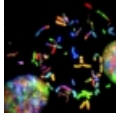
Further information

- Innovations to facilitate a greener world
- Vierter Gentechnologiebericht

The article is part of the following dossiers



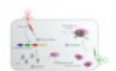
Cell and gene therapies: from bench to bedside



Genetic diagnostics: technology reaches the limits of what is medically reasonable



Progress expands bioethical boundaries



CRISPR/Cas – genome editing is becoming increasingly popular

genetic diagnostics

genomics

gene therapy

stem
cell

synthetic biology

biomaterials

genetic engineering

basic
research

plant breeding

CRISPR/Cas