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Article

Promissory ethical regimes: publics and public goods in genome editing for human health

Matthias Wienroth[1,2,*] **and Jackie Leach Scully**[2,3]

[1]Department of Social Sciences, Squires Building, Sandyford Road, Northumbria University, Newcastle upon Tyne, NE1 8ST, UK, [2]Disability Innovation Institute, University of New South Wales, Morven Brown Building, High Street, Sydney, New South Wales 2052, Australia and [3]Policy, Ethics and Life Sciences Research Centre, School of Geography, Politics and Sociology, Newcastle University, Henry Daysh Building, Claremont Road, Newcastle upon Tyne, NE1 7RU, UK

*Corresponding author. E-mail: matthias.wienroth@northumbria.ac.uk / m.wienroth@gmail.com

Abstract

This paper analyses promissory discourse for genome editing and human health in the UK, attending to the articulation of public goods and their beneficiary publics. Focusing on promissory reasoning about an emerging technology field as anticipatory and ethical considerations as integral to such debates, the notion of ethical regime as a mode of governance is applied to the concept of promissory regime. By analyzing key documents and interviews with opinion leaders—thus focusing on the discursive dimension—an enabling promissory ethical regime for genome editing and its contestation are identified. This regime posits scientific knowledge production now, and improved treatment or prevention of hereditary diseases later, as key goods of genome editing for human health and as a sociotechnical project worthy of support. Specific publics are created as beneficiaries. These publics and goods play out as ethical rationales for the promissory governance of the emerging field of human genome editing.

Key words: ethical regime; genome editing; governance; promissory discourse; public good; publics

1. The promise of an update

Genome editing refers to the rapidly emerging ability to make—in a qualitatively better way than previously possible—targeted and controlled changes in the DNA and RNA of humans and other organisms[1] Scientific research in genome editing has progressed considerably over the last two decades, and, especially, since the realization of the CRISPR/Cas9 technique for human genome editing in 2012,[2] the promise of precise, versatile, and affordable genetic changes in somatic and germline cells has entered the realm of feasibility. Advocates of genome editing refer to its capacity for directed genomic change and to the broad continuum of potential applications that mark it out as enabling. Others emphasize the potentially disruptive[3] nature of genome editing and call for a broad societal consensus on its necessity and appropriate use before further development of the technology.

Information on genome editing produced by a variety of sources addresses interested publics without assuming they have significant scientific knowledge, offering an introduction to genome editing that emphasizes the technology field's enabling nature. The UK debate is characterized by a plethora of promissory references to the potential(s) and future(s) of the capacity to 'edit' and 'engineer'[4] the human genome. These metaphors evoke notions of skill, craft, and most crucially of improving on or 'updating'[5] a body of work. While health and ill health are clearly portrayed as key concerns to the intended audiences, the notion of the update is particularly encompassing and promissory. Like 'edit', it articulates an imaginary of *correction* or *restoration* rather than *disruption* of the human genome. A further key message is inevitability, coupled with an affirmative mode emphasizing both the potential benefits *and* society's capacity to regulate the field so that any negative impacts can be avoided.

This paper addresses the developing promissory regimes of genome editing in the UK since 2015 during a period when a series of high-profile statements were published by British science institutions. Using a sample of key ethical documents and opinion leaders' views, we examine how influential opinion-maker voices in the public discussion identify particular goods that genome editing will provide and also which publics are imagined as the beneficiaries of these goods. This illuminates which ethical concerns are articulated in the sociotechnical imaginaries of genome editing and how promissory regimes are structured by these ethical concerns.

2. Sociotechnical imaginaries, ethics, and promissory regimes

Sociotechnical imaginaries are collectively produced visions of what constitutes a good society.[6] They contribute to the structuring of anticipatory discourse[7] that aims to integrate foresight and engagement about emerging technologies into programmes of support and development.[8] The ability to develop and act upon such imaginaries by negotiating plausible visions[9] and actionable programmes depends on interactions between sociotechnical networks,[10] eventually producing distinct *ethical regimes* that both reflect and shape the sociotechnical imaginary's values and norms about desired

futures.[11] The term ethical regime describes the arrangement of systems and frameworks, values and norms that govern research, and potential clinical interventions[12]; ethical regimes may change over time, and so require constant negotiation work. Ethical discourses around as-yet un(der)developed technologies are promissory, since they are an anticipatory as well as regulatory element of sociotechnical imaginaries: they reassure publics that future actions will be ethical and serve the ideal of a good society.[13] Active work is required to develop a durable infrastructure in which such imaginaries are realised and which can assure audiences that the processes of knowledge production and use, and their governance mechanisms, are legitimate and ethical and that the emerging materials and knowledges are subject to an ethical regime that produces public goods for appropriate, deserving publics. Promissory ethical regimes are thus emerging deliberative governance frameworks, drawing on expectations, visions, and statements of intent in attempting to materialize practices, structures, and relationships toward a desirable future based on shared values.

3. Publics and public goods

The design of sociotechnical projects involves the promissory articulation of public goods that the technology *may* generate and of the publics who *might* benefit. In this paper, publics and public goods are taken as *discursive elements*[14] in the development of *promissory regimes* of genome editing. There has been significant scholarly discussion of different publics and their perceptions of science,[15,16,17] especially in relation to the communication and governance of risk[18,19] and the contrasting scientific deficiency versus political competence of the 'public in general'.[20] Mike Michael describes public engagement as not merely expressive (i.e. enabling people to voice their citizenly concerns) but also constitutive: participants in variously choreographed forms of engagement are 'performing' and eventually 'make' a public. Public engagement often entails relating an undifferentiated 'public in general' to an equally undifferentiated 'science in general'. Michael's concept of 'publics-in-particular'[21] describes groups with an active stake in a given technological issue that necessarily emerge alongside the development of the technology. Publics-in-particular for any technology develop through complex, dynamic and unending interactions between political, economic, clinical, moral and other influences. Part of this process involves people identifying themselves within a public-in-particular, for example as candidates for a future genome editing trial.[22] In our study, we decided to focus on the role of 'expert'[23] stakeholder perspectives in 'creating the framework of ethical discourse' by assigning public goods and, in tandem, publics.[24]

The discourse of *public goods* is closely related. *Public goods* are articulated to resemble properties and services made available to members of a community and the practicalities of who could or should benefit from what opens up the relational, dynamic nature of publics-in-particular. The public connotation does not necessarily derive from the provision of these goods via a public body. Michel Callon has argued that any difference between public and private goods is only arrived at through negotiations about rationales of, and access to, the said goods.[25] Difference derives from the expectation that no such benefits will be unreasonably restricted to certain groups and that they are not subject to zero-sum considerations.[26] More specifically, goods are discursively related to specific publics, that is, constituencies who meet the articulator's specific criteria. It is becoming axiomatic that the negotiation of public goods should also be subject to public forms of deliberation and governance, especially in life science innovations, as was the case for mitochondrial replacement, and increasingly so for genome editing. In our analysis, we apply the concept of public goods to the claims and ideas expressed in the data sources we analysed.

