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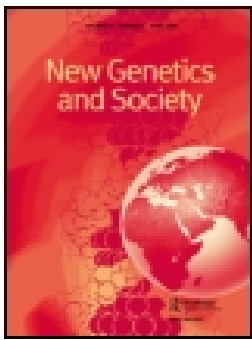
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## RESEARCH ARTICLE

# The unexpected and unanticipated announcement of the “world’s first” gene edited babies: breaching, repairing and strengthening community boundaries

Rebecca Dimond <sup>a\*</sup>, Jamie Lewis<sup>a</sup> and Alice Sumner<sup>b</sup>

<sup>a</sup>*School of Social Sciences, Cardiff University, Cardiff, UK;* <sup>b</sup>*School of Medicine, Cardiff University, Cardiff, UK*

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The 2018 announcement that the world’s first babies had been born following gene editing was unexpected and unanticipated. In this article, we focus on the reaction to the announcement and explore how this revealed implicit and explicit assumptions about the role and responsibilities of scientists and scientific standards. Through analysis of media coverage and public commentary about the birth of the “world’s first,” we identify how the event was constructed as a breach of scientific norms. We begin by identifying the use of an “if true” narrative, which contributed to the meanings of the technology and the births following the initial announcement. We consider two dimensions to the concept of “breach,” as an individual act of transgression and as a rupture of community norms. Finally, we consider the work of the broader scientific community in repairing the damage and their attempts to strengthen its boundaries to prevent future transgressions.

**Keywords:** Gene editing; scientific norms; breakthrough; regimes of normativity; genome editing; breach

## Introduction

Gene editing involves adding, deleting, or otherwise manipulating genetic material. It includes several different techniques, the most recent, and arguably most notable, is known most popularly as CRISPR (clustered regularly interspaced short palindromic repeat). CRISPR has been celebrated as a game changer, a revolution and a new frontier (Doudna and Charpentier 2014) and, in the opening remarks to the first

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\*Corresponding author. Email: [dimondr1@cardiff.ac.uk](mailto:dimondr1@cardiff.ac.uk)

world summit on gene editing in 2015, as a “new era in human history” (Olson *et al.* 2016). Gene editing is one part of a long history of attempting to understand, and potentially change, the human genome. In particular, it has been used to successfully “treat” somatic conditions such as some types of childhood blindness, spinal muscular atrophy, and sickle cell disease, and in 2015 it was used in research on non-viable human embryos. Its recent rapid development, ease of use and broad applicability including the editing of human sperm, eggs and early embryos has acted as a catalyst for many countries and institutions to initiate debates and calls for evidence to explore the scientific, social and ethical implications of such techniques. Of course, with any novel technology there are risks of unintended effects. To borrow words from Donald Rumsfeld, one “known unknown” of gene editing is an “off target” effect, the introduction of an unintended genetic change. The potential to manipulate human genetic material, and possibly introduce “genetic” errors underlines the significance of the distinction between somatic cells and germ line cells, where those changes could be inherited by future generations alongside other “known unknowns.” But this distinction is not simply a question of safety. The boundary between somatic and germline is fundamental to the ethics and practice of human gene editing (Cwik 2020), demarcating a “red line” between what might or might not be considered ethical and therefore socially acceptable.

On 26th November 2018, there was an unexpected and unanticipated announcement that the “world’s first” gene edited babies had been born in China (Marchione 2018),<sup>1</sup> indicating that the “red line” had been crossed. The Second International Human Genome Editing summit in Hong Kong summit began that week, becoming the inadvertent site where details about the birth and the technology used were revealed, and the technology (in terms of its first use resulting in a human pregnancy) given its first public platform (Wahlberg *et al.* 2021). The first day of the summit was hastily reorganized, with the Chair, David Baltimore, inviting the scientist involved, He Jiankui, to explain and defend his work, at which point he confirmed that twin babies had been born, and a second pregnancy was in progress. The organizing committee concluded that:

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. (Baltimore *et al.* 2018, emphasis added)

Further details surfaced over the course of the days that followed, with Jiankui facing extensive national and international scrutiny. By the end of the week, the Chinese Academy of Medical Sciences condemned the work and declared that it was not in accordance with Chinese government regulations (Wang *et al.* 2019).

Occurring against a backdrop of extensive national and international debates exploring the potential future of gene editing, the fact that the announcement of

the “world’s first” babies was unexpected and unanticipated was significant. The announcement was roundly criticized by the scientific community and media, highlighting implicit and explicit assumptions about the rights and responsibilities of scientists. Questions were asked about the scientific community’s ability to monitor its own members, and its preparedness to respond to rapid technological developments that had moved from the treatment of illness to altering the germline. In this article, we draw primarily on UK media coverage of the week of the announcement, exploring those initial reactions and what they revealed about the “regimes of normativity” in heritable gene editing.

### **Bioscientific scandals and celebrations**

Gene editing is part of a long history of biotechnical developments, a history which itself has been marked and moulded by both scientific controversy and celebration. For example, the first transfer of rDNA into humans was performed in 1980 to treat beta thalassemia, but without ethical approval, resulting in Martin Cline, the US clinician-scientist, losing his grant and resigning. Deaths and severe illness resulting from early trials were carefully represented as a normal cost of scientific practise, which enabled progress in the research field to continue relatively unscathed (Addison 2017).

