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Irresponsible research? Dis/qualifying the gene editing of human embryos

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ABSTRACT

This paper examines current controversies around the use of gene editing on human embryos. Gene editing techniques (such as CRISPR/Cas9) have raised numerous questions to do with governance, security, control, legislation, regulation, ethics, responsibility, and economics. While the controversy around CRISPR/Cas9 is multifaceted and multi-layered, I focus in this paper on one key issue, namely the characterizations of, and demarcations between, responsible research and irresponsible research. I draw upon three key sites of debate and contestation: the international summits on human gene editing held in 2015 and in 2018, and the public reactions following the announcement of the birth of two gene-edited babies in November 2018. As I will show, irresponsible research is the result of a process involving various kinds of dis/qualifications and demarcations. An individual scientist is singled out, experiments are scrutinized for their legality and safety, ethical and moral stances are questioned, a scientific announcement is transformed into a provisional knowledge claim: these are the key features of a process that I propose to call 'irresponsibilization'. This irresponsibilization of research is inevitably entangled with calls for further action: irresponsible research should be contained, the veracity of knowledge claims need to be confirmed, and institutions and decision-makers are called to act.

KEYWORDS

irresponsible research, controversies, CRISPR/Cas9, gene editing, human embryos, He Jiankui, boundary-work, irresponsibilization

Introduction: (dis)qualifications in science

'I understand my work will be controversial'. Biophysicist He Jiankui (from the Southern University of Science and Technology in Shenzhen) made this prediction in a video he posted on YouTube on the 25th of November 2018. In that video, He announced the birth of twin babies whose genes he had modified through the technique of gene editing. The prediction turned out to be right. The days that followed saw a large number of articles and reactions, almost all of which condemned his experiment. The event reminds us of another experiment, also based on gene editing, to have caused noteworthy controversy. The latter experiment was published in 2015 (Liang et al. 2015) and marked the beginning of gene editing as a public controversy. Reactions to both experiments followed a similar pattern: comments were made in both the academic world and in the public, both experiments were severely criticised, and calls were made for further inquiries and debates around the ethics, responsibility, governance and legality of such endeavours. A term frequently used in the discussions about gene editing, and that serves as the starting point of my analysis here, is the term 'responsible', as well as its opposite, 'irresponsible'.

The notion of 'responsible research and innovation' is today prominent in academic and science-policy circles. Over the past few years, an institutionalization of the notion took place, through the establishment of chairs, observatories (i.e. the *Observatory of Responsible Innovation*), journals (the *Journal of Responsible Innovation*), courses and conferences, and its inclusion in European research programmes. I have argued elsewhere that we need to think of responsible innovation in terms of 'devices', that is, the material and discursive assemblages that serve to enact the ideal of responsible innovation (Meyer 2015). The question is not so much how responsible innovation could or should be defined, but what the notion performs and how it circulates: through which kinds of devices (such as guidelines, policy frameworks or public debates) does it travel, materialize and become institutionalized? The use of the notion of responsibility has, of course, also raised criticism. In the field of synthetic biology, to take but one example, the use of the term remains vague and without real practical consequences - it is mainly the moral dimension which is discussed without addressing the political dimension (Grunwald 2012).

So while in recent years, academic work has reflected upon 'responsible' research and innovation (see e.g. Hellström 2003; Rip 2005; Owen and Goldberg 2010), much less has been written about its contrary: irresponsible research and innovation. As Owen et al. (2012: 753) argue, one reason for this might be that while responsible research 'seems hard to argue against – few would argue for irresponsible research and innovation'. They further ask whether an innovation that seems 'responsible' might be viewed as 'irresponsible' when it potentially supports a 'dysfunctional, and unsustainable capitalist socio-economic world order' (Owen et al. 2012: 755). One of the few authors having proposed a definition of the term is Rene von Schomberg (2015: 56), who writes: 'irresponsible innovation is reflected in

practices where stakeholders were unaware of the importance of societal context, or where stakeholder interactions were unproductive in the resolution of conflicts'.[1]

Calling a research practice 'irresponsible' also brings to the fore the more general question of the valuation and evaluation of research. Recent books, such as *Value Practices in the Life Sciences and Medicine* (Dussauge et al. 2015), have called for dialogue between economic sociology and science and technology studies to study valuations (see also Stark 2011 and Vatin 2009). How, then, should we study valuations and qualifications in the field of genomics and, in particular, of gene editing? How are qualifications such as 'responsible' or 'irresponsible' made? Dussauge et al. (2015) propose to follow controversies, instabilities, temporalities and devices and to examine the multiplicity of values. In the field of gene editing, such a method seems fruitful as controversies around gene editing are indeed visible and since multiple kinds of valuations are being made: technical ones (praising the speed and accuracy of gene editing), biological and medical ones (imagining its benefits for human health), economic ones (via the filing of patents and the creation of firms) and ethical ones. One could, then, be tempted to analyze the co-existence between these valuations or, to the contrary, the domination of certain values (i.e. technical efficacy and safety) over others. However, in the case of gene editing, we have to move beyond the study of values and valuations as such. The controversies around He's use of gene editing in human embryos forces us to think not only about the valuation but also about the devaluation of scientific practices - calling a practice 'irresponsible' is, in this sense, a form of *disqualification*.