4. The genome editing discussion in the UK

The genome editing discussion in the UK is distinctive. It plays out as a deliberative governance approach to health-related research that positions publics as partners in dialogue.[27] Since the late 1990s, the role of patients and publics in UK health research and care has shifted from that of medical subjects to one of essential partners, resulting in a present-day health policy framework that arguably sees publics as assets to the political economy of the UK's national biomedical project.[28]

Within this context, growing political and commercial ambition for genomic science is evidenced in a series of developments, including the establishment of the UK Biobank as 'a national and international health resource with unparalleled research opportunities'[29] and the public announcement in late 2012 by then Prime Minister David Cameron of a project to sequence 100,000 genomes from National Health Service (NHS) patients with cancer or a rare disease by 2017. The Department of Health established a company, Genomics England, to manage the 100,000 Genomes Project and 'to bring the predicted benefits of genomics to NHS patients' as well as to advance research.[30] In October 2018, the NHS then announced a new genomic medicine service, including the expanded goal of sequencing 5 million genomes over the next 5 years.[31] The political importance of genomics to the positioning of the UK in the global scientific and healthcare landscape shapes the policy, professional, and public discussion of genomic medicine's ethics and regulation. Genome editing can be seen as the latest and so far most high-profile iteration of that.

Genome editing is not one technology but a growing field of technologies and applications, and this diversity needs to be taken into account in any ethical, regulatory, and public debates. Distinctive ethical and practical challenges are likely to emerge for individual technologies, and responding to them has the potential to shift social and moral norms. Since 2015, concerted efforts have been made to identify areas that require urgent ethical and legal deliberation, most pressingly clinical applications that would entail germline (heritable) editing.

The UK has seen significant policy discourse around genome editing, involving some of the country's key players in science governance. In September 2015, a joint statement[32] by the Academy of Medical Sciences, the Association of Medical Research Charities, Cancer Research UK, the Biotechnology and Biological Sciences Research Council (BBSRC), the Medical Research Council (MRC), the Progress Educational Trust, the Wellcome Trust, and the Wellcome Trust Sanger Institute strongly advocated the further development of genome editing research. Also, in 2015, the Hinxton Group[33] released a statement in favour of further scientific and technological development. However, the statement emphasized that

ethical evaluation of the technology field is needed before clinical applications should be considered. In February 2016, the first UK license for the use of the CRISPR technique in a human embryo was granted, generating significant media coverage.[34,35,36] Three months later, Sciencewise[37] and the Nuffield Council on Bioethics[38] reported on the need for public engagement in discussions of genome editing. In September 2016, the Nuffield Council on Bioethics published an early ethical review, defining genome editing and its key applications while making the case for further ethical deliberation. This report was referenced in a POSTnote[39] on genome editing by the Parliamentary Office of Science and Technology and also in a position paper by the Church of England.[40] In November 2016, the Genetic Alliance UK, an umbrella body for over 180 patient organizations, joined the public debate by urging more engagement with patients, offering data on patients' perceptions of and key concerns about genome editing.[41] The Chief Medical Officer's annual report for 2016 made several references to genome editing in its discussion of genomic service provision in the NHS.[42] In 2017, the House of Commons Science and Technology Committee released a brief scoping report to prepare for further deliberation[43] and, in September of the same year, the Genetic Alliance UK and the Progress Educational Trust, supported by the Wellcome Trust, released their report on the *Basic Understanding of Genome Editing*, with key recommendations on content, mode, language, and visualizations in public communication about the field.[44] Within a couple of years, the subject of genome editing had well and truly arrived on the UK's science policy agenda.

Within the academic and research-focused science policy communities, many senior scientists currently propose a linear narrative where the first step must be to establish the safety and efficacy of the technologies, next consider what to use them for, and only then enter into a debate about whether that use is socially acceptable. Some of the professional and policy statements mentioned above, however, suggest that these aspects should be considered in parallel. There are critical voices in the UK setting, challenging the scientific focus on the primacy of feasibility, safety, and efficacy and calling instead for a prior and broader societal discussion of the social norms and human values that underpin the supposed need for technologies such as genome editing. These voices share some concerns about the commodification of humans and the potential for using germline gene editing technology to disrupt social covenants on norms of parenthood and care, reproductive freedoms, race and ethnicity, disability and diversity, and so on. While these critiques are levelled within the UK regulatory context that permits genome editing research on early embryos but prohibits clinical application, they are nevertheless informed by the very different regulatory situations in other countries, ranging from very restrictive to moderately permissive.

5. Methodology

This was a scoping study combining (1) documentary examination of four key statements and reports on human genome editing published between 2015 and 2017 and (2) thematic content analysis of five semi-structured face-to-face interviews with key informants from genomic science held between October 2017 and February 2018. The selected documents were authored by key decision-makers representing a variety of major stakeholder groups in genome editing. They are easily available to a wide readership and have become cornerstones of the UK policy debate.[45]

To complement the documentary analysis, in-depth interviews were held with five selected key informants. These respondents were chosen because they had been, or were recommended by, co-authors or reviewers of a major report on genome editing at the time of the research. These individuals are senior figures within biomedical science, ethics, research, and public policy and are well placed to provide insights into the thinking of the main agencies shaping the public discourse of goods and beneficiaries of genome editing in the UK. The interview informants work in professional areas with specific but distinct interests and roles in genome editing. They were: two academic scientists working on genome editing in animal models; one public engagement specialist from a major national research funding organization that invests heavily in genome editing; one university-based ethicist with extensive experience in ethical governance in genome research; and one social analyst involved in public deliberation and policy discourse about genome editing. The interviews provide some detail on how genome editing resembles or differs from related technologies in terms of the public goods and publics produced and, as such, offer contextualizing information to the reports on genome editing by placing the debate alongside previous and ongoing biotechnological discussions.

Each interview was held at a place and time of the interviewees' choice, lasted approximately 1 hour, and was audio recorded and transcribed by one of the authors (AUTHOR1). Both authors then took part in the thematic content analysis. Once themes were identified, they were cross-referenced across all interviews to get a qualitative sense of commonality and strength. Given the small number of interviews and subjective nature of responses, we were primarily interested in characterizing *shared* ideas about beneficiary publics and public goods rather than differences between professional roles.

