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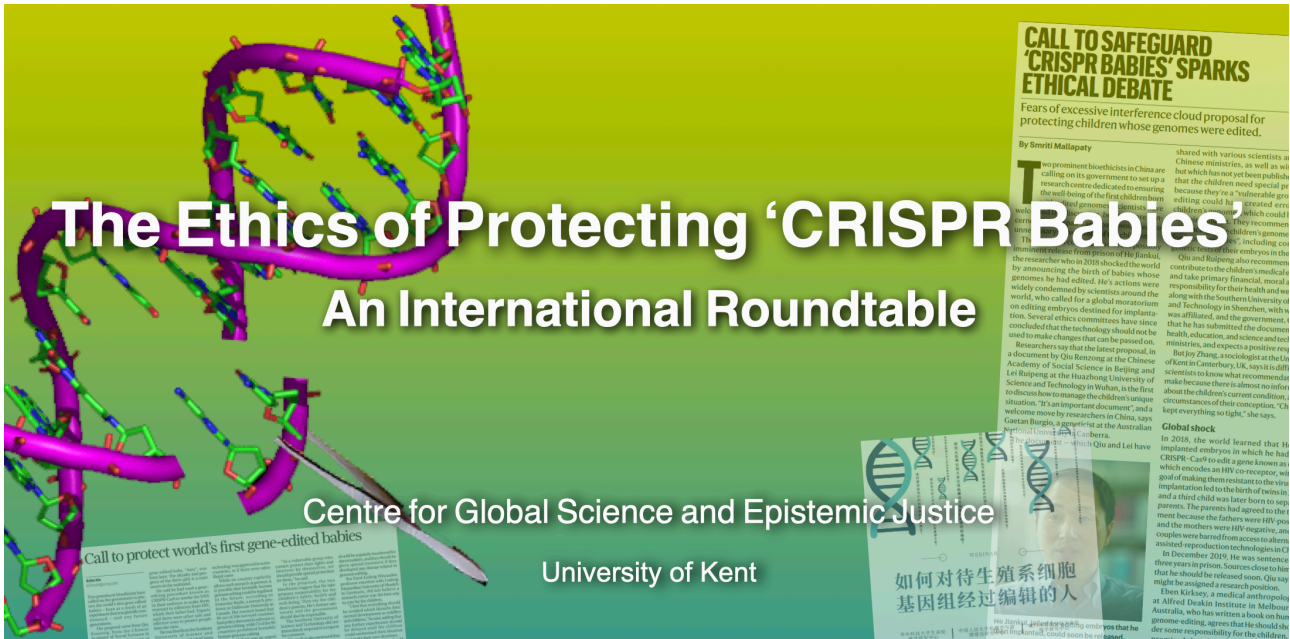
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Summary Report

5 April 2022

(Updated on 6 April 2022 with complete contributors' biographies)

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* To cite this report: Centre for Global Science and Epistemic Justice (2022) *The Ethics of Protecting 'CRISPR Babies': An International Roundtable Summary Report*. April 2022, Canterbury: University of Kent.

* **Disclaimer: The views expressed in this event are the independent views of the participants and do not reflect the views of any institution.**

Summary Report

The Ethics of Protecting ‘CRISPR Babies’: An International Roundtable

Hosted by the [Centre for Global Science and Epistemic Justice](#), University of Kent

Introduction

The international roundtable was convened as a response to two leading bioethicists, Ruipeng Lei and Renzong Qiu who proposed a [‘special protection’](#) to be set up in China for the world’s first three genome-edited children, ‘a new group of vulnerable population’. Describing the three children, Lulu, Nana and Amy, as the result of Jiankui He’s ‘genetic mayhem’, Lei and Qiu proposed that a proactive protection plan was warranted by ‘moral obligations for future generations’.

The Centre for Global Science and Epistemic Justice (GSEJ) invited 10 panellists from the life sciences, bioethics, anthropology, sociology and patient and stakeholders’ groups to reflect on what constitutes the ethics of protecting genome-edited children and (future) individuals in comparable situations, and on how open and inclusive deliberation on this issue can take place in and with China. The event was held on 18th March 2022 on Zoom. It was chaired by GSEJ’s Director Dr Joy Zhang, who had a series of in-depth conversations with academics in China in the five weeks leading up to the roundtable to understand the evolving situation. Six other participants who were involved in these conversations were also invited to attend the meeting.

We chose the format of a roundtable deliberately so as to give equal importance to all perspectives. The roundtable proceeded in alphabetical order with one exception. In recognition of the importance of patients’ perspectives, we invited Jay Johnson, who experienced long-term medical follow-up after gene therapy, to open up our discussion.