To talk of disqualification also resonates with some of the key arguments made by Thomas Gieryn. He has argued that the spaces in and around the edges of science are a perpetually contested terrain and what is at stake is the credibility and authority of science within 'credibility contests'. These contests, he shows, divide into three sorts of 'boundary-work': expulsion, expansion, and protection of autonomy. Expulsion – the notion that is most relevant for the present paper – is defined as a process by which 'Real science is demarcated from several categories of posers: pseudoscience, amateur science, deviant or fraudulent science, bad science, junk science, popular science' (Gieryn 1999: 16). This kind of boundary work, through which 'good' scientific practice is demarcated from 'bad' scientific practice, mobilizes various kinds of argumentations and justifications. This paper explores what kinds of arguments and principles are mobilized in order to do this demarcation work or, as many scientists put it, in order 'to draw the line'.

The material presented in this paper stems from three sources. First, the two international summits on human gene editing, held in 2015 (in Washington) and in 2018 (in Hong Kong), have been analyzed in detail via the recorded video webcasts and the final statements of the events. Second, the video material released by He Jiankui has been examined in terms of its content. Third, the press coverage of He's announcement was analyzed. I have chosen to focus upon these different arenas (conferences, videos, press articles) because they are

[1] Schomberg argues that there are different types of irresponsible innovation, one of them being technology push. He takes the example of Monsanto who aimed to push GMOs on the European market, with regulations being focused on the issue of safety only, at the expense of 'the broader environmental, social and agricultural context' (Schomberg 2015: 57). Another author who talks of 'irresponsible research and innovation' in an article is

empirically-rich sites in which the qualifications and disqualifications of human gene editing are rendered explicit and negotiated publically.

The paper is structured as follows. In the next section, I focus on CRISPR/Cas9 by looking at its history, its qualifications, and by providing some elements of the genealogy of the controversy. Thereafter I concentrate on the first international summit on human gene editing held in December 2015. After this, I analyze He's announcement of the birth of two gene-edited babies and describe the reactions and debates at the second international summit on human gene editing in November 2018 (at which He gave a presentation). In the final section, I examine the reactions in the press and regarding the YouTube video and provide an overview of the arguments and main terms used to comment on He's research.

CRISPR/Cas9: history, promises, controversies

While CRISPR sequences were first described in 1987, it is only since the 2000s that their ability to 'edit' genes has been recognized and studied (the name CRISPR, for Clustered regularly interspaced short palindromic repeats, dates from 2002 – and Cas9 is the name of an enzyme capable of cutting DNA).[2] CRISPR/Cas9 is celebrated by scientists for being a 'powerful' tool. The CRISPR/Cas9 technology makes it possible to change genetic sequences more easily and quickly than traditional biotechnology methods. The technique has thus been called 'gene scissors' and 'Swiss army knife' and it allegedly allows 'surgical' precision at startling speed. Its potential has been widely reported in the scientific community and in the media: it has been called the 'iPhone of biotechnology' (see Galanopoulo 2016) and words like 'revolution' and 'breakthrough' are frequently used. Some describe it as the greatest advance in biotechnology since the PCR machine (see Ledford 2015a). Terms like 'precise', 'cheap', 'easy', 'efficient', 'versatile', 'specific' are often used to qualify the technology. At the 2015 *International Summit on Human Gene Editing* (ISHGE), some superlatives were even used, describing CRISPR/Cas9 as being an 'amazingly efficient technology' (Rajewsky 2015 at ISHGE) and having an 'exquisite sensitivity' (Weissman 2015 at ISHGE). Natural scientists' attitude towards CRISPR/Cas9 is, in general terms, a positive, optimistic, and promissory one.

This enthusiasm does not, however, prevent researchers from arguing that more research needs to be done to fully understand the technology. 'Unintended consequences' need to be studied, 'improvements' in terms of specificity, toxicity, and delivery need to be made, and the methods for identifying off-targets should be compared and standards for measuring accuracy be determined. Lander (2015 at ISHGE) has cautioned that editing genes might have consequences and called for 'humility' and the need to understand complexity. For example, editing the CCR5 gene could foster a lower frequency of HIV, but lead to a higher frequency of the West Nile disease. A similar, inverse relation can be found

[2] For a history of the scientific aspects and development of CRISPR/Cas9, see Morange (2015).

between diabetes and Crohn's disease. 'We, as a field, still have a lot of work to do' argued Joung (2015 at ISHGE).

Despite these uncertainties and need for further research, there is a rather general consensus amongst scientists that, at least on a genetic level, CRISPR/Cas9 is a precise and effective tool. The wider physiological, bodily, and ecological effects and consequences of the technology are more difficult to assess and also more contested. As Haker (2015 at ISHGE) argued 'unpredictable side-effects cannot be studied in a lab'. Although CRISPR/Cas9 might be precise in deleting, adding or changing specific nucleotides within cells, living organisms as a whole need to be considered: 'biological consequences rather than mutations per se are more relevant' (Kim 2015 at ISHGE).

CRISPR/Cas9 holds the potential to treat genetic diseases and transform plants and animals for agricultural applications. The technique has been applied to many organisms such as bacteria, mice, fungi, humans, monkeys, butterflies, or rabbits. Frequently cited examples include the creation of sterile mosquitos (to prevent the spread of malaria), of cows without horns, and of non-browning mushrooms (see Kirksey 2016). In the medical domain, the technique has been considered to treat for instance HIV, Leber's blindness, sickling disorders, cystic fibrosis, beta thalassemia. But potential 'enhancements' have also been debated: muscles, height, intelligence, etc. In terms of publications, there are today over 12000 articles containing the term CRISPR, out of which about half stem from the US, a fifth from China, followed by Germany, Japan and England (sources: Web of Science and Scopus).