Of course, one of the most well-known iconic transgressions was the colloquially known “Hwang scandal.” Hwang Woo-Suk’s work on cloning human embryos and retrieving stem cells was initially framed and celebrated as a bioscientific breakthrough, helping to establish South Korea as a new biotechnological “powerhouse,” and Hwang as a world-renowned scientist and international leader (Chekar and Kitzinger 2007). It soon became apparent, however, that Hwang had contravened several ethical principles, including enrolling junior colleagues as egg providers. Although most media continued to emphasize scientific progress, a more conclusive transformation occurred when scientists began to question Hwang’s findings. The two scientific articles which had contributed to the celebration of this work as a “breakthrough” were then retracted with the admission of scientific fraud.

There are parallels with the Hwang case and our gene editing example, particularly in attempting to make sense of how such an event manifested. Alongside questions about personal motivation and the craving for recognition (as we discuss later in our analysis), focus turned to the context within which scientists work, where scientific progress was propelled by patriotism and national interest (Chekar and Kitzinger 2007). In contrast to our gene editing case, the media itself was seen as part of the problem. It was criticized for failing to question Hwang’s work, and instead being enchanted by, and propagating, the “utopian hype surrounding therapeutic cloning” (Jensen 2010, 3).<sup>2</sup> The eventual reaction to the Hwang scandal was also significant, resulting in a “moral atomic bomb,” with a

new focus on “ethical modernization” to create “a more trustworthy and ethical society” (Kim and Park 2013, 375).

In the case of the *birth* of a “world first,” media coverage has a particularly performative capacity, as both public witness to and public record of the birth, while actively constructing its cultural meaning (González Santos, Stephens, and Dimond 2018). For instance, the birth of Dolly, the world’s first cloned sheep, was announced in 1997 when she was seven months old. In contrast to the Jiankui gene editing case, disclosure of Dolly’s birth was carefully stage managed, through an embargoed press release to coincide with a publication in *Nature* (Wilmut, Schnieke, and McWhir 1997). Several photographs circulated as “evidence,” mostly of Professor Sir Ian Wilmut, alongside his creation (Bauer and Gaskell 2002). The birth of Louise Brown, the first baby conceived using in vitro fertilization (IVF) in 1978, was marked in a similar way, with now iconic photographs of Patrick Steptoe, and others in the clinical team such as Sir Robert Edwards holding her.

Representing a development as a “first” renders invisible the complex history and development of technologies. Dolly was celebrated as a first, even though she was actually the 227th attempt, and the successful birth of the first test tube baby effectively conceals the generally low rate of success of IVF (Callaway 2016). Public reception was at a critical point, particularly because the second attempt at creating a second test tube baby had failed. In this context, the first birth might have been framed as a stroke of fortune or even as “rogue science.” However, instead, it was presented as a “sign of hope” in declining times. Steptoe and Edwards were celebrated as British pioneers, where the evocation of both nostalgia and hope was able to garner public support (Dow 2017). Louise Brown’s birth was celebrated as a solution for infertility, but she also represented a “a new future of scientific discovery and technological innovation that could restore the economic fortunes of the country” (Dow 2017, 66). This framing of the first birth as a successful development provided the foundations and the catalyst for the development and growth of the assisted reproductive industry. As a result of the new possibilities of reproductive technologies, an independent body was set up to oversee embryo research. This eventually led to the establishment of the Human Fertilisation and Embryology Authority (HFEA), which now monitors and licenses human tissue and embryo research in the UK under the Human Fertilisation and Embryology Act 1990.

Finally, there are striking similarities between the announcement of the world’s first gene edited babies, and the similarly unexpected and unanticipated announcement of the first baby born using mitochondrial donation in 2016 through an American-Mexican collaboration. Mitochondrial donation is a reproductive technique which can prevent the transmission of maternally-inherited mitochondrial disease. The backdrop against which this first birth was judged was that a year earlier, in 2015, the UK became the first country to legalize mitochondrial donation, with many other countries initiating scientific and public discussions

(Dimond and Stephens 2018). The lead scientist Dr Zhang was often quoted as saying that Mexico was chosen because “there are no rules” in Mexico (González Santos, Stephens, and Dimond 2018). Zhang, was widely criticized for breaking legal and ethical guidelines, and the case raised questions about the long-term impact on science, particularly in terms of public trust and the efficacy of scientific regulation.

### **Social and ethical implications of heritable gene editing**

The first International Summit on Human Gene Editing took place in 2015 (Jasanoff, Hurlbut, and Saha 2015), with the 12-member organizing committee concluding that proceeding with clinical use of heritable gene editing would be irresponsible until safety had been fully explored and there was “broad societal consensus about the appropriateness of the proposed application” (Olsen *et al.* 2016, 7). There have been signs, however, of a potential shift towards acceptability. The US National Academy of Sciences and National Academy of Medicine (2017, 145) highlighted “heritable germline genome editing trials must be approached with caution, but caution does not mean they must be prohibited.” At the time, UK news outlets acknowledged this shift, stating “this is the sound of scientists gearing up for the debate of their lives” (Moody 2017). The later Academy report went even further, specifically tasked with “defining a responsible pathway” for clinical use of heritable gene editing (NAM 2020). The increased urgency to explore the implications was noted by the UK Nuffield Council on Bioethics (2018) “deliberately intervening in the human genome for the purposes of selecting traits of future children has now become a real and distinct possibility” (pvii). Their conclusion that heritable gene editing could be ethically acceptable in some circumstances prompted news outlets to suggest this signaled a “green light,” although the report itself recommended caution. Changing UK law to enable heritable gene editing was noted as “a very long way off and, indeed, might never arrive,” with the recommendation of encouraging societal debate and engagement with countries and international organizations, “to help develop international norms for the law and governance of genome editing” (pvii). Despite these shifts towards potential acceptability, the biological and moral risks of intervention remain significant, and are part of the reason why Jiankui has evoked such strong emotions. Drawing on Mary Douglas (1966) “matter out of place,” Morrison and De Saille (2019, 6) explain how Jiankui “contravened what might be the most important cleanliness taboo because it is the only one approaching unanimous agreement by all parties in the field: that GGE [human germline gene editing] is not safe enough to be used *yet*.”