Panellist input

Jay Johnson, Director of Volunteers at Action Wellness, participated in a small study of the [Sangamo BioSciences therapy](#) in 2010. The study enrolled 12 people infected with HIV in an open-label, nonrandomised first study of ‘gene editing’ in humans. Scientists removed cells from the patients using a zinc-finger nuclease (ZFN) to permanently disable these cell’s CCR5 gene and then dripped the cells back into their bloodstreams. To become HIV free was what motivated Johnson to participate in this clinical study. He was the first participant who had an adverse reaction after receiving the edited cells. This included chills and stomach pain. However, reflecting on his experience, Johnson highlighted the care and responsiveness of medical staff, and commented that ‘the unknown is scary but [the staff at the University of Pennsylvania, where the trial took place] made it so much easier for me to go through the whole process’. Following the treatment, Johnson had 10 years of medical follow-up at the University of Pennsylvania. He described the follow-up appointments as ‘very short and sweet’ which allowed him to carry on working and enjoying daily life as normal. He also expressed strong support for similar clinical studies on diseases which have a large impact on society.

Sarah Chan, a bioethicist at the Usher Institute, University of Edinburgh, commented both on the procedural and substantive aspect of protecting CRISPR babies. She considered it commendable that Chinese bioethicists were proactively taking steps to try address this issue. However, in its current form, the call for protection risked perpetrating exactly the type of discrimination that they sought to prevent. Firstly, the proposal’s framing of protections as justifiable on the basis of the wellbeing of hypothetical future people could be dangerous, as it diverted the focus away from the people who were in need of protection today and could, conceivably, end up harming the three children in China. Secondly, ‘genomic over-protectionism’ needed to be avoided. This is to say, bioethicists or experts in any single area should not arrogate to themselves the responsibility and ability to make decisions about what should or should not happen in peoples’ lives. Rather, public dialogue is needed. We need not have discussions about what happens to people without those very people being part of the discussion. To avoid genomic over-protectionism is also to avoid possible coerced eugenics. Babies born naturally may also have different types of mutations, but are not subjected to surveillance. So what justifies putting individuals born as a result of genome editing under increased reproductive surveillance, and for whose benefit is this? Lei and Qiu’s proposed protections are unconvincing on these questions. Vulnerability itself can be a ‘vulnerat-ing’ concept which denies individual agency. Thirdly, there should be a clarification about whether we are protecting people from being subject to improper human agency or whether we are protecting people from genetic risks. Chan argued that we should be focusing our efforts on current and near future people and that we should be protecting them from the type of bio-surveillance that was suggested by the draft proposal.

Ryan Ferrell joined Jiankui He’s team as a consultant in August 2018. As documented in the book, [The Mutant Project](#), Ferrell worked to slow down He’s research, but was only able to stop one implantation attempt. At the roundtable, Ferrell shared valuable insights on the concerns of the families involved in He’s study. Ferrell first highlighted that it is very easy to downplay the stigma and daily plight that the HIV communities in China are facing,

including job insecurity and restricted access to ordinary medical care. This contributes to a sense of abandonment by Chinese and Western societies, as reflected in three participants' letters to a Chinese court in February 2019. Ferrell suggested these families want access to a compassionate and independent healthcare team, which would provide basic and specialty health care such as genetic counselling as and when relevant. The two families have reason to fear simple primary care visits in context of HIV and an unsympathetic global response. Ferrell also pointed out that a moratorium of the technology evades difficult discussions for the broader field. One key lesson from Jiankui He's case was that top-down governance, both in China and in Western scientific bodies, faltered and has not self-corrected. Ferrell called for reflection on the human factors in research culture that affected this incident.

Benjamin Hurlbut, Associate Professor in the School of Life Sciences at Arizona State University, first echoed Chan's view that no responses, however well-intended and well-designed, ought not be imposed on children in the name of responsibility. He contended that just as these children were once a side demonstration for a technical project, they also risk becoming a side of demonstration for ethical responsibility. He warned about the possibility of these children becoming a platform for constructing 'regimes of response', either in the name of atonement or of rectification, which turns them into an instrument in the service of bioethics rather than the other way around. Hurlbut thus went further and challenged the notion of 'we' in experts' framing of the responsibility to proactively intervene. He argued that the most fundamental condition to assist these families was to recognise that one can only become part of 'we' in sharing responsibilities with these families at the families' invitation. Hurlbut proposed that the kind of healing that this situation demanded was a 'responsibility to understand'. What is needed is not fetishising the difference of how these children were born but a kind of humility to turn the gaze back upon ourselves to understand how this has happened. In regards to an elite-led protection proposal, Hurlbut cautioned that the imagination of a heroic caring and saving was what created CRISPR babies in the first place. Hurlbut instead called for contextualised understanding and serious interrogation on what the pathology was, for which a risky intervention was considered as a compelling treatment. This is a reflection needed globally.

