



Revolution in the gene laboratory: what do citizens demand?

Targeted gene alteration is becoming easier with new methods in biotechnology. What does the population think? The BfR has made it possible for consumers to vote on this.

Heat-resistant wheat, gene therapy against hereditary diseases, the body's own cancer defence genes. All of this could come true with the help of novel DNA scissors. Genome editing is the technical term for precisely cutting out and replacing individual gene sequences/hereditary molecules (DNA). Customised editing of genetic material has been practised for several years. "But only 14 percent of the population are familiar with the new technology," explains private lecturer Dr. Gaby-Fleur Böl, Head of the Risk Communication Department at the BfR. This was shown by the biannual BfR surveys on consumer topics. "In a democracy, revolutionary technological methods that raise ethical and socio-political questions should be publicly discussed and public participation should be facilitated." In order to achieve this dialogue, the BfR utilises and explores the approach of consumer conferences.

BfR consumer conference on genome editing

The BfR wanted to know: what do consumers think about the use of DNA scissors to alter the genome of plants, animals and humans? This was debated by 20 randomly selected men and women, sometimes heatedly but mostly objectively, at the BfR consumer conference on the application of genome editing in nutrition and human health. The conference was held over the course of three weekends in Berlin in 2019; two were used for preparation, and on the third, everyone came together for the final meeting with an expert hearing,

the drafting of the consumer vote and the vote's public presentation. "Consumer conferences are an instrument for making the opinions of the population visible and for taking them into account in political decisions," explains Dr. Leonie Dendler, who is providing scientific support for the project at the BfR and is conducting research into how scientific institutions can make the best use of regular participation procedures. Consumer conferences focus on the discourse on benefits and risks and not the representativeness of opinions.

Genome editing: from breeding to design

People have always influenced the genetic blueprint through breeding, initially through selection. Starting in the 1970s, genetic engineering made it possible to transfer entire hereditary factors (genes). Modern procedures can alter the individual genetic material (genome). To do this, the hereditary molecule DNA is cut through to remove or add genes. This edits the genetic material – hence the term "genome editing". The most well-known method is CRISPR/Cas9, which was developed by microbiologist Emmanuelle Charpentier from the Max Planck Unit for the Science of Pathogens.

What is a consumer conference?

This is a moderated method of direct citizen participation in contentious public issues. It captures a differentiated – but not representative – opinion of citizens. This aims to make the diversity of opinion in a society more visible and incorporate it into the socio-political decision-making process. The result is a vote that is presented to decision-makers. This method is particularly useful for topics with low levels of public awareness. In 2006, the BfR held a consumer conference on nanotechnology. The concept is based on the model of so-called “consensus conferences” originating from Denmark.

Recruiting citizens

The BfR used posters, social media and radio to find citizens all over Germany for the consumer conference. 147 people applied. Socio-demographically similar profiles were identified to allow for the selection of a heterogeneous group: by age group, gender and professional status. “From these groups, 10 women and 10 men were selected at random to include many different opinions, thought-provoking impulses, socio-political demands as well as hopes and fears,” says Head of BfR Communications Böl. Each participant received a reimbursement of 500 euros.

Information-based discussions

To ensure that the consumer group take an information-based approach to the topic, an external communications agency led the consumer conference. The BfR did not take part in the moderation, discussion and drafting of the vote and in fact only organised the process: researching specialist texts on genome editing, requesting expert participation and inviting politicians, representatives from the industry and the public to present the vote at the Federal Press Conference building as well as transmission via the internet. A scientific advisory board with experts in the fields of technology assessment, social science and risk management ensured that information was balanced.

The consumer vote

The consumer vote is a mirror of society. From the outset, it is highlighted that “as the consumer group was made up of a diverse range of people, the views

expressed are accordingly heterogeneous”. The vote describes the opportunities and risks of genome editing in general and for humans, animals and plants in four chapters. Each chapter contains specific demands and policy guidelines. “The result is really fascinating,” says Dr. Emilia Böhm, who as Scientific Officer at the BfR was responsible for executing the project, “as it contains very specific legislative proposals and demands as well as laying out guiding principles for a value-based societal handling of the technology. For example, the vote states: “It is important that no new technology obfuscates or thwarts the necessity for society to become more sustainable.” In the vote the consumer group suggests that if there are diverging opinions, not the technology but the final product should be assessed.

What happens with the vote?

The vote was presented to representatives from politics, science, industry and consumer associations. In its accompanying scientific research, the BfR is evaluating the societal response to the vote and investigating how the participatory dialogue with the population can be improved and how success can be measured. In a before-and-after survey on participants’ attitudes to genome editing, it is also being investigated whether an intensive exchange on a topic can change attitudes. These are important findings for improving the risk communication of the BfR, which contributes to political decision-making. A follow-up meeting with the consumer group is scheduled for 2021. ■

More information:
www.bfr.bund.de/en > A-Z index: genome editing



20 people, 3 weekends and a 15-page vote – the conference procedure

20 people, strangers until then, meet for the first time at a venue in Brandenburg over a meal – the start of the **first conference weekend**. They get to know each other in a moderated process and exchange views on the scientific, technical and social issues around genome editing and their expectations of the vote. Specialist articles, websites, podcasts, books – a variety of sources are presented so that participants can quickly familiarise themselves with the topic. “The intensive familiarisation phase was good. A trusting atmosphere was created in which we had very heated discussions with each other; but they were always well-meaning, respectful and never rude,” describes one participant.

They get together again three weeks later: is genome editing safe compared to conventional plant breeding? Is it ethically permissible to enhance athletic performance or to alter the genome of human embryos to reduce their risk of contracting HIV? These are questions that the consumer group wants to clarify, also with the help of experts. The group invites 14 of 32 possible experts to a hearing. They formulate questions; the vote’s focus is being refined. “I invested a lot of time, read specialist articles sent to me by others in the group in the evening.” – “Everyone was always concerned about striking a balance in the matter;” describe the participants. “I was impressed by how committed everyone was,” comments one participant.

On the third weekend, the 20 people meet for the last time for the **three-day concluding conference**. The schedule is tight: expert hearing, drafting the vote and the vote’s public presentation. “The expert hearing was rewarding, the discussions very worthwhile. Better than any article,” the “votees” remarked several times. “We struggled to find the right wording in our vote.” It resulted in a 15-page booklet, solidly filled with thoughts and demands for politics, the economy and society, which is presented to the public on Monday morning at the Federal Press Conference building by two members of the consumer group and broadcast worldwide via livestream. They begin: “Those who are crazy enough to think they can change the world are the ones who do it. We are 20 of those people.” – “The vote is a plea to politicians, and we demand that the results be taken into account in any further decisions. We were all highly motivated.” – “Read it! Reflect on it. Act on it.”