In 2015 CRISPR/Cas9 became a publicly visible technology. In early 2015, in two articles published in *Nature* and *Science*, scientists called for a moratorium on the technology (Lanphier et al. 2015, Baltimore et al. 2015).[3] In April 2015, an article on the modification of human embryos was published in the journal *Protein & Cell* (Liang et al. 2015). While the articles published in *Science* and *Nature* precede this publication, their authors were aware of its imminent publication (Frow 2015). The publication by Liang et al. (2015) marks the beginning of the public controversy. The technique has made it to the cover of various magazines and journals, including *The Economist*, *Nature* and *Time*. Throughout the year 2015, gene editing became an increasingly visible and 'hot' topic. It became even the subject of humorous comments on Twitter in July 2015: 'CRISPR is so powerful it can edit its own history', 'CRISPR was originally called CRISPER but it editted [sic] itself', 'Darwin had it all wrong. It was't [sic] survival of the fittest - It was random attacks by Cas9'.

CRISPR/Cas9 became the object of a rich and multifaceted controversy. Concerns have been raised about ethical issues, about economic issues related to patenting[4], about environmental and health risks, and about the possibility to produce new kinds of weapons. CRISPR/Cas9 and its use to do 'gene drives', for instance to eradicate mosquitos, raises important legal questions. The use of gene drives in 'the wild' might signify the end of the

[3] Following the 2015 article, there have been calls for a moratorium (Lanphier et al. 2015), for a summit on gene editing (Baltimore 2016) and for a governance and coordination committee (Marchant and Wallach 2015).

[4] A 'fierce battle' around patents has been reported (Ledford 2016).

'biocontainment' era (Lezaun 2017, see also the 2018 special issue on gene drives in the *Journal of Responsible Innovation*). A global governance of gene editing might be difficult to achieve, since there are national differences regarding ethics – i.e. between the US and China (Jiang and Stevens 2015) - and since the legal and moral status of embryos can be subject to controversies and renegotiations in a country (Jiang and Rosemann 2018).

The issues raised resemble the types of issues that can be observed in debates around GMOs and synthetic biology, which generally revolve around 'ELSI' issues, that is the ethical, legal, and social implications of science. The status and traceability of organisms modified via CRISPR/Cas9 is, for instance, considered by some as a key problem: should they count as GMOs or not? (see i.e. Bartkowski et al. 2018) Another issue is the question of whether CRISPR/Cas9 is really that precise or if there are problems with so-called 'off targets'. And, more generally, where should the line between acceptable and non-acceptable practices be drawn and who are the legitimate actors and institutions to do so?[5]

The end of November 2018 marks the beginning of a second, highly visible, episode in the controversy. It was sparked by Chinese scientist He Jiankui, who announced the birth of two babies he had genetically modified as embryos by using gene editing. Just after this announcement, that immediately hit the headlines worldwide, He spoke at the second international summit on human gene editing held from November 27th-29th at the University of Hong Kong. At this conference, he said that his research had been submitted to a scientific journal, but has not been published yet. I will return to this meeting later.

The first international summit on human gene editing: 'it would be irresponsible'

Let us have a closer look at the first *International Summit on Human Gene Editing* that took place in Washington in December 2015, an event jointly organized by American, Chinese and British science academies. The summit was held in response to growing concerns raised within the scientific community about the use of gene editing on human embryos – concerns that were sparked by the publication by Liang et al. (2015). At first look, the summit resembles any other international academic conference, where academics present their work in a scholarly format (via presentations of about 10 or 15 minutes, the use of PowerPoint, and by answering questions). However, the summit was unlike any conventional academic conference: it was organized in response to a pressing issue, it was very publicized, it addressed issues of governance, it issued a final statement, and its audience exceeded well beyond the scientific community. While parallels can be made with the 1975 Asilomar

[5] While a common way to analyze controversies is to do a 'mapping' of the various actors and their positions, the controversies around CRISPR/Cas9 show that we also need, in a sense, to 'map the mapping' and analyze the boundary-work that is done when gene editing is qualified, disqualified, called 'responsible' or 'irresponsible'.

conference on recombinant DNA, the summit was a more complex, transdisciplinary, and mediatized event than the former.[6]

Emma Frow (2015) has analyzed the main similarities and differences between the debates of the 1975 Asilomar conference and those of the international summit on human gene editing. During both conferences, the topic of security was very prominent while issues around intellectual property were virtually absent. As for the differences, she notes that themes such as governance, biosafety, and societal implications have been explicitly addressed in 2015, while they were not in 1975. The papers by Parthasarathy (2015) and Jasanoff et al. (2015) both suggest that Asilomar provides a poor model because the conference was not able to anticipate and address the ethical, social and economic aspects and, consequently, the authors suggest a more critical and broad framing, and a more democratic governance of gene editing.[7]

Throughout the summit, the metaphor of the 'line' was often used, be it for stating where it should/will be drawn, or to argue that more thoughts should be given when doing so. Here are some examples:

> 'Altering the human germline for clinical purposes is a line that should not to be crossed at this time [… it] would propagate over generations and what is done in this vein in one country will have consequences in others' (Holdren 2015 at ISHGE).
>
> '[It] could let us down slippery slopes that we did not want to go into' (Serageldin 2015 at ISHGE).
>
> 'If we are going to deem certain indications as permissible, can we identify a regulatory and oversight approach that will allow us to be comfortable that we can draw a line?' (Daley 2015).
>
> '[…] thoughtful distinctions between areas where it might be permissible and it might be worthy and areas we should not go as a community' (Daley 2015 at ISHGE).
>
> 'The grey line will not be, the boundary line will not be between somatic and germline, it will be between various grades of enhancement' (Church 2015 at ISHGE).

Other participants argued, on the other hand, that the line was difficult to draw:

> 'The bright line we may wish to draw between laudable and questionable uses of gene editing techniques is much more porous than we may realise' (Benjamin 2015 at ISHGE).
>
> 'The line between medical or therapy on the one hand, and enhancement or improvement on the other hand, is inherently blurry and subjective' (Darnovsky 2015 at ISHGE).

