

Looking Back into the Future

CRISPR and Social Values

BioGovernance Commons Seminar
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Looking Back into the Future: CRISPR and Social Values BioGovernance Commons' Open Discussion with Chinese Academics

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On 11 February 2023, the Centre for Global Science and Epistemic Justice at the University of Kent hosted an open discussion on CRISPR technology for and with Chinese academics, titled 'Looking Back into the Future: CRISPR and Social Values'. This was part of the [BioGovernance Commons](#) initiative founded by us in the summer of 2021, which functions as a trusted forum for researchers inside and outside China to meet regularly, under the motto "sharing perspectives on shared challenges." The event lasted more than 2 hours and attracted participants from 13 different countries, as well as academics from at least 12 of the 34 provincial jurisdictions in China. In total, approximately 110 people attended the meeting, 70 of which were based in China.

Executive Summary

As organisers, we highlight these main points from the event:

1. We've exposed that there is little substance behind the ambitious Duchenne muscular dystrophy (DMD) gene therapy that Dr. Jiankui He, the scientist behind the illegal heritable human genome editing, has been boasting about to global patients. We were concerned that he might endanger another vulnerable population if his new venture remains unchecked.
2. Our event nudged [Chinese media](#) to publicly challenge Dr. He for the first time on his DMD research. As a result Dr. He has [announced that he will prioritise research rather than social media promotion](#).
3. The discussion exposed regulatory and communicative gaps in China which we hope will receive due attention from relevant authorities. It became apparent in the discussion that there was no clarity about what type of restrictions Chinese authorities had imposed on Dr He's research after the CRISPR babies controversy, and what institutions were responsible for enforcing these restrictions. Chinese participants have made explicit calls for more regulatory clarity within China.
4. Three university CRISPR scientists, Prof. Shihui Yang, Prof. Li Su and Prof. Shangxian Xie, shared their diverse views on how bioethical guidelines function (or fail to function) in everyday research in China.
5. As discussants, bioethicist Prof. Ruipeng Lei and legal scholar Prof. Jiayou Shi provided a brief review on how bioethical and legislative discussions have shifted in China since 2018 and speculated on future regulations.
6. 'Can the Chinese scientists speak?' Similar to our [previous events](#), we noticed that Western media bias and Chinese censorship habitually 'mute' Chinese scientists. We believe the best way to demystify 'Chinese science' is to enable more ordinary scientists to have a voice in both domestic and international debates. We hope both the strengths and limits of our event can inspire more colleagues to improve the ways we promote critical yet constructive international dialogues.

Our Main Aim

We convened this session because China is an important player in the responsible development of gene technologies globally, yet how bioethics *actually* functions in

everyday innovation in China may remain elusive. More importantly, little is known about the state of academic discussion on CRISPR genome editing in China and Chinese scientists' views on this. This is why we invited three Chinese CRISPR scientists at different stages of their careers and with varied experience of policy or public engagement experience. They were Professor Li Su, Professor Shihui Yang, and Professor Shangxian Xie.

Another factor that prompted us in organising this session is that we wanted to hear more voices from ordinary Chinese scientists, and not just a few elites. We were fully aware that practical constraints and institutional censorship prevented us from hearing more diverse voices from China. For many (if not the majority of) Chinese academics, speaking to Western media or speaking publicly in a domestic setting often requires lengthy institutional approval procedures. Participating in academic events is one of the few exceptions where Chinese colleagues can express their views publicly and exchange ideas freely with an international audience. In line with BioGovernance Common's commitment to promote inclusive and democratic discussions, we wanted this event to enable Chinese voices from different levels and from different disciplines. To facilitate the participation of Chinese academics, we decided to use Chinese as the main language, with simultaneous translation in English.

Our main aim, as was stated in our [event announcement](#) and in communications sent to participants, has always been to encourage more Chinese scientists and bioethicists to engage in open dialogue on this important topic both in China and internationally.

