

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/144875/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Dimond, Rebecca , Lewis, Jamie and Thomas, Gareth 2021. Editorial: Themed issue: Understanding the technical and social landscape of gene editing. *New Genetics and Society* 40 (4) , pp. 361-366. 10.1080/14636778.2021.2004032

Publishers page: <https://doi.org/10.1080/14636778.2021.2004032>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



# Editorial: Themed issue: Understanding the technical and social landscape of gene editing

Rebecca Dimond, Jamie Lewis, and Gareth Thomas

In 2018, while speculating on the future of *New Genetics and Society*, the editors of the journal stated:

If we were to look ahead, perhaps with a wistful view to what we think would be interesting to read about, the expanded availability, over the past two or three years, of gene editing technologies (such as CRISPR) indicates an area of great potential (Hedgecoe and Tutton 2018: 1).

This themed issue is an acknowledgement of the emergence and significance of gene editing technology, which has already been described as contributing to a new era in human history, that is, as a revolution, a game-changer, and a disruptive technology. Gene editing has proved to be an inexpensive, expeditious, and effective technique that can target and edit (by deleting, adding, or otherwise modifying) genetic material. As such, it has broad applicability in the clinical, agricultural, and industrial arenas, while it has also proven popular in less formal settings such as for 'biohacking' techniques (DIY biology). Our focus in this themed issue is the relevance of gene editing for human health. Somatic gene editing has already proved successful and is contributing to the development of therapeutic benefits for some types of childhood blindness, spinal muscular atrophy, and sickle cell disease (Ledford, 2020). Reproductive (germline) gene editing is more controversial, and there has been increasing concern about the rapid pace of development. Concerns about risk include the introduction of unintended genetic changes (known as 'off target' effects), which would be irrevocable and irreversible, meaning that there are significant 'known unknowns' about the long-term health implications for the child.

*New Genetics and Society* has a long history in documenting the emergence of new technologies and the ensuing debates (see, for example, Parry (2003), Haddow *et al.* (2010) and Sleeboom-Faulkner *et al.* (2011), to name a few). Many authors continue to debate the risks and benefits of gene editing, following a familiar path of assessing new technologies in terms of their safety, ethics, and public opinion (Martin *et al.* 2020, So *et al.* 2021). The UK, in particular, employs a closely regulated yet liberal approach to supporting new reproductive technologies and, in February 2016, Kathy Niakan (Francis Crick, UK) became the first scientist in the world to be granted a licence to use gene editing on human embryos. It was only a year earlier, in 2015, that we witnessed the organisation of several significant international events and institutional documents in which the benefits and risk of gene editing were debated. The conclusions from many such events were that gene editing could be permissible in certain circumstances in the future.

In November 2018, gene editing became a significant topic of attention in popular media across the world. He Jiankui, a scientist based in China, claimed that he had created the first genetically edited babies. Jiankui was widely criticised for conducting unethical research and for working outside of the tacit agreement within the scientific community that gene editing was at too premature a stage to enter clinical practice. This case revitalised calls to develop a global consensus on regulation, particularly given the rapid pace of developments in gene editing technology, and the need to consider the public good within the global landscape (Mulvihill *et al.* 2017).

Social scientific commentary has emerged alongside the development of gene editing, particularly through a bioethics lens. Special issues on gene editing were published in 2015 in the *American Journal of Bioethics* (Scott 2015), in *Bioethics* in 2019 (Ranisch and Ehnj 2020), and in the recently established *The Crispr Journal* which dedicated an issue to the ethics of human germline editing (see, for example, Jasanoff *et al.* 2019). Taken together, these contributions have highlighted questions about: national differences in regulation and the possibilities of a moratorium; the significance of language and use of metaphors; consent and individual choice, and; how to assess harms and risks while still supporting social justice.

In this editorial, we provide a glimpse of the different kinds of efforts and energies mobilised by the development of gene editing tools in its short lifespan. Whilst gene editing is still a nascent technology, these three articles, taken together, constitute a concerted approach to treat gene editing as a site of critical social scientific attention.

The first article by Ayo Wahlberg, Dong Dong, Priscilla Song, and Zhu Jianfeng – *The platforming of human embryo editing: prospecting “disease free” futures* – focuses on the case of He Jiankui and, specifically, the public ‘platforming’ of gene editing. It begins by documenting Wahlberg’s personal experience of being at the international summit where Jiankui was afforded the time and space to account for himself and his work. The article includes a photograph of Jiankui presenting a slide which details the different processes which make up gene editing. Wahlberg *et al.*’s paper suggests that this marked a significant moment in terms of how the technology of human embryo editing was performed as a new configuration of reproductive and genetic technologies shaped by socio-technical imaginaries of a disease-free future. Drawn from an ‘assemblage ethnography’ of observations, commentaries, and reports about the first birth, the authors maintain that the 2018 International Gene Editing Summit was significant because of its performative elements, where this ‘world first’ was presented and where meanings were ‘thickened’ (Gonzalez Santos *et al.* 2018). It was this moment, when Jiankui presented, that human embryo editing was platformed, alongside the prior development of the technologies and the subsequent reactions (i.e., of the world’s media and of scientific communities). Their understanding of platforming is informed by Peter Keating and Alberto Cambrosio (2000) as well as Sarah Franklin’s (2013: 22) work which explains the development of IVF as:

a platform, a stage, and a launch pad by means of a translational imaginary that was animated by the prospect of future kinships not only between parent and child, but between technology and offspring.