There has since been a growing body of research exploring the social and ethical implications of heritable gene editing noting the Jiankui case (see for example Dimond, Lewis, and Thomas 2021; Jasanoff, Hurlbut, and Saha 2019; Ranisch and Ehni 2020). Much of this work explores the resonance of Jiankui’s work on

science and society. What it means for public engagement, trust in science and science regulation is particularly relevant for this article. Scientists who move beyond the boundary of acceptable practice, such as Jiankui, risk undermining a “legitimate science,” yet there is also recognition of the opportunities this provides, to ensure transparency and clarity in future, and a greater role for anticipatory governance (Nelson, Selin, and Scott 2021). The Jiankui case brought a sense of immediacy to questions about consultation, and when publics should have their say on technological development and their uses (Iltis, Hoover, and Matthews 2021). While many institutions recommend greater public (upstream) engagement, it is not always clear what shape this might take, particularly within a diverse landscape of national and international regulation, which frame issues and enroll publics in different ways (Meyer 2022; Mahalatchimy 2021).

The case has been described as not just a cautionary tale *about* science and scientists, but also a cautionary tale *for* science (Greely 2019, 2021). Indeed, more scientists are now questioning the effectiveness of self-regulation (Waltz, Juengst, and Edwards 2021). The framing of the Jiankui case is important to note and might have implications for how future transgressions are understood. Self-scrutiny and introspection have been described as the paradox of “irresponsibilization,” where “irresponsible research, something that should have been prevented, nonetheless yielded an important discussion about and institutional statements on responsibilities” (Meyer 2022, 140). As with the Hwang scandal, it is the culture in which science operates which is brought into the foreground, with the speed and capital accumulation of the innovation economy clashing with “older values that stressed prudence, integrity, and responsibility” (Kirksey 2021, 235).

Echoing an argument made by Scully and Rehmann-Suter (2001) in relation to gene therapy, and Pickersgill (2012) in relation to ethical governance, Martin and Turkmendag (2021) use the concept of “regimes of normativity,” to understand these recent developments. “Regimes of normativity” (in part based upon the concept of a “socio-technical regime”) is a heuristic device employed to understand the moral and ethical principles which frame scientific developments. In this case, developments in genetics have meant heritable gene editing is technically feasible and therefore “thinkable.” When something becomes “thinkable,” it can thus become (socially) feasible. Martin and Turkmendag highlight the Nuffield Council on Bioethics’ reports as sites where these points of contention are identified (and resolved), and therefore as a pivotal moment for the future of the field. Heritable gene editing raises similar points of contention to other genetic developments, such as making a distinction between treatment and enhancement, navigating the moral status of the embryo, and the (dis)entanglement of science from ethics. The reports helped establish a focus on parental reproductive rights, framing human genetic modification as potentially the “only hope” to have a healthy genetically related child, and confirming legitimate public health resources to avoid disability or disease, all of which contribute to its acceptability and desirability.



Our analysis of the reaction to the announcement of the “world’s first gene edited babies” contributes to this body of sociological inquiry, both acknowledging the specifics of this case, and its broader implications. With the prediction that the Jiankui case “will stand as one of the most controversial human experiments in post-World War II science” (Krimsky 2019) it is important to consider how and why it constituted a breach, thus revealing the hidden work and enduring legacy of scientific success and failure.

## **Methods**

With the media playing a key role in public communication of science and scientific developments (Gregory and Miller 1998), media coverage offers a “real time” opportunity to explore the meanings and social implications of new technologies. Media is a site of knowledge production, “an arena through which policy battles are fought” (Kitzinger, Williams and Henderson 2000, 206) where decisions are made about how to frame and interpret issues, and which voices are enabled or silenced. The days and weeks immediately following a disclosure represents a critical time period. Our media analysis of these moments is influenced by others who have similarly focused on key scientific moments, such as Dolly the cloned sheep (Haran *et al.* 2008), the birth of twins to a 60 year old woman (Campbell 2011), the world’s first “saviour sibling” (Nerlich, Johnson, and Clarke 2003), and the first “test tube” baby (Dow 2017). González Santos, Stephens, and Dimond (2018) examined reactions to the surprise announcement of the birth of the first baby born using mitochondrial donation, by conducting an international comparison of media coverage in the first two days. They noted that meanings were “thickened” through media representation in that critical time period. Technical and cultural feasibility of the technologies were established by focusing on particular narratives (such as “saving lives,” or scientific progress) while obscuring others (such as the complexity of a technique or its histories).