The problem of demarcation was also - albeit more briefly - raised in a more spatial and institutional sense. Indeed, the use of CRISPR/Cas9 in non-academic circles is also possible: members of the do-it-yourself biology community are beginning to use CRISPR/Cas9 (see

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[6] Further comparisons with other forms of international governance of science and technology can be made (i.e. through the OECD, the IPCC, or ISO norms), where we also see processes of boundary-work and (re)definitions of expertise at stake (see Laurent 2016).

[7] The latter stated that 'the human genome is not the property of any particular culture, nation, or region; still less is it the property of science alone. It belongs equally to every member of our species, and decisions about how far we should go in tinkering with it have to be accountable to humanity as a whole'.

Ledford 2015b, Wolinsky 2016) and a *DIY Bacterial Gene Engineering CRISPR Kit* has been launched after a successful crowd-funding campaign.[8]

The following comment was made about DIY biology:

> 'control becomes excruciatingly difficult. […] Thanks to CRISPR, it can probably be done by two guys with BS degrees in a garage and a couple of hundred dollars […] They are not visible to the regulatory system' (Greely 2015).

During a question and answer session, a member of the audience further asked the following question:

> 'how do you feel that these regulatory frameworks or potential regulatory frameworks […] could potentially apply to a technology where you see DIY CRISPR kits, or a lot of money going into private practices where they're potentially not going to be seen. How do you hope to keep a level of transparency and open publication in an environment where potentially a lot of the stuff could go off the public record in some ways?' (Neederhauser 2015 at ISHGE).

As we see, the 'line' drawn between acceptable and inacceptable research is not just an abstract entity, it is not the result of a purely discursive thought experiment. On the contrary, it is a social, material and political practice. It brings to the fore issues of regulation and control. 'Drawing the line' is a practice staged in front of – and for - a collective, as the usages of terms such as 'we', 'community', and 'international' demonstrate. And it is a practice that has political, institutional, and practical consequences, in other words, it is meant to leave a 'trace'.

The notion of responsibility was mobilised throughout most of the meeting, with participants talking of a need for a 'responsible' course forward (Cicerone 2015 at ISHGE), and a 'heavy responsibility for our society' (Baltimore 2015). One of the speakers contended that an anticipatory and collective responsibilization (bringing together scientists and social actors) was needed and that the responsible research and innovation framework offers guidelines to facilitate the development of governance instruments for gene editing (Reiss 2015 at ISHGE). (The European Oviedo Convention, which prohibits the modification of the human genome for reasons other than health-related, was one of the most frequently mentioned frameworks during the summit.)

In his final comments at the summit, David Baltimore, the co-chair of the event, explained that the organizing committee had crafted a statement in which the words 'moratorium' and 'ban' were deliberately not used. He also stated that a much longer statement would have been appropriate. The final statement differentiates between fundamental/pre-clinical research, clinical research on somatic cells, and clinical research on germline cells. The statement is in favor of fundamental research ('research is clearly needed and should proceed') and of research on somatic cells ('they can be appropriately and rigorously evaluated') under the condition that work is carried out within ethical and legal frameworks.

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[8] In 2017, an event called 'CRISPR-kitchen' was organized in Munich for which the DIY CRISPR Kit was bought. The participants (about 20 people including artists, scientists and so-called biohackers) did, however, not use the kit as its use would have been illegal in Germany. Instead, the event was organized around discussions on ethical and governance issues, including a debate with the German regulator, as well as scenario-writing exercises (personal communication with a participant).

Research on germline cells could be envisaged 'in principle', but numerous problems have been identified (from technical difficulties to ethical considerations) and the final statement reads:

> It would be irresponsible to proceed with any clinical use of germline editing unless and until (i) the relevant safety and efficacy issues have been resolved, based on appropriate understanding and balancing of risks, potential benefits, and alternatives, and (ii) there is broad societal consensus about the appropriateness of the proposed application. Moreover, any clinical use should proceed only under appropriate regulatory oversight. At present, these criteria have not been met for any proposed clinical use: the safety issues have not yet been adequately explored; the cases of most compelling benefit are limited; and many nations have legislative or regulatory bans on germline modification. However, as scientific knowledge advances and societal views evolve, the clinical use of germline editing should be revisited on a regular basis.

The position of the summit's organizing committee is clear-cut: it declares that it 'would be irresponsible' to use gene editing for clinical purposes. The statement assembles a variety of entities to articulate this position: science, society, regulations and legislations. This qualification of germline editing as irresponsible is furthermore provisional and future-oriented: it is irresponsible 'unless and until' certain conditions are met, and it is to be 'revisited' as both science and society might change.

Numerous countries have issued reports and statements about gene editing after the summit, including the UK, the US, Germany, France, the Netherlands, India, Denmark, Canada, and Australia.

The second international summit on human gene editing: 'it was irresponsible'

Let us look now at the video titled *About Lulu and Nana: Twin Girls Born Healthy After Gene Surgery As Single-Cell Embryo*' (duration: 4'43'') posted on YouTube by the He Lab on the 25th of November 2018.[9] It is likely that He decided to post the video in reaction to the fact that a document containing his application for the trial had been posted online (Regalado 2018).[10] In the video we see He in his laboratory talking directly at the camera. He announces the birth of Lulu and Nana (both names are pseudonyms, as are the names of their parents) who underwent gene surgery at the single-cell stage in order to prevent HIV infection. He states that the gene surgery worked 'safely', that the pregnancy of their mother Grace was 'normal', and that the babies are 'as healthy as any other babies'. He also explains that the

[9] The He Lab has posted four other videos in which more details about the ethics and process of the experiment are given. Several issues are discussed in these videos: the problem with enhancement and 'designer babies', in vitro fertilization, ethical principles, and the reasons for having chosen gene editing for HIV (both for 'safety' reasons and for its 'real world medical value').