Hubert Kang, who oversees the operation of Institutional Review Boards of BGI-Shenzhen and of China National GeneBank, provided updates on China's regulatory development since [the Second International Summit on Human Genome Editing](#) in December 2018. China has approved gene therapy clinical trials for treating lung cancer, head and neck cancer, melanoma, lymphoma, HPV, and HIV. The latest development was China's 2021 approval of [EdiGene's CRISPR/Cas 9 gene-editing hematopoietic stem cell therapy](#) for sickle-cell disease. The Ministry of Science and Technology, National Health Commission and State Administration for Market Regulations are key national regulators for genome editing in China. One month after Jiankui He announced his experiment, China's National Natural Science Foundation expanded its bioethical requirements for all applications. A few months later, China's [National Science and Technology Ethics Committee](#) was established. The city of Shenzhen, where Jiankui He was based, further strengthen its local review system by promulgating city-wide [Ethical Review Guidelines of Biomedical Research Involving Human Participants](#). In 2020 China revised its [civil code](#) and [criminal law](#), which recognises unethical experiments on genes in adults or embryos

as a violation of a person's fundamental rights. China's first national [biosecurity law](#) also banned the unethical collection, preservation, use and outbound supply of genetic resources.

Eben Kirksey, an anthropologist at Alfred Deakin Institute in Melbourne, first pointed to the long tradition of thinking about medical morality in China and rebuked a Western-centric view on bioethics. He recounted how his extensive fieldwork in China helped to understand the values that shaped Jiankui He's experiment. He argued that the public values and discourse that have shaped the 'China Dream' were also reflected in the ethical conversation about disruptive innovation and the entrepreneurial spirit Jiankui He embraced. For Kirksey, both the making of CRISPR babies and the protection for them are not just about an autonomous consenting subject. It's very important to expand the scope of ethical investigation to take into account of how medical morality is enmeshed in a network of human relationships. For example, the real-life cost of social stigma for the HIV community in China (such as employment discrimination) should be taken into account. Kirksey also drew the comparison between Louise Brown (the first human born after in-vitro fertilisation), who was a public figure the moment she was born and the three CRISPR babies whose identities were, as an important ethical decision made within the lab, well-protected from the start. Similar to other panelists, Kirksey opposed too much protection or surveillance. He applauded Jiankui He for offering the children insurance plans for the first 18 years of life, but noted that the insurance companies would not issue the plans because the babies were born prematurely. Kirksey encouraged further discussions about how funds from He might be used to reimburse the ongoing health care expenses for the three children. He advocated evidence-based discussions, where potential health issues can be identified by and responded to by limited new genomic studies. He considered that Chinese bioethicists had a leadership role in making consequential recommendations about this particular case and about this field broadly. He maintained that key values of China's long tradition of medical morality, which may differ from Christian-based bioethics, are worth highlighting when recommendations are made at the national and international levels.

Ruipeng Lei, the lead Chinese bioethicist who championed the special protection plan for the three genome-edited children, elucidated some of the background of the draft proposal as well as recent public discussions held in China. Lei stated that the moral imperative she and Qiu felt in drafting a protection plan was rooted in the fact that the health risks faced by the three children were essentially 'unknown unknowns'. It's an unprecedented uncertainty for the world. She emphasised that the draft recommendations were only 'a preliminary attempt to start a sustainable future conversation' and that it was 'not intended to be a concluding piece'. The discussion within the Chinese bioethics community started on 8 January 2022 at Renmin University when a small group of social scientists joined a bioethics forum on how to protect genome-edited children. On 12 January, Lei made a short presentation at a Sino-UK symposium on the legal aspect of genome editing which was sponsored by the UK Embassy in Beijing and in collaboration with the Nuffield Council. On 13 March, Lei's research centre at Huazhong University of Science and Technology and the Centre for Bioethics at Xiamen University co-hosted a webinar on how to treat germline edited persons. The event was free and was open to the public. Nearly 140 participants with different disciplinary background attended. A key theme of the 13 March webinar was how 'the best interests' of the children should be identified. Lei

confirmed that most of her colleagues in China were 'strongly in support of further research and consultation on this issue'. Roundtable participants, Di Zhang, Haidan Chen, Hui Kang were particularly keen to avoid a one-sided view, driven either by scientific or bioethical experts. Lei also stressed that views of the family and of the three children should always be given due consideration.

While Lei recognised Sarah Chan's point that bioethical discussions needed to keep an appropriate balance between the needs of current and future generations, Lei insisted that uncertainties posed by germline editing warranted extra precaution. The damage to genomes caused by editing could be severe but hard to detect, identify and measure with current technology. Given that public discussion has just been initiated in China, Lei considered it important to ask questions rather than providing answers:

- How does germline genome editing affect our gene pool and the wellbeing of future generations?
- How do we evaluate germline genome editing from different moral and cultural perspectives?
- What moral duties do the present generation have for the future generation?
- What kinds of genetic mayhem will be caused by the heritable CCR5 genome editing?
- Are the three genome edited children entitled to be classified as a vulnerable group?
- What are the benefits or harms for them to be classified as the vulnerable group?
- How do we identify the 'best interests' of the three genome edited children? Who should make these decisions?
- How do we define special protection? What is the moral distinction between protection and restriction? How do we observe this distinction in practice?
- What are the specific mental and social risks for genome edited children?
- What kind of special protection is morally justifiable and practically feasible?
- Who should be responsible for offering special protection?
- Is it necessary for us to establish the mechanism to care for them?
- Is it justifiable and feasible for us to evaluate the special protections offered to them? If so, how?