Wahlberg *et al.* consider the reactions of scientists across the world and people involved in organising the gene editing summit to Jiankui’s announcement. They describe the broader implications both for China (i.e. being perceived by others as a potential site for fraud/illegal activity), but also for individuals who might have known about his work before the birth was announced. What is especially interesting in the authors’ account is the possibility of a future without gene editing (‘even if human genome editing never makes it from bench to bedside’), but where the summit would still have resonance. By highlighting the platforming of human genome editing, they explicitly state that this does not make it acceptable – and it is this notion of ‘acceptability’ that is the central tenet of the next paper in the issue.

There are similarities between Wahlberg *et al.*’s contribution and the second article – Paul Martin and Ilke Turkmendag’s *Thinking the unthinkable: How did human germline genome editing become ethically acceptable?* – in this themed issue. Both papers acknowledge their established expertise in this field, which helps them to make sense of new developments as events unfold (Wahlberg *et al.*) or

through the historical context (Martin and Turkmendag). Their contributions complement one another, with Wahlberg *et al.* documenting a pivotal event, and Martin and Turkmendag explaining how we have arrived at this point in the first place. However, whereas Wahlberg *et al.* acknowledge the moment of transgression, particularly focusing on the aftermath of Jiankui's 'revelation', Martin and Turkmendag focus more on the broader discourse which shapes the acceptability of gene editing.

Martin and Turkmendag develop the concept of a 'regime of normativity' (loosely based upon the concept of a 'socio-technical regime') to understand the moral and ethical principles which, along with more formal regulations, frame the work of scientists and the expectations of scientists and wider society. Combined with the possibilities forged through the development of the technology itself, Martin and Turkmendag utilise their concept of the regime of normativity to explore how debates concerning gene editing have evolved, and to explain how human genome editing is now 'thinkable'. Important to stress, here, is that gene editing is technically feasible and thus 'thinkable', and, as it is 'thinkable', it thereby becomes (socially) feasible.

Martin and Turkmendag compare the UK approach to gene editing with the US approach, drawing upon key institutional documents and debates (some as far back as the 1980s). They focus on several technologies such as gene therapy, IVF, stem cells, and mitochondrial donation, each of which contribute to the broader normative regime. For example, each technology presents particular issues, such as making binary distinctions between enhancement and therapy, avoiding disability/disease, the moral status of the embryo, reproductive rights, and separating ethical questions from scientific ones. While the birth of the world's first 'test-tube' baby in 1978 enabled the framing of IVF as a technology of hope, it also introduced the possibility to be used to prevent disease or disability. They suggest that it was not until 2010 that results began to surface, demonstrating some success for an emerging market around developing therapies for rare genetic disease.

Martin and Turkmendag's gaze is predominantly focused upon the 2018 Nuffield Council on Bioethics report – *Genome Editing and Human Reproduction: Social and Ethical Issues* – as the 'landmark' publication, which had already influenced the process of assessing gene editing in subsequent reports, particularly in establishing the normative regime of parental reproductive rights as distinct from eugenic practices. Human genome modification can be framed as the 'only hope' to have a healthy genetically related child, and a public health issue around the treatment of rare genetic disease. They also acknowledge ethical issues which prominently focus on the risks of a 'slippery slope' to genetic enhancement. This, they suggest, forms the pathway for how a controversial technique becomes 'thinkable' and legitimate.

The third and final article in this themed issue is written by Ying-Qi Liaw, Ilke Turkmendag, and Kathryn Hollingsworth (*Reinterpreting 'genetic identity' in the regulatory and ethical context of heritable genomic editing*). The authors take a markedly different approach to the previous two articles, namely, by framing their article around the notion of 'genetic identity' and the ways in which it plays an implicit and explicit role in debates about gene editing. Liaw *et al.* pose two questions: 1) is international regulation effective in regulating genetic identity?, and; 2) if human gene editing is considered safe for clinical use, how can the interests of the children born via this technique be protected? To do this, Liaw *et al.* track the blurry concept of genetic identity and how it was afforded meaning within debates on gene editing in both UK and international contexts. They suggest that unpacking the concept is essential, particularly because the legalisation of mitochondrial donation in the UK highlighted how 'genetic identity' could be 'easily manipulated to serve the ends of different interest groups'. Principally, their paper is a call to arms, suggesting that a more extensive debate is required centring on 'genetic identity' in the context of preserving and protecting the human species.