[10] At the second international summit on human gene editing, He argued that information about his experiment had been 'leaked'. Let us note, here, that He also hired a US public-relation professional (Ryan Ferrell).

main motivation was to give the babies an 'equal chance and a healthy life', for their father Mark suffers from HIV and 'employers fire people like Mark, doctors deny medical care'.

In the video, He also discusses issues beyond the birth of the two babies. First, he calls the babies a 'gift beautiful and wholesome for society'. Second, he mobilizes the story of Louise Brown, the first baby being born via in-vitro fertilization (IVF). He argues that while initially there was 'media-hyped panic', IVF made it possible to 'help more than 8 million children' before adding that 'gene surgery is another IVF advancement'. Finally, he outlines his position on human enhancement: 'Their parents don't want a designer baby, just a child who won't suffer from a disease. […] Gene surgery is and should remain a technology for healing [… Enhancement] should be banned'. Aware of the potential negative reactions to his announcement, he declares 'I understand my work will be controversial, but I believe families need this technology and I'm willing to take the criticism for them'.

He narrates his experiment as being of scientific, medical, ethical and social significance. While doing so, he both draws upon a historic comparison with IVF (to dedramatize and normalize his announcement) and he refers to medical and social problems in the present. This strategy of comparison and positioning is, for instance, similar to that of Kim Jeong Hun's team at Seoul National University who, in order to explicate the use of CRISPR/Cas9 to cure angiogenesis-related blindness, also drew upon arguments made in other disciplines and countries (Yang et al. 2018). What is also noteworthy is that He puts families and babies at the forefront in his argumentation with, at times, a rather poetic and romantic tone through the use of words such as 'love', 'gift', and 'Grace'. His ethical position can be summarized as a form of 'family-centered ethics'.

The day after the video was posted, He gave an interview to the Associated Press (Marchione, 2018). In that interview, he stated: 'I feel a strong responsibility that it's not just to make a first, but also make it an example […] Society will decide what to do next'.[11]

The timing of the video and the interview must be underlined: He's announcement broke the news at the eve of the second international summit on human gene editing, held from November 27th to 29th at the University of Hong Kong.[12] He had been invited to speak at that summit, but its organizers 'didn't know the story that was going to break' when inviting him (Lovell-Badge 2018). So let us have a look now at this meeting in order to examine how He was introduced, how he presented his results and the comments and questions that were raised.

When introducing He's talk, the chair of the session gave some guidelines: He was going to have 'a chance to explain what he's done', he asked the audience to allow him to speak 'without interruptions', and he said he could cancel the whole session if he wanted to. The chair emphasized that the conference respected a 'strong tradition of allowing free speech'. The chair then asked He to come to the stage, but it took almost 40 seconds for the latter to

[11] In that interview, geneticist/chemist George Church is quoted in favor of the experiment: 'I think this is justifiable'.

[12] The event was convened by the Academy of Sciences of Hong Kong, the Royal Society, the U.S. National Academy of Sciences, and the U.S. National Academy of Medicine.

do so, causing some nervousness and laughter. When He finally hit the stage, he was greeted with some applause and with a lot of flashlights by the photographers who were present.

In his talk, He first presented some general facts and figures about HIV. He then explained the specific gene he is working on: the CCR5 gene. He presented research on CCR5 in mice, in monkeys and, finally, in human embryos. He talked about the efficiency of CRISPR/Cas9, as well as the problem of off-targets. Towards the end of his presentation he gave some elements on the clinical trial: that patients had been informed of the procedure and the risks, and that they were given the opportunity to leave the trial without implantation or having the wild type implanted. 'The couple elected to implant this [gene-edited] embryo', he explained. He stated that his team will continue to assess the effects of gene editing and that the plan was to monitor the development of Lulu and Nana over the next 18 years at least.

In the question and answer session that followed, a large number of questions were asked. The first questions concerned the CCR5 gene, its possible effects on other bodily functions and the reasons for doing research on this specific gene. He's answer was that HIV was lethal and that it represents a 'global challenge'. In a follow-up question, the chair then referred to:

> 'another paper *published* a couple of years ago suggesting that actually mice with mutations in CCR5 have *enhanced* cognitive ability. So that poses an issue, because have you inadvertently caused an *enhancement* […]? Do you think we *really* know enough about CCR5 and its role?' (Lovell-Badge 2018, emphasis in original).

In his response, He declared that he was against the use of gene editing for enhancement, and that the paper in question needed more verification. In answering another question, He gave further details about the trial: that there were initially eight couples in the study, out of which one dropped out, and that the trial has been 'paused'.

Before opening questions to the public, David Baltimore, the chair of the summit, made a few comments. He argued that the use of gene editing of human embryos 'would still be considered irresponsible', that it was not a 'transparent' process, and that it was not medically necessary. He concluded by saying that He's experiment represented a 'failure of self-regulation by the scientific community'.