Robin Lovell-Badge, CBE, FRS, FMedSci is a senior group leader and head of the Laboratory of Stem Cell Biology and Developmental Genetics at the Francis Crick Institute. Lovell-Badge pointed out that since Jiankui He's presentation at the Second International Summit in 2018, there has been no follow-up or verification on his original data that is available in the public domain. This has made it difficult for any proper medical evaluation on any likely risk. Given that there are people born naturally with CCR5 mutations, including people living in China, these three children should not be considered as 'unique'. It is possible to conduct a genetic test by taking a blood sample to see if the altered CCR5 genes in any of the three children offer HIV protection. Lovell-Badge objected using the term 'genetic mayhem' to describe the three children. Jiankui He was ethically and scientifically wrong. It was an inappropriate use of a technology that was well acknowledged as not yet safe for clinical applications. However, given that the three children are alive, they may not be that much different from other people, who naturally have mutations. One needs to be careful with using extreme language such as 'genetic mayhem'. Lovell-Badge was of the view that Lulu, Nana and Amy need to be protected,

with careful and subtle monitoring of them. But they should be treated like any other child. Their lives should not be invaded by any particular measure.

Helen O'Neill is an expert in reproductive and molecular genetics at the University College London. Helen listed four elements that needed to be addressed. The first was the ethical question of whether germline editing should have been done or should ever be done again. The second was the scientific question on the experimental outcome, the steps that were taken and choices made on certain gene variants. The third was the personal question of medical misconduct. The fourth was what has happened or may not have happened to the babies themselves. Naturally these questions are inter-related, but it is important to treat them separately when it comes to discussing what has happened and what will happen in the future. O'Neill emphasised that instead of focusing on what could go wrong, greater attention should be paid to the lessons learned. She agreed that there was no need for genetical exceptionalism to treat the babies differently. What was needed, O'Neill argued, is an ethical sensitivity whereby we feel the need to talk at length about what could, should or might happen, with sufficient scientific evidence and a decent understanding of the context. From a clinical embryology perspective, there is much that we can learn about genome editing from current clinical IVF practice. Scientifically, there is little value in putting these children under special protections plans. More importantly, O'Neill highlighted that we shouldn't automatically assume proper genetic monitoring equals an arduous and burdensome experience. We live in an age where some genetic testing can be done at home with a saliva kit, and monitoring can be achieved through an app whereby the parents ask their children questions in a non-clinical setting. There is much we could do with minimum intrusion.

Ayo Wahlberg, an expert on the development and routinization of reproductive technologies at the University Copenhagen, drew on his extensive work on childhood cancer [families who have opted to participate](#) in a [whole genome sequencing research project](#). 'Surveillance life' is not new healthcare. Wahlberg referred to the example of TP53, a gene whose mutation increases the chance of many cancers. There is a lively debate among bioethicists and geneticists on what kind of surveillance if any should young children enrol in before they turn 18. Clinical conditions such as Lynch syndrome have clearly established mutations with clearly established surveillance programmes. On the question of how children should be informed of their genetic condition, Wahlberg's [empirical research](#) found that when to tell children mattered far less than how the family approached the topic. In the case of the CRISPR babies, it is not yet clear what surveillance is relevant. But, how we talk about them is still significant. Wahlberg suggested that, when describing health risks of the three children, approaching genomic questions in terms of known 'clinically actionable mutations' on the one hand, and 'variants of unknown significance (VUS)', on the other, may be more appropriate. He insisted that even when [surveillance life](#) is necessary, it remains a family affair and needs to be normalised as much as possible. The conversation that parents and children at some point have needs to be assisted by genetic counselling and informed by empirical research, both when as regards enrolling in/embarking on relevant lifelong surveillance programmes and as regards any questions families might have concerning family planning. Wahlberg also noted that as technology ushered us into new territories, roundtable conversations were a necessary process for us to develop and reflect on ways to talk about things we didn't know how to talk about before.

Discussion

While a key theme of the roundtable discussion was on how individuals and different professions should better understand how to position themselves in relation to genome editing and its social consequences, **Sarah Chan** hoped to see more deliberations on the next steps forward. This pertained not only to China as three and half years after the genome edited babies were born, globally we're still wrestling with how to prepare both the governing structure and the discourses that are essential for future resilience against similar situations. **Robin Lovell-Badge** pointed out that we don't refer to people as products of pre-implantation and genetic testing. In a similar vein, labelling these children as CRISPR babies in need of special protection required good reasons, such as the detection of deleterious mutations as a result of the editing.