Publicly accessible information such as newspapers, television documentaries, fiction and institutional reports form part of the “public eye,” providing a lens through which people relate to and understand a particular problem (see for example Turkmendag’s (2018) analysis of the mitochondrial donation debates). We draw from a range of publicly available documents to consider the way the birth was announced, alongside the reactions it provoked. Our methodological approach is conventional qualitative content analysis (Hsieh and Shannon 2005), a similar approach to thematic analysis (Braun and Clarke 2021) which enables the identification and analysis of patterns across a dataset. Most pertinently when working with texts, it is important to “establish the meaning of the document and its contribution to the issues being explored” (Bowen 2009, 33). Throughout, we acknowledge the significance of the production of documents and events, and as “topics” in themselves (Prior 2008). Newspaper articles can tell us of the setting and of the zeitgeist. Our media analysis begins when the first story appeared, on

Monday 26th November 2018, one day before the start of the 2018 Human Genome Editing summit. Our analysis then extends to the following months as further details and responses were revealed. Our timeline corresponds with the “initial” and “after” period described by Calabrese *et al.* (2020) in their analysis of twitter coverage of the announcement.

We identified relevant news articles through searching for “news” “CRISPR” and “babies” “gene editing” and “Jiankui,” and used the newspapers’ websites to identify further articles. We began by searching for articles, which were published between 26th November and 2nd December 2018, and then widened the search for articles published subsequently. We analyzed online coverage of print newspapers, which covered a broad range of readership and political stances, including right-leaning outlets such as The Times, The Mail and The Sun, center ground newspapers such as The Independent, and left leaning newspapers such as the Guardian and The Mirror. AS initially coded the articles, with RD and JL developing the coding through a re-reading of the data. We systematically recorded all instances where views were expressed about Jiankui, his work, and its reported implications for science and society. We also used an iterative, purposeful approach to identify and draw from institutional reviews and reports published both before and after the announcement, which documented the rapidly evolving landscape of gene editing. The main themes that were generated through this analysis, and which we present in this article, are the “if true” narrative, the concept of “breach,” and its repair.

### **The “If true ...” narrative**

News reports in the first week presented a homogenous narrative, identifying a “world first,” that it involved the creation or birth of a baby, and noting a connection with China (either the nationality of the scientist involved or the birthplace of the babies). Equally prominent in headlines was the term “claims,” and that it was one individual scientist making these assertions:

Chinese scientist *claims* to have created ‘world’s first genetically edited babies’ (Telegraph 26/11/18)

World’s first gene-edited babies created in China, *claims* scientist (Guardian 26/11/2018)

World’s first genetically altered babies born in China, scientist *claims* (Independent 26/11/2018)

News reports were emphatic in their statements that the event was notable, and newsworthy. However, we identify the terminology of “claiming” as part of an “if true” narrative, which dominated initial coverage of the announcement, and which we discuss in this first data section. The prominence of the “if true” narrative is an indicator of the extent to which the announcement was both unexpected and unverified. Some journalists and commentators were explicit in their framing,

recognizing the act as both scientifically and ethically transformative, for example, as stated in one of the first reports, “*If true*, it would be a profound leap of science and ethics” (Marchione 2018). But ambiguity was also present, as one report noted “The *shocking claims* have yet to be independently verified by experts and published in a journal, though *if true*, would represent a monumental leap in biomedical research” (Yan 2018). The use of the words *shocking claims* here highlights the unexpected and unanticipated nature of the announcement and underlines how Jiankui was deemed to fall short of the required and expected performance of a scientist, with its framing as “monumental,” suggestive of its broader significance. Similarly, in an opinion piece, Malik (2018) noted the potentially ambivalent positioning of the announcement, “His *claim* is unverified, but *if true*, it would signal a landmark moment in human genome editing.”

At times Jiankui’s work was recognized as having an uncertain status, where its future implications are unknown, and where its meanings would be revealed over time. Joyce Harper, a genetics professor at University College London for example had stated, “There’s nothing published at the moment suggesting we’re anywhere near it, but *breakthroughs* can happen overnight. The next few weeks are going to be really interesting” (Appleyard 2018). Here, we can see the productive capacity of the “if true” narrative: the framing of the event as a potential or future bioscientific breakthrough, although not at the current time. The “next few weeks” was identified as an anticipated period of change following the announcement, where the revealing of additional information would likely lead to more certainty, and the subsequent erosion of the “if true” narrative. Robin Lovell-Badge, a member of the WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing, also noted the potential to use the language of breakthrough but ruled this out because of the decisions made by Jiankui, maintaining “I’m very critical of calling this a scientific breakthrough because he’s messed up all along” and that evidence was required to confirm the report:

Lovell-Badge said that ... the only way to convince the world would be if an independent, qualified, lab tested the DNA of the parents and the two babies to show that the genes had been edited. “Nothing that I’ve been shown says it’s false. But the evidence I’ve seen is not yet good enough”. (Sataline and Sample 2018)

Here, there was a suggestion of a threshold in determining the acceptability of the evidence. The use of the words “independent” and “qualified” are significant, revealing the standards through and against which science can be judged as legitimate. Media reports highlighted what might be considered appropriate evidence, including peer review publication, ethical scrutiny and informing colleagues. Numerous articles repeated the concern that it had not been independently confirmed. The “if true” narrative was so prominent (and Jiankui’s work presented as so clearly breaching scientific norms), that it meant, for some, the story should not even be acknowledged until further verification. Indeed, a member

of the Chinese Academy of Social Science was critical of allowing Jiankui to speak at the summit, suggesting the claim “should not be on our agenda” until it had been “reviewed by independent experts” (Petit 2018b).