After Baltimore's statement, the floor was opened up to questions by the public. A large number of questions were posed: why alternative techniques (such as sperm washing) had not been used; who the trial was discussed with; how the ethics were reviewed; what He's responsibility was; how he managed to recruit and convince parents; what the sources of funding were; if he expected and anticipated the 'buzz'; how informed consent was gained; how the wellbeing of the babies can be proven if their identity remains secret; whether He was willing to openly share the paper he had submitted and the consent forms that he used. In sum, the questions revolved around the technical, ethical, practical, financial, legal, and communicational aspects of He's experiment. In his responses, He defended his research and gave some more details about the process. He also explained that he felt 'proud' of his achievement - a term quoted in many press articles reporting on the summit. One of the final questions – to which He did not really provide an answer – was why, despite there being an international consensus, he had 'crossed this line' and done it 'in secret'. The final statement of the summit contained the following lines about the issue:

> 'At this summit we heard an unexpected and deeply disturbing claim that human embryos had been edited and implanted, resulting in a pregnancy and the birth of twins. We recommend an independent assessment to verify this claim and to ascertain whether the claimed DNA modifications have occurred. Even if the modifications are verified, the procedure was irresponsible and failed to conform with international norms. Its flaws include an inadequate medical indication, a poorly designed study protocol, a failure to meet ethical standards for protecting the welfare of research subjects, and a lack of transparency in the development, review, and conduct of the clinical procedures' (Organizing Committee of the Second International Summit on Human Genome Editing 2018).

It is interesting to note that He is not mentioned personally in this statement, there is just a mention of 'a claim' that has been made. He's announcement is thus not considered as a proven fact, but as a provisional knowledge claim that needs further verification. The statement does not only disqualify He's announcement, it also criticizes his whole experiment on a variety of grounds: scientific, medical, legal, and moral. It does so, in particular, by saying what it is *not*: transparent, ethical, safe. In sum, we see that this dis/qualification is, in fact, based upon a threefold process: He's results are 'downgraded', the entirety of the process that led to these results is criticized, and the lack of connection to existing collective entities (norms and standards) is condemned.

The final statement of the summit is not the only collective reaction to He's announcement. Several other responses can be mentioned: the German Ethics Council stated that using gene editing on embryos was 'irresponsible' and represented 'a serious violation of ethical obligations' (26th of November 2018, my translation), the Genetics Society of China and the Chinese Society for Stem Cell Research issued a joint statement to 'strongly condemn it for the extreme irresponsibility, both scientifically and ethically' (27th of November), and the French National Consultative Ethics Committee issued a statement declaring that 'a red line has been crossed' and called for a 'stronger global governance' (29th of November 2018). The Southern University of Science and Technology in Shenzhen distanced itself from He's work, and investigations were launched to determine the legality of the experiment. In early December, the press reported that He had gone missing.

Reactions in the press

In addition to the two international summits on human gene editing, I have also analyzed the reactions in the press after He's announcement. For doing so, I have searched the *Europresse* database for articles published from the 25th of November onwards, by using the search terms CRISPR and He Jiankui.[13] At the time of writing (mid-December 2018), my search yielded 2084 results. Most articles were published over the three days that followed

[13] I searched for articles regardless of their country of publication. The analysis presented in this section does, of course, only apply to the articles available via the Europresse database. Some regions and countries outside the Western world are underrepresented (for example, there are only 78 articles from Asia, and 3 articles from the Middle East among the 2084 articles). Apart from this methodological problem, the case also raises the more general issue of symmetry and the problem when Western assessments and theories are used to make sense of events in China, but not vice-versa (on the issue of symmetry and post-coloniality see Law and Lin 2017).

He's announcement (462 articles on the 26th of November, 388 on the 27th of November, and 474 on the 28th) and less than 100 per day have been published from the 1st of December onwards.

A first result is that the majority of the articles take a critical stance towards He's research. Terms that appear frequently in articles are, in the following order: irresponsible (in 177 articles), unethical (146 articles), illegal (90 articles), and dangerous (50 articles). Excerpts from the final statement of the 2018 summit – i.e. that 'the procedure was irresponsible and failed to conform with international norms' - are frequently quoted. Some terms are a bit unexpected, such as the term 'misconduct' (appearing in 10 articles), which is usually employed to denote the fabrication of scientific data. For instance, a *BBC News* article quotes Robert Winston, a professor of fertility studies/science and society: 'If this is a false report, it is scientific misconduct and deeply irresponsible. If true, it is still scientific misconduct' (quoted in Roberts 2018).

I then searched a selection of these articles (150 articles) according to two criteria: the kinds of arguments and judgments made to condemn He's research; and the specific terms and notions used to do so. In doing so, my aim was to provide a first, exploratory analysis of these arguments - an analysis that needs to be refined in further work. The following table summarizes the key results:

Argumentation	Terms used
poor/bad science	scientific misconduct, flawed, opaque, not peer-reviewed
problematic scientist	rogue, Doctor Frankenstein, cavalier
ethics	unethical, immoral, reckless
responsibility	irresponsible
risk/safety	dangerous, crazy, pandora's box, *jugar con fuego* (playing with fire)
legality	violation, illegal
other	*lanceur d'alerte* (whistleblower)