Why We Invited Dr. Jiankui He

During the planning of this event, it came to our attention that due to political sensitivity, China has not yet had an open discussion on CRISPR technology and ethical governance with Dr. Jiankui He since he announced [his illegal experiment with heritable human genome editing in 2018](#), for which he was sentenced to three years in prison. However, since being released, Dr. He has resumed genome research. He has publicly launched an ambitious plan for his current gene therapy research on Duchenne muscular dystrophy (DMD) to enter clinical trials by March 2025 and has been actively recruiting patients. As Dr. He has effectively become a taboo topic within China, most people avoid discussing him in public. Thus, a pervasive side effect of Chinese censorship is that this has left Dr. He considerable freedom to self-promote on social media, leaving his claims unchecked and unchallenged. In planning this event, we've consulted a number of key regulators and academics, and have noticed a shared, yet unspoken, concern that there is no clarity or transparency over how Dr. He's research is held accountable.

We consider it is important for Chinese academia to be able to discuss controversial cases in public. We also consider it critical to have a frank conversation about Dr. He's current

research to understand how accountability is established, and to ensure that the exploitation of desperate patients and vulnerable individuals will not happen again.

Thus, similar to the other three speakers, we invited Dr. He to give a talk addressing the theme of the seminar 'Looking Back into the Future'. That is, we've asked all speakers to *look back* at their research experience and comment on how ethics and scientific research can be better integrated and shed light *into the future*, on what they see as the types of dialogues or actions needed.

Dr. He accepted our invitation in December 2022. Seventeen hours before the event, we the organisers learnt from [Dr. He's Twitter](#) account that he was 'not ready to talk about [his] experience in the past 3 years.' We were deeply disappointed by this. But we thought it would still be a valuable opportunity to provide clarity on his ongoing research with DMD patients and what has been put in place to ensure such ambitions will be carried out responsibly and ethically.

We also anticipated that Dr. He may use this event as a publicity stunt and may refuse to engage with critical questions. However, we considered that given his active recruitment campaign of DMD patients, having his refusals to clarify key questions recorded in a public event was also of public interest. We made clear at the beginning of the event, that what is said and what is left unsaid in the meeting are equally informative.

Our Approach to the Media

Given that Dr. Jiankui He had used the Harvard closed-door event and an invitation from the University of Oxford to create the false illusion of academic endorsement, we took extra care of not having this public event hijacked by any individual's public relation narrative.

Since the [Guardian's interview](#) with Dr. He was published on 4 February, we've received many media requests around the world to attend this event.

We needed to balance transparency and fairness as well as the practical concerns that the presence of global media may discourage many Chinese participants from attending. The approach all four convenors (Ben Ouaghran-Gormley, Lei, Vogel and Zhang) of the BioGovernance Commons initiative agreed on was to only invite academic journals and Chinese scholarly media. We thus declined request for attendance from all other media.

As the aim is to promote openness in and with China, we did not impose Chatham House rule. In fact, we were very clear in communications with all participants that selected scholarly media would be present. We further reminded participants of this point during the event.

Participants were also informed that we recorded the event only for note-taking purposes, and that the video would not be shared. Our intention to publish a summary of the event so that the main points of discussion would be made public knowledge was also made clear before the event.

A Summary of the Speakers' Input

Dr. Jiankui He delivered the opening talk. Although we asked the other three speakers to give 15-minute presentations, we gave Dr. He a 40-minute slot. This was in recognition of the complicated history of his research, and we wanted to give him sufficient space to share and elaborate on his plans and his views. At the event, Dr. He's presentation 'CRISPR Gene Editing: How Revolutionary Biotechnologies Make Our Lives Better' lasted only 25 minutes, which mostly consisted of explaining basic scientific knowledge, such as the structure of DNA. He spent much time paying tribute to other well-celebrated major scientific advancements and breakthroughs, before slipping in his own research, of which Dr. He only talked for 1 minute and 50 seconds. This included confirming that he aimed to raise 50 million Chinese RMB through charity and enter clinical trial by March 2025. He mentioned the plan of setting up an international ethics committee for his current lab, but did not give any specification on its membership, plan or timeline. He was of the view that society was supportive of using gene editing to cure disease and that the regulations in both the US and in China should be made clearer. At the end of the presentation, Dr. He read out the presentation slide that 'heritable embryo gene editing are not allowed in human clinical practice, either in China or other countries'. When later pressed by a professor from Shanghai Jiaotong University if he thought that heritable human genome editing should be 'banned', Dr. He declined to comment.