Sonia Ben Ouagrham-Gormley, associate professor at Schar School of Policy and Government at George Mason University, queried to what extent we can distinguish naturally occurring mutations and those that were manipulated in the lab. This would be useful to clarify if the children are to be protected against too many intrusions in their private lives. **Helen O'Neill** confirmed that we are already able to tell CRISPR driven mutations from naturally occurring ones with a biopsy from a saliva sample. **Lovell-Badge** added that possible mosaicism during CRISPR gene editing may mean a single sample could miss or over-represent gene changes. But the technical aspect of genetic follow-up was not intrusive. **Eben Kirksey** noted that, with the broad horizon of possibilities that new technologies open up, the discussion on CRISPR babies has wider implications. That is, how do we live with possible technical accidents and create conditions for people who might be deemed as abnormal by society to flourish. Relatedly, **Jay Johnson** commented that for a long time his HIV status was in the closet. In the 1980s and early 1990s, HIV was also a highly stigmatised subject in the US. Johnson, as a practicing nurse at the time, was worried about losing his job. When he participated in the Sangamo research and the Associated Press got ahold of the story, he needed to 'come out' again to his neighbours and colleagues. However, people embraced him with support and compassion. Johnson concluded that, 'the whole experience of going through the study was interesting but the reaction I got from my friends and colleagues was amazing'.

Haidan Chen, bioethicist at Peking University, asked **Katie Dow**, Deputy Director of the Reproductive Sociology Research Group at the University of Cambridge about the lessons that could be drawn from the early phase of the U.K. media discussion on IVF. Dow has carried out archival research on representations of IVF in the British media, focusing particularly on [newspapers and TV documentaries covering the birth of the first 'test-tube baby'](#), **Louise Brown**. She noted that when Patrick Steptoe and Robert Edwards established pregnancy in Louise Brown's mother, one of their main fears was that Louise would be born with abnormalities which would be a catastrophe for the type of science they championed. While the manner of Louise Brown's conception became controversial, at the time of her birth, the UK coverage was almost entirely positive. This was because IVF was seen as a technical assistance to reinforce a normative goal, that is assisting natural birth resulting from heterosexual marriage. Patrick Steptoe was concerned about the use of IVF and other assisted reproductive technologies beyond heterosexual couples.

[The human-interest angle that the British press used](#), such as depicting the Browns as an ordinary and respectable family, established a subsequent frame for IVF and contributed to its rapid normalisation. In short, Dow reminded the panel that the development of ethical regulation and practices in a country is also a process of self-renewal and reinvention of that nation's projected values on science. She also cautioned about the underlying assumptions that goes with describing people as babies and children in English and how it could affect how we perceive responsibility towards them. **Ayo Wahlberg** added that that the discussion highlighted the tension between exceptionalism and normalisation. He noted that Jay Johnson, a pioneer in receiving gene-editing treatment, has been through a very exceptional moment in history, but can still go about everyday life as others do. Wahlberg noted that we need to ensure that Lulu, Nana and Amy have access to all the health care they need, but we also need to create a language that helps to 'de-exceptionalise' and to enable them to lead autonomous lives. We need to continue the conversation Qiu, Lei and colleagues in China have started, and through the conversation, develop the appropriate language together.

Di Zhang from Peking Union Medical College noted that to his knowledge, many Chinese bioethicists would concur with Chan's and Hurlbut's views. He underlined the importance of de-exceptionalising these young individuals and supported Ryan's view that the families' needs should taken precedence over 'expert opinions'. Di Zhang noted that academics in China have limited influence over top-down decisions but there is much that can be done to help these families through non-government channels. He also offered an amendment to Eben Kirksey's view. That is, while there are contextual particularities in China's medical morality, the core values embraced by China are also shared universally. More importantly, Di Zhang deemed it important to bear in mind that China's contribution to the global governance of genome editing should not be that of cultural particularity, but should be better articulation of shared values and shared interest. **Ryan Ferrell** agreed with Di Zhang that while socio-political contexts may vary, culturally, societies may have much more in common than often assumed. He further elaborated on the layers of regulatory failures he witnessed surrounding Jiankui He's research. Ferrell was emphatic about avoiding the practice of naming-and-shaming, but wanted to use this as an opportunity to reflect on why it was difficult to bring visibility to certain social struggles, and to where Chinese bioethicists can exert their influence. A number of participants raised the point of promoting a safe and more enabling environment nationally and transnationally for individuals with concerns or key information to speak out. **Robin Lovell-Badge** emphasised that openness is critical in shaping governance and avoiding future mistakes in this area. He also highlighted that the WHO has already started such works as outlined in the WHO Expert Advisory Committee's Recommendations on human genome editing. This includes working in partnership with a wide range of groups, people and institutions, within and beyond the global public health community, to identify mechanisms for the effective reporting of illegal, unregistered, unethical or unsafe research and to promote the best possible open science. **Sonia Ben Ouagrham-Gormley** commented that to some extent, the discussions on Lulu, Nana and Amy have been 'one-way', for they and their family have restricted communications to the outside world on what they desire. **Eben Kirksey** observed that what emerged from the discussion was a genuine interest in pivoting away from blame but towards responsibility. In response to Di Zhang's comment, Kirksey clarified that his point was not on a West/East divide, but that values are situated in cultural and historical context. Understanding any scientific research, and evaluating

appropriate responses, required taking into account that context. Kirksey believed that there was a general consensus among participants that, firstly there was still much information that could be shared and secondly, official channels may not be the best (or only) approach to provide care and help for the families. There was a potential for an international group of individuals with different experts to work together to tackle difficult issues.