6. Key reports and statements

This section presents an analysis of four widely publicized and discussed statements and reports on human genome editing from the UK, focusing on how public goods and their associated publics are articulated. The documents include the Joint Statement of UK Research Funders (2015), the Hinxton Group Statement (2015), the Nuffield Council on Bioethics' 'Genome editing: an ethical review' (2016), and the report by the Genetic Alliance UK on 'Genome editing technologies: the patient perspective' (2016).

The two 2015 statements can be firmly located in an environment of alert responsiveness to what the Joint Statement calls 'rapid technological developments in this area' with CRISPR/Cas9, and a marked increase in the number of scientific publications on genome editing since the journal *Nature Methods* crowned 'gene editing' the method of the year 2011.[46] These statements and subsequent reports emerged in the context of the realization that the velocity of developments would increase, as would interest by new players: the relative ease of use of CRISPR/Cas9 expands the groups that could be involved in editing the genome. Simultaneously, economic and innovation policy interests have emerged, prompting some direct and less direct responses in the four documents discussed here.

6.1 The Joint Statement of UK Research Funders 2015

This brief but often-referenced statement focuses on the 'potential to improve health' and 'therapeutic effect' as long-term gains from editing the genome in human cells. In doing so, it reflects the way that the UK's professional and public discussion of genomic science is based firmly on the therapeutic imperative. Still, the signatories emphasize that clinical applications require much more basic research,[47] arguing that 'research using genome editing tools holds the potential to significantly progress our understanding of many key processes in biology, health and disease'. The statement reflects on the field of genome editing as organically emerging, suggesting a history of a so far safe development of the technological foundations of genome editing. The statement indirectly calls upon decision-makers to build upon this history by 'clearly demarcating' frameworks for research and for clinical use and ensuring that the research community retains the lead in the field; against whom is not made clear but is likely to be players in applications, for example, commercial health technology and service providers, as well as applied researchers in countries with less stringent research governance.[48]

The statement therefore links value primarily with research-based knowledge production but contextualizes it in terms of safety frameworks and knowledge that enables future clinical application for somatic cell editing. The statement keeps open the possibility that research may also lead to germline applications. For the signatories of this document, the key constituency remains the research community affected by decisions about genome editing, and they indirectly enroll decision-makers in science/research/innovation and related policy-makers in developing an ethical framework for further work.

6.2 The Hinxton Group Statement 2015

The Hinxton Group statement places genome editing within a decades-long history of genetic modification in animals and of ethical debate about human genome modification. The Group points out that, while more recent technological developments do not change the ethical issues, the scientific environment overall (genetic/genomic knowledge and capacities, decrease in costs, and globalization) has significantly shifted toward enabling the unregulated use of new techniques. The Group aims therefore to inform debate and decision-makers who are seen as an active audience and less as an affected public.

The Statement focuses on assisted reproduction and germline editing in embryos, identifying two broad affected publics: prospective parents and communities in which heritable conditions are prevalent and where clinical intervention in reproduction may be relevant. Nevertheless, the authors only tentatively approach clinical use, suggesting instead that considerable further basic research is needed, re-framing the current value of genome editing not as direct health improvement but as the expansion of knowledge:

> Genome editing has tremendous value as a tool to address fundamental questions of human and non-human animal biology and their similarities and differences. […] it is our conviction that concerns about human genome editing for clinical reproductive purposes should not halt or hamper application to scientifically defensible basic research. (pp. 2–3)

The focus on research extends to any kind of basic research that may generate useful knowledge for clinical applications. The Group remains agnostic about the future trajectory for genome editing, framing it as dependent on research as well as on deliberation and good governance, advocating further support and development of the technology until 'all safety, efficacy and governance needs are met' (p. 4). The statement makes a clear distinction between research and application and prioritizes further support for the former like the authors of the Joint Statement of UK Research Funders.

6.3 The Nuffield Council on Bioethics ethical review 2016

The review provides a detailed introduction to scientific and medical aspects of genome editing, scoping potential application fields, and identifying key ethical questions. Its overall assessment finds that 'while the scientific merits are overt, the practical and ethical significance of these recent developments is far harder to discern' (p. 1). It describes an environment of scientific push rather than societal pull based on 'demand from researchers and high-profile advocacy by the developers and early adopters, and enabled by the conditions and culture of research in the biological sciences' (p. 14) but also a demand by those actors in the health research sector who want access to early stage technologies, such as patients or relevant charities, or to develop marketable therapies, such as commercial developers (p. 44). The potential public is described broadly as benefiting from research into 'understanding of health and disease' (p. 35) and the further development of editing techniques. A second broad area of potential benefit is clinical therapy, for example, for cancer: 'Cell-based therapies have potentially significant advantages over conventional treatment options in terms of both effectiveness and legacy, since the modified immune cells selectively and continuously attack the cancer cells without damaging unaffected tissues' (p. 41). Other potential areas mentioned include infectious diseases such as hepatitis and AIDS, rare diseases such as muscular dystrophy, and xenotransplantation.

The review also covers enhancement, ranging from preventative gene therapy aiming to 'reduce the risk of conditions for which genetic variations are known risk factors, or to prevent disease, for example by enhancing immunity' (p. 50), to reproductive interventions that may be understood as the "'consumerisation" of human biology' (p. 52). Genome editing in human reproduction is identified as one of the areas most urgently in need of ethical deliberation (p. 115).

The discussion indicates how the Nuffield Council on Bioethics identifies some of the key publics involved in genome editing. These range from clinicians, to specific groups of patients, and on to the future consumers of genome editing. The report also refers directly to 'human subjects' in research and potential trials of a 'therapeutic product' (p. 44), to charities, and to commercial interest in genome editing.

6.4 The Genetic Alliance UK (2016) report

The Genetic Alliance UK is an umbrella association of patient organizations. Their online survey of attitudes to genome editing received over 200 responses, primarily from individuals with genetic conditions, family members and carers. The survey covered five areas: awareness of and interest in genome editing; uses; access to treatments; regulation; and the big

picture (risk versus benefit). The report identified three key themes for the future of genome editing: research, treatment, and prevention.

The report notes that respondents show significant support for genome editing for research and medical treatment or prevention. Any use should be based on informed consent, and treatment should be managed by expert clinicians. Respondents emphasized both need and equity for access to such treatment. Enhancement in the absence of medical need was reported as having significantly less support in the survey responses. The notion of the 'designer baby' appears (pp. 22–23), tempered by the authors' assessment that selective enhancements will not be possible for some time yet.

While respondents showed concern about commercial providers of genome editing services, many suggested that both the NHS and companies should be able to offer editing services in the UK, the EU, and globally, indicating an appetite for consumer choice in a market offering diverse techniques and services. The report also suggests that respondents prefer regulation based on existing modes of deliberative engagement, including a role for patients in a multistakeholder approach involving government, researcher, and clinicians. Respondents also expressed interest in an international approach to regulation, which aligns with their desire to have access to global service providers.