Prof. Shihui Yang from the School of Life Sciences, Hubei University, was the deputy head of State Key Laboratory of Biocatalysis and Enzyme Engineering. CRISPR technology in his research on industrial microbiology. He noted that life scientists' engagement with bioethics cannot be taken for granted. His interest in engaging with ethics discussions was mostly propelled by his founding of the Hubei Provincial Association for Synthetic Biology. He noted that it was scientific journals in China that put him in contact with bioethicists, and helped him to get access to social science events. Through his teaching experience both in China and in the US, Prof. Yang pointed out that drawing science students' attention to biosecurity and bioethics debates could be a common challenge in university education, and should be seen as important as developing cutting-edge technologies. To improve bioethical literacy among Chinese scientists, Prof. Yang suggested that a stronger presence of bioethical discussions at academic conferences and international competitions, such as iGEM, may be a more effective way. He also pointed out the important role international collaboration plays at promoting bioethical awareness. His final slide summarised his talking points as 'ABCED': Attention, Balance, Collaboration, Discussion, Education.

Prof. Li Su from Huazhong University of Science and Technology uses CRISPR in her cancer research. She agreed with Dr. Jiankui He's view that any life scientist who doesn't know how to apply CRISPR to their research is outdated. While CRISPR may not always be a 'necessary' tool, it is an effective one. Her slides showed past work her team have published on how [biosecurity can be better managed in China](#) and on an [innovative approach they've experimented with undergraduate training of biosecurity](#). Her take on bioethics is rooted in her commitment on promoting 'One Health', which is a collaborative, multisectoral, and transdisciplinary approach to promote sustainable human and environmental wellbeing. But Prof. Su also pointed out an often ignored aspect, that is, there is an equal need for social science students to understand avant-garde science. This was the rationale for her to introduce the module 'Modern Life Science Experiment' specifically for social science students. This point was later echoed by Prof. Shihui Yang when answering a question at the end of the seminar. Prof Yang pointed out a frustration that there have been research findings in China that cannot be put into application due to broad regulations. He called for more scientific literacy of policy makers and regulators, so that Chinese regulators can have a more differentiated approach that recognises varied applications and development stages of an innovation.

Prof. Shangxian Xie was also from Huazhong University of Science and Technology and belongs to a younger generation of Chinese scientists. He uses CRISPR in his microbiological and animal research. He recounted his misconception of bioethics during his student years, in which he thought ethics were limited to conceptual debates on morality and values. It was when he started his PhD study in the US, and when he was asked to sign forms on bioethics and biosecurity before starting to work in the lab that he realised ethics had concrete legal implications too. He pointed out that different sub-fields within science have their own ethical norms and language. While it is not unusual for scientists to move between research topics or running projects in different sub-areas at the same time, it cannot be taken for granted that scientists necessarily know what appropriate ethical procedures they should comply with. One personal anecdote he shared was that as a scientist who mainly worked with microorganisms, he was well aware of what type of environmental assessments and protection procedures were needed. So when he applied for a national grant monitoring changes in mice faeces in relation to microorganism intake, he did not know a separate ethics review for animal-related research was needed until the university's research office rejected his proposal. He pointed out that regional disparity in ethics assessment and enforcement standards remain a challenge in China. Prof. Xie emphasised both in his talk and in his answer to participants' questions of intrinsic conflicts between science and ethics. He underlined the explorative and future-oriented nature of science, and contrasted this with the restrictive and history-based characteristics of bioethics. How to balance these two conflicting forces, for Prof. Xie, was the key challenge. He suggested that this should be a key task for BioGovernance Commons as the initiative brings together interdisciplinary and intercultural input.