Of course, cautionary language is not wholly atypical in unverified news reports, which tend to temper their language until an event has been substantiated. But by co-opting some dissenting voices from the scientific community, it is apparent that the “if true” narrative is part of a broader rhetoric of concern predicated on aspects of credulity, veracity and ethicality. Following Mulkay (1993, 723), a rhetoric here is “an inter-related set of background assumptions plus typical assertions that are evident in participants’ discourse on a particular topic.” But, more, the “if true” narrative was so pervasive in all the accounts it formed a signal of suspicion and doubt. This framing troubles the whole event, questioning the veracity of the account and as such the trustworthiness of Jiankui and his actions, positioning the reader as a naysayer.

The “if” narrative was also, at times, associated with a much bleaker future. The “if” narrative reflected a Mary Shelley trope, enabling commentators to be imaginatively dark and despondent. Monstrous often refers to the unknown in grotesque form. Of course, new biomedical research has routinely been described as Frankensteinian when conjuring up impure forms (see Douglas 1966). As Haran et al. (2008) highlight though, such references to Frankenstein are much more commonly evoked in relation to reproductive technology than other kinds of scientific advances. In relation to public reactions to the birth of Dolly the sheep, this recurring theme was noted by Brown (2000, 109) as a “rehearsal of monstrous human reproductive futures.” In relation to the gene editing case, commentators acknowledged the potential repercussions of an unknown experiment. For example, Julian Savulescu, Professor of ethics at Oxford University stated: “*If true*, this experiment is monstrous,” and “These healthy babies are being used as genetic guinea pigs. This is genetic Russian Roulette” (Knapton 2018). Dr David King, Director of Human Genetics Alert also qualified his statement through the “if true” narrative and presented it as an Oppenheimer-type world changing event, “*If these claims are true*, the world has changed – it’s a day that I and many others have dreaded” (Knapton 2018). In their opinion piece, Hasson and Darnovsky (2018) concurred:

The claims, which have been subject to strong attack in the hours following the announcement, have not been verified, but *if true*, they would constitute recklessly unethical human experimentation and a grave abuse of human rights.

The “if true” narrative enabled the rhetoric of fear to be expressed with considerable legitimacy, directly and specifically linking to a moment in the history of technological development. Further underlying this legitimate claim of fear is the extent to which Jiankui’s work could be understood as a criminal act. An explicit expectation was that the claims would be investigated by an authority such as the Chinese government and academic institutions who would establish the facts, and

this is exactly what happened. The announcement of the babies' existence, and the circumstances in which it was made, represented multiple transgressions. This was evident in the statement made by Lord Robert Winston, Emeritus Professor of fertility studies at Imperial College, London, and a notable scientific commentator, which framed both the falsification of the results and a breach in scientific protocol and etiquette as misconduct, "If this is a false report, it is scientific misconduct and deeply irresponsible. *If true*, it is still scientific misconduct" (Blakely 2018). The public commentary of the Jiankui case began shifting from questioning the veracity of the story (if true), to questioning the moral responsibility of the scientist and the possible implications (what if true).

What we are highlighting here is that there are moments of ambivalence or ambiguity immediately following the announcement of an unanticipated event, before meanings become thickened, where tacit assumptions about science, its community and its rights and responsibilities might be made visible. The "if true" narrative represented a space of uncertainty, which enabled the wider scientific community to distance themselves from Jiankui by publicly commenting and expressing their reticence. It was also a productive space, where sense could be made of the event. This space was used to express strong sentiments about the desirability and ethicality of the development, and to announce that investigations would need to take place to establish the facts. By making visible the expectations of community, the presence of the "if true" narrative itself suggested a fundamental breach of those expectations.

### **Breach: individual and community failings**

There are two main definitions of the term, breach. The first is an act of breaking a law, agreement, or code of conduct and the second concerns a gap in a wall, barrier, or border. Drawing on the first definition, we consider how the announcement was framed in terms of an individual transgression that breached an implicit code of conduct. Jiankui was criticized for undertaking the work, for his explanation as to why the procedure was necessary, and for his personal motivations. Such overt criticism is atypical in science (Hesselmann and Reinhart 2019). Drawing on the second definition we consider how Jiankui's work was represented as a longer-term threat to the community, where the response was to repair the potential fracture, and strengthen community borders.

### **Breach: individual failings**

Boundary work (Gieryn 1983) was performed by the scientific community to highlight how Jiankui transgressed the expected and desirable characteristics of a cutting-edge scientist. Professionally, Jiankui was positioned as a non-expert, as a (bio)physicist unfamiliar with clinical trials. He was criticized for not having the correct kind of expertise and training, particularly in the environment of

human genetic manipulation. Although unclear whether referring to Jiankui personally or to the field in general, Lovell-Badge's reproach was clear, "It's a very foolish thing to embark on what's clearly a very novel, provocative technique when you clearly don't fully understand the gene you're working with" (Tang 2018).

Jiankui's personal motivations were also questioned. Coverage on the first day described Jiankui's revelation in terms of forgoing patient safety in favor of his own personal benefit, "A number of leading scientists have suggested that he is guilty of a cynical attempt to seize headlines before the event" (Blakely 2018). Personal failings were identified in much of the commentary. The event was described by Sarah Chan, a bioethicist at the University of Edinburgh, as a "cheap publicity stunt" (Knapton 2018), again evoking the "if true" narrative: "*Whether or not* the veracity of these reports is eventually borne out, making such claims in a way that seems deliberately designed to provoke maximum controversy and shock value is irresponsible and unethical" (anon 2018c). The framing as an unapologetic pursuit of personal fame, which is apparent in the media coverage is a transgression of the normative expectations concerning scientists as dispassionate, objective and understated. Scientists who do not fit the image of a "modest witness" can attract doubt as to their status and their account (Haran et al. 2008).