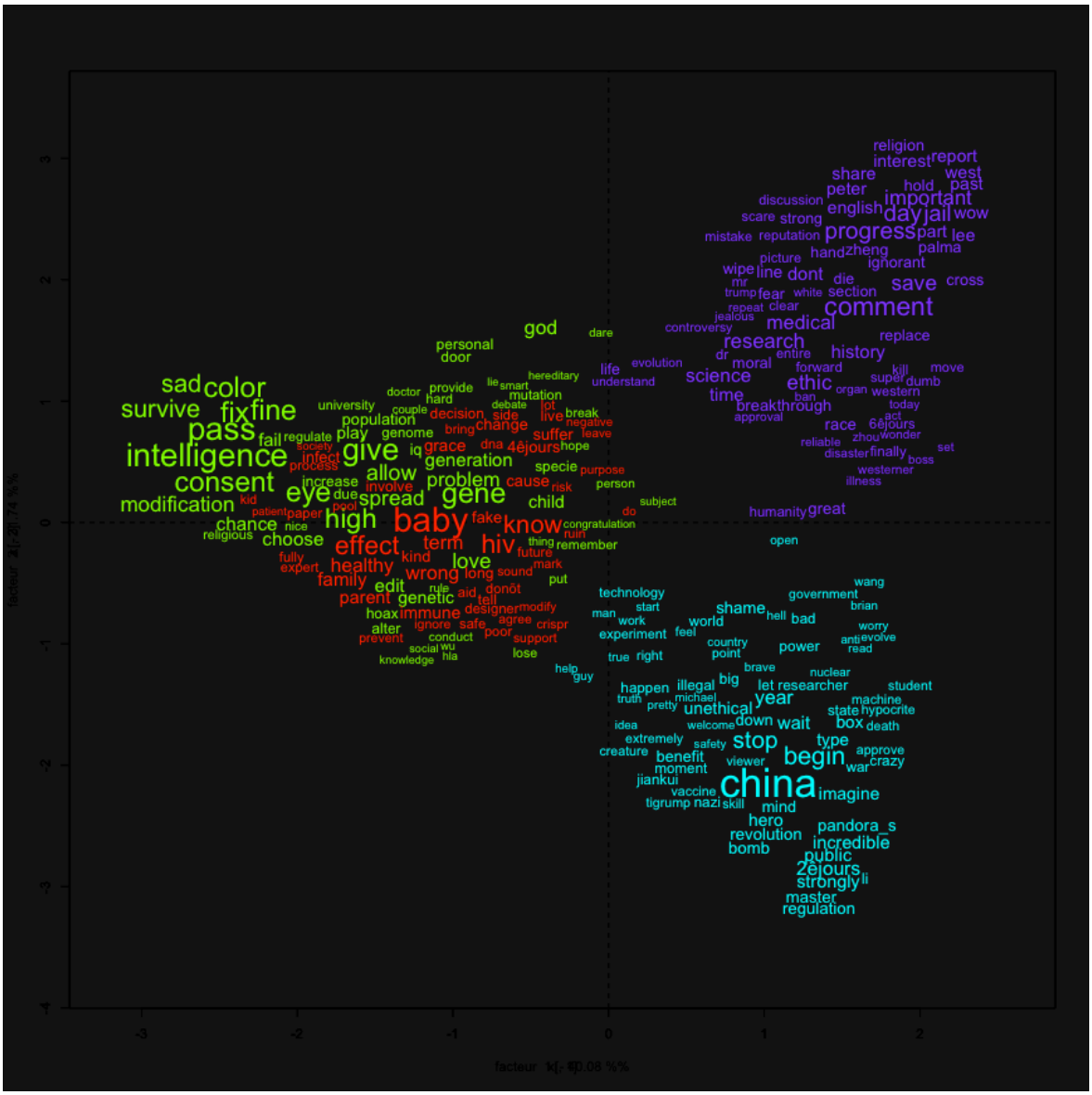
Table 1: Arguments and terms used in the press about He's research.

The specific way in which He made his announcement has also been criticized. In an article published in *La Reppublica*, physician/immunologist Alberto Mantovani writes: 'I am profoundly preoccupied, not to say scandalized, regarding both the form and the content of the announcement. […] I am outraged about the method: because you don't announce on YouTube an event like this, which requires a critical evaluation from the scientific community' (Mantovani 2018, my translation). In some articles, there are also references to popular culture: the movie *Gattaca* by Andrew Niccol (13 articles), the novels *Frankenstein* by Mary Shelley (43 articles) and *Brave New World* by Aldous Huxley (7 articles).

Only very few positive comments about He can be read in the press. In one article, the question is raised whether He could play the role of a whistleblower, albeit unintentionally (the article, in French, uses the term *lanceur d'alerte*; the term whistleblower is not present in any other article). Second, several articles cite some colleagues of He, who compare him to

Einstein and call him 'clever'. For instance, an article published in the *New York Times* (that cites the Chinese news website *Jiemian*) says that in his youth, He 'built a small laboratory at home, believing that he could be China's Einstein' (Wee and Chen 2018).

Apart from articles in the press, I have also examined the comments made in the comments section below the YouTube video announcing the birth of Lulu and Nana. Several words are particularly noteworthy. First, the word 'shame' has 49 occurrences in the comments (making it the 13th most used term), with many comments along the lines of 'as a Chinese, I feel shame'. The use of positive terms is also notable: the words 'brave' and 'proud' are both used 7 times in comments that approve of He's experiment, and the word 'congratulations' is used 14 times. I have further analysed the comments via a multidimensional text analysis by using the software *iRaMuTeq*.[14] This analysis yields three main clusters of words (see image 1).



[14] *iRaMuTeq* is a program, based on the Max Reinert classification method, for the multidimensional and statistical analysis of a corpus of text. My corpus did not include comments made in a language other than English, nor replies to specific comments (but it included first names). Further analyses could address these issues.

First, there is a cluster (in green and red) that we could call 'ontologies and effects of gene editing' that revolves around the modification of genes and its effects on human health. Second, there is a cluster (in purple) that we could call 'responsible research and medicine' concerned with the ethics and the wider historical and social context of gene editing. Third, there is a cluster (in light blue) we might call 'irresponsible research' that contains many negative qualifications. The discussions of the technical and social features of gene editing seem closely entangled: the intermingling of words about the physiological and technical aspects (in green) and words about the social aspects (in red) points in this direction. However, there is a strong discursive distance between responsible research (purple cluster) and irresponsible research (blue cluster) – an interpretation that resonates with the recurrent use of metaphors around 'drawing' the line.