Ruipeng Lei further explained that their proposal of special protection to the CRISPR babies was not intended to deny them as equals, but to ensure their equity towards developing a good life. She agreed with Robin Lovell-Badge that more transparency and open discussion was required for a scientifically-informed evaluation of the children's needs. She stated that this is what bioethicists are trying to promote in China. The 13 March webinar was a latest effort. **Di Zhang** identified that bioethicists and social scientists in China can take concrete actions on prompting regulatory updates. Part of the reason HIV couples saw Jiankui He's experiment as a solution was because they were excluded from accessing assisted reproductive technologies (ART) in China. When the relevant legislation was made 20 years ago, it made sense as such clinical practice was immature in China and could not safeguard against HIV infection. However, now ART has become safe for HIV couples but they are still denied these service by outdated regulations. For Di Zhang, the bigger issue is not the three children, but the well-being of Chinese HIV community in general. **Robin Lovell-Badge** added that there should be flexibility built into regulations that allow a case-by-case examination. The [WHO recommendations on Human Genome Editing](#) suggested the incorporation of diverse governance approaches. In addition, lessons can be learnt from the discussions on [mitochondrial replacement therapy \(MRT\)](#). **Hubert Kang** pointed out the importance of genetic counselling is often undervalued and misunderstood by the public as well as academics. Proper genetic counselling would have helped desperate patients not to be misled by scientific entrepreneurialism. **Ben Hurlbut** argued that stories that get told by experts shape the life trajectories of people who inhabit those lines, as well as the trajectories of science and ethical apparatus that are used to justify them.

It was a shared view among participants that the roundtable had been highly productive and that the conversation should continue, possibly in a public form.

Additional Chair Communication

Prior to the meeting, the convenor of the roundtable, **Joy Zhang** communicated her views to participants through emails and direct conversations. Thus she did not repeat her perspective during the roundtable or discussion but summarises them as follows:

Firstly, bioethicists (and Science and Technology Studies scholars) play a critical role in democratising social and policy discourses on emerging science in China, as is detailed in [previous empirical studies](#). This point is often neglected, due partly to the restricted representation of the Chinese bioethics community, which reinforces a common apprehension that Chinese academics are necessarily an extension of the state's political apparatus. In fact, protection of genome-edited persons has been complicated by bioethicists' own struggle for open and inclusive discussions. There is an imperative for the Global North to recognise that engaging and enabling this community is key to promoting accountable science and innovation in and with China.

However and secondly, the Chinese bioethics community is in dire need of conducting empirically-informed research on the views of scientific practitioners and general publics in China. Indeed, for China's science to establish global influence, it first needs to render 'epistemic justice' to its own people. This pertains not only to social discrimination or power-asymmetries in patient-doctor relations. It also pertains to bioethical and scientific communities themselves who need to expand policy discussions beyond a few elites.

Read in context, the draft proposal's fixation on 'future generations' and on protection were Chinese bioethicists' (misplaced) efforts to correct the very conditions, noted by a few participants, which gave rise to the CRISPR scandal in the first place, such as an exploitative development mentality and a persistent lack of social security. This ironically misplaced good intention further accentuated the necessity for future proposals to be in sync with cultural and technological developments and lived experience.

Finally, panellists pointed out a number of wider implications of the discussion. A further question is whether or not the CRISPR babies protection discussion could be a turning point for Chinese bioethics. In contrast to previously observed [post-hoc pragmatism](#) which shuts down debates in the face of global criticism, this time, we've seen commendable efforts from Chinese colleagues to open up the discussion domestically and internationally. Many roundtable participants have pointed out the need for a new 'language' to articulate our relationship with emerging technologies. Surely it is of mutual significance to the world and to China, to have bioethicists from [the world's second largest country for the life sciences](#) substantively contributing to co-developing a language that is of cosmopolitan resonance.

Key Take-away Points

- There is a shared objection to genetic exceptionalism as the grounds for protecting genome-edited individuals. Instead, the meeting advocates a sensitive and compassionate approach that prioritises the individuals and their families' wishes, informed by scientific facts.
- The healthcare of genome-edited children should be approached in the same way that the healthcare of all children should be, with the involvement of such specialties as clinical genetics to provide genetic counselling as and when relevant.
- Socially de-exceptionalising the three children is required to enable them to lead normal lives. Empirical research and historical lessons must feed into this de-exceptionalising process.
- Instead of blame, the panel calls for a collective introspection of global scientific and social scientific communities to reflect on the social problems that gave rise to Jiankui He's research and to the decisions of the parents. Concrete actions, such as updating fertility policies and addressing social stigma can make a meaningful difference to the life quality of HIV community in China.
- The panel also calls for the promotion of a safe and more enabling environment nationally and transnationally for individuals with concerns or key information to speak out.
- There is a need to develop more appropriate vocabularies to accurately reflect the nature of the challenge embodied by new technologies and their social consequences.
- Transnational collaborations could help create conditions for gene-edited persons and others in comparable situations to flourish. Multi-disciplinary international conversations such as this one must continue.