Criticisms of Jiankui's work also included his rationale and justification for the work. Questions were asked about medical need, particularly where there were suitable alternatives (the aim of the procedure was to protect the babies from developing HIV through contact with their HIV diagnosed father). On this point, Julian Savulescu noted: "This experiment exposes healthy normal children to risks of gene editing for no real necessary benefit." and for Chan, "Putting these children at such drastic risk for such a marginal gain is unjustifiable" (anon 2018c). Conversely, it was also within the framing of scientific justification where the most support was shown. Jiankui defended himself by explaining the stigmatized identity of HIV in China and this argument gained some traction. George Church, from Harvard University, for example, was reported as agreeing that HIV was a "major and growing public health threat" and that in this context, heritable gene editing was "justifiable" (Keach 2018). Positives were acknowledged in Jiankui's work in respect to the experience of living with illness, with the "if true" narrative transforming to "if possible": "Jiankui's work may be unethical, but there is nothing ethically superior in condemning future generations to terrible medical conditions *if it were possible* safely to eliminate them" (Malik 2018).

The summit was an important platform (Wahlberg et al. 2021) for Jiankui to try and defend himself and respond to scientific scrutiny. He was criticized for not admitting to a breach, or even acknowledging that he had made questionable and unethical choices. Headlines in that first week, for example, declared Jiankui as intransigent, "proud" and "defiant." His "vague responses" prompted concerns, including "Did Jiankui know enough about the technology to ensure that the children would be healthy, or might they contract other deadly viruses?"

He insisted he did know enough” (Sataline and Sample 2018). Jiankui’s failure to offer an adequate explanation for his pursuit and procedures at the conference represented a breach of the expectations around transparency and disclosure. News articles reported that scientists “said they were appalled the scientist had announced his work without following scientific protocols, including publishing his findings in a peer-reviewed journal” (Sataline 2018) and that “a YouTube video was an inadequate way of announcing scientific findings” (Kuo 2018a). Such responses suggested that, unlike the Dolly the sheep example, Jiankui’s engagement with YouTube videos breached expectations of how work should be submitted to a rigorous process of scrutiny that would confer legitimacy and credibility, and thus the timing and location of disclosure were not considered appropriate. Disclosure only becomes a notable issue then when there is suspicion of transgression, as in this case, when the announcement was unexpected and unanticipated.

### **Breach: the norms of the scientific community**

Jiankui’s perceived personal failings were so frequently mentioned because of what they signified, that he had put his own aspirations above that of the community. Jiankui’s work was criticized by commentators as being out of sync with the scientific community, and therefore capricious and risky. The process was deemed before its time, “premature, dangerous and irresponsible” (Best 2018), “far too premature to attempt” (Petit 2018a) and even more explicitly, was considered “shocking and unacceptable” because it “violated the ethical bottom line that the academic community adheres to” (Yan 2018). One criticism was that Jiankui had not sought guidance from others and had purposefully maintained secrecy. Lack of transparency was identified in withholding information from participants, team members and scientific colleagues and institutions (those directly involved in the process or those with a potential regulatory role). Jiankui was criticized for not telling his team that they were using edited embryos, for disclosing his work only after the babies were born and for ambiguity over when or whether his work had ethical approval.

Jiankui’s defence highlighted a fine line between secrecy, privacy, transparency, and disclosure. While we might understand “secrecy” as the antithesis of Mertonian communism, aspects of bio- scientific work are often restricted from others (see Lewis and Atkinson 2011). An element of secrecy, here, was defended as ethical responsibility, where keeping staff “in the dark” was intended to “keep some participants’ HIV infection from being disclosed” (anon 2018a). Indeed, Jiankui did not agree that his work was conducted in complete secret, not in the sense that he was purposefully preventing others from scrutinizing his work, naming several scientists with whom he had communicated his intentions. But, many of those scientists denied that they had condoned his work. Where communication was admitted, it was described as informal and that they were unaware of

the immediacy of the situation, thus strengthening the boundary between theory and practice. This was the case for Dr William Hurlbut an ethicist at Stanford University, who said that while he had spent “many hours” talking with Jiankui about situations where heritable gene editing might be appropriate, “I knew that was his long-term goal. I just didn’t think he would push so imprudently. I worried his enthusiasm for what he was doing was so high that he might proceed faster than he should” (Kuo 2018b). Here, informal and sometimes hypothetical discussions are framed as a normal part of scientific work. Organizations also distanced themselves from Jiankui, both the University which employed Jiankui and the hospital which was said to have approved the work rejected claims that they were aware of his actions.

### **Repairing the breach**

We have described how Jiankui was presented as a maverick, or “rogue scientist” (Greely 2019, 2021) someone who transgressed rules and guidelines, and how many individuals and organizations rejected the claim that they had previous knowledge of his intentions. Such acts are consistent with the first definition of “breach,” as breaking a code of conduct. Who knew (and by association, who had facilitated or condoned the work) became an important question. Indeed, who was in the “circle of trust” was still being asked months later (Cohen 2019). Yet the fact that this work was conducted without others knowing arguably had deeper-rooted implications for the scientific community and led to attempts to strengthen the ties that bind the gene editing community<sup>3</sup> together.