Discussion: the irresponsibilization of gene-edited human embryos

This paper has focused on the controversies raised by the use of CRISPR/Cas9 on human embryos between the years 2015 and 2018. Gene editing is, both in 2015 and in 2018, a broad and international issue: international norms, protocols, ethics, transparency, and safety are all mobilized in order to make sense of it. However, the ontology of gene editing has changed between these years with the announcement in November 2018 of the birth of two gene-edited babies. On the one hand, for He Jiankui, gene-edited embryos are of scientific, medical and socio-cultural interest: they can be produced in a safe way, they can solve a medical problem (HIV) and social problem (discrimination). He justifies his experiment by outlining a family-centered ethics and stressing his own 'responsibility' to go ahead. But He's position is not one of 'anything goes': the boundary between healing and enhancing, he argues, should not be crossed.

On the other hand, for the scientific community, the existence of gene-edited embryos is a provisional claim to be verified. He's experiment is criticized on a variety of grounds (scientific, medical, legal, and ethical) and by deploring the lack of transparency and the non-respect of collective norms and standards during the process. When we compare the final statements of the first and the second summit on human gene editing, we see a switch in tone and in content. The tenses shift from a hypothetical and provisional 'would be' to a definite and retrospective 'was'. And, while the first statement talks rather generally about 'the use of' a technology, the second statement unpacks the various phases of one particular experiment, condemning at once its design, process, results, and communication. What has remained constant, however, is that the clinical use of gene-edited embryos is disqualified by being defined as 'irresponsible'.

When comparing the reactions to He's announcement made at the 2018 summit to the reactions written in the media we find similar arguments. In both arenas, the experiment is criticized by drawing upon scientific, medical, legal, and ethical arguments, and similar terms (i.e. irresponsible, unethical, illegal, and dangerous) are used. We also observe the use of similar metaphors, such as drawing and crossing lines that show that boundary-work is omnipresent in both arenas. However, there is at least one noteworthy difference. The

geopolitics of the experiment are articulated differently. The summit enacts an *international* community: human gene editing is defined as an issue requiring global governance, and the bringing together of different nations, disciplines and 'the public'. In the press and in the comments on the video, the experiment is narrated in a more dramatic way, with more emphasis on national identity and reputability. This is especially visible in the analysis of the comments on the video, which yielded a cluster of words concerned with the ethics and the historical and social context of gene editing, and another cluster concerned with irresponsible and illegal practices.

While definitions of responsible research and innovation are abundant, 'irresponsible research' has remained ill-defined. To put it this way, irresponsible research usually serves as the silent and negative ground against which the positive figure of responsible research stands out. 'Irresponsible research' can, on the one hand, thus be defined by what it is not: it is not ethical, transparent, interactive, mutually responsive, inclusive, reflexive, and so on and so forth. But, on the other hand, we also need to provide a 'positive' definition of irresponsible research. So what, then, *is* irresponsible research?

Irresponsible research is, above all, the result of a process: it is performed via a heterogeneous set of practices involving qualification and demarcation. An individual scientist is singled out, experiments are scrutinized for their legality and safety, ethical and moral stances are questioned: these are some of the features of a process that we could call 'irresponsibilization'.[15] This irresponsibilization of research is inevitably entangled with calls for further action: irresponsible research should be contained, the veracity of knowledge claims need to be confirmed, and institutions and decision-makers are called to act. Irresponsible research forces those who - intentionally or not - defend responsible research to mobilize themselves, raise their voice, produce knowledge and make decisions. This seems to make the process of 'drawing the line' between acceptable and inacceptable research easier, quicker, and sharper.

Social scientists have the tools to analyze gene editing in various ways, by: analyzing the controversies it raises; studying its governance; tracing the continuities and discontinuities in relation to wider developments in biotechnology; considering the kind of futures and promises that are articulated. We could, also, further compare the present story to institutional and public dis/qualifications of other experiments that raised controversy (i.e. the birth of Dolly the sheep, the Tuskegee syphilis experiment, the experiments on hepatitis A at Willowbrook State School). And, finally, it is worth exploring in more detail how the public is, or is not, invited, mobilized and imagined in public debate.[16] More empirical

[15] Yannick Barthe (2017: 231-239) provides an account of 'responsibilization' and its relationship with 'victimization' in his book about the victims of nuclear tests. He outlines the process of responsibilization: i.e. identification of a responsible entity from which accountability is demanded, demonstration of a link between a specific cause and a damage done, tension between responsibilization and deresponsibilization. The similarities and differences between responsibilization and what I call irresponsibilization need to be further explored.

[16] See: the analysis by Rose et al. (2017) of public engagement activities about gene editing that took place at the 2015 Wisconsin Science Festival; Rosemann et al. (2017) who have called for transnational and comparative studies on the public perceptions of gene editing; and McCaughey et al. (2016) whose online survey shows rather

studies on gene editing that further look into these issues would be welcome. My main aim in this paper was to study the controversies around gene editing through a specific lens, by examining the grammars, registers and metaphors of (dis)qualification.[17] I hope, thereby, to have shown that it can be fruitful to focus upon the politics and ontologies of irresponsible research 'in-the-making'.

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positive attitudes towards health-related applications, but negative attitudes regarding non-health-related applications of human gene editing.

[17] Further work could examine in more detail how values and positions are articulated by various kinds of actors (biologists, ethicists, policy-makers, NGOs, industry, etc.) and examine whether there are differences across national contexts (see O'Mahony and Schäfer (2005) and the issue on 'Stem Cell Technologies 1998-2008: controversies and silences' in Science as Culture (2008)).

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