Appendix: List of Participants and Panellists' Biographies

Event organiser and chair

Joy Y. Zhang is a sociologist with a first degree in medicine. She is the Founding Director of the Centre for Global Science and Epistemic Justice at the University of Kent. She received her PhD from the London School of Economics and Political Science under the supervision of Sarah Franklin. Her thesis was examined by Ulrich Beck and Christoph Rehmann-Sutter. Her research investigates the transnational governance of scientific uncertainty and the decolonisation of knowledge production. Conceptually, her work contributes to sociological theories of risk, cosmopolitanism, decolonisation and subaltern politics. She has undertaken empirical studies on stem cells, synthetic biology, genome editing, food movements and environmental politics. She is the author of four academic monographs: [The Cosmopolitanization of Science: Stem Cell Governance in China](#) (2012), [Green Politics in China: Environmental Governance and State-Society Relations](#) (2013), [The Elephant and the Dragon in Contemporary Life Sciences: A Call for Decolonising Global Governance](#) (2022) and [Democratic Participation and the Cosmopolitics of Science: Why Scientific Citizenship Matters in the 21st Century](#) (2023).

Panellists

Sarah Chan is a Reader in Bioethics at the Usher Institute, University of Edinburgh; she is currently an Associate Director of the Centre for Biomedicine, Self and Society and a Deputy Director of the Mason Institute for Medicine, Life Sciences and Law. Previously, from 2005 to 2015, she was a Research Fellow in Bioethics at the University of Manchester, first at the Centre for Social Ethics and Policy and from 2008 the Institute for Science Ethics and Innovation. Sarah's research focuses on the ethics of new biomedical technologies, including gene therapy and genetic modification; stem cell and embryo research; reproductive medicine; synthetic biology; and human and animal enhancement. Her current work draws on these interests to explore the ethics of emerging modes of biomedicine at the interface of health care research, medical treatment and consumer medicine, including population-level health and genetic data research; the use of human biomaterials in both research and treatment; and access to experimental treatments and medical innovation. Sarah is a Co-Investigator on the UK Pandemic Ethics Accelerator, a project funded by UKRI that brings together ethical expertise from across the UK to identify and address challenges raised by the Covid pandemic.

Ryan Ferrell was a consultant hired by He Jiankui starting in August 2018. Much of his experience is documented in Eben Kirksey's book: [The Mutant Project](#).

J. Benjamin Hurlbut is Associate Professor in the School of Life Sciences at Arizona State University. He is trained in science and technology studies (STS) with a focus on the history of the modern biomedical and life sciences, and his research lies at the intersection of intersection of STS, bioethics and political theory. He studies the changing relationships between science, politics and law in the governance of biomedical research and

innovation, examining the interplay of science and technology with democracy, religious and moral pluralism, and public reason. He is the author of [Experiments in Democracy: Human Embryo Research and the Politics of Bioethics](#) (2017) and co-editor of [Perfecting Human Futures: Transhuman Visions and Technological Imaginations](#), (2016), as well as numerous articles and book chapters. He holds an A.B. from Stanford University and a Ph.D. in the History of Science from Harvard University. He was a postdoctoral fellow in the program on Science, Technology and Society at the Harvard Kennedy School.

Jay Johnson is the Director of Volunteers at Action Wellness, a Direct Case Management agency for people living with chronic illness including HIV. Jay holds a Bachelor of Science degree in Health Administration and a MBA. He is also a retired nurse. He has been living with HIV for 31 years and participated in the small study of the [Sangamo BioSciences therapy](#), the first use in humans of gene editing in 2010. Jay loves traveling, dancing, and spending time with friends and family. He currently lives with his partner of 17 years and their four furry kids (cats) in Philadelphia.

Hubert Kang oversees the operation of Institutional Review Boards of BGI-Shenzhen and of China National GeneBank. He also lectures at the BGI-College (also known as the BGI Education Center, University of Chinese Academy of Sciences). His work focuses on promoting effective ethical oversight and ethical reviews, with a particular interest in genomics. He has been part of various national research programmes. Currently, he is part of the National Key Research and Development Program project 'Synthetic Biology Ethics, Policy and Regulation Framework Research' and the Ministry of Education funded project 'Intellectual Property Issues in Synthetic Biology Development'. He has translated several academic monographs which has helped to promote cross-cultural idea exchange. He is also the member of the Morality & Ethics Committee of the Chinese Society of Genetics, the member of the Charity and Ethics Committee of the China Health Information and Health Medical Big Data Society.