Even on that first day following the announcement, media reports recognized the potential long-term implications. Much of the press writing was future-oriented, questioning what (irreversible) damage Jiankui’s work will have on the scientific field, and for society more broadly. Nuffield Council on Bioethics expressed deep concern: “The possibilities raised by heritable genome editing could have significant implications for individuals and for all of society” (Blakely 2018). Gene editing as a germ line technology was a specific point of contention, “we need as a society to think hard and fast about when and where we are willing to take the risks that come with any new therapeutic treatment, particularly ones that could affect future generations” (Gabbatiss 2018). While the statement by 120 Chinese scientists noted the significance of the event, that “Pandora’s Box has been opened, but we may still have a chance to close it before it is irreparable” (Kuo 2018a), others felt that the change was irrevocable. William Hurlbut, for example, stated, “Now the door is open to this and will never close again. It’s like a hinge of history” (Kuo 2018b).

It is often difficult to distinguish between regulator and the regulated with science at the vanguard. Scientists engage in self-regulatory acts, in which they are active participants in the construction of new regulatory protocols (see Stephens, Lewis, and Atkinson 2013). But as this article has already described, this



event occurred against a varied landscape of national regulation (Ishii 2017). For some, Jiankui's work was evidence that regulation was too porous, that "there [was] a failure of self-regulation by the scientific community" (anon 2018b). Others, such as Hasson and Darnovsky (2018) described self-regulation as now "fanciful thinking":

Jiankui's scientific grandstanding is an attempt to take a shortcut past the one point of agreement that has unified both those who promote altering the genes of future generations and those defending the existing agreements to forego it: because the decision will have such far-reaching societal effects, it must not be left to scientists alone.

Concerns about the future of the field following such a significant transgression echo those expressed following the birth of the first baby born through mitochondrial donation, particularly by scientists in Mexico, where regulatory debates had been taking place at the time of the announced birth (González Santos, Stephens, and Dimond 2018). In both cases, questions about regulation were sometimes misrepresented as an *absence* of governance. Such concerns reflect a broad recognition of the complexity of regulating scientific innovation, which incorporates the needs of individuals and society, as represented by the burgeoning field of "Responsible Research and Innovation" (see for example Owen, Stilgoe, and Macnaghten 2013). For many this presented the risk of "a wider assault on the whole idea of genome editing" (Malik 2018). Dr Porteus was reported to have attempted to discourage Jiankui, by telling him, "It was irresponsible, that he could risk the entire field of gene editing by doing this in a cavalier fashion" (Petit 2018b). Reflecting elements of personal failings, community values and of the importance of public trust in science, Kathy Niakan, who was granted the first UK research licence in 2016 to use heritable gene editing on human embryos (but not for a pregnancy), was quoted as saying, "There is a real danger that the actions of one rogue scientist could undermine public trust in science and set back responsible research" (Appleyard 2018).

The Jiankui case also highlighted the work of regulatory bodies, who are required to design the future into present planning (Akrich 1992). "Known unknowns" need to be planned for if scientific developments are to be considered publicly acceptable, a move from the "if true" narrative to a "what if true" narrative. The World Health Organisation responded by taking a stronger leadership role, producing three recommendations based on transparency, responsible stewardship of science and inclusivity, which aimed to strengthen the scientific community and restore public trust. One of the recommendations was to establish an international registry of all those involved in human heritable gene editing, including funders of the research, and where failure to register would be considered a "fundamental violation of the principle of responsible stewardship of science" (WHO 2019, 5). Their recommendation that journals should only publish results of registered research is an acknowledgment of the dispersal of

responsibilities of ethical practice within the community, a focus on responsibility which was also emphasized in updated Chinese guidelines (Cyranoski 2019). There were also renewed calls for community consensus around national and international regulation (Lander 2019; NAM 2020). These calls represented an explicit invitation to the international scientific community to strengthen its internal mechanisms, to ensure that such a momentous announcement, which was both unexpected and unanticipated, could never happen again. Such repair work was also present in the Hwang case (Haran *et al.* 2008) and after the birth of the first test tube baby, which established more formal regulatory structures. This closing of ranks and the public statements that boundaries need to be policed was a response by the broader community to solidify the cracks that Jiankui was perceived to have created in the public's trust of gene editing.

## **Conclusion**

In 2019, Jiankui was sentenced, alongside two of his colleagues, to three years in prison for his role in creating the world's first gene edited babies. During the court case, Jiankui was described as acting "in the pursuit of personal fame and gain" and someone who had "disrupted medical order," and "crossed the bottom line of ethics in scientific research" (BBC 2019). This was an individual act of transgression that ruptured the scientific community's norms.

This article has explored how this breach was represented in initial media coverage. Shapin (1988) maintains that the normative framework to which scientists should adhere is blackboxed, hidden, implicit, part of the fabric of doing science but rarely made explicit, especially to the public. The actions of Jiankui, the very public admonishment by scientists and the ways in which they distanced themselves from his work made visible some of these shared rules, both formal and informal. Martin and Turkmendag's (2021) "regimes of normativity" is conceptually fruitful to help understand how the work of gene editing scientists is guided by a negotiated set of norms and principles in which scientists' expectations converge. But the public announcement of Jiankui's work did not simply bring these to light, it was the catalyst for drawing up the boundaries as to what is acceptable and what is not. Our article shows how mostly western scientists, commentators and media positioned Jiankui as a maverick, one that was not adhering to the scientific community's ethical framework and concerns. In doing so they were contributing to shaping and settling this framework.