Importantly, Liaw *et al.* explore ‘genetic identity’ as a ‘narrative identity’, where the right-to-know genetic heritage becomes significant not because of the value *per se* of genetic material, but because of the meanings of genetic identity and relatedness attributed by the child. They say that this renewed focus has benefits for the child; it can help future reproductive decisions, but it can also encourage greater accountability from policymakers and clinicians by making the process and its implications more visible. Notwithstanding these points, the authors acknowledge the conceptual and practical ambiguities concerning the right to retain genetic identity, and likewise, how the right to access knowledge about conception would be difficult to enforce. As with the two other articles, Liaw *et al.* end with a thought for the future. Given its importance, yet noting the barriers, they state that they will watch with interest how the concept of genetic identity is introduced and navigated in future debates about human gene editing.

While we were writing this editorial, the World Health Organisation published their report and recommendations following the expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing (WHO 2021). Its recommendations are broad, including WHO taking a stronger moral leadership role, encouraging international registries, and supporting ‘education, engagement and empowerment’. Overall, it recognises the significant opportunities and challenges of gene editing, as do the contributions in this themed issue. This issue contributes to the debate about the social implications of a rapidly developing technology, and we as a collective encourage social science scholars to continue to explore: notions of hope and anticipation; assessments of risks and benefits; ethical and moral distinctions between germline and somatic gene editing; patient, professional and public perspectives, and; the nature of trust in public health bodies and regulatory frameworks of new genetic technologies. There will be little doubt that *New Genetics and Society* will be at the forefront of these discussions and debates.

## Bibliography

- Franklin, S. 2013. *Biological Relatives: IVF, Stem Cells and the Future of Kinship*. Durham, NC: Duke University Press.
- González Santos, S.P., Stephens, N. and Dimond, R. 2018. “Narrating the First ‘Three-Parent Baby’: The Initial Press Reactions from the United Kingdom, the United States, and Mexico.” *Science Communication* 40 (4): 419–441.
- Haddow, G., Bruce, A., Calvert, J., Harmon, S.H. and Marsden, W. 2010. “Not ‘Human’ Enough to be Human But Not “Animal” Enough to be Animal – The Case of the HFEA, Cybrids and Xenotransplantation in the UK. *New Genetics and Society* 29 (1): 3–17.
- Hedgecoe, A. and Tutton, R. 2018. “Editorial.” *New Genetics and Society* 37 (1): 1.
- Keating, P. and Cambrosio, A. 2000. Biomedical platforms. *Configurations* 8(3): 337-387.
- Jasanoff, S., Hurlbut, J.B. and Saha, K. 2019. “Democratic Governance of Human Germline Genome Editing. *The CRISPR journal* 2 (5): 266–271.
- Ledford, H. 2020. “Quest to Use Crispr Against Disease Gains Ground” *Nature* 577 (7789): 156–157.
- Liaw, Y.Q., Turkmendag, I. and Hollingsworth, K. 2021. Reinterpreting ‘genetic identity’ in the regulatory and ethical context of heritable genome editing. *New Genetics and Society* [Online First].
- Martin, P.A. and Turkmendag, I. 2021. Thinking the unthinkable: how did human germline genome editing become ethically acceptable?. *New Genetics and Society* [Online First]

- Martin, P., Morrison, M., Turkmendag, I., Nerlich, B., McMahon, A., de Saille, S. and Bartlett, A. 2020. "Genome Editing: The Dynamics of Continuity, Convergence, and Change in the Engineering of Life." *New Genetics and Society* 39 (2): 219–242.
- Mulvihill, J. J., Capps, B., Joly, Y., Lysaght, T., Zwart, H. A., Chadwick, R. and the International Human Genome Organisation (HUGO) Committee of Ethics, Law, and Society (CELS). 2017. "Ethical Issues of CRISPR Technology and Gene Editing Through the Lens of Solidarity." *British Medical Bulletin* 122 (1): 17–29.
- Parry, S. 2003. "The Politics of Cloning: Mapping the Rhetorical Convergence of Embryos and Stem Cells in Parliamentary Debates." *New Genetics and Society* 22 (2): 177–200.
- Ranisch, R. and Ehni, H.J. 2020. "Fading Red Lines? Bioethics of Germline Genome Editing." *Bioethics* 34 (1): 3–6.
- Scott, C. 2015. "Treading the Line Between Sensational and Ground-Breaking Science." *The American Journal of Bioethics* 15 (12): 1–2.
- Sleeboom-Faulkner, M. 2011. "Regulating Cell Lives in Japan: Avoiding Scandal and Sticking to Nature." *New Genetics and Society* 30 (3): 227–240.
- So, D., Sladek, R. and Joly, Y. 2021. "Assessing Public Opinions on the Likelihood and Permissibility of Gene Editing Through Construal Level Theory." *New Genetics and Society* [Online First].
- Wahlberg, A., Dong, D., Song, P. and Jianfeng, Z. 2021. The platforming of human embryo editing: prospecting 'disease free' futures. *New Genetics and Society* [Online First].
- WHO. 2021. *Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. Human Genome Editing: Recommendations*. Geneva: World Health Organization.