The Genetic Alliance survey asked respondents to indicate the balance of benefit and risk they thought genome editing offered: 136 out of 153 responses indicated a clear weighting toward benefits.

6.5 Summary of the reports

The analysis of these four reports suggests that, overall, two main public goods dominate the genome editing discussion in the UK: (1) the advancement of genetic and genomic knowledge using genome editing techniques and (2) the improvement of quality of life via progress in healthcare. The minimal consensus across these four documents is that the field is still firmly in the realm of research and not yet a candidate for clinical application. At the same time, much of the *public* discourse (e.g. as seen in the Genetic Alliance's survey results) is about ensuring the safe future application of genome editing. Notably, none of these published statements (nor, as we shall see, the interview data) seriously question whether resources should go toward genome editing in the first place.[49] The documents also suggest that basic research and ethical deliberation need to be undertaken simultaneously, ideally involving a wide range of different stakeholders.

In line with these public goods, the sociotechnical imaginary of these documents configures the key beneficiary publics as the research community and individuals/families for whom genome editing might be therapeutic. The documents show more variation in terms of imagined publics than in public goods. For example, although the Joint Statement of UK Research Funders targets the research community, it also articulates the need for timely engagement with a range of potential public audiences, including 'biomedical and social scientists, ethicists, healthcare professionals, research funders, regulators, affected patients and their families, and the wider public'. By comparison, the Genetic Alliance focuses entirely on 'the profound unmet need' of individuals with specific genetic conditions (p. 34) and their hope that genome editing will lead to new treatment and/or prevention.

7. Interview data

Like the documents, in the interviews, the advancement of knowledge is given as a central motivating good driving the need for progress in the field. Advancement toward developing procedures and techniques for genome editing comes prior to developing clinical contexts. The following quote illustrates several of these points:

> […] my feeling is it would have to be safer because people are going to be so jittery about the technology that they're going to expect a very high standard of efficacy.… And not just because of what's already available, in the minds of some people anyway, through PGD, but because of some of these other… These genes, Jesse Gelsinger,[50] you know, where things have gone horribly wrong. They're going to want to make sure as much as it's possible to make sure—and it never is completely—as much as is possible, that there are not going to be any bad outcomes which would of course potentially cause a reaction against the whole enabling approach. Enabling in the minds of some people. So people like me by the way, I think it's a discussion of how to handle it, really. It's not for me a question of whether it should be done; it's about making sure it's done right. (Scientist 1)

Several informants put forward the argument that *scientific knowledge* about the human genome and genome editing techniques is a public good *in itself*. Genome editing is described as holding the 'potential to be revolutionary in research—to help inform our understanding of human biology',[51] and the technology is cast as part of a virtuous cycle in which 'scientific knowledge is a major driver of it, and [so is] anything that feeds into scientific knowledge' (Interview with scientist 2). Other proponents of genome editing in research, such as the Hinxton Group, have also argued that emerging knowledge is a valuable enough public good to override other ethical or precautionary considerations: 'concerns about human genome editing for clinical reproductive purposes should not halt or hamper application to scientifically defensible basic research'.[52]

Moreover, the good of genomic knowledge is nearly always contextualized in terms of *future* applications in clinical contexts—as the Academy of Medical Sciences report noted, 'a powerful technology that has the potential to improve health'.[53] This reinforces the second major public good found in these interviews, namely *improved quality of life and health* at the collective and the individual levels.

> It can alleviate or prevent heritable disease, if we're talking about heritable genome editing; and it can prevent disease that's genetic if we're talking about somatic genome editing. (Scientist 1)

The interview responses indicate that the capacity for genome editing to deliver public goods is highly dependent on scientific variables, such as achieving maximum precision in targeting alleles; avoiding somatic changes that affect the germline; limiting interventions to desired effects (e.g. avoiding off-target effects or mosaicism); keeping open future manipulation (e.g. by clearly marking edited loci); and understanding long-term impacts on the genome and the stability of any changes.

Interview respondents draw the scope of the technology field to include somatic and germline editing and even more promissory applications as indicated by the scientist who describes genome editing as part of 'the whole enabling approach'. Emphasis is placed on 'necessary repairs within the patient's body'[54] along a continuum between treatment—for example, using somatic cell editing—and enhancement of traits using germline editing, but with ethical 'boundary markers' along the continuum, where prevention of ill health is more likely to be considered ethical than selective enhancement of traits not directly related to health. This reflects the longstanding biomedical consensus that genome editing may be indicated for conditions affecting relatively small numbers of people and concentrating on possible early 'wins' in assisted reproductive technologies (ARTs). Nevertheless, other areas were also proposed. One trajectory for research is to further develop the understanding of genomic mechanisms, exploring ever more complex areas and moving future health-related treatment options beyond rare diseases, for example, interventions to enhance resilience against trauma and sepsis, and so becoming more of a general public good. The emergence of interventions like these, some interview respondents argue, changes ethical and regulatory deliberation significantly:

> Let's say you could gene edit people so that they would heal more quickly from bone fractures or something. […] Some people are more likely to develop sepsis than others, some people are more likely to respond well to treatment in intensive care. […] You'd think, well, if something could be done to make people more likely to survive trauma […] so that seems much less likely to be politically contested. I can imagine a landscape emerging which is different to the one we currently have. (Ethicist)

Casting genome editing as a contributor to the public good of better quality of life and health raises considerations of equity and equality:

> […] in a world where our resources are finite, how much does it cost to have to put resources here rather than somewhere else? […] we're talking about it from a genetic point of view, so once you have the child who's got this particular condition and you're managing […] the child for 12 years […] how many children or other people are suffering and dying because the medication and the healthcare treatment that's going there is now not available elsewhere? (Scientist 1)

Here, genome editing technologies are contextualized in a world of limited resources, in which the capacity to prevent genetic disease might enable the resources currently dedicated to treatment and care of individuals with specific genetic conditions to be redirected toward other healthcare areas and contribute to more equitable access to treatment. Another scientist interviewed suggested:

> […] we make value judgements as a society – or somebody on behalf of society makes value judgements about which treatment to be given where; and the so-called postcode lottery and this type of issue exist today; and some treatments are too expensive and some are not. So could this become… Could this be a way…? […] It's the distribution; […] it's how you get to those individuals, whether it's 10,000 or two. How you deliver it to those individuals. (Scientist 2)

Unlike the written reports, some interviewees candidly contested the linear linkage of research investment now and health pay-off later, questioning how certain we can be of the later benefit and what the consequences in terms of public backlash might be if the promised pay-off does not materialize:

> […] there is a whole range of other things that we can spend our money on in the NHS [National Health Service]: the care for the elderly etc., so, you know, it's not just about the ethics of genome editing in the sense of whether it's safe or it is acceptable in terms of disability and so on. It's also about 'is this an ethical way to spend money when there are so many other things we can spend money on?' (Ethicist)

As they describe the public goods they see genome editing producing, these opinion makers evoke, and effectively produce, two broad publics. The first consists of *experts and decision-makers*: research scientists, research funders, regulators, ethicists, clinicians (as potential commissioners of genome editing), some patient groups, and companies involved in the production and use of genomic data. The second broad public includes potential *users or groups likely to be most directly affected* by regulatory decisions, such as communities with rare genetic diseases and (in)fertility issues but also wider general publics who might benefit from interventions that would currently be considered enhancement, such as making their physiology more resilient to infection or trauma and more responsive to healing. The current key *public-in-particular*, however, consists of patients who participate in research or receive treatment:

> The most likely relevant publics, at least to begin with, will be patients. For instance, patients that have taken part in the 100,000 Genomes Project; or ones who are likely to have their genome sequenced as the result of the conditions they have. (Public engagement professional employed by a major research funder)

Both documents and interviews demonstrate how this public is centered in the discourse of genome editing in terms of the value of developing genome editing technologies as clinical interventions and in terms of their personal experience of genetic disease.

> So these six, seven, eight thousand so-called monogenic conditions, there are thought to be somewhere in the order of a million people with one of these conditions in the UK … Individually, they're not that common…most of them, but added together, they add up to something. (Scientist 1)

As discourse identifies publics, it also generates a sense of solidarity with these enactments of publics-in-particular. For example, one specifically articulated public contains those who would like to have genetically related children with significantly reduced chances of developing a genetic disease, as referred to by one interviewee:

> Because mum and dad probably would say 'well we don't want our kid to have Huntingdon's disease. Thanks ever

> so much, but we want to kind of prevent that if we can by using this method'. (Scientist 1)

Solidarity is also generated for those who are imagined as wanting to go further, such as those who would like to enhance their children in medically relevant ways, as a form of prevention for illnesses that are linked to genetic predisposition but are not (currently) perceived as genetic (or rare) diseases:

> […] they'll say 'look, we want to have kids' and their genome sequences will go up into the cloud, some supercomputer will say: […] Okay, so if you just go ahead willy-nilly, then there's a 62% chance that your child will die of hypertension before they're 63 years old. … But then your next door neighbour, they went and did this and they had something similar, but for coronary heart disease, and [after editing, the probability] went from 68% […] to .006%. (Scientist 1)

Wider publics are therefore invoked as part of a promissory regime that expands the relevance of genome editing to many, perhaps most members of society, while still anchoring the present-day discussion in clinical and medical contexts.

8. Discussion: an enabling ethical regime

Both documentary and interview data indicate that the sociotechnical imaginary of genome editing for human health posits two key public goods of (1) advancing knowledge about human biology and (2) raising the quality of life via progress in healthcare. A promissory ethical regime has developed that highlights three aspects validating and materializing this sociotechnical imaginary. The first is a strong focus on acquiring more scientific knowledge, especially in genomics, both because knowledge or knowledge production is a good in itself and in order to understand how to apply it effectively. As a good in itself, knowledge production is made distinguishable from the future application of that knowledge. This distinction effects a discursive separation of the ethical debates about *research*—emphasized by adding the term 'basic'—from any potential *medical applications* of such knowledge. The distinction is also a practical one since the genome editing technologies likely to have major clinical impact are generally considered to be still far from implementation: the current focus is therefore on working with animal models and human embryos ('basic research') to develop the necessary knowledge base for future use. Both documents and interviews present a framework in which the ethical route toward development of genome editing is via the laboratory and of animal models leading on to clinical trials.[55]

A second feature of this promissory ethical regime is the need for transparent and open public debate about genome editing. However, as evidenced by the key UK reports analyzed in this paper, the ethical regime itself effectively limits public debate to confirming the further development and use of genome editing (both for somatic cells and germline interventions) rather than opening up discussion of the long-term aims of human genome editing and the possibility of a moratorium. The key participants in this public debate are imagined to be patient groups, policy makers, and regulators, with secondary involvement from science funders and academic researchers. Nonetheless, for some of our interviewees, a strategic approach to public engagement about genome editing is still to emerge in part because both public goods and publics are not yet clearly defined enough:

> At the moment [the field] feels too big for us to say, 'right, we're going to have a strategy on how to engage the public about genome editing,' because not only is the technology so big, but the implications are so broad, and the affected publics are so wide as well. (Public engagement professional employed by a major research funder)

The third aspect is the call for legislation to prevent misuse of the technology. Here, parallels with assisted reproductive technologies are most frequently invoked, with reference to 'designer babies' and other perceived abuses. Several reports share the view that the existing governance framework in the UK, in particular, the Human Fertilisation and Embryology Act 2008 and its executive body the Human Fertilisation and Embryology Authority (HFEA), is adequate for the research and development of genome editing technologies. This view is shared by other bioethicists and commentators who argue, for example, that 'We should feel confident that our regulatory system in this area [of genome editing] is functioning well to keep science aligned with social interests.'[56] Similarly, the 2016 report by the Genetic Alliance UK proposes an ethical framework in which

> there is an obvious line, already drawn, between the use of reproductive technology for therapeutic purposes, and the use of such techniques for human enhancement. […] We expect this treatment/enhancement distinction will remain fundamental to the way that technology such as this is regulated.[57]

In other words, the ethical distinctions that have structured the regulation of other technologies are adequate to regulate genome editing. This confidence is based on arguments of similarity: *technical* similarity between genome editing and existing technologies, such as preimplantation genetic diagnosis or mitochondrial replacement therapy, as well as similarity of *aim*.[58]

While this analysis shows how genome editing is cast as contributing to public goods for publics-in-particular, there are also many challenges and contestations to doing so, including whether funds should be spent on developing these technologies, what kind of value judgements are mobilized, and what kind of changes can genuinely be considered to be public rather than mostly private goods. The ethical regime sketched here is an *enabling one*: its baseline is that genome editing is fundamentally in the public interest because of the public goods it will deliver, if properly regulated, and therefore any ethical or regulatory framework needs to make genome editing possible. Such a regime must also articulate limitations or alternative futures to be avoided to justify the efforts to bring about the positive future vision. As Richard Tutton has argued in a study of future-oriented statements of commercial actors, 'the co-articulation of pessimistic and promising futures in such statements constitute an important site of anticipatory practice'.[59]

An alternative regime of *reproductive skepticism* is voiced by critics who portray genome editing as very unlike other

existing modification methodologies because of its capacity to effect heritable changes in assisted reproduction. The alternative regime of reproductive skepticism is far from dominant in either the expert documents or interviews analyzed for this paper,[60] but it is a powerful element of the wider public and academic debates. A key feature is a strong distinction between somatic and germline editing, with only the former framed as ethically acceptable. In the current setting, an enabling discourse prioritizes proximate goods rather than potential (and less foreseeable) long-term impacts, while critical views express concern about the potential for enhancement and the pursuit of longer-term posthumanist ideals. The enabling approach is further challenged by arguments from disability studies and disability rights activists that germline editing makes unjustified value judgements about the quality of lives lived with certain impairments.[61]

We identified in the enabling regime a preoccupation with retaining public trust against any possible future negative publicity. In a variation on this, the regime of reproductive skepticism shows concern that any scientific support for germline editing, which generally is less accepted by the general public, will damage the popular perception of science, referencing other areas of past contestation, such as the early days of assisted reproduction.