Initial commentators questioned whether the claim was true in the first instance, instantly casting doubt on the veracity and trustworthiness of Jiankui and the work he was doing. This was then recast as untrustworthy in another form. Jiankui was identified as an attention seeker, lacking the requisite expertise to be conducting this type of work unqualified and cast as an outsider. Those involved in gene editing science did work to show there is nothing inherently unethical in the science itself, instead this was a case of pathological individualism, with Jiankui

disconnected from the ties that bind the broader scientific community. Publicly framed this way enabled the science of gene editing to be free from any charges of unethical behavior, and for basic science in this area to continue, with a renewed sense of the importance of self-regulation. This explains the resounding impact of Jiankui's work and the need for such extensive repair work, Jiankui's work was "polluting" because it was premature and risked the field's legitimacy (Morrison and De Saille 2019).

We highlighted how the "right time" is an implicit, often blackboxed expectation in science. The criticisms of the Jiankui case tended to point to this being a breach because he was out of step with the rest of the gene editing community. Jiankui's work was problematic "not so much because of *what* he did, but *when*" (Morrison and De Saille 2019, 2). Jiankui's work represented the first human use of heritable gene editing resulting in a pregnancy, at a time when stakeholders were only starting to discuss the new technology and its (mis)alignment with social expectations. Yet while Doudna warned "the bottom line is that CRISPR technology is too early a stage for human germline applications" (Angrist *et al* 2020, 334), future speculation has now become imminent, "we no longer have the silver lining of slow technical progress for further moral reflection" (Feeney *et al.* 2021, 2). Calls for a moratorium were in part an attempt to consider these "known unknowns" and to prevent the technology from moving to clinical use without a consideration of social and ethical concerns. Regimes of normativity are created in culture, they are mutable, malleable and change with time. It might be argued then that Jiankui was before his time, moving forward with the technology too fast and out of step with societal acceptance. Scientists have often been positioned as risky actors requiring constraint (Lewis and Atkinson 2011), with regulation playing a pivotal role in controlling their work. Without this oversight, Jiankui was framed as a dangerous actor.

Questions and criticisms of Jiankui and his work are representative of transgressions of broader scientific norms, breaches of both individual and collective responsibilities. Our work contributes by highlighting media as part of the regime of normativity, acting as both a witness to an event, but also as an active participant in meaning making. Media coverage is an important tool for scientists, with press conferences and media briefings becoming an expected norm in the disclosure of scientific advances. Strategies supporting science communication will often include media training for scientists, helping them excel in communicating complex scientific developments to the public and to cope with intense media interest. The establishment of the independent Science Media Centre in 2002 is evidence of how public trust in science is taken seriously. It confirms the prominence and value of science communication, aiming to provide "accurate and evidence-based information about science and engineering through the media, particularly on controversial and headline news stories when most confusion and misinformation occurs" (Science Media Centre 2022). Much of our analysis highlights the symbolic significance of scientific developments being unexpected

and unanticipated. Here, there are important similarities between the reaction to the first born through mitochondrial donation, and the first born through gene editing. Both stories were broken by journalists, and on the cusp of an international scientific conference. Several elements that we have discussed, particularly in the affordance of the “if true” narrative, suggest the lack of preparedness of Jiankui for when the news became public, which further undermined trust in his work. This contrasts with the stage-managed events supporting the framing of a successful first “test tube” birth, and in the case of Dolly the sheep, timed to coincide with the scientific publication suggesting transparency. And as we have seen, heroes and villains are produced in the process of becoming public. News coverage and commentary, particularly linked to the presentation of a “first,” offers an important and timely lens to understand the reactions to, and meaning making processes associated with science, scientists and society.

Finally, returning to Meyer (2022), the concept of “irresponsibilization” leads to the question of who is responsible for these breaches? Does responsibility reside with one maverick scientist or is the broader gene editing community also answerable? Our identification of the “if true” narrative, which was evident and consistent across publications, presented and confirmed the event as breach. But it also offered a productive space for the gene editing community to come together, mobilizing around the central trope of gene editing as an ethically forward-thinking science when conducted responsibly. That is, Jiankui was cast as a villain and the scientific community as the hero. The breach and its repair have opened up a new imagined future for heritable gene editing.

## Notes

1. An article was published the day before but attracted less attention (Regaldo 2018 and see Kirksey 2021 for the swift reaction of the scientific team to this initial publication). YouTube videos had also previously been posted by Jiankui, although these had not gained traction until the news broke.
2. We note that hype is often highlighted in relation to media coverage, but it should not be discussed uncritically. Caulfield and Condit (2012), for example, note the many elements of the ‘hype pipeline’, including institutional pressure to publish and commercialize, alongside marketing and media practices. They highlight how the contribution to hype itself is not a breach but rather is co-opted as part of the scientific process, expected of scientists, because it can stimulate public, political and institutional investment.
3. The shared language and expectations of what is methodologically robust and ethically sensitive good science suggests this is a geographically dispersed community of practice (Lave and Wenger 1991).

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The unexpected and unanticipated announcement of the “world’s first” gene edited babies: breaching, repairing, and strengthening community boundaries.

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## ORCID

Rebecca Dimond  <http://orcid.org/0000-0003-1974-7289>

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