A Summary of the Discussion

We had approximately 40 minutes for discussion. Approximately 2/3 of the questions were asked by Chinese participants. Given a lack of substance of Dr. Jiankui He's presentation and opaqueness of his 2018 scandal, not surprisingly most of the questions were directed to him. We were disappointed that Dr. He refused to engage in any discussion beyond his prepared talk. Below is a list of questions that were asked by participants based in and outside of China:

- Are you restricted in doing any type of research in China?
- Are you restricted from speaking about the research you did from three years ago, either by the Chinese government, your former university, or the families?
- What kind of concerns do you have moving forward?
- What your thoughts are on communicating with media, rather than bioethicists or other academic peers, about your research?
- Could you please say more about your current DMD research procedure? Given this is a disease which may benefit from early interventions, what is your planned age range of patients?
- Are you restricting your DMD research to somatic gene therapy, or does it incorporate germline research?
- What's your plan on making your gene therapy accessible to patients?
- What's your view on whether human germline editing should be banned?
- What's your view on China's subsequent regulations in genome editing? Do you think it has become more relaxed or more tightened?
- It is expected that China's Ministry of Science and Technology and the National Health Commission will promulgate even more guidelines and regulations in this area. Do you think this is a good thing or a bad thing? Or do you have any comment on this?
- You've mentioned in your talk that China's governance is not yet comprehensive. Could you say a bit more about where the regulatory gaps are and how you think these gaps can be addressed?
- What shapes your understanding of bioethical concerns? Is it through university education, your training abroad, research culture in China or something else?

To all the questions ask, Dr. Jiankui He refused to answer but asked participants to send him their questions by email. Despite the lack of response from Dr. He, Chinese participants engaged in the discussion and expressed diverse views. A professor from Shenzhen expressed the view that the Chinese authorities' penalty on Dr. He was too harsh. In his view, there has been an aggravated antagonism between ethicists and scientists in China. He referred to David Baltimore's 1975 Asilomar Conference on recombinant DNA as a model in leading bioethics discussion. This reference provided stark contrast to Dr. Jiankui He's refusal to engage in the seminar. Those who are familiar with China's life sciences may recall that early contemporary development of Chinese bioethics and biogovernance were scientist-led. Huizhen Sheng who worked on human-rabbit hybrid embryos and Huanming Yang who led China's participation in the Human Genome Project are two key examples of scientists who led the discussion about bioethics.

Weiwei Cao from Shanghai University was 'upset' that Dr. He refused to answer any questions. She said while she admired He's venturesome courage, she was disappointed that He made little comment on social values and failed to mention any possible negative implications of his research on human subjects. She was deeply disappointed that neither the time in prison nor the bioethical and legal guidance from the wider Chinese academic community had made him take ethical and social issues more seriously. She asked He to consider how one small step for one scientist, such as his 2018 heritable human genome editing experiment, could create significant backlash to his peers and stall the field. Cao was of the view that contemporary science cannot be developed behind closed doors. China needs to engage with global dialogues.

Lucy Gao from Chinese Academy of Science said she was able to feel some sincerity from Dr. He, as he did agree to talk about his work. But she was equally frustrated that nothing of substance was shared 'I think he does want to connect with the wider world and have better exchange,' said Gao, 'so I invite him to make more effort in addressing questions raised by academics and the public.'

There were also two longer inputs from Chinese colleagues.