Both the enabling and the skeptical ethical regimes are similar in being promissory, proposing rationales for particular kinds of ethical understanding and regulation, anticipating which technologies, capacities, needs, and issues may arise, and proposing governance that indirectly steers how genome editing should be understood, and which governing parameters should be adopted to shape it. The enabling regime posits scientific knowledge production now, and improvement of treatment or prevention of hereditary diseases in the future, as key public goods of genome editing for human health. Its associated key publics are families with hereditary diseases. The enabling regime is deterministic, considering genome editing as something that is already applied in research and testing and so cannot be put back into the box. Interestingly, the skeptical regime is also built on a notion of technological inevitability in that it considers that once germline genome editing has been permitted, its misuse would be inevitable.

It should be emphasized that the technology of genome editing is far from unique in generating an enabling ethical regime. Indeed, it fits within a broad sociotechnical imaginary built up over a series of historical precedents in the UK that, as Dimond and Stephens note, is 'inherently amenable' to technological implementation.[62] However, each technology is distinctive and exists in a particular social and political context, and its associated enabling ethical regime is similarly distinctive.

A comparison with the debate over developing mitochondrial replacement technology (MRT) is particularly instructive in highlighting the public goods and publics identified compared to the case of genome editing. The major public good evoked in the MRT discussion was the possibility of rapid progress toward the clinical benefit of intervening to prevent the transmission of mitochondrial disease. This contrasts strongly with our analysis of genome editing discourse, where most documents and interviewees prioritize the acquisition of knowledge and insist that it is separable from far-distant application. In line with this, the primary public-in-particular benefitting from MRT was the small number of families at risk of mitochondrial disease, and their children. What is particularly interesting here is that, until the discussion of legislative change began in the early 2000s, mitochondrial disease was virtually unknown to non-specialists, unlike the broad notion of 'genetic disease', which is much more familiar to the general public. Unlike the public constituted by genetic disease, then, the public-in-particular of those affected by mitochondrial disease was effectively brought into being by the ethical debate and inserted into the sociotechnical imaginary over a very short space of time. In the various reports and recommendations about mitochondrial research and the law that appeared between roughly 1998 and 2016,[63,64] virtually no use was made of arguments about the good of knowledge in itself, of the benefit to researchers outside the area of mitochondrial disease, or of the other potential beneficiaries of MRT, such as older infertile women or same-sex couples wanting to have genetically related offspring. Perhaps, the radical and controversial step of permitting a (contested) form of genetic manipulation, previously forbidden under UK law, required a focus on a rapidly achievable clinical benefit that could be carefully restricted to a numerically small, vulnerable group and the potential for more extensive use to be downplayed.[65] This is in stark contrast to the enabling discourse of genome editing described in this paper. Another contrast with genome editing is that expert discussion of MRT presented the chance for families with mitochondrial disease to have *genetically related* children as a central good delivered to this restricted population. In the discourse of genome editing, the good of genetic relatedness, although important, is not nearly so central.

9. Conclusion

This analysis has built on the understanding that reasoning about an emerging field of technology is anticipatory and that ethical considerations are an integral aspect of sociotechnical imaginaries. The promissory expectations of genome editing become manifest in actual and discursive infrastructure building, such as the establishment of various scientific and social scientific oversight groups to deliberate genome editing—sometimes involving self-identification by the commissioners or authors. In a promissory context, ethical regimes anticipate the moral futures of a specific concern or material—in this case, the human genome—and also of emerging technologies that engage with such concerns and materials. The articulation of publics and public goods becomes part of the attempt to frame and structure an emerging field. By associating specific publics and public goods with values and norms, the promissory ethical regime prescribes a role for the technology in the trajectory toward a specific desirable future. These publics and goods then provide ethical rationales for the suggested promissory (i.e. future) governance of the emerging field of research.

The 'expert' UK discussion of genome editing for human health, including its regulatory dimension, has therefore produced a generally enabling climate, with a focus on scientific research to improve the understanding of the technology in order to advance toward clinical treatment and prevention of genetic diseases. However, our analysis suggests that the UK's enabling promissory ethical regime for genome editing *calls into being* the relevant publics-in-particular rather than scrutinizing who constitutes them. A form of public discourse

that includes representation from more, and more varied, public interest groups might reflect different norms about public goods than the 'expert' sociotechnical imaginary we have explored here. The Nuffield Council on Bioethics, for example, has strongly advocated a broader and more inclusive public engagement that goes beyond the current emphasis on professional and academic inputs. Greater differentiation of potential users of genome editing may be necessary to break away from subsuming all either as research participants or under a generic notion of patient. A further distributed deliberative governance approach to public debate can reflect on what might be hidden assumptions about goods and publics, as well as make visible previously invisible, or ignored, publics and public goods. Bringing those assumptions to light in a broader and more inclusive debate might help ensure that science/research/innovation policy is 'enabling' without being 'deterministic'.