Eben Kirksey is an American anthropologist who writes about science and justice. He is best known for his pioneering work in [multispecies ethnography](#)—an approach to studying human interactions with animals, plants, fungi, and microbes. Duke University Press published his first two books—[Freedom in Entangled Worlds](#) (2012) and [Emergent Ecologies](#) (2015)—as well as one edited collection: [The Multispecies Salon](#) (2014). Recently, he introduced new approaches to [chemo-ethnography](#) in collaboration with Nicholas Shapiro. Currently he is Associate Professor (Research) at Alfred Deakin Institute in Melbourne, Australia. The Institute for Advanced Study in Princeton, New Jersey, hosted Kirksey for the 2019-2020 academic year, where he finished his latest book: [The Mutant Project](#). Personal website: <https://eben-kirksey.space/>

Ruipeng Lei is Professor of Bioethics, Executive Director of the Centre for Bioethics, School of Philosophy, Huazhong University of Science and Technology, China. She is the Vice President and Secretary-General of the Chinese Society for Bioethics and Board Member of Chinese Society for Ethics. She has researched and advised the Chinese government on regulatory issues regarding organ transplant, human genetic resource, synthetic biology, genome editing and biobanking. She is the PI of China's National Key Research and Development Program, 'the Ethical and Policy Framework of Synthetic Biology' and the PI of National Major Social Science Grant, 'Philosophical Investigation of

BioBanking in the Era of Big Data'. She was Research Fellow at Harvard School of Public Health 2003-2005. She is a Hastings Center Fellow and a member of the WHO COVID-19 Ethics and Governance Working Group.

Robin Lovell-Badge, CBE, FRS, FMedSci is a senior group leader and head of the Laboratory of Stem Cell Biology and Developmental Genetics at the Francis Crick Institute. He obtained his PhD in embryology at University College London (UCL) in 1978, with Martin Evans. After postdoctoral research in the Genetics Department at the University of Cambridge and at the Institut Jacques Monod in Paris, Robin established his independent laboratory in 1982 at the Medical Research Council (MRC) Mammalian Development Unit, UCL, directed by Anne McLaren. In 1988 he moved to the MRC National Institute for Medical Research, which was incorporated into the Francis Crick Institute in 2016.

Robin is well known for his discovery of *Sry*, the Y-linked testis determining gene, and for subsequent work that established pathways involved in the initiation and maintenance of gonadal sex. Robin's lab also discovered the *Sox* gene family, revealed that *Sox2* is important for pluripotency in the early embryo and how several *Sox* genes are critical for development of the central nervous system, the pituitary, and for stem cells in these systems. In addition to its fundamental interest, Robin's work is of clinical relevance.

Robin is also active in public engagement and policy work, notably around stem cells, genetics, human embryo and animal research, and in ways science is regulated and disseminated. For example, he has served on committees for the Human Fertilisation and Embryology Authority contributing to changes in the UK laws around human embryo research, and for the Royal Society, US National Academies of Science, and WHO, exploring applications of human genome editing and its governance. He has received the Louis Jeantet Prize for Medicine (1995), the Amory Prize (1996), the Feldberg Foundation Prize (2008), the Waddington Medal of the British Society for Developmental Biology (2010), the ISSCR Public Service Award (2021), and the Genetics Society Medal (2022).

Helen O'Neill is a lecturer in Reproductive and Molecular Genetics and Director for the MSc in Reproductive Science and Women's Health at the Institute for Women's Health, University College London (UCL). Her research focuses on preimplantation embryo development and the use of genome editing to assess understanding and treatment of disorders of infertility. Dr O'Neill has an honours degree in Genetics, an MSc in Prenatal Genetics and Fetal Medicine from UCL and did her PhD and postdoctoral research on the genetics of ovarian development in the Department of Stem cell biology and developmental genetics at the National Institute for Medical Research. She lectures both masters and medical students and is active in public engagement involving genome editing. Dr O'Neill is CEO and Founder of [Hertility Health](#), a precision medicine-based approach to reproductive health and fertility.

Ayo Wahlberg is Professor MSO at the Department of Anthropology, University Copenhagen. His research has focused on the development and routinization of reproductive technologies in China and beyond. Ayo is the author of [Good Quality – the Routinization of Sperm Banking in China](#) and co-editor of [Selective Reproduction in the 21st Century](#).

Discussion participants:

Sonia Ben Ouagrham-Gormley - Associate Professor, Schar School of Policy and Government at George Mason University

Haidan Chen- Associate Professor, School of Health Humanities, Peking University

Katie Dow - Deputy Director, Reproductive Sociology Research Group, University of Cambridge

Lucy Lu Gao - Associate Professor, Institute for the History of Natural Sciences, Chinese Academy of Sciences

Di Zhang - Associate Professor, Peking Union Medical College

Observer

Smriti Mallapaty - Senior Reporter for Asia-Pacific region, *Nature*