Prof. Ruipeng Lei, who co-chaired the event, provided a brief review of China's bioethics discussions on genome editing, chiefly from her personal work experience. She noted a series of key events. This included 1) the 8th National Bioethical Annual Conference hosted by Fudan University between 16-18 November 2018. Prof. Lei chaired a session on potential abusive use of genome editing. This was also the first time she met Jiankui He, 2) the adoption of 'ethical governance' into China's national agenda, through the Central government's founding of the [National Science and Technology Ethics Committee](#). 3) A series of domestic discussions on the protection of genome edited individuals between January and March 2022. This included a joint bioethics discussion held jointly by Huazhong University of Science, Renmin University and Technology and Xiamen University on 13 March 2022. Approximately 138 participants joined the meeting. That was China's first open discussion on the bioethics of supporting individuals born through heritable genome editing. This national meeting was prompted by the 18 March 2022 [International Roundtable](#) that was convened by the Centre for Global Science and Epistemic Justice at the University of Kent, which demanded transparency and democratic deliberation on this issue. 4) in March 2022, China's central government promulgated the '[Guidelines on Enhancing Ethical Governance of Science and Technology](#)'. This has led to the establishment of a dedicated task force on university education on ethics in science and technology. 5) In addition to a revised version of the *Implementing Rules for Human Genetic Resources Management*, Lei also speculated that a revised and updated version of the *Measures for the Ethical Review of Biomedical Research Involving Humans* will also be published soon. It is expected to be wide in scope, incorporating all research involving human material or human data. It is also expected to impose similar requirements on ethical committees and ethical review procedures in hospitals, universities and other research institutes alike

Jiayou Shi, Professor of Law at Renmin University took part in writing Article 1009 of China's Civil Code in 2020, which specified that all clinical and scientific research that is related to human genome and human embryos have to comply with relevant legislation, administrative rules and guidelines. In 2020, China's Criminal Law also expanded its Article 336 that prohibits reproductive genome editing and human cloning. Prof. Shi also drew attention to an increasing legislative attention to inter-generational fairness in China. Prof. Shi further commented on Dr. Jiankui He's remark in his recent Guardian interview that he acted '[too quickly](#)'. Shi pointed out that there were different ways to comprehend what was 'too quick': It could be a technical pre-maturity, in which a technology was applied before its safety and effectiveness was tested. But Shi considered Dr. He acted 'too quickly' because he took action before giving his action due ethical consideration.

Looking Back into the Future: The BioGovernance Commons' Perspective

Looking back at the organisation, delivery and initial perception of this seminar, we found ourselves at the crossfire of Western biases against Chinese science and China's intensified censorship. We had similar experiences with our previous events on biosecurity and on supporting the individuals born from heritable genome editing.

Since Jiankui He publicised our event through his Guardian interview, we have received unfounded criticisms from the media and academic peers of rehabilitating He's reputation, whitewashing China and tarnishing the reputation of the field of bioethics and biogovernance. Our main aim of encouraging more Chinese academics to engage in open dialogue on this important topic both in China and internationally was repeatedly brushed aside by these criticisms.

For individuals and institutions based in China, to host an open discussion on controversial issues is often extremely challenging, as concerns over social stability often restrain discussion. Political sensitivity of the event's topic also demands a neutral platform. The BioGovernance Commons initiative is honoured to be a host and enabler for such an important debate.

We are conscious that participants of this seminar may consider the 'worthiness' of attending such an event differently. Some considered that its worthiness lies in knowing more about Jiankui He's past and present scandals, some wanted to know the inner working of Chinese science and Chinese politics, some were curious to learn global peers' views. Depending on what one hoped to get out of the seminar, participants may have left the event feeling informed, enlightened, puzzled, or disappointed.

As organisers, we consider all the efforts worthwhile, as our 150-minute event has helped minimise the chance of another scandal exploiting desperate patients and vulnerable

individuals. We believe that Chinese scientists' calls for regulatory clarity at the event is more meaningful than commentaries from global observers. We are delighted that the event has enabled Chinese media to publicly question Jiankui He's research and alerted Chinese authorities to regulatory gaps.

We highlight that avoidance of engaging with controversial cases and individuals may effectively leave questionable research projects unchecked and unchallenged. Neither should investigations into controversial cases be shrouded in secrecy or having access to information as a privilege of a small circle of (political or academic) elites. We hope both the strengths and limits of our event can inspire more colleagues to improve the ways in which we promote critical yet constructive international dialogue.