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Notes

1. Nuffield Council on Bioethics (2016: 4, 12).
2. E.g. Jinek et al. (2012).
3. For a review of the concept of 'disruptive technology', see e.g. Danneels (2004).
4. The Academy of Medical Sciences et al. (2015).
5. See, for example, the Royal Society's 2016 animated video 'What is gene editing and how does it work?', available at https://youtu.be/XPDb8tqgfjY (accessed on 4 June 2018).
6. Jasanoff and Kim (2009: 123).
7. Pickersgill (2011).
8. Barben et al. (2008).
9. Selin (2011).
10. Callon (1999).
11. Marris and Calvert (2020).
12. Radin and Kowal (2015).
13. Stephens et al. (2013).
14. Warner (2002: 50).
15. Engdahl and Lidskog (2014).
16. Haerlin and Parr (1999).
17. Wynne (2006).
18. Jacob and Hellström (2000).
19. Lidskog (1996).
20. Michael (2009).
21. Michael (2009).
22. Rommetveit and Wynne (2017: 143).
23. In our understanding of the UK's specific landscape of expertise around bioethical issues, we draw from Ashcroft (2004), Chadwick and Wilson (2018), Chan (2015), Hedgecoe (2009), and Jasanoff (2005).
24. Gunnarsdottir and Rommetveit (2017).
25. Callon (1994).
26. Schmid et al. (2012: 54).
27. Reubi (2012).
28. Wienroth et al. (2019).
29. https://www.ukbiobank.ac.uk/.
30. https://www.genomicsengland.co.uk/.
31. https://www.gov.uk/government/news/matt-hancock-announces-ambition-to-map-5-million-genomes.
32. The Academy of Medical Sciences et al. (2015).
33. The Hinxton Group represents an international, multidisciplinary consortium of scholars from social sciences, humanities, and sciences. The group is led by a committee of scientists and bioethicists, including Sarah Chan, Ruth Faden, John Harris, and Julian Savulescu, whose work on ethical and policy aspects of biotechnologies, for example, for human embryo and stem cell research, has significantly informed the ongoing UK biotechnology debate: http://www.hinxtongroup.org/.
34. Siddique (2016).
35. Knapton (2016).
36. BBC (2016).
37. Sciencewise is a UK Government-funded body, developing public dialogue projects with diverse British publics on topics that are related to Government-identified strategic priorities: https://sciencewise.org.uk/.
38. Sciencewise and Nuffield Council on Bioethics (2016).
39. Parliamentary Office of Science and Technology (2016).
40. Church of England (2016).
41. Genetic Alliance UK (2016).
42. The Chief Medical Officer (2017).
43. House of Commons Science and Technology Committee (2017).
44. Genetic Alliance UK and Progress Education Trust (2017).
45. The 2016 platform report produced by the Nuffield Council on Bioethics is included, but the 2018 report on human reproduction and genome editing is not since it was published after the analysis was completed.
46. Nature Methods Editorial (2012).
47. However difficult it may be to uphold the distinction between basic and translational in genome editing (Nuffield Council on Bioethics 2016: 40).
48. Concerns that seem to have been proven correct on the later examples of Chinese researchers editing genes in human embryos since 2015, cf. Cyranoski (2019); and researchers from the USA conducting mitochondrial replacement in Mexico in 2016, cf. Palacios-González and Medina-Arellano (2017).
49. In addition to the reports and scientists referenced here, see also Chneiweiss et al. (2017).
50. Jesse Gelsinger was a young man who died during a clinical trial of a gene therapy at the University of Pennsylvania in 1999. Subsequent inquiries indicated severe flaws in the informed consent process of the trial.
51. Genetic Alliance UK (2016: 34).
52. The Hinxton Group (2015).
53. The Academy of Medical Sciences et al. (2015).
54. Nuffield Council on Bioethics (2016).
55. Note, however, that a distinction is made between somatic and germline editing in terms of research and application.
56. Bioethicist Dr Sarah Chan, Gallagher (2016).
57. Genetic Alliance UK (2016).
58. In practice, the current ethical regime and its governance structure does leave space for future legislation once applications using CRISPR variants become available for clinical application.
59. Tutton (2011: 425).
60. These sources, especially the documents, focus on proximate goods closely linked to health-related research outcomes. While longer-term concerns are raised at times in both documents and interviews,

the dimension critical of genome editing tends to be associated with the human enhancement narrative, which is often framed as a less realistic concern in the current debate.

61. Of course other selective technologies do the same, but the critique here highlights the potentially irreversible nature of germline genome editing.
62. Dimond and Stephens (2018b: 133).
63. Craven et al. (2016).
64. Appleby (2015).
65. Dimond and Stephens (2018a).

References

The Academy of Medical Sciences, Association of Medical Research Charities, Biotechnology and Biological Sciences Research Council, et al. (2015), *Genome Editing in Human Cells – An Initial Statement* <https://acmedsci.ac.uk/file-download/37773-55e6b4e90f49c.pdf> accessed 29 Oct 2018.

Appleby, J. B. (2015) 'The Ethical Challenges of the Clinical Introduction of Mitochondrial Replacement Techniques', *Medicine, Health Care, and Philosophy*, 18: 501–14.

Ashcroft, R. E. (2004) 'Bioethics and Conflicts of Interest', *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, 35: 155–65.

Barben, D., Fisher, E., Selin, C., et al. (2008) 'Anticipatory Governance of Nanotechnology: Foresight, Engagement, and Integration', In: E. J. Hackett, O. Amsterdamska, M. Lynch, et al. (eds) *The Handbook of Science and Technology Studies*, pp. 979–1000. Cambridge, MA, London: The MIT Press.

Callon, M. (1994) 'Is Science a Public Good? Fifth Mullins Lecture, Virginia Polytechnic Institute, 23 March 1993', *Science, Technology, & Human Values*, 19: 395–424.

—— (1999) 'Actor-Network Theory—The Market Test', *The Sociological Review*, 47: 181–95.

Chadwick, R. and Wilson, D. (2018) 'The Emergence and Development of Bioethics in the UK', *Medical Law Review*, 26: 183–201.

Chan, S. (2015) 'A Bioethics for All Seasons', *Journal of Medical Ethics*, 41: 17–21.

The Chief Medical Officer. (2017), *Generation Genome* <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/631043/CMO_annual_report_generation_genome.pdf> accessed 29 Oct 2018.

Chneiweiss, H., Hirsch, F., Montoliu, L., et al. (2017) 'Fostering Responsible Research with Genome Editing Technologies: A European Perspective', *Transgenic Research*, 26: 709–13.

Church of England. (2016), *Genome Editing MPAC Position Paper* <https://www.churchofengland.org/sites/default/files/2017-11/Genome%20Editing%20MPAC%20Position%20Paper.pdf> accessed 6 Jun 2018.

Craven, L., Herbert, M., Murdoch, A., et al. (2016) 'Research into Policy: A Brief History of Mitochondrial Donation', *Stem Cells*, 34: 265–7.

Cyranoski, D. (2019) 'The CRISPR-Baby Scandal: What's Next for Human Gene-Editing', *Nature*, 566: 440–2.

Danneels, E. (2004) 'Disruptive Technology Reconsidered: A Critique and Research Agenda', *Journal of Product Innovation Management*, 21: 246–58.

Dimond, R. and Stephens, N. (2018a) 'Three Persons, Three Genetic Contributors, Three Parents: Mitochondrial Donation, Genetic Parenting and the Immutable Grammar of the 'three x x'', *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 22: 240–58.

—— (2018b) 'Enacting Ethical Futures', In: *Legalising Mitochondrial Donation: Enacting Ethical Futures in UK Biomedical Policy*, pp. 131–42. Basingstoke: Palgrave Macmillan.

Engdahl, E. and Lidskog, R. (2014) 'Risk, Communication and Trust: Towards an Emotional Understanding of Trust', *Public Understanding of Science*, 23: 703–17.

Gallagher, J. (2016), 'Scientists Get 'Gene Editing' Go-Ahead', *BBC*, 1 February <https://www.bbc.co.uk/news/health-35459054> accessed 12 Jun 2018.

Genetic Alliance UK (2016), *Genome Editing Technologies. The Patient Perspective* <http://www.geneticalliance.org.uk/media/2623/nerri_finalreport15112016.pdf> accessed 6 Jun 2018.

Genetic Alliance UK and Progress Education Trust. (2017), *Basic Understanding of Genome Editing. The Report* <https://pet.ultimatedb.net/res/org10/Reports/genomeediting_report.pdf> accessed 5 Jun 2018.

Gunnarsdottir, K. and Rommetveit, K. (2017) 'The Biometric Imaginary: (Dis)trust in a Policy Vacuum', *Public Understanding of Science*, 26: 195–211.

Haerlin, B. and Parr, D. (1999) 'How to Restore Public Trust in Science', *Nature*, 400: 499.

Hedgecoe, A. (2009) '"A Form of Practical Machinery": The Origins of Research Ethics Committees in the UK, 1967–1972', *Medical History*, 53: 331–50.

The Hinxton Group. (2015), *Statement on Genome Editing Technologies and Human Germline Genetic Modification* <http://www.hinxtongroup.org/Hinxton2015_Statement.pdf> accessed 24 Oct 2018.

House of Commons Science and Technology Committee. (2017), *Genomics and Genome-Editing: Future Lines of Inquiry* <https://publications.parliament.uk/pa/cm201617/cmselect/cmsctech/854/854.pdf> accessed 29 Oct 2018.

Jacob, M. and Hellström, T. (2000) 'Policy Understanding of Science, Public Trust and the BSE–CJD Crisis', *Journal of Hazardous Materials*, 78: 303–17.

Jasanoff, S. (2005) *Designs on Nature: Science and Democracy in Europe and the United States*. Princeton, NJ: Princeton University Press.

Jasanoff, S. and Kim, S. H. (2009) 'Containing the Atom: Sociotechnical Imaginaries and Nuclear Power in the United States and South Korea', *Minerva*, 47: 119–46.

Jinek, M., Chylinski, K., Fonfara, I., et al. (2012) 'A Programmable Dual-RNA-guided DNA Endonuclease in Adaptive Bacterial Immunity', *Science*, 337: 816–21.

Knapton, S. (2016), 'British Scientists Granted Permission to Genetically Modify Human Embryos', *The Telegraph*, 1 February <https://www.telegraph.co.uk/science/2016/03/12/british-scientists-granted-permission-to-genetically-modify-huma/> accessed 2 Jun 2018.

Lidskog, R. (1996) 'In Science We Trust? on the Relation between Scientific Knowledge, Risk Consciousness and Public Trust', *Acta Sociologica*, 39: 31–56.

Marris, C. and Calvert, J. (2020) 'Science and Technology Studies in Policy: The UK Synthetic Biology Roadmap', *Science, Technology & Human Values*, 45: 34–61.

Michael, M. (2009) 'Publics Performing Publics: Of PiGs, PiPs and Politics', *Public Understanding of Science*, 18: 617–31.

Nature Methods Editorial. (2012) 'Method of the Year 2011', *Nature Methods*, 9: 1.

Nuffield Council on Bioethics. (2016), *Genome Editing. An Ethical Review* <http://nuffieldbioethics.org/wp-content/uploads/Genome-editing-an-ethical-review.pdf> accessed 16 Dec 2017.

Palacios-González, C. and Medina-Arellano, M. D. J. (2017) 'Mitochondrial Replacement Techniques and Mexico's Rule of Law: On the Legality of the First Maternal Spindle Transfer Case', *Journal of Law and the Biosciences*, 4: 50–69.

Parliamentary Office of Science and Technology. (2016) 'Genome Editing', *POSTnote*, 541: 1–4 <https://researchbriefings.files.parliament.uk/documents/POST-PN-0541/POST-PN-0541.pdf>.

Pickersgill, M. (2011) 'Connecting Neuroscience and Law: Anticipatory Discourse and the Role of Sociotechnical Imaginaries', *New Genetics and Society*, 30: 27–40.
Radin, J. and Kowal, E. (2015) 'Indigenous Blood and Ethical Regimes in the United States and Australia since the 1960s', *American Ethnologist*, 42: 749–65.
Reubi, D. (2012) 'The Human Capacity to Reflect and Decide: Bioethics and the Reconfiguration of the Research Subject in the British Biomedical Sciences', *Social Studies of Science*, 42: 348–68.
Rommetveit, K. and Wynne, B. (2017) 'Technoscience, Imagined Publics and Public Imaginations', *Public Understanding of Science*, 26: 133–47.
Schmid, O., Padel, S., and Levidow, L. (2012) 'The Bio-Economy Concept and Knowledge Base in a Public Goods and Farmer Perspective', *Bio-based and Applied Economics*, 1: 47–63.
Sciencewise and Nuffield Council on Bioethics. (2016), *Public Dialogue on Genome Editing. Why? When? Who?* <http://nuffieldbioethics.org/wp-content/uploads/Public-Dialogue-on-Genome-Editing-workshop-report.pdf> accessed 24 Oct 2018.
Selin, C. (2011) 'Negotiating Plausibility: Intervening in the Future of Nanotechnology', *Science and Engineering Ethics*, 17: 723–37.
Siddique, H. (2016), 'British Researchers Get Green Light to Genetically Modify Human Embryos', *The Guardian*, 1 February <https://www.theguardian.com/science/2016/feb/01/human-embryo-genetic-modify-regulator-green-light-research> accessed 12 Jun 2018.
Stephens, N., Atkinson, P., and Glasner, P. (2013) 'Institutional Imaginaries of Publics in Stem Cell Banking: The Cases of the UK and Spain', *Science as Culture*, 22: 497–515.
Tutton, R. (2011) 'Promising Pessimism: Reading the Futures to Be Avoided in Biotech', *Social Studies of Science*, 41: 411–29.
Warner, M. (2002) 'Publics and Counterpublics', *Public Culture*, 14: 49–90.
Wienroth, M., Pearce, C., and McKevitt, C. (2019) 'Research Campaigns in the UK National Health Service: Patient Recruitment and Questions of Valuation', *Sociology of Health & Illness*, 41: 1444–61.
Wynne, B. (2006) 'Public Engagement as a Means of Restoring Public Trust in Science - Hitting the Notes, but Missing the Music?', *Community Genetics*, 9